

# Disability and Health in Ohio Public Health Needs Assessment Ohio Disability and Health Program

June 2013

## Ohio Disability and Health Program



**Health Promotion**



**Access to Care**



**Emergency Preparedness**

This report was supported by the Centers for Disease Control and Prevention Cooperative Agreement Number 5U59DD000931-02. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

For more information, please visit the Ohio Disability and Health Program website at <http://nisonger.osu.edu/odhp> or call 614.688.2928.

Citation: Yang, Y., Havercamp, S. M., Riddle, I. K., Coleman, E. S., Sahr, T. R., & Ashmead, R. D. (2013). Disability and Health in Ohio Public Health Needs Assessment. (Available from the Ohio Disability and Health Program, <http://nisonger.osu.edu/odhp/reports>)

## Table of Contents

Executive Summary.....	4
Introduction .....	5
Data Sources and Disability Measures .....	5
Ohio Disability Prevalence .....	8
Adult Disability Prevalence .....	8
Child Disability Prevalence .....	13
Health Status of Ohioans with Disabilities .....	16
Health Promotion .....	17
Access to Health Care .....	22
Emergency Preparedness .....	26
Somali Community .....	30
Conclusion .....	30
Future Directions .....	31
References .....	32
Ohio Disability and Health Program Staff and Team Members .....	34
Ohio Disability and Health Program Disability Community Planning Group .....	35

## Executive Summary

According to population surveys, 26.5% of adults (BRFSS) and 18% of children (OMAS) in Ohio report having a disability. Furthermore, people with disabilities (PWD) when compared with those without disabilities have more barriers to quality health care, are more likely to suffer from a chronic disease, have higher rates of poor health behaviors and risks, and have worse outcomes during emergency situations. Many of these issues faced by Ohio's disability community can be mitigated or prevented with raised awareness, increased education, higher-quality and accessible health care, more-inclusive health promotion programs and policies, improved infrastructure, and disability-engaging planning processes.

The Ohio Disability and Health Program (ODHP), a Centers for Disease Control and Prevention (CDC) funded program, aims to improve Ohio's capacity to address these issues. As part of ODHP's strategic plan, ODHP conducted a public health needs assessment in an effort to obtain a clear understanding of the comprehensive health status and needs of Ohio's disability population regarding disability prevalence, health care access, health promotion, and emergency preparedness. This report discusses the methods involved and sources utilized to collect and analyze the quantitative and qualitative data included in this assessment. Data presented are gathered from the 2010 and 2011 Behavioral Risk Factor Surveillance System (BRFSS), 2012 Ohio Medicaid Assessment Survey (OMAS), 2009-2011 American Community Survey (ACS), 2013 ODHP online survey, 2013 ODHP open forums, and 2013 ODHP Somali focus group. Some key findings and disparities highlighted in this report include:

	<u>Ohioans with Disabilities</u>	<u>Ohioans without Disabilities</u>
Did not get needed health care:	• 59.5%	• 27.0%
Smoke daily:	• 47.9%	• 37.1%
Are overweight:	• 44.4%	• 30.1%
Fair/poor health status:	• 43.9%	• 8.7%

- There is an increased estimate of disability prevalence among black/African American adults.
- The Appalachian region has the highest estimates of adult disability prevalence when compared with metropolitan, suburban, and other rural regions of Ohio.
- Among PWD, inclusive health promotion programs were most preferred compared with programs only for PWD or only for PWD and caregivers/family/friends.
- 60.5% of PWD reported not having an emergency plan if required to evacuate one's home.

The findings from this public health needs assessment will be used to inform and guide ODHP's strategic plan. The data gathered will help ODHP to identify better strategies while bolstering various activities underway. Some of the results will also serve as a baseline for ODHP to measure the progress and impact of the program. Beyond ODHP, it is encouraged that other partners, organizations, programs, and individuals review and utilize this report to move forward on the mission of improving the health outcomes and lives of people with disabilities in Ohio.

## Introduction

The Ohio Disability and Health Program (ODHP) is a Centers for Disease Control and Prevention (CDC) three-year (2012-2015) funded program with goals to promote health, improve emergency preparedness, and increase access to health care for Ohioans with disabilities. The ODHP is a partnership between the Nisonger Center at The Ohio State University, the Ohio Department of Health, the University of Cincinnati University Center for Excellence in Developmental Disabilities (UC UCEDD), and the Ohio Colleges of Medicine Government Resource Center. ODHP also collaborates with the disability community through the Disability Community Planning Group (DCPG), which consists of organizations, agencies, and individuals across the state. The DCPG was formed to serve as an advisory panel to guide and assist in program activities. Ohio is one of 18 states that receives funding for this statewide capacity-building project to improve the health of people with disabilities (PWD).

ODHP uses the World Health Organization's International Classification of Functioning concept of disability. Disability is defined as a functional limitation in activities of daily living or related to a health condition and associated with significant impairment, activity limitation, and participation restrictions. Impairments may involve hearing, vision, movement, thinking, remembering, learning, communicating, mental health, or social relationships. These impairments may occur at any point in time across the lifespan.<sup>1</sup>

To inform and guide program activities, ODHP conducted a public health needs assessment of children and adults with disabilities living in Ohio. This report provides information on disability prevalence for the Ohio populace as well as access to health care, health promotion, and emergency preparedness for people with and without disabilities. It incorporates data from multiple population surveys to provide a snapshot of disability in Ohio at this point in time. A separate document, 2013 Ohio Disability Data Report, summarizes these quantitative findings at <http://nisonger.osu.edu/odhp/reports>. Additionally, qualitative data and quotes obtained from statewide open forums and results from an online survey are presented throughout this report.

*"I think, sometimes, we let umm, the disabilities... their disability, just overshadow that they have the same needs we all have..."*

*– Open forum participant*

## Data Sources and Disability Measures

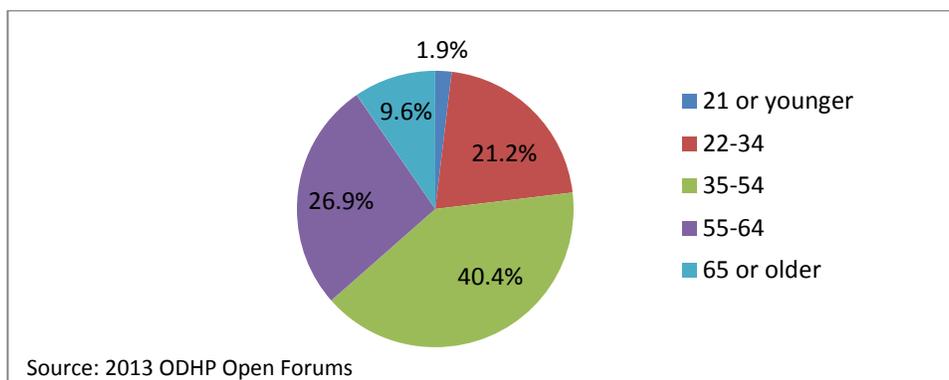
Six main sources of data are examined in this report: the 2012 Ohio Medicaid Assessment Survey (OMAS),<sup>2</sup> the 2010 and 2011 Behavioral Risk Factor Surveillance System (BRFSS),<sup>3</sup> the 2009-2011 American Community Survey (ACS) 3-year estimates,<sup>4</sup> three ODHP open forums, an ODHP online survey, and an ODHP Somali focus group. The ACS data includes estimates from the full sample as well

as the Public Use Microdata Sample (PUMS). In the OMAS, BRFSS, and ACS, disability is assessed by multiple questions to create an indicator that approximates disability status. The questions that relate to disability differ for each survey, which creates three unique definitions that attempt to approximate disability. The differences in these approximations of disability are, in some cases, large enough that these identified disability groups should not be considered comparable.

The OMAS adult approximation of disability is defined by variables indicating needed long-term day-to-day assistance, needed special therapies, a potential disabling mental health condition, needed assistance for adults with special healthcare needs that are in fair or poor health, or involvement in certain disability benefit programs. For children, variables indicating need for atypical care or services, activity limitations, need for special therapies long-term, a potential disabling mental health or developmental condition, or involvement in certain disability benefit programs are used to approximate disability. The BRFSS approximation of disability uses two questions asking about activity limitation due to a physical, mental, or emotional problem and also any health problems requiring special equipment. The ACS uses questions asking about hearing, vision, cognitive, ambulatory, self-care, and independent living difficulty to approximate disability. Only hearing and vision questions are asked about children under 5 years of age, and the independent living difficulty question is not asked of those younger than 17 years of age.

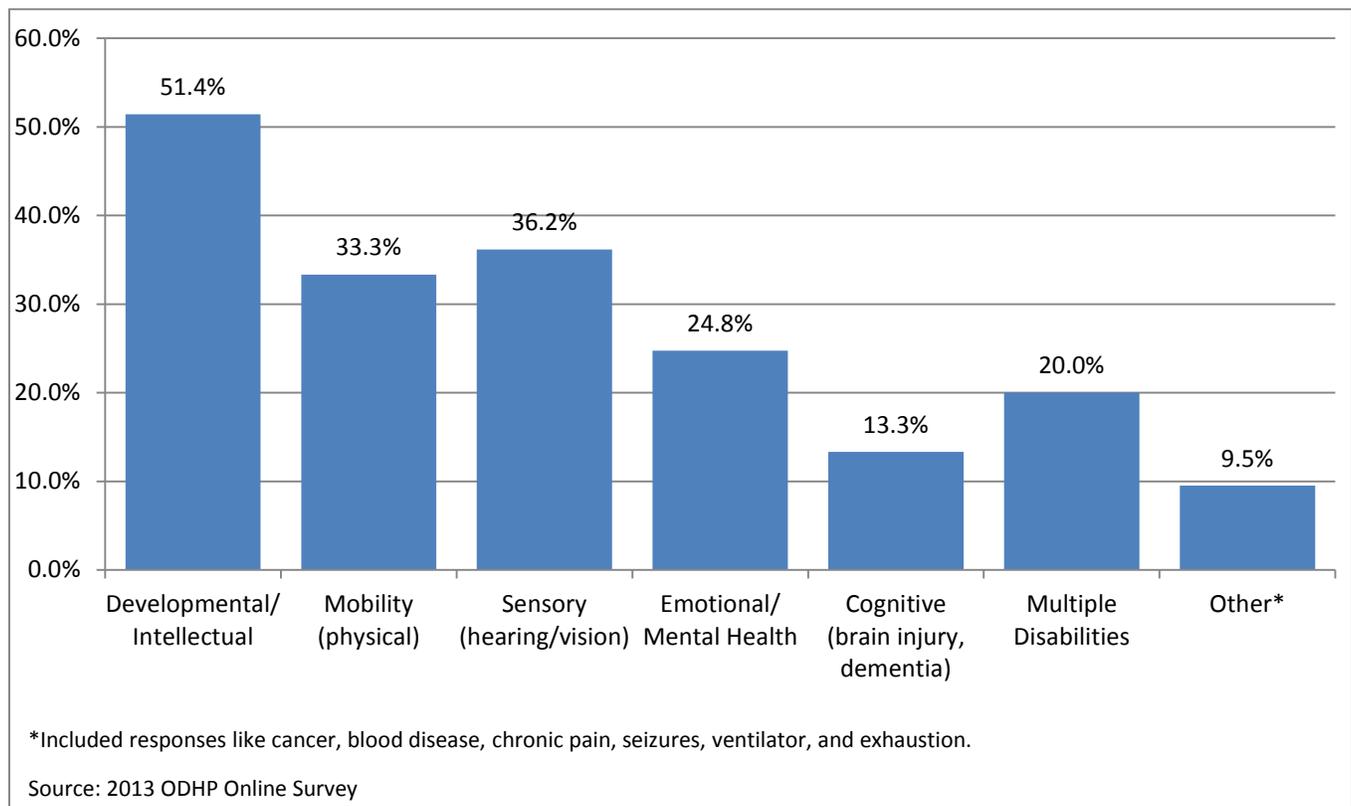
ODHP held a total of three open forums in northeast, central, and southwest Ohio and disseminated an online survey in early 2013 to receive input regarding access to health care, health promotion, and emergency preparedness from people with disabilities, family members/caregivers of people with disabilities, disability advocates, and professionals working with individuals who have disabilities. A total of 60 participants attended the open forums; 27% were male while 73% were female. Open forum participants represented a wide age range with the majority of participants' ages ranging from 35 to 54. About 65% of forum participants reported either having a disability or being a caregiver of someone with a disability. Of the total group, 30% reported having one or more disabilities. The remainder of the participants identified as a disability advocate or a professional working with people who have disabilities.

**Figure 1: Open Forums – Participant Age Breakdown**



The ODHP online survey, which was made available in both English and Spanish, recorded a total of 149 respondents (142 English, 7 Spanish). Given that respondents could skip questions by choice or automatically, due to skip logic based on how a previous question was answered, the number of respondents for each question was variable. The number of respondents per question ranged from n=72 to n=142. The survey reached residents of Ohio spanning across 25 counties. Respondents of the ODHP online survey included people with disabilities, caregivers of people with disabilities, and disability advocates. Respondents were asked to answer the survey questions in view of their own disability, the disability of the person for whom they provide care, or the disability community in general if the former two were not applicable.

**Figure 2: Online Survey Disability Breakdown Reported by PWDs/Caregivers of PWDs**



In mid-2013, ODHP also conducted a focus group among the Somali community in central Ohio to gain insight and perspectives from Somalis regarding disability and health. With central Ohio having the second-largest Somali population in the United States, obtaining feedback from this group is important in understanding the diverse health needs of Ohio’s disability population.<sup>5</sup> Additional details are discussed later in this report.

## Ohio Disability Prevalence

### Adult Disability Prevalence

Self-reported disability prevalence estimates for Ohio adults ranged from 15.9% to 26.5% across the data sources. In Figure 3 we see that the OMAS and ACS estimates are relatively similar, while the BRFSS estimate is much larger. We also calculate a prevalence estimate from the ACS PUMS removing those who identify as having hearing difficulty to mimic the upcoming BRFSS disability questions. The BRFSS utilizes phone interviews (without allowing for proxy interviews), which excludes most people who are Deaf or hearing impaired. We note that the OMAS 2012 estimate is only for adults ages 19 and older, the Ohio Medicaid program adult eligibility age threshold, while the others include 18-year-olds. The 18-year-olds were not removed from the ACS and BRFSS estimates in an effort to maintain the integrity of the estimator.

**Figure 3: Ohio Adult Disability Prevalence**

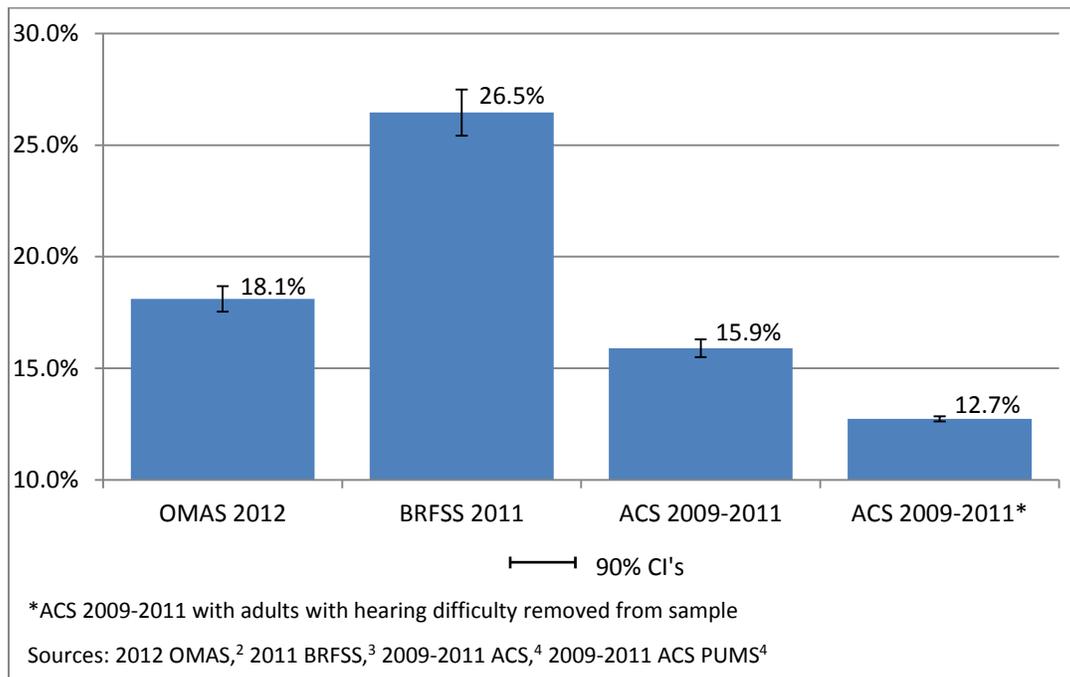
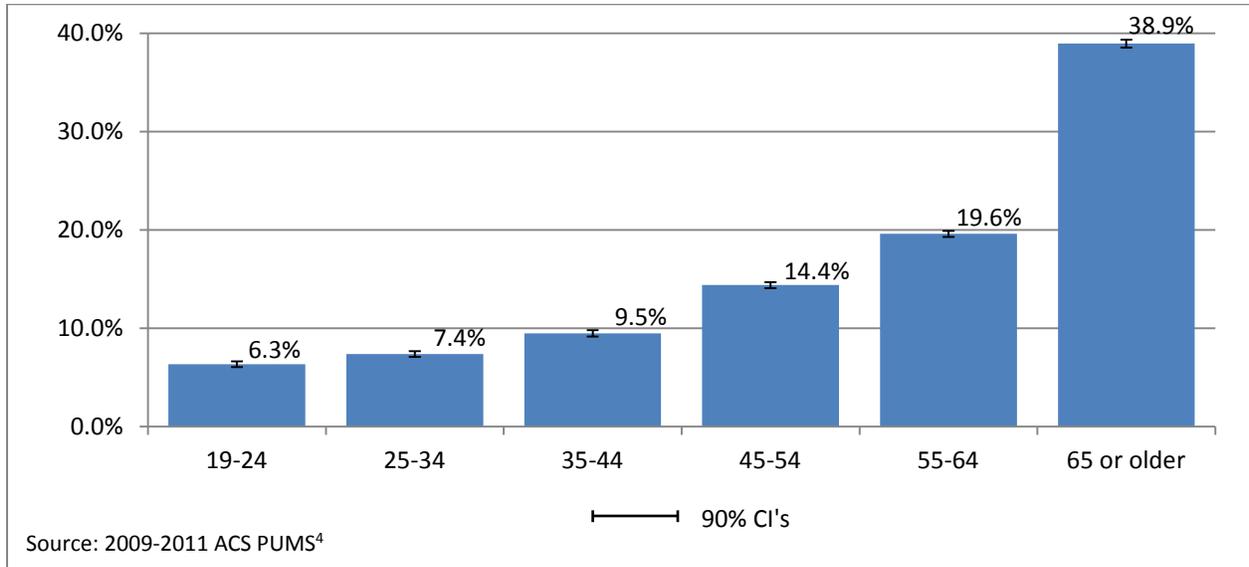


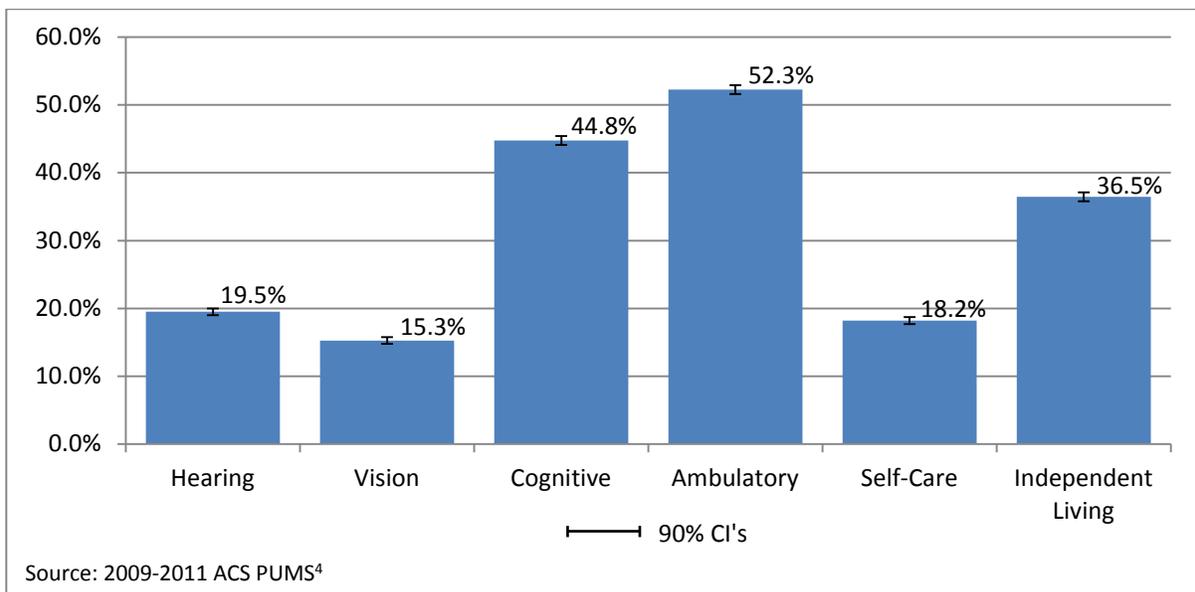
Figure 4 shows us that disability prevalence is closely associated with age in adults. We see that prevalence of self-reported disability steadily increases with age from 6.3% among 18- to 24-year-olds to 38.9% among those ages 65 and older.

**Figure 4: Ohio Adult Disability Prevalence by Age**

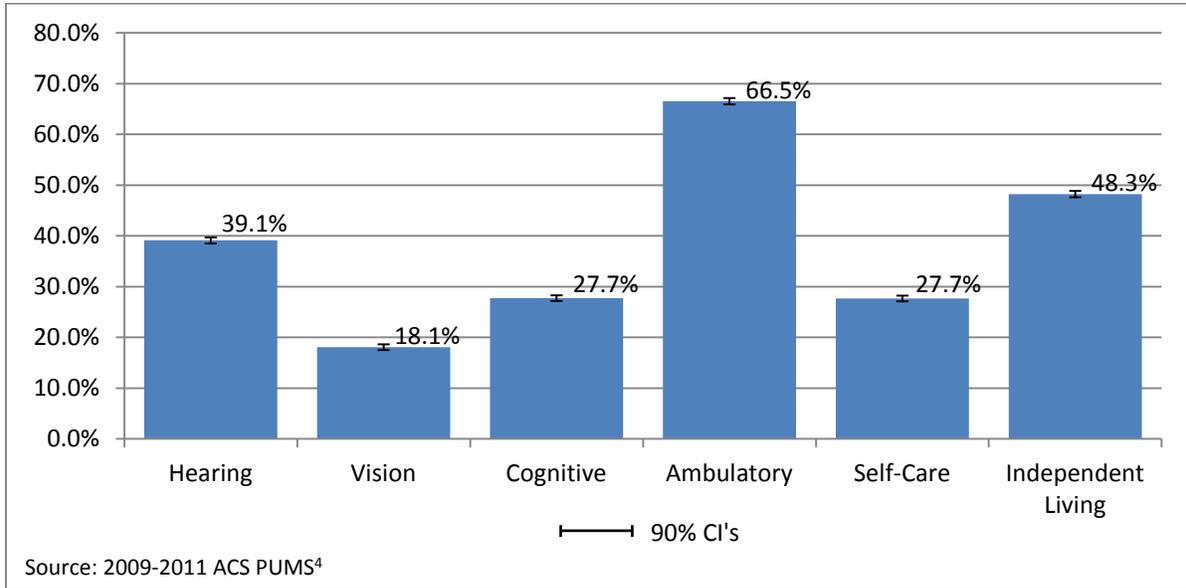


In Figures 5 and 6 we see the individual disability types among those who reported having a disability. Ambulatory, cognitive, and independent living difficulties are the most commonly reported. Adults with a disability 65 and older report a greater degree of hearing, vision, ambulatory, self-care, and independent living difficulty than younger adults.

**Figure 5: Disability Type Among Ohio Adults Ages 18-64 With a Disability**



**Figure 6: Disability Type Among Ohio Adults Ages 65 and Older With a Disability**

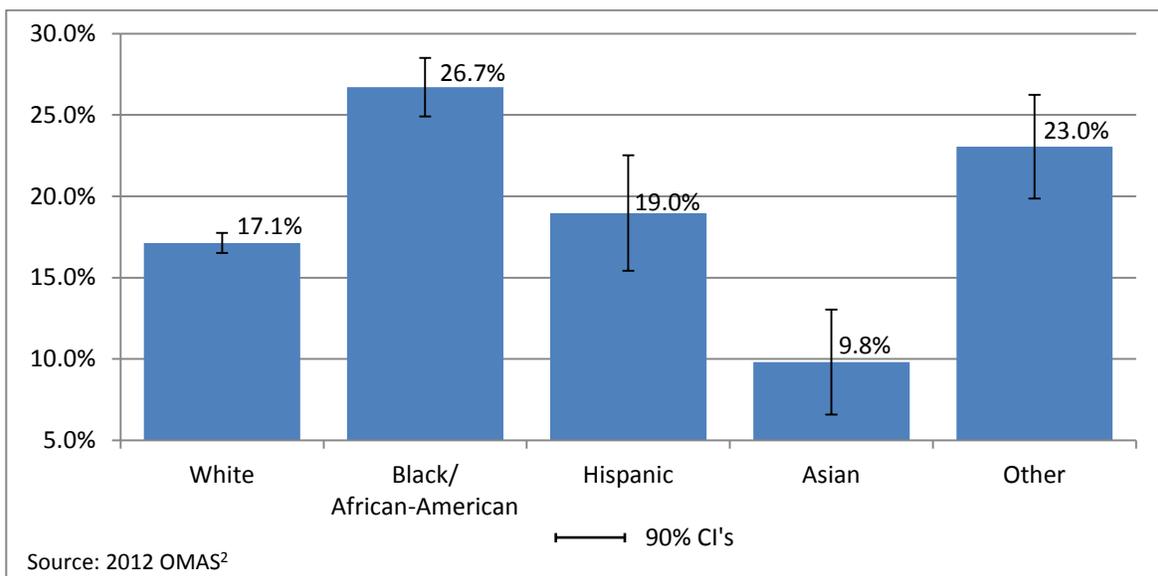


*“When I reached 65, there was a big change in what happened at the doctor’s office. Medicare allows for a 15-minute visit, and more than once, I was asking a question when the doctor was leaving the room. One time, they took me out in the hallway, let me stand until he was between patients, I could finish my conversation.”*

*– Open forum participant*

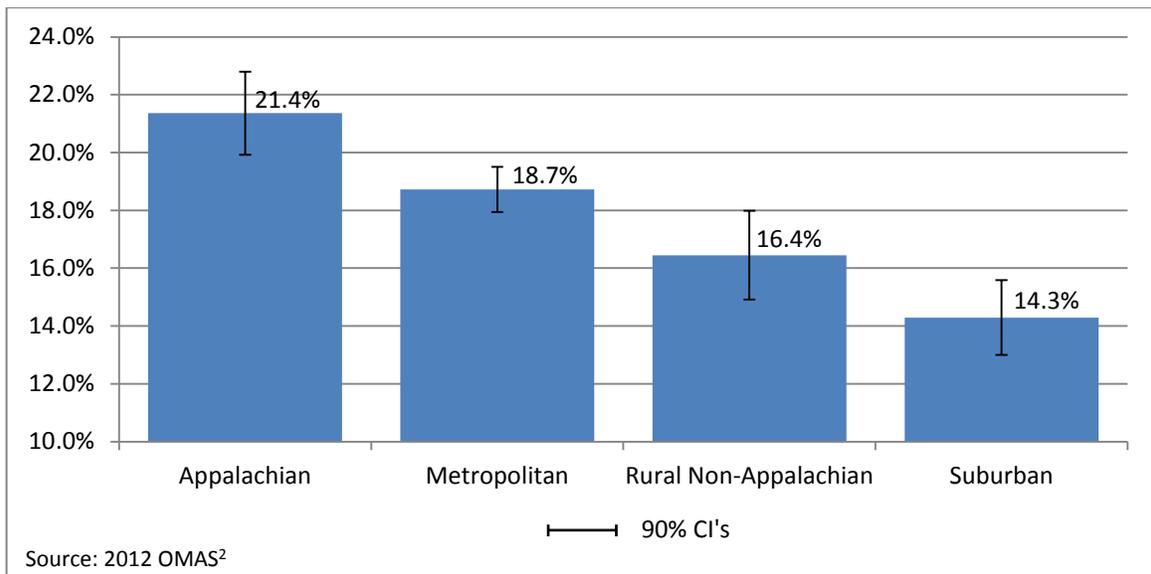
Figure 7 shows the self-reported prevalence of disability among adults by race-ethnicity. We see that prevalence of disability in black/African American adults is considerably higher, 26.7%, compared with 17.1% for white adults. Asian adults reported the lowest disability prevalence at 9.8%.

**Figure 7: Ohio Adult Disability Prevalence by Race-Ethnicity**



Across Ohio, we see that rates of self-reported disability vary significantly across geographic regions. In Figure 8 we see the self-reported adult disability prevalence for those living in Appalachian, metropolitan, rural non-Appalachian and suburban county types. Appalachian adults reported the highest prevalence of disability at 21.4%. Suburban adults reported the lowest prevalence of disability at 14.3%.

**Figure 8: Ohio Adult Disability Prevalence by County Type**

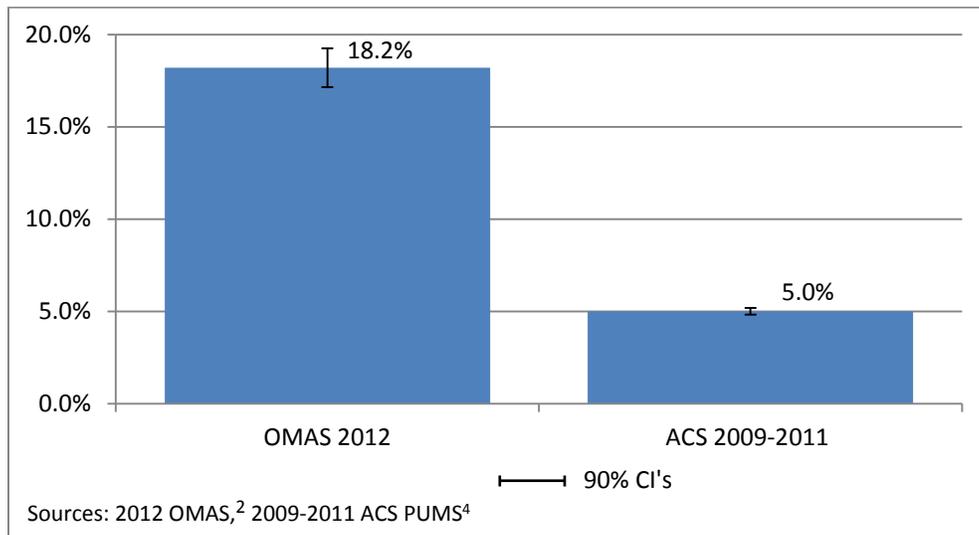




## Child Disability Prevalence

Disability prevalence estimates for children vary considerably across data sources. Figure 10 shows the OMAS estimate is 18.2%, while the ACS estimates is 5.0%. This is due to the differences in the disability screening questions in the two surveys. Looking at disability by prevalence in Figure 11 we see that prevalence increases with age. Disability prevalence is much lower for children ages 5 and younger in part because the ACS only captures hearing and vision difficulties at these ages, whereas for children over the age of 5 cognitive, ambulatory, and self-care questions are asked as well.

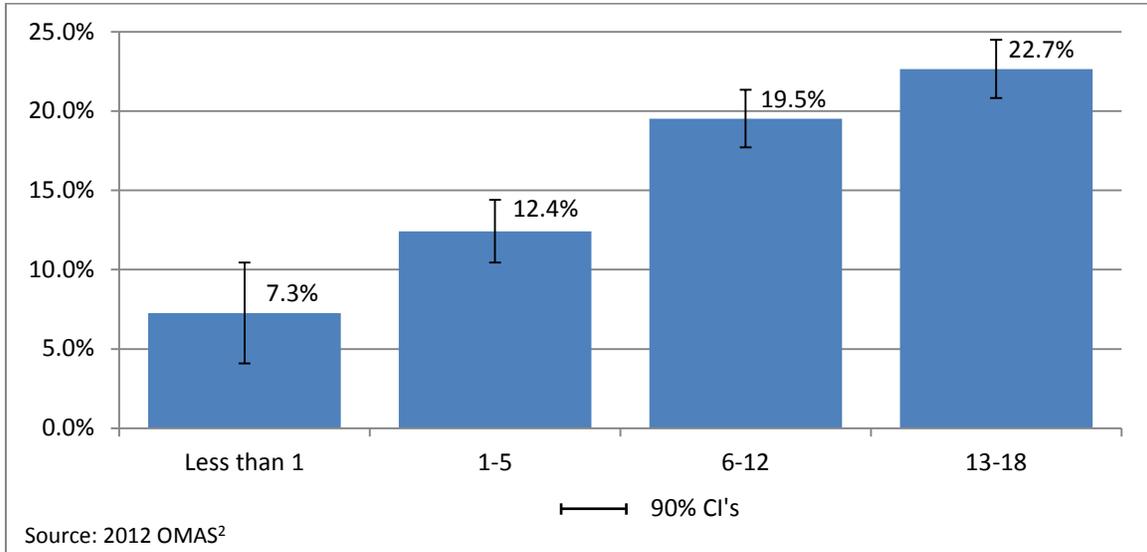
**Figure 10: Ohio Child Disability Prevalence (Ages 18 and Younger)**



*“Dental care is a big barrier in the [rural] area. Parents pretty much have to drive over an hour to their specialist because dentists in the area don’t want to, um, I guess they’re... I don’t know if it’s fear, or if they’re not feeling like they’re capable of handling children with multiple disabilities because there’s fear when they walk into the office and there’s only so much they’ll tolerate, so that’s a big barrier locally.”*

*– Open forum participant*

**Figure 11: Ohio Child Disability Prevalence by Age Category**

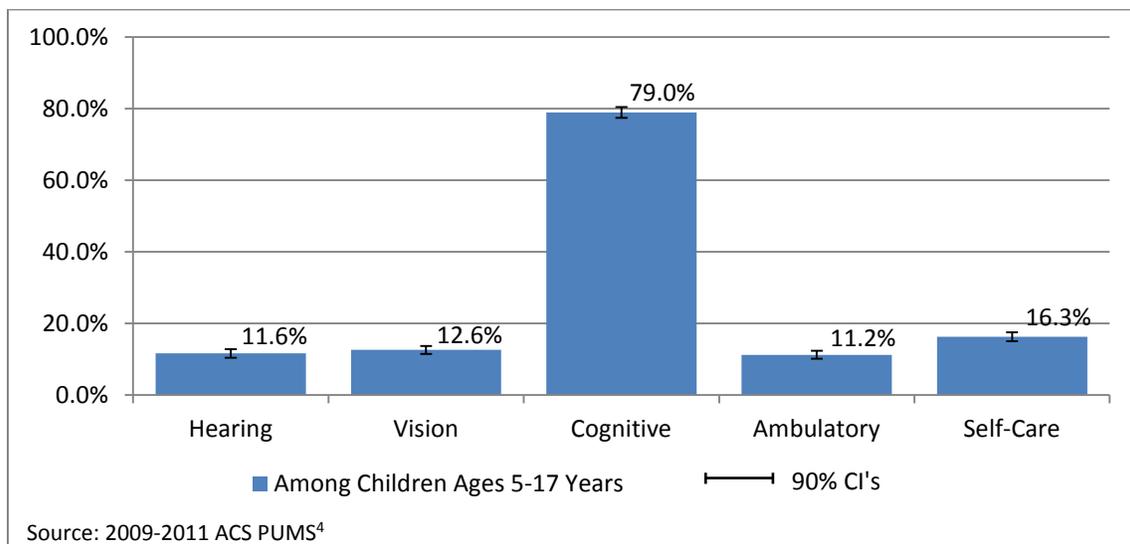


*“So as the kids get, you know, are growing into an adult, where you can’t see your pediatrician anymore, it is a big overwhelming host of issues that you know, trying to find someone to go to, trying to find somewhere to get into, and having someone who understands.”*

*– Open forum mother of a daughter with disability*

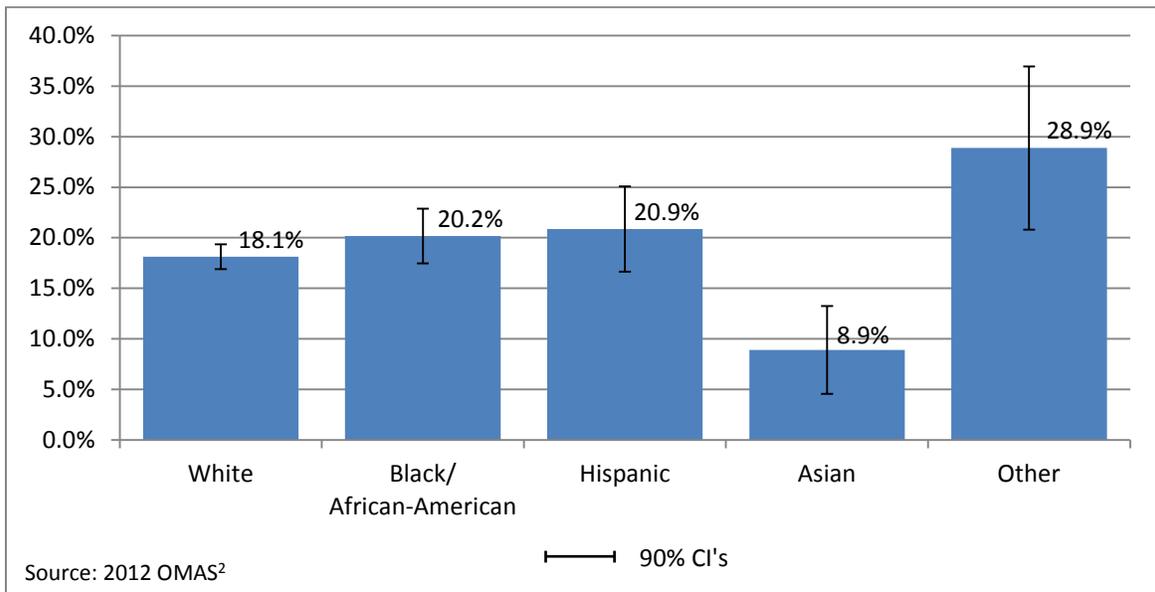
Figure 12 shows the disability types among children reported as having a disability. The most commonly reported type by far was a cognitive difficulty with 79.0% of children with disabilities aged 5 to 17 having a cognitive difficulty. Children under 5 years of age were excluded from this part of the analysis because the disability types reported by the ACS for children under 5 were related only to hearing and vision difficulty.

**Figure 12: Ohio Disability Type Among Children With a Disability**

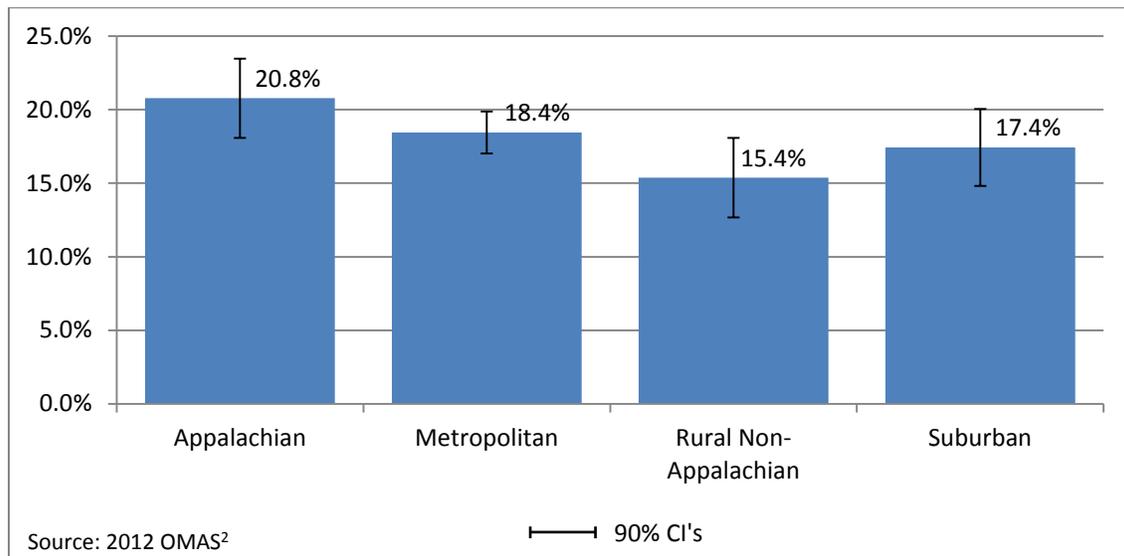


Figures 13 and 14 show child disability prevalence by race-ethnicity and county type. We do not see the increased disability prevalence in black/African American children that we saw in adults. The disability prevalence among Asian children is much lower compared with the other groups, which is similar to the pattern we observed in adults. By county type, we see a similar trend for children as adults, suggesting a higher prevalence of disability in Appalachian counties. It should be noted that confidence intervals in Figure 12 are fairly wide, which indicates the low precision of these estimates. This pattern of disability prevalence for children by county type is similar to that of adults with the exception that children in rural Non-Appalachian counties showed a lower prevalence than in suburban counties.

**Figure 13: Ohio Child Disability Prevalence by Race-Ethnicity**



**Figure 14: Ohio Child Disability Prevalence by County Type**



## Health Status of Ohioans with Disabilities

Figure 15 shows the reported health status of adults in Ohio by disability status. Survey respondents were asked the question, “In general, would you say that your health is excellent, very good, good, fair, or poor?” In Ohio, adults with disabilities are much more likely to report worse general health compared with adults without disabilities.

**Figure 15: Ohio Adult Health Status by Disability Status**

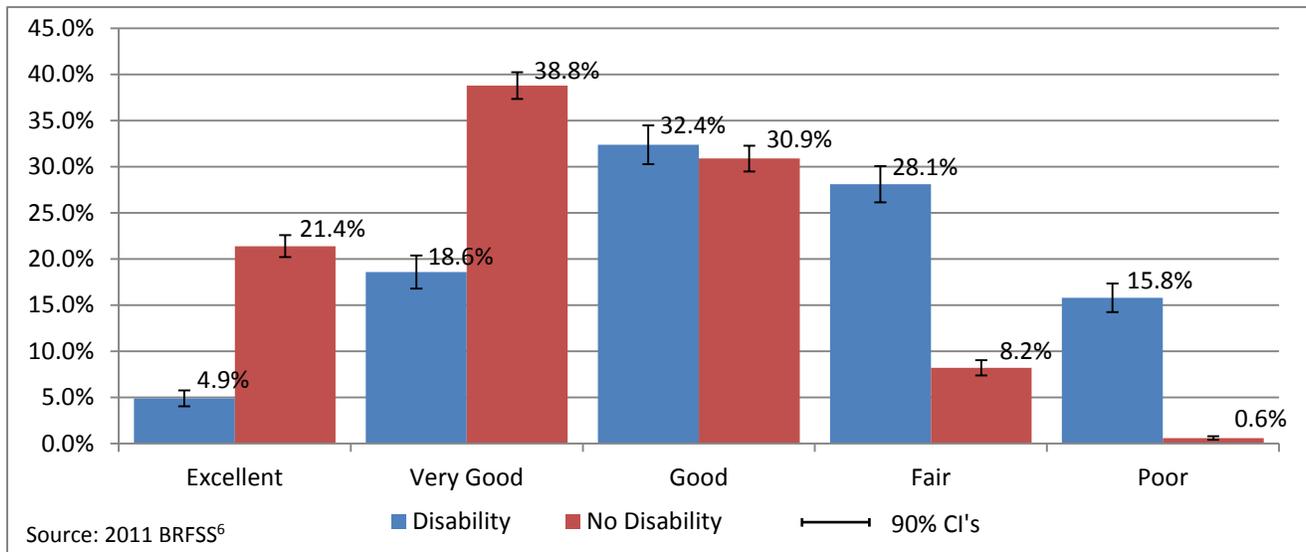
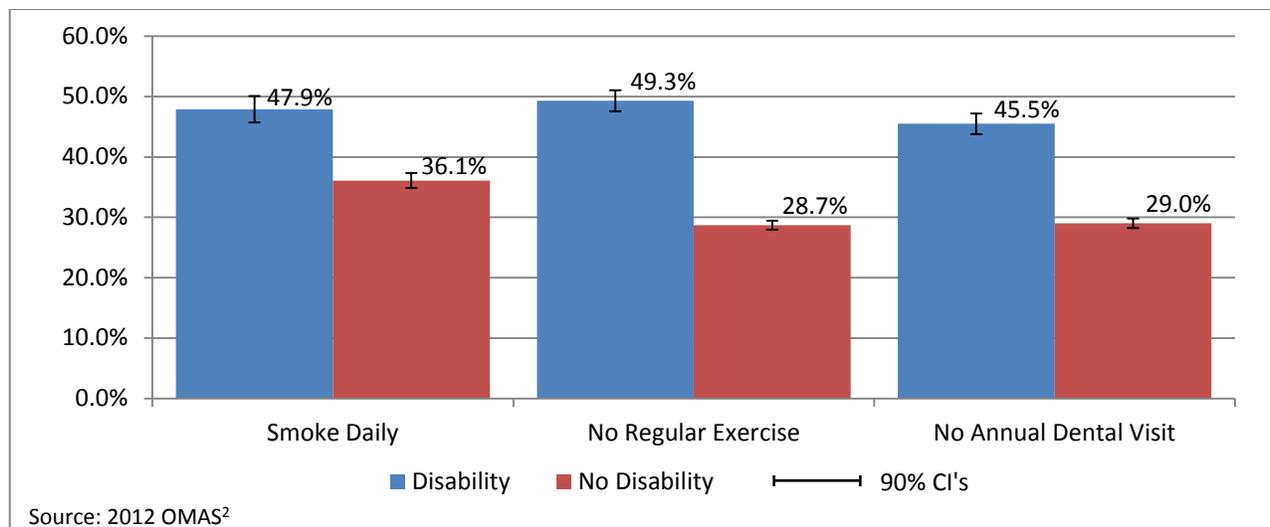


Figure 16 shows striking differences in the health risk behaviors for adults with and without disabilities. We find that among adults with disabilities 47.9% report smoking daily, 49.3% report not regularly exercising, and 45.5% report not visiting the dentist annually, compared with 36.1%, 28.7%, and 29%, respectively, among adults without disabilities.

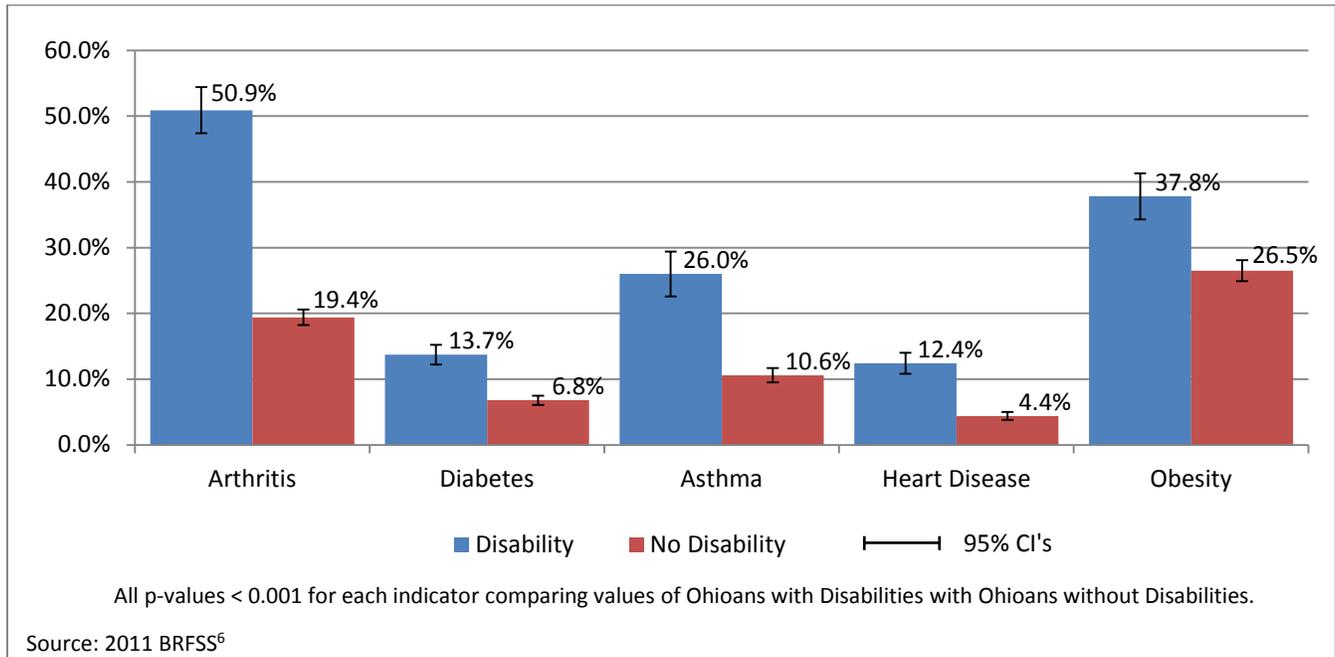
**Figure 16: Ohio Adult Health Risk Behaviors by Disability Status**



*"[What] I hear a lot from seniors is, 'I'm 75 years old, I'm not going to worry about how I eat, you know?' You know, it's a different population from kids, definitely train kids now and maybe they'll make better decisions down the road, but, when you're 80 years old and you have diabetes, do you really care? I mean, I think that's the biggest thing."*

*– Open forum participant*

**Figure 17: Ohio Chronic Health Conditions**

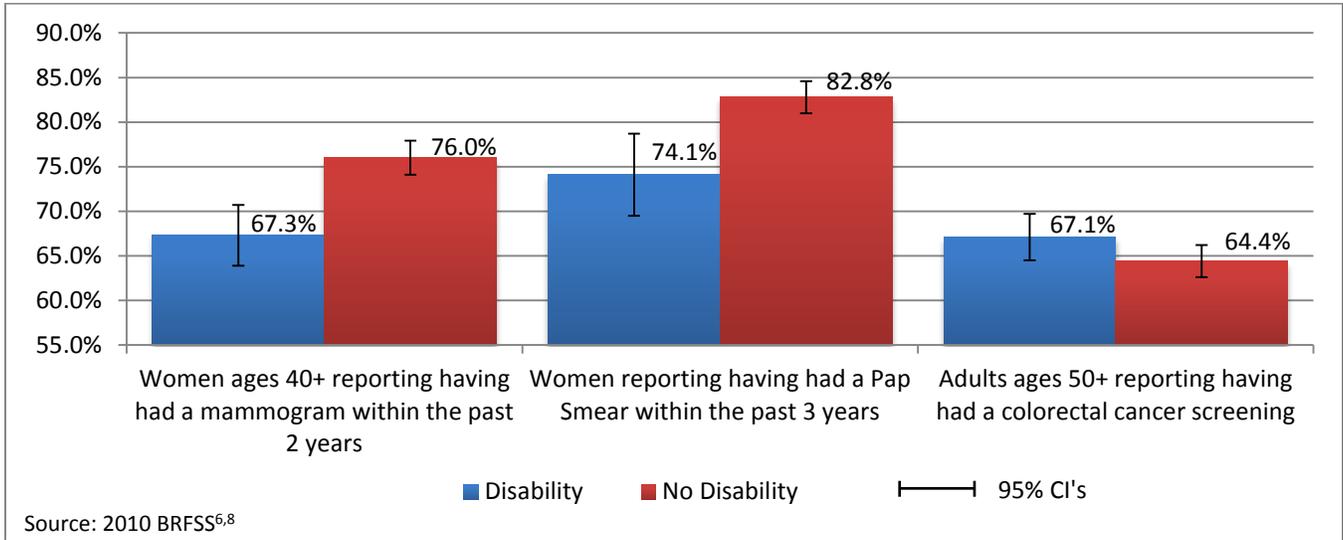


Ohioans with disabilities have an increased need for healthcare and prevention resources as they are more likely than Ohioans without disabilities to have chronic health conditions such as arthritis, diabetes, asthma, and heart disease as shown in Figure 17.

## Health Promotion

Healthcare providers have often failed to consider chronic health conditions, risk factors, and preventive measures for people with disabilities.<sup>7</sup> Research shows that some individuals with disabilities are unaware of their health risks and the need for screening and preventive services. As seen in Figure 18, women with disabilities in Ohio report receiving preventive screenings such as mammograms and pap smears at lower rates than women without disabilities. Additionally, many people with disabilities also report that some healthcare providers focus on their disability and fail to deal with primary care issues and health and wellness.<sup>7</sup> Prevention and wellness services are often not discussed between the provider and someone with a disability given the limited time available during a standard office visit.<sup>7</sup>

**Figure 18: Ohio Preventive Healthcare Screenings**

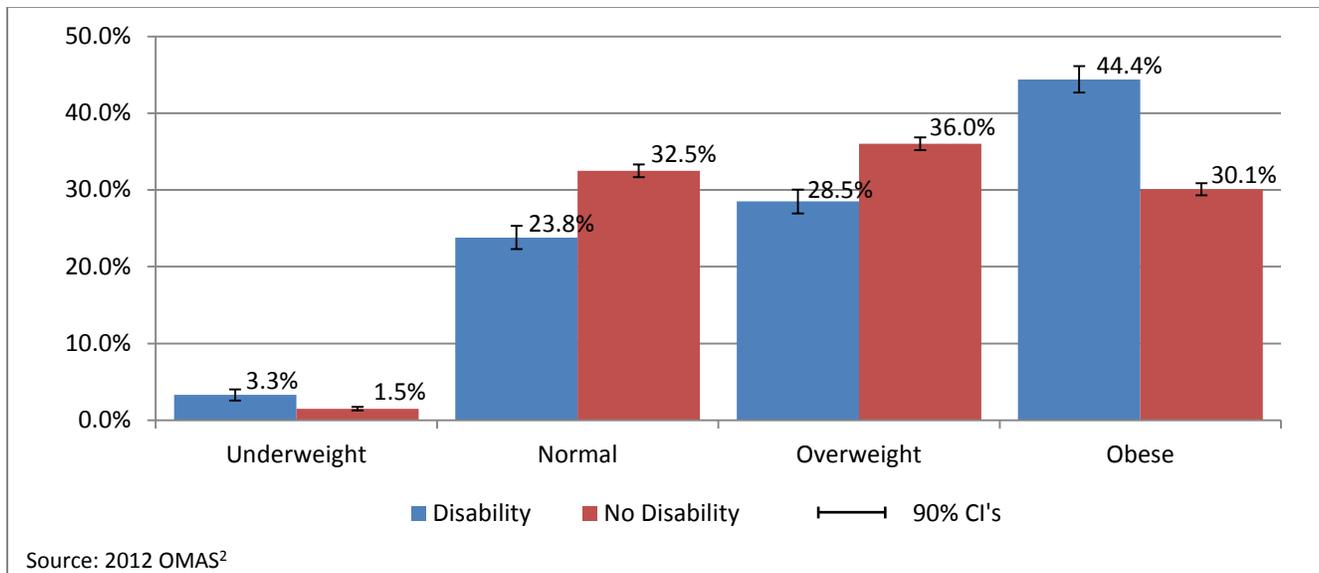


*"...the doctor mentioned to me, [my daughter with cerebral palsy] needs the same kind of preventive health care as anybody else, but I think sometimes we just focus on the disability and forget, you know, they need a pap smear, they need a mammogram, they need all those kind of things that we all need."*

*– Open forum mother of a daughter with disability*

Figure 19 shows BMI categories for those with and without disabilities. Obesity prevalence is higher in adults with disabilities (44.4%), compared with adults without disabilities (30.1%).

**Figure 19: Ohio Adult Body Mass Index (BMI) Category by Disability Status**



*“No one can actually transfer me or they’ll say ‘just stay in your [wheel]chair,’ or ‘we don’t have to take your weight because we have no way to take you out of your [wheel]chair.’”*

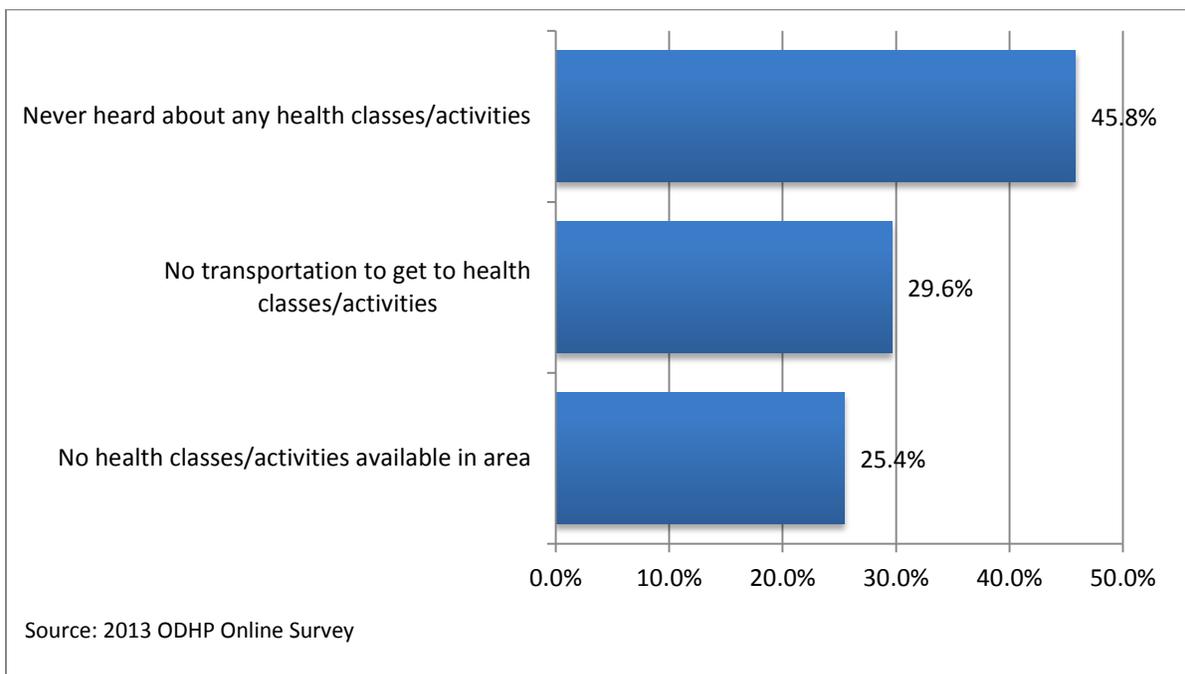
*– Open forum participant using a wheelchair*

*“My mother has cerebral palsy and wears leg braces. She weighed about 80 pounds at her last visit. She’s had progressive weight loss. The nurses look at her and [say], ‘it’s a hassle to take your braces off, don’t worry about it, just step on the scale.’”*

*– Open forum woman who has a mother with a disability*

Health promotion programs provide opportunities for people to learn to live healthier lifestyles. However, barriers exist that prevent people with disabilities from participating and fully benefiting from available programs. Figures 20 and 21 show some of the issues that ODHP online survey respondents reported people with disabilities experience as well as the health promotion topics people with disabilities may be most-interested in.

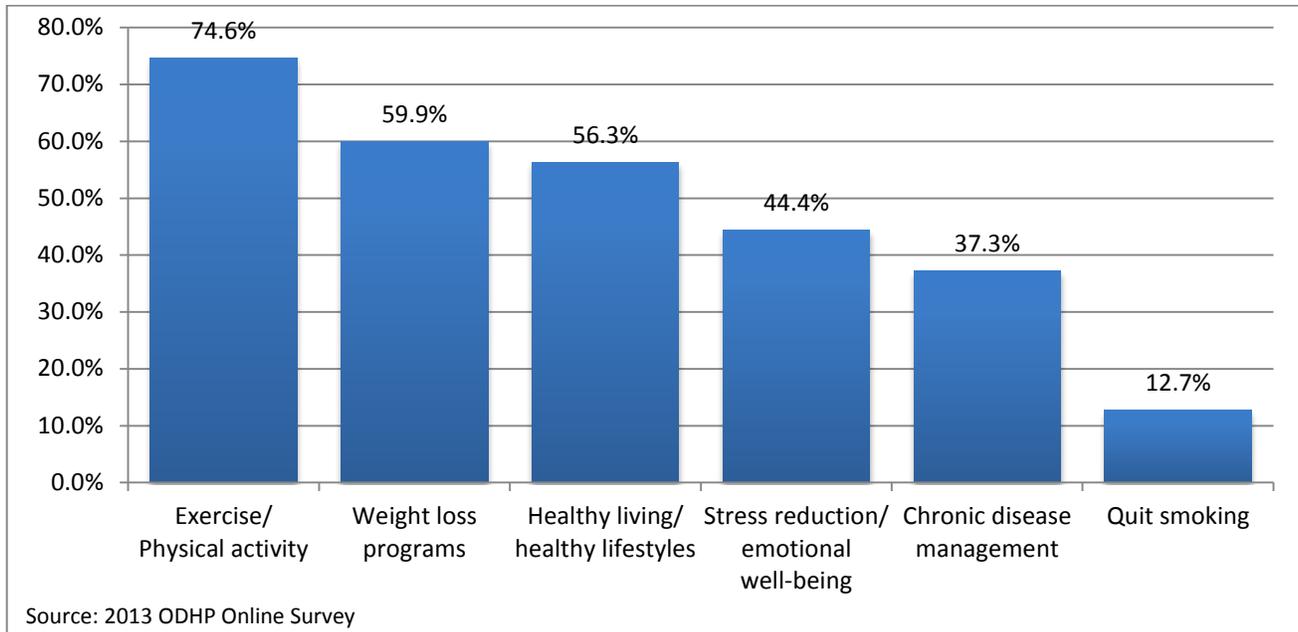
**Figure 20: Top 3 Reported Barriers to PWD Participation in Health Promotion Programs**



*“I’m not thinking about it until I get affected by it, right? So if something, obviously if something bad happens, then I’ll deal with it. But until then, meh? You know, things are good. So it’s like, if I don’t have to go into my doctor, I’m not gonna. I’m hard-headed, if I get sick, I’ll deal with it and deal with it, until I absolutely have to [see a doctor].”*

*– Open forum man using a wheelchair*

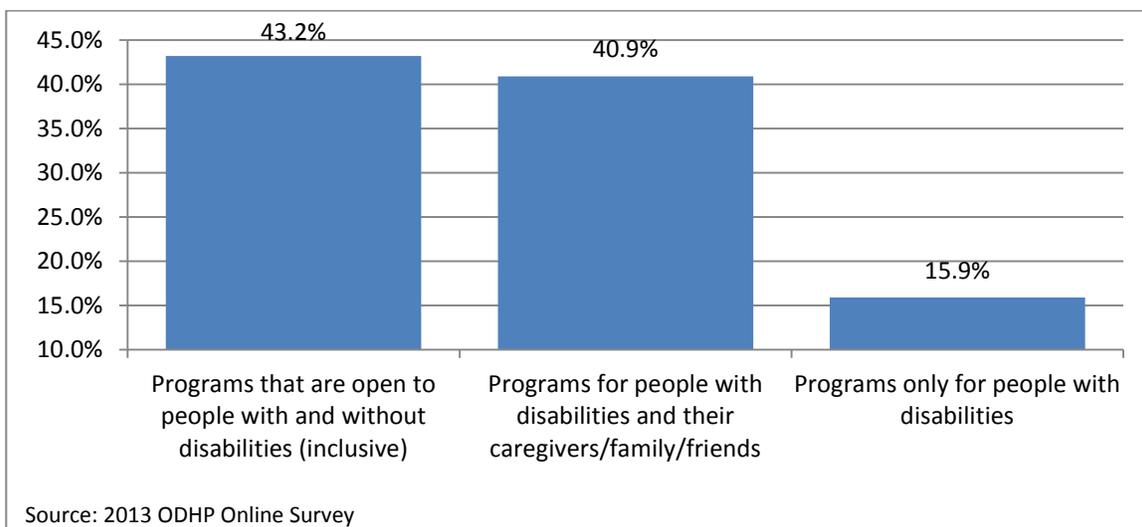
**Figure 21: Health Promotion Programs PWD Report They Would Participate in if Accessible**



*“My son is a person with autism and doesn’t read at all to my knowledge. Doctors just give him a bunch of brochures and say ‘here, have your mom read these to you.’ It would be great to have more information that is less print oriented and written at an education level that is lower or simpler. We are not all geniuses.”*

*– Open forum mother of a son with disability*

**Figure 22: Most-Preferred Type of Health Promotion Program Among PWD**



When asked which type of health promotion program is most preferred by people with disabilities, the majority of online survey respondents ranked inclusive programs that are open to people with and without disabilities as their most-preferred choice (as shown in Figure 22).

Ohio health status and exercise rates for adults with and without disabilities are reported in Figure 23 and compared with the national rates. In Ohio, 43.9% of adults with disabilities reported a fair or poor health status compared with 8.7% of adults without disabilities. Also, 40.8% of Ohio adults with disabilities reported no exercise in the past month compared with 22.2% of Ohioans without disability. Ohio rates are very similar to national statistics on these indicators.

**Figure 23: Ohio/National Comparisons of Health Status and Exercise by Disability Status**

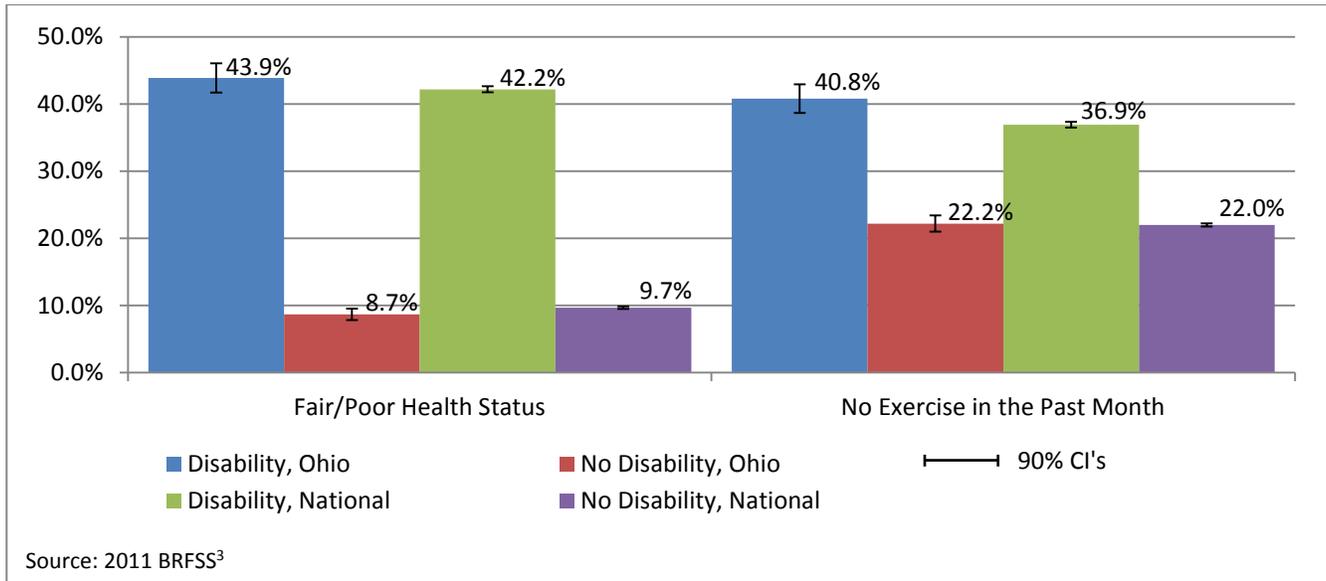
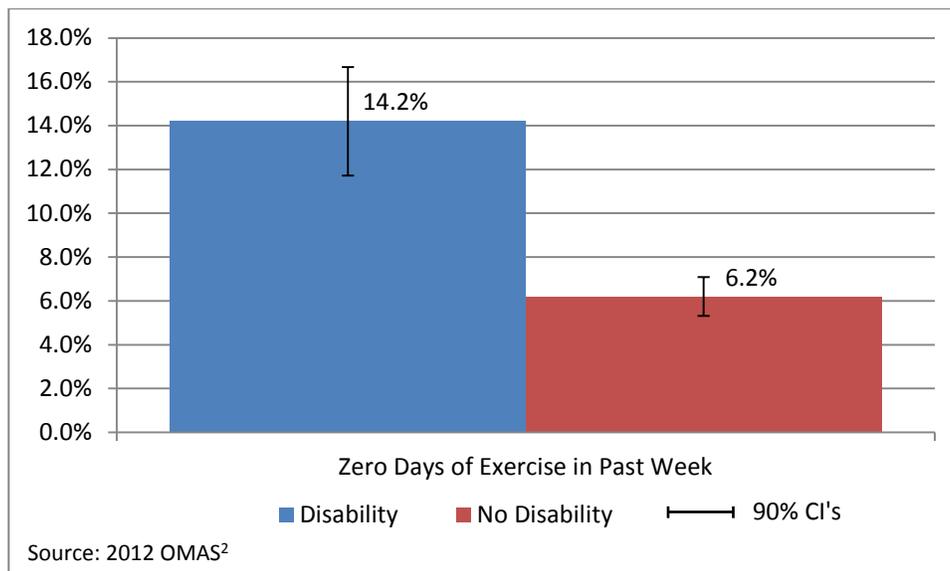


Figure 24 shows the percentage of children with and without disabilities who exercised zero days in the past week. In Ohio, it was reported that 14.2% of children with disabilities did not exercise in the past week compared with 6.2% of children without disabilities.

**Figure 24: Ohio Child Exercise Behavior by Disability Status**



*“You have to wonder if, um, if families, or caregivers, or people who are doing direct care with individuals that have disabilities, just let them have what they want just because they feel bad they’re living with what they’re living with. You have to wonder, because honestly, I let [my daughter who has cerebral palsy] do whatever she wants to do, you know. I mean, I need to admit that... There is some level of guilt that goes with being a parent of a kid that has any disability but especially many disabilities. I know as I speak to my own. So there’s a level of guilt that you live with every single day. So, if she wants to eat junk food all day, I think, but if she had some way [of communicating] that’s what she wanted, I don’t know, I mean, I just wonder if that’s part of it, if that plays a role as well.”*

*– Open forum mother of a daughter with disability*

Often times, people, including healthcare professionals, can make inaccurate assumptions regarding the quality of life for people with disabilities. There is evidence showing that in most cases, people with disabilities rate their own quality of life much higher than others around them do.<sup>9</sup> These assumptions and attitudes can have a negative impact on the health of people with disabilities as healthcare providers may consequently not recommend various preventive services or health behavior changes, which can lead to undesired health outcomes.<sup>9</sup>

*“We’ve had that with doctors too saying, ‘well he doesn’t need another surgery, it’s going to cause him discomfort, you might as well wait.’ I said, ‘No, if it’s going to increase his independence, we’re going to do this now while he’s young, so he can be more independent in the future.’”*

*– Open forum mother of a son with disability*

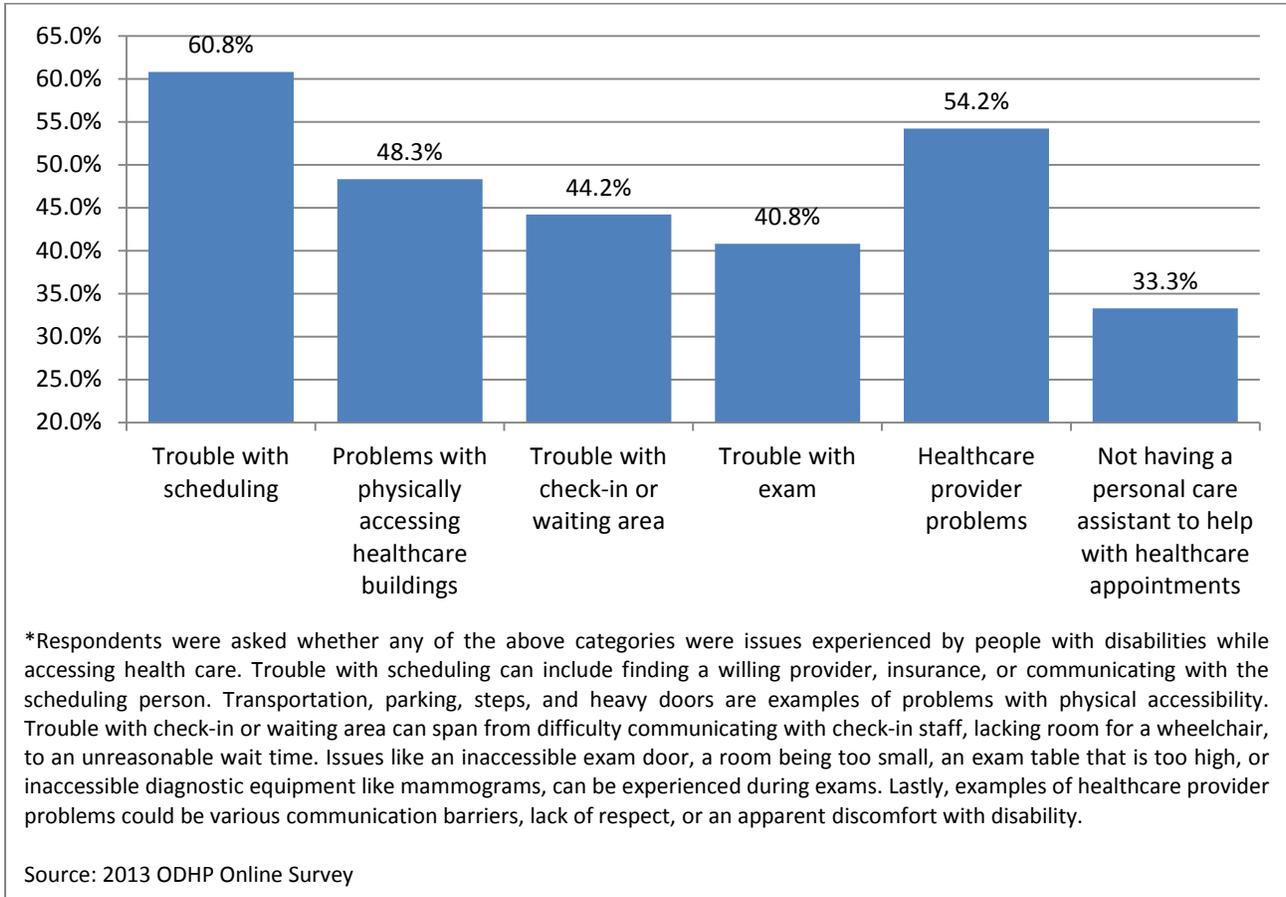
## **Access to Health Care**

People with disabilities tend to have less access to healthcare services than the general population and therefore experience unmet healthcare needs.<sup>10</sup> For people with disabilities, getting health care can be difficult due to physical and attitudinal barriers. Access includes parking spaces close to entrances, well-placed ramps or curb cuts, and doors that are wide and easy to open so that people with disabilities can get into buildings. People with disabilities need access to service areas (e.g., counters and exam tables) and accessible materials (e.g., large print).<sup>11</sup> Additionally, a lack of care coordination and access to specialty care seemed from the forum input, to be a considerable barrier for families handling one or more disabilities.

*“What I have experienced is when [families of people with disabilities] have multiple healthcare delivery systems, they don’t know how those systems work together, so that becomes a barrier for them. What happens is, because they don’t know how they work together, often, they may, you know, [go] without the care... and because they don’t know what they have, they don’t know how to use it.”*

*– Open forum participant*

**Figure 25: Reported Health Care Access Problems Experienced by PWD\***



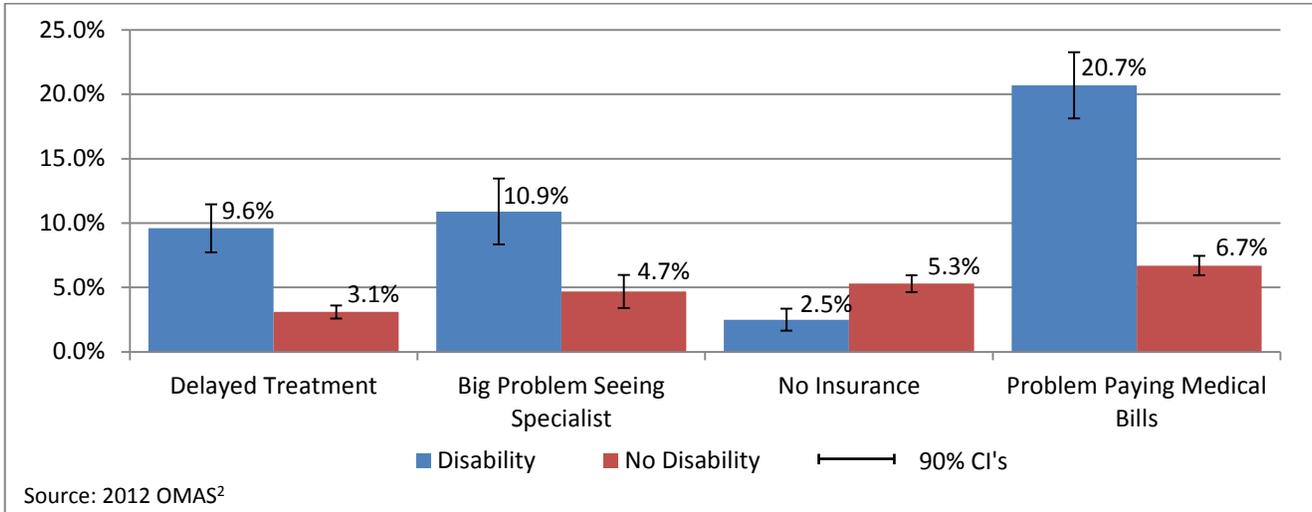
Among ODHP online survey respondents, many topics were reported as healthcare access barriers experienced by people with disabilities. As shown in Figure 25, over 60% found difficulty scheduling healthcare appointments and over 50% report problems directly with the healthcare provider exist.

*“I’m legally blind and deaf. They hand me papers and say, ‘here, fill this out; read this.’ I try to explain that I may not look like I have that type of disability, but I do. I get a look of complacency, like I’m causing a problem.”*

*– Open forum participant who is blind and deaf*

Figure 26 shows that among Ohioans with disabilities, 9.6% report delayed medical treatment compared with 3.1% among Ohioans without disabilities. Ohioans with disabilities also report having more problems with seeing a specialist when needed, 10.9% to 4.7%, and having problem paying medical bills, 20.7% to 6.7%, compared with Ohioans without disabilities.

**Figure 26: Ohio Adult Access to Care by Disability Status**

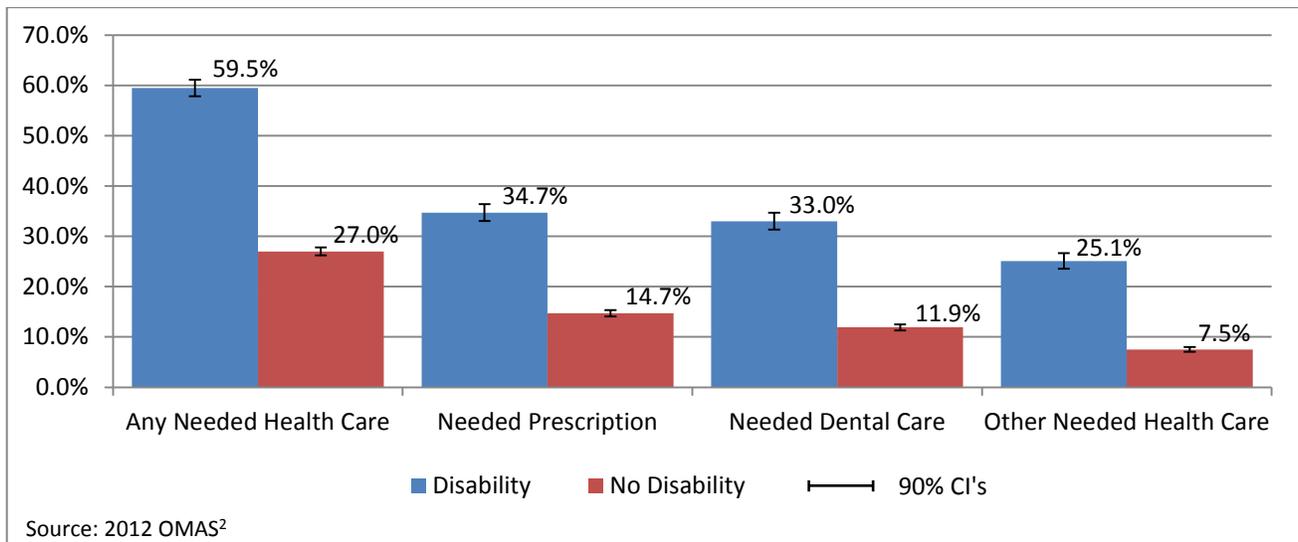


*“My issue now is transition, trying to get into adult care and finding an adult provider that will understand or are comfortable with a non-verbal person or someone that can’t, you know, [my daughter with cerebral palsy] may not necessarily be able to tell them what hurts. They’re going strictly off what I say, God forbid something happens to me so then you have another host of issues.”*

*– Open forum mother of a daughter with disability*

Adults with disabilities reported not getting needed health care, prescriptions, and dental care at rates more than double those without disabilities as can be seen in Figure 27. Here needed health care includes needed dental, prescription, vision, mental health or counseling services, or other health care. Examples in the other health care category include a medical exam and medical supplies and equipment.

**Figure 27: Ohio Adult Access to Care – Did Not Get Needed Care by Disability Status**

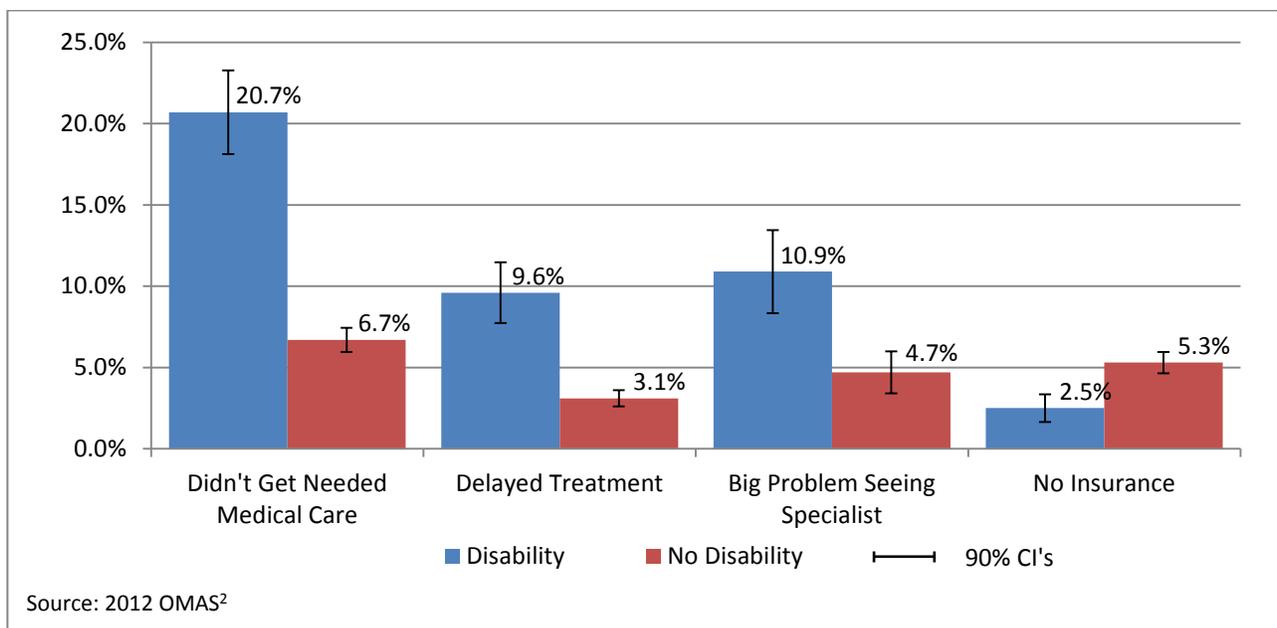


*"I think doctors are compassionate if it comes directly from the client, so the question is, how do we help the individual become their advocate. I think when you have a disability, there are esteem issues sometimes and you generally don't want to make waves, or you're going to be very aggressive, and we need to teach everybody how to be assertive. It's hard in the deaf world because they will become [frustrated], and body language gets misunderstood by medical providers, and they look at them saying, oh well this person has bipolar issues. And it's kind of like, wait a minute doctor, that's not true, it's frustration that you're seeing."*

*– Deaf open forum participant*

Regarding children with disabilities, Figure 28 shows that compared with children without disabilities, children with disabilities are reported more likely to not get needed medical care, have experienced delayed treatment, and have big problems seeing a specialist. These access issues are problematic for children with disabilities in Ohio despite the fact that the uninsured rate for children is quite small overall. In fact, children with disabilities in Ohio are more likely to have insurance than those children without disabilities.

**Figure 28: Ohio Child Access to Care by Disability Status**



*"I'd love to see more pediatric specialists between the hospitals in the state expanding out to [rural areas] for access. So many parents can't afford to take time off or drive. It's such a challenge to access the therapies and things their kids need. When you're living out in more rural areas, it's harder to reach those. I wonder if some of the children would have a better life if they were able to access those things. It's harder for people that live in a very rural community; they don't want to have to move just to access those [specialty services] for their children. Some people don't understand what's available out there until it's put into their area."*

*– Open forum mother of a son with disability*

Barriers to accessing health care brought up during the ODHP open forums revolved around both physical and attitudinal issues. These concerns include an inability to physically access doctors' offices or exam equipment as well as concerns that doctors may not be effectively attending to the needs of patients with disabilities and their families.

*"Accessible parking is an issue. They have accessible [parking] spots, but you cannot get [in to the office]. We've had to change pediatricians because they had steps and wouldn't do anything about it."*

*– Open forum participant*

*"There's an overall attitude you run into sometimes, and it's not all the time, but it's a good bit of the time that the doctors [think they] know more than you do [about your child]. But there's this gap that [doctors] have to recognize, the fact that as a parent being there for your child or loved one [who has a disability] 24/7, there are things that you're gonna know that even as a doctor, they're just not gonna know because they're not there every day... and the best care we've had are when good doctors are looking at us and asking us, 'what do you think and what are you encountering?' because we are our children's and our family's experts because we're there every day... you gotta recognize that kids are doing things... at home that they might not see in the doctor's office."*

*– Open forum mother of a daughter with disability*

*"[Healthcare professionals] want me to put my 21-year-old daughter down and transition her [from wheelchair to exam table]. I have a bad neck and told the nurse I physically was unable to transition her, and she looked at me like 'well I can't do it'; she came back after talking with two other people, and said 'she doesn't have to leave her wheelchair after all.'"*

*– Open forum parent of a daughter with disability*

ODHP open forum participants shared specific perspectives from the Deaf community regarding their experiences communicating with healthcare professionals. There seems to be a lack of understanding on how to communicate appropriately between a physician and a Deaf patient.

*"What I find happens a lot is that the medical community does not fully understand their obligation under the ADA to provide interpreters. They believe that they can write things out to a person or lip-read."*

*– Open forum participant*

## **Emergency Preparedness**

In the event of an emergency, people with disabilities may need assistance from emergency personnel. Disabilities can vary from person to person, and therefore it is important for first responders to understand how to assist and evacuate people with disabilities carefully and quickly.<sup>12</sup> Vulnerable

populations, such as disabled individuals, children, and the elderly, are at a particular risk in disaster scenarios, and it is important to consider that addressing their needs in preparedness efforts could dramatically improve their outcomes when disaster strikes. Persons with disabilities (PWD) tend to suffer worse health outcomes than the general population when disasters occur.<sup>13,14,15</sup> Evidence suggests that in most cases, people with disabilities are poorly represented in the emergency planning process.<sup>13</sup> Furthermore, including individuals with disabilities in the emergency planning process would likely benefit members of the general population, who could experience situational disability as a result of a disaster.

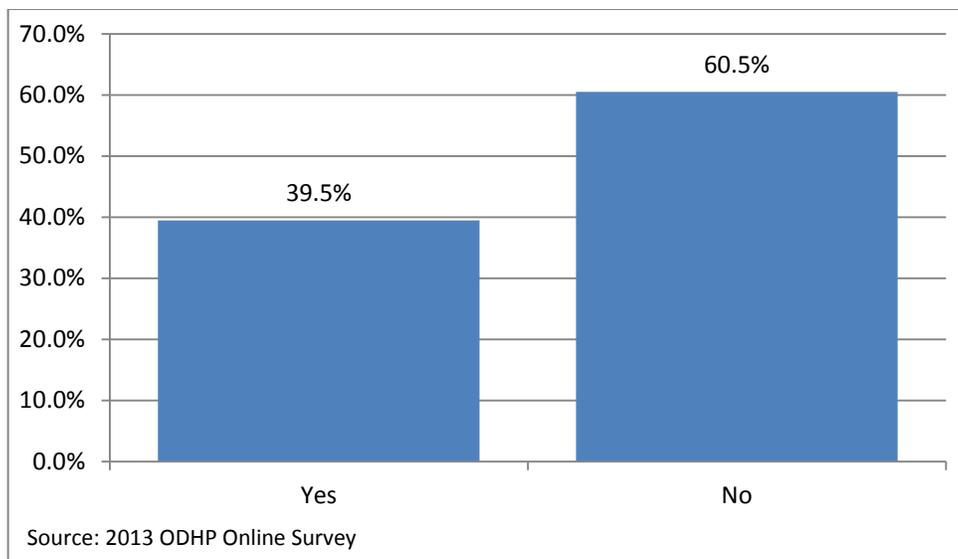
*“Usually that beeping thing that goes off on your TV and you see something running on there, but you know, if the power goes off, Deaf people are concerned about ‘how does somebody tell me there’s a [tornado warning], other than through the buddy system?’ Then the next real problem is, ‘I need an EMS,’ they come out, ‘how do I communicate with this person as to what, you know, unless I have a family member with me, there’s no way to communicate as to [what] my needs [are] with an EMS.’”*

– Open forum participant

*“In public schools, most public schools say they have emergency preparedness in place for kids with disabilities, but many of them don’t have very realistic plans. One building has several floors and one elevator but it is an emergency and their plan is to carry people in wheelchairs, IN their wheelchairs down from the third floor in an emergency... No, they haven’t practiced it.”*

– Open forum participant

**Figure 29: Have an Emergency Plan if Required to Evacuate Your Home?**

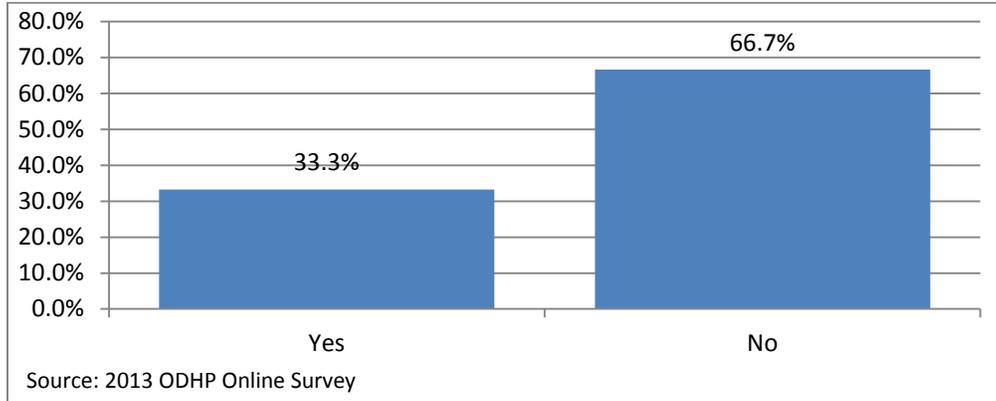


Of those who answered “no” in Figure 29, 69.4% reported that they do not know where to get planning tools and information to make an emergency plan/kit.

*“You know, if you want to have a bag handy that you can leave in a hurry, they always tell you to have an emergency kit. Well, the problem you run into is that Medicaid and a lot of insurances only cover so many. So when you’re trying to have medication ready to go in an emergency, pull-ups or diapers, things like that, do you have enough to really be able to make a bag out of it or are you really going month to month off of what you have and is covered so that’s not always identified too.”*

*– Open forum mother of a son with disability*

**Figure 30: Have an Emergency Plan if Required to Shelter in Place for an Extended Period of Time?**



Of those who answered “no” in Figure 30, 73.1% reported that they do not know where to get planning tools and information to make an emergency plan/kit.

**Figure 31: Where One Would Go if Neighborhood was Told to Evacuate During an Emergency**

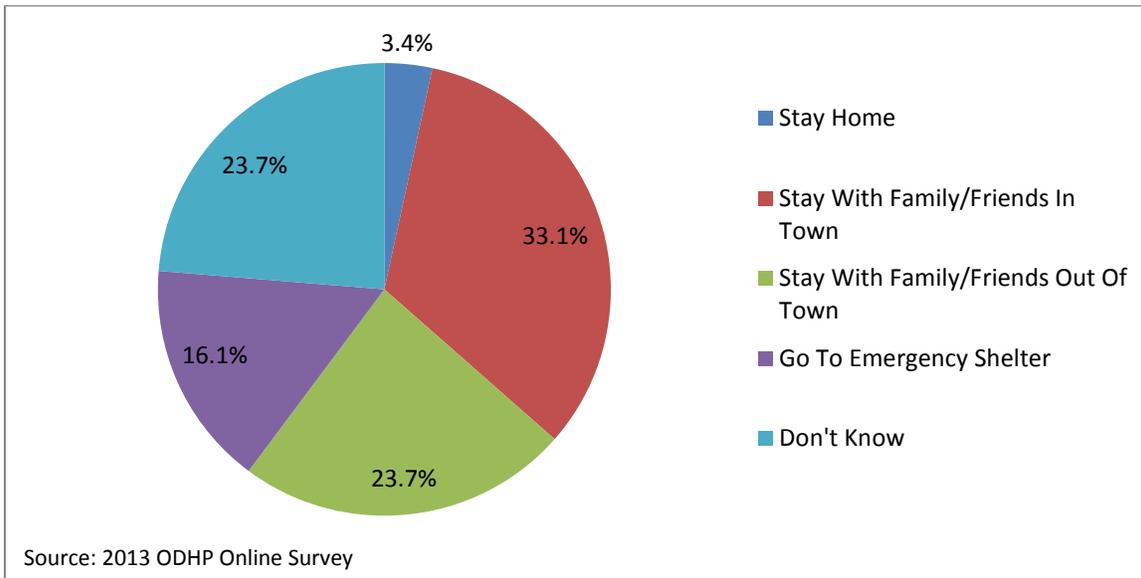


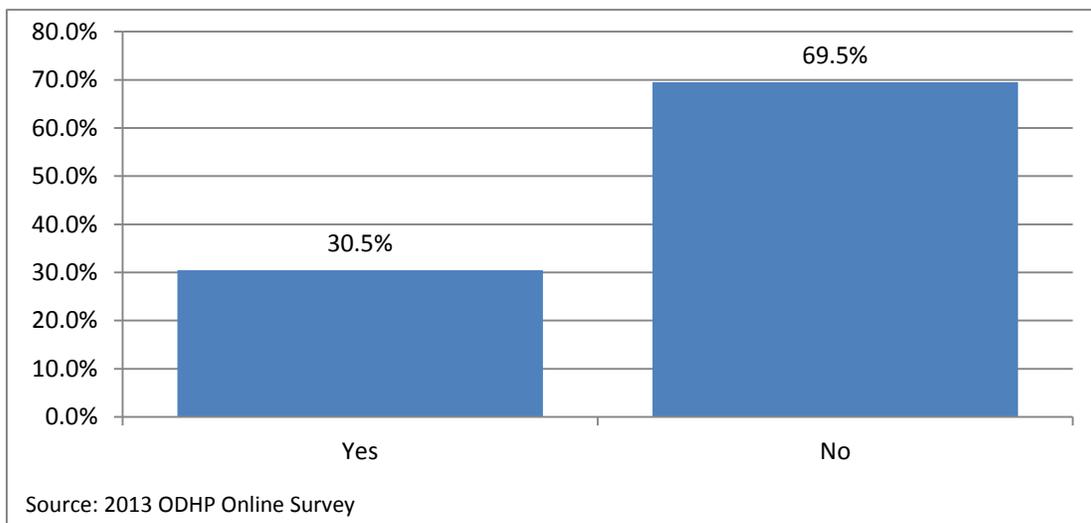
Figure 31 shows that 23.7% of ODHP online survey respondents do not know where to go if their neighborhood was told to evacuate during an emergency. Strikingly, 41.5% of survey respondents also reported that they do not know where and how to get information in case of an emergency/disaster.

*“A lot of senior citizens and people with disabilities live alone. They don’t have support other than their friends or families that live away. A big issue with natural disasters is being able to get out, having someone to check to make sure people with disabilities are out of their homes or are in safety location they’re supposed to go to, or if they know where they’re supposed to go to.”*

*– Open forum participant*

It is important that people with disabilities living in the community know where to find resources regarding shelters that can accommodate their disability needs should an emergency situation occur. The majority (69.5%) of ODHP online survey respondents reported not knowing how to find this kind of shelter information as shown in Figure 32.

**Figure 32: Respondents Who Know How to Find Information for the Closest Shelter That Can Handle Their Disability Needs During an Emergency/Disaster**



*“I was really kind of horrified at some of the suggestions [made regarding emergency plans] You have a family, and they want to split the family and send the child with a disability or in a [wheel]chair or that needs some nursing, to one facility and then, you know, so only one parent can go with that child. So if I, as a single parent, and I’ve got four kids, what do I [do]? I can’t send the other three [kids] somewhere else.”*

*– Open forum mother of a daughter with disability*

Of the ODHP online survey respondents, 61.5% reported having experienced an emergency and had to deal with emergency workers. Of those with this experience, 76.4% felt first responders were great and had no difficulty with the disability; 11.1% felt first responders acted uncomfortable with the disability; and 12.5% felt the reaction of first responders to the disability made the situation worse.

## **Somali Community**

Columbus, Ohio, is the second-largest home to the Somali community in the United States, after Minneapolis-St. Paul, Minnesota.<sup>5</sup> It is estimated that 45,000 Somalis reside in Franklin County of Ohio.<sup>16</sup> Given that Ohio has one of the largest Somali populations in the country, ODHP found it important to reach the Somali community to gain their perspective and insight.

ODHP held a focus group among a small community of Somali immigrants living in Columbus, Ohio, in May 2013. This particular community was selected because it was a concentrated community of Somalis and ODHP had a competent interpreter who is from and trusted by the community to help facilitate the focus group. A total of 19 people participated; out of whom, 3 were male and 16 were female. Almost all the participants (18) were from Somalia and 1 was from Nigeria. There was some difficulty getting the participants to think specifically about the barriers and needs of people with disabilities among their community. In fact, one Somali focus group participant was Deaf but neither she nor anyone else in the group seemed to recognize profound hearing loss as a disability. It became clear that the Somali community faces substantial barriers to the healthcare system due to lack of health insurance, patient-provider communication and comprehension issues, and a mistrust of medical providers. Participants shared that often times, they would just deal with their medical issues on their own by ignoring them because of the said barriers. It seemed that the needs of the overall Somali community overshadowed any specific needs associated with a functional impairment or disability. In addition, health promotion and emergency preparedness are not priorities due to barriers accessing preventive health care or not having the resources to know what to do in emergency situations.

## **Conclusion**

The Ohio Disability and Health Program has utilized a mixed-method approach to understanding the health needs of Ohioans with disabilities across the lifespan. Multiple sources of data such as population surveys and open forums were analyzed to estimate disability prevalence, measure indicators of access to health care, understand the health behaviors, and identify emergency preparedness needs of Ohio's disability population. Though approximations of disability vary by data source, consistent patterns are shown providing us with important information. Estimates of adult disability prevalence range from 16% to 26% while estimates of child disability prevalence range from 5% to 18%, depending on the approximation of disability. Additionally, findings show increased disability prevalence in Appalachian counties and among black/African American adults.

ODHP's public health needs assessment identifies many disparities where higher prevalence of health risk behaviors, poor health outcomes, and worse access to health care exist among Ohioans with disabilities compared with Ohioans without disabilities. Examples of these disparate rates include

reporting delayed treatment, issues seeing specialists, problems paying medical bills, and not getting needed health care, prescriptions, and dental care. Similar disparate trends were also found for health promotion measures when comparing these two populations such as smoking rates, lack of regular exercise, reported poor or fair health status, obesity, and other chronic diseases.

This needs assessment helps paint a picture of the health status, behaviors, and needs of Ohio's disability population. The quantitative data illustrates the compelling gaps in services, education, policies, and empowerment that exist for people with disabilities compared with their counterparts. Furthermore, the qualitative pieces of this assessment confirms many results found from the analyzed surveys while shedding light on the actual stories and perspectives of individuals with or impacted by disability in Ohio. This report is well suited to educate stakeholders on the health status of people with disabilities living in Ohio. Additionally, the findings can be used to inform strategic planning of programs, practices, and other initiatives intended to improve the lives and health outcomes of Ohioans with disabilities.

*“If we had a program that brought us all there, brought these families and all these caregivers [of people with disabilities] together, and guide us on programs where you know where you’re going and where to go for that help, I think that would be [useful]. I know it would be for me.”*  
– Open forum woman with a mother who has Alzheimer’s

## **Future Directions**

ODHP will utilize the findings from this public health needs assessment report to inform, assess, and direct its strategic plan moving forward to better achieve program goals.

The findings that people with disabilities, compared with people without disabilities, have high and disparate rates of chronic disease and cigarette use support ODHP's objective of increasing preventive health screenings among people with disabilities through increasing accessibility of mammography facilities and federally qualified health centers. Findings reinforce ODHP's priority to collaborate with the Ohio Department of Health's Tobacco Prevention and Cessation Program to further reach people with disabilities. In addition, the disability community voiced communication barriers among physicians and patients with disabilities. ODHP will emphasize its role as a resource to providers, businesses, and individuals on improving the quality and efficacy of communication in patient-provider relationships.

Data obtained that people with disabilities lack the resources, knowledge, and plans necessary during emergencies will guide ODHP's emergency preparedness goal. As ODHP works with Ohio's state and local emergency management agencies, attention will be given to the whole community planning framework to integrate the functional needs of the disability community into the emergency planning process. It will also be vital for ODHP to identify effective ways to educate and increase exposure of emergency response activities among people with disabilities so they can be as prepared as possible.

## References

1. World Health Organization. *International Classification of Functioning, Disability and Health (ICF)*. Geneva, Switzerland: World Health Organization. 2001.
2. Ohio Medicaid Assessment Survey (OMAS). The Ohio Colleges of Medicine Government Resource Center. <http://grc.osu.edu/omas/>. Accessed May 13, 2013.
3. The Behavioral Risk Factor Surveillance System (BRFSS). Centers for Disease Control and Prevention. <http://www.cdc.gov/brfss/>. Accessed May 13, 2013.
4. The American Community Survey (ACS). United States Census Bureau. <http://www.census.gov/acs/www/>. Accessed May 13, 2013.
5. Community Research Partners. Counting the Franklin county Somali population. *CRP Data Bytes*. 2009;2(Spring 2009):1-8. [http://www.communityresearchpartners.org/uploads/DataBytes/DataByteNo2\\_SomaliPopulation.pdf](http://www.communityresearchpartners.org/uploads/DataBytes/DataByteNo2_SomaliPopulation.pdf). Accessed May 20, 2013.
6. Centers for Disease Control and Prevention. Ohio health overview. Disability and Health Data System. <http://dhds.cdc.gov/profiles/profile?profileId=3&geoTypeId=1&geoids=39>. Updated February 6, 2013. Accessed May 20, 2013.
7. National Council on Disability. The current state of health care for people with disabilities. [http://www.ncd.gov/rawmedia\\_repository/0d7c848f\\_3d97\\_43b3\\_bea5\\_36e1d97f973d?document.pdf](http://www.ncd.gov/rawmedia_repository/0d7c848f_3d97_43b3_bea5_36e1d97f973d?document.pdf). Published September 30, 2009. Accessed May 20, 2013.
8. Centers for Disease Control and Prevention. Disability data: colorectal cancer screening – 1 year at a time. Disability and Health Data System. <http://dhds.cdc.gov/dataviews/view?viewId=768>. Updated February 6, 2013. Accessed May 20, 2013.
9. Shakespeare T, Lezzoni LI, Groce NE. The art of medicine: disability and the training of health professionals. *The Lancet*. 2009;374(9704):1815-1816. doi:10.1016/S0140-6736(09)62050-X.
10. World Health Organization. Disability and health. <http://www.who.int/mediacentre/factsheets/fs352/en/index.html>. Published November 2012. Accessed May 20, 2013.

11. Centers for Disease Control and Prevention. Disability and health: accessibility. <http://www.cdc.gov/ncbddd/disabilityandhealth/accessibility.html>. Updated October 12, 2012. Accessed May 20, 2013.
12. Centers for Disease Control and Prevention. Disability and health: emergency preparedness. <http://www.cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html>. Updated October 29, 2012. Accessed March 26, 2013.
13. Fox MH, White W, Rooney C, Rowland JL. Disaster preparedness and response for persons with mobility impairments: results from the University of Kansas Nobody Left Behind study. *J. Disabil. Policy Stud.* 2007;17(4):196-205.
14. Gerber BJ, Norwood F, Zakour M. Disasters, evacuations and persons with disabilities. [http://www.disabilityevacuationstudy.org/NIDRR\\_Indiv\\_Finding\\_Report\\_Disaster\\_Evacuations\\_FIN\\_AL\\_6-10.pdf](http://www.disabilityevacuationstudy.org/NIDRR_Indiv_Finding_Report_Disaster_Evacuations_FIN_AL_6-10.pdf). Published April 2010. Accessed May 15, 2013.
15. Sullivan HT, Häkkinen MT. Preparedness and warning systems for populations with special needs: ensuring everyone gets the message (and knows what to do). *Geotechnical and Geological Engineering.* 2010;29(3):225-236.
16. Roble A, Rutledge D. *The Somali Diaspora: A Journey Away*. Minnesota: University of Minnesota Press; 2008.

## Ohio Disability and Health Program Staff and Team Members

### The Ohio State University Nisonger Center

Susan Havercamp, PhD, *ODHP Program Director*  
Yiping Yang, MPH, CHES, *ODHP Program Coordinator*  
Rosalind Gjessing, BA, *Clinical Research Assistant*  
Annie Witte, BA, *Former Program Assistant through May 2013*  
Rebecca Monteleone, *Student Assistant*  
David Ellsworth, BS, *Student Assistant*

### The Ohio Department of Health

Jessica Foster, MD, MPH, FAAP, *Physician Administrator, Bureau for  
Children with Developmental and Special Health Needs*  
Anureet Benipal, MPH, *ODHP Policy Specialist*

### University of Cincinnati University Center for Excellence in Developmental Disabilities

Ilka Riddle, PhD, *ODHP Co-Investigator and UC UCEDD Director*  
Erica Coleman, MS, *Health Activities Coordinator*

### The Ohio Colleges of Medicine Government Resource Center

Tim Sahr, MPH, MA, *Director of Research and Analysis*  
Robert Ashmead, MS, *Research Specialist*

## ODHP Disability Community Planning Group (DCPG)

American Council of the Blind of Ohio ----- Ann Gazelle  
Autism Society of Ohio ----- Barbara C. Yavorcik, Marla Root  
Creative Living ----- Marilyn Frank  
Deaf Services Center, Inc. ----- John L. Moore, Marsha Moore, T.J. Veppert  
Disability Rights Ohio ----- Mike Kirkman  
Down Syndrome Association of Ohio ----- Marge Barnheiser  
Easter Seals ----- Pat Luchkowsky  
Goodwill Columbus ----- Janet Ehrhardt  
Health Policy Institute of Ohio ----- Amy Rohling McGee  
Medicaid Health Systems, Ohio Dept. of Job & Family Services ----- Icilda Dickerson, Mary Pearson  
National Federation of the Blind of Ohio ----- J. Webster Smith  
National Organization of Parents of Blind Children of Ohio ----- Carol Akers  
Ohio Association of Community Health Centers ----- Randy Runyon, Heather Porter  
Ohio Association of the Deaf ----- Verne Taylor, Irene Tunanidas, Linda Mahmood  
Ohio Colleges of Medicine Government Resource Center ----- Jerry Friedman  
Ohio Department of Aging ----- Jane Byrnes  
Ohio Department of Aging's Strategic Partnerships Division ----- Marc Molea  
Ohio Department of Developmental Disabilities ----- Janet Winterstein  
Ohio Department of Education ----- Mark Smith, Thomas Lather  
Ohio Department of Health ----- Anne Harnish  
Ohio Department of Health's Office of Health Preparedness ----- Tina Krempasky  
Ohio Department of Mental Health ----- Tracy Plouck  
Ohio Department of Veterans Services ----- Rick Hatcher, Deborah Kieffer  
Ohio Developmental Disabilities Council ----- Carolyn Knight, Kay Treanor, Tammy Waller  
Ohio Emergency Management Agency - Nancy Dragani, Patrick Sheehan, Brad Schwartz, Todd Barstow  
Ohio Governor's Office of Health Transformation ----- Monica Juenger  
Ohio Rehabilitation Services Commission ----- Karen Johnson  
Ohio School for the Deaf ----- Janet Gordon  
Ohio Self Determination Association ----- Dana Charlton  
Ohio State School for the Blind ----- Cynthia Johnson, Dawn Henslee  
Ohio Statewide Independent Living Council ----- Kay Grier, Mary Butler  
People First Ohio, Inc. ----- Sadie Hunter, Joellen Hunter  
The Arc of Ohio ----- Gary Tonks, David Lewis  
The Brain Injury Association of Ohio ----- Suzanne Minnich  
The Ohio Governor's Council on People with Disabilities ----- Donna Foster  
The Ohio State University ADA Coordinator's Office ----- Scott Lissner  
The Ohio State University College of Public Health ----- Phyllis Pirie  
The Paralyzed Veterans of America, Buckeye Chapter ----- Sharon Moster, Carl Harris, Robert Thomas

**Ohio Disability and Health Program**

The Ohio State University Nisonger Center

357 McCampbell Hall, 1581 Dodd Drive Columbus, OH 43210

phone 614.688.2928 | fax 614.366.6373 | <http://nisonger.osu.edu/odhp>

 [www.facebook.com/OhioDisabilityandHealthProgram](http://www.facebook.com/OhioDisabilityandHealthProgram)  [www.twitter.com/OhioDHP](http://www.twitter.com/OhioDHP)