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Survival Coalition of Wisconsin Disability Organizations Says Legislature's COVID-19 Response Helps; Is not Enough

Members of the Survival Coalition of Wisconsin Disability Organizations reacted today to the legislature's COVID-19 response bill with both gratitude and concern about the ability to meet future needs. Wisconsin is already far behind the actions of at least 44 other states who have moved critical COVID-19 plans forward for federal approval and several others whose state legislatures committed considerable state funding to address the emergency. Wisconsin did not.

"Passage of this legislation is the first step towards drawing down additional federal Medicaid funding to help address critical needs, however Survival Coalition continues to have great uncertainty about whether the day to day needs of people with disabilities will be met during the COVID-19 crisis and beyond," says Lisa Pugh, Co-Chair of Survival.

Survival Coalition praises the legislature for passing critical provisions that will allow for hardship or supplemental payments to home and community-based services (HCBS) providers, allow services to be provided remotely, and relaxing certain prescription drug refill restrictions. However, the bill passed by both houses of the legislature includes no new state funding or other assurances of targeted support for home and community-based services, like Family Care, IRIS and the Children's Long-Term Support program. The State Department of Health Services (DHS) has indicated that any increased federal Medicaid funding alone will not be enough to address needs in these programs.

While new federal Medicaid funding will likely ensure hospitals and other critical acute care settings can meet the health care needs of people who get ill and get health insurance to the newly unemployed, many people with disabilities across Wisconsin are going without daily supports and are unsure if the small business providers who support them will be able to weather the crisis and remain in business.

"We are glad the legislature approved significant parts of the federal waiver plans requested by the Department of Health Services," says Beth Swedeen, Co-chair of Survival. "These provisions will ensure essential flexibilities are in place so people can continue to receive at least some of the supports they need. We are very concerned about what will happen to folks the longer this situation persists."

"DHS needs additional funding to ensure things like hazard pay for direct support professionals and to secure personal protective equipment for the community-based workforce," says Kit Kerschensteiner, Co-Chair of Survival. "When people are able to stay in their homes, they are healthier. We need this workforce to stay on the job and healthy, too."

The Survival Coalition this week issued a second statewide COVID-19 survey to assess how people are doing. Early results from the survey indicate people are extremely isolated and, in some cases, their health is being compromised. See survey excerpts below.

“After weeks of social isolation family caregivers are reaching their breaking point and people with disabilities are sharing stories of great anxiety,” says Lisa Pugh, Co-Chair of Survival.

Survival Coalition is disappointed the legislature included unnecessary provisions in the bill that go beyond the timeframe of the public health emergency, including a permanent and significant reduction in Certified Nursing Assistant CNA training hours. A targeted bill to address a public health crisis should not include permanent changes to state policy.

Survival Coalition is comprised of more than 30 statewide disability organizations that advocate and support policies and practices that lead to the full inclusion, participation, and contribution of people living with disability.

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Investing in People with Disabilities

Quotes from Survival Coalition COVID-19 Survey Respondents

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. — The Vang family, Dane 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

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 workplace. 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

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 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

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

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

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 master's) 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