Mind the Gap! Advancing Data Equity to Improve Population Health Equity for People With Disabilities

Michelle Fong, LEND Trainee, MPH student
NH-ME LEND, Institute on Disability, University of New Hampshire

Introduction

THE UNIVERSITY OF MAINE
Center for Community Inclusion and Disability Studies
University Center for Excellence in Developmental Disabilities

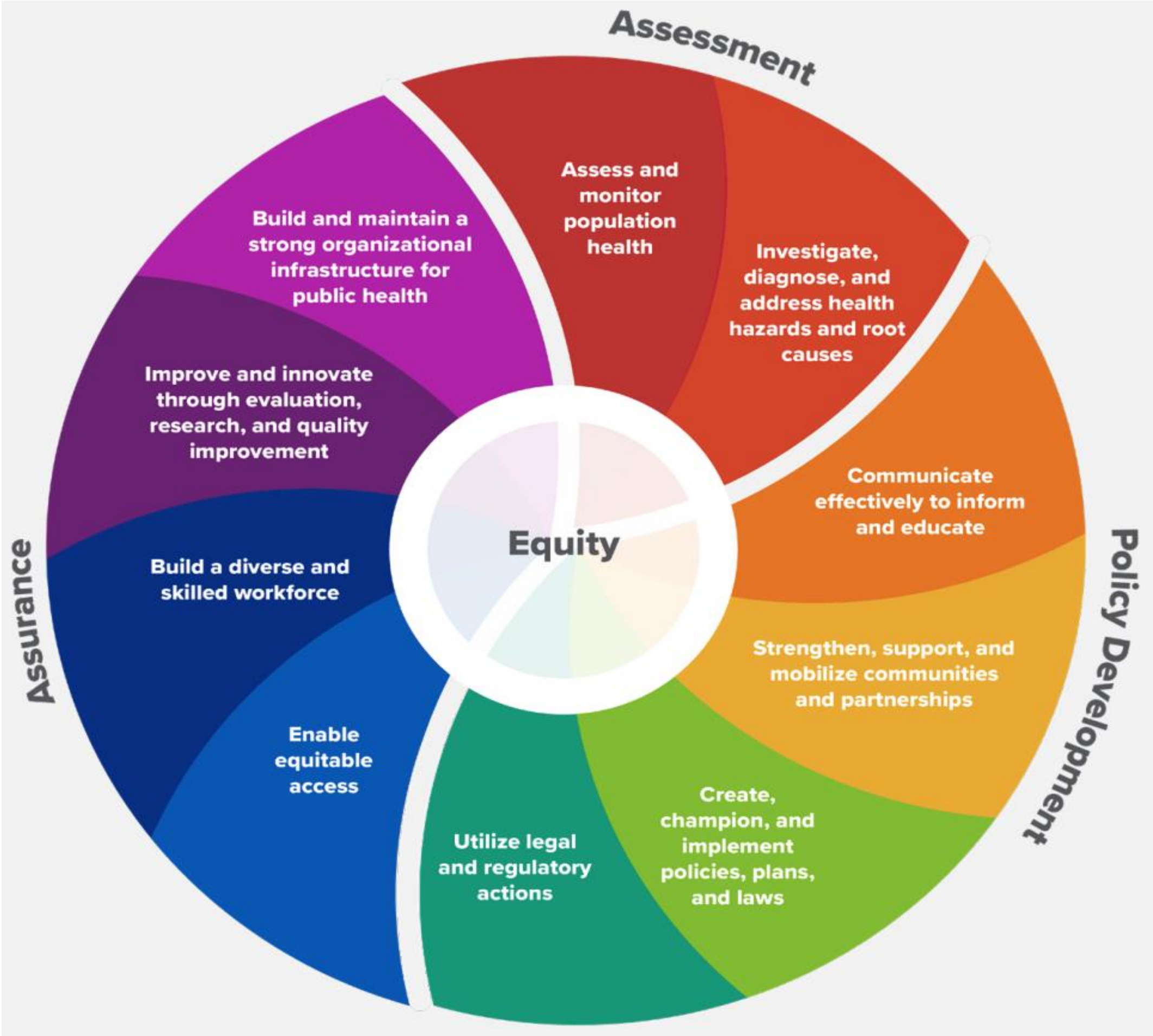
The **Center for Community Inclusion and Disability Studies (CCIDS), Maine's University Center for Excellence in Developmental Disability (UCEDD)**, carries out a variety of education and research activities designed to improve the social and health equity of people with disabilities (PWD). CCIDS sought to examine the health equity of Maine's population with intellectual and neurodevelopmental disabilities (IDD/NDD) regarding Covid-19. However, we encountered a data gap. Therefore, we **examined the drivers of data gaps for people with disabilities (PWD) to make recommendations for improving their health equity by ensuring their representation in public health data, the evidence base for policymaking**.

Leadership Mentors: Dr. Alan Cobo-Lewis, Ph.D., Dir. CCIDS and Susan Russell, Associate Director, CCIDS

Activities:

- Conducted data and literature searches and reviews
- Established lines of communication with Maine's Office of Population Health Equity, Disability Rights Maine, and the Maine CDC
- Attended two webinars
- Conducted legislative research
- Authored a white paper
- Produced and presented a policy brief to Maine's federal delegation

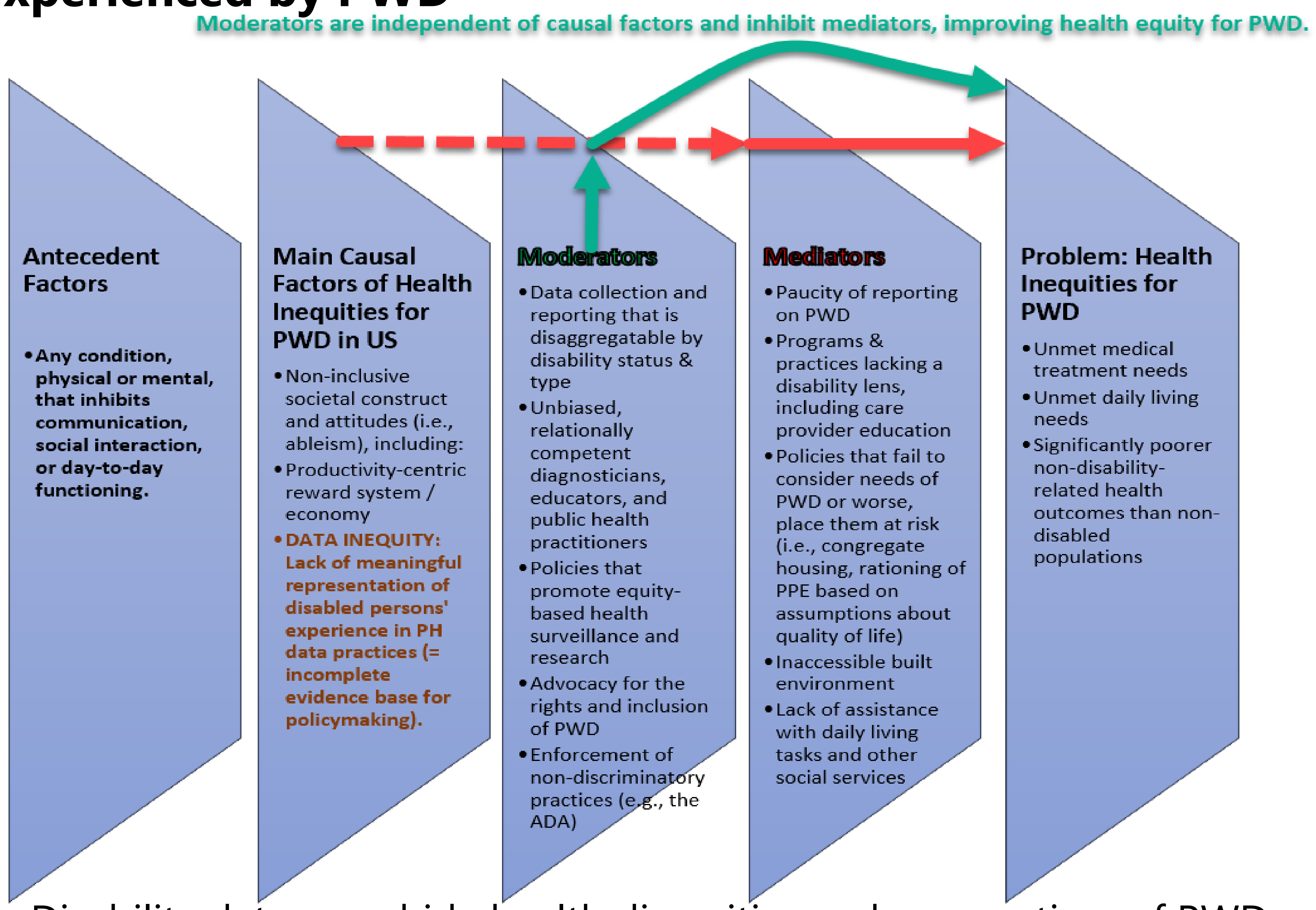
Figure 1. Population wellness is the aim of the 10 essential public health services and equity is at their core [1]



Results:

- 27% of adults[2] and almost 20%[3] of children (**305,218** people)[4] in **Maine**, and 26%[5] of adults and 4.3%[6] of children (nearly **70.6 million** people[7]) in the **US** have at least one disability.

Figure 2. Causative theory for health disparities experienced by PWD



Moderators are independent of causal factors and inhibit mediators, improving health equity for PWD.

Antecedent Factors
- **Any condition, physical or mental, that inhibits communication, social interaction, or day-to-day functioning.**

Main Causal Factors of Health Inequities for PWD in US
- Non-inclusive societal construct and attitudes (i.e., ableism), including:
- Productivity-centric reward system / economy
- **DATA INEQUITY: Lack of meaningful representation of disabled persons' experience in PH data practices (= incomplete evidence base for policymaking).**

Moderators
- Data collection and reporting that is disaggregatable by disability status & type
- Unbiased, relationally competent diagnosticians, educators, and public health practitioners
- Policies that promote equity-based health surveillance and research
- Advocacy for the rights and inclusion of PWD
- Enforcement of non-discriminatory practices (e.g., the ADA)

Mediators
- Paucity of reporting on PWD
- Programs & practices lacking a disability lens, including care provider education
- Policies that fail to consider needs of PWD or worse, place them at risk (i.e., congregate housing, rationing of PPE based on assumptions about quality of life)
- Inaccessible built environment
- Lack of assistance with daily living tasks and other social services

Problem: Health Inequities for PWD
- Unmet medical treatment needs
- Unmet daily living needs
- Significantly poorer non-disability-related health outcomes than non-disabled populations

- Disability data gaps hide health disparities and perspectives of PWD, **perpetuating harmful biases**.[8,9]
- **3 Types of data gaps** exist for PWD. They are the lack of **1)** disaggregatable data, **2)** granular prevalence data, and **3)** data from inaccessible surveillance tools.

Figure 3. Data equity is key to health equity

Data Equity → **Evidence-Based Decision-Making** → **Health Equity**

- The Americans With Disabilities Act (ADA)[10] is a US law that upholds civil rights protections for PWD under the 14th amendment.[11,12] **Exclusion of PWD from benefits enjoyed by other US populations is illegal.**
- **Frameworks exist for improving data equity for PWD and for achieving equity in healthcare and health emergency planning.**[13,14]
- Health equity **drives cost savings and increases self-reliance and productivity of PWD and their caregivers** which can lead to health and economic gains across generations.[15,16,17]
- Health data linked with disability data provide **accountability** and a **basis for trust** in leaders who seek meaningful health progress for PWD.[18]

Conclusion

The collection and reporting of public health data that represent health outcomes, voices, and experiences of PWD are essential to driving down health disparities, an ethically, legally, and fiscally sound goal. **Data equity for PWD fosters attunement of policies and practices that drive *ability*** rather than disability, offering PWD a fair and just opportunity to attain optimum health and to thrive in their communities.

Three major determinants must be optimized to achieve health data equity for PWD: **1)** the legal data privacy framework (e.g. HIPAA), **2)** interoperability of data language and systems across domains, and **3)** alignment of states' data laws & practices.

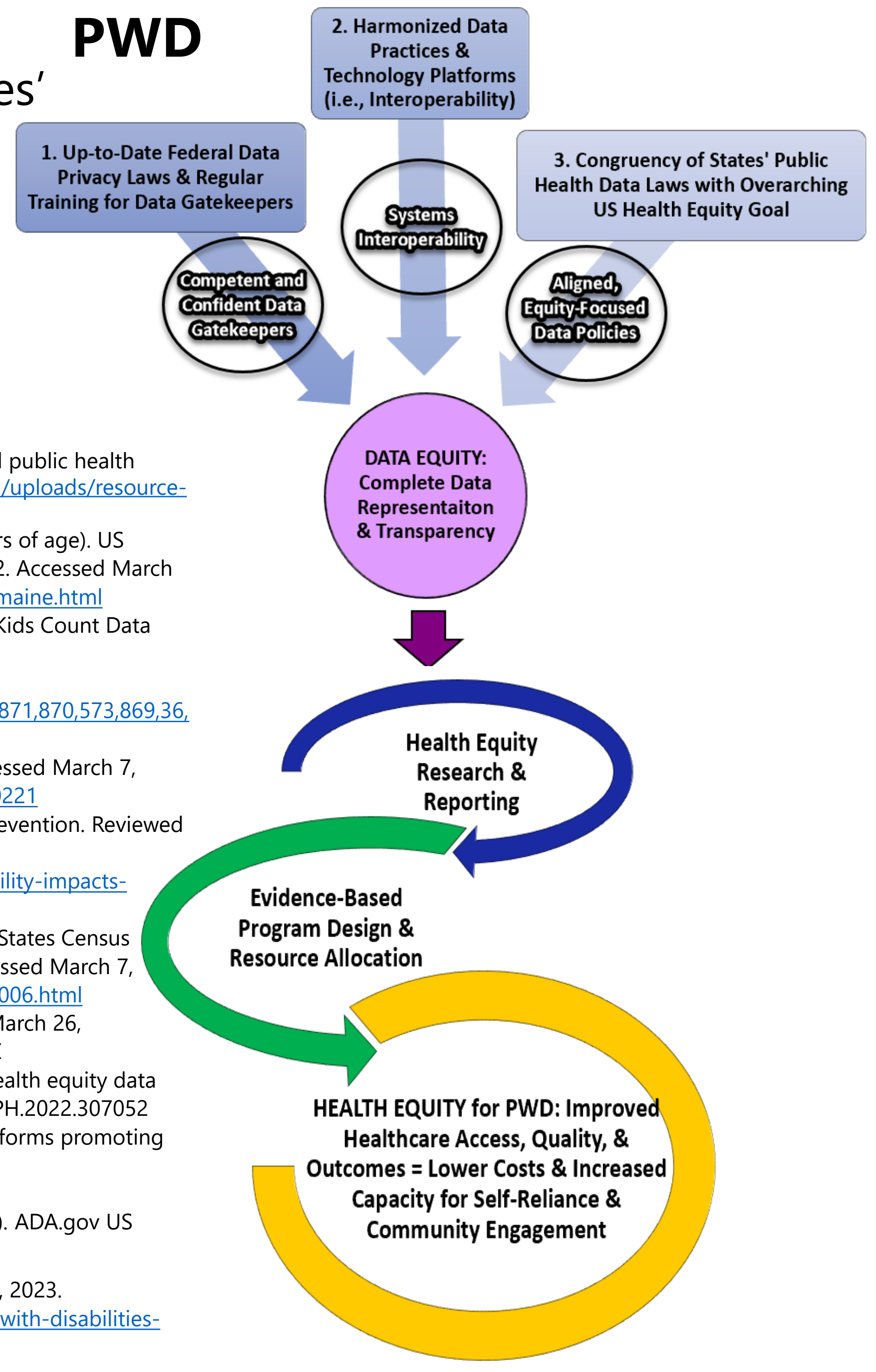
Recommendations

Twelve recommendations designed to encourage data equity for PWD were made in two general areas:

I. **Achieving congruency** of states' data laws

II. **Shifting mindsets** around the collection & reporting of health data for PWD

Figure 3. Three determinants of data equity and how they influence health equity for PWD



1. Up-to-Date Federal Data Privacy Laws & Regular Training for Data Gatekeepers
2. Harmonized Data Practices & Technology Platforms (i.e., Interoperability)
3. Congruency of States' Public Health Data Laws with Overarching US Health Equity Goal

Competent and Confident Data Gatekeepers
Systems Interoperability
Aligned, Equity-Focused Data Policies

DATA EQUITY: Complete Data Representaiton & Transparency

Health Equity Research & Reporting
Evidence-Based Program Design & Resource Allocation
HEALTH EQUITY for PWD: Improved Healthcare Access, Quality, & Outcomes = Lower Costs & Increased Capacity for Self-Reliance & Community Engagement

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