A message from Mike Thirtle, Ph.D.

While the United States has acted with speed and scale to support small businesses and our frontline health worker heroes in this COVID-19 crisis, a key group of heroes has been left behind: the health workers who provide essential supports to people with developmental disabilities and the nonprofit charities who make this work their mission.

I need your help to ensure they are not forgotten.

As background, there are more than 6 million Americans with developmental disabilities. They are vulnerable, need help to differing degrees and are supported by an existing social safety net. They also are at much higher risk for severe COVID-19. Like us all now, they feel loss because a beloved family member or friend can no longer come to visit, and hasn’t been able to for many weeks.

For many, understanding why is more difficult. They often live in homes with other people with disabilities, and they are a part of all of our communities. That today we see them as such is a testament to the progress and great humanity of our nation.

People with developmental disabilities are supported by Direct Support Professionals (DSPs). DSPs help the people they support however needed, every minute of their day. They have a deep commitment to making their lives the best possible. Our DSPs are motivated by professionalism and their love for the people they support. Their work is complex: they administer medications, perform tube feedings when needed and respond to urgent medical situations. They are working 24/7 in homes with people known or suspected to have COVID-19.

DSPs are saving lives by diligently doing the infection control work, maintaining separation where needed, and keeping homes clean and people healthy. Many DSPs are working extra hours to cover shifts lost to sick or unavailable co-workers. In this pandemic, our DSPs are heroes too.

As a nonprofit provider, Bethesda employs 2,000 DSPs and other frontline staff in 13 states, with more than 300 homes and programs. We value the people with disabilities we serve above all. To ensure their well-being in this crisis, we have supported our DSPs as much as possible through emergency actions that are both absolutely necessary and unavoidably costly. We – like hospitals – have had to buy and provide our teams with personal protective equipment. Critical staffing needs have necessarily led to significant labor cost increases. These emergency costs will continue until this pandemic abates.

Other good charities that share our mission are experiencing these same financial shocks. Together, we comprise a crucial part of our nation’s social safety net that is now at risk.

We need our nation’s help to survive. Our areas of focus include:

- A temporary 12 percent increase in the Federal Medical Assistance Percentage (FMAP) with some of the increase dedicated specifically for home and community-based services. State
Medicaid programs need additional federal funds to increase rates for frontline Medicaid providers to help offset the unexpected costs associated with keeping people with disabilities safe and healthy during the COVID-19 pandemic.

- Include temporary payments to DSPs and provide frontline essential health care worker incentives to maintain the frontline workforce. Providers for people with developmental disabilities, which historically have dealt with more than a 50% turnover rate, are struggling even more to maintain a workforce during the pandemic.
- Provide funding to not-for-profits of all sizes impacted by the COVID-19 pandemic and encourage charitable giving by allowing individuals to donate now and deduct it from 2019 taxes.
- Provide federal guidance that direct support professionals (DSPs) are considered essential health care workers. Ambiguity exists as to whether DSPs are considered essential under the general definition of “health care workers” found in the CARES Act. Clarification is needed to ensure that DSPs are included under the definition.
- Expand access to personal protective equipment (PPE). The federal government must take steps to secure an expansion of protective equipment for frontline caregivers, including DSPs.

In our request for support, we are joined by people with disabilities who are speaking up for themselves. Click here for a video message from Kurt Rutzen, Bethesda disability advocate.

Now, for my big ask: Please click here to visit the Bethesda Action Center, where within a minute or two you can directly ask your lawmakers to help. Acting today is essential. Please consider sharing this message with others as well.

As we work through this crisis together as a nation, I urge you to please remember our six million fellow Americans with developmental disabilities and their families, the organizations that help them, and the brave DSPs who are there for them every day.

Thank you.

Mike Thirtle, Ph.D., is President and CEO of Bethesda.