Involving People with Disabilities in the CHA Process

People with disabilities may face misconceptions, stigma and discrimination that can affect their physical and mental health. This diverse group of people may encounter other barriers that impact their ability to be healthy, including inaccessible health care facilities, services and programs; communication challenges; and public infrastructure barriers that make it difficult to use transportation, traverse streets and sidewalks, and access public buildings and spaces.

In September 2023, the National Institutes of Health recognized people with disabilities as a population facing health disparities that need to be addressed. https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities.

People with disabilities hold a wealth of knowledge about their own health conditions; with that in mind, be sure to involve people with disabilities in the CHA planning processes, even before mapping assets to identify priorities. Doing so will help ensure a robust understanding of the needs and assets of people living with disabilities in the community.

Before You Begin

When working with people with disabilities, respect both their strengths and needs:

- See the person and not the disability, recognizing that disability does not equate to poor health.
- People with disabilities have the right and the ability to live independently in the community.
- People with disabilities are the best people to provide information about their own health, including discussing nutrition and physical activity.

Consider the following key goals when working with people living with disabilities:

- Reducing social inequities with the goal of improving health.
- Promoting living independently in the community.
- Increasing access to health care and inclusive information about health care.
- Improving access to behavioral health care.
- Increasing access to healthy lifestyle behaviors and health-promoting interventions.

9 CHA Toolkit Steps and How to Engage People with Disabilities

STEP 1

Map Development

Asking the right questions and continually engaging people with disabilities throughout the CHA process can help identify priority health needs.

Strategic questions for the CHA team to consider include:

- What factors impede people with disabilities from accessing health care and leading a healthy lifestyle?
- What knowledge do health care and social service providers have about working with people with disabilities?
- What attitude do service providers have toward people with disabilities and are they trained in disability etiquette?
- How accessible is the built environment in your community?
- Is accessible transportation available in your community?
- Do some local policies disproportionally affect people with disabilities?
- Is adapted equipment readily available for people with disabilities so they can enjoy equitable access and participation?

When reviewing existing data related to people with disabilities:

- Consider the sample of the population within the data.
  - Identify which groups are represented and if certain groups or demographics are excluded from data collection or analysis.
  - Consider if the sample is representative of people with disabilities living in the community.
- Examine if other factors that can compound health disparities — such as socioeconomic status, race, ethnicity, income and insurance — were considered or collected and how they were considered within data analysis.

Ensure all tools and communications are accessible, and use pictures to support communications where appropriate. Online tools, including website links, should be usable by screen readers. Current guidelines can be found at ada.gov/resources/web-guidance/.

Build Relationships

People with disabilities are a large and diverse group in terms of age, sexual orientation and gender identity, race and ethnicity. One person with a disability does not represent the wide range of health and inclusion needs of others living with disabilities. Thus, it is important to engage with a variety of people living with different disabilities, including people with mobility issues, sensory challenges — blind or low vision, or deaf or hard of hearing — and cognitive or emotional limitations.

Community members with intellectual and developmental disabilities and those with psychiatric disabilities are particularly important to involve in order to ensure a wide scope of understanding and representation.

Ways the CHA team can be intentionally inclusive of people with disabilities include:

- Involve people with disabilities in strategic planning and decision-making processes regarding changes to services or service delivery.
- Create an advisory committee that includes individuals with disabilities.
- Become an A.L.L.Y. in the community for people with disabilities, as defined by the Centers for Disease Control and Prevention. cdc.gov/ncbddd/humandevelopment
- When scheduling gatherings, rather than simply stating that facilities and services are accessible, provide detailed information about accessibility so individuals can decide for themselves if it is accessible for them.

Tips for ensuring a diverse group of stakeholders with disabilities participates in the CHA process or serves on the CHA advisory committee or both include:

- Reach out to organizations that work with historically marginalized communities to include individuals with disabilities who also belong to those communities.
- Connect with local Centers for Independent Living. acl.gov/programs/centers-independent-living/list-cils-and-spils
- Reach out to the regional ADA Technical Assistance Center; there are 10 centers across the U.S., and all are well connected within their communities. adata.org/find-your-region
- Reach out to other local organizations that support people with disabilities, including those supporting veterans and their families or promoting healthy behaviors such as adaptive recreation and sports, and healthy eating.

Develop Community Profile

People with disabilities may have a higher risk of poor health outcomes; and if they belong to a historically marginalized group, that risk is even higher.

- Some people living with disabilities have higher rates of secondary conditions such as obesity, diabetes, chronic pain and heart disease than those without disabilities.
- It is important to also consider people with disabilities living in low-income and rural areas. Ensuring accessible transportation within rural areas is particularly important.
- Inaccessible housing can limit the ability of people with disabilities to get out of their home and conduct their daily activities.

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- Health care access may be particularly challenging for people with disabilities, and limited access to preventive care can result in delayed detection and diagnosis of conditions not related to their disability.

The prevalence of these potential challenges reinforces the need for a unified community approach to improve access to care.

STEP 4

Increase Equity with Data

When collecting data related to people with disabilities, two categories of data can be particularly valuable:

1. Outcomes related to healthy living opportunities — such as physical activity, nutrition, participation in the community and inclusion.
2. Data related to service providers throughout the community, including whom they serve and their disability-related training and experience with inclusion and accessibility.

Remember: People with disabilities are a diverse group, and they may not fit neatly into categories that align with specific diagnoses and medical codes.

Throughout the data collection, analysis and interpretation processes, consider the intersectionality of disabilities with other factors, such as age, sexual orientation and gender identity, race and health conditions. It may be helpful to review the interpretation of the data with stakeholders and people living with disabilities.

Available data sources, which are unique to people with disabilities:

- Behavioral Risk Factor Surveillance System, which stratifies data by state: cdc.gov/brfss/index.html
- National Survey on Health and Disability: ihdps.ku.edu/nshd
- American Community Survey data (six disability questions): census.gov/programs-surveys/acs/

STEP 5

Prioritize Needs and Assets

When it is time to determine which health needs and assets to prioritize, consider a concept embraced by many people in the disability rights movement: "Nothing about us, without us." Community feedback needs to be integrated into every step of the prioritization process.

Hospitals, health systems and community partners can align priorities with the needs expressed by people with disabilities from the community and prioritize equity and access. To learn about the principles of disability inclusion and health promotion, visit cdc.gov/ncbddd/disabilityandhealth/index.html.

STEP 6

Document and Communicate Results

When disseminating information about the CHA process and findings, ensure that all communications are inclusive and accessible to all.

- The report should be written in a way that promotes understanding, dignity and respect for people with

disabilities. For example, use person-first language and avoid jargon in all communications. To learn more about communicating with and about people with disabilities, visit cdc.gov/ncbddd/disabilityandhealth/materials/factsheets/fs-communicating-with-people.html.

- Make results available in different formats — for example, audio, text, printed, electronic, large print and Braille — to reach as many people as possible.
- When using an electronic version, ensure compatibility with screen readers.
- Create alt text for all images and provide image descriptions when possible. See guidelines for alt text here: accessibility.huit.harvard.edu/describe-content-images. See guidelines for image descriptions here: americananthro.org/accessibility/image-descriptions/.
- Share data across social media channels and use the network of organizations supporting people with disabilities to help raise awareness of CHA results.

Other ways to engage the community:

- Engage local advocacy groups and disability organizations to better understand the community landscape.
- Host dialogues with community members and present CHA results at accessible venues.
- Invite people with disabilities to discuss the CHA findings with hospital teams to raise awareness of community needs and associated health disparities.

STEP 7

Plan Equity Strategy

When assessing the impact of CHA strategies for people with disabilities, think beyond traditional medical outcomes and measure factors such as access to and inclusion in community living, health care and independent living.

Examine existing policies and protocols to ensure they use inclusive language and directives, and explore potential training to guarantee inclusive implementation of potential strategies.

Strategies may differ for different disability groups. For example, the needs and strategies to reach people who are deaf or hard of hearing are likely different than the needs and strategies to reach people who use a wheelchair. Guidelines and frameworks to use for disability-inclusive solutions include:

- Community Health Inclusion Dashboard and the Guidelines, Recommendations, and Adaptations, Including Disability, from National Center on Health, Physical Activity and Disability (NCHPAD): inclusion.nchpad.org
- NCHPAD's inclusive Community Implementation Process: solutions.nchpad.org/tool/nchpads-inclusive-community-implementation-process-nicip/
- Community Health Inclusion Index: nchpad.org/fppics/CHII_Manual.pdf

STEP 8

Develop Action Plan

Collaborate with relevant organizations and take advantage of resources and funding opportunities when developing an action plan. Consider connecting with the following organizations:

- Centers for Independent Living: acl.gov/programs/aging-and-disability-networks/centers-independent-living
- ADA National Network's Find Your Region webpage: adata.org/find-your-region
- Paralyzed Veterans of America: pva.org
- Special Olympics: specialolympics.org
- National Center on Health, Physical Activity and Disability: nchpad.org/
- National Federation of the Blind: nfb.org
- Easter Seals: easterseals.com
- Local offices for disabilities
- Organizations focused on specific disability groups, such as the National Multiple Sclerosis Society (nationalmssociety.org/), Brain Injury Association of America (biausa.org/), United Spinal Association (unitedspinal.org/), Amputee Coalition (amputee-coalition.org/) and more

Resources

Seek resources to better understand the legal and policy requirements around disabilities, as well as how to support community living for people with disabilities. Examples include:

- Administration for Community Living Website: acl.gov
- Americans with Disabilities Act (ADA) guidance and resources materials: ada.gov/resources/web-guidance/
- ADA National Network for information, guidance and training: adata.org/

Funding

Apply for capacity-building funding from state and/or federal funding agencies. Work with private foundations, charities and nonprofit organizations that support people with disabilities, as they may release funding opportunities and support for projects addressing inclusion and accessibility.

STEP 9

Evaluate Progress

Examine data collection efforts to ensure data related to disabilities is being collected, is meaningful and is measuring what is intended.

Consider various methods of data collection such as surveys, short interviews with community stakeholders and secondary analysis of existing data.

Collecting data at the beginning of the process, as well as at key points throughout, captures progress more effectively than one-time efforts.

When addressing the primary and secondary drivers that can positively influence health objectives:

- Increase access and inclusion in areas that are deemed priorities by people with disabilities.
- Consider the impacts of the physical and the social environments on access, inclusion and discrimination.
- Simultaneously consider small changes that can be impactful and larger, long-term systemic changes.

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