

Honoring Disability in Your Community-Centered Data Practices

Purpose: 1 in 4 adults in the United States are disabled. A portion of your clients and staff—whether they have notified you or not—have a visible or invisible disability or impairment. Ensuring your spaces and programs are accessible to people of all abilities is a crucial aspect of an inclusive program and workplace. Additionally, your program or organization may value measuring how people identify with disabilities, or what barriers they are facing in accessing services and resources. In this emPower Tool we discuss ways of thinking about disability, making your spaces and services accessible, and considerations for when and how you may want to collect data on disabilities. Also see the [Centering Community in Your Data Practices emPower Tool](#).

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What is a Disability?

The **medical model** assumes an individual's identity is a problem in need of fixing or curing, rather than an aspect of one's identity.

The **social model** focuses on society and the barriers (physical and attitudinal) that impair people with disabilities from interacting with their environment. Barriers need the fixing.

Types of Disabilities include:

- Cognitive, Intellectual, and/or Developmental Disability or Impairment
- Physical Disability or Impairment
- Visual Disability or Impairment
- Deaf or Hearing Impairment
- Mental or Behavioral Health Impairment

Accommodations

To ensure your programs & workplace are inclusive of people with disabilities, consider:

- Changing physical spaces as needed
- Changing policies, practices or procedures
- Providing additional supports & services
- Using **universal design**: designing spaces & services to be accessible to people with a wide range of abilities. Supporting people with disabilities benefits everyone!

Questions to Consider

- What **counts** as a "visit" or "contact"? Must it be in person? Is this creating a **barrier**?
- Have any clients exited the program because they needed services in person? Or virtually?
- **What** data are you gathering about disability? How much do you **really need** to know?
- Can you gather information about **accommodations** without asking about individual **conditions**?
- **Why** are you gathering this data? How do you let your clients know why you're asking?
- How are you **protecting** your clients and their privacy?
- Who has **access** to the data once collected? Is it necessary for each person to have that access?
- How do you get data to the **right staff** without violating privacy/making clients repeat themselves?
- How are client needs **changing** over time? Do you have a process to stay informed and responsive?
- Do clients have the info they need to make **informed decisions** about how their data is used?

For your staff:

- What accommodations are you comfortable and prepared to provide?
- Are there accommodations you don't feel able to provide?
- What supports do you need from management?

Data Privacy & Security

Information and data about disability is **individually identifiable health information (IIHI)**. An individual's IIHI is their own, and they should have autonomy over **what** is shared and stored, and **with whom**.

While not all IIHI is covered by federal privacy rules, we suggest using HIPAA standards with disability data:

- Remove names and identifiable information on all disability-related data in reporting
- Limit sharing information with staff to *only what is absolutely necessary* to meet accessibility needs
- Notify clients of their rights and how the data will be used at the first point of data collection
- Get additional signed authorization for disclosure beyond what is included in the first data collection

For more info about HIPAA, see [OCR's Privacy Brief: Summary of the HIPAA Privacy Rule](#)

Choose Your **Why** to Determine Your **How** and **When**

Why: To Make Your Services Accessible

- What clients need to be able to receive your services won't always be obvious; conditions affect people in various ways.
- This data should typically be collected **opened and optional**.

Why: To Be Responsive to Client Needs

- Disability is not static; anyone can become disabled and impacts can change over time.
- Develop feedback loops so needs expressed by clients are reflected back to your data system and the right staff are informed.

Why: To Report to Funders

- Funders typically use one of the definitions used by federal agencies.
- Typically, this data is best gathered at **intake and/or an annual survey** of clients
- Consider whether reporting requirements align with equity goals and client autonomy

Why: To Make Classes/Events Welcoming

- Ask again when **registering for events/classes**, in-person or virtual
- Whenever possible, share pics/ map of the layout, and/or a description of the space.
- Share planned accommodations, like ASL interpretation or the event will be recorded.

When: Discovery/Referral, Intake, Case Notes, Event Registration, Annual Survey

The best time to gather disability data will depend heavily on your **why**.

Consider each step of data collection in your organization's work and determine how each intersects with disability and potential barriers.

Then, consider if the data needed for that part of your work was already gathered or if another data point is needed.

Staying up to Date

Have a process for the right people at the right level to know the client needs. (See *Data Privacy & Security*) Examples:

- Letting a class instructor know they need to provide an outline of the material to the class.
- Providing a Home Visitor with a list of accommodations for each specific client.
- Giving an event planner a list of accommodation needs without client names.

How: Depends on your Why

The **why** will inform what to share with clients when gathering data about disabilities.

Be sure to inform clients that providing the info is optional, how it will be used, if it will be shared with any outside organizations, and (when possible) what accommodations you are able or not able to provide.

Funder requirements example:

"This program receives funding from [funders] who require that we report on the number of clients who are disabled according to the following categories."

General accommodations example:

"In order to best serve your needs, please let us know if you have any needs or concerns regarding accessibility. This information will not be shared outside of our organization and will only be used to support your access to our services."

Environment description example:

"This event takes place at [location] at [address]. There is a ramp entrance located on the south side. (see map)...Please let us know if you have any needs, questions, or concerns regarding access to this venue. This information will not be shared..."

Specific service options example:

"Check-ins with our home visitors may be done in-person or via video call. Please let us know which method you prefer, and any needs, questions, or concerns you have regarding meeting this way."

Why NOT to ask...

- If there are others around to whom the client may not wish to disclose this information, wait until you can ensure their privacy.
- If your organization does not have the ability to provide accommodations, be honest. Just asking about disability is not an accommodation.
- To satisfy your own curiosity: make sure the details you are asking for serves a purpose to avoid requiring clients to disclose unnecessarily.