Disability & Philanthropy Forum

INCREASING DISABILITY INCLUSION BY TRACKING PARTICIPATION

October 8, 2021

I. Introduction:

Disability is part of human diversity, some of the infinite threads woven through the fabric of our world. Across the globe, more than one billion people live with some type of disability. The Disability & Philanthropy Forum seeks to increase the participation of people with disabilities in the philanthropic sector. When we have people with disabilities at the table as executive leadership, employees, board members, and grantees, our foundations will begin to represent the broad perspectives, knowledge, and adaptability of our communities, and the sector will become more innovative and equitable. The purpose of this paper is to provide guidance to philanthropy partners about how to track disability within their staff and boards, and ultimately their grantees.

There is no consistency in demographic tracking across philanthropy. Some grantmakers ask staff directly for information, others use third-parties. Often, questions about disability are absent. Even when the question is asked, due to widespread stigma and discrimination, many disabled people may be hesitant to self-disclose unless they require an accommodation to effectively do their jobs. Others are unaware that they fall under the definition of disability, and/or do not know about their legal rights to reasonable accommodations.[1]

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1. A reasonable accommodation is "any change to the application or hiring process, to the job, to the way the job is done, or the work environment that allows a person with a disability who is qualified or the job to perform the essential functions of that job and enjoy equal employment opportunities. https://adata.org/factsheet/reasonable-accommodations-workplace

Tracking disability in demographic surveys is one way that employers can signal that they welcome and seek to increase the number of disabled staff and board members, and want to create a universally designed workplace that reduces barriers to participation. The following offers general guidance, and some sample questions to integrate into your overall demographic surveys. We do not recommend issuing a separate disability survey. Note that the questions in Section III have not yet been validated by research, but are based on questions that have been used by organizations with input from people with disabilities. As new information emerges, this guidance will be updated.

II.   Guidance for tracking disability as part of diversity

A. Include disability as part of overall demographic tracking

This guidance is for including disability in foundations' and organizations' overall demographic tracking processes. Disability cuts across class, gender, race, and ethnicity, but being disabled disproportionately affects those living in [poverty](#), [women](#), and [people of color.](#) Understanding disability in the context of these other dimensions of diversity will yield important information to inform your diversity and inclusion strategies. The following information should be included in the overview of your overall survey.

B. Explain why the information is being collected

Emphasize that disability is a dimension of diversity and that you are proud to have people with disabilities as part of your team. For example, part of the "why answer this survey" explanation may be simply that "a diverse team enables us to live our values and better connect with our communities." Clarify that when you know more about your employees you can create a more effective, welcoming and inclusive workplace. For purposes of complying with the Americans with Disabilities Act (ADA), make clear that your purpose in asking applicants or employees whether they have a disability is in order to increase the representation and participation of people with disabilities in the workplace.

C. Clarify how the information will be used

1. **Inform change:** Under the ADA, employers may ask about disability in order to increase recruitment, hiring and promotion. Give examples of how you use your survey to inform your organization's work, recruitment or operations. For example, will you use it to increase recruitment and hiring goals? Will you use the information to universally design your workplace?

2. **Individual information:** Is your survey anonymous? While most diversity surveys or employment applications/questionnaires are anonymous, even those that are not must clarify that disability information will be kept confidential and indicate who will have access to the information. If responses are not anonymous, clarify that the survey response will not trigger the reasonable accommodations process, and point to your policies for requesting such accommodations.

3. **Aggregate information:** Will aggregate results be shared? If so, with whom will they be shared? Consider what protocols will be put into place (e.g., minimum number of respondents) to ensure that individual respondents cannot be identified.

4. **Answers are voluntary:** Allow individuals to skip questions or include a "decline to respond" response. Legally, an employee does not have to disclose a disability unless they require a reasonable accommodation to do their job. Under the ADA an employer cannot require an individual to self-identify but they may ask for voluntary self-disclosure if they are doing so in order to increase the diversity of people with disabilities in the workplace.

D. Clarify your definition of disability.

For U.S. funders, help respondents to your survey understand what you are asking by making it clear that disability is broadly defined under the

ADA as amended.[2] The law protects people from discrimination if they have a mental or physical impairment that substantially limits one or more major life activities. Major life activities are those functions that are integral to most people's daily lives. Examples of major life activities are breathing, walking, talking, hearing, seeing, sleeping, caring for one's self, performing manual tasks, and working. Major life activities also include major bodily functions, and as a result many chronic illnesses are considered disabilities under the law. If you are an international funder, refer to the United Nations Convention on the Rights of Persons with Disabilities, which focuses on the interaction of physical and mental impairments with societal barriers that prevent full and equal participation. [3]

One example of the significance of clearly identifying what disability means is provided by the Diversity Among Philanthropic Professionals Survey (DAPP) developed by Change Philanthropy. In 2018, respondents were simply asked whether they self-identified as having a disability. In 2020, the question was expanded to provide respondents with more information about various types of disabilities. Responses increased from 6.3% of respondents to 12.6% of respondents who self-identified as having a disability. This increase reflects the power of survey questions to educate respondents about whether they meet the definition of disability that offers protection from discrimination under the ADA.

In addition, by offering specific examples of disabilities, the survey was able to capture more detailed information on whether people with significant disabilities were in the workforce.

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2. https://adata.org/faq/what-definition-disability-under-ada.
https://adata.org/faq/what-are-major-life-activities. See the full language of the ADA as amended in 2008 here: https://www.ada.gov/pubs/adastatute08.htm#12101. This statute more specifically defines major bodily functions in Section 12102, 2(B).

3. For international funders the UN Convention on the Rights of Persons with Disabilities Definition should be considered: Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.
https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

E. Update your information regularly

Some employers ask employees to fill out demographic information only at hire. However, anyone can acquire a disability at any time. We recommend updating disability information at least every 5 years as required for federal contractors, and ideally every two years.

III. Sample Survey Section

Three options for integrating disability into your demographic survey follow. Regardless of which question you ask, integrate the following introductory language into your overall survey instructions. Note that none of these questions have been validated by research. As more information comes to light, they will be updated.

Introduction for all questions - integrate into your overall survey instructions

[Name of Employer] values disability as an important dimension of diversity in our workforce and leadership. We will use the information from this survey to achieve our goal of increasing the representation and participation of people with disabilities in our workplace. Your individual answers will be confidential and represented solely in aggregate data.

Alternative Question 1 - Simple

Introduction

Disabilities include a wide range of physical and mental conditions, as recognized by the Americans with Disabilities Act (ADA) and the UN Convention on the Rights of Persons with Disabilities. Disabled people may be blind, deaf, have mobility impairments or be a little person (a person with dwarfism). A person with a disability can be someone with Attention-Deficit/Hyperactivity Disorder (ADD or ADHD), a learning or speech disorder, a psychiatric disorder, or any chronic illness. Autistic people and people with epilepsy, cancer, diabetes, multiple sclerosis or cerebral palsy all are included under the definition of disability.   This is not a complete list of every kind of disability. It is intended to give you a sense of the broad range of physical or mental conditions that count as a disability.

Question

Yes, I have a disability

If you are comfortable doing so, please identify your disability: **(open text field)**

No, I do not have a disability

I prefer to self-describe **(open text field)**

I prefer not to answer

Alternative Question 2 - Detailed, ADA focused including significant and other disabilities

Rationale: including this level of detail may be a good way to reinforce employees' understanding of the broad definition of disabilities even if they don't read the introduction. Also the types of disabilities will enable employers to have more knowledge about how they can universally design their workplaces, and to capture whether people with more significant disabilities are in their workforce.

Introduction

Disabilities include a wide range of physical and mental conditions, as recognized and protected from discrimination by the Americans with Disabilities Act (ADA) and the UN Convention on the Rights of Persons with Disabilities. The list below is not a complete list of every kind of disability. It is intended to give you a sense of the broad range of physical or mental conditions that count as a disability and are protected from discrimination under the law.

You may check as many as apply or use the text box to write in.

I have the following disability :

Blind or low vision

D/deaf or hard of hearing

Mobility disability

Communication disability (including using a device to speak)

Intellectual disability (including Down Syndrome, Fragile X syndrome)

Developmental disability (including Autism, Cerebral Palsy)

Learning disability (including dyslexia, dysgraphia, auditory processing disorder)

Mental health disability (including depression, anxiety disorder, bipolar disorder, Attention Deficit/Hyperactivity Disorder (ADHD))

Little person (dwarfism)

Limb difference

Facial difference

Chronic illness (including diabetes, Crohn's disease, cancer, auto-immune diseases)

My disability is not listed here

My disability is **(open text field)**

OR

I do not have a disability

I prefer not to answer

Alternative Question 3 - Focused on functional activities and tasks consistent with the International Classification of Functioning, Disability and Health (ICF)[4]

Rationale: Focusing on functional issues rather than medical diagnosis emphasizes the removal of barriers to participation rather than an individual condition.

Introduction

Disabilities are conditions that substantially limit one or more major life activities, as recognized by the Americans with Disabilities Act (ADA) and the UN Convention on the Rights of Persons with Disabilities. The following list is adapted from a survey by the American Public Health Association and addresses functional difficulties that are caused by physical, mental or emotional conditions.

Question

I have the following disability

Deaf or have serious difficulty hearing

Blind or have serious difficulty seeing, even when wearing glasses

Serious difficulty walking or climbing stairs

Serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition

Difficulty communicating, using your usual (customary) language, for example difficulty understanding or being understood because of a physical, mental, or emotional condition

Difficulty dressing or bathing because physical, mental, or emotional condition

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4. A functional approach is based on the World Health Organization's International Classification of Functioning, Disability and Health (ICF) https://www.who.int/standards/classific_tions/internation-al-classifi_ation-of-functioning-disability-and-health

Difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition

Other **(open text field)**

I do not have a disability

I prefer not to answer

To learn more about disability disclosure and demographic tracking, please visit the following resources on the Disability & Philanthropy Forum:

- Journey to Inclusion Webinar on Disability Participation: Demographic Tracking and Self-Identification

- The Importance of, and Strategies for, Encouraging Self-ID of Disability

- Moving the Needle on Employing People with Disabilities: What to Know About Collecting Disability Data