



THE UNIVERSITY OF
MAINE

**Center for Community Inclusion
and Disability Studies**

University Center for Excellence in Developmental Disabilities

***Mind the Gap:
A White Paper on Maine's Missing COVID-19 Surveillance Data,
How They Perpetuate Health Disparities for Maine Citizens with
Disabilities, and What Can be Done to Increase Maine's
Public Health Data & Service Equity***

April 18, 2023

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Table of Contents

Executive Summary..... 1

 Findings 2

 Recommendations 3

 Federal / State..... 3

 State 4

 Conclusion..... 5

Abstract..... 1

I. Background 2

 Disability in Maine and the US..... 2

 Covid-19 and Disability 2

 Health Equity and Data Equity 4

 Figure 1. Equity is at the Core of the 10 Essential Public Health Services¹⁷ 4

 Figure 2. Data Equity Drives Health Equity 5

 The Cost of Health Disparities..... 6

 Data Gaps, Missed Opportunities 6

II. Problem Statement..... 7

 Disability Data Gaps Perpetuate Health Inequities for Maine Disabled Persons 7

 Figure 3. Causative Theory for Health Inequities of PWD 9

 Discrimination and the ADA..... 9

 A Systemic Problem 10

 1. Proper Maintenance of and Expertise in Data Privacy Frameworks and Practices 11

 2. Harmonization of Health Data Domains and Jurisdictions 11

 3. Alignment of States’ Data Laws and Policies with Overarching National Health Equity Goals and Guidance 12

 Figure 4. Three Major US Determinants of Data Equity and Health Equity 14

III. Recommendations 14

 Federal / State..... 15

 State 16

IV. Conclusion 18

REFERENCES..... 19

Executive Summary

Equitable health data represents all populations and can be linked to their common characteristics. Maine's Covid-19 data can be disaggregated by gender, race, ethnicity, and age, but **not by disability status or type**.¹ It is an example of inequity in data collection, or a data gap, that prevents analysis of pandemic health outcomes for Mainers with disabilities. Further, it is a barrier to equitable planning for the next health emergency. Data gaps perpetuate the invisibility of people with disabilities (PWD) to policymakers, enabling biased decision-making that leads to unnecessary and sometimes unethical health barriers for them. Encountering Maine's Covid-19 data gap regarding PWD drove research that elucidated such important points as:

- 27% of adults and almost 20% of students in Maine - **342,575 people** - have at least one disability.^{2,3,4}
- Disabled people **consistently experience health disparities**.^{5,6}
- Health disparities are **costly at all levels of society and contribute to generational poverty**.^{7,8}
- The **Americans with Disabilities Act (ADA)** declares the **right of meaningful representation** for this historically vulnerable population alongside every other one in America.^{9,10,11}

In the US, three major determinants drive data equity for PWD and other populations:

- **Relevance of and expertise in data privacy frameworks and practices**,^{12,13,14,15,16,17,18,19,20}
- **Harmonization of practices and technology in health data domains and jurisdictions**,^{5,6,14,16,18,19,20,21}
- **Alignment of states' data laws and policies with overarching national health equity goals and guidance**^{14,15,21}

Fortunately, rationale and guidance to address data equity for PWD exists.^{18,19,22,23,24,25,26,27}

Its translation and dissemination for practice will afford PWD a fair opportunity to maximize their health. Moreover, it will benefit society by building human capacity for self-reliance and positive health and economic outcomes that lift up generations. Twelve recommendations for action at the state and federal levels are made below.

Findings

The research process revealed the following key points:

- I. Maine has the following **three types of data gaps for PWD**:
 - 1) Lack of **disaggregatable disability data**. (e.g., Covid-19 data for IDD/NDD and all other disabilities),
 - 2) Lack of **granular prevalence data**. (e.g., disability type by county),
 - 3) **Inaccessible surveillance tools**. (e.g., The Maine Integrated Youth Health Survey (MIYHS),²⁸ a survey that excludes responses from any youth who cannot answer its questions without the assistance of another person.) (Korey Pow, ME CDC presentation of MIYHS to Midcoast Public Health Council, November 15, 2022)
- II. **Data gaps are recognized as familiar challenges to health equity work for PWD throughout the nation**, hiding both positive and negative health outcomes and preventing comparison with other populations.
- III. The Institute of Medicine (IOM)²⁷ has urged that **1) standardized disability definitions be developed using the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) as a foundation, 2) disability data be collected alongside other demographic data elements**, separate from medical data, and **3) a national disability health surveillance network be implemented**. It further

emphasized that the **lack of disability statistics was a serious shortcoming for public and private efforts to remove barriers and build community inclusion for PWD.**

- IV. The Americans with Disabilities Act (ADA) is a US law that upholds civil rights protections for PWD under the 14th Amendment of the US Constitution. **Exclusion of PWD from benefits enjoyed by other US populations is illegal.**^{10,11}
- V. At least one state, **Oregon**, collects disability status and type along with other demographic data elements due in large part to their passage of **HB 2134, “REALD”**.^{29,30}
- VI. The **legal data privacy framework in the US is commonly cited as an excuse for not collecting, analyzing or reporting disability data.**^{12,13,14,15,16,17,18,19,20}
- VII. **Data policies and practices in numerous health domains lead to interoperability challenges** between health information technology (HIT) systems and data elements.^{5,6,14,16,18,19,20,21}
- VIII. **States’ rights to determine their public health data practices and platforms has led to varying laws and policies that hinder the comparability of health data for PWD.**^{14,15,21}

Recommendations

The following recommendations were made to promote action at both the federal and state levels that advance data equity for PWD. Justifications and guidance for each can be found in the full white paper. The last five would appropriately position Maine, the Dirigo State, as a leader in its accountability and trust-building with regard to achieving health equity for PWD and all stakeholders.

Federal / State

1. Collect data to improve quality and equity in addition to simply proving compliance.¹⁷

2. Review and revise federal data privacy laws and provide education about them regularly.^{14,15,17,19,21}
3. Designate PWD as a Special Medically Underserved Population under the Public Health Services Act (i.e., Code of Federal Regulations, Title 42).^{13,31}
4. Incorporate a focus on the ADA and disability health equity when reviewing equity for other underserved groups.¹⁸
5. Tie states' Medicaid, Maternal & Child Health, and other block grant funding to substantive evidence of health equity for PWD.¹⁸
6. Require disability training to be integrated into professional programs for healthcare, education, public health, and social services providers.⁶
7. Address ableism through the strengthening and enforcement of non-discrimination laws.¹⁸

State

1. Standardize the collection of disability status and type as demographic data elements across all public health surveillance and reporting instruments, including death certificates.^{6,12} Report disaggregated health outcomes for Mainers with disabilities on a one-page equity dashboard.¹⁸ Provide needed resource grants.
2. Improve the timeliness, granularity, and public-facing transparency of health data. Utilize geospatial data elements to visualize areas of need and deploy resources to them.¹⁶
3. Review statewide public health HIT platforms and standards, including those in rural practice settings. Recommend and budget for improvements to optimize their interoperability.¹⁵

- a. To the extent possible, codify funding and practices for sustainable congruency between public health data goals and policies across all domains.¹⁵
4. Develop and implement a disability health equity index⁶ utilizing input from a multisectoral advisory board including at least one of each of the following: self-advocate from Maine’s disabled population, caregiver of a person with a disability, and a trained disability rights advocate.
5. Fund public health research on Covid-19 and other health conditions of interest and the challenges they pose to PWD and their caregivers across the eco-social and life course models.¹²

Conclusion

To drive down health disparities for people with disabilities, it is crucial to collect and report public health data representing their health outcomes, voices, and experiences. Data equity for PWD fosters the attunement of policies and practices that reduce disability by driving *ability* instead, offering PWD a fair and just opportunity to attain health and thrive in their communities.

Achieving data equity for PWD depends on ensuring that data privacy laws promote health equity for all populations. In addition, the standardization of disability definitions and data practices across health domains and technology platforms, and the harmonization of federal, state, and organizational data laws and policies are instrumental. Aligning states’ data laws offers the greatest opportunity to understand and address health disparities for PWD within and across states. Maine’s commitment to an overarching goal of health equity must propel this work.²⁷ Concurrently, national health leadership’s consistent dissemination to state leaders of the rationale and guidance for its achievement and their support through funding will power state’s efforts. Finally, leadership at all levels must ensure that the spirit and letter of the ADA are carried out in all public health surveillance domains.

Abstract

Background: Data equity, the meaningful representation of all populations in the collection, analysis, and reporting of data, is foundational to health equity. Regrettably, a gap in Maine’s public health data prevents analysis of Covid-19 health equity for the 27%² of adults and almost 20%³ of students with disabilities in-state. **Objective:** To advance health equity for people with disabilities by analyzing the drivers of Maine public health data gaps and providing actionable recommendations for addressing them. **Methods:** A literature search was conducted for themes including Covid-19 health equity for people with disabilities (PWD), data equity for PWD, and data equity for other populations. Information was also obtained through meetings, webinars, and disability and health data policy research. **Results:** National and international statistics show that the pandemic exacerbated health disparities for PWD and their caregivers.^{13,32,33} Comparative analysis of health equity for Maine PWD is barred because Maine’s Covid-19 data are systematically missing elements that prevent their disaggregation by any disability for 305,218 adults^{2,4} and 37,357^{4,8} children. Despite compelling ethical, legal, and financial considerations, many states have disability data gaps, preventing health equity research and perpetuating biases in health decision-making by providers, planners, and policymakers. Three major determinants drive data equity in the US. **Conclusion:** The National Council on Disability (NCD),¹⁸ Center for Medicare and Medicaid Services (CMS),¹⁹ National Academy of Medicine (formerly the Institute of Medicine, IOM),²⁷ and others^{22,23,24,25,26} have provided both rationale and guidance on achieving data equity for PWD, but clarity on an overarching health equity goal and consistent dissemination and proactive support to states from federal health leaders will be critical to advancing the work.

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I. Background

Disability in Maine and the US

Maine covers approximately 35,380 square miles³⁴ in the northeastern corner of the continental United States. Most of the state is rural and the population is just over 1.38 million people⁶ with slightly more females than males³⁵ and a median age of 44.8 years.³⁵ Maine has a predominantly White population (94.2%) with people of other races making up the balance in the following proportions: Black/African American (1.8%), Two or More Races (1.9%), Asian alone (1.4%), American Indian/Alaskan Native (0.7%), and Native Hawaiian and Pacific Islander (0.0%).⁴ 2.0% Of the population is of Hispanic/Latinx ethnicity.⁴ More than one in ten Mainers (11.5%) lives in poverty.⁴ One in four Maine adults (27%)² and one in every five students (19.4%)³ have a disability, making PWD the state's largest vulnerable population with members from across all other demographic categories. National statistics show one in four adults (26%)³⁶ and one in about 21 children (4.3%)³⁷ have at least one disability. Given its size, it is reasonable to expect data collection and reporting to be a priority for this population at both state and federal levels in the pursuit of effective and equity-centered public health policymaking.

Covid-19 and Disability

The population with disabilities was known to consistently experience health inequities in the form of inferior healthcare access, quality, and outcomes even prior to the Covid-19 pandemic.^{6,13} National statistics reveal that during the pandemic, health disparities for PWD were exacerbated.^{6,13} As an example, persons with intellectual disabilities (ID) suffered significantly more diagnoses of Covid-19, endured more hospitalizations, longer hospital stays and more severe disease outcomes (e.g., mechanical ventilation), and had higher 30-day readmission rates and higher mortality rates than PWOD.^{13,32,38} In New York as of April 6, 2020, 9.5% of the population with ID had suffered Covid-19 mortality compared with only 4.0% of the non-ID population.¹² Poignantly, even though PWD had greater intent to become vaccinated, they received fewer vaccinations than PWOD because they experienced additional barriers to



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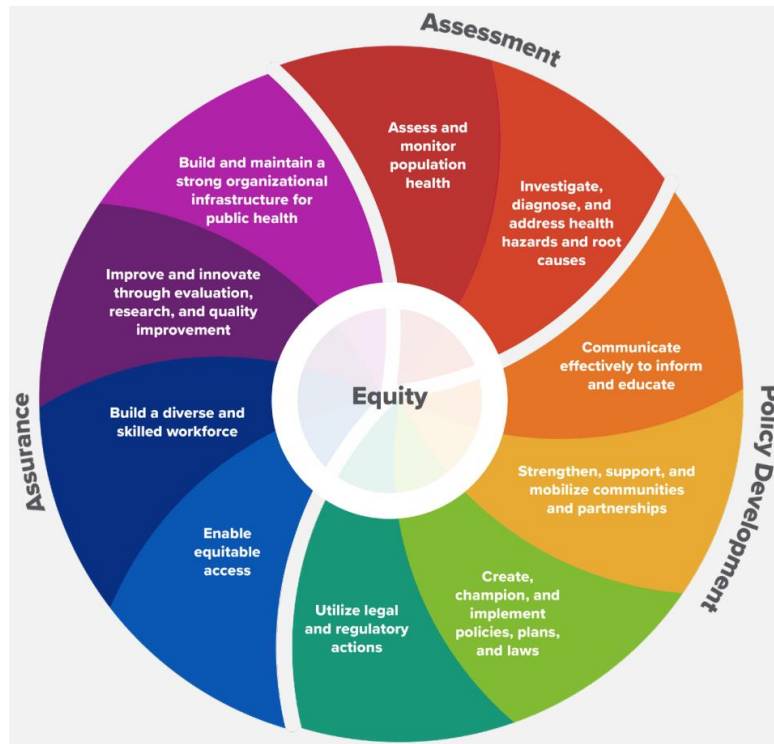
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accessing them.³⁹ Ableism is a culture of mind⁴⁰ that assigns value to a person and their quality of life based on their abilities rather than their humanity.⁴¹ Ableism among providers and health decision-makers is thought to be a major contributor to health disparities alongside barriers such as care costs and lack of transportation.¹⁸

For public health practitioners and stakeholders in the community of PWD, it is natural and compelling to examine whether every state's disabled population fared the same, worse, or better than national results. The Center for Community Inclusion and Disability Studies (CCIDS), Maine's University Center for Excellence in Developmental Disability (UCEDD), is federally funded under the Title V Maternal and Child Health Block Grant Program⁴² to carry out a variety of education and research activities designed to give Mainers with disabilities a voice and to improve their social and health equity. CCIDS Sought to determine Covid-19 vaccination, hospitalization, and mortality outcomes for Mainers with intellectual and neurodevelopmental disabilities (IDD/NDD), and to compare those outcomes against the same for Mainers without IDD/NDD, and against national results for the two populations. However, Maine's public health data gap prevented this important analysis. Reasons cited by the ME CDC were lack of consistent collection of disability data and lack of resource capacity to link data sets where they did exist. (email from Nancy Birkhimer, Manager Accreditation and Performance Improvement, Public Health Operations, ME CDC, November 15, 2022) This exemplifies Sabatello et al's¹² observation that given the known risk factors and consistently poorer health outcomes for people with disabilities, disability status and type should be considered essential public health data but are not systematically collected.

Health Equity and Data Equity

Figure 1. Equity is at the Core of the 10 Essential Public Health Services⁴⁴



Health equity means that all persons and populations have a “...fair and just opportunity to attain their highest level of health.”⁴³ As visualized in Figure 1,⁴⁴ equity lies at the core of public health practice. Every essential public health service is delivered through an equity lens to ensure the broadest reach across populations or to target policies and interventions to the needs of vulnerable ones. The identification and remediation of health disparities by the most equitable, efficient, and effective means is integral to the moral, ethical, and fiduciary obligations of a government funded by its people.⁴⁵ Health equity is, therefore, central to the mission of executive-branch public health agencies at both the federal and state levels.

To assess population health equity, health outcomes (e.g., Covid-19 vaccinations, hospitalizations, and mortality) must be linked to population characteristics (e.g., disability). Complete and disaggregatable data and their transparency to public health practitioners and community advocates alike are requisite to achieving health equity because they are vital to

assessment and effective, improvement efforts. Comparing indicators of health and care access across populations identifies disparities and advances the discovery of systemic barriers to health equity. This is how data drives evidence-based decision-making (EBDM), promoting precision in health improvement program development and deployment.⁴⁴ By leveraging discoveries from equitable data, precious resources are saved and EBDM that equalizes opportunities for population health both day-to-day and in health emergencies is powered. (Figure 2)

Figure 2. Data Equity Drives Health Equity



Sabatello et al¹² observed that since the pandemic, improving health equity of racial and ethnic populations has received a great deal of attention but publicity and research about health equity for PWD is scarce. Demographic characteristics common to people define populations. Maine’s Covid-19 data is disaggregatable by many demographic characteristics including age, geography, gender, and race, but not by disability.¹ Both points are striking to note in light of the fact that PWD are the nation’s and Maine’s largest population experiencing consistent health disparities.¹² The US Department of Health and Human Services (DHHS) in its Healthy People 2030 objectives for the nation,⁴⁶ set numerous objectives to advance the health equity of PWD, including one specifically aimed at improving the data equity of national health surveys. To guide this work, we need only turn to the IOM’s 2007 urging to standardize disability definitions and create a national disability monitoring system.²⁷ The IOM recommended using the World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) as a foundation from which to build standard disability definitions.²⁷ Additionally, the IOM recommended a comprehensive effort be undertaken to develop systematic surveillance of health in the America’s PWD, including collection of disability status and type as demographic

data on all health surveys.²⁷ Significantly, it also championed separating disability, a social construct, from other medical conditions in all health and vital statistics records.²⁷

The Cost of Health Disparities

Health inequity imposes a financial burden on society and sustains generational disadvantages such as poverty and poor health.⁷ Health inequities are evident when only some families must forego healthcare or use household wealth to finance it, when healthcare providers experience burnout from treating patients repeatedly because their poor living conditions are incompatible with wellness, when employers lose worker productivity (or workers), when governments incur social welfare payments and are unable to collect taxes, and when states and countries experience lower gross domestic product (GDP).⁷ When one study totaled the four-year direct healthcare costs of different racial and ethnic populations in the US, then raised all 4-year health outcomes to the level of the healthiest population, the savings were estimated to be between \$216 to \$244 billion.⁸ Stated another way, if all of the populations had been as healthy as the healthiest one for the four years studied, direct healthcare costs would have been reduced by \$216 to \$244 billion.⁸ This figure does not account for the further savings that would have been realized from lowered disability and premature death rates.⁸ The moral obligation for health-related social justice is compelling on its own. While results may vary for PWD, this study suggests that there is an equally paramount economic justification for state and federal governments to invest in health equity for all, beginning with data equity.

Data Gaps, Missed Opportunities

Maine's data gap that prevented answers to CCIDS's original research question is significant. Data elements identifying individuals with IDD/NDD were missing from the Covid data set and further, the set could not be linked to any disability data elements. This is one of three types of data gaps noted here. The second type is lack of disability prevalence data over Maine's geography, such as by county. This type of data enables analysis and substantiation of need by locale and empowers precision in resource utilization planning. An example is the lack of county-level data on the prevalence of mental health (MH) conditions and Attention Deficit Hyperactivity

Disorder (ADHD), a risk factor for numerous negative health and economic outcomes.^{47,48,49,50,51,52,53} A third type of data gap exists when data collection instruments are inaccessible to disabled persons, effectively excluding their experiences and opinions and making their perspectives invisible to researchers and decision-makers who rely on public health data as valid evidentiary sources. An example of this is the Maine Integrated Youth Health Survey (MIYHS),²⁸ which does not capture the responses of disabled youth who need in-person assistance answering its questions. (Korey Pow, ME CDC presentation of MIYHS to Midcoast Public Health Council, November 15, 2022)

Practices that limit data transparency to the public and exclude PWD perspectives from public health data sets are, at best, lost opportunities to understand disabled persons' experiences with everything from Covid-19 to daily teen life and health. The opportunity to discern beneficial best practices in Maine or elsewhere is lost when we cannot compare results from different jurisdictions. Additionally, when a data set does not include authentic engagement with the disabled population, stigmatization and disparities persist.⁵⁴ Any conclusions drawn from such data are implicitly biased toward an abled viewpoint. In the words of health policy expert, Annie Fine, *"If you don't exist in the data, you won't exist in the eyes of policymakers."*⁵⁵ Evidence from these incomplete data sets is then utilized for decision-making and translated into practice, perpetuating structural bias toward ableist policies and practices and marginalizing the experiences of PWD.¹⁴ At their worst, practices that cause data gaps for PWD exact a tremendous cost by interfering with EBDM and inhibiting the identification of and justification for remedying health disparities.

II. Problem Statement

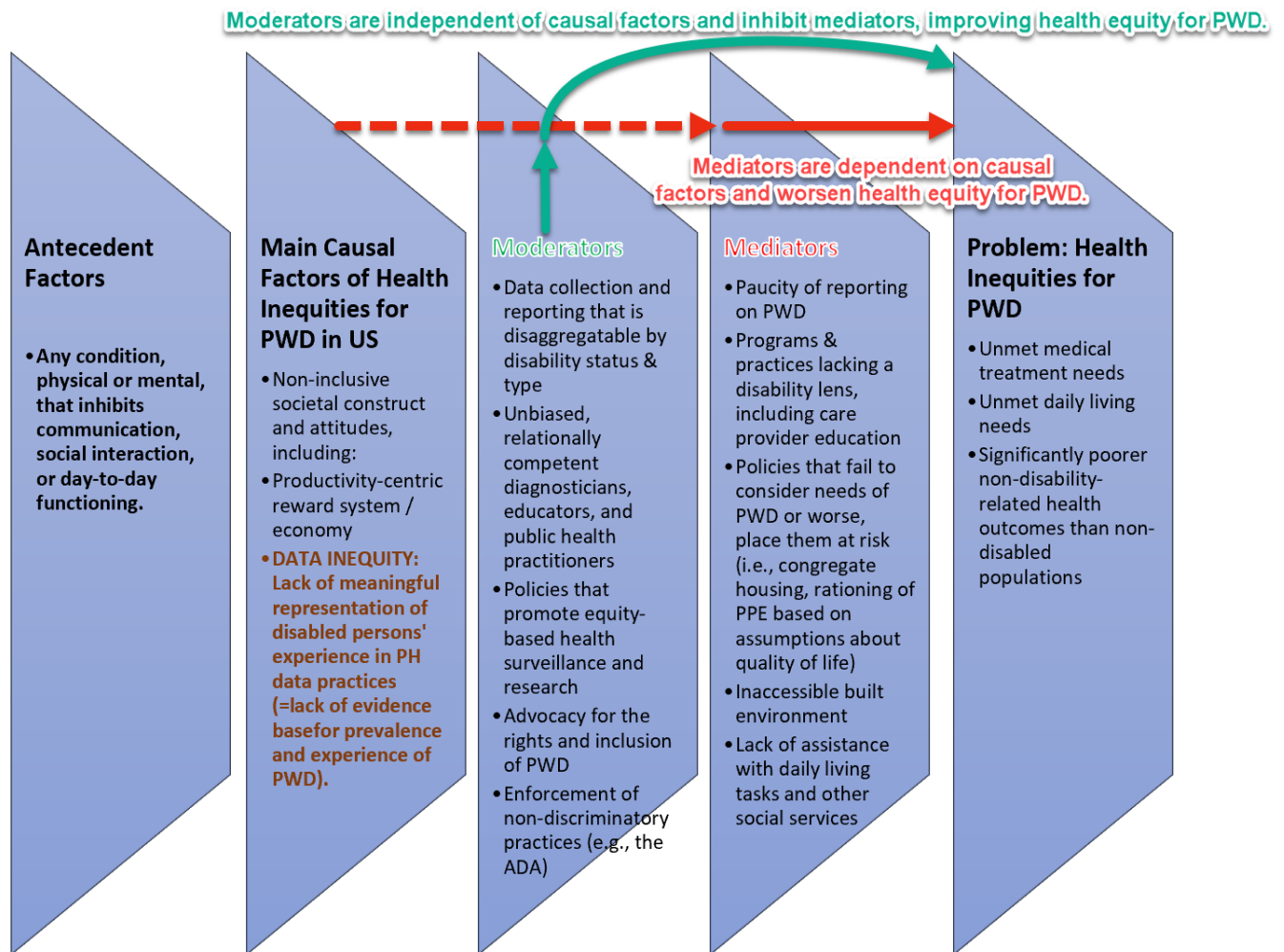
Disability Data Gaps Perpetuate Health Inequities for Maine Disabled Persons

National^{6,13,32} and global^{56,57} evidence indicates that Maine adults and students with disabilities, experience consistent health disparities which intensify during health emergencies like the pandemic. Without public health surveillance data that is disaggregatable by disability

status and type, Mainers with disabilities are not effectively represented or served. This alone is a manifestation of inequity. Moreover, it is a particularly egregious one because it obscures probable further health inequities. Gaps in Maine’s public health disability data are a barrier to studying and strategizing for evidentiary policymaking and targeted preventive and interventional health initiatives. Specific to CCIDS’s original research question, the absence of Covid-19 data linked to disability status and type has 1) prevented the understanding of vulnerabilities of Mainers with disabilities during the pandemic, and 2) hindered consideration of them and their needs by public health authorities as they plan and deploy policies for the next health emergency.

Societal constructs across life settings which simultaneously create a state of disability and marginalize it are the major causative factors for health disparities between abled and disabled populations. Public health data transparency is a pivotal moderator, reducing the problem of health inequity for PWD. This is because it contributes to the development of other moderators, such as unbiased and relationally competent diagnosticians, educators, and surveyors of public health and vital statistics data, consistent funding to support public health surveillance and research, and advocacy for the rights and inclusion of persons with disabilities. Mediators of health inequity for PWD are related to and amplify its causes. They include disability bias, inaccessibility to public health surveillance instruments, lack of health care, and lack of assistance with daily living tasks. All of these are perpetuated by public health data gaps and opacity regarding PWD. (Figure 3)

Figure 3. Causative Theory for Health Inequities of PWD



Discrimination and the ADA

Equity struggles for PWD are not new. In their research for development of a disability-inclusive pandemic response framework, Jesus et al⁶ stated that persons with disabilities have been recognized as “...a minority group frequently vulnerable to stigma, discrimination, marginalization, and socially determined disadvantages.” The passage of Section 504 of the 1973 Rehabilitation Act⁹ banned discrimination based on disability by recipients of federal funds.¹⁰ This was the first time that the exclusion of people with disabilities was legally defined as discrimination, with the US Congress endorsing the view that societal barriers and prejudices,

rather than disability, result in barriers to the achievement of equitable social and economic status.¹⁰ In 1990, the landmark civil rights law, the Americans With Disabilities Act (ADA),¹¹ moved beyond applying the law only to federally funded entities. It made clear that disabled persons, like all others in the US, enjoy comprehensive civil rights protections under the 14th Amendment of the US Constitution.¹⁰ The ADA’s passage through Congress sent the message that allowing fundamental discrimination and injustice toward PWD harms all of US society.¹⁰ Contemporary reaffirmation of civil rights protections can be found in post-covid legal reforms in the area of constitutional assurances to abate health inequities.¹⁴ Applying the lens of the ADA suggests close scrutiny of whether Maine’s disability data gaps may be considered discriminatory.

A Systemic Problem

Maine’s disability data gaps, especially relative to Covid-19 data, are not unique. A survey of seven other states’ Covid-19 dashboards revealed similar data gaps (e.g., New Hampshire,⁵⁸ Massachusetts,⁵⁹ Vermont,⁶⁰ Florida,⁶¹ New York,⁶² Texas,⁶³ California⁶⁴). If data is disaggregated on these sites, it is by age, gender, race, and ethnicity, or a combination of these. Disability status is not presented, presumably because it was not sufficiently captured to allow for disaggregation. Some states collected limited data elements for intellectual disability.⁶⁵ One state, Oregon, stood out for its Covid-19 website coverage, including a “Health Equity Data” tab leading to granular and data about Covid-19 in minority populations, including PWD.²⁹ Oregon’s adoption of House Bill 2134³⁰ in 2013, directing health providers to report race, ethnicity, language, and disability (REALD) data for care encounters, was instrumental to this result. Aside from rare examples like Oregon, evidence from peer-reviewed literature,^{6,12,13,14,16,54} two reports^{33,66} and a letter¹⁸ from the National Council on Disabilities, and a report from the Center for Medicaid and Medicare Services (CMS)¹⁹ all point to disability data gaps being a recognized systemic problem. Three major determinants emerged as important themes in solving this issue. The first is proper maintenance of and expertise on data privacy frameworks and practices,^{12,13,14,15,16,17,18,19,20} second is harmonization of practices and technology in health data domains and jurisdictions,^{5,6,14,16,18,19,20,21} and third is alignment of states’ data laws and policies with

overarching national health equity goals and guidance.^{14,15,21} Figure 4, below, provides a graphic representation of how these three determinants influence data and health equity.

1. Proper Maintenance of and Expertise in Data Privacy Frameworks and Practices

It is recognized that the legal framework around health data sharing is often cited as a barrier to the collection and sharing of health information.^{15,19,22} Components of the law, such as the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule,⁶⁷ have not kept up with modern technology (e.g., online surveys).¹⁴ Further, fear of running afoul of it and other rules and policies leads to what has been described as a “culture of no”⁶⁸ when public health practitioners and advocates attempt to gain access to data in the course of their work. Overcoming that fear is cardinal to achieving data transparency for the public good. To that end, HIPAA’s provision for PH data collection (45 CFR 164.512(b))⁶⁹ intentionally allows for the sharing of data for public health purposes. Routine training and dissemination of facilitation tools are needed to increase the confidence and competency of data gatekeepers at all levels. Further, continual review and revision of HIPAA and other policies around data sharing are needed to keep them relevant and congruent with national and state public health objectives.

2. Harmonization of Health Data Domains and Jurisdictions

Numerous sources contribute to public health data sets such as required disease reporting, vital records, surveys, and medical records. The health information technology (HIT) utilized to gather, analyze, and store data often differs across health entities and jurisdictions. Further, different health domains (i.e., healthcare, public health, insurance) have differing data collection policies, procedures, and criteria. Ideally, all data collection elements and vocabulary would be standardized, and HIT would be interoperable, or able to seamlessly link up.^{19,68} This kind of data sharing and analysis would power initiatives at all levels to drive precise action for improvements in population health equity. In reality, the jumble of data practices, technology, and purposes across health entities significantly challenges data transparency and interoperability.

In spite of the jumble, the trend is toward the unification of data gathering, reporting, and sharing.^{14,15,30,16,20,21,22,68} The Center for Medicaid and Medicare Services (CMS) recognizes data gaps and is setting the bar for standardized and meaningful data collection and practices across the US healthcare system.¹⁹ Additionally, CMS is aligning its practices with the United States Core Data for Interoperability (USCDI) standards which prescribe the use of certain vocabulary and the collection of certain data elements, including disability status, to facilitate data sharing.¹⁹ As the nation's largest healthcare payer,¹⁹ CMS policies and practices influence significant swaths of health data. However, CMS jurisdiction is limited to only those entities that rely on it for payment. Data practices for approximately 331.7 million Americans covered by private insurance⁷⁰ and 28 million not covered by insurance⁷⁰ remain subject to a mosaic of rules, practices, and technology platforms.

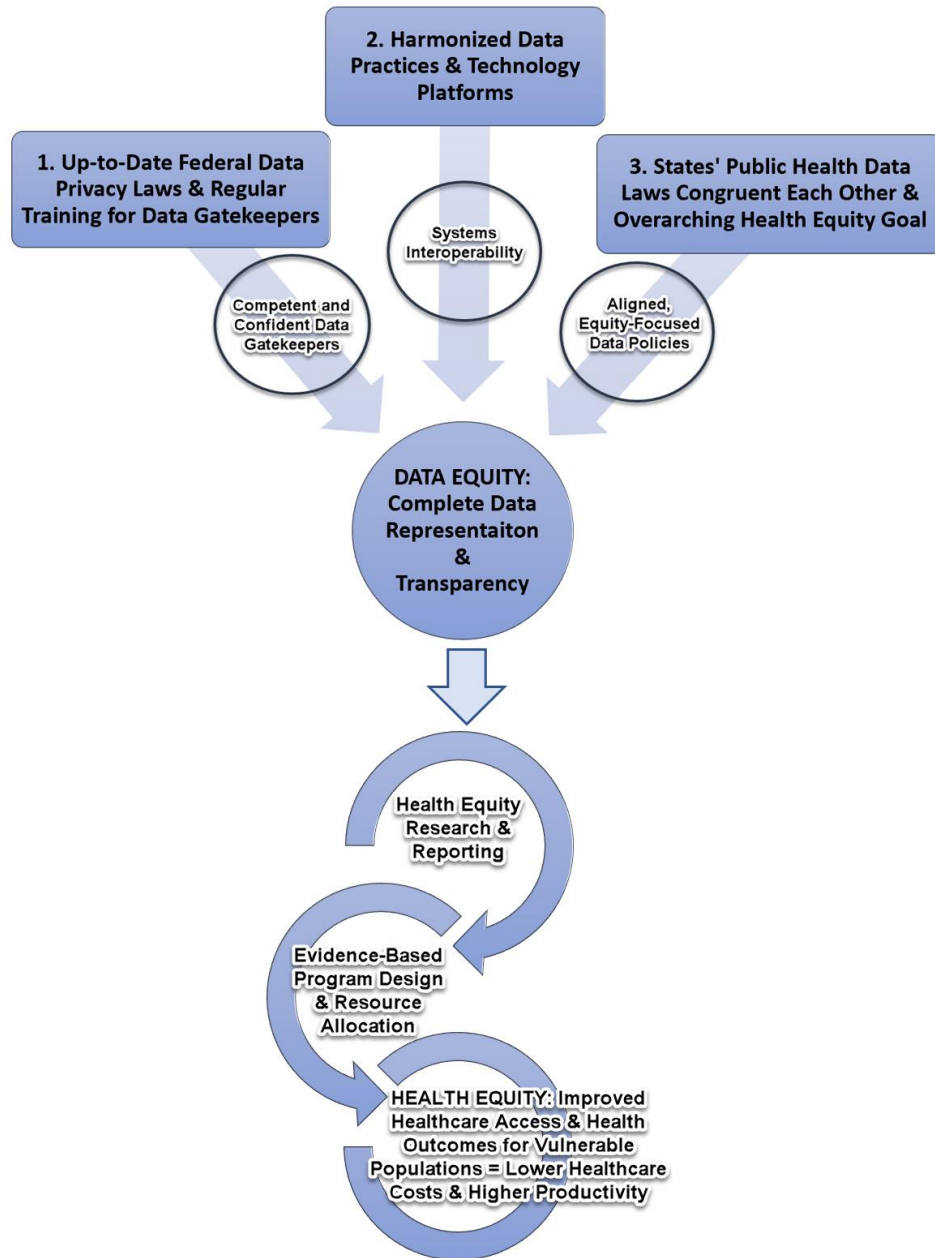
3. Alignment of States' Data Laws and Policies with Overarching National Health Equity Goals and Guidance

To advance data interoperability, why not just pass a federal law prescribing standard data practices across the nation? Because in the US, the federal government is tasked with limited “enumerated powers” under Article I, Section 8 of the Constitution.⁷¹ Further, the 10th Amendment reserves for the states all other powers not given to the federal government by the Constitution.⁷² Public safety, health, and welfare powers fall squarely into states' jurisdiction.²¹ Therefore, the procedures, technology, and criteria to be used for the collection of public health data in each state are at the discretion of that state's government, not the federal government. States can choose to adhere to guidance from federal agencies when it exists, but they are not compelled. The advantage of federalism is that state governments are given flexibility to be more responsive to contextual factors within their populations and geography. Major disadvantages relevant to data sharing and analysis are barriers to interoperability of HIT and comparison of consistent data sets within and across state lines.

States' Covid-19 data gaps with respect to PWD typify the consequences of a decentralized data policymaking in a guidance vacuum. Federal guidance was sparse as the Covid-19 pandemic

began and states were essentially left to determine their own data practices.²¹ This resulted in their implementation of a variety of procedures and varying platforms used for collecting differing data elements. The inconsistent and incomplete data sets produced pose challenges to in-state and between-state health outcomes research.²¹ As pointed out by Sapat et al²¹ in their analysis of data equity and the pandemic, “...the devolution of authority and the absence of a consistent federal message have engendered serious health consequences for state populations.” Cooperation between states in the standardization of data practices and platforms is a critical step toward improving population health equity and reducing the cost burden of downstream acute care nationwide.^{8,19,21} Though federal rulemaking cannot direct state public health data policy and practices, federal grantmaking is a positive leverage point for influencing state-level decision-making. Alternatively, penalties for non-compliance with federal laws such as the ADA and executive orders may also nudge decision-makers toward desired data equity objectives. In the absence of federal authority over states’ public health data practices, linking funding decisions to the documentation of health equity for PWD, or states’ advancement toward it, would be a strong promoter of data equity and the unification of states’ data practices.⁶⁶

Figure 4. Three Major US Determinants of Data Equity and Health Equity



III. Recommendations

The advancement of health equity for individuals with disabilities has recently received attention at both the state and federal levels, with data equity emphasized by the latter. Maine’s Governor Mills proposed \$84 million in the state’s current annual budget in support of health

program development for PWD.⁷³ Further, as detailed in Executive Order #13985,⁷⁴ the Biden-Harris Administration committed to advancing health equity and gave a nod to data practices, declaring “...the first step is to gather the data necessary to inform that effort.” Data transparency that allows assessment of progress toward meaningful results for PWD promotes accountability of leaders for the allocation of resources and engenders trust between them and all stakeholders.²¹

The following twelve recommendations promote data and health equity through the expansion and inclusivity of federal and state public health data policy and practices. Seven are suggested for action at both the federal and state levels. The remaining five rely on Maine, the Dirigo State, to lead the way.

Federal / State

- 1. Collect data to improve quality and equity in addition to simply proving compliance.**¹⁷
This brings a lens that encourages the achievement of value in care through the identification of challenge areas and causative research that increases the cost-effectiveness of program development and deployment.
- 2. Review and revise federal data privacy laws and provide education about them regularly.**^{14,15,17,19,21} This will prevent them from becoming irrelevant or worse, a barrier to public health improvement. Further, it will equip and empower data gatekeepers to share data while promoting health equity.
- 3. Designate PWD as a Special Medically Underserved Population under the Public Health Services Act (i.e., Code of Federal Regulations, Title 42).**^{13,31} This would require the National Institutes of Health to establish Centers of Excellence and engage in research to identify health disparities by disability status, enabling identification of barriers to care and their removal by policymakers.¹³
- 4. Incorporate a focus on the ADA and disability health equity when reviewing equity for other underserved groups.**¹⁸ Health research, interventions, and surveillance is already

happening for other demographic groups. Viewing health equity through a disability lens will necessitate the collection and sharing of disability data elements for PWD.

5. **Tie states' Medicaid, Maternal & Child Health, and other block grant funding to substantive evidence of health equity for PWD.**¹⁸ This will drive accountability for meaningful action toward elimination of structural biases. Like #4, monitoring indicators like the percentage of licensed health providers who have had disability training, the met and unmet health needs of PWD, and the progress toward health equity relative to other populations necessitates the collection and sharing of disability data elements.
6. **Require disability training to be integrated into professional programs for healthcare, education, public health, and social services providers.**⁶ This would reinforce disability competency and expertise, and reduce discriminatory practices that enforce normalcy assumptions and disvalue the voices of PWD in data practices as well as day-to-day health interactions.
7. **Address ableism through the strengthening and enforcement of non-discrimination laws.**^{9,10,11,18} Providing tools such as disability data frameworks and examples of discriminatory data practices, especially around collection and reporting, would help guide conduct for ethical and inclusive data.

State

8. **Standardize the collection of disability status and type as demographic data elements across all public health surveillance and reporting instruments, including death certificates.**^{6,12} **Report disaggregated health outcomes for Mainers with disabilities on a one-page equity dashboard.**¹⁸ **Provide needed resource grants.** Look to Oregon's HB 2134³⁰ as a basis for Maine data law. Further, the IOM clarified that disability status or type is not a cause of death. Rather, the proximal disease condition to death is.^{6,12,18} Accurately reporting health data, including cause of death, along with disability status and type will allow more precise program planning and resource allocation to prevent severe

outcomes and avoid premature mortality in PWD.^{6,12,18} Further, it will enable monitoring of health equity indicators and contextual factors.³⁹ Providing a dashboard will relieve pressure from nonprofits and other organizations serving PWD, often in crisis-mode, that do not have the capacity to perform research and monitoring activities.¹⁷

9. Improve the timeliness, granularity, and public-facing transparency of health data.

Utilize geospatial data elements to visualize areas of need and deploy resources to them.¹⁶ This will power both agency and community-driven health improvements and save resources by informing decision-makers who must prioritize their allocation.

10. Review statewide public health HIT platforms and standards, including those in rural practice settings. Recommend and budget for improvements to optimize their interoperability.

This will facilitate data sharing between data systems in Maine’s public health, healthcare, insurance, and social service settings.^{17,19} Look to CMS¹⁹ and the Robert Wood Johnson Foundation’s National Commission to Transform Public Health Data Systems⁷⁵ for best practices.

- a. **To the extent possible, codify funding and practices for sustainable congruency between public health data goals and policies across all domains.**¹⁵

11. Develop and implement a disability health equity index⁶ utilizing input from a multisectoral advisory board including at least one of each of the following: self-advocate from Maine’s disabled population, caregiver of a person with a disability, and a trained disability rights advocate. Data transparency is intrinsic to the determination of Maine’s baseline score (current) and tracking. Set an index goal and timeline for its achievement. Incorporate the target into the ME DHHS Maine Health Improvement Plan and incentivize its achievement as well as provide grants to build capacities needed on the way to its achievement. This will concurrently increase data equity and accountability for health equity, as well as engender trust between state government and Maine residents, especially PWD.²¹

12. **Fund public health research on Covid-19 and other health conditions of interest and the challenges they pose to PWD and their caregivers across the eco-social and life course models.**¹² Bear in mind the differing experiences of PWD in rural versus urban settings when considering research questions.¹⁶ Research demand for data on PWD will spur the standardized collection of disability data elements. Further, results from these studies will facilitate the development of accurate, effective, and inclusive plans to prevent and minimize the impact of illnesses and health emergencies on this vulnerable population, saving direct care costs plus costs of further disability and premature death.^{7,8,16}

IV. 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 health and thrive in their communities.

Three main factors are instrumental to achieving data equity for PWD both in Maine and across the US: ensuring that data privacy laws promote health equity for all populations, standardizing definitions of disability and data practices across health domains and technology platforms, and harmonizing federal, state, and organizational data laws and policies. The alignment of states' data laws offers the greatest opportunity to understand and address health disparities for PWD within and across states. In Maine, a commitment to an overarching goal of health equity must propel and sustain this work.²⁷ Concurrently, national health leadership's consistent dissemination of the rationale and guidance for its achievement to state health leaders and provision of support through funding will power state's efforts. Finally, leadership at all levels must ensure that the spirit and letter of the ADA are carried out in all public health surveillance domains to ensure health equity for people with disabilities in Maine and across the nation.

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