**Disability Demographic Data Collection Guidance:**

**INTRODUCTION:**

The following guidance is intended to help your bureaus begin to collect useful disability data in a standardized way across the City. Historically disability data has been limited. The Census Bureau only collects data on disability through the American Community Survey (ACS) beginning in 1999 and the Survey of Income and Program Participation (SIPP) starting in 2014. The current data available around disability statistics is further compromised by the social stigma’s associated with identifying as a person with a disability. Older Americans, for example who are 35% more likely to experience a disability over the age of 65…rarely identify themselves has having a disability.

The questions we want bureaus to use for the City are based on these federal surveys, as well as Multnomah counties and the Washington Group on Disability Statistics. Our questionnaire varies from these because:

* We want to be inclusive of more identity within disability. While many people are reluctant to identify as having a disability, others are very aware and embrace their identity and we wanted to respect identity language.
* We want to collect data that would be useful to the City in practical ways for resource allocation and accommodation. For example, if we know we have a high concentration of people who identify as being Deaf or hard of hearing in North Portland we can make sure a City event, like a budget forum in that area, will have sign language and CART at the event without the need to request it ahead of time. We have heard time and again from the community of people with disabilities that they often do not attend City events because it requires more work on their part to be accommodated when able body people can just show up.
* We want to collect data that could help us in planning and decision making. If we have good data around types of disability crossed with geography it would help many bureaus such as Parks, Housing, PBEM and PBOT prioritize locations for elements like accessible housing and shelters, curb cuts and playground features.

We attempted to combine descriptors from the population data questions with our identity based choices, to reduce non-identification by providing action based questions and, so if bureaus wanted they could still disaggregate City data with some of the population data.

**Current Recommended Template:**

Government programs, services, and events sometimes have barriers that prevent people with all kinds of bodies/minds from being part of what we offer. We want to understand and eliminate these barriers. We’re asking these questions so we can plan easier-to-access programs, services, and events.”

Do you find it challenging to access City events, programs or services because of lack of accessibility or a need for additional support? [ ]  Yes [ ]  No

If yes, please describe the nature of your need for additional access.  Check all that apply:

[ ]  Mobility or other physical (Do you have serious difficulty walking or climbing stairs?)

[ ]  Visual (Do you have serious difficulty seeing. Do you use a screen reader, large print etc?)

[ ]  Hearing (Do you have difficulty hearing, use ASL, cart etc?)

[ ]  Intellectual, Developmental, Cognitive (Do you have difficulty concentrating, remembering, understanding, or making decisions?)

[ ]  Speech or Communication (Using your usual language, do you have difficulty communicating)

[ ]  Mental Health (Do you have difficulty with mood, behavior or thinking even with medication)

[ ]  Invisible (Do you have a disability that is not readily apparent by your general appearance)

[ ]  Do not wish to disclose

[ ]  Other:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Do you identify with having or living with a disability? [ ]  Yes [ ]  No

**DEFINITIONS:**

Here we are defining our terms and how they correlate to the ACS.

**Do you identify with having or living with a disability?** is a catch all of disability identity. This can be very helpful in assessing where the data you collected is close to the percentage of people living in Portland with disabilities. Based on data from Multnomah Count we know roughly 17-22% identify as having some kind of disability. If for example your survey results show 17-22% of the respondents answered yes to the first question you know you have done a good job outreaching the general population of people with disabilities.

The first question correlates to ACS **Disability Status** defined by the ACS as: The U.S. Census Bureau used six questions to identify people with disabilities. A response of "yes" to any one of the questions indicates that the person in question has a disability-vision, hearing, cognitive, ambulatory, self-care, and independent living. However, the questions related to cognitive, ambulatory, self-care, and independent living are not used to identify disability in individuals less than five years old, and the question related to independent living is not used to identify disability in individuals less than 18 years old.

**Mobility or other physical disabilities** is capturing people who use mobility devices such as walkers, wheelchairs, scooters, crutches, canes as well as people who would require assistances entering or evacuating a building with stairs.

This question correlates to what the ACS defines as an **Ambulatory Disability**: In the ACS, individuals five or more years old who responded "yes" when asked if they had "serious difficulty walking or climbing stairs."

**Visual** is capturing people who identify as being blind or low vision. We emphasized assistive technology in this question as this is important information when creating outreach material and designing websites.

This question correlates to what the ACS defines as **Vision Disability**: In the ACS, individuals who indicated "yes" when asked if they were "blind or ... [had] serious difficulty seeing even when wearing glasses."

**Hearing** is capturing people who identify as being Blind or hard of hearing. We emphasized interpretation and assistive technology as this important information for bureaus who need to be able to accommodate requests for not only ASL interpreters and cart, but also sign language in other languages and assistive listening devices for people who use hearing aids.

This question correlates to what the ACS defines as **Hearing Disability**: In the ACS, individuals who indicated "yes" when asked if they were "deaf or ... [had] serious difficulty hearing."

**Intellectual, Developmental, Cognitive** is capturing people who identify as living with a developmental, cognitive or intellectual disability. This can include but is not limited to people who live with Autism, brain injury, Downs Syndrome, and dementia.

This question correlates to what the ACS defines as **Cognitive Disability**: In the ACS, indi­viduals who indicated "yes" when asked if due to a physical, mental, or emotional condition, they had "serious difficulty concentrating, remember­ing, or making decisions."

**Speech or Communication** is capturing people who identify having speech or communication disabilities. This can include difficulty with speech and verbalization or being understood. People with speech and communication disabilities can often have an easier time with pictograms and or texting options, or may benefit from amplification devices.

The ACS does not collect data related to Speech or communication disabilities.

**Mental Health** is capturing people who identify as living with a mental health disability. This can include but is not limited to people who live with depression, PTSD, Schizophrenia, bi-polar disorder. That affects their mood, behavior, and thoughts. These affects may interfere with a person’s ability to make and maintain meaningful relationships; to care for themselves; and to carry out daily life functions (work, school, etc.). This information can be helpful to bureaus around delivering services using trauma informed practice and/or training staff in things like mental health first aid.

**Invisible** is capturing people who live with disabilities that can limit their ability to perform one or more task of daily living but who are often overlooked in disability data collection because they may appear not to have a disability or their disability is not always actively limiting them. People with hidden disabilities can include but are not limited to HIV, Cancer, Fibromyalgia, Diabetes, seizure disorder and colitis. We felt it was important to capture people in this group though the data may not readily be useful without a deeper disaggregation.

**Do not wish to disclose and Other:** Unlike population data around disability we felt it was important to give people the option of opting out of further identifying their disability as well as the option of self-identifying something that was not captured by our identifiers.

**Note:**

We chose not to capture two categories of the ACS data set. We felt these questions were much more useful for organizations that provide social services to people with disabilities. If your bureau would like to utilize these ACS questions you may along with the questions we put forward for the standards but be sure to consider what the data will inform before doing so.

**Independent Living Disability (ACS)**: In the ACS, individuals who indicated "yes" when asked if due to a physical, mental, or emotional condition, they had difficulty "doing errands alone such as visiting a doctor's office or shopping."

**Go-Outside-Home Disability (ACS)**: An individual with difficulty going outside the home alone to shop or visit a doctor's office because of a physical, mental, or emotional condition lasting at least six months.

RESOURCES:

The following websites may be helpful if you want to do a deeper dive into disability data:

<http://www.washingtongroup-disability.com/washington-group-blog/sampling-blog/>

<https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html>

<https://www.census.gov/topics/health/disability/guidance/data-collection-sipp.html>

Link to the data that supports 17-22% of Portlanders live with a disability:

<https://www.ohsu.edu/xd/research/centers-institutes/oregon-office-on-disability-and-health/data-statistics/index.cfm>

Link to data support 35% of people over the age od 65 live with a disability:

<https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2017OlderAmericansProfile.pdf>