



## Survival Coalition COVID-19 survey reveals deep concerns for people with disabilities and older adults

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(MADISON) -- More than 700 people with disabilities and older adults who say they use Wisconsin's long-term care programs are concerned about the impact COVID-19 will have on the daily in-home supports they and their families rely on to keep them healthy and safe. Survival Coalition has been distributing a statewide survey over the last week, intending to use the feedback to inform the Department of Health Services and policymakers of both immediate and long-term concerns and needs.

More than 85,000 older adults, people with physical disabilities, people with intellectual disabilities, and children with disabilities rely on Family Care, IRIS, and Children's Long-Term Care waiver programs to stay in their homes and out of expensive Medicaid-funded institutions. During the COVID-19 crisis, many of the services provided through these programs have discontinued or changed significantly.

The supports and services people responding to the survey are most concerned about being disrupted include: personal care or homecare (40%), prescription medication supply (31%), respite (28%), employment services (27%), transportation to medical appointment and essential services (23%), day services (23%), mental health services (23%), rehabilitative or habilitative services (14%), residential placements (12%), durable medical equipment (12%).

"Many people are worried that the programs they have relied on and are now closed or offering only basic services will never open again," said Beth Swedeen, Survival Co-Chair. "Home and Community Based providers have responded to the public health emergency, but now face an uncertain financial future. Workers are being laid off and many provider organizations are reporting they will go out of business in weeks without revenue."

While some people have family members and can temporarily manage if in-home supports and services are reduced, many do not have the ability to manage if their care needs increase or their care workers or family fall ill with COVID-19.

51% of respondents say they do not have a way to get the in-home supports and services they need if their careworkers or family members become infected with COVID-19.

"People are fearful of what will happen to them. Where will they go if they are no longer able to stay in their homes?" said Lisa Pugh, Survival Co-Chair. "Family members are getting stressed. What will family caregivers do if they get sick? Disaster plans are not in place."

If supports and services are reduced or become unavailable as a result to COVID-19, people expressed a number of things they are really concerned about: they won't be able to remain in their homes (30%), won't be able to get help in a medical emergency (30%), will lose care workers (33%), or lose their jobs (27%), their mental health will decline (45%), isolation from support network and community (54%),



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losing daily living skills or physical strength (25%), not getting the routine daily care to prevent pressure sores and other conditions that impact future health (20%), being able to afford delivery and other services (17%).

“We heard from family members who are also health care professionals and need to report to work who have now lost the professional support they need to do this,” said Kit Kerschensteiner, Survival Co-Chair. “Many families are faced with the impossible challenge of providing 24/7 supports to children and adults with disabilities or frail elders while working from home.”

As the COVID-19 pandemic progresses, Survival Coalition will be conducting follow up surveys to hear directly from people with disabilities and older adults about their changing situations and impact COVID-19 is having on Wisconsin’s community based long-term care system.

On March 18<sup>th</sup>, Survival Coalition sent recommendations to the Governor and Legislature on what the state needs to do to help high risk populations self-isolate, prevent spread of COVID-19, make sure people are getting the in-home supports and services they need, and to protect the businesses and workers who provide critical long-term care and other services: [http://www.survivalcoalitionwi.org/wp-content/uploads/2020/03/SurvivalCoalition\\_Covid-19Concerns\\_031820-FINAL.pdf](http://www.survivalcoalitionwi.org/wp-content/uploads/2020/03/SurvivalCoalition_Covid-19Concerns_031820-FINAL.pdf).

## Quotes from real people in long-term care from the survey

*“My job is considered essential and I have a child who is at high risk for this [COVID-19]. There is currently nothing in place to allow me to quarantine and either file for unemployment or just be ensured my job is still there for me if I choose to quarantine without pay. With a workplace of less than 50 employees I am stuck. Either go to work and risk bringing this home to my child with disabilities who more than likely would not make it through, or stay home get fired no money for food and loose our home with no income. Information to help with this would be greatly appreciated. I’m sure I am not the only one in this situation.”*

*“Parents are home taking care of the whole family, not just the children with disabilities. Many have lost their incomes, and now are providing support 24/7 with no compensation.”*

*“Knowing that a plan of care/working hours can be flexible during this time to support the hours of care a person would need to follow CDC and DHS recommendations. Like, shelter in place, limit your exposure, only a contact group of 5 or less - that’s for total exposure. It is essential for the medically fragile population to have flexibility of their cares and to DIRECT their cares by limiting their exposure, as would be acceptable of any other person.”*

*“Have IRIS be flexible with the 40 hour/ week limit per worker. My workers will likely need to put in more than 40 hours. Day services are closed and employment is suspended.”*



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*[What are the] “best ways to get food and medications into our home without risk of transmitting the virus.”*

*“For the hourly pay to increase again for paid caregivers. Support them with supplies needed to keep them safe while providing cares.”*

*“Reassurance that services will return to normal after crisis passes.”*

If you or someone you know is using a long-term care program and have an immediate need or question, you should contact your managed care organization care manager, IRIS consultant, or county case worker.