

March 31, 2020

**Re: Strategies to enhance community supports & health services for people with disabilities (PWDs) during the COVID crisis**

To Governor Pritzker, Dr. Ngozi Ezike, & members of the Illinois COVID Crisis Response team;

Thank you for your excellent leadership during this crisis. We are grateful to have leadership that is forward thinking and willing to act decisively in the interest of the public and individual citizens. We are writing to offer suggestions to pressing problems, and to seek your assistance in strengthening our systems of care and support for a group that is particularly vulnerable and historically marginalized: people with disabilities. (We believe the needs of our senior citizens who are also vulnerable could be met with similar solutions as well).

In representing the undersigned, I am a physical medicine and rehabilitation physician, disability/clinical ethicist and medical educator. We represent a network of over 50 Chicagoland and National disability care professionals and advocacy organizations. Under the best of circumstances, our acute health care systems are ill-equipped to care for people with disabilities. We believe the most important strategy to support the lives of people with disabilities as the COVID crisis surges **is to support their critical community networks and supports in order to keep them out of hospitals, emergency rooms and nursing homes.** We outline in the table below urgent priority issues<sup>1</sup> and potential solutions. Rest assured there are many more issues the group has identified, and are eager to help address. Please know that we won't just bring you problems but promise to volunteer our collective wisdom and services to create meaningful solutions.

Urgent Need	Promising Action
<b>Lack of ability to get testing, medical and treatment options in the community and home settings for PWDs.</b> Most outpatient care clinics are closed; it is difficult to find a Medicaid home health agency that is willing	<b>Immediately develop regionally designated centers for the care of PWD staffed with Mobile Integrated Health Unit Capacities, disability competent staff and telehealth capacities to support PWD (and older adults).</b> Such a mobile health unit could

<sup>1</sup> See example from two recent story links:

- **"Resident of Oak Forest group home for adults with developmental disabilities dies of complications from COVID-19A..."** (4 others in home now positive) <https://www.chicagotribune.com/suburbs/daily-southtown/ct-sta-south-suburban-covid-19-deaths-st-0329-20200327-oucf75lpsvbsveqh6qktz35kea-story.html>
- **'We want to live': At-risk adults, home health care workers fear coronavirus**<https://www.usatoday.com/story/news/investigations/2020/03/26/coronavirus-strains-home-health-care-putting-vulnerable-risk/5083219002/>

and able to provide care for COVID + and complex disabled patients

perform in-home assessment and urgent evaluations, testing including for COVID, treatment, and network with telehealth supports. This model has been pioneered with success by The Boston Commonwealth Care Alliance, an integrated provider health plan dedicated to the care of seniors and adults with disabilities.<sup>2</sup>

Urgent Need	Promising Actions
<p><b>Immediate care and/or placement options for PWD who:</b></p> <p>(1) are COVID+ but not sick enough to be in a health care facility and cannot be isolated in place;</p> <p>(2) are experiencing disruption in care due to erosion of personal assistance services and home care; or</p> <p>(3) need to be isolated immediately because the caregiver is COVID+, a person in the facility or home is positive, or suspected of having the infection.</p>	<p><b>Develop respite/care options for PWD that can be implemented within hours for each scenario.</b></p> <p>(1) <b>Use LTACs and IRFs (as capacity allows) which have negative pressure rooms, vent and respiratory care capacities, onsite 24/7 nursing and respiratory therapy.</b> There would need to be strong telehealth support from critical care specialists.</p> <p>(2) and (3) <b>Designate and convert hotel floors for care of PWDs</b> staffed with a nurse, CNA or PA services, appropriate supplies and equipment, networked for telehealth support, which has capacity and option to allow caregiver and staff to “live in”. Allow PAs and family caregivers for the PWD to “live-in,” and to participate with direct care. This is particularly important for elderly parents/caregivers who cannot provide hands-on physical care but can direct care</p> <p><b>Inpt Rehab Facilities (IRF) or Long term, acute care hospitals can also be used, especially for those with more complex care needs and disabilities, as capacity allows.</b> These units have trained staff, specialized equipment, 24/7 nursing, and in some cases 24/7 respiratory care support. Earmark those individuals who use respiratory</p>

<sup>2</sup> See <http://www.commonwealthcarealliance.org/about-us/cca/innovations-that-improve-member-experiences/mobile-integrated-health>.

equipment and home ventilation toward LTACs and those IRFs with vent capacity  
*Note: For all three scenarios, access to immediate rapid COVID testing and ability to communicate with regional center for immediate placement and transport is necessary. The regional center would be networked with facilities and receive daily updates for monitoring available beds and capacity.*<sup>3</sup>

Urgent Need	Promising Action
<p><b>Support and protection for the personal assistance pipeline and home caregivers.</b> There is a desperate need for PPE, emergency back-up services, and protections for workers, particularly those who do not have health insurance themselves, who take public transportation between homes, or who are expected to try to find and pay for their PPE.</p>	<p><b>Prioritize access to PPE for personal assistants, family caregivers, home health workers, staff and residents in community homes and intermediate care facilities.</b> Centralize PPE resources through the regional centers and make supplies readily available without cost to facilitate and support low paid personal assistance workers and health care aides in provision of care. In the absence of traditional PPE, immediately curate and ramp-up production of best feasible alternatives with input from infection control specialists.<sup>4</sup> Provide ongoing virtual support and training of PAs and caregivers for infection control including protocols for cleaning, reusing, and extending the life of PPE, medical supplies, equipment. If necessary, consider having the PA or aid shelter in place with PWD who require extensive personal and medical care and/or develop a closed system with safe transportation and stable relationships.</p>

<sup>3</sup> Would the CMS guidelines released yesterday offer the needed flexibility to implement, help fuel, and work out the reimbursement and financing structures, particularly for Medicaid? See <https://www.cms.gov/newsroom/fact-sheets/additional-backgroundsweeping-regulatory-changes-help-us-healthcare-system-address-covid-19-patient>

<sup>4</sup> “UIC engineers pitch in to ease shortage of protective gear for health workers: A face shield that can be made in 20 seconds” <https://www.chicagotribune.com/coronavirus/ct-protective-face-shield-hospital-chicago-20200326-6evh5w3y2zegplgk3bdxhs5yl4-story.html>.

Hand sewn face mask developed by and ER doc and his wife that incorporates a vacuum cleaner HEPA filter cutout. <https://www.youtube.com/watch?v=W6d3twpHwis>.

We thank you for your consideration of our suggestions and hope to hear from you soon. As health professionals, disability activists, and private citizens, know that we cannot proceed without the State's leadership and support. By working in partnership we believe we have the potential to create real solutions that can help save the lives of some of our most vulnerable citizens, as well as decompress the stresses of our first responders and acute health care system providers.

Respectfully submitted;



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