

OPINION, VIEWPOINT

How governments should maintain disability services during the pandemic

BY ARI NE'EMAN

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COVID-19 has descended. To save lives and mitigate the burden on the U.S. healthcare system, we must shelter in place.

But where does that leave people with disabilities, especially the many who need special services and service providers to survive?

To contain the pandemic, governments have, for good reason, promoted containment measures such as sheltering in place and social distancing — staying away from other people to avoid spreading infection. But as Catalina Devandas Aguilar, the United Nations' special rapporteur on the rights of persons with disabilities, **said last week**, these measures “may be impossible for those who rely on the support of others to eat, dress and bathe.”

People with disabilities are already at greater risk for complications emerging from infection. There is a lot that governments can do to ensure that vital services remain available to them even during this crisis.

As a disability rights advocate who has spent the past 15 years working on public policy regarding disability services, I believe governments can save lives if they take certain simple steps.

In the United States, the declaration of a national emergency **allows states to authorize** many changes, and to do so after the fact — meaning that states often need not wait for permission to proceed. In other countries, governments should make sure their own declarations of emergency include measures to ensure the safety, survival and rights of people with disabilities.

Lift caps on worker overtime: Many U.S. states limit the number of hours a support worker can deliver services, to prevent governments and providers from having to pay overtime wages. These restrictions have become increasingly common over the past several years.

Some states, including **Massachusetts**, have lifted overtime caps in response to the crisis, and others should follow this example.

Other governments should also follow suit for self-directed services — in which people with disabilities hire their own workers — and adjust the rates for reimbursement to agencies to ensure payment for overtime work. The pandemic is severely limiting the ability of people with disabilities to find service providers. Lifting these restrictions can help the existing workforce provide service to those who need it.

Permit family members to serve as support workers: Different states and countries have diverse policies when it comes to paying parents, spouses and other family members to serve as support workers. Even those that do allow this practice often restrict ‘legally responsible relatives’ — such as parents of minor children — from delivering services, to avoid compensating them for things they might be doing anyway.

Whatever the merits of such restrictions in normal times, governments must consider lifting them during this pandemic.

For the next several months, any policy that forces people with disabilities to have unnecessary contact with those outside their homes will expose them to greater risk in the midst of the pandemic. Given that risk, lifting restrictions on paying family caregivers, including legally responsible relatives, is a desperately needed emergency measure.

Authorize reimbursement for support workers in hospitals: The people hospitalized during the pandemic are likely to include many with disabilities, because some disabilities increase the odds of medical complications from the virus.

Many of these people — especially those who have intellectual and developmental disabilities that affect their communication and behavior — will need help to manage their hospital stay. Many struggle to make their communication understood or are more likely to have meltdowns or outbursts that could lead to restraint if they do not have access to a familiar support person.

People with disabilities will be safer in hospitals if they can maintain contact with familiar and longstanding support workers. State governments typically prohibit paying community support workers while the person they serve is in a hospital. They should relax this policy during the pandemic.

Authorize retainer payments to maintain community placements: When people who use community-based services, such as attendant care or supported-living services, are hospitalized for long periods, their community services may lapse before they come home. 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 with someone else.

These outcomes could easily become permanent, as housing and services are difficult to reestablish once lost and could result in the person with the disability becoming institutionalized.

Governments should plan to use ‘retainer payments’ to pay community-based service providers while people with disabilities are in the hospital. This approach would prevent people with disabilities from being institutionalized when they leave the hospital.

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 also help protect people with disabilities from contracting the virus, because their support workers will not feel pressured to work while sick.

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. But too often, these ‘temporary’ placements become permanent ones through simple inertia.

People with disabilities have a right to live in the community.

Governments should avoid institutional settings to house those displaced by the pandemic, even on a temporary basis. If they do use this option, they should articulate a plan for returning individuals to the community and ensuring that they do not lose their community provider relationships.

Ensure continued oversight of nursing homes, group homes and institutions: Guidance from the U.S. Centers for Disease Control and Prevention **restricts all visitation** to nursing homes except for end-of-life situations. Many other institutions, group homes and other group residences have also severely restricted visitation from family and friends.

People with disabilities in these settings face a double risk: the increased possibility of infection, and the risk of abuse and neglect as a result of lax external oversight.

To mitigate these risks, governments should allow people responsible for protecting the rights of the residents to enter them even during the pandemic, as **the state of Oregon** has.

All of these changes must happen as quickly as possible to save lives during this pandemic.

We are in a time of unprecedented crisis, beyond anything any of us have seen 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 in Waltham, Massachusetts, and a doctoral student in health policy at Harvard University. He served as executive director of the Autistic Self Advocacy Network from 2006 to 2016.