



**Survival
Coalition**

of Wisconsin Disability Organizations

Issues that Impact People with Disabilities in Wisconsin: Background Papers



Introduction

The Survival Coalition of Wisconsin Disability Organizations is a cross-disability coalition of more than 40 state and local organizations and groups. For more than 20 years, Survival has been focused on changing and improving policies and practices that support people with disabilities of all ages to be full participants in community life.

Survival has prepared these issue papers to provide background and a disability perspective for elected officials, candidates for office and other policymakers and advocates. Many people with disabilities access programs and services funded by the federal, state, or local governments to support them in maintaining their health, accessing education and employment, and participating in their communities. As policy makers, you will make decisions on programs and services that are critical to the independence and the lives of people with intellectual and developmental disabilities, physical disabilities, mental health conditions, sensory disabilities, and aging adults.

The issues discussed in these background papers impact many Wisconsinites. The Center of Disease Control (CDC) estimates that 26% (1 in 4) of adults have some type of disability. Survival Coalition invites candidates and elected officials to include the disability perspective as you deliberate on policies for employment, transportation, education, health care, voting, mental health, and long-term care. Our Coalition leadership and member organizations are available to address questions and serve as a resource for you.

COVID-19 has created new challenges for Wisconsinites with disabilities to access the services they rely on to maintain their health and independence. Since many people with disabilities are at greater risk for COVID-19, it is essential that policy makers prioritize the needed funding and policies to provide and maintain vital services in a manner that is safe, accessible, and person-centered. COVID-19 relief legislation and policies must address funding to state and local government to sustain vital services for people with disabilities including funding for Medicaid, Home and Community Based services, transportation, and support for students with disabilities and public schools.



HOME AND COMMUNITY BASED LONG-TERM CARE

Who are the people impacted by this issue?

74,000 Wisconsinites are in one of Wisconsin's home and community-based long-term care programs (Family Care, IRIS, PACE, Partnership) which serve people with physical disabilities, people with intellectual and developmental disabilities, and older adults.

These programs keep people with disabilities and older adults living and working in their communities. In-home supports and services are cost effective. On average, supporting people to stay in their own homes is significantly less expensive than nursing homes and other Medicaid-funded institutional settings. In its 2013 report on Family Care, the Department of Health Services reported to the legislature that "the greater availability of services under entitlement delay the need for more intensive and expensive services" and "Cost savings result from ensuring that services are delivered in the right amount, at the right time, and in the right setting."

Home and Community Based Services are important to local economies and bring businesses and jobs into communities for a diverse set of professionals including nurses, home health care, direct care, rehabilitative and habilitative therapists, specialized therapists, vocational, day service and transportation, and many other important professions. Many family caregivers rely on the supports their loved ones receive in Family Care and IRIS to keep them in the workforce.

Aging and Disability Resource Centers (ADRCs) also play an important role in the HCBS long-term care system by providing unbiased options counseling and access to information, resources and supports that help caregivers continue to support their loved ones in homes and communities for as long as they are able. These services are available to everyone, not just those who qualify for publicly supported long-term care. By connecting people with services early, they often delay the time people need to access Medicaid-funded services.

Why is Home and Community Based LTC important?

People who live in and are connected to their communities are more independent, healthier, and safer. Most people are choosing to remain in their own homes as long as possible; state programs that help people stay where they want to be is good public policy. Working age people with disabilities and older adults who can remain independent with support on daily tasks are best served by home and community-based services and not nursing home or institutional care. The COVID-19 crisis has demonstrated the significant risks to both people with disabilities and older adults in congregate settings.



HOME AND COMMUNITY BASED LONG-TERM CARE

How are supports for Home and Community Based LTC funded?

Family Care and IRIS are Medicaid waiver programs. The federal government contributes about 60% of the actual cost of services, the state contributes about 40%.

What are major concerns related to Home and Community Based LTC?

Many people in Family Care and IRIS rely on direct care workers to provide in-home supports— like dressing, bathing, meals, household chores and tasks, getting ready for work, transportation and management of chronic health conditions—to remain employed, independent, and contributing members of their communities. Despite the critical nature of direct care positions, low wages and few benefits result in high worker turnover rates.

A lack of available home and community based direct care workers may force people to receive less care, go without the care they need, or unnecessarily force people into nursing homes at great expense to the state and individuals' independence. Many family caregivers are providing significant resources and personal labor to fill in the caregiving gaps the best they can, but this is not sustainable. About 75% of adults with I/DD live at home, with parents and, later in life, their siblings. More than a quarter live with a caregiver over age 60, and a disproportionate share of caregiving is placed on black American and American Indian families.

How has Home and Community Based LTC been impacted by the COVID-19 pandemic?

COVID-19 is particularly dangerous to people with disabilities, older adults, and people with certain underlying conditions. Community based services that do not rely on settings that concentrate high-risk individuals in the same space offer a safer approach; research supports that people with greater levels of community engagement are safer.

People who live in or receive services in group homes, day service or prevocational facilities, nursing homes or assisted living facilities and other group settings are at extreme risk. The COVID-19 pandemic has underscored that movement towards independent living, community based-employment, use of virtual services, and use of remote technology and monitoring can be used to achieve greater safety and independence for participants and cost-savings for the state.



MEDICAID

Who is impacted by this issue?

Wisconsin's Medicaid program provides critical health and long-term supports and services to more than 1 million Wisconsinites. Nearly two-thirds of Wisconsin Medicaid participants are older adults, people with disabilities or children, many of whom have disabilities.

In Wisconsin, adults and children with disabilities may access the Medicaid program in many different ways and through programs that have different names.

- ⇒ Medicaid including the BadgerCare program and Elderly, Blind Disabled (EBD) Medicaid provide access to acute and primary care and are vital to health care security.
- ⇒ Many Wisconsinites with disabilities and older adults use a specialized long-term care program such as Family Care or IRIS to provide the support they need to stay in their home and participate in their community.
- ⇒ Children with significant disabilities may access support through the Children's Long Term Support, Children's Community Options Program (CCOP), and mental health programs such as Comprehensive Community Services (CCS).
- ⇒ Medicaid card services fund essential services like personal care which is help with things like bathing, dressing and eating. More than 15,000 people in Wisconsin use personal care annually.

People with mental health needs and /or a substance use disorder may access services through Medicaid programs such as Comprehensive Community Services (CCS), Community Support Program (CSP) or Community Recovery Services (CRS). Mental health crisis services are also a Medicaid funded services. These programs are administered by counties and tribes.

Why is this issue important?

Medicaid is much more than basic health care for people with disabilities. It provides funding for services that are not covered by other types of insurance and are vital to the independence and health of people with different types of disabilities.

Examples:

- ⇒ Long term supports such as personal care services that provide assistance with bathing, toileting, and other basic needs; supportive home care, employment supports, meaningful community-based day activities and more.
- ⇒ In home therapy, home modifications, respite and other critical supports for children with significant disabilities and their families.
- ⇒ Psycho social rehab services such as employment support, daily living skills, peer support.
- ⇒ Non Emergency Medical transportation (NEMT) to transport Medicaid members who need to get to and from medical services, but do not have transportation. Because so many Medicaid members are non-drivers, transportation to medical appointments is essential to ensure access to needed health care.



MEDICAID

How are supports for this issue funded?

Medicaid funding is a partnership of federal, state, and in some cases county government.

The federal medical assistance percentage (FMAP) is the portion of total Medicaid spending supported by federal matching funds. The federal match varies for different Medicaid programs from 60% to 100%. The state or in some cases Wisconsin counties, pay for the local match. Wisconsin has received increased COVID-19 federal matching for certain services.

Federal Medicaid matching funds are approximately \$5 billion annually and are the largest funding source for Wisconsin's Medicaid programs and help to ensure that state general purpose revenue tax dollars can be used for other essential purposes.

More than 2/3 of Medicaid spending in Wisconsin is on people with disabilities and older adults. Medicaid is a flexible program that allows states to design supports and services to meet emerging needs, underserved populations and respond to economic or other changes, including situations like the COVID-19 pandemic.

What are major concerns related to this issue?

There is a shortage of medical professionals who accept Medicaid in some key specialty areas including mental health and dental care. Medicaid reimbursement rates are lower than commercial insurance and targeted reimbursement rates can be important as part of a strategy to address access issues.

Wisconsin has the opportunity to increase access to health care for thousands of uninsured Wisconsinites by allowing BadgerCare eligibility to increase from 100% to 138% of the Federal Poverty Level (FPL). Increasing Medicaid eligibility will also allow workers who support people with disabilities to work more hours (currently many workers who need health care for themselves or their families are forced to reduce their work hours and earnings to maintain eligibility for BadgerCare.) The federal government is supporting states to make these eligibility changes by increasing the federal match – estimated to amount to a net savings of \$200 million for Wisconsin (according to a January 2018 LFB estimate). This change will result in a significant reduction in spending of state tax dollars.

How has this issue been impacted by the COVID-19 pandemic?

Access to Medicaid has increased in importance due to COVID-19. With the rising rate of unemployment, many Wisconsinites have lost access to employer provided health care insurance and are enrolling in Medicaid. Access to health is especially important during a pandemic.

Many direct support professionals who care for people with disabilities do not have access to employer provided insurance and have struggled to access vital care during the COVID-19 pandemic. The pandemic has elevated the importance of providing these frontline workers with access to insurance and expanding Medicaid eligibility would be a significant and cost effective option for meeting this need.



EMPLOYMENT

Who are the people impacted by this issue?

Wisconsin's Employment First law establishes community integrated employment (CIE) - typical employment at a community job at regular wage - as a priority for people with disabilities. The number of working-age people with disabilities who are employed has decreased significantly during the pandemic, a 17% reduction as of May. A year ago, in 2019, 19% of working-aged people with a disability were employed, compared to 66% for people without a disability. Among people with intellectual and developmental disabilities in Wisconsin's Long-term care system (Family Care/IRIS) only 16% are working in competitive-wage jobs, while 55% who are not working say they want a paid job. Nationally, studies consistently show that managers positively view people with disabilities, regarding them as easy to supervise and producing as much work, or more than co-workers without disabilities.

Why is this issue important?

When people with disabilities work, they reduce reliance on public benefits and report better mental and physical health. The turnover rate for employees with disabilities is 8% compared to 45% for other workers; 87% of customers say they prefer companies that hire people with disabilities.

Wisconsin is having success in getting people with disabilities to work, but there is more to be done. Project SEARCH trains students with significant disabilities for a variety of jobs and has a nearly 90% employment success rate. The Division of Vocational Rehabilitation (DVR) is serving more clients than ever before. Wisconsin PROMISE demonstrated successful strategies for moving youth with disabilities and their families from reliance on public benefits to work and increased economic independence. Still, many people with disabilities who want to work are being left behind. Currently, working-age adults in Wisconsin's long-term care system are still only employed at levels of 4% to 10%, and COVID-19 has further eroded those numbers. Many people with disabilities say they want to work in the community but are not connected to employment supports.

How are supports for this issue funded?

People with disabilities use a variety of supports and funding to seek and maintain employment. Youth in transition are entitled to transition supports through their school until age 21. This may include job training, internships, job exploration, job coaching and more. Some youth and adults may also be eligible for the state's Division of Vocational Rehabilitation (DVR) program. DVR is a federal/state program designed to obtain, maintain, and advance employment. Funding for the program is primarily provided by a federal vocational rehabilitation grant (78.7%) with state matching funds (21.3%). Adults who meet eligibility for the state's long-term care programs (they must meet financial and functional requirements) may use employment supports through programs like Family Care, IRIS and Family Care Partnership. People enrolled in county mental health programs may use Community Recovery Services. CRS helps individuals living with a mental illness reach their full potential, including employment. Currently CRS is only available in 15 counties.



EMPLOYMENT

What are major concerns related to this issue?

In 2018 Wisconsin Medicaid long-term support waivers served approximately 43,000 working age individuals, yet only 3,873 were employed in Competitive Integrated Employment (CIE).

Some WI facility-based providers already are shifting their business models towards community integrated employment supports to respond to families and people with disabilities who want work in the community with positive results. Employment service providers need short term funding to continue this transformation. Survival Coalition supports a one-time competitive grant fund to get more people to work.

Long-term care programs do not yet prioritize employment on plans for working age people and providers are not reimbursed appropriately for the work it takes to secure employment. Survival Coalition recommends that DHS implement a tiered rate system across long-term care programs that takes into consideration a person's individual employment support needs, unique situations resulting from COVID-19, and prioritizes competitive integrated employment.

People with disabilities want to save their earnings without fear of losing their eligibility for the healthcare they need. ABLE accounts are tax free savings accounts that many states are taking advantage of. Wisconsin does not have an ABLE program and the state has done little to help people sign up for accounts.

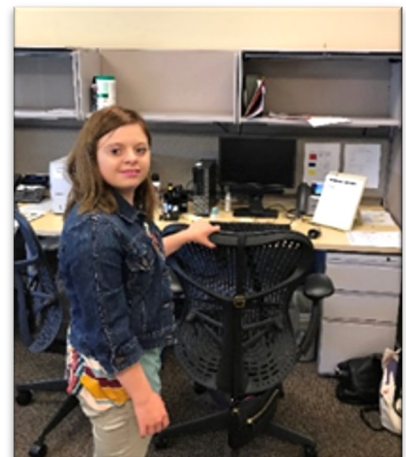
Transportation is a major barrier to work as public transit routes have been cut and rural areas have limited options. Employers and communities should be supported to develop transportation solutions that help people with disabilities connect with jobs in their communities.

People with mental health needs require specialized supports to be successful in employment, which can be a key part of recovery. Currently these type of supports are not available statewide.

Wisconsin should be a model employer of people with disabilities – making changes and accommodations to positions and hiring practices that ensure state government reflects the state's population of people with disabilities.

How has this issue been impacted by the COVID-19 pandemic?

Just like the rest of Wisconsin, many people with disabilities are out of work due to the pandemic. Unfortunately, the employment rate for people with disabilities has continued to lag and getting people back to work is bound to be difficult. Employment services providers have gone months without payments and the lack of revenue threatens to put many out of business, further reducing options for people with disabilities.



EDUCATION

Who are the people impacted by this issue?

Wisconsin public schools educate nearly 855,000 students; among those students, 14% or about 102,350 have disabilities and qualify for special education services through an Individualized Education Plan (IEP). Wisconsin supports students with disabilities in 12 program areas, including speech/language, learning disability, autism, emotional/behavioral disability, and intellectual disability. Examples of services include education related therapies, classroom accommodations, modified curriculum, and additional staff support.

Why is this issue important?

Research shows that even students with the most significant disabilities can make progress in grade level content when provided with appropriate supports. Survival Coalition supports high expectations for all students with disabilities. This means students must be fully included in their general education curriculum and classroom, learning alongside their peers and provided with support to be career and workforce ready. An investment in quality public education for every child with a disability should result in access to postsecondary education or competitive employment in the community and the skills to live independently with necessary supports.

How are supports for this issue funded?

Special education services are funded at three levels: federal, state, and local.

Federal: The 1975 federal law that became the Individuals with Disabilities Education Act (IDEA) was originally passed with the intention to federally-fund 40% of special education costs, but the reality has never matched the promise. Federal funding currently covers less than 15% of the costs of special education.

State: Wisconsin's 2019/2021 state budget included the first increase for special education in over a decade, such that the state was to reimburse districts for 26% of special education costs in FY2020 and 30% in FY2021. However, twenty years ago Wisconsin's reimbursement rate was 35.8% and has fallen over the years from a high of 60% of special education costs.

Local: School districts are responsible under federal law to provide a free, appropriate education for students with disabilities. The portion of special education costs not covered by federal and state funding must, therefore, come from local levies. As costs have risen across time, with federal and state funding failing to keep up, Wisconsin's school districts have been increasingly pressed to make difficult choices. Although special education enrollment has declined modestly over the past decade, costs have increased by an estimated 18.3%.

What are major concerns related to this issue?

Wisconsin students with disabilities are less likely than their non-disabled peers to graduate in four years with a regular diploma; score proficiently on standardized tests; and work in the community after completing high school. In addition, students with disabilities are too often educated in segregated environments, and are far more likely than their non-disabled peers to experience inappropriate seclusion and/or restraint and to be suspended or expelled from school. Students of color with disabilities have some of the poorest outcomes in our state and also when compared nationally.



EDUCATION

In recent Survival Coalition surveys, families have shared significant concerns around loss of staff, poor implementation of services, increases in disciplinary measures and concerns for their children's future.

How has this issue been impacted by the COVID-19 pandemic?

The statewide closure of schools in March 2020 created unprecedented challenge for students with disabilities and their families. District efforts to move to virtual learning have varied in their support for students with disabilities. Technology-related access and implementation challenges have been rampant, as well as scheduling challenges for parents who have struggled to juggle working from home, caring for children with complex needs at home, and facilitating education for students who need significant individual attention. The pandemic and the focus on virtual instruction has shed light on the digital divide with an estimated 40,000 students without access to the tools needed to benefit from instruction. Families remain concerned that new protocols put in place to reopen schools may be difficult or impossible for some students to comply with. Many students have fallen behind and will need additional special education services to make up for education they did not receive during the school closure or may have trouble accessing in the new school year. Families are also concerned for safety as the pandemic continues, and how to balance their students' medical needs with their social, emotional, and educational needs.



MENTAL HEALTH

Who is impacted by this issue?

Mental health and substance use disorders affect individuals from all segments of Wisconsin communities. One in five Wisconsinites experience diagnosable mental health symptoms in any given year and more than 230,000 adults have been diagnosed with a serious mental illness.

- ⇒ An estimated 18.44% of Wisconsin adults (807,000) have a diagnosable mental illness. An annual average of about 360,000 adults aged 18 or older with any mental illness (45.2%) from 2011 to 2015 received mental health services.
- ⇒ An estimated 21% of Wisconsin's children have a mental illness. Some children receive mental health services through other public systems or through private insurance, but a treatment gap of about 34% remains.
- ⇒ In Wisconsin over 900 people die by suicide each year, an increase of 40% between 2000-2017 – but only 52% had received mental health treatment at some point.
- ⇒ At least 30% of men in prisons and 60% of those in county jails have diagnosable mental health conditions.
- ⇒ Mental health conditions often co-occur with other chronic health conditions, and adults living with psychiatric disability die on average 25 years earlier than other Americans.
- ⇒ Opioids related complications resulted in 829 deaths in 2018 and 3,731 emergency room visits in 2019.

Why is this issue important?

Mental illnesses are treatable, and people do recover, even from serious mental disorders. However, untreated and undertreated mental illnesses can have a negative impact on an individual's physical, social and financial wellbeing. Mental illness impacts graduation from high school, lost workdays; add cost to the long-term care system; and when co-occurring with other chronic health conditions significantly increases mortality.

Individuals with mental illness can recover and manage their condition successfully. To accomplish this they need access to community-based, recovery-oriented, trauma-informed system of care which integrates mental health, substance use and primary care to ensure early identification and intervention. Recovery services and supports must be flexible and available to people where they live in the least restrictive setting appropriate to meet their needs and consistent with their choice. Community supports should focus on helping an individual to live as fully and independently as possible with the equal opportunities and quality of life.

How are supports for this issue funded?

Services and supports may include therapy, medication, psycho-social rehabilitation, peer support, benefits counselling, housing, transportation, and employment services. These services are funded by private insurance, as well as by Medicaid and Medicare. However, there is a continued lack of parity for funding and coverage of interventions needed to treat and recover from mental health issues which results in increased untreated or undertreated conditions. In Wisconsin, counties have the lead role in administering behavioral health services, including community programs such as Comprehensive Community Supports (CCS), Coordinated Services Teams (CST) and crisis services. Mental health is also addressed by public education services, including special education.



MENTAL HEALTH

What are major concerns related to this issue?

- ⇒ The lack of access to adequate, high quality community-based mental health treatment and treatment for substance use disorders has contributed to people being placed in costly out-of-home and institutional settings, being confined to jails, prisons, or involvement in the juvenile justice system.
- ⇒ Variations between counties in the amount and scope of services provided has led to inequity in services depending on where the individual lives.
- ⇒ Provider shortages limit the ability of children and adults to experience the full benefit of these programs. 49 of Wisconsin's 72 counties are designated as "Mental Health Professional Shortage Areas." This shortage is especially severe for people covered by Medicaid, or in rural areas. Access to psychiatric services, especially child psychiatrists is at a crisis point in much of the state.
- ⇒ People of color who experience mental health crises are disproportionately subjected to coercive and punitive responses including involuntary treatment, jail holds, and incarceration.
- ⇒ Wisconsin lacks linguistically competent mental health services for deaf and hard of hearing. More mental health providers able to communicate directly with people who are deaf, hard-of-hearing, and deaf blind, through American Sign Language and other modes of communication, as well as knowledge of Deaf Culture are needed.
- ⇒ Children and youth with disabilities are overrepresented in the justice system. 2016 data from Wisconsin's Department of Corrections indicates at least 70% of the then current population at Lincoln Hills and Copper Lake were classified as having one or more disabilities; most with a mental health diagnosis or emotional disorder. More attention and resources must be devoted to promoting best practices in youth-focused programming and positive policy changes that will improve outcomes for youth and their families.

How has this issue been impacted by the COVID-19 pandemic?

Many people with mental health needs are at higher risk of COVID-19 and related complications for a variety of reasons including instable housing, limited resources for social distancing, and a high incidence of co-occurring chronic health conditions. Therefore community mental health workers should be classified as essential workers and have access to Personal Protective Equipment (PPE), sanitation supplies, and testing.

Telehealth has become an important way to access mental health services during this time. Wisconsin Department of Health Services has provided additional flexibility to help consumers access telehealth services. This has exposed disparities and inequities for those who cannot access telehealth because of geography, equipment, internet access, fiscal constraints, ability or disability.

Studies indicate that the pandemic could have negatively impact children's physical and mental health, and yet parents don't have the appropriate mental health or counseling resources to help their children or themselves. Potential prolonged school closures and home confinement may mean that children who were receiving mental health services through schools or outpatient clinics may no longer have access to treatment.



SUPPORTING CHILDREN WITH DISABILITIES AND THEIR FAMILIES

Who are the people impacted by this issue?

Approximately 56,000 children in Wisconsin have a significant physical, developmental, or behavioral disability such as cerebral palsy, autism, or Down syndrome that results in eligibility for home and community-based services. Of these, about 14,000 participate in one or more healthcare coverage or long-term support programs such as BadgerCare, Katie Beckett Medicaid, the Children's "Waiver" and Children's Community Options Program (COP). These programs provide primary healthcare coverage such as autism treatment and therapies and long-term supports that help prepare children for school, participation in their communities, preparation for adult living and employment. These programs also support participating families with information, assistance with care and resources. For example, home modifications make it possible for families take care of their child with disabilities and go to work. For many families, Medicaid coverage is in addition to their private insurance, which often does not cover many of the medical and long-term care services needed for children with disabilities.

Families of children with disabilities in Wisconsin face unique challenges and the impact of a child with disabilities can be profound.

- ⇒ 28% of families live below the Federal Poverty Level (FPL) compared to 16% without children with disabilities
- ⇒ 56% of families report financial hardship
- ⇒ 25% of family members have to cut back or stop working to care for their child
- ⇒ 23% of families report usually or always feeling stress compared to 5% of families without children with disabilities.
- ⇒ Nationally, less than 48% of mothers who have a child with a disability report being in good health compared to 64% of mothers without children with special needs.

Why is this issue important?

Children and youth with significant disabilities may need unique supports to fully participate and benefit from school, work and community experiences that benefit all children. The programs that pay for these supports and services, like Medicaid and Medicaid Waivers, are essential to family health and wellness. The families of children with disabilities are the most important resource to ensure their child is healthy and included and connected with their community. Added responsibilities beyond typical parenting include critical roles as advocates, care coordinators, benefits navigators and 24/7 caregivers. Supports and services for families in these roles lead to full community inclusion, is cost effective and needs to become a major focus in our public systems.

When families have access to the right information, training, and navigation assistance, their success increases. Without these services and supports the only option for a family who has critical needs is to place their child "out of home" – either in an institution or specialized foster care. Supporting families prevents crisis and the need for more costly services and maximizes the use of existing "generic" community, health, and school-based supports.



SUPPORTING CHILDREN WITH DISABILITIES AND THEIR FAMILIES

How are supports for this issue funded?

Children with the most significant disabilities in Wisconsin are eligible for Medicaid funded acute, primary, and long-term supports and services. In many cases this is in addition to a family's private insurance.

Medicaid is a state and federal funding partnership. The federal medical assistance percentage (FMAP) is the portion of total Medicaid spending supported by federal matching funds. The typical federal match for child disability programs is 40% state and 60% federal.

The Children's COP program is funded with state General Purpose Revenue (GPR) and is used to pay for those things families may need that are not Medicaid allowable such as care of a sibling while parents are with the child with a disability in the hospital.

What are major concerns related to this issue?

Unlike the adult long-term care programs, home and community-based supports for children has a statewide wait list. Eligible children with the most significant disabilities are the only Medicaid population in Wisconsin on a wait list due to lack of funding. While the Wisconsin legislature has approved funding to serve a specific number of children, they have not changed the funding mechanism to serve all eligible children as they did for adults with disabilities in Family Care and IRIS Medicaid waiver programs. The long-term solution to ending the wait is to change the budget language to fund all eligible children rather than the current language based on a specific number. This change will finally end the wait and create equity between children and adult systems.

Another major concern is lack of access to information and assistance that can help families navigate and coordinate complex systems such as special education, healthcare, employment, and the coordination between public and private benefits. Many families who have children with disabilities talk about how hard it is to find help. Supporting families can reduce or even eliminate reliance on formal disability services. Like ADRCs which serve adults and seniors, Wisconsin can create a statewide access network of *Child Disability Resources (CDRs)* that specialize in information, assistance, and benefits counseling for children with disabilities and their families.

How has this issue been impacted by the COVID-19 pandemic?

Like many families during COVID-19, families of children with disabilities have to make decisions about keeping their family safe and healthy, when and how to return to work, when and how their child participates in school and engages with the larger community. Unlike typical families, families with a child with disabilities may have additional considerations. The child may have to stay home due to additional health risks from contracting COVID-19; they may be unable to practice social distancing or wear a mask due to their disability or need for care; childcare settings may be unwilling to take a child needing these additional cares; consequently families may be unable to return to work or be faced with trying to work from home if allowed by their employer and take care of their child at the same time. With children home all day, many families have had to take on additional roles during COVID-19, becoming the teacher, nurse, 24/7 caregiver, while at the same time working and taking care of all family members.

For many this is not sustainable without assistance.

Additionally, Wisconsin's family medical leave policies do not offer paid leave options, nor do they allow for leave for the types of intermittent care responsibilities, meetings and coordination duties required of parents. This can force families to choose between work which is essential for the entire family and the care needs of the child with disabilities.



TRANSPORTATION

Who are the people impacted by transportation?

Non-drivers include people with physical, mental health, or intellectual/developmental disabilities, older adults, and low-income workers who cannot afford to maintain personal vehicles, students, and adults who prefer not to drive.

Impacts of inadequate transportation extend beyond non-drivers themselves. Without access to adequate transportation, non-drivers must depend on family and friends and often miss out on needed medical care, social interactions, and sustainable employment.

Why is transportation important?

Non-drivers are not able to get where they need to go on their schedule; transportation barriers affect large segments of the population across Wisconsin and is the number one concern of people with disabilities.

Lack of affordable and accessible transportation impacts people's job choices, housing options, medical care, and ability to independently conduct personal business. Social isolation is a serious and growing problem; transportation is critical to keep people engaged with their community and maintain social networks. Few or no transportation options limit workforce mobility and economic development.

Many direct care workers who provide daily care and support for people with disabilities and older adults are low-income and rely on public transportation to commute to client homes.

What are major concerns related to transportation?

People with disabilities and older adults have identified consistent transportation barriers and challenges. In a 2018 statewide survey of more than 500 respondents the following common themes were identified:

- ⇒ Transportation program is for a specific population or is a one-ride/one purpose program that does not allow people to use the same ride to accomplish multiple tasks,
- ⇒ Transportation services don't go where riders need to go, including key medical/governmental/business destination, between towns, or across county lines
- ⇒ Transportation is not available at times needed
- ⇒ Transportation is unreliable, scheduled rides are late, do not come, or get cancelled
- ⇒ The overall capacity to provide transportation is inadequate to meet all the transportation needs of riders.
- ⇒ Rides must be scheduled too far in advance, cannot accommodate changes to rider's schedule or needs.



TRANSPORTATION

How is transportation funded?

There are several federal and state programs that provide grants to help support transportation services, but they all come with statutory parameters (age, income, disability status, geographic area...) limiting what populations are served. These limiting factors creates a fragmented transportation system, in some cases, working against each other.

How has transportation been impacted by the COVID-19 pandemic?

Many non-drivers are essential workers and rely on public transit to get to their jobs. Likewise, non-drivers who need to hospitals, pharmacies, grocery stores and other essential services depend on public transportation.

The pandemic has caused public transportation to quickly implement ways to maintain social distancing and sanitation, but it has also demonstrated its necessity. Without it, non-driving populations and essential workers would be stranded.



VOTING RIGHTS

Who is impacted by this issue?

The issue of voting rights impacts Wisconsinites who are eligible to vote and have a disability. The CDC indicates that 26% (1 in 4) of adults have some type of disability, so this is a significant number of voters, and a diverse population. Although the disability vote is potentially large, people with disabilities are underrepresented at the polls. The *Rutgers University Fact Sheet on Disability and Voter Turnout in the 2018 Elections* notes a 10.4% gap in Wisconsin voter turnout between citizens with and without disabilities.

Why is this issue important?

Voting is one of the most fundamental rights of our democracy. It is imperative that people with disabilities have a voice in choosing their elected officials, because once elected, they will make decisions about programs and services that are vitally important to Wisconsinites with disabilities. Many people with disabilities access programs and services funded by the federal, state, or local governments to support them in maintaining their health, accessing education and employment, and participating in their communities.

How are supports for this issue funded?

Elections are supported by a combination of federal, state, and local government funding. Historically, states have authorized local jurisdictions (counties or cities/towns) to run elections on their behalf following state-specified rules, and have expected local jurisdictions to pick up most of the bill. A few examples:

- ⇒ In Wisconsin, local governments are responsible for selecting accessible voting machines from a list approved by the state, and for purchasing this equipment.
- ⇒ Accessibility audits of polling places are paid for by a combination of federal funds and state funds.

What are major concerns related to this issue?

The Americans with Disabilities Act (ADA), Help America Vote Act (HAVA) and other federal laws are intended to protect the rights of voters with disabilities, but many still experience barriers to exercising their constitutional right to cast a ballot. Some of the barriers reported by voters with disabilities include:

Accessibility concerns

- ⇒ Polling place accessibility concerns, that may limit access for voters who use mobility aids such as walkers or wheelchairs.
- ⇒ Communication barriers, such as those experienced by deaf voters.
- ⇒ Each polling place is required to have an accessible voting machine to allow voters with disabilities, including those who are blind or low vision, to vote privately and independently. Many voters benefit from the accessible voting machine; however, other report that the machines are not available, not functioning correctly, or that poll workers are not aware of this option and do not offer this choice to voters.
- ⇒ Inaccessible ballots. Wisconsin does not have a screen reader accessible, ADA compliant absentee ballot. Voters who rely on assistive technology to vote privately and independently do not have equitable access to absentee voting.



VOTING RIGHTS

Photo ID: Many Wisconsin residents who have a disability do not drive; they do not have a driver's license and may not have other acceptable photo ID required to vote. While a free ID for voting can be obtained at Department of Motor Vehicle (DMV) offices, it may be difficult to get transportation to the DMV. This is a concern across the state, and may be an additional challenge in rural area due to limited hours at DMVs.

Failure to provide accommodations: The law requires access to disability related accommodations, such as the ability for voters who have difficulty accessing their polling place to vote curbside, access to a signature guide, or the option for a voter with a disability to have someone assist them with completing their ballot if desired. Some voters report that they are denied an accommodation or that it is not available.

Transportation: Because so many voters with disabilities are non-drivers, transportation to the polling place is a major barrier.

Limited training for poll workers: Poll workers play an important role in supporting voters and ensuring that elections are accessible and inclusive. Poll worker training requirements of two hours don't allow much time to cover accessibility, disability related accommodations, accessible communications, and other disability related topics.

How has this issue been impacted by the COVID-19 pandemic?

Because many people with disabilities have high vulnerability for COVID-19, voting in person has become high risk, yet many experienced barriers to absentee voting. During the 2020 April and May elections, there was a significant increase in the number of voters with disabilities who reported barriers to voting. Some of the barriers that emerged or increased due to COVID-19:

- ⇒ For those who needed a state Photo ID for Voting, the DMV closure and lack of access to safe transportation made it virtually impossible to obtain the needed ID.
- ⇒ Absentee voting was preferred due to the pandemic, however, difficulties many voters with disabilities struggle with the requirement to provide a copy of photo ID because of limited access to technology or limited ability to upload or copy photo ID.
- ⇒ Blind voters and others who rely on assistive technology to vote privately and independently did not have equitable access to absentee voting as Wisconsin does not have an ADA compliant screen reader accessible absentee ballot.
- ⇒ The witness requirement for absentee ballots was a barrier for some voters with disabilities who live alone, and could not safely get their ballot witnessed.
- ⇒ No Special Voting Deputies in care facilities; no family members or other visitors to assist. Residents were not allowed to leave facilities to vote in person, but may not have received assistance with voter registration or requesting an absentee ballot.



WORKFORCE

Who are the people impacted by this issue?

In 2019, Wisconsin employed 72,060 Direct-Care Workers. These workers are the backbone of Wisconsin's Long-Term Care system. Wisconsin's Direct Care workforce is essential to the health and independence of people with disabilities, the elderly and their families. A history of inadequate wages and lack of opportunities career growth has maintained an ongoing, statewide crisis.

It is projected in 2026 Wisconsin will need to employ 93,072 workers to provide this necessary care to children and adults with disabilities, and the elderly.

Why is this issue important?

These workers (personal care, home health) provide essential care to children and adults with disabilities, as well as, the elderly to ensure adequate supports to lead safe and healthy lives in their own homes. Consistent access to community-based direct care workers prevents unnecessary costly hospitalizations and deters admission to more expensive long-term care settings.

Direct Care workers provide necessary care that allows family caregivers to maintain their own employment, health and well-being, as well as, their contributing roles in their own communities.

How are supports for this issue funded?

Wisconsin's Long-term care workforce is funded through one of Wisconsin Medical Assistance Long-Term Care Programs. In Family Care, Managed Care Organizations receive a monthly capitated payment from the Department of Health Services and in IRIS (Include, Respect, I Self-Direct) individuals direct their long-term care supports through a monthly budget allocation. Eligible children connected to the Children's Long-Term Support Waiver receive funds via a county based case management system. Some personal care services are also funded directly using the individuals Medicaid card.

What are major concerns related to this issue?

Wisconsin providers and consumers are reporting great difficulty in recruiting and retaining quality direct care workers. A 2018 survey of long-term care providers found that: more than 50% of providers indicated they were unable to compete with other employers; 54% had no applicants for vacant caregiver positions; 83% indicated that there were no qualified applicants for caregiver openings; and 25% denied admissions to their facilities due to the lack of caregivers.

A recent Survival Coalition survey revealed that 85% of long-term care recipients don't have enough workers to work all of their shifts. 60% also report that they get sick more often when they don't have enough workers.

The inability to attract and retain direct care workers has resulted in many long-term care recipients going without essential care compromising their health, safety, and their ability to live in the community.

Wisconsin Department of Workforce Development reports the need for personal care and home health aides continues to increase by almost 30% per year. The fastest growing occupation in Wisconsin.



WORKFORCE

How has this issue been impacted by the COVID pandemic?

Wisconsin's Direct Care Workforce shortage was amplified during the COVID due to multiple factors. A statewide Survival Coalition survey of more than 500 disability and older adult service providers shows nearly 20% of these small businesses fear they are not financially sustainable as a result of COVID-19.

The loss of any portion of these providers will only amplify the provider shortages that already exist and result in people not getting needed supports and services that keep them healthy and able to stay in their homes.

Home and community-based providers were not recognized as essential workers. This led to lack of PPE for workers, increased costs to providers to support hazard pay or additional training, as well as, retention issues due to higher payments from unemployment than hourly pay rates.



**Survival
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