

Bridging the Data Gap: Disability Inclusion in Community Health Assessments

Makhari Dysart and Hannah Wells

Funding Statement

This project was conducted by the Institute on Disabilities with funding provided by the Arc of Pennsylvania through the Pennsylvania Department of Health from the CDC's National Initiative to Address COVID-19 Health Disparities Among Populations at High-Risk and Underserved.

The Pennsylvania Department of Health takes no part in and is in no way responsible for any analysis, interpretations, or conclusions.

Overview of Presentation

Introduction to Community Health Assessments

Project Overview

Project Findings

Recommendations for Practice

What are Community Health Assessments?



Provide a snapshot of the wellbeing of a specific community



Use primary and secondary data to understand local needs



Identify public health challenges and priority populations

Community Health Assessments for Hospitals and Health Departments

- Required for accreditation and non-profit status
- Should reflect the voices, needs, and lived experiences of medically underserved groups
- Inform hospitals and health departments as they set improvement goals



What are Improvement or Implementation Plans?

Community Health Improvement Plans (CHIPs) and Implementation Plans (IPs):

- Based on CHAs and CHNAs
- Plan health interventions over a three-year period
- Address topics such as access to care, mental health, food access, transportation, safety, and other core social determinants of health

Why this Matters: The Disability Data Problem

- 37% of Pennsylvanians have a disability
- Disability health data gaps exist locally and nationally
- Needs assessments are a critical place for local health data
- **Are PWD being meaningfully included enough for these assessments to support health equity?**

Our Project: Key Questions

- How are these community health assessments including people with disabilities?
- Is the information they are gathering coming from disabled voices?
- Are disability advocates and organizations represented in the leadership of the teams conducting these reports?
- Are people with disabilities included in the improvement goals set by these organizations?

Methods

- Identified a list of all PA hospitals and health departments
- Compiled all available documents (161 hospitals and 10 health departments)
- Searched documents using disability-related key terms
- Compiled and analyzed all mentions of disability

Our Findings

Overall Findings

While disability is frequently mentioned, there is a lack of meaningful disability inclusion

- Lack of standard minimum inclusion
- Pervasive use of the medical model of disability
- Little to no targeted outreach
- Low inclusion in planning documents

How was Disability Discussed?

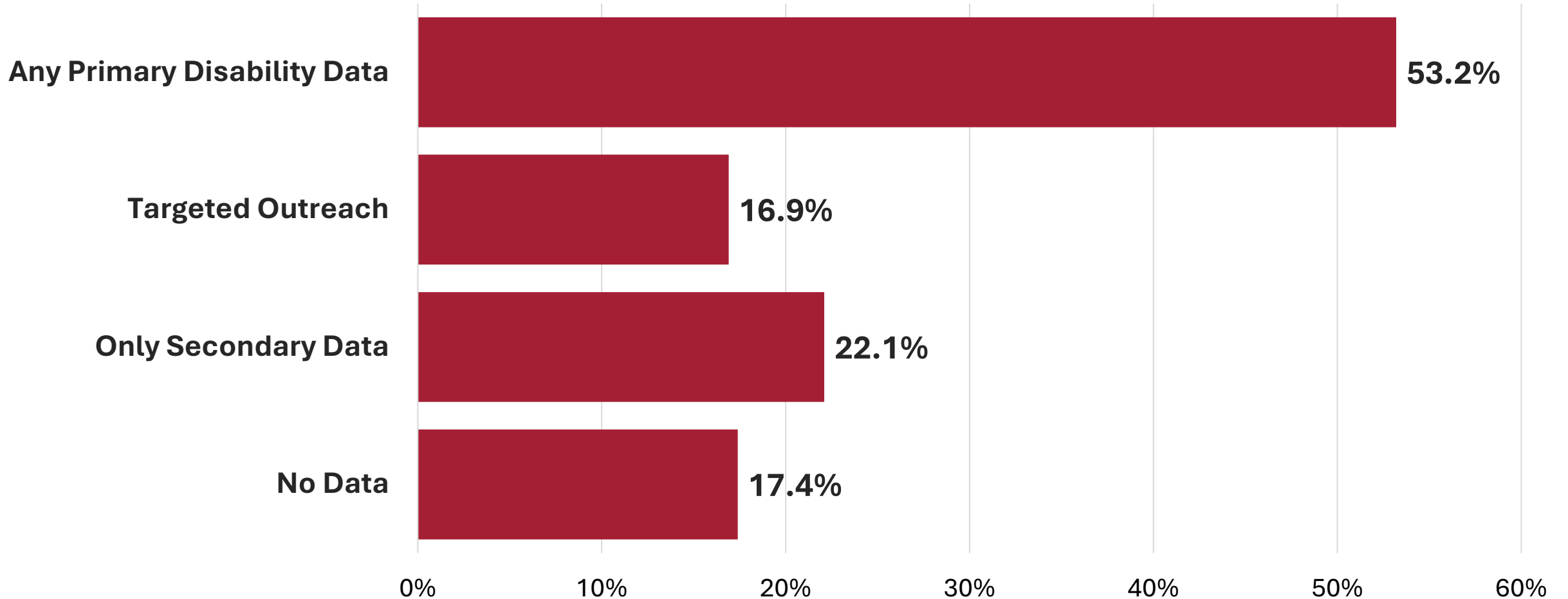
- Most organizations mentioned disability in **some** way
- Use varied by section and data source, with no consistent approach
- Primary data more often reflected lived experience, and secondary data relied on generalized categories

Gaps in Disability Inclusion

- **1 in 3** did not include disability demographics
- **More than half** (60%) did not recognize people with disabilities as disproportionately impacted
- Mentions of disability overrepresented older adults and children, with lower representation of working age adults



Where is the data from?



Models of Disability Used

Medical Model

- Disability positioned as deficit, burden, or outcome to prevent
- Linked to disease, aging, chronic conditions
- Emphasis on screening, treatment, cost, DALYs
- Disability itself framed as the barrier

“Instead, a public health focus on reducing disability-adjusted life years (DALYs) prioritizes the prevention of disease for an entire population instead of focusing on the treatment of individual conditions. The use of DALYs also serves as a reminder that disability is consequential to quality of life.”
-a PA Psychiatric Hospital

Models of Disability Used

Social Model

- Disability recognized as a population experiencing disparities
- Barriers located in systems and environments
- Emphasis on access, equity, lived experience
- Some inclusion in health equity and DEI frameworks

“Equity in health care involves ensuring that all individuals have access to the resources they need to achieve optimal health. This includes addressing systemic barriers that disproportionately affect marginalized groups, such as racial and ethnic minorities, the LGBTQ+ community, and individuals with disabilities.”

- A PA General Hospital

Models of Disability Used

- **78% of organizations mentioning disability used the medical model in some way**
- Over half of organizations (54%) predominantly used the medical model
- Still, many used the social (58%) but fewer predominantly used the social model (37%)

Community Perspectives

Community perspectives focused on healthcare infrastructure and social support

Major themes

- Accessibility across systems (healthcare, transportation, housing)
- Discrimination (provider bias, intersectional experiences, community belonging)
- Fragmented systems of support (gaps at transition age, gaps in community-based supports, poor coordination of transition out of hospital setting)

Representation in Goal Setting

Nearly 85% of organizations did not include people with disabilities in their planning documents

Key Gaps:

- More likely a priority population than disability-specific goal
- Goals were narrower than community-identified needs
- Disability rarely included in social and economic priorities
- Limited focus on community-based services

Inclusion of goals and priorities

Goals by Category	Organizations (n) with included goal or priority	Organizations (n) with disability-inclusive goal or priority	Percent (%) of goals that are disability-inclusive
Quality of Life Goal	131	8	6.11%
Healthcare Infrastructure Goal	148	22	14.86%
Physical Environment Goal	39	5	12.82%
Social and Economic Goal	40	2	5.00%
Power/Societal Rules Goal	28	12	42.86%
Other	27	1	3.70%

Insights From CHNA Practitioners on Disability-Inclusive Practice



- **High-Quality and Inclusive Primary Data**
 - Intentional primary data collection that broadens who is reached and how people can participate
- **Collaboration, Trusted Messengers, and Closing the Loop**
 - Ongoing engagement, shared interpretation of findings, and continued review of goals over time
- **Institutional Barriers and Leadership Engagement**
 - Disability inclusion is constrained when leadership views community engagement and disability through outdated or compliance-driven lenses

From Findings to Action

Action Overview



Language and Framing Recommendations

- **Identify** people with disabilities as a population experiencing health disparities
- **Avoid** framing disability as a negative outcome
- **Recognize** the role of structural, environmental, and attitudinal barriers in shaping health.

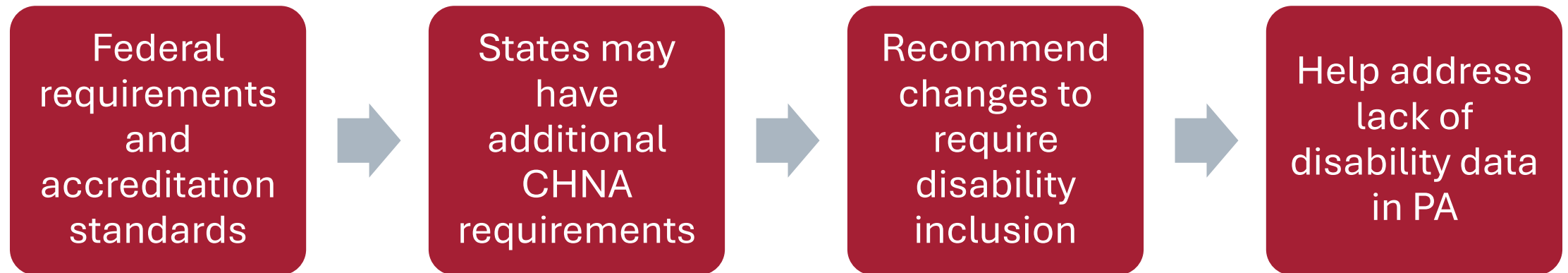
Process and Action Recommendations

- **Collaborate** with other local hospitals and health departments
- **Conduct** targeted primary data collection that meaningfully engages stakeholders within the disability community
- **Collect** and report demographic data
- **Sustain** partnerships with community organizations
- **Include** people with disabilities in assessment leadership, planning, and interpretation of findings
- **Elevate** the disability community as a priority population in planning goals

Recommendations for Advocates and Supporters

- **Participate** in data collection for your area
- **Share** opportunities with your local disability community
- **Join** steering or advisory committees
- **Work** with community-based organizations
- **Ask** your hospital and health department to increase disability inclusion within their documents

Policy Recommendations



Why This Matters

- Health needs assessments are a critical place for local health data
- One of few processes with required interventions and sustained funding
- An opportunity for greater collaboration across stakeholders

What's Next?

Advocacy

Publications

Future
research

Thank you! Questions?

Thank you!

The Arc of Pennsylvania
Taye Hallock, Aidan
Campagnolio, Ellie Lord,
Rachel Calvosa, Haleigh
Leslie

Contact Information

Makhari Dysart:
mdysart@temple.edu

Hannah Wells:
hwells@temple.edu