STEM Assessment and Reporting Tracker

Health and Service Differences

Survey Introduction

This survey asks questions about hearing, vision, mobility, concentration, learning, communication, and mental health. Your answers will help us find health and service differences among people with and without functional difficulties. There are 7-9 questions that will take approximately 5-10 minutes to complete.

Health and Service Differences Questions

The following questions were taken verbatim from READLD:

McGee, M.G. (2020). Race, ethnicity, language and disability (READLD) implementation guide. Portland, Oregon: Oregon Health Authority, Equity and Inclusion Division. (READLD site; link to survey instrument (English - PDF) and Implementation Guide PDF)

- Important note from McGee et al. (2020): "These functional limitation questions were extensively tested to ensure that they work well to capture most people with disabilities. Notice how none of the questions relating to disability contain the word disability."
- Implementation note: please use "Health and Service Differences" in participant-facing materials.

Prompt for Participants

"Your answers will help us find health and service differences among people with and without functional difficulties. Your answers are confidential."

*Written surveys also include: (*Please write in "don't know" if you don't know when you acquired this condition, or "don't want to answer" if you don't want to answer the question.)"*

Question Wording	Rationale
Are you **deaf** or do you have **serious difficulty hearing**? † Yes [*If yes, at what age did this condition begin? _____] † No † Don't know † Don't want to answer	See Table 4 below
Are you **blind** or do you have **serious difficulty seeing**, even when wearing glasses?	See Table 4 below

† Yes [*If yes, at what age did this condition begin? _____] † No † Don't know † Don't want to answer	
Please stop now if you/the person is under age 5	
Do you have **serious difficulty walking or climbing stairs**? † Yes [*If yes, at what age did this condition begin? _____] † No † Don't know † Don't want to answer	See Table 4 below
Because of a physical, mental or emotional condition, do you have **serious difficulty concentrating, remembering or making decisions**? † Yes [*If yes, at what age did this condition begin? _____] † No † Don't know † Don't want to answer	See Table 4 below
Do you have **difficulty dressing or bathing**? † Yes [*If yes, at what age did this condition begin? _____] † No † Don't know † Don't want to answer	See Table 4 below
Do you have **serious difficulty learning how to do things most people your age can learn**? † Yes [*If yes, at what age did this condition begin? _____] † No † Don't know † Don't want to answer	See Table 4 below
Using your **usual (customary) language,** do you have **serious difficulty communicating** (for example understanding or being understood by others)? † Yes [*If yes, at what age did this condition begin? _____] † No	See Table 4 below

† Don't know † Don't want to answer † Don't know what this question is asking	
Please stop now if you/the person is under age 15	
Because of a **physical, mental or emotional condition**, do you have **difficulty doing errands alone** such as visiting a doctor's office or shopping? † Yes [*If yes, at what age did this condition begin? _____] † No † Don't know † Don't want to answer	See Table 4 below
Do you have **serious difficulty** with the following: **mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations?** † Yes [*If yes, at what age did this condition begin? _____] † No † Don't know † Don't want to answer † Don't know what this question is asking	See Table 4 below

Question wording from MSC 0074 rev.12/30/2020

Rationale

From McGee, M.G. (2020). Race, ethnicity, language and disability (REALD) implementation guide. Portland, Oregon: Oregon Health Authority, Equity and Inclusion Division. (READ Implementation Guide PDF)

The following text was taken verbatim from their excellent Implementation Guide:

Why ask about disability?
"Health inequities between people with disabilities and people without are well-documented (See for example: Campbell, Sheets, & Strong, 1999; Lennox, Beange, & Edwards, 2000; McGee, 2014; Turk, Scandale, Rosenbaum, & Weber, 2001; Wisdom et al., 2010). Collection of information about a disability allows you to identify and eliminate preventable social and health inequities."

Challenges of defining disability
Altman (2014, p. 3) shows the challenges of defining disability, particularly just one definition of disability. Disability can be any of the following:

• Self-identifying as having a disability
• Defined as having a specific impairment
• Having an impairment with functional limitations
• Focusing on functional limitations specifically, or
• Results of person or environment interaction (environmental barriers and supports).

Therefore, there is not just one definition of disability.

"**How does REALD define disability?"**
"REALD disability questions are designed to capture disability prevalence (population) to identify and address social and health inequities. There was a need to identify people with disabilities who are more likely to experience inequities due to their disability or functional limitation. There was a need to do this well with a minimum set of questions. To ask if and how people identify as people with disabilities does not capture well the population. Many people with disabilities do not identify as disabled (Altman, 2014). To ask people about their medical diagnoses or impairment also has limitations. This is because people can have an impairment, but not have any limitation that puts them at greater risk to experience discrimination or exclusion (Altman, 2014).

For these reasons, the REALD questions were based on functional limitations. Six of the seven disability questions are from the American Community Survey (ACS) survey. The ACS disability questions used today originated from the work of a federal interagency work group brought together in 1997 by the Office of Management and Budget. The work group was told they could have up to six questions (Brault, Stern, & Raglin, 2007). This work group agreed that four domains (vision, hearing, mobility and cognitive functioning) identified most people with disabilities. Two more questions were added "that could be used for monitoring independent living and the need for services" (Brault et al., 2007). These questions also needed to meet the needs of different agencies collecting disability as a demographic (Brault, Stern, & Raglin, 2007). The resulting six ACS questions must be used as a set to assure a meaningful measure of disability (Brault, Stern, & Raglin, 2007). These functional limitation questions were extensively tested to ensure that they work well to capture most people with disabilities. Notice how none of the questions relating to disability contain the word disability. The intent of these questions is specified in Table 4. See Appendix A for a summary of what is known about the reliability and validity of the ACS questions."

Taken verbatim from McGee et al., 2020:

Table 4: Underlying intent of American Community Survey disability questions

Question	Intent of Disability Questions
Hearing: Are you deaf or have serious difficulty hearing? (all ages)	To identify people who have: ● Hearing limitations or difficulty of any kind, even when using a hearing aid (if they wear one). For example, they may have difficulty hearing when they are in a noisy environment, or difficulty distinguishing sounds from various sources.
Vision: Are you blind or have serious difficulty seeing, even when wearing glasses? (all ages)	To identify people who have: ● Vision problems of any kind, even when wearing glasses or contact lenses (if they wear them). They may have difficulty seeing things close or far away even with glasses.
Memory or cognitive: Because of a physical, mental, or emotional problem, do you have serious difficulty remembering, concentrating, or making decisions? (age 5+)	To identify people, age 5 and older who have some problems remembering or concentrating. They may: ● Have difficulties finding their way around ● Have difficulties concentrating on what they are doing ● Forget where they are, or ● Forget what month it is. “Making decisions” was added to indicate severity. We do not intend to capture difficulties remembering or concentrating because of common everyday situations such as high workload or stress, or because of substance abuse.
Mobility: Do you have serious difficulty walking or climbing stairs? (age 5+)	To identify people, age 5 and older who have some limitation or problems of any kind getting around on foot. They may: • Have difficulty walking more than a block • Not be able walk up or down steps without difficulty.
Self-care: Do you have difficulty bathing or dressing (age 5+)	To identify people, age 5 and older who have difficulty with taking care of themselves without assistance from others. Washing and dressing represent tasks that occur each day. These are basic activities. Note: If the person is using an assistive device or has a person to help them with this care, it is likely they have difficulty with self-care.
Independent living: Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping (age 15+)	To identify people, age 15 and older who have difficulty doing errands alone. The intent of this question about doing errands alone was to “capture underlying difficulties due to mobility and to mind capacity” (U.S. Census Bureau, 2015, pp. C3-43). The question is not intended to capture difficulty in doing errands due to lack of access to transportation or other resources. One should consider the actual errands a person typically does (as opposed to the listed activities of shopping or going to the doctor’s office).

Source: Brault, M., Stern, S., & Raglin, D. (2007). Evaluation report covering disability. American Community Survey Content Test Report; Current Population Survey Interviewing Manual, 2015 (Uses the same ACS questions).

The six ACS disability questions in REALD also have a follow-up question if a person answers yes. This follow-up question is, “At what age did this condition began?” The question acknowledges differences in potential social, educational and health inequities by when the disability or limitation first acquired. For example, someone who became hard of hearing before the age of three has a very different lived experience than someone who became hard of hearing later in life. It is important to know about these differences within groups so that we can identify and address inequities. Capturing age data expands the ability of the analyst to:

- Create subgroups by age acquired functional limitation
- Create subgroups by length of time with a functional limitation, and
- Be able to control for length of time with a functional limitation.

These health inequities can be seen in the research that examined the relationship between the age when the disability was first acquired, and health status (Jamoom, Horner-Johnson, Suzuki, Andresen, & Campbell, 2008). Their findings suggested that, those who acquired their disability after age 21, even after controlling for current age and other demographic characteristics, were more likely to report fair or poor health than those who acquired their disability before age 22.

The seventh disability question is from the Behavioral Risk Factor Surveillance System (BRFSS) survey. (Does a physical, mental,or emotional condition limit your activities in any way?). We recommend asking this question after the ACS questions as the BRFSS question may be perceived by some people as offensive. This is particularly true from the viewpoint of the social model of disability, in which it is the inaccessible and discriminating society that is disabling, not the individual (Barnes, 2014).

Comparing BRFSS and ACS disability estimates

REALD uses disability questions from both the ACS and BRFSS survey. However, results can differ greatly due to differences in sampling and non-response bias in BRFSS. The percent of people with disabilities in Oregon age 18 and over, ranges from 17.4 (American Community Survey, 2013-2017 estimates) to 26 percent (2016 Behavioral Risk Factor Surveillance Survey) (see Figure 3). An article by Gettens, Lei & Henry (2015) demonstrated how, by re-weighting Massachusetts BRFSS data, the BRFSS disability prevalence estimates to be more in line with the ACS figures.

Disability over the life-course and why it matters

It is important to distinguish disability as:

- An upstream determinant of health (disablism)
- An outcome, or
- Both.

For example, the age distribution of disability by race and ethnicity shows how after age 60, the number of people with disabilities noticeably increases. In addition, it is not always at the same rate (see Figure 4). It is important to know about these differences within the groups so we can identify and address inequities. To address these differences we can ask when the person

acquired the disability or functional limitation. This is in line with the recommendation by Jamoom and colleagues (2008) to allow researchers to "examine possible differences in the relationship between age at onset and self-reported health within specific impairment groups." For example, analysis of OHP data revealed that about one-third of a sampling of new enrollees reported:

- Having a functional limitation
- Acquiring their disability before age 18, and
- Currently being between age 18 and 44.

This may reflect the impact of disability, as a social determinant of health, leading to enrollment in OHP. (For more information see this report: Assessment of Race, Ethnicity, Language and Disability (REALD) Data Quality in the Oregon Health Plan ONE System, page 33).

> These approaches enable a life course perspective, which
> "…recognizes that health trajectories are particularly affected at certain times in life: (1) health status results from the cumulative impact of experiences in the past and the present, (2) the environment affects the capacity to be healthy and function effectively in society, and (3) health inequities reflect inequities that go beyond genetics and personal choice." (Krahn et al., 2015, p. 199)."

Limitations of the REALD disability questions

OHA designed REALD disability questions to capture disability prevalence (population) to help identify and address social and health inequities. However, there are limits to the use of disability responses. For instance, responses to the REALD disability questions do not indicate severity of the functional limitation, nor can they help ensure that accommodation needs are met (Buckley et al., 2012)."

Self-report vs. perceptions (of others)

A study by Buckley and colleagues 2012) indicated the following did not align:

- Clinical views of impairment in cancer screening, and
- Self-reports by patients.

As noted by the authors, most patients with disabilities who require help with personal care needs, such as bathing or dressing "were not perceived by their clinicians and clinic staff members to have physical limitations that potentially would impede cancer screening" (Buckley et al., 2012, p. 1349). Discordance between perceptions by others and self-report are likely influenced by:

- Visibility of the disability
- Impact of functional limitations, and
- Other contextual factors.

This is even more significant as the study also found that patients with disabilities who require help with personal care needs were less likely to be screened for cervical or breast cancer.

Disability FAQs

(These are also taken verbatim from McGee et al., 2020)

Aren't disability questions such as those in the REALD considered protected medical information?
No. These questions focus on "functional limitations" rather than diagnosis, disability identity or impairments. It would be difficult to know the person's actual medical condition based on answers to these questions.

Can we use these questions to determine eligibility for services?
These questions were designed to capture data about most people with functional limitations. For most social service programs, these questions would not be enough to determine eligibility. Further, you do not want to make eligibility contingent on people answering the REALD questions.

Why not just ask one disability question?
It is not possible to rely only on one question such as "Does a physical, mental, or emotional condition limit your activities in any way?" to identify people with disabilities. This question would not adequately capture all people with disabilities. For example, a person who is deaf and uses American Sign Language (ASL) at Gallaudet University, an inclusive university for deaf and hard of hearing students, may say their hearing loss does not limit their activity. Rather, it would be the non-signers at Gallaudet who would experience "activity limitations." Further, if we only asked one question we would not be able to identify and address inequities of different groups of people with disabilities. Not all people with disabilities experience the same inequities. For example, it may be that people who are deaf or have serious difficulty hearing, are less likely to apply for OHP, compared with other people with disabilities. This could prompt us to consider if this is due to communication challenges and limited outreach. As another example, it may be that people who are deaf or have serious difficulty hearing, are less likely to maintain employment, compared to non-disabled people and other people with disabilities. This data could prompt us to consider unique barriers identified by deaf and hard of hearing who work. There may be a separate set of barriers identified by hearing people using wheelchairs, for example. The seven questions help us consider differences among people with disabilities with respect to social and health inequities.

Can we rephrase the disability questions to make it easier to read?
If you rephrase or paraphrase questions it can change how people answer. This compromises our ability to compare response to other data sources using the same questions used on nearly all federally-sponsored surveys. This includes the U.S. Census Bureau and American Community Survey. We recognize that some people may not know how to answer or interpret the questions. The U.S. Census Bureau developed very helpful probing tips for interviewers or data collectors to help you ask disability questions.

Why ask about self-care and independent living difficulty?

The intent of the question about bathing and dressing was to capture those who have difficulty with self-care. “Washing and dressing represent tasks that occur on a daily basis and are basic activities.” The intent of the question about doing errands alone was to “capture underlying difficulties due to mobility and to mind capacity” (U.S. Census Bureau, 2015, pp. C3-43). Why ask about age one acquired a condition or disability? This follow-up question is to acknowledge that disability status can be both or either an upstream determinant of health or a health outcome. Further, one’s exposure to social and educational inequities (e.g., in educational attainment) is a function of when the person acquired their disability, and how long they have lived with a disability. For example, someone who became hard of hearing before the age of three will have a very different lived experience than someone who became hard of hearing later in life. This is due to differences in language acquisition and language access. This may result in inequities in educational attainment and consequently employment earnings. A study conducted by Loprest and Maag revealed that individuals who acquired a disability before age five, compared with those who acquired a disability later in life, as well as non-disabled people, were less likely to complete high school (2003). It is important to know about these differences within subgroups so we can identify and address social and health inequities. What is known about the validity of the demographic disability questions? Development and testing of the disability questions used in the ACS began in the 1990’s. The first use of demographic disability questions was in the U.S. Census Bureau 2000 sample survey. In 2003, the disability questions in the ACS were changed due to a commitment to “clarify the intent of the question” (Stern & Brault, 2005, p. 3). In 2004, members of the ACS working group from the National Center for Health Statistics and U.S. Census Bureau collaborated to conduct an evaluation with in-depth cognitive testing on the ACS disability questions (Miller & DeMaio, 2006). The current demographic disability questions in the ACS are a result of this in-depth testing (Altman, Madans, & Weeks, 2017; Brault et al., 2007). For an in-depth review of the content testing conducted, see here.

Alternative Approaches

These questions have been extensively vetted and testing. It is recommended to use these questions as proposed by McGee et al., 2020.

Upcoding to NIH Demographic Categories

Disability categories are not reported to National Institutes of Health in progress reports. No upcoding information is included.

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