Disability Rights
Michigan

2023 Disability Health Equity Report

DRMich.org

SECTION 1

Introduction

In October 2021, the National Council on Disability reported:

"COVID-19 exacted a steep toll on certain populations of people with disabilities, and the events that unfolded during the pandemic, including measures to mitigate the spread, posed unique problems and barriers to people with disabilities [...]" (p. 1):

- People with intellectual or developmental disabilities, and medically fragile and technology-dependent individuals, faced a high risk of being triaged out of COVID-19 treatment when hospital beds, supplies, and personnel were scarce; were denied the use of their personal ventilator devices after admission to a hospital; and at times, were denied the assistance of critical support persons during hospital stays. Informal and formal Crisis Standards of Care (CSC), pronouncements that guided the provision of scarce healthcare resources in surge situations, targeted people with certain disabilities for denial of care.
- Limited opportunities to transition out of congregate settings to community-based settings, to mitigate the risk of contracting the virus, revealed continuing weaknesses and lack of sufficient Medicaid Home and Community-Based Services (HCBS).
- The growing shortage of direct care workers in existence prior to the pandemic became worse during the pandemic. Many such workers, who are women of color earning less than a living wage and lacking health benefits, left their positions for fear of contracting and spreading the virus, leaving people with disabilities and their caregivers without aid and some at risk of losing their independence or being institutionalized.
- People with disabilities and chronic conditions who were at particularly high risk of infection with, or severe consequences from the virus, were not recognized as a priority population by many states when vaccines received emergency use authorization.
- Students with disabilities were cut off from needed in-person special education services and supports and were given last or no priority when schools attempted to preserve educational opportunity. Some students under the jurisdiction of the Bureau of Indian Education faced an especially challenging combination of Internet barriers on Indian and rural lands.
- People with disabilities have historically been underrepresented in the workforce even in robust economic times and the pandemic exacerbated this long-standing problem.
- Deaf, Hard of Hearing, Deaf-Blind, and Blind persons faced a profound communication gulf as masks became commonplace, making lipreading impossible and sign language harder.
- Both youth and adults who had mental health disabilities that predated the beginning of the pandemic experienced measurable deterioration over its course, made worse by a preexisting shortage of community treatment options, effective peer support, and suicide prevention support.

Disability Rights Michigan (DRM) received COVID-19 Supplement IV grants to ensure greater equity and access to vaccinations for people disproportionately impacted by COVID-19, with a focus on individuals with disabilities, their family members, and caregivers. This grant led to DRM project work that identified inequities in the COVID-19 public health response for individuals with disabilities in our state. These inequities reflect broader healthcare access and social determinants of health disparities for the disability community. This report gives the background and context of these disparities, lessons learned from DRM's vaccination grant project work, and recommendations for improving health equity for Michigan's disability community.

SECTION 2

Background

Understanding Health and Social Equity for People with Disabilities

Disability-related disparities in healthcare are nothing new. The Disability Civil Rights Movements that gained momentum in the early 1970s paved the way for the passage of landmark civil rights legislation for those with disabilities. For the first time in U.S. history, the signing of regulations contained in Section 504 of the Rehabilitation Act gave the disability community broader access to public services, including healthcare, by making it illegal for any program or entity that receives federal funding to discriminate or deny access because of disability. These rights and protections expanded further with the passage of the Americans with Disabilities Act (ADA) in 1990 and the Affordable Care Act (ACA) in 2010.

Though these rights for individuals with disabilities are critical, significant obstacles remain to ensure equitable access to healthcare for the disability community. These include: a lack of attention to this unique demographic in social determinants of health strategies; diversity, equity, and inclusion (DEI) efforts and curricula; healthcare data collection practices; the lack of an adequate community-based direct support workforce; and continued reliance on forced institutional living status.

More broadly, to address these inequities, there must also be a shift in how we think of disability. Disability activists around the world have moved away from the medical model of disability, which seeks to fix or get rid of a condition that is medically diagnosed as a disability. This model does not adequately address the limiting factors that impact individuals with disabilities' functioning in a society that was not designed with them in mind. Instead, disability activists embrace the social model of disability, which seeks to change the physical and social environment to be more inclusive and welcoming of all people, including those with disabilities.

Disability and Social Determinants of Health

Social determinants of health (SDOH) are non-medical factors that influence health outcomes. Housing stability, food security, access to transportation, and racial discrimination in healthcare delivery are common SDOH focus areas. Across the board, the lack of disability data and the impact of disability on SDOH lead to strategies that are insufficient to address the unmet needs of this demographic and other intersectional identity groups that are most vulnerable to healthcare inequities.

Housing Stability and Disability

Housing stability, or safe, sufficient, secure housing, is essential for positive health outcomes. Homelessness is the opposite extreme of housing stability. According to a study by Lurie et al. (2015), homelessness is far more common among people with disabilities. Approximately 30% of the U.S. homeless population has a mental disability and, in some cities, 70% of the homeless population has a mental illness. However, specific data on homeless individuals with disabilities is limited. Very few localities gather data on disabilities other than mental illness or physical disabilities, ignoring millions of individuals who have developmental, vision, hearing, speech, language disabilities, or behavioral disorders.

In a 2022 Michigan League for Public Policy report, Cassidy explained specific conditions in the state that contribute to housing disparities for older adults and people with disabilities. In Michigan, renter households living at or below 30% of the area median income are 77% more likely than all other renter households to include older adults or people with disabilities. For every ten Michigan renter families in this income bracket, less than four renter units are affordable, and even less are physically accessible for individuals with specific disability-related mobility needs. The COVID-19 pandemic further exposed housing injustice in our state as Michigan renters with disabilities faced a greater risk of eviction than those without disabilities. Though COVID-19 exacerbated disparities, Cassidy revealed that prior to the pandemic, renters with disabilities were still more likely to be evicted due to the combination of low incomes, higher costs of living, and outright discrimination (2022).

Food Security and Disability

Access to sufficient, safe, nutritious foods that meet individual dietary needs is also necessary for good health. There are higher rates of food insecurity among households that have at least one person with a disability than for households in which no one has a disability; however, knowledge of the relationship between disability and food insecurity remains limited (Butrica et al., 2022).

Research by Butrica et al. (2022) that explored this link suggests that counties with a large share of residents with disabilities are limited in their availability and accessibility of food establishments. These same counties also have a larger share of food establishments that likely provide mostly unhealthy food options, like snack foods and sugar-sweetened beverages. The high cost of living with a disability may also force people to make trade-offs between buying food and paying for their other needs. This theory is supported by other research that demonstrates a household that includes a person with a disability needs 28% more income to maintain the same standard of living as a similar household in which no one has a disability; a phenomenon known as “the disability tax” (Cassidy, 2022).

Ivees Rublee and Sloane (2022) found that like other disparities in social determinants of health, food insecurity for the disability community was exacerbated by the COVID-19 pandemic. The U.S. Department of Agriculture (USDA) calculated that, in 2020, disabled adults faced food insecurity at more than twice the rate of their non-disabled counterparts. Due to the significantly lower wages earned by people with disabilities, many rely on programs like the Supplemental Nutrition Assistance Program. Although people were encouraged to stay home to avoid risk of infection in the earlier phases of the pandemic, those who depended on SNAP benefits had no way to use their benefits to shop for food online.

Ivees Rublee and Sloane (2022) analyzed how the federal government’s response to this problem failed to consider the unique barriers faced by the disability community. Launched in 2019 and expanded in 2020, USDA pilot programs in several states, including Michigan, sought to minimize food insecurity by allowing SNAP users to purchase SNAP-approved food items online and have them delivered through participating retailers. While the pilot programs did alleviate food insecurity for some, they did not make SNAP benefits fully accessible to everyone in the disability community. For example, 40 percent of people with disabilities over the age of 15 do not have access to the internet at home, blocking their ability to use the SNAP online purchasing programs. Members of the disability community are also less likely than people without disabilities to own computers or mobile devices. Furthermore, 98 percent of online websites, including food retailers, do not meet web content accessibility guidelines. 2021 data from the U.S. Census Bureau’s COVID-19 Household Pulse Survey provided the most compelling evidence of these failures, with 55.7 percent of disabled Medicare recipients under the age of 65 reporting not having enough food or not having access to the foods they wanted.

Access to Transportation and Disability

Access to transportation is strongly linked with health outcomes because people must have sufficient, affordable, accessible transportation to get to medical appointments, go grocery shopping, and be socially active in their communities. A lack of access to transportation often results in social isolation and loneliness, particularly for those who do not drive or do not have access to a vehicle (Henning-Smith et al., 2020).

The feeling of loneliness has many harmful consequences for health. According to Blazer (2020, as cited in Simard & Volicer, 2020), these include an increased risk of depression, alcoholism, suicidal thoughts, aggressive behaviors, anxiety, and impulsivity. Some studies found that loneliness is also a risk factor for cognitive decline and progression of Alzheimer’s disease, recurrent stroke, obesity, elevated blood pressure, and mortality (Cacioppo et al., 2015, as cited in Simard & Volicer, 2020).

A 2021 data report from the Eldercare Locator, a national public service of the U.S. Administration on Aging, indicated 372,146 inquiries were received that year. Twenty-two percent of these inquiries were related to transportation, more than any other category, including in-home services (12 percent) and housing (11 percent). Though it is likely the pandemic negatively impacted transportation access, the 2018 Eldercare Locator Data Report also indicated transportation-related inquiries ranked highest among all calls received even before the onset of the COVID-19 pandemic. (Eldercare Locator, 2018).

Studies also show transportation was a key issue in access to healthcare services during the pandemic, including access to COVID-19 vaccines. According to the Center for Disease Control and Prevention (CDC) study Disparities in COVID-19 Vaccination Status, Intent, and Perceived Access for Noninstitutionalized Adults, by Disability Status — National Immunization Survey Adult COVID Module, United States, May 30–June 26, 2021," the top cited difficulty in getting the COVID-19 vaccine for unvaccinated adults with disabilities was "getting to vaccination sites." For vaccinated adults with disabilities, this was the second most cited difficulty after "vaccination sites not being open at convenient times." In another study regarding vaccine access for people with disabilities, transportation was the fourth most cited barrier to getting a COVID-19 vaccine among both rural and urban respondents; Distance was the third (Myers et al., 2021).

Data from a recent report by the University of New Hampshire Institute on Disability (UNH IOD) shows that in Michigan, people tend to rely more heavily on personal vehicle ownership than other modes for their transportation needs (2023). Almost all Michigan residents (97 percent) live in households with at least one car, but 11 percent of Michigan residents with disabilities do not own any cars. This low level of private vehicle ownership among disabled residents may suggest that the high cost of vehicles, especially those modified for wheelchair access, makes car ownership out of reach for many Michigan residents with disabilities (Rahman, 2022). The lower rate of private vehicle ownership may also account for the higher dependency on public transit for Michigan residents with disabilities (three percent) compared to residents without disabilities (two percent; UNH IOD, 2023).

Individuals with disabilities, including older adults who have a naturally higher rate of disability, need public transit options to lead active, healthy lives (UNH IOD, 2023; Henning-Smith et al., 2020). A study of individuals with disabilities living in Southeast Michigan found that people with disabilities who did not have access to public transportation would use it if it were available and it would improve their quality of life (Milefchik, 2018). Though Michigan's disabled and aging make up a larger share of the population than both Midwest and national averages, transportation access for these groups is limited by the lack of diversity of transportation options, especially in rural areas of the state (Rhyan, 2023; Kostyniuk et al., 2012). Michigan invests far less in transit than other states and the quality and availability of transit services is severely limited. According to data from the National Transit Database (as cited in Transportation Riders United [TRU], 2020), the Metro Detroit region trails behind 38 other U.S. metro regions when it comes to per capita transit investment, despite it being the 11th largest metro region in the country. Michigan also has atypical legal and constitutional restrictions that limit state-level support for transit, blocking much-needed public transportation advancements for people with disabilities (Condon et al., 2022). Private ride-hailing companies like Uber and Lyft offer an alternative transportation option for many who do not own a car but do not offer the accessibility features guaranteed by public transit services (O'Connell-Demenech, 2022); nor do they provide the climate-friendly benefits of public transit that make for a healthier living environment for everyone (Condon et al., 2022).

Racial Discrimination and Disability

According to the CDC, non-White people experience discrimination in healthcare not experienced by their White counterparts. Racial and ethnic minority groups, throughout the United States, experience higher rates of illness and death across a wide range of health conditions. Additionally, the life expectancy of non-Hispanic/Black Americans is four years lower than that of White Americans. Interpersonal and structural racism has been the focus of health equity efforts that seek to improve conditions for people of color in socioeconomic areas such as housing, education, employment, and others.

What is not often considered in these efforts is the intersection of race and disability. UNH IOD data show that disability prevalence is higher among non-White people than White people. For example, in Michigan, Black residents had a higher share of people with disabilities (17 percent) than White residents (11 percent).

The intersection of racism and ableism also plays a major role in poor health outcomes. For instance, both Black and disabled people were more likely to die of COVID-19 infection than their White or nondisabled counterparts (Ndugga et al., 2022; Gleason et al., 2021). However, less data for public analysis was made available throughout the pandemic for each group, let alone for members of both groups. Ethnicity data on vaccination rates and deaths were less frequently available for all states, with only 48.1 percent of states and territories reporting ethnicity for vaccines and 40.7 percent for deaths (Aliseda-Alonso et al., 2022). Disability status was not reported for vaccine or death rates for any state or territory (Aliseda-Alonso et al., 2022).

This absence of data leaves us with very little information to guide interventions or strategies that address health inequities. Furthermore, even though disability prevalence is significantly higher among people of color, strategies to increase access to healthcare for communities of color do not necessarily address the unique and specific barriers faced by disabled members of those communities. Disability is often an afterthought, rather than a variable considered worthy of consideration in planning programs that mitigate the harmful consequences of structural racism. By leaving out the most marginalized members of already marginalized groups, social determinants of health strategies will never fully succeed.

Diversity, Equity, and Inclusion (DEI) and Disability

It is also important to include the historical context of discrimination against people with disabilities in DEI curricula. Ableism, like racism, is both interpersonal and structural and is ingrained in the fabric of society. While the physical elements of accessibility are critical for advancing equity for individuals with disabilities, so are the social and cultural components. Assumptions about competency, quality of life, and other disability-based stereotypes result in explicit and implicit bias that affect medical decisions for people with disabilities, some of which involve denial of life-saving treatments or medications (National Council on Disability, 2019).

Organizations and employers of all sizes, across all sectors of our economy, have made progress in recognizing cultural backgrounds and race, ethnicity, and gender-based barriers in the workplace through DEI training and other related DEI programs. While DEI is invaluable for advancing equity, the absence of the A (Accessibility) in most DEI programming speaks volumes about how disability has been left out of the DEI conversation.

On June 25, 2021, President Biden signed the Executive Order on Diversity, Equity, Inclusion, and Accessibility in the Federal Workforce to further advance equity within the federal government. As defined in the executive order, accessibility is:

> The design, construction, development, and maintenance of facilities, information and communication technology, programs, and services so that all people, including people with disabilities, can fully and independently use them. Accessibility includes the provision of accommodations and modifications to ensure equal access to employment and participation in activities for people with disabilities, the reduction or elimination of physical and attitudinal barriers to equitable opportunities, a commitment to ensuring that people with disabilities can independently access every outward-facing and internal activity or electronic space, and the pursuit of best practices such as universal design. (The United States Government, 2021)

Including accessibility in DEI curricula is one way we can advance health equity for individuals with disabilities. Over a quarter of adults living in the U.S. have a disability (CDC, 2023). Without making disability a part of the conversation, we cannot adequately move the health equity needle.

Disability and Data

Advancing health equity is impossible without data. Data informs strategies to address inequities in healthcare delivery and the socioeconomic conditions that influence health outcomes. However, disability data is rarely collected unless it is for research solely focused on disability itself.

As described by Swenor (2022), the COVID-19 public health response is the perfect example of how the lack of disability data results in data gaps that erase inequities and social justice for the disability community. For example, in April 2020, the U.S. Census Household Pulse Survey was launched to assess the impact of the pandemic on US households. Data was disseminated biweekly to inform federal and state response and recovery planning. However, it did not include standard questions about disability until April 2021, during the second year of the pandemic (Swenor, 2022; U.S. Census Bureau, 2020). Within the first weeks that disability questions were asked in the survey (April 14 to April 26, 2021), data emerged that showed people with disabilities were at a disproportionate risk of food insecurity and experienced a lack of access to healthcare during COVID-19 (Assi et al., 2022).

Despite requirements of Section 4302 of the Affordable Care Act to include the capability for electronic health records (EHRs) to contain disability status, significant gaps in disability data in EHRs also prevented tracking of COVID-19 testing, vaccination, and mortality among people with disabilities during the pandemic (Swenor, 2022; Kaundinya, 2022). Much of the data that was available have come from people with disabilities living in congregate care settings, like nursing homes, or are limited to people with intellectual and developmental disabilities (Swenor, 2022). One of the most regularly cited statistics regarding COVID-19 and disability comes from a study by Jefferson Health which found that people with intellectual disabilities are six times more likely to die of COVID-19 infection (Gleason et al., 2021). However, one of the commonly misunderstood aspects of disability is that disability does not, inherently, affect a person's life expectancy. Disability data gaps remove opportunities for evidence-based policies and the reach of mitigating efforts to prevent unnecessary illness and death for people with disabilities (Swenor, 2022).

Swenor (2022) further explained why disability data is critical in all spheres of study, even those outside of disability-specific issues. Limiting disability data collection to disability-specific issues creates barriers to using data sets across varying systems, including healthcare, food access, housing, transportation, education, employment, voting, etc. Therefore, disability data must become a core dimension of all demographic data. Broad disability data collection is the key to finding the root causes of health inequity for people with disabilities and other intersecting identities and developing strategies to end it.

Workforce Capacity and the Direct Care Workforce Crisis

Workforce capacity is critical in health equity and the healthcare system's response to public health emergencies. While hospital workforce shortages were a focal point of the COVID-19 public health emergency, long-standing direct-care workforce shortages also reached crisis levels during the pandemic.

The Administration for Community Living reported that millions of people who depend on home and community-based services to maintain their independence experienced service disruptions or were forced to move into nursing homes or other institutions, compromising their health and safety during the pandemic (2022). This crisis did not end with the end of the COVID-19 public health emergency. Recent reports show that more than three-quarters of direct care service providers are not accepting new clients, and more than half have cut services because of the direct care workforce shortage. In addition, high direct care staff turnover averages nearly 44 percent across states (National Core Indicators Intellectual and Developmental Disabilities [NCI IDD], 2022).

The direct care workforce crisis is not only a public health concern for individuals with disabilities. The Administration for Community Living laid out key issues fueling the crisis, including poor wages and lack of benefits, including health insurance, for direct care workers themselves (2022). Therefore, health equity strategies must include initiatives to improve the recruitment and retention of direct care workers. The health of millions of people with disabilities and those who provide their direct support services depend on it.

Institutional Bias

Other than hospitals, the devastation of the COVID-19 pandemic was most pronounced in nursing homes and long-term care facilities that house older adults and people with disabilities that are prone to the harshest consequences of COVID-19 infection (New York Times, 2020). As concluded in a cohort study by Bartley et al. (2018), even in non-emergency times, there are significant health benefits to community-dwelling versus living in congregate care settings. Unfortunately, though most prefer to live in their own homes, it can be difficult for people who have long-term care needs to maintain an adequate level of support to do so. Historical institutional biases in the Medicaid program and in patterns of healthcare spending in Michigan contribute to the lack of community housing choices for members of the disability community.

SECTION 3

Lessons Learned from Disability Rights Michigan Vaccine Advocacy

DRM Vaccination Program

In November 2021, DRM formed the Vaccine Advocacy Team (VAT) for COVID-19 work. DRM's primary mission in this project was to get shots in arms. The strategies used to find people willing and eligible for COVID-19 vaccinations changed as the project progressed. Initially, DRM conducted broad outreach efforts through food pantries, churches, child welfare providers, area agencies on aging, and local health departments. Early work included scheduling home-based vaccination visits and facility-based events for the state's contracted mobile vaccine clinic providers.

The project work changed significantly in July 2022 when the state paused funding for mobile vaccine clinics, moving DRM to contract with one of the providers, DocGo, directly. At the same time, DRM staff broadened community engagement efforts to include community centers, homeless shelters, public housing settings, and permanent supported housing. DRM also worked with a parallel rollout of mobile vaccine services provided by the Wayne Health Mobile Unit, working with Wayne State University's Developmental Disabilities Institute to collaborate on vaccine events such as the Special Olympics in Detroit.

Due at least in part to DRM advocacy, 4,208 individuals received COVID-19 vaccinations from the beginning of the project through June 2023. This number includes vaccinations referred to mobile clinics (624), vaccinations administered directly by DRM's contract clinical provider (2,846), and vaccinations indirectly facilitated by DRM staff at events with other providers (738). DRM also facilitated flu shots and other collateral health care services in addition to COVID-19 vaccines.

The people benefiting from these vaccines are hard to find people, in home settings, public housing, and community facilities. Just over half (52%) of vaccinations given either directly or through referrals occurred in community events, while 38% occurred in facilities and 10% at home. Among the same group of vaccinations, 26% identified as Black or African American, 4% identified as Hispanic, 64% were age 50 or older and 49% identified as having a disability.

DRM utilized a portion of their grant funding to provide modest incentives at DRM facilitated vaccine clinics in the form of $25 gift cards. These incentives had a tremendous impact on COVID-19 vaccination numbers due to the targeted areas for clinics often being those with high rates of poverty. There is not only a significant link between poverty and disability, poverty is arguably the single largest determinant of health (Goodman et al., 2017, Pan American Health Organization and World Health Organization). Modest financial rewards are also a powerful tool in encouraging people struggling with poverty to make healthy choices. Patient financial incentives are scientifically proven to increase preventative care including and beyond vaccinations (County Health Rankings & Roadmaps). DRM advertised incentive availability in clinic flyers, social media posts, and other DRM VAT communications.

VAT staff crafted messaging that was specifically designed to reach everyone, even those who typically experience communication barriers or have limited access to the internet. Modes included brochures, print and electronic newsletters, a website landing page, mailed information packets, and social media. Special care was taken to ensure all communications met disability accessibility standards. Due to DRM messaging, over 63,000 people received information about vaccines, DRM, and its vaccination activities by the end of June 2023.

Throughout the duration of VAT project work, DRM also worked closely with the Michigan Developmental Disabilities Institute (MI-DDI) and the Autism Alliance of Michigan (AAoM) to develop certification criteria for healthcare providers as Michigan Vaccination Partners (MVP). The certification criteria require providers to undergo disability training, make vaccination sites accessible and sensory-friendly, and market services as disability-friendly (Wayne State University, 2023). One of the key requirements of becoming an MVP-certified healthcare provider is collecting disability data at the point of service. This data allowed us to not only evaluate whether we were reaching our target demographic but to change the way healthcare providers think about the value of capturing this information to advise appropriate follow-up care and treatment plans and refer to other community-based services or resources as needed.

DRM Community Engagement

Since the early stages of DRM VAT project work, VAT staff has established numerous partnership agreements with outside groups to share DRM Vaccine Advocacy information and/or host community vaccination clinics. DRM initiated over 100 partnerships by the close of June 2023. These partnerships were the result of VAT research and networking efforts to find trusted community leaders across many sectors, including many from organizations with a focus on marginalized populations. Community leaders included constituents from Disability, Black, LGBTQ, and Parent empowerment groups, Civil Rights groups, Faith Leaders, and others. DRM listened to these leaders to learn what their communities needed and how to create clinic experiences that were accessible, integrative, and specific to those needs.

DRM VAT staff also made connections with schools, food banks, homeless shelters, local health departments (LHDs), community mental health agencies, child welfare agencies, behavioral health agencies, Area Agencies on Aging, Centers for Independent Living (CILs), The Arc, United Way, and the Michigan Department of Health and Human Services (MDHHS). This approach allowed DRM to not only facilitate community outreach events that offered COVID-19 vaccinations, but to get vaccine program information in the hands of trusted communicators from the local grassroots to the state-wide level.

Many community groups also have constituents who are homebound or had challenges with getting to traditional vaccination sites. Establishing partnerships with these groups evolved into a referral system for the DRM VAT team to facilitate in-home vaccinations through contracted and non-contracted mobile units, as well as local health departments.

Community engagement and partnerships are the bedrock of DRM's vaccine advocacy success. Even organizations and groups without a specific focus on disability had valuable insight into the needs of their communities. These needs inherently intersect with those of people with disabilities. DRM VAT staff took a backseat in planning vaccine outreach as much as possible, allowing community leaders to lead, while DRM facilitated mobile health services and offered support.

Whenever possible, VAT team staff networked to leverage additional community resources to provide added benefits, beyond vaccines, for a more integrative, holistic clinic experience. Food, hygiene products, clothing, health education, social service program linkages, and other resources were often pulled from a variety of local community organizations with a stake in the health and well-being of their communities. DRM also built trusting relationships with organizations and groups who previously had no knowledge of DRM advocacy services. This opened opportunities for DRM to provide education and training on disability rights and sensitivity and for them to become disability self-advocates for their own communities.

Advocates can learn important lessons from DRM vaccine work. Widening the net of engagement to community leaders and marginalized groups beyond the disability community, while keeping a focus on accessibility and inclusion for those who have disabilities, maximizes impact. Health equity strategies that target only those who have medically defined disabilities may miss many with complex, intersectional identities and needs. To improve access to healthcare and healthy living opportunities, disability must be integrated, not singled out.

SECTION 4

Focus Groups, Clinic Interviews and Stories

Through every phase of DRM Vaccine Advocacy work, data collection and analysis has included the direct involvement of people with disabilities themselves as well as the organizations who provide them direct services. Gathering and using data effectively is critical to create sustainable, systemic improvements to the health equity landscape for individuals with disabilities.

First Project Survey

Initial project activity included writing and revising several drafts of both a printed and online survey for individuals with disabilities, family members, and caregivers in Michigan. This survey was for the purpose of assessing barriers to vaccination specific to Michigan's disability community to guide DRM's vaccination project work.

VAT staff met with the Michigan Developmental Disabilities Institute (MI-DDI) for feedback to guide the development of the survey and established partnerships with more than five organizations with links to the disability community for their assistance with disseminating the survey when it was finalized.

DRM VAT staff piloted the vaccine survey, made revisions based on feedback, and began dissemination on January 31, 2022. Staff conducted periodic monitoring of survey responses to identify data trends and created reports for VAT team research and use in outreach activities. Survey data gaps were also identified for follow-up after the survey close date of March 31, 2022, to address healthcare access and equity beyond COVID-19 vaccines.

In June 2022, DRM released a survey report based on 155 completed vaccine survey responses with recommendations and implications for future healthcare. Recommendations were based on the following survey-identified barriers to vaccination:

- Lack of guardian consent
- Vaccine registration issues
- Vaccination site not sensory-friendly/Over-stimulating environment
- Vaccine availability (early in the vaccination rollout)
- Transportation/Travel issues
- Lack of adequate personal care supports
- Lack of in-home availability of vaccines/boosters
- Communication barriers at the vaccination site
- Lack of physical accommodations at the vaccination site

The recommendations included broad-level guardianship reform for court-appointed guardianships and support for alternatives to guardianship, including supported decision-making. Other recommendations included a multi-pronged approach for working with mobile health partners and partnering with community leaders to deliver vaccines and other health services to people where they are. This recommendation is a cornerstone of VAT outreach, as DRM-mobile unit partnerships allow VAT to bring vaccines to accessible locations, where people feel safe, including in their own homes. This method of delivering vaccines and healthcare services was supported by the general understanding that the best healthcare is that which is integrated and comprehensive at the point where people receive it. This report was shared with community partners and stakeholders at both the state and federal level.

Data Mapping

Early in 2022, DRM VAT staff met with epidemiologists from the Wayne State Phoenix Project, which has access to data files to create demographic maps overlaying disability and vaccine data. DRM facilitated completion of a high-disability, low-vaccination heat map and circulated to VAT team members. DRM VAT staff also began work on a combined vaccine hesitancy and social vulnerability index, as well as a dashboard to show how many people DRM assisted with obtaining a COVID-19 vaccine.

DRM VAT staff facilitated the creation of three more sets of heat maps overlaying community and homebound COVID-19 and flu shots facilitated by the DRM VAT team with vaccination uptake and disability prevalence. VAT staff used these maps to measure progress in targeted regions of the state and evaluate future vaccine outreach targets. Staff also shared the heat maps with grant and community partners to measure collective impact and evaluate future collaborative work.

DRM also shared dashboard data provided by DRM's contracted mobile health partner. The dashboard data includes aggregated demographic data of shots facilitated, including race, ethnicity, age group, self-reported gender, and self-identified disability status. These map and dashboard data tools had a significant impact on the successful facilitation of shots in arms in several low vaccination rate areas throughout the state where disability was previously not counted among key social vulnerability or demographic considerations.

Disparities in healthcare, as well as the underlying causes for these disparities, cannot be accurately measured without disability data. Yet many people who have disabilities will deny they have one, or even symptoms of one, based on internalized ableism or fear of how they will be treated if their disability is revealed. Examples of this internalized stigma include how many individuals who received COVID-19 or flu vaccines at DRM clinics answered the disability status questions during the registration process:

- VAT Staff observed some people in a variety of clinic settings who used mobility aids, such as walkers, canes, or wheelchairs, answering, "No" to the questions, "Do you have a disability?" and BRFSS question "Do you have difficulties with mobility?"
- At a mobile vaccination clinic at an assisted living facility, VAT staff observed mobile unit staff repeat BRFSS question, "Do you have difficulty hearing?" four times, in a room without background noise, before they heard the question, to which they replied, "No. Not more than anyone else here."
- VAT staff observed people in a variety of clinic settings answer affirmatively to BRFSS questions about having significant difficulties with certain day-to-day function, yet answer "No" to the identity question, "Do you have a disability?"

This issue seemed most prevalent among individuals who are elderly. Older persons are likely to correlate disability with the negative stereotypes associated with aging. Additionally, disability in older age is often considered just a part of aging rather than a 'real' disability (Leahy, 2022). However, definitions of ageism itself often include a fear of expected disability in old age. In fact, ageism and ableism are so intertwined, that research suggests a need to redefine ageism to take ableism into account more (Van der Horst & Vickerstaff, 2022). Eliminating or reducing ableism would, in turn, greatly reduce ageism and the poor health outcomes of older adults with disabilities.

People of color with disabilities may also experience a difficult choice when it comes to whether to "show up" or disclose their disability. Many disabilities are invisible and often disabilities will remain unacknowledged because of overlapping negative stigmas in a community (Grace, 2019).

Clinic Interviews and Home-Based Stories

The stories of individuals attending DRM vaccination events spoke volumes about the lack of health equity in the communities served. Here are some examples taken from one event at a south-central Michigan homeless shelter:

- One person had hypertension and needed monitoring and medication as well as dental care. They had insurance but missed several appointments with doctor due to transportation scheduled by insurance company falling through/not showing up. They were also having trouble getting medication. They were thankful for the monthly vaccine clinics provided at the shelter, saying if COVID clinic was not held at the shelter they would not have gotten vaccinated for COVID and would go to the ER for other care.
- Another person had recently been released from the hospital due to pneumonia. They had experienced ongoing cough and difficulty with climbing stairs since having COVID. Person is diagnosed with PTSD and seizures. The person needed surgery, but it could not be scheduled due to nowhere to discharge to for recovery. Person needed dental care and vision checked. Client had insurance but could not get health care due to transportation issues.
- A third person needed neck surgery. They need to go to a specialist out of county because no one in their community has the necessary specialization. Person had not been able to secure transportation through insurance. Person had nowhere to be able to discharge/recover if surgery was scheduled.

- Another person with prostate cancer had insurance and a primary care physician but had not been to the doctor in over two years. They also needed vision and dental care. They reported difficulty in obtaining transportation for health care appointments.
- A person with COPD, heart palpitations, difficulty climbing stairs, difficulty breathing when laying down, cough that won't go away (smoker's cough), and arthritis reported not having a wellness check in a very long time. They had been receiving COVID and flu vaccine at The Shelter vaccine clinics. They had insurance coverage. They also needed vision testing and dental care.
- A person with herniated discs and osteoarthritis reported being denied Medicaid coverage despite receiving Supplemental Security Income (SSI). They recently returned to Michigan from Texas. They showed advocate a denial letter from Michigan Department of Health and Human Services. The letter indicated they were not eligible for Medicaid because they did not meet the need (marked box said they were not a parent of a child under 18, not pregnant, and not disabled). They are unable to go to the doctor for medical care.
- A person with mental health needs reported it had been more than five years since having a wellness checkup. They reported need for mental health care, physical therapy, vision, and dental.
- A person with mobility issues had insurance but reported main issue for not receiving health care was transportation. They had several prescribed medications that needed to be filled and taken. They reported they needed vision care and need for dentures.
- A person with PTSD, anxiety and depression reported not having a wellness checkup for over one year. They did not currently have insurance or a primary care provider.

These individual stories shared common themes. Although many of the individuals had insurance coverage, nearly all lacked ready access to preventive care, mental health services, dental care, and vision care. Transportation and access to medications were frequent barriers to basic wellness. Despite these barriers, all these individuals received access to vaccinations through mobile services that came to them.

DRM also facilitated over 350 home-based vaccinations through June 2023. Most of these individuals were referred to DRM by their local health departments, Area Agencies on Aging, home care providers, hospice agencies, or Disability Networks. Some of the recipients included:

- A 73-year-old man with cerebral palsy, his 75-year-old caregiver with a heart condition, and the caregiver's 70-year-old wife with diabetes.
- A 77-year-old woman with lymphodemia, fibromyalgia, and arthritis who could not get out of her public housing unit.
- An 81-year-old woman with end stage COPD and her 60-year-old companion with arthritis.
- A 90-year-old man with orthopedic disabilities and his 86-year-old wife with autoimmune disorder.
- A 79-year-old stroke survivor who could not leave her home.
- Three family members – a 76-year-old woman with cognitive disabilities, her 76-year-old husband with mental illness and hearing loss, and their 57-year-old caregiver with multiple sclerosis.
- An 82-year-old woman with mobility limitations, her 41-year-old daughter, and the daughter's 4 children, 2 with disabilities. The caregiver managed a public housing complex where DRM had provided a community clinic.

Like the shelter constituents, people in need of home-based vaccinations lacked ready access to health care. These individuals were interested and able to receive health care when it was brought to them.

Disability Health Equity Focus Groups

DRM Vaccine Advocacy Project work opened doors to identifying barriers faced by Michigan's disability community in accessing not just vaccinations, but all types of healthcare.

In August 2023, DRM VAT staff facilitated two focus group sessions to gauge the impact of disability within the context of the health equity landscape. Eligibility to participate was based on the following factors:

- Must reside in Michigan.
- Must fit into **at least one** of the following categories:
  - Have a disability.
  - Be a relative of or have a close personal relationship with a person or people with disabilities.
  - Work directly for or have a professional relationship with a person or people with disabilities.

DRM's vaccine advocacy work contributed to the building of many relationships with people who met one, or in several cases, more than one of these eligibility criteria to participate in the focus group sessions.

As recommended for qualitative research, the participants were sampled deliberately to ensure the information acquired in the focus group discussions provided a full understanding of the subject matter under study. VAT staff used direct communication methods in inviting potential participants to explain the focus groups' purpose and the value of their input to the discussions. Visa gift card incentives were also offered for participation in the focus groups.

Eleven individuals participated in the focus group discussions, with five people participating in the first focus group session and six participating in the second session. Of the eleven participants, all of whom are Michigan residents, 7 have disabilities, 4 have a family member or close personal relationship with someone who has a disability, and 6 have a professional relationship with someone/people who have a disability. *(Added together, these categories do not equal eleven because some of the participants met more than one of the above eligibility criteria.)*

The focus group questions were designed to address challenges that are often overlooked in health equity research and mitigation strategies and confirm DRM's recommendations to advance disability health equity align with the experiences of those who would be most impacted by them. Participants were encouraged to speak as openly as they felt comfortable but to avoid revealing very detailed information about their personal lives. Participants were also assured that all responses were valid and they were not obligated to discuss topics they did not have relevant experience with or were not comfortable discussing.

Both focus group session discussions were based on the responses to the same eight multi-part questions. Before beginning, the facilitator explained that in the questions, "you" refers to the person (or people) with disabilities and if a participant did not have a disability, they should answer the questions in the context of their relationship with the individual(s) with disabilities based on their own observations and experiences. The resulting discussions were recorded for analysis.

Disability Health Equity Focus Group Questions:

1. In your opinion, can you see your primary care physician or other health professionals often enough to maintain your well-being and lead a healthy life? Why or why not?
2. Do your healthcare providers treat you with dignity and respect? Do they provide you with the accommodations you need to have comfortable and productive visits or appointments? What changes could make your experiences more pleasant or helpful to you?
3. Do you have healthcare coverage? If so, does it adequately cover prescription costs, including medications, durable medical equipment, surgical procedures, or other healthcare expenses that you have? Do your out-of-pocket healthcare expenses fit comfortably within your budget? Please explain.
4. Do you experience any barriers outside of medical ones that impact your health and well-being? These can include things like no or limited access to safe, affordable housing, transportation, nutritious foods, employment, or any other socioeconomic factor.
5. Do you, or have you ever, used telehealth services? In your opinion, what are the benefits and/or drawbacks of telehealth? Would you use telehealth, or use it more, if it were available for any of your specific healthcare needs? Why or why not?
6. Do you receive any home or community-based care or assistance? Please explain how these services and their quality, or a lack of services, affect your health and well-being. What other types of external support, if any, would help you lead a healthier life?
7. Does your race, ethnicity, gender, sexual orientation, religious beliefs, or disability impact the quality of healthcare you receive? Please explain.
8. Are there any other health-related challenges you've experienced that we have not had a chance to discuss? If yes, what are they and what do you believe would remove or lessen those challenges?

Disability Focus Group Discussion Themes

Social Determinants of Health - Lack of Access to Affordable, Accessible Housing and Transportation

The most frequently cited theme in both focus group discussions was social determinants of health barriers; Specifically, access to transportation and affordable, accessible housing were cited as having a significant impact on participants' health. Focus group discussions demonstrated how these social determinants of health barriers, and others, overlap and intersect with each other, creating complex, structural issues that can only be addressed through systemic advocacy and change.

> "I think as a person with a disability the transportation, and I use a wheelchair, so it might look different for other people, but obviously, um, as you may or may not know, the wheelchair accessible vans and conversions can be such a high cost. Even used wheelchair accessible cars can sometimes be like the cost of a sports car, so it's just really hard to obtain. And Ann Arbor, luckily, has a bus system, but Metro Detroit, so I grew up in Novi and spend a lot of time in Novi, doesn't have that nice public transportation." (Participant 6, Session 2)
>
> Reply from Participant 8: "Transportation is a big obstacle for people."
>
> "For me, generally speaking, I, in the past, did not have a problem seeing my primary care. My other health professionals were difficult because it's hard to get an appointment and medical transportation if I need assistance. I do drive but sometimes I need assistance with getting my wheelchair out of the car, or something like that, but it can be difficult." (Participant 7, Session 2)
>
> "My past teacher, I talked to her quite frequently about, how do I get to my appointments if my mom couldn't take me. She's like, "You could call Medicaid," but that's not reliable. I think another issue is transportation being reliable." (Participant 5, Session 1)
>
> "I was just going to say one of the big barriers I see with some of our members that I'm working with is being able to get into their primary care doctor in a timely manner, but even if they can, you know a lot of times the providers are willing to put them on a cancellation list or something like that. But then a lot of times transportation is an issue because they, you know with the medical transportation, they require a three-day notice. If the doctor's office calls you today and says, "Can you be here at 3?" Then they can't. You know, they may not have transportation to get there." (Participant 2, Session 1)

Some discussion involved how the cyclical relationship of disability and poverty impact access in all social determinants of health areas.

> "Access to the funding sources does require dependence on public federal benefits, such as Medicaid, which they have, so I think the socio-economic part is standing out to me because it's just this whole system that sort of, wants to keep people with disabilities in poverty, to rely on Medicaid and then receive funding. But I think my caregiver, cost of caregivers, is at least 60 or 70,000 per year. For basically, to keep me up out of bed, and being able to have employment and live independently. So that's a high cost, but necessary." (Participant 6, Session 2)
>
> "This is for the people that I work with. There's a lot of problems with transportation, getting to and from different places. Affordable housing is a big thing. I had a gentleman who was being evicted last year. Probably took me…almost a year to find him a place to go. So that's always a big problem with people. Getting to the grocery store, getting to doctor's appointments. Buying nutritious foods is also a big thing because a lack of money a lot of people I work with that are on Social Security income have. It makes it very difficult." (Participant 8, Session 2)
>
> "The social economic factors play a huge role because of the extra expenses tied to your disability. And then finding adequate accessible, let alone affordable, housing. And if you're not in a position to purchase a house and have it modified [it] is a problem. […] I'm going to say housing plays a huge role [in health]. Having a sense of security, being in a safe neighborhood, being able to get out, have a walkable, or in my case, rollable community, being able to utilize public transportation, all of that does not just play into health and the social determinants of health, but it's a huge stressor, because if you don't feel comfortable and safe, it can affect your mental health, and if you have, like I do, a neuromuscular disorder. Anything that affects my mental or emotional health affects my ability to physically move around and communicate, so it's a big issue." (Participant 7, Session 2)

One participant described why a lack of affordable, accessible housing and the surrounding living conditions forced them to relocate their family to another city.

> "You know, and for me was, especially when I was living in Detroit, which was not this beautiful part of Detroit, but the world that I was living in, wasn't the best. […] there's countless broken sidewalks. You know, my children, if we wanted to go anywhere, we'd have to go out in the streets, you know, to go and […] that is dangerous in itself. You know, there's no healthy grocery stores, depending on the area in Detroit, there's different factors like whether there is no close hospital. […[Yeah, so not the best." (Participant 9, Session 2)

Telehealth and In-Home Medical Visits

Telehealth was the most cited exception to access to healthcare and the associated transportation challenges. Most participants preferred telehealth options when the type of healthcare sought did not require an in-person examination by a medical professional:

Participant 3, (Session 1) described the benefits of using telehealth for mental health appointments and how it not only eliminated the associated transportation challenges, but allowed for more control and flexibility in setting appointments at times that were convenient for them:

> "It was helpful and there's a lot of humor that can come into that too, because you spend a lot of time saying, 'Why am I wasting all the gas money coming to see you, you know, when we can just do it this way?' So yeah, it was very helpful to be able to use the phone because there are times when I couldn't do transport anyway, but I think during that time when I was using telehealth, I mean obviously it was during COVID, but I think it's something that they might want to consider using [long term]. I mean, I found it a lot easier to use telehealth in that instance, because it's a lot easier to just say, you know, if I needed a visit, 'Hey, can I get a visit now?' instead of having to wait a little bit or come to the office to see you or whatever." (Participant 3, Session 1)

Greater independence (or less dependence on others) was another cited benefit of telehealth:

> "I'm lucky to have a family and significant other who drives me, but yeah, I'm not able to drive myself. So definitely the telehealth aspect has made it a lot easier to see professionals and I use that a lot. Like whenever I can do a video call, it's nice to not have to ask a family member or caregiver to drive me." (Participant 6, Session 2)

Participant 4 (Session 1) said telehealth was a preferred alternative to in-person visits for many people who are immunocompromised, due to exposure risks in doctors' offices and other healthcare settings:

> "Just being an immunocompromised person, you know, due to the nature of treatments for arthritis, and like, in that community, we like having telehealth appointments wherever possible because it limits our exposure to people, right? I take some serious medication to suppress my immune system, so going out in public with unmasked people, I would, I would prefer having a telehealth appointment when at all possible." (Participant 4, Session 1)

Yet another cited benefit of telehealth was the access to care it gives to those who live in more isolated rural communities:

> "We serve 17 counties in the tip of the mitt and telehealth is better than no health." (Participant 1, Session 1)

While most of the focus group participants prefer to use telehealth when it is available, one participant cited challenges with using telehealth due to communication challenges.

> "I'm my own guardian, so sometimes it's hard for me to explain over the phone, in words, what's going on, so it's easier for them to look at me and say, 'Oh yeah, I see what you're talking about.'" (Participant 5, Session 1)

This challenge highlights the need for telehealth to continue to be an option, rather than a replacement, for in-person healthcare visits. While only one participant described having such an arrangement, in-home medical visits were another cited exception to the common theme of transportation challenges associated with healthcare access.

> "For me, it's kind of a hard question because I use a home health, like a, a doctor comes to my house, so they're kind of come on their own schedule, but I feel like if I need to see them, I can just call up and ask and they'll schedule me as soon as possible [...] I don't have to depend on having staff to drive me on that particular day, which means that my attendance will be perfect because they're coming to me and so I don't have to worry about my health sliding because I miss appointments or whatever, you know?" (Participant 3, Session 1)

Lack of Accommodations in Healthcare Settings

More than 30 years after the enactment of the Americans with Disabilities Act (ADA), a survey of 714 U.S. outpatient physicians revealed that 35.8 percent knew little or nothing about their legal responsibilities under the ADA, and 68.4 felt that they were at risk for ADA lawsuits (Iezzoni, 2022). In March 2021, DRM collaborated with the State of Michigan and 11 other advocacy organizations to create a set of guidelines for testing and vaccination accessibility. The guidelines, "Accessibility at Michigan Vaccination Sites," included proposed protocols for accommodations, community empowerment, effective communication, cultural competency, and data. The introduction reads: "The following guidance on accessibility aims to attain equity by providing tailored strategies for individuals with disabilities. When such targeted universal design is implemented, society benefits." (Michigan Department of Health and Human Services, 2021)

Focus group discussions revealed how the lack of accommodations in traditional healthcare settings exacerbates the difficulties with getting proper medical treatment, in a safe and comfortable environment.

> "In most primary care physicians' offices, if you don't go to an office where they see senior citizens, or it's a specialty that has to do with a certain disability, getting in the exam room is a challenge, moving from your chair to the bed is a challenge, I have to have most of my examinations in my chair." (Participant 7, Session 2)
>
> "In my experience with my mom. the specialists are okay, because she sees Parkinson's people, so they seem to be set up and the infrastructure is there. But her primary care is a disaster in terms of setting appointments and follow-up and knowing and understanding the limitations that we have. Getting her there and managing her appointments [is difficult]." (Participant 11, Session 2)
>
> "They do provide accommodations for me, like when I go to my primary care doctor, they put me in a procedure room because it's a lot quicker. Whether you have a disability or not, you shouldn't have to be put in a procedure room because all rooms should have enough space to put a wheelchair or whatever they have, whatever device that they use, they should be able to move safely, be able to do that without hitting things, or knocking into things." (Participant 5, Session 1)
>
> "For an eye doctor that can be challenging to get up to the thing to, you know, get your prescription, and get your face in there [laughs] so that you can get your glasses." (Participant 3, Session 1)
>
> Reply from Participant 5: "Like when I go to my eye doctor, my mom has to put me on her lap because I can't do the stuff in my regular chair. So we make that accommodation but it shouldn't be that way. That's what I was trying to get at earlier. It shouldn't be, I have to just disengage from what I'm comfortable doing to make accommodations for myself."

This comment reflects a pattern of focus group question responses that have to do with individuals having to compensate for a lack of accommodations through their own means.

> "We have a lot of people who are hard of hearing and deaf and, of course, I think most of the time, they have to provide some of their own interpreters when they go. I think if you're in a hospital, and you're in a bad way in a hospital, they'll get an interpreter for you. But I think general office visits, I kind of got a feeling you probably need to bring your own." (Participant 1, Session 1)

Participants shared that when they are unable to work around a lack of accommodations, healthcare professionals are unable to provide proper care and treatment. This includes a lack of physical accommodations as well as insufficient modifications to communications or policies and procedures.

> "If you do get an appointment with a gynecologist, it's hard to get the proper care because they don't know how to really deal with you if you can't get on the table, get in the stirrups, and be physically capable of moving in the way that they need you to move." (Participant 7, Session 2)
>
> "One ability that impacts, that affects, quality of healthcare is, some of the people I work with have developmental disabilities but they have a little more trouble communicating. And It's hard to be in a doctor's office when they have their time commitments. What are they allowed to see you for? Maybe 15, 20 minutes? And then you have somebody who can't understand, or needs more time to express themselves, and can't always understand everything. As some of those people age, and some of them are, that I work with, are in their 30s, mid 30s and early 40s, and I think that probably, that ability to, you know, have a conversation affects their quality of health care, especially if they don't have somebody, like an advocate, going with them." (Participant 1, Session 1)

A possible explanation for the lack of accommodations was given by one participant, who described the limitations of legislation and providers only meeting the bare minimum standards for compliance.

> "Me, personally, I think it's more money and also they're not obligated to do some of those accommodations. Like having a door opener, because they're under compliance already. So like, it's those types of things that would make it easier, but they choose not to do those because they're under compliance with the ADA." (Participant 5, Session 1)

Lack of Access to Specialty Care and Home Supports

Whether or not participants experienced issues with transportation to get to doctor's appointments, limited access to specialty healthcare, especially for those who are on Medicaid, was a recurring theme in focus group discussions.

> "You know, being in northern Macomb County, where you can throw a rock and find four different doctor's offices, there, we have enough primary care physicians in this area. But those specialty providers, that's where the shortages show. [...] with rheumatology, we've been on a set schedule, but now I'm having an issue that I probably should be seen sooner rather than later, but I, they don't, have any available appointments. So yeah, there's such a shortage of rheumatologists in the US. That's a problem for everybody." (Participant 4, Session 1)
>
> "Yeah, I agree, because I live in Niles, I have to go all the way up to Grand Rapids to see some of my specialists. They can only treat me there, and that's the only place that is accessible for me to get into as well. It makes it extremely hard." (Participant 5, Session 1)
>
> "Like right now I'm trying to find a dentist that takes Medicaid because I turned 21. But the only people that take it are MSU. And that's a long drive away from my house. So I can't go get adequate dental care because of the Medicaid." (Participant 5, Session 1)
>
> "I, in the past, did not have a problem seeing my primary care. My other health professionals were difficult because it's hard to get an appointment. [...] Getting appointments is difficult because a lot of physicians have a lot of patients." (Participant 7, Session 2)

One participant described the difficulties in finding a healthcare provider who accepts Medicaid for someone who already has difficulties finding providers they feel comfortable seeing while having a disability.

> "I think part of it though is getting into healthcare and I'm working with someone right now who went through a long process to pick out a doctor they thought they felt comfortable with at a clinic. They thought they'd feel comfortable only to find out that this clinic is now not, is not wanting to take any new patients that are on Medicaid or might be on controlled substances. So that's gonna put a huge barrier up to that person, and it's going to make it a lot harder for them to access [healthcare]. And that's not even in one of our rural communities." (Participant 1, Session 1)

Staffing shortages, staffing retention, and difficulty obtaining reliable, trustworthy direct care staff were among the home support services challenges that were cited.

Participant 6 (Session 2) first brought up the issue of staffing shortages when speaking to the challenges with getting to doctor's appointments and how they have had to fall back on family members to assist them:

> "I mean, I do hire caregivers, personal care attendants, but there's been staffing shortages, so sometimes it will be my mom helping me out, or my significant other."

Participant 6 revisited this issue later in the session when speaking on the socioeconomic barriers of healthy living.

> "I think I mentioned earlier, there is an ongoing shortage of personal care attendants, or caregivers, however you want to call them. [..] but it's definitely a big factor in my life as, for all of my activities of daily living, from brushing my teeth, getting my hair washed, shower, toileting. Everything in my life requires full assistance from somebody else and it's just been, there's a lot of factors at play there. [...] There are low wages for these employees. No benefits at all."

Two participants in Session 1 discussed these same challenges.

> "One of the problems is when we're trying to get staffing, it's hard to find people with the willingness to do that job long term. It's one of the toughest things for us to find." (Participant 3, Session 1)
>
> Reply from Participant 5: "So yes, and they don't get paid enough to do what they do either."
>
> Participant 3: "That is true."

A participant with professional experience with the issue also commented:

> "I can one hundred percent agree with them, that it is really hard to find anybody. I know when I worked at CMH we worked a lot with CLS [Community Living Supports] workers and just them trying to find staff, that was so hard, and the turnover, like they were saying, like they would get somebody that they finally trust and then they may leave, or something happens and they have to then learn to trust someone else." (Participant 2, Session 1)

Bias and Attitudinal Barriers to Healthcare

VAT staff experienced second-hand blaming and shaming based on the ableist assumption that people who have not been vaccinated for COVID-19 (or who are not up to date) must not want to be. In these instances, the burden of responsibility for one's health is unfairly placed entirely on persons themselves, rather than the vast set of physical, political, and socioeconomic factors that impact a person with a disability's access to vaccines and other healthcare services. Long-held societal values and beliefs also reinforce the idea that people who lack self-sufficiency, regardless of the reason, are undeserving of assistance. This form of discriminatory thinking is deeply ingrained in American culture and the values of self-responsibility and hard work. It is experienced even by people with disabilities who are health care professionals themselves. In one study, healthcare faculty, staff, and students with disabilities described experiences of disability being minimized, dismissed, or directly disbelieved:

> One thing I found most shocking, ever since I got interested in medicine and started shadowing and volunteering, and then as a med student, I just have been unbelievably **shocked by how intolerant of chronic illness and disabilities most physicians really are**. (Jeanette, Staff; Feldner et al., 2022)
>
> I feel like for certain conditions…**it's that kind of victimizing, victim blaming**. It's like this shaming and blaming that happens in the context of trying to like make people healthier, encourage people's health. And you're like, "This is not productive at all". All we're doing is completely discriminating and throwing these groups of people under the bus for reasons that are out of their control. (Justin, Faculty: Feldner et al., 2022)

DRM focus group participants experienced or witnessed discrimination and social prejudice against individuals with disabilities and other intersectional identities in healthcare and other areas linked to health outcomes. It is impossible to quantify all instances in which structural or interpersonal biases may have played a role in the challenges discussed in these focus group sessions. However, there are several examples of participants discussing feeling directly disrespected, dismissed, and dehumanized because of their disability or other marginalized identity, within the context of their health, or healthcare.

> "Pain is something that I deal with a lot. It's a symptom of my connective tissue disorder and that's when I run into doctors, like really feeling disrespected by them. I've had two within, like, the last few years tell me that "at least it's not cancer" when I'm talking to them about my pain. And that happens very quickly in the conversation. Like they don't wanna have a conversation with me about my life and, yeah, just the effects that my disability has on my day to day. And oh, one more point. I also will get the like, "Well, what do you expect?" response. Like, "You have this disability, like, what do you expect? Of course, you're going to be in pain." So, yeah, that's my experience. I would say they're disrespectful." (Participant 10, Session 2)
>
> "Oftentimes if I have a new doctor, that doesn't know me, they can be very condescending. So in my opinion, that's very disrespectful. Like, if they're always looking for someone else to be with me to answer questions as opposed to feeling like I'm capable of answering questions myself, which I find to be disrespectful. In addition, when my son was younger, going to the physician with him was a challenge, because he has health conditions that were not able to be seen by the naked eye. As his mother, I knew when something was off base, or something was going on. And communicating that to the doctor was difficult, like they didn't believe me. It got to the point where I had to bring my mother or my significant other just to simply say what I had just said for them to take me seriously. So that is a challenge when it comes to getting healthcare." (Participant 7, Session 2)
>
> "Something I also found with the people that I work with is that a lot of times, if I'm working with somebody that's in a wheelchair and they go to a doctor or they go to, are hospitalized or whatever, you'd be surprised at how many of the healthcare providers just think because you're in a wheelchair that you can't take care of yourself, that you can't live on your own, that you have to have a guardian. I've fought that fight a lot over the last few years." (Participant 8, Session 2)
>
> "My first primary care physician, once I became an adult, the respect really just wasn't there, so much so that when I asked her about having a pap smear and those types of things, she told me I kind of didn't need that […] very disappointing and hard to hear. On the flip side with urgent care, some doctors want to talk about my disability when I'm really not there for that. Kind of a bias toward disability. Physicians need to be educated about disability and respect people with disabilities by not having preconceived ideas about what they're supposed to do with their

> life, but just treat them like a patient like they would treat other patients." (Participant 9, Session 2)
>
> "Being on my own I run the risk of choking or aspirating, so, having a caregiver with me puts my mind at ease, even if, so a lot of times they'll say we'll only pay for hands-on services, but there are, like, downtimes. That part, again, is all about advocacy and kind of knowing what language to speak. Getting into the system when I was 18, it was all mind boggling and made me feel like less of a person. I'm just getting out of high school, this is years ago, getting on services, but I always go back to that. And I wish that in high school there was some sort of guidance or mentorship in getting into these services. What I also didn't realize that was very relevant in my life, that when you move counties, obviously when you move out of state you're going to have to go through their services in that state, but even within the state of Michigan, oh my gosh, that's a whole…it's almost like they don't think of you as the same person, needing the same supports, because I'm actually in the process of moving 30 minutes to another county and I'm being told that I might not qualify for as many hours as I do in Ann Arbor, because the funding is better in Ann Arbor." (Participant 6, Session 2)
>
> "One thing I've noticed in my journey because I have a rare disease, is that the language to describe what is happening with me versus what my doctors know to be happening with me. There's a real, it's lacking. And I could see that really for any disease, not just a rare disease, but that really came to a head for me when I was trying to, when I was in my interview to get on disability. The way I was describing my experience versus the way my, the person, the doctor I was seeing who was, you know, qualifying me for disability benefits, the way they articulated it, it didn't align. In that instance, there were real world repercussions. I didn't get on disability after that. I had to get a lawyer, which I've now learned is a common occurrence. But yeah, those are frustrating, eye-opening experiences for me. Yeah, I will say in disability, I feel like there's a lot of nuance and in science there isn't as much room for nuance. And so I think these doctors kind of just go about it in the way that they're trained to be very objective and not necessarily thinking outside of the box or anything like that. So. Yeah." (Participant 10, Session 2)

Institutional and impersonal biases that impact the quality of healthcare are not limited to disability. Belonging to more than one marginalized identity group compound negative perceptions and associated healthcare challenges for those with intersectional identities.

> "I'm actually on the voting panel for the American College of Rheumatology, as a patient, for clinical practice guidelines. So I have a lot of knowledge in rheumatology. So when it comes, when it comes to talking to physicians, I can speak their language. There's less of a bias towards me because I have that knowledge base. But is that fair to other BIPOC, disabled women that present in their office? Probably not, right? The data shows that black women, in particular, receive subpar healthcare." (Participant 4, Session 1)
>
> "It's not on the list, but age. I've seen it. It's disturbing. And I'm getting up there too and it's, it's really troubling. Again, the entire infrastructure is just not set up for an aging population. Disabilities or not, and it's just really disturbing." (Participant 11, Session 1)

Several participants commented that one potential remedy to the structural problems described throughout these discussions was taking a more holistic approach to medicine and healthcare, specifically through increased coordination of care, communication, and preventative healthcare measures.

> "When you talk about health equity, I think care of the whole person really fits into this. When we go into a physician's office, they're focused on the medicalized area and they don't see you as a human being that is multi-dimensional and needs other things, it's hard for you to really feel healthy and cared for in a whole sense. […]we haven't really discussed wellness, and that's a huge part of health, and the fact that medical providers only focus on immediate needs. […] when it comes down to addressing the social determinants of health issues that impact the all-around health of a person, if those were addressed sufficiently then the cost of healthcare would probably drastically decrease." (Participant 7, Session 2)
>
> "The infrastructure fails at every level. Unfortunately, and this is really where I start to, you know, smoke comes out of my ears is that none of the infrastructure around healthcare and public health care, they don't talk to each other […] It's, it made me realize how nobody is talking to each other and when there are changes that there is no coordination. And, you know, I lay blame at the top, basically, because they're supposed to be coordinating all of this. […] I like the idea of, you know, peer mentors for the physicians and their staff. It's not just them, it's their staff too, because their staff are usually the people

> who are on the phones, and the inability of the people who are answering the phones to provide some of these connections. So, yeah. I hope that, not just during the pandemic, just everyone's daily lives can be changed a bit for the better and you know, this is all about wellness and preventative medicine. We don't get sick, we don't cost the system. […] I'd like to see better communication among the agencies and doctor's offices, health care, and life care as well." (Participant 11, Session 2)

Another proposed solution to the issues was increasing education and outreach efforts to allow individuals and communities a better opportunity to be self-advocates.

> "One of the accommodations that could be made are not just the physical accommodations, but communication accommodations and a lot more time for appointments and, and communication aides and those sorts of things. But see, nobody tells you about those things. You have to know what you're asking for, and that's another issue as well. You have to know what you want. You have to know what those words are. A lot of people don't tell you those things. […] Education inspires employees of hospitals and families. Just being able to know that, 'Yeah, you can ask for this. You have the right to do this.'" (Participant 5, Session 1)
>
> "We might need to do outreach with people that, based on your socioeconomic question only, I wouldn't have thought of it otherwise, but some people that are in minorities in our bigger cities especially, or pockets where there's different racial groups throughout our state, I don't know if they, they probably have even less access than we're talking about. I mean, it's almost like we need to try to get into their communities like their neighborhood ethnic food grocery stores and stuff, and try to put posters up or, you know, encourage whatever we can figure out like moving forward as far as access to healthcare and how to advocate for yourself and how to ask for telehealth. And I, I bet, I'm just guessing as we're talking, that's probably an area that, that isn't getting much help, because a lot of those communities will help themselves if they have a disability expertise within their little communities. That's what I'm wondering. I'm just putting that out there." (Participant 1, Session 1)

SECTION 5

Recommendations

Bring health care services to people where they are, rather than making them come to clinics.

COVID-19 vaccines became widely available in the second year of the pandemic, yet, for a variety of reasons, many people experienced difficulties in getting to a vaccination site. Mobile health services made it possible for DRM to reach thousands who may not have been able to get access to needed vaccines and other health services otherwise. Many who may not feel comfortable in traditional clinic settings also benefit by having vaccines and other medical services available in familiar settings where their individual needs are accommodated, including their own homes. The use of mobile health units during the COVID-19 pandemic proved how effective they are for reaching those who do not ordinarily have equitable access to health care. Though the expansion of telehealth greatly improved access to healthcare for many people with disabilities, immunocompromised, and in isolated rural areas, mobile healthcare services can fill the gaps in healthcare that cannot be filled by telehealth alone. There are similar lessons for advocates. Health equity efforts should include funding to expand mobile health units and the scope of mobile health clinic services to bring essential health services to people where they are.

Fix the public transit system to increase access to health care.

Mobility challenges for people with and without disabilities can be greatly reduced by a well-funded, robust public transit system. Public transit not only provides an accessible, low-cost means for getting to medical appointments, it reduces loneliness and isolation, which is associated with many negative health outcomes. Michigan is overly dependent on private vehicle ownership, leaving those who cannot drive to go without access to healthcare, nutritious foods, and the ability to socialize in their communities. Michigan legislative policies that control transportation funding must be updated to reflect the critical need for more transit funding, especially as the older adult population continues to increase in our state and across the country. Additionally, increased coordination between local transit agencies will ensure that people's healthcare is not limited to the boundaries of their local transit service's area of operation.

Count the disability community when measuring health trends and impacts.

Disability must be a key demographic for collection and consideration in healthcare, including the electronic health record (EHR). Numerous studies have shown that disability, as a demographic data point, is often overlooked, or entirely forgotten. These disability data gaps are often the reason health equity strategies fail or are only minimally successful. Limiting disability data collection to disability-specific issues hides the immense role disability plays in non-disability-specific contexts. Intersectionality, and the disproportionate rates of disability among other marginalized populations, supports the need to count disability across all socioeconomic systems and to employ disability-specific interventions in social determinants of health strategies.

Provide modest incentives to promote health and health care.

As with any private good or service, incentives for healthcare motivate people to invest in and prioritize their health. The effectiveness of financial incentives reflect a key social determinant of health - poverty. Modest financial rewards are a scientifically proven and effective tool in increasing preventative care for those most impacted by poor socioeconomic conditions and social determinants of health barriers.

Base advocacy assistance on proactive and thorough engagement with local communities.

This is a way to accurately identify community needs, promote self-determination and empowerment, and build long-term trust. A holistic approach to healthcare is necessary to address the underlying causes of health inequities. This type of comprehensive, coordinated care can only be achieved through the collaboration of healthcare providers, social services, and local community organizations and leaders.

Work toward short- and long-term solutions to staffing shortages.

The best-designed health care and support systems fail if there is no one to implement them. Staff shortages permeate every aspect of supports benefiting the disability community. They are rooted in historically underfunded and overly complicated and medicalized provider systems. Short-term solutions revolve around rate reforms, while long-term solutions revolve around a reassessment of how health care services and community supports are valued and provided.

Address accommodations, discrimination, institutional bias, and ableism.

The COVID pandemic highlighted the need for advocacy to improve accommodations, expand the use of universal design, combat discrimination, work toward a support system allowing all people with disabilities to live in their communities, and dismantle ableism. Advocacy to support the disability community must address basic access to the places where health care is provided and the means for doing so and must further go beyond these day-to-day civil and service rights issues to address longstanding cultural bias and invisibility.

Conclusion

The COVID pandemic left an indelible mark on the disability community and their allies. “The Coronavirus pandemic has disproportionately impacted people with disabilities, not because the virus targets disability, but because long-standing shortcomings in numerous systems predictably left us vulnerable,” said National Council on Disability Chairman Andrés Gallegos in October 2021 (National Council on Disability). At the same time, the response to the pandemic brought with it lessons on what happens when our support systems eliminate barriers to care and support and provide sufficient resources to combat health issues. It is our hope that these valuable insights will not be lost, both as tools for responding to future crises and as guidance for addressing longstanding institutional and cultural issues affecting people with disabilities.

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