



Disability Guidelines and Standards for City of Boston Services

VERSION AND FEEDBACK

Version 1.0.0 ([See version control history](#))

Developed in partnership with members of the Disabilities Commission, Disability Policy Consortium, and members of the disability community in Boston, these guidelines and standards are the first version of how we expect City employees to collect data from constituents about disability. These guidelines will evolve over time as we figure out how to apply them throughout City services and get direct feedback from the people we serve. We greatly appreciate any thoughts, questions, or feedback you'd like to share at TechGovernance@boston.gov.

OVERVIEW

When we design and run programs and services, we create an experience for constituents that can benefit them. In fact, our *main* objective is to achieve an outcome that benefits our constituents. These experiences consist of processes that are carried out in physical and digital spaces. We create data whenever we capture information, in either digital or physical forms. The design of a service and the data collection matters: How and what we ask might change how the process works in later steps. These processes also generate administrative data to reflect government processes, as well as other data that can be used to improve policies or programs. However, our goal as a City is to provide inclusive and accessible experiences for all constituents and our workforce when they interact with the City of Boston. **We designed this document as a set of standards and guidelines that can support our public servants in determining when and how they should collect information about constituents' disabilities.**

These guidelines and standards seek to acknowledge the impact that barriers to access have on our constituents' lives and the importance of providing services that meet the needs of all constituencies. When public servants fail to consider

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accessibility in designing and delivering services, we risk making it harder or even impossible for members of the disability community to access the services we provide. On the other hand, collecting information can also increase risks of identification for vulnerable groups and may discourage participation. Data can be a powerful tool to understand disparities and to drive equitable outcomes. But, embedding the collection of data into government programs can have negative consequences for the people those services and programs were intended to help in the first place. These consequences can be magnified when data collection is mandatory or tied to other Personally Identifying Information (PII). *As these are complex issues that involve trade-offs, we expect the standards and guidelines to evolve.*

Language matters. How we refer to other people, how we categorize and write about them, how we enter it into our databases, and how we present that information — all of it matters. Language has consequences. We built these guidelines and standards to support our public servants and give our constituents and colleagues the respect they deserve. We also understand that the dialogue and conversations around disabilities are complex and evolving. As such, we are engaged and will continue to engage in dialogue with community members to update this guide. These guidelines and standards were drafted with input from community members. They are intended to be updated and revised through active governance and a structured process by which we decide what we do through feedback from those impacted by our decisions.

PURPOSE

These guidelines and standards support public servants who design and operate services, programs, and policies, to provide more inclusive and accessible experiences. In particular, we aim to support individuals with disabilities who are often not represented in the data we collect or well served by the services we provide. The guidelines and standards specify when and how to collect disability data throughout government processes. Collecting the right amount of data in the right way will ensure that we **deliver accessible services** to people with disabilities while **ensuring their dignity and privacy** to the best of our ability.

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SCOPE

These guidelines and standards follow the implementation of the [Gender-Aware Guidelines and Standards](#) and are intended to support the Mayor's vision of an inclusive city for everyone. They should be followed by departments and agencies when conducting City business both digitally and in-person. The guidelines and standards provide some flexibility, acknowledging that the processes and collection of data might be subject to specific constraints from the Americans with Disabilities Act and related regulations. As such, **public servants should use both the Gender-Aware and Disability guidelines and standards as they design or revise new programs and services to ensure accessibility and inclusion are embedded being met in all aspects, from service delivery to equitable hiring practices.** We also expect departments and agencies to invest time in revising existing processes to deliver a more respectful and dignified experience to all of our residents.

GOALS

To achieve this purpose, these guidelines and standards have four goals:

- **Define** key terms public servants should understand related to disability (see Appendix)
- **Help** departments think through when asking constituents about their disabilities is necessary and appropriate for delivering City services
- **Provide** standard language that departments should use when they've determined they need to ask constituents about disabilities
- **Align** the standards in this document with state, federal, or other data systems that have limitations in how they record this data

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GUIDELINES FOR COLLECTING DISABILITY DATA

GUIDELINE 1 DISABILITY DATA COLLECTION SHOULD BE PART OF A DEPARTMENT'S BROADER ACCESSIBILITY STRATEGY

Collecting data can inform accessible service delivery, but data collection alone does not make services more accessible. Departments are encouraged to tie disability data collection back to service delivery as often as possible.

Do's

- **Know what you are going to do with disability data before you collect it.** There can be many good reasons to collect disability data, such as understanding how our services need to evolve to meet constituent needs. Compared to race and gender data, disability data is typically not required as often for federal reporting. This gives public servants much more discretion to be intentional about collecting constituent disability data.
- **Be transparent about data collection and use.** Only collect data if you can clearly communicate intentions to participants. Tell participants proactively how you plan to use this data (most important) and how it will be stored and shared after collection.
- **Consider using proactive data collection to shape service delivery.** In some cases, it may be possible to collect information about constituents' disabilities prior to events or service delivery. This offers an opportunity for public servants to ensure everyone can access whatever services or resources are being offered by modifying their service delivery plan in advance.



Don'ts

- **Do not “collect data for data’s sake”.** Constituents don’t like unnecessary questions about disability, especially if they aren’t carefully thought through or used to benefit people with disabilities.
- **Avoid linking disability data to personally identifying information.** Disability data, combined with personally identifying information (PII)¹ and other information that uniquely identifies a person presents risks to people’s privacy. **Disability data should only be linked to personally identifiable information when absolutely necessary**, like for a program qualification or reasonable accommodation.

GUIDELINE 2 FOCUS ON WHAT PEOPLE NEED, NOT THE SPECIFIC DISABILITIES THEY MAY HAVE

Departments are encouraged by the Commission for Persons with Disabilities to collect disability data **focused on what people need to access services and participate in City programming (“data about accommodations”)**. Unlike asking about the type of disability or a specific disability that a person may have, data about accommodations is much more relevant for service planning and delivery. It also avoids asking questions that might be considered invasive by constituents or using terms that may not reflect how constituents with disabilities see themselves. Additionally, not all individuals who meet the legal definition of disability identify as such, but they still have access needs which the City should strive to meet. Finally, data collection about accommodations stands to benefit **all constituents**, even those who may not identify as disabled.

Do's

- **Trust that constituents know what they need.** People with disabilities are the experts on their lived experience and what they need. When they ask for accommodations, listen to them and respond in a helpful way.

¹ Personally identifying information (PII) is a combination of last name, first name or initial, with any one of the following: Social Security Number, driver’s license, state ID card, Passport number, financial account (checking, savings, brokerage, CD, etc.), credit card, or debit card numbers.



Don'ts

- **Don't use euphemisms for 'disability'.** 'Disabled' and 'disability' are not bad words. In fact, they are the most accepted terms within the community. Older terms (e.g. 'handicapped') are considered offensive. Euphemisms (e.g. 'handicapable,' 'specially-abled,' "differently-abled") can convey to disabled people that the speaker is uncomfortable with disability. Although this guideline advises City staff to focus on accommodations, that does not mean that the term 'disability' should be avoided when engaging with constituents who have disabilities.
- **Do not use disability data collection to evaluate, diagnose, or judge people.** It is inappropriate for any demographic data collected about constituents' disabilities to be used to evaluate, diagnose, or otherwise judge what people are capable of or their worth. If City staff have any questions about how disability should be approached in the context of hiring, consult Appendix 1 later in this document or contact the Disability Commission at disability@boston.gov.

GUIDELINE 3 OFFER MULTIPLE WAYS FOR PEOPLE TO PARTICIPATE

Because disabilities can directly affect how people take in and respond to information, inclusive and accessible data collection needs to offer multiple routes for participation. For example, consider whether participants have the option to read the question on paper, fill out the question online, or have the question read to them (via phone call or in person). Provide multiple ways for people to participate in data collection to cover the range of ways people can respond.

Do's

- **Use disability data questions to assess how accessible your data collection methods are.** Although not exhaustive, the [disability data standard](#) provides a sort of checklist for staff to review. Consider how easy or hard it would be for a constituent to participate in data collection if they had any one (or more) of the needs listed in the standard.

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- **Allow for active and passive data collection.** Constituents can vary significantly in how much interaction they want to have with City staff (this is not limited to constituents with disabilities). In addition to different modes of data collection (written, verbal, digital), try to offer constituents flexibility in terms of how much social interaction is required to participate.

Don'ts

- **Do not assume that you know what accommodations a constituent might need.** Not all disabilities are visible to outside observers and some disabilities can vary significantly over time, even during the same day.

HOW TO COLLECT DISABILITY DATA

Once you have determined that you should collect data about disability, all City agencies, departments, and offices are expected to use the language and procedures outlined in the standard below.

1. Only ask questions about disability data **that serve a specific purpose.**
2. Establish and communicate **clear privacy protection mechanisms** for the data you collect. Be ready to share with participants:
 - a. why you are collecting the data
 - b. what you will do with the data
 - c. what mechanisms you use to protect their privacy²

STANDARD DISABILITY DATA QUESTION

QUESTION LANGUAGE

² For details on how to protect this data (collecting it, managing it, storing it, sharing it, etc.), please follow the [City's Data Security Policy](#) and talk to the Law Department when you create any data-sharing plans.

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The following question is being asked to collect data about the accessibility needs of our community. To request specific disability accommodations for an event or service, please contact the staff organizing the event.

Which of the following do you typically need in order to participate in City of Boston events and services? (Select all that apply):

- American Sign Language (ASL) interpretation
- Closed Captioning (CC) of spoken audio
- Large Print font, printed materials for important information
- Braille printed materials for important information
- Plain language / simplified documents for important information
- Maps of the physical layout of the space
- Screen-Reader Compatible Interfaces for digital information
- Wheelchair access
- Service Dog Handler
- Seating / areas of rest (e.g. chairs, benches)
- Sensory friendly space
- I need something else (Write-In)

BEST PRACTICES WHEN IMPLEMENTING THE STANDARD

Practice 1: Familiarize yourself with City processes and supports related to accessibility.

- **RESOURCES FOR STAFF**

- Staff from the Commission for Peoples with Disabilities (CPWD) can assist departments in thinking through how to collect data (and, more generally, deliver services) accessibly. They can be reached at disability@boston.gov.
- The Language and Communications Access (LCA) department is available to all City of Boston employees to ensure all residents have language and communication access. LCA can provide funds for



communications based accommodations, such as captions, American Sign Language (ASL), and Braille. They can be reached at lca@boston.gov.

- Please note that American Sign Language (ASL) is a complete, natural language that has the same linguistic properties as spoken languages, with grammar that differs from English (National Institute on Deafness and Other Communication Disorders).
- **If collecting data in-person**, ensure that you have resources available to communicate with a Deaf person.

- **RESOURCES FOR CONSTITUENTS:**

- The CPWD already has processes in place to help constituents request accommodations to access or participate in services (including data collection). Consider including the following text on constituent-facing data collection efforts:
 - “If you need accommodations to participate in this data collection effort, you can contact:
Mayor’s Commission for Persons with Disabilities
617-635-3682 (voice) or 617-251-2718 (text)
Email: disability@boston.gov
- **Note:** It is significantly more efficient to proactively design your data collection exercise with a focus on accessibility rather than have the CPWD step in after the fact.

If more guidance is needed to ensure data collection is inclusive, contact the Disability Commission at disability@boston.gov.

Practice 2: Even if a third-party is collecting or managing data on behalf of the City of Boston, they should comply with the standards. You should include the standards in the specifications of the work with these third parties.

If you have technical questions about how to implement these guidelines and standards for your City service, please reach out to techgovernance@boston.gov.



HOW WE WROTE THIS AND GRATITUDE

HOW WAS THIS DOCUMENT DEVELOPED?

We engaged with experts from Disability Policy Consortium to run focus groups with members of the disability community. We were intentional about engaging with people who identify with different disabilities, such as: Blind/low vision, Learning Disability, Physical disability/mobility impairment, Deaf/Hard of Hearing, Chronic health Disability, Intellectual Disability/Cognitive Disability, and Communication Disability. We compensated people for their time and for their guidance. These guidelines and standards are shaped by their experiences. By engaging with community members in the development of this document, we intend to rebuild trust between the City and its constituents. By listening and taking action together, the government and constituents can build a more dignified and strong community.

ACKNOWLEDGEMENTS

This is the product of collaboration and teamwork. Foremost, we acknowledge the residents and constituents who participated in the conversations and research. Their voices had an impact on the direction of this work. We hope their trust and insights usher in a more dignified experience for other residents. We benefited from the insights and expertise of Colin Killick, Maggie Sheets, Dennis Heaphy, Ellysheva Bunge-Zeira, and Vanel Joseph from Disability Policy Consortium who have been critical to building this work. We also acknowledge the team members who led the work across three City cabinets and multiple departments.

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APPENDICES

APPENDIX 1: KEY TERMS AND DEFINITIONS

The following section introduces various definitions of disability that were considered to develop this document. Note that each of these definitions or surveys have their own limitations - some miss key domains of disability (e.g. mental health disabilities) and others use language that is controversial or disliked by members of the disability community. This is why the City of Boston considered these definitions as inputs, but ultimately chose to develop its own standard rather than rely on an existing one.

DISABILITY IDENTITY

Disability identity is described as a “sense of self that includes one’s disability and feelings of connection to, or solidarity with, the disability community”³. Social identities, including disability, affect how individuals view themselves and how they understand and respond to the world around them. Affirming how people choose to identify themselves is important because identity is a nonlinear process and different individuals may be in different stages of how they perceive and interact with their identity.

AMERICAN COMMUNITY SURVEY DIMENSIONS OF DISABILITY

The American Community Survey (ACS) provides six dimensions of disability, defined by areas of functional difficulty. The ACS determines “disability status” based on answers to the following questions:

- **Hearing Disability** (asked of all ages): Is this person deaf or do they have serious difficulty hearing?
- **Visual Disability** (asked of all ages): Is this person blind or do they have serious difficulty seeing even when wearing glasses?
- **Cognitive Disability** (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

³ Forber-Pratt, A. J., Merrin, G. J., Mueller, C. O., Price, L. R., & Kettrey, H. H. (2020). Initial factor exploration of disability identity. *Rehabilitation psychology*, 65(1), 1–10. <https://doi.org/10.1037/rep0000308>

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- **Mobility Disability** (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?
- **Self-care Disability** (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?
- **Independent Living Disability** (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

DEFINITION FOUND IN AMERICANS WITH DISABILITIES ACT (ADA)

The ADA definition (below) is helpful to know, even if it's not used often in this standard, because it shows up a lot in federal law. The definition is broad and includes people with current disabilities, people who have a history of having a disability, and people who don't have a disability but who are regarded as having one.

The ADA National Network defines disability as “a person who has a physical or mental impairment that substantially limits one or more major life activities. This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability.”

DEAF WITH A CAPITAL “D”

Capital D, **Deaf**, refers to a culture of people who share beliefs, practice, and their own language, American Sign Language (UMass Amherst). This culture does not identify Deaf as a disability. People who refer to themselves as lower-case “d” deaf may identify as disabled, or they may not. This highlights the importance of allowing people to identify themselves (if they choose to) and not assuming how someone may identify.

PERSON FIRST VS. IDENTITY FIRST LANGUAGE

Person first language is when you put the person before their disability (for example: Person with autism, person with hearing loss, person with dwarfism). This language can sometimes reinforce the **lack of accountability** on society's part to remove systemic barriers and provide **more accessible environments**. However,

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many persons with disabilities who prefer person first language want to encourage others to see **beyond** their disability and recognize that disability is not the only thing that defines their identity. They are a person above all else.

Identity first language is when you acknowledge that a person's disability is a part of their identity (for example: autistic person, Deaf Person, Little Person). This language is being adopted by many subsections of the disability community as it encourages accepting disability as a **normal part of the human existence**. Many disabled people who use identity first language want to encourage others to recognize their disability as an **integral part** of their identity, as it impacts how they navigate the world as much as their skin color or gender expression.



APPENDIX 2: IMPLEMENTATION NOTES

These guidelines and standards are meant to be followed by all departments and agencies. However, we recognize that implementation of the guidelines will take time, and that there are specific circumstances where the implementation will require changes to process, technology, or training.

The full implementation of the Disability Guidelines and Standards will take time. Therefore, for a period of time, some City services will use language that doesn't align with these guidelines. Our goal is to transition all of the City services to be in compliance with the standard.

Please note that this document is not intended to set personnel policy. For any HR related policies or practices relevant to employees of the City of Boston please go to [Beacon](#).

If you have questions about how to implement these guidelines and standards for your City service, please reach out to techgovernance@boston.gov.



CHANGE CONTROL

VERSION NUMBER	APPROVED/ REVISED BY	EFFECTIVE DATE	DESCRIPTION OF CHANGES
1.0.0	Chief Equity Officer, Disabilities Commissioner, Chief Information Officer		First version of the Disability Guidelines and Standards for City Services