

Comments of the CCD Emergency Management Task Force to the U.S. Senate Committee on Health, Education, Labor and Pensions concerning the White Paper on Preparing for the Next Pandemic

June 26, 2020

The Consortium for Citizens with Disabilities (CCD) Emergency Management Task Force welcomes the effort by the U.S. Senate Committee on Health, Education, Labor and Pensions' to prepare for the next pandemic. CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. During the COVID-19 pandemic numerous CCD task forces have been working to ensure that the nation's emergency preparedness, response and recovery systems account for those with access and functional needs in their policies and operations. The following comments align themselves with the efforts of those many task forces [see CCD COVID-19 <http://c-c-d.org/rubriques.php?rubpage=58>] as well as with recommendations offered by the Partnership for Inclusive Disaster Strategies.

Unfortunately, the *White Paper on Preparing for the Next Pandemic* does not directly address the rights and needs of people with disabilities during a pandemic nor the devastating infection and fatality rates of people with disabilities in institutional facilities. People who live in nursing facilities, long-term care facilities, assisted living facilities, group homes, psychiatric facilities, detention facilities, prisons, and jails are at greater risk by virtue of the fact that they live in these facilities.

As reported in *Forbes* on May 26, 2020, 42 percent of the U.S. COVID-19 deaths are from nursing facilities and assisted living facilities. This means that nearly 50 percent of COVID-19 deaths come from 0.6% of the U.S. population. People of color with disabilities are disproportionately represented in this death toll.

Transparency and Information Needed Concerning Infections and Deaths in All Institutions - CCD has expressed its support for the steps announced by the Centers for Medicare and Medicaid Services (CMS) to ensure transparency and information about infections and deaths in nursing homes. These steps include: (1) requiring nursing homes to inform residents, their families and representatives of cases of COVID-19 in their facilities; (2) requiring nursing homes to report cases of COVID-19 directly to the Centers for Disease Control and Prevention (CDC), as well as to state and local officials; and (3) requiring nursing homes to fully cooperate with CDC surveillance efforts around COVID-19 spread. These same requirements should be extended to all institutional settings -- including ICF-IIDs, IMDs, substance use disorder treatment facilities, and psychiatric residential treatment facilities -- and other Medicaid-funded congregate settings where older adults and people with disabilities live, including group homes and assisted living facilities. The need for transparency, information and

data collection is equally as critical to protecting the safety and welfare of people in these settings as they are for residents of nursing homes - <http://c-c-d.org/fichiers/LTSS-Co-Chair-Letter-re-institutional-and-congregate-care-and-COVID19-final.pdf>.

Data Collection About People with Disabilities in Congregate Settings is Critical -

Beyond addressing the immediate need for information about infection spread within institutions, the effects of the pandemic exacerbate the civil rights concerns already present with the widespread overreliance on institutional care for people with disabilities. The Americans with Disabilities Act's integration mandate and the Supreme Court's Olmstead decision prohibit the needless institutionalization and segregation of people with disabilities. Now, people with disabilities are not only isolated and segregated in institutional settings but at risk of death in those settings. Furthermore, transitions out of these institutions have largely come to a halt due to the pandemic. In many cases, information concerning COVID-19 testing, cases, and deaths in these facilities remains hidden from the public. Information about COVID-19 testing, cases, and deaths of people with disabilities in institutional facilities as well as in community settings is critically important for those individuals, for their families, for staff, and for the public. Further, this information is important to collect and report on a national basis in order to better understand the impact of the virus on people with disabilities and to inform strategies to prevent its spread—including strategies to improve compliance with the ADA's integration mandate in the current environment. <http://c-c-d.org/fichiers/COVID-disability-data-collection-letter-2020-4-27.pdf>

People with Access and Functional Needs Must Have the Supports and Resources to Live in the Community -

States should use FEMA funds to decongregate nursing facilities and other institutional settings. Congress must clarify that people in nursing facilities, intermediate care facilities, state psychiatric facilities and other congregate settings are eligible for ESG-funded programs, regardless of length of stay. To ensure direct support professionals (DSPs), personal care attendants, and other direct care workers, and the people they serve are protected, they must have access to adequate PPE. Moreover, Congress must ensure that people with disabilities coming from congregate settings and institutions are eligible for any emergency rental assistance, housing, and homelessness resources that may be included in the next coronavirus relief package. In the long-term, permanent affordable housing solutions and supports are key to ensuring people with disabilities can remain in the community and successfully transition from congregate settings. Congress must increase investments in proven solutions, including targeted programs such as Mainstream Vouchers and Section 811 Supportive Housing, as well as Housing Choice Vouchers, the National Housing Trust Fund, and other programs - http://c-c-d.org/fichiers/FAQs_Disabilities.pdf

While the HEROES Act includes an important targeted 10 percent FMAP increase for Medicaid home and community based services (HCBS), this broad enhancement will not be sufficient to allow states to avoid massive and unsustainable cuts to these indispensable programs, which are often first on the chopping block because they are

not considered “mandatory” under Medicaid law. Dedicated funding is necessary to keep people with disabilities and aging adults safely in their homes and communities, and avoid reliance on costly institutional settings that have proven particularly dangerous during this epidemic. <http://c-c-d.org/fichiers/CCD-LTSS-TF-Letter-to-Senate-on-Pakage-Four-5-29-20.pdf>

Congress Must Pass the Real Emergency Access for Aging and Disability Inclusion (READI) for Disasters Act, H.R. 3208, and S. 1755 – <http://c-c-d.org/fichiers/READI-and-COVID-letter-to-EdLabor.pdf> - This legislation would address and advance solutions for many of the problems we see arising in the response to COVID-19. Had this legislation been enacted, the National Commission on Aging, Disability and Disasters would be positioned to offer critical and timely guidance and direction to federal, state, tribal, territorial and local agencies responding to this public health emergency. The Commission could have forestalled inadvisable proposals such as those advanced by the Department of Education to waive provisions of the Individuals with Disabilities Education Act and Rehabilitation Act of 1973 [<http://c-c-d.org/fichiers/CCD-Ed-TF-letter-to-Congress-on-IDEA-waivers--COVID-final.pdf>] or recommended that hospital and other healthcare provider visitor policies include reasonable modifications for people with disabilities who need the physical presence of a support person in order to ensure equal access to health care [<http://c-c-d.org/fichiers/Sign-on-letter-supporters-in-hospitals-governor.pdf>]. Other provisions in the bill would provide technical assistance to covered recipients and sub-recipients of federal funds to comply with the Rehabilitation Act and Americans with Disabilities Act (ADA) and would allow for contracts with Centers for Independent Living and other organizations with disability-centric subject matter expertise to assist recipients to ensure that programs, facilities, communication and services are accessible to individuals with disabilities, older adults and others with access and functional limitations. H.R. 3208 and S. 1755 would also offer financial support for creation of centers for training and technical assistance to state, tribal, territorial and local emergency management, public health and social service agencies to aid these agencies in serving covered individuals in the most integrated settings appropriate to their needs. These centers would also be tasked with researching and disseminating information about promising and good practices for protecting the civil rights of people with disabilities in COVID-19 and future public health emergencies and disasters.

The Disaster Relief Medicaid Act (DRMA) Would Prevent Unnecessary Institutionalization of People with Disabilities - <http://c-c-d.org/fichiers/CCD-Emergency-Mgmt-and-LTSS-TF-Support-Letter-for-DRMA.pdf> - Under the Disaster Relief Medicaid Act, (H.R. 3215 and S. 1754) individuals that are eligible for Medicaid and who must move to another state because of a disaster would be able to continue accessing their Medicaid supported services. In an era where concurrent disasters involving storms and a pandemic are increasingly likely, this becomes even more important. States receiving designated Relief-Eligible Survivors would be provided with resources to support their Medicaid needs. The DRMA would also provide technical assistance and support to states to develop innovative best practices to respond to an influx of out-of-state individuals with disabilities and create a grant program to assist

states in developing an emergency response corps to provide home and community-based services. Of particular importance is the 100% federal match in resources going to the services provided to displaced individuals with disabilities to overcome any concerns that host state populations could be disadvantaged.

People with disabilities — one in four Americans — cannot be left out of the country's preparations for the next pandemic. This includes over 2 million people with disabilities in nursing facilities and other institutions. It must be noted that these individuals are not admitted to nursing facilities simply because of their age; they are admitted because they are unable to secure appropriate disability services and supports to live at home and in their community.

Based on the foregoing narrative, the CCD Emergency Management Task Force joins the Partnership in suggesting a 6th recommendation to the *White Paper on Preparing for the Next Pandemic*, as follows:

Ensuring that all people with disabilities, including older adults with disabilities, are equally protected in a pandemic, as well as future public health emergencies and disasters by:

- Protecting the lives and enforcing the rights of people with disabilities in their communities,
- Increasing home- and community-based services (HCBS),
- Establishing *Money Follows the Person* as an entitlement,
- Increasing the home healthcare workforce,
- Increasing affordable, accessible housing,
- Increasing and ensuring the availability of Personal Protective Equipment (PPE) for people with disabilities, the home healthcare workforce, and direct service providers,
- Passing the READI for Disasters Act
- Passing the Disaster Relief Medicaid Act

To truly ensure that people who live in congregate settings will not be at higher risk of contracting and dying from any other outbreak of infection, they must be diverted and transitioned from those settings. This can only be done by investing in sufficient HCBS to prevent institutionalization, support people with disabilities in successfully transitioning back to the community and maintaining adequate supports and services (who chose) to remain/live? at home.

Failure to address these gaps will lead to preventable deaths in the next pandemic. Policies that protect the rights of people with disabilities in the next pandemic are not simply a good idea, but are critical to saving lives. The current pandemic has made this abundantly clear.

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