

Press Packet: COVID-19 impact on people with disabilities & older adults

Quick Facts

- Almost 500 people with disabilities and older adults representing 78% of Wisconsin counties responded to Survival Coalition’s COVID-19 survey.
- In Wisconsin 36.5% of adults (1,612,619 people) are at high risk of serious illness if infected by COVID-19¹.
- People living in congregant settings like nursing homes and group homes are at higher risk.²
- In Wisconsin more than 85,000 people rely on in-home personal care, home health, and many other services to stay in their own homes and out of hospitals and nursing homes.
- People in Family Care, IRIS, and Children’s long term care rely on personal and home health workers for daily care like bathing, dressing, getting into and out of beds and wheelchairs, and prevention of serious conditions—like pressure sores and obstructed bowels—that can lead to hospitalization.
- The direct care workforce—already in crisis—does not have the needed gloves, masks, and protective equipment to protect themselves from getting infected or potentially exposing our most vulnerable populations to the virus.
- These essential workers—average wage \$11.54³—are caring for people even as their staffing becomes even more strained without overtime, hazard pay, paid sick time, and often are without employer sponsored health insurance.
- Many people are alone, and completely dependent on paid staff.
- Many families, including elderly parents, are being strained to the breaking point as they try to fill in caregiving gaps, often while struggling to homeschool children and work from home

Key Survey Findings:

- 40% worry if they get COVID-19 and are hospitalized they might not meet hospital triage criteria and may not get a ventilator because of age or disability
- 37% report that families are providing some or all daily personal care support instead of their normal paid staff
- All respondents are experiencing disruptions and reductions in the supports and services they need to stay healthy or allow family members to work, including losing personal care and home health care, transportation to get to essential businesses and medical appointments,

¹ <https://www.kff.org/global-health-policy/issue-brief/how-many-adults-are-at-risk-of-serious-illness-if-infected-with-coronavirus/>

² <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html#nursing-homes-or-long-term-care-facilities>

³ <https://phinal.org/policy-research/workforce-data-center/#tab=State+Data&var=Wage+Trends&states=55>



Survival Coalition

of Wisconsin Disability Organizations

prescription drugs and durable medical supplies, therapies that are needed to stay or become more independent.

- In the next two weeks, people are very or extremely concerned being unable to get help if there is a medical emergency, not knowing what to do if they are not getting the help they need, losing their careworkers, and losing the routine care needed to maintain health.

In their own words: what is happening in people's lives across the state

We are very worried about one or both of our wheelchairs breaking down. We need a doctor's note in order to get it fixed and it's deemed as a non-essential medical appointment. Even if we could get the doctor's note. Our local place that would fix it is closed right now and aren't able to come into people's homes.—Jason and Julie, Eau Claire

My wife and I started experiencing symptoms that are consistent with Covid 19 but we have not gotten tested and are unsure if we will be able to be tested any time soon... My brother Xue requires around the clock care and supervision making it hard for us to care for him with our symptoms.—Kong and Houa Vang

My primary concern is what will happen if I am not able to care for him due to having to self-isolate at home or am hospitalized. I am my son's legal guardian as well as his caretaker - it would be difficult to find someone else to take over the guardianship duties if I am hospitalized.—Michelle, Bayfield County

My daughter Chloe is non-verbal and has a significant cognitive delay. Currently she is home 24/7 and we have no supports. It is very difficult to care for her and work at the same time. I am worried if I test positive and am hospitalized, I may not have a family member or trusted person allowed in with me to help me communicate with doctors and understand what they are saying.—Sara, Outagamie County

Covid 19 has limited my ability to continue Physical Therapy. I was injured in a fall and am learning to walk again.—Brettny, Washington County



Survival Coalition

of Wisconsin Disability Organizations

*I am at my aunt's house because I have a family member sick with coronavirus. My mom is with me. I am unemployed hopefully temporarily—
Emily, Fond du Lac County*

If my brother cannot go into work or daycares, then I must care for him 24/7 while also trying to maintain my employment.—Amy, Dane County

Our concern is that his job as a package handler at Fedex is considered essential and he doesn't comprehend "Social Distancing" at the work place. We could have him not go to work but do not know of any provisions that allow people with disabilities to leave their job for this reason and have the ability to return.—Cyndi, Waukesha County

Special needs students on my caseload are having difficulty receiving services that are normally face-to-face—Daniel, Bayfield County

As a caregiver, I am working 14 hours a day, 7 days a week because of no respite and no day programming.—Eleanor, Manitowoc County

When COVID-19 arrived in the US and the quarantine and the safer at home act was implemented it caused our entire routine and support system to be disruptive all at once and very rapidly. My child doesn't do well with change, so you can imagine the behaviors that I have experienced due to the quarantine. It took me 3 to 4 years to build the support my child was finally receiving and it was all gone in what seemed like a blink of my eye. Then we were told that we would be doing everything from home as long as it was able to be approved. It has been a very slow process. We are actually still waiting for approvals for some supports as I write this. We ended up going at least 2 solid weeks with no supports or therapies. I also worry about losing the in-home support workers that took me 4 years to find. There hours have been reduced greatly or brought to 0. —Gena, Dunn County

I'm worried that if I get or one of my roommates get CO-VID 19 I will have no place to live.—Jack, Dane County



Survival Coalition

of Wisconsin Disability Organizations

I am concerned about my family and my caregivers getting sick, here or in the community. I know it is my choice to stay in my own home if I get sick, but I don't want to harm others either.—Janis, Portage County

I have a 73 year old brother that I provide care for. Because I am considered an essential worker, I have tried to reassure him that his medication, meals, laundry, hygiene care and home chores will not go undone. He worries that should I become ill, no one will be there to care for him.—LaDette, Milwaukee

I am still working at my grocery store 4 days a week because they need me and I like to work. But I'm having trouble getting my rides to work now due to the virus.—Lily, Dane County

I fear both for my son's health and the health of his support persons. Support persons are also frontliners who have had close contact with other high risk people in his apartment complex.—Maria, Rock County

Being out of the house and in the community is a big part of my mental health treatment. Some of my providers are not able to work the hours they used to, for various reasons, and the places that I liked to go are closed to stop the spread of the virus. all of my workers which I miss the ones who aren't coming and I am worried about them.—Olaf, Bayfield County

If spouse (caregiver) becomes sick & lv home for care, client will need 20 hrs of additional support in order to remain in home setting—Patricia, Dane County

Colleen's day program has been closed since March 13, 2020 due to the Coronavirus. She usually attends 5 days a week. This program provides structure, activities and friendships and respite which we have come to depend on. It is in danger of permanently closing. There are no other options if it closes due to lack of funding.—Teryl, Waukesha County



Survival Coalition

of Wisconsin Disability Organizations

My son is 6, nonverbal autistic with sensory issues. This is his 4th week off school and without all these services. He is not able to do worksheets or online work due to his intellectual disabilities. I am doing the best I can but I'm not a trained special ed teacher (and his teacher is working on her masters) nor a therapist. He is regressing and losing gains he had made. The longer the kids are off school the more time he will have to lose those hard won skills. —

Wendy, Milwaukee County

Kimber's caregivers. Her voice, her hands, her feet. She requires assistance in everything. They are unemployed now. Our biggest concern is for caregivers who fall through the cracks, and can't get unemployment. They rely on taking care of our daughter for their sole source of income. It's so important to take care of those, who take care of others. Our daughter is difficult to care for, and finding those special people who love her like we do, is rare. You'll never realize it until you have to depend on someone else to feed you, bath you, dress you, change your diapers. —Kimber, Racine County