

COVID-19 has descended. To save lives and mitigate an imminent overwhelming of our country's healthcare system, we must shelter in place. But where does that leave for services to people with disabilities, especially for the many who must get this assistance to survive?

People with disabilities feel they have been left behind," announced Catalina Devandas, the UN Special Rapporteur on the rights of persons with disabilities, earlier this week. "Containment measures, such as social distancing and self-isolation, may be impossible for those who rely on the support of others to eat, dress and bathe."

What can governments be doing to facilitate continuity of vital services for people with disabilities during the current crisis? How can this be done in a way that minimizes disruptions to efforts to fight the virus through social distancing and containment? Here are a few measures governments around the world should take, if they haven't already:

Lift caps on worker overtime: Many jurisdictions limit the number of hours a support worker can deliver services, in order to avoid governments and providers having to provide overtime pay. In the United States, these restrictions have become increasingly common over the last several years, after the federal government required overtime pay for home care workers in 2015. Already, some states, including Massachusetts, have lifted overtime caps in response to the crisis.

Other jurisdictions should follow suit for self-directed services (where people with disabilities hire their own workers) and ensure reimbursement rates to agencies let them lift internal overtime caps. The virus is severely limiting the ability of people with disabilities and families to find workers. This can help make the existing workforce go further.

Permit Family Members to Serve as Support Workers: Different areas have radically different policies when it comes to paying parents, spouses and other family members to serve as support workers. Even many jurisdictions that do allow paying family caregivers restrict "legally responsible relatives" – like parents of minor children – from delivering services, for fear of compensating workers for things they would be doing anyway.

Whatever the merits of such restrictions in normal times, they must be lifted in light of the coronavirus. Containment measures are designed to limit contact between separate households. Any policy that makes it harder for people with disabilities to limit their contact with those outside their home is dangerous and will cost lives. People with disabilities are already at greater risk for complications emerging from infection.

Lifting restrictions on paying family caregivers, including legally responsible relatives, is a desperately needed emergency measure to protect a vulnerable population during the pandemic.

Authorize Reimbursement for Support Workers to Assist People with Disabilities in the Hospital: Despite our best efforts to protect those most at-risk, some people with disabilities will be hospitalized during the pandemic. Many people with disabilities, especially those with intellectual and developmental disabilities impacting communication and behavior, will require additional assistance to manage hospitalization. Hospitals are dangerous places for people with disabilities in the best of times – and during a pandemic, they will be all the more so.

People with disabilities are safer if they can maintain contact with familiar and longstanding support workers during a hospitalization. Typically, Medicaid law limits the ability of states to pay for community support workers while the person they serve is in a hospital. This policy should be relaxed in the crisis. While support worker access to hospitals will be dependent on infection risk considerations, wherever

possible, payment barriers should not preclude people keeping their regular support relationships in place, even during a hospitalization.

This approach will help keep people with disabilities safe and ensure that those who are familiar with them are ready to advocate for their rights and make their needs and preferences understood in the hospital environment.

Authorize Retainer Payments to Maintain Community Placements During Hospitalization: When people who use community-based services are hospitalized for long periods, a serious problem often emerges: their community services may disappear before they can come back. Since state Medicaid agencies typically cannot pay community providers at the same time someone is in a hospital, many people find themselves discharged only to learn that their personal care attendants have found other jobs or that their group home has filled their slot.

Governments should plan to use “retainer payments” to continue to pay community services providers while people with disabilities are in the hospital during the current crisis. Such an approach will ensure that people with disabilities will not be institutionalized as a result of a hospitalization depriving them of their usual provider relationships. Such an outcome could easily become permanent, as housing and services are very difficult to re-establish once lost.

Paid Sick Leave for Support Workers: Paid sick leave should be a right for all workers whose lives are being disrupted by this crisis. It is particularly important for workers delivering services to high-risk populations, such as people with disabilities. This will not only prevent support workers and their families from suffering economic hardship, it will help protect people with disabilities from contracting the virus, since their support workers will not feel pressured to work while sick and potentially infect them.

Avoid “Temporary” Institutional Placements: In prior crises, such as hurricanes and other natural disasters, people with disabilities in many states have been moved from the community into nursing homes and other institutional settings, ostensibly on a temporary basis. People with disabilities have a right to live in the community.

Governments should avoid any unnecessary use of institutional settings to house those displaced by the outbreak, even on a temporary basis. Too often, such “temporary” placements become permanent ones through simple inertia. If this option is used, governments should articulate a plan for returning individuals to the community and ensuring individuals do not lose their community provider relationships in the process.

Ensure Continued Oversight of Congregate Settings: New CDC guidance for nursing homes now restricts all visitation except for end-of-life situations. Many other institutional and congregate care settings have also severely restricted visitation from any external family or friends. People with disabilities in these settings face a double risk: not only does the congregate environment increase the possibility of infection, particularly as many nursing facilities have lax infection controls, but the isolation from external oversight may also increase the risk of abuse and neglect.

To address this, governments should classify as “essential persons” – authorized to enter nursing homes and institutions even amidst visitation restrictions – those who have ongoing rights protection obligations. For example, [Oregon’s March 10th guidance](#) regarding nursing homes explicitly permitted Long Term Care Ombudsman and Adult Protective Services staff to continue to visit amidst restrictions.

On all of these matters, governments must take action swiftly. In the United States, the federal government explicitly allows states to authorize many of these changes (including retroactively) through

[Appendix K of the 1915\(c\) waiver](#), a special component of one of the United States' main vehicles for funding community-based disability services that can be invoked by states in emergency situations. In other countries, governments should make sure their own declarations of emergency include measures specifically designed to ensure the continued safety, survival and rights of people with disabilities.

We are in a time of unprecedented crisis, beyond anything any of us have seen before in our lifetimes. As the world scrambles, it is our sacred responsibility to ensure that people with disabilities are not left behind.

Ari Ne'eman is a Visiting Scholar at the Lurie Institute for Disability Policy at Brandeis University and a doctoral student in Health Policy at Harvard University. From 2006 to 2016, he served as executive director of the Autistic Self Advocacy Network.