

**Final Report:**

**Landscape Scan of Maine's**

**Public Health Data Equity Practices**

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**Language disclaimer:** Language is a powerful tool that shapes meaning and understanding. This report uses person-first and identity-first language interchangeably to reflect the diverse ways the disability community identifies. Person-first language places the person before their disability. Identity-first language embraces disability as a fundamental aspect of one's identity and places identity first. For more information about combating ableism through language, we recommend the following:

- National Disability Rights Network: Communicating About People with Disabilities  
<https://www.ndrn.org/resource/communicating-about-people-with-disabilities/>
- National Center on Disability and Journalism: Disability Language Style Guide  
<https://ncdj.org/style-guide/>
- Autistic Self-Advocacy Network: Identity-First Language  
<https://autisticadvocacy.org/about-asan/identity-first-language/>

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## **About CCIDS and DRM**

### **Center for Community Inclusion & Disability Studies (CCIDS)**

CCIDS brings together the resources of the university and Maine communities to enhance the quality of life for individuals with developmental disabilities and their families. Our statewide mission is met through interdisciplinary education, research and evaluation, community engagement, and dissemination of state-of-the-art information that reflect the guiding principles of inclusion, diversity, universal design and access, and social justice.

To assure a statewide focus, CCIDS collaborates with and works to enhance existing networks throughout Maine (including networks that serve people in rural communities and other unserved and underserved populations, such as culturally and linguistically diverse populations). These networks include the Maine Developmental Disabilities Council (DDC), Speaking Up for Us (SUFU), Maine Parent Federation (MPF), Maine Consumer Information and Technology Exchange (Maine CITE), Maine's Independent Living Center (Alpha One), and other advocacy organizations and state and community agencies throughout Maine.

CCIDS, located in Orono, is a recognized administrative unit of the University of Maine: the flagship, land-grant campus of the University of Maine System and part of a national network of congressionally authorized University Centers for Excellence in Developmental Disabilities sponsored by the Office on Intellectual and Developmental Disabilities (OIDD) within the U.S. Department of Health and Human Services (Grant No. 90DDUC0136).

### **Disability Rights Maine**

Disability Rights Maine (DRM) is Maine's designated Protection and Advocacy (P&A) agency, a 501(c)3 organization authorized and mandated to protect and advocate for the rights of Maine people with disabilities. DRM's mission is to advance justice and

equality by enforcing rights and expanding opportunities for people with disabilities in Maine.

DRM represents individuals whose rights have been violated or who have faced discrimination based on their disability. Additionally, DRM offers training on rights and self-advocacy while actively advocating for reforms in public policies.

DRM believes that people with disabilities must:

- Be treated with respect and be free from abuse;
- Control the decisions that affect their lives;
- Receive the services and supports necessary to live independently;
- Have the opportunity to work and contribute to society;
- Have equal access to the same opportunities afforded all people and
- Fully participate in all aspects of society, including education, work, and community.

DRM is part of a nationwide network of disability rights organizations established by Congress to protect the rights of all individuals with disabilities.

# **Executive Summary**

## **Purpose**

This project is a foundational step in strengthening health equity for Mainers with disabilities by improving Maine's public health data equity practices. The product identifies strengths and gaps in Maine's public health data system related to disability data collection, analysis, and reporting. Moreover, it provides actionable recommendations for addressing the gaps and frameworks that help conceptualize the journey to both data and health equity.

To examine healthcare access and health outcomes across communities, health data must be able to be disaggregated and analyzed for each community within a society. This work is facilitated by collecting data as demographic elements, as is commonly done with race, ethnicity, gender, and age. To identify data practices concerning Maine's disability community, this scan focused on the following questions:

1. What are Maine's significant sources of public health data?
2. Do these sources include disability data?
  - If yes, how is it gathered, examined, and shared?
  - If no, what obstacles prevent the collection of disability data?
3. How do Maine's disability services and other state agencies use data to make decisions affecting people with disabilities?

## **Why is disability data important?**

Even though people with disabilities are the largest minority group, disability data practices are not yet on an equal footing with those for other U.S. minority populations, such as racial, ethnic, and gender-based groups. The resulting lack of representation negatively impacts the health equity and civil rights of people with disabilities.

Varying definitions of disability perpetuate an ongoing debate about how to phrase disability questions and analyze responses appropriately. However, the urgent need for more equitable health outcomes, health emergency planning, and equitable data governance practices for this population emphasizes the need for immediate action instead of waiting for the “perfect” definitions and methodology. Data practices and reporting can be adapted over time according to stakeholder and community feedback and evolving best practices, much as they have been adapted over time for race, ethnicity, and gender. Disaggregated data reveal inequities that do not appear in aggregate data. Moreover, they can help prioritize resources, target policies, and tailor programming.

## **Current Public Health Practices in Maine**

Maine's public health data landscape is diverse and complex, with information gathered from various sources, including federal and state health surveys, registries, electronic medical records, hospital discharge datasets, vital statistics, and multiple state executive branch agencies. While the Maine Center for Disease Control (ME CDC) is central to public health data, state offices frequently contract with outside organizations for data collection, analysis, and reporting. Three different Electronic Health Record platforms are used within Maine's four major healthcare systems, increasing the fragmentation.

None capture standardized disability data as a demographic element.

Additionally, our interviews revealed a need for continued conversations and education, as shown by a general lack of awareness about disability as a demographic data element and confusion when conceptualizing disability, with the frequent conflation of disability and medical conditions across state agencies and healthcare systems.

Across the board, Maine's health data system leaders and stakeholders are open to working toward more inclusive and equitable data and health practices. However, commitment is needed at a strategic leadership level to provide the necessary funding



and prioritization to remove significant barriers to the work, such as effectively addressing privacy concerns due to small sample sizes, ensuring accessibility of data collection and reporting processes, and resolving questions about data ownership.

## **Recommendations**

The following short- and long-term objectives will support increased data equity for Mainers with disabilities.

### ***Short Term Objectives***

1. **Educate:** Train healthcare providers and data collectors on the importance of disability data, proper collection methods, and privacy practices, including the public health exception to the HIPAA Privacy Rule.
2. **Engage:** Engage individuals with disabilities and disability advocacy groups in reviewing and improving current data collection practices and providing input throughout the data life cycle.
3. **Acknowledge AI:** Integrate disability data collection and analysis into AI and machine learning initiatives in government and healthcare.
4. **Develop an Interagency Task Force:** Create an interagency task force to manage the transition to more equitable state-wide disability data practices.
5. **Share Guidance:** Issue guidance to state agencies and healthcare systems on including disability status in all demographic data collection.
6. **Standardize Disability Data Collection:** Develop standardized disability questions and categories across state agencies. Using the ACS-6 as a starting point allows for identifying trends over time and across geographic areas.
7. **Be Accountable:** Implement strategic public health role objectives and regular audits of public health data practices to address needs and identify areas for immediate improvement.

## *Long Term Objectives*

1. **Legislate:** Enact legislation requiring and ensuring resources for collecting demographic disability data across all state health agencies and healthcare systems.
2. **Re-boot:** Invest in modernizing data systems to improve interoperability and accommodate disability data as a core demographic variable.
3. **Commit to Implementation:** Implement a comprehensive public health data strategy equalizing disability data and health equity practices with those for other populations. Recruit needed expertise and procure updated technology to overcome obstacles.
4. **Partner:** Establish ongoing community partnerships to ensure continuous improvement and relevance of disability data practices.
5. **Report:** Create an ongoing public reporting system on disability health indicators, equity, and progress in data collection efforts.
6. **Educate Across the Lifespan:** Develop academic and professional training programs to build a citizenry and workforce skilled in disability-inclusive data practices.
7. **Mobilize:** Collaborate with other states and federal agencies to establish best practices and data-sharing protocols for disability health data.
8. **Prepare for AI-Accelerated Decision-Making:** Treat disability data as important as race or gender to ensure that future AI systems are built on fair information. This will result in AI tools that can spot and address health disparities, improve access to public services, and lead to better policies for all Maine residents.

## **Conclusion**

With Maine agencies and healthcare systems currently analyzing health results across demographics other than disability, equitable data collection for Mainers with disabilities is crucial for achieving fair healthcare access and outcomes. Including disability status as a demographic element would enable health improvements for

Mainers with disabilities, who currently face significant disparities. Due to gaps, varying disability classifications, and poor engagement with the disability community, federal health data is limited in its characterization of state-level health equity. To address this, Maine's future health data collection efforts should prioritize equity and involve people with disabilities throughout the process, ensuring inclusivity and addressing disparities within the context where they live, work, and play.

# Introduction

## Purpose

This scan serves as a starting point for improving Maine's data equity practices and, ultimately, enhancing health equity and quality of life for Mainers with disabilities. A landscape scan is a tool used to identify strengths and gaps in a particular area of interest.<sup>1</sup> This report characterizes Maine's public health data sources and practices regarding disability data and provides context for those practices.

This report lays the groundwork for improving the equity of healthcare access and health outcomes for Mainers with disabilities. By first understanding the status of Maine's data practices and how they fit into the pursuit of health equity, Maine's public health workforce can take effective, goal-oriented action and focus and justify resource allocations for the work ahead. This information is crucial for policymakers, healthcare administrators, and advocates working to ensure that Maine's disability community, along with other minority and historically marginalized communities, can achieve their best health. Using the U.S. Centers for Medicare & Medicaid Services (CMS) Health Equity Framework 2022-2032<sup>2</sup> (Figure 1) as a guide, data equity emerges as the first of five steps in ensuring that Mainers with disabilities have an equitable opportunity to achieve their best health.

**Figure 1. CMS Framework for Health Equity Priorities<sup>2</sup>**



To examine healthcare access and health outcomes across communities, health data must be able to be disaggregated and analyzed for each community within a society. This work is facilitated by collecting data as demographic elements, as is commonly done with race, ethnicity, gender, and age. To identify data practices concerning Maine’s disability community, this scan focused on the following questions:

1. What are Maine's significant sources of public health data?
2. Do these sources include disability data?
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## Context

### Background

Two studies and the experiences of many Mainers with varying disabilities led to this scan. First, a white paper<sup>3</sup> sponsored by the University of Maine's Center for Community Inclusion and Disability Studies (CCIDS) highlighted the lack of Maine data on the COVID-19 outcomes of vaccination, hospitalization, and deaths. These outcomes were disaggregated by race, ethnicity, gender, age, and zip code but not by disability status or type. This was because either those data elements were not collected or they were collected as elements other than demographics, making it extremely labor-intensive to correlate outcomes to them. In essence, the COVID-19 experiences of Maine's largest minority population, people with disabilities, were invisible, negatively impacting research efforts, policy decisions, and resource allocations that might have provided meaningful insights, interventions, and planning for Maine's next health emergency.

The second study resulted in a 2023 report<sup>4</sup> released by Disability Rights Maine detailing disparities in healthcare access and health outcomes for Mainers with disabilities. This report found that there is a lack of data available regarding Mainers with disabilities, which leads to a lack of inclusion of disabled Mainers in policy and program development, a key element in identifying and addressing health disparities. Both reports pointed to disability data gaps as a public health problem and a root cause for health-related inequities for Mainers with disabilities.

Over recent years, national momentum has been built to improve data equity, including for people with disabilities. In the U.S., health disparities remain prevalent and unaddressed for people with disabilities, even though they are the largest minority group, at an estimated one in four adults.<sup>5</sup> Disparities compound when additional systemic oppression from other demographic factors such as race, gender identity, or

socioeconomic status intersect. Studies have shown that compared to people without disabilities, disabled people are:

- Significantly more likely to have unmet medical, dental, and prescription needs,<sup>6</sup>
- Three times more likely to have arthritis, diabetes, or a heart attack,<sup>7</sup>
- Five times more likely to report a stroke, chronic obstructive pulmonary disease, or depression,<sup>7</sup>
- Less likely to receive a pap smear or mammograms,<sup>8</sup> and
- More likely to have a lower life expectancy.<sup>9</sup>

Given these substantial disparities in health care access, quality, and outcomes experienced by individuals with disabilities it is imperative that data collection efforts capture their unique experiences and characteristics.

## **Trends & Changes Over Time**

Over the past three decades and especially since the early 2000s, there have been significant changes and emerging trends in disability data reporting, primarily driven by evolving societal understanding of disability and advancements in data collection methods. One major shift has been the move away from the medical model of disability towards a social model, which recognizes disability as an interaction between an individual's condition and environmental barriers.<sup>10</sup> Another significant trend has been the push for more granular and specific data on disability types. Rather than treating disability as a single category, there is an increasing effort to collect data on various types of disabilities (e.g., physical, sensory, cognitive, psychosocial).<sup>11</sup> This granularity allows for more targeted policy interventions and service provision. This conceptual change has influenced how questions about disability are framed in surveys and censuses. For instance, the U.S. Census Bureau revised its disability questions in 2008 to focus more on functional limitations rather than specific medical conditions.<sup>12</sup> In its American Community Survey,<sup>13</sup> the following six binary response questions, now known as the “ACS-6,” were developed and implemented:

1. Is this person deaf, or do they have serious difficulty hearing?
2. Is this person blind, or do they have serious difficulty seeing even when wearing glasses?

3. Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?
4. Does this person have serious difficulty walking or climbing stairs?
5. Does this person have difficulty dressing or bathing?
6. Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone, such as visiting a doctor's office or shopping?

In October 2023, a Federal Register notice proposed changing the disability questions in the U.S. Census from the American Community Survey questions to those based on the Washington Group Short Set (WG-SS).<sup>14</sup> The WG-SS is comprised of six questions that reflect the idea of disability as based on the World Health Organization's International Classification of Functioning, Disability, and Health.<sup>15,16</sup> Switching to the WG-SS would align the United States with the international standards set by the United Nations. However, after receiving over 12,000 comments, the U.S. Census Bureau decided to continue using the ACS-6 questions.<sup>14</sup> Concerns presented in the comments included limitations in the measurement of disability in both the ACS-6 and WG-SS, the inability to compare longitudinal data, and the potential impact on program funding and services.<sup>14</sup> This demonstrates the ongoing conversation on how best to capture disability data. Additionally, there has been a growing recognition of the importance of intersectionality in disability data, acknowledging that negative social impacts of other demographic biases, such as those toward race, gender, and socioeconomic status, are additive with those toward disability bias.<sup>17,18</sup>

As a result of the public's shift toward acknowledging the human rights of people with disabilities, legal requirements<sup>19,20,21,22</sup> intended to advance their health equity have come into existence. For example, collecting disability status to assist with identifying and reducing health disparities in historically marginalized populations is discussed in the Affordable Care Act (ACA)<sup>22</sup>. Enacted in 2011, Section 4302 of the ACA<sup>22</sup> directed the Secretary of the U.S. Department of Health and Human Services (US DHHS) to set up standards for collecting race, ethnicity, sex, primary language, and disability status.



As a result, a rule<sup>23</sup> was issued by US DHHS that specified standard demographic questions, the ACS-6, for collecting this data. The rule explicitly required all federally funded self-report population-based health surveys to include these questions.<sup>23</sup> However, healthcare systems were not explicitly mentioned in the rule. As a result, confusion exists about the applicability of Section 3402<sup>23</sup> beyond federal surveys, and healthcare systems do not consistently collect these data.

Advancements in technology have enabled more sophisticated data collection and analysis methods, including administrative data linkages and electronic health records that supplement survey data. There is also a growing emphasis on longitudinal studies to track disability status over time, recognizing that disability can be a dynamic rather than static characteristic.<sup>11,24</sup> These changes reflect a broader trend towards more comprehensive, nuanced, and actionable disability data to inform policy and practice.

## **Clarifying Disability as a Demographic Data Element**

Considering disability data as demographic elements means removing it from medical data elements and conceptualizing it as a population-defining characteristic instead. A disability is any condition of the body or mind that makes it more difficult for someone to do certain activities or interact with the world around them in the same way as most of society.<sup>25</sup> While disability may result from an illness or medical condition, it is not one inherently. Recording disability as a medical data element confounds instead of distinguishing the two concepts and complicates the disaggregation of data. Frequently, the same factors that impact a disabled person's ability to access healthcare are rooted in bias and stigma, just as with other demographic populations.<sup>26</sup> Therefore, it should be possible to assess public health initiatives for people with disabilities as they can be assessed for any other demographic population.

## **Urgency Regarding Artificial Intelligence (AI)**

The rapid growth of artificial intelligence (AI) in government and healthcare decision-making makes it crucial to implement fair data practices, especially for disability

information. As AI systems increasingly shape policies, resource distribution, and healthcare choices, fair representation of people’s experiences in the data used for training them is imperative.<sup>27</sup> If we do not improve our data collection methods and uses in preparation for this eventuality, AI-driven decisions have the strong potential to perpetuate systemic discrimination, including against people with disabilities. Results will include misguided “evidence-based” AI outputs that lead to unfair policies, misuse of resources, and health initiatives and healthcare plans that do not meet the needs of disabled individuals.

## **Impact**

Even though people with disabilities are the largest minority group, disability data practices are not yet on an equal footing with those for other U.S. minority populations, such as racial, ethnic, and gender-based groups. The resulting lack of representation negatively impacts the health equity and civil rights of people with disabilities. Varying definitions of disability across government agencies,<sup>28</sup> as well as among people with disabilities, perpetuate an ongoing debate about how to phrase disability questions and analyze responses appropriately.<sup>29</sup> However, the urgent need for improved health equity and equitable data governance practices for this population emphasizes the need for immediate action instead of waiting for the “perfect” definitions and methodology. Data practices and reporting can be adapted over time according to stakeholder and community feedback and evolving best practices, much as they have been adapted over time for race, ethnicity, and gender.<sup>29,30</sup> Disaggregated data reveal inequities that do not appear in aggregate data. Moreover, they can help prioritize resources, target policies, and tailor programming.

Our scan reveals a cross-organizational contextual gap in knowledge about data equity practices for Mainers with disabilities and their critical role in improving their health equity. Without a vision and leadership toward health equity for Mainers with disabilities, lack of resources and overwhelm rule the day for staff within Maine’s state agencies and healthcare systems who desire and are making incremental steps toward

equitable data and health practices but are limited by their day-to-day objectives, available hours, and funding. Data system stakeholders are largely open to improvements but need integrated strategic role objectives, education, and financial support for the tools and expertise necessary to overcome the obstacles they face. The current underrepresentation of Mainers with disabilities in state public health statistics has perpetuated a lack of awareness and inclusion by leaders and a scarcity of meaningful programs and services for this population. Moreover, without data, it is difficult to monitor progress over time, hindering accountability for achieving health equity and leading to an erosion of trust between people with disabilities and caregivers, the government, and healthcare providers.<sup>31</sup>

## **Methodology**

A combination of methods was used to answer our questions about Maine's public health disability data collection, analysis, and reporting.

A Rapid Evidence Synthesis<sup>32</sup> was conducted, which included relevant literature, websites, webinars, key data stakeholder interviews, and network mapping to visualize health data flow between state, non-government, and national organizations and decision-makers. Literature included peer-reviewed journal articles, books, state and federal laws and executive agency rules, scholarly magazine articles and editorials, and reports from large health advocacy organizations such as Kaiser Family Foundation and Robert Wood Johnson Foundation. Knowledge was developed in three domains: 1) historical, current, and desired disability data practices and contextual factors driving them; 2) the prevalence of people with disabilities in Maine and their representation in Maine's public health data; 3) relevant federal and state laws and executive branch rules. Searches were conducted using Google Scholar and Google. Literary results were limited to those written in English and produced since 2019. Snowball sourcing was conducted from relevant literature citations and stakeholder references, including sources such as PubMed, Springer Publishing, MDPI, Maine.gov, CDC.gov, and Congress.gov.

In addition, semi-structured “listening” interviews and email contacts were conducted with 18 stakeholders, including data gatekeepers, analysts, and leaders in healthcare, state executive agencies, contract data organizations, and public health and disability advocacy. Meeting notes were recorded and analyzed for key takeaways from individual sessions and overlapping themes.

## **Limitations of this scan**

The duration of this project and stakeholder availability limited the number of interviews that could be conducted. Seasonality, such as summer holidays and vacation time, contributed significantly. Additionally, some organizations did not respond to repeated inquiries. Because of this, there are gaps in our knowledge and reporting for certain institutional practices.

The lack of a standard directory listing Maine’s public health data sources and their contacts required reviewing and collating information from numerous websites. This report is not intended to be an exhaustive inventory of national and state health data sources. Instead, it covers Maine’s significant sources, defined as those that are relied upon most often for data used as evidence for state government and organizational public health decision-making.

The project advisory board reported 50% lived experience with disabilities. We did not question interviewees about their disability status. Ensuring the participation of stakeholders with lived disability experience in the next actionable steps toward more equitable data practices will deepen understanding and help to prioritize objectives.

## **Maine’s Public Health Data**

### **Structure & Flows**

Maine’s public health data landscape is diverse and complex, with information gathered from various sources, including federal and state health surveys, registries,

electronic medical records, hospital discharge datasets, vital statistics, and multiple state executive branch agencies. See Appendix A for an inventory of Maine's major public health data sources. The Maine Center for Disease Control (ME CDC), a division of the Maine Department of Health and Human Services (ME DHHS), plays a central role in utilizing data from national and state health surveillance. The ME CDC also collaborates with healthcare systems to conduct the tri-annual Maine Shared Community Health Needs Assessment<sup>33</sup> (ME SCHNA) and leads the subsequent development of the State Health Improvement Plan<sup>34</sup> (SHIP). Of note, the scope of the ME CDC's role excludes implementing SHIP objectives, which diffuse to other state agencies and non-government organizations.

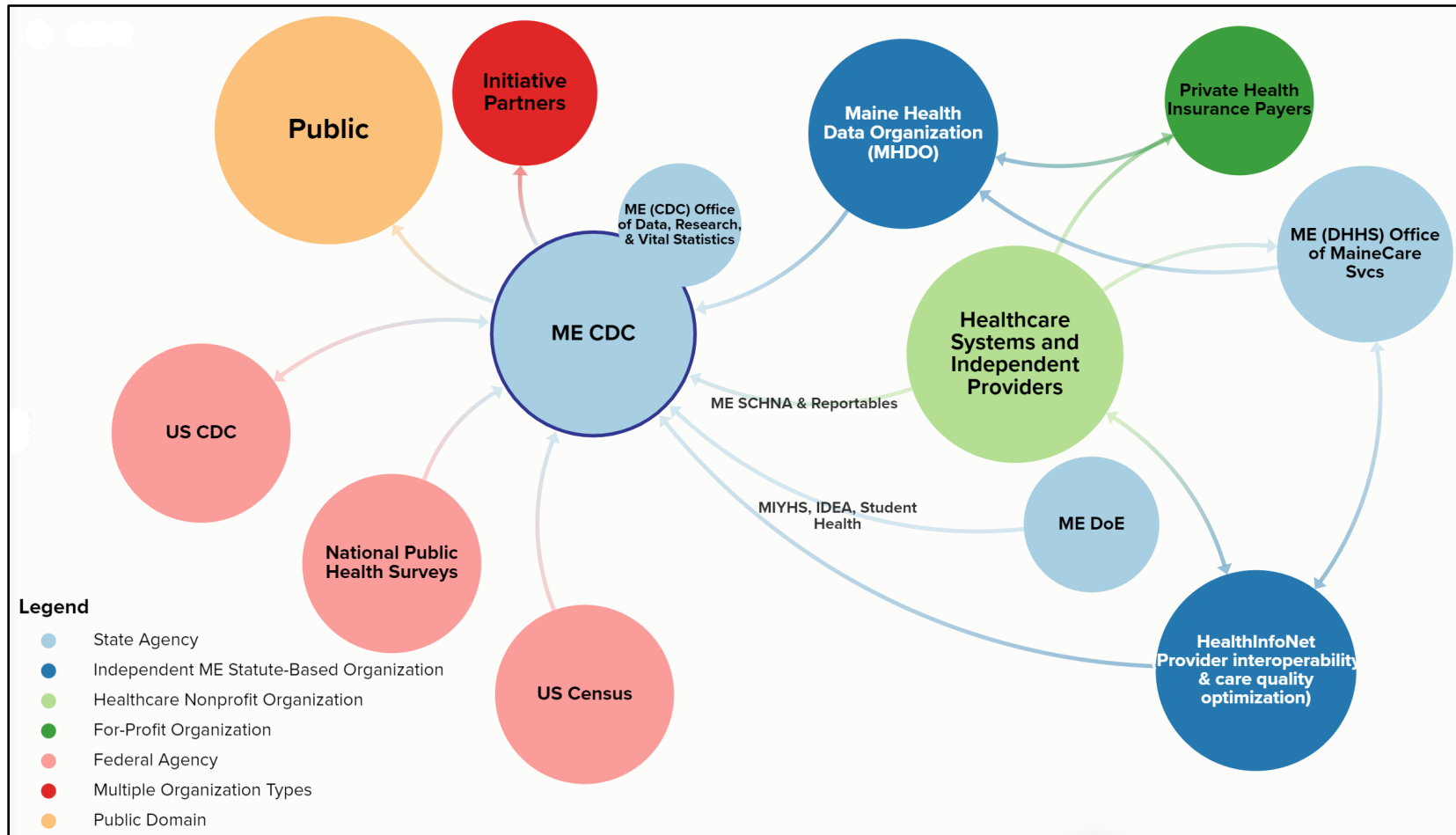
Several state-funded and contract organizations contribute to compiling and processing Maine's healthcare and insurance claims data. These include the Maine Health Data Organization (MHDO) and HealthInfoNet, Maine's Statewide Health Information Exchange (HIE), which assist with research, quality initiatives, and data interoperability, respectively. While these entities provide valuable support in data management and analysis, the overall landscape of public health disability data collection in Maine is outside their purview and in the hands of healthcare, payers, and government employees. Sourcing and data collection practices are fragmented according to organizational mission scopes and policies. Opportunities for standardization of data elements and improved coordination of collection practices to better serve the needs of Mainers with disabilities abound.

Maine's four major healthcare systems, MaineHealth, Northern Light Health, Maine General Health, and Central Maine Medical Center, utilize three different EHR platforms, each capturing disability data (or not) according to internal policies. Currently, none capture the ACS-6 as demographic data elements. Some independent providers still use paper patient records. Nationally and in Maine, healthcare systems vary in their collection, storage, access, and use of disability data within electronic health records (EHR). When collected, it is rarely in the form of demographic data.<sup>11</sup> For this reason,

disability data is often absent from clinical quality improvement projects, where other demographic information may be used to identify inequities.<sup>35</sup> With the rise of EHRs, patient data can be available to providers across healthcare organizations and can be used in real-time assessment of trends, such as with the COVID-19 pandemic.<sup>11</sup> This is beneficial for communities of patients whose data are represented. Work is happening at the national level that will trickle into Maine's healthcare system's EHRs. For example, for those systems that use the EHR developed by Epic Systems (32.9% of U.S. acute care hospitals),<sup>36</sup> the University of Colorado Anschutz's Disability Equity Collective worked with Epic to develop a structure within its software for collecting disability status.<sup>36</sup> The current version relies on providers referring to a list of possible functional limitation data elements and posing non-standardized "yes or no" questions to patients. Answers are entered as demographic data elements.<sup>36</sup> The field is not set up in a question format, which can impact inconsistency in how the data is collected and how patients respond, but this is a goal.<sup>36</sup> This version should be available for users if they choose to include it in their systems by 2025, and it may take longer to become a "forced" update.<sup>36</sup> Of note, most healthcare systems rely on contractors to transition, modify, or upgrade their Epic platform, so it will be imperative to educate contractors about the importance of demographic disability data elements.<sup>36</sup>

Cross-system data sharing and analysis is conducted through Maine's Statewide Health Information Exchange (HIE), HealthInfoNet.<sup>37</sup> For example, Maine's HIE connects healthcare systems for patient record sharing in real-time and conducts quality improvement projects for state health data stakeholders such as Maine CDC, the Office of MaineCare Services, and healthcare providers.<sup>37</sup> Figure 1 below depicts Maine's public health data network structure and primary process flows.

**Figure 2. Maine Public Health Data Network Map**



## Key Stakeholder Insights

One of the most important findings from our research and interviews was legislation and resulting activities. In March 2024, Maine enacted LD 1948<sup>38</sup> to amend the State Data Governance Program led by the Department of the Secretary of State and the Commissioner of Administrative and Financial Services. Through this work, the State is currently inventorying the collection and availability of 13 demographic data elements across all state agencies. Disability is one of these elements. The State's goal is to finish inventorying by January 2025 and then begin developing standard definitions and collection procedures for each demographic data element.

In addition to the ongoing data governance work, key takeaways and themes surfaced from listening interviews with selected state public health data system stakeholders.

1. **Leadership and Responsibility:** The Office of Population Health Equity (OPHE) within the Maine CDC is the presumptive primary entity responsible for state health equity work, including for Mainers with disabilities.
2. **Awareness and Conceptual Clarity:** There is a widespread lack of awareness about disability as a demographic data element and clarity in conceptualizing disability, with frequent conflation of disability and medical conditions across state agencies and healthcare systems.
3. **Procedures:** A significant gap exists in disability data collection, analysis, and reporting compared to other state minority populations. However, there is cross-organizational openness to implementing improvements, including:
  - Standardizing data sets;
  - Collection as demographic elements;
  - Increasing accessibility to data sets and reports;
  - Eliminating structural biases.
4. **Accountability:** Clear objectives and accountability measures for disability data practices supporting health equity research and initiatives are notably absent.



5. **Implementation Barriers:** The following obstacles to the implementation of equitable disability data practices were cited:
  - Privacy and confidentiality concerns (see further details below);
  - Data integrity and ownership issues;
  - Resource constraints (funding, expertise, infrastructure, time);
  - Liability issues (e.g., Does disability data collection create a duty to act?).
6. **Data Access Barriers:** Public health data sets are difficult to attain through both public and interagency channels. This is true across organizations and hinders research, advocacy, and quality improvement projects. Further, finding and accessing disability data, reports, and key contacts for disability health equity issues on Maine’s major public health and healthcare system websites is difficult, impeding collaboration and advocacy efforts ([see further discussion in next section, in Sticking Points: Inclusion in Data Collection and Reporting for Mainers with Disabilities](#)).
7. **Healthcare System Interoperability and Data Gaps:** Major healthcare systems use varying health information technology platforms, none collecting disability status or type as a demographic element in patient records. Opportunities exist for data collection improvements, standardization, and harmonization across healthcare systems.
8. **Extended Timeline for Improvement:** State-level data systems and governance improvements are anticipated to take five or more years to implement, evidencing a lack of urgency toward 1) current barriers to health equity experienced by Mainers with disabilities, and 2) the looming use of inequitable training data for machine learning and artificial intelligence, resulting in the perpetuation of biased decision-making.
9. **Data Generalization Concerns:** MaineCare disability-related data and federal survey data are heavily relied upon for state programmatic decisions serving all Mainers with disabilities, with limited consideration for their generalizability to the Mainers with disabilities from families who choose not to participate or do not qualify for MaineCare.

10. **Affordable Care Act, Section 3402:** The applicability of this law to non-profit healthcare systems is unclear. Maine's healthcare systems tend to rely on their EHR platforms' designs for determining what data is collected and how, and its compliance with regulatory standards. However, none of them collect disability data as a disaggregatable demographic element or use the ACS-6, as detailed in the U.S. HHS's final rule.

## **Sticking Points**

The following common pitfalls stall efforts to implement more equitable data practices. This is especially true when stakeholders lack the strategic objectives, technical expertise, tools, and resources needed for innovative solutions.

## **Privacy Concerns Due to Small Sample Sizes**

A common concern about including disability status in demographic data and disaggregating Maine population data by disability is the potential for privacy breaches due to small samples in areas of low population density. This limitation to statistical research on health data is common, and best practices<sup>39,40,41</sup> have been developed to address the issue, such as:

- Examine ways data is collected and how it impacts who is represented among the data;
- Include people with disabilities in the entire process, from project development, data collection tool development, data interpretation, and dissemination;
- Create transparent data storage and data use policies.

Public health leaders' commitment to overcoming obstacles posed by data privacy issues will manifest as strategic goals, specific role objectives, appropriate and ongoing training, and procurement of the necessary technical tools and professional expertise.

## **Inclusion in Data Collection and Reporting**

Data equity practices include considering the accessibility of data collection instruments and reporting. Collection and reporting methods, language, and rules can serve to include or exclude people with disabilities. For example, surveys that exclude respondents who cannot answer without assistance or have multiple versions but only one with disability questions, such as the Maine Integrated Youth Health Survey (MIYHS),<sup>3,42</sup> do not equitably represent the daily experiences of Maine's disabled population.

Frequently, just as with many other websites across the internet, government and healthcare system websites with public health data are inaccessible to people with disabilities due to a lack of compatibility with assistive technologies, such as screen readers. A 2022 research study<sup>43</sup> examined the accessibility of COVID-19 vaccination dashboards. The number of website errors and accessibility issues from all 50 states, plus six territories, were identified and ranked using a framework developed from the Web Accessibility Evaluation Tool (WAVE).<sup>44</sup> Encouragingly, Maine ranked within the top third, with only one error identified in the accessibility of their COVID-19 vaccination dashboard.<sup>43</sup> As of April 2024, the Department of Justice published a final rule<sup>45</sup> under Title II of the ADA<sup>19</sup> clarifying the obligations of state and local governments to make their websites and mobile applications accessible. Compliance with the rule will reduce barriers to representation and data accessibility for people with disabilities and advance the effective identification and remediation of health inequities they experience.

While Maine's vaccination dashboard met most accessibility guidelines, Maine's Department of Health and Human Services (ME DHHS) failed to include disability status or type as demographics in collected COVID-19 data. This resulted in its characterization of COVID-19 outcomes by race, ethnicity, gender, age, and zip code, but not by disability status.<sup>3</sup> An unintended consequence of this omission was the neglect of Maine's disabled population in the subsequent distribution of Coronavirus

Response and Relief Act<sup>i</sup> funds<sup>46,47</sup> according to those statistics (interview with Eden Silverthorne, Associate Director, Office of Population Health Equity, ME CDC, August 23, 2024).

Underrepresentation of the population with disabilities and exclusion from benefits offered to other US populations are incongruent with the ADA<sup>19</sup> and other relevant disability and civil rights jurisprudence.<sup>20,48</sup>

## **Data Ownership**

Data leadership determines collection, analysis, and reporting methods. As such, they wield power to represent or “disappear” individuals and populations and their lived experiences. Data sovereignty, decolonization, and democratization are all terms used to describe concepts of data ownership by the populations it represents, a goal of equitable data practices.<sup>49,50</sup> While the principle is sound, our scan revealed challenges with the practical application of this concept. If the responsibility and authority for data are transferred to populations, the ME DHHS must consider fundamental questions about their continued role in health data collection, analysis, and reporting. Further, the ME CDC and all communities must grapple with ensuring data integrity and completeness so that resulting statistics and conclusions will hold value.

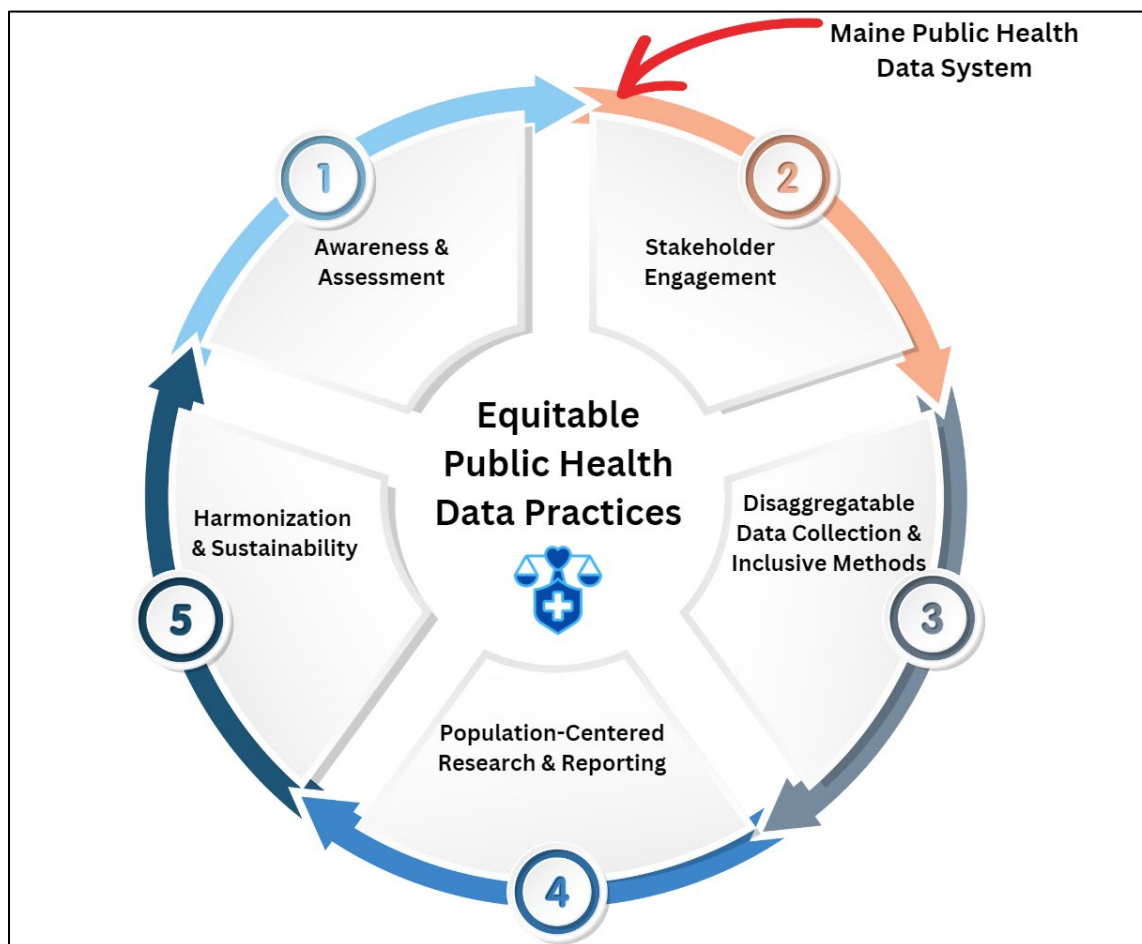
Taken collectively, these findings indicate that a clear vision and strategy from public health leadership is needed to achieve health equity for Mainers with disabilities. Prioritizing data equity and committing to the technical expertise and infrastructure required to address barriers and sticking points are crucial. Maine’s efforts to improve disability data equity are nascent, and positive momentum is building. Figure 3 represents a suggested continual progress cycle for improving data equity practices. The red arrow indicates Maine’s status in the cycle. Acknowledging progress and addressing challenges will require collaborative efforts from an interdisciplinary workgroup of stakeholders and policymakers. An overall motivation toward health equity

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<sup>i</sup>The Consolidated Appropriations Act of 2021 was used to appropriate funds for the Coronavirus Response and Relief Act.

and an openness to data equity practices from our interviewees translate to Maine's window of opportunity for coordinated action.

**Figure 3. A Suggested Continual Progress Cycle for Improving Data Equity Practices with Maine's Status Regarding Disability Data Equity**



## Recommendations

Because collecting disability data is a burgeoning movement and has not yet been done consistently by states or healthcare systems in the US, a lack of evidence exists to inform best practices.<sup>36</sup> However, states and systems have begun to act, including Oregon and Washington, the University of Colorado, and the University of Michigan Medical School.<sup>11</sup> Their models and implementation experiences provide

valuable evidence on which to base decisions about improving Maine’s disability data practices. The following objectives, goals, and stakeholder engagement considerations are offered as an informed starting point and part of an overall strategy. They should prompt discussions and help to further develop and prioritize the next steps for aligning individual state and healthcare organizations to achieve a common goal of health equity for Mainers with disabilities.

### **Short-term objectives for improving data equity practices**

1. **Educate:** Train healthcare providers and data collectors on the importance of disability data, proper collection methods, and privacy practices, including the public health exception to the HIPAA Privacy Rule.<sup>51,52</sup>
2. **Engage:** Engage individuals with disabilities and disability advocacy groups in reviewing and improving current data collection practices and providing input throughout the data life cycle.
3. **Acknowledge AI:** Integrate disability data collection and analysis into AI and machine learning initiatives in government and healthcare.
4. **Develop an Interagency Task Force:** Create an interagency task force to manage the transition to more equitable state-wide disability data practices.
5. **Share Guidance:** Issue guidance to state agencies and healthcare systems on including disability status in all demographic data collection.
6. **Standardize Disability Data Collection:** Develop standardized disability questions and categories across state agencies. Using the ACS-6<sup>12</sup> as a starting point allows for identifying trends over time and across geographic areas.
7. **Be Accountable:** Implement strategic public health role objectives and regular audits of public health data practices to address needs and identify areas for immediate improvement.

## Long-term goals for systemic improvements

1. **Legislate:** Enact legislation requiring and ensuring resources for collecting demographic disability data across all state health agencies and healthcare systems.
2. **Re-boot:** Invest in modernizing data systems to improve interoperability and accommodate disability data as a core demographic variable.
3. **Commit to Implementation:** Implement a comprehensive public health data strategy equalizing disability data and health equity practices with those for other populations. Recruit needed expertise and procure updated technology to overcome obstacles.
4. **Partner:** Establish ongoing community partnerships to ensure continuous improvement and relevance of disability data practices.
5. **Report:** Create an ongoing public reporting system on disability health indicators, equity, and progress in data collection efforts.
6. **Educate Across the Lifespan:** Develop academic and professional training programs to build a citizenry and workforce skilled in disability-inclusive data practices.
7. **Mobilize:** Collaborate with other states and federal agencies to establish best practices and data-sharing protocols for disability health data.
8. **Prepare for AI-Accelerated Decision-Making:** Treat disability data as important as race or gender to ensure that future AI systems are built on fair information. This will result in AI tools that can spot and address health disparities, improve access to public services, and lead to better policies for all Maine residents.

## Stakeholder opportunities

Improving Maine's equitable data practices for people with disabilities presents numerous opportunities for stakeholder involvement throughout the data life cycle. Individuals with disabilities, their families, and disability advocacy organizations can play a crucial role by participating in public forums, joining advisory committees, and

providing firsthand experiences to inform data collection, analysis, and reporting methods. These stakeholders can help ensure that the questions and data collected reflect the lived experiences of people with disabilities in Maine.

Healthcare providers, administrators, and public health professionals also have essential roles. They can contribute their expertise to develop more inclusive data collection protocols, improve the accessibility of health surveys, and identify gaps in current practices. Academic institutions and researchers in Maine can partner with state agencies to design and conduct studies that address specific data equity issues. Technology companies, contractors, and data specialists can collaborate with the state and healthcare systems to create innovative data collection, analysis, and reporting solutions prioritizing accessibility and inclusivity. By actively engaging diverse stakeholders, Maine can create a more comprehensive and equitable approach to public health data that accurately represents and serves its entire population, including those with disabilities.

## **Conclusion**

With Maine agencies and healthcare systems currently analyzing health results across demographics other than disability, equitable data collection for Mainers with disabilities is crucial for achieving fair healthcare access and outcomes. Including disability status as a demographic element would enable health improvements for Mainers with disabilities, who face significant disparities. Due to gaps, varying disability classifications, and poor engagement with the disability community, federal health data is limited in its characterization of state-level health equity. To address this, Maine's future health data collection efforts should prioritize equity and involve people with disabilities throughout the process, ensuring inclusivity and addressing disparities within the context where they live, work, and play.



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## Appendix

### Maine Public Health Data Sources<sup>ii</sup>

Organization(s)	Data Instrument(s)	Disability data as demographic elements?	ACS-6 as demographic elements?
Ofc. Of Data, Research, & Vital Statistics, ME CDC	ME Behavioral Risk Factor Surveillance System (BRFSS)	No; as a Core Section (#8 in 2024 version)	Yes
State-Federal cooperative program	Census of Fatal Occupational Injuries	Unknown	Unknown
ME CDC, ME DoE	Maine Integrated Youth Health Survey	No* (one version of four has disability questions)	No
ME CDC	Vital records (e.g., births & deaths)	No	No
ME CDC	Maine Cancer Registry	Unknown	Unknown
ME CDC	Pregnancy Risk Assessment Monitoring System (PRAMS)	No	No
ME CDC	Maine Tracking Network (environmental hazards & health effects)	Unknown	Unknown
ME CDC / Providers	Division of Disease Surveillance	Unknown	Unknown
ME CDC / Providers	Influenza Surveillance, Sentinel Provider Program	Unknown	Unknown

<sup>ii</sup> Information in this table was derived from interviews, email contacts, and [Maine Department of Health and Human Services. Center for Disease Control & Prevention. Maine Public Health Data Reports. Accessed August 28, 2024. https://www.maine.gov/dhhs/mecdc/phdata/data-sources.htm](https://www.maine.gov/dhhs/mecdc/phdata/data-sources.htm)

<b>Organization(s)</b>	<b>Data Instrument(s)</b>	<b>Disability data as demographic elements?</b>	<b>ACS-6 as demographic elements?</b>
<b>ME CDC, Maine's Healthcare Systems</b>	Shared Community Health Needs Analysis (SCHNA) (Tri-annual combination of ME-based data collection & national statistics)	Yes, starting in the current cycle.	Not verbatim but covers ACS-6 disabilities plus adds questions to cover other disabilities not captured by ACS-6.
<b>ME DoE</b>	DoE student data, disseminated annually	No. IDEA-related disability data only	No. Administrative classification of IDEA-qualifying disabilities.
<b>ME Dept. of Public Safety</b>	Justice, fire, and other emergency response data	Unknown	Unknown
<b>MaineHealth</b>	Electronic Medical Records (EPIC), SCHNA	No	No
<b>Northern Light Health</b>	Electronic Medical Records (CERNER), SCHNA	No	No
<b>Maine General Health</b>	Electronic Medical Records (inpatient: Altera; outpatient: TouchWorks), SCHNA	No	No
<b>Central Maine Medical Center</b>	Electronic Medical Records (Epic), SCHNA	Unknown	No* (*As indicated by sources outside this organization.)
<b>Healthcare Payers: Private Insurance</b>	Inpatient and outpatient claims	Dependent on encounter records	No
<b>Healthcare Payers: Medicare, MaineCare</b>	Inpatient and outpatient claims	Dependent on encounter records	No



Organization(s)	Data Instrument(s)	Disability data as demographic elements?	ACS-6 as demographic elements?
<b>State-Level Data Partners</b>			
<b>Maine Health Data Organization</b>	Patient and claims data collection & processing from all payers and providers operating in Maine (Note: All secondary data, but pooled only by MHDO)	n/a	n/a
<b>HealthInfoNet</b>	Interoperability between healthcare systems, providers, and payers	n/a	n/a

\*Indicated by sources outside this organization.

## **Participating organizations and agencies**

Human Services Research Institute

HealthInfoNet

Maine Center for Disease Control & Prevention (CDC)

Maine CDC Office of Population Health Equity

Maine Department of Administrative & Financial Services

Maine Developmental Disabilities Council

Maine Department of the Secretary of State

Maine Hospital Association\*

Maine Office of Aging & Disability Services

Maine Permanent Commission on Status of Racial, Indigenous, & Tribal Populations

Maine State Archives

Maine General Health\*

MaineHealth\*

Northern Light Health

State of Maine Office of Information Technology Project Management Office

\*Representatives corresponded via email only. All other organizations were met online via Zoom.