

## **COVID-19 Impact on People with Intellectual and Developmental Disabilities, their Families, and the Direct Support Workforce**

### **Briefing Paper**

The current Coronavirus pandemic poses an even greater risk to people with I/DD than it does to people without disabilities. People with I/DD are more likely to have underlying health conditions that leave them more susceptible to the pandemic and, unfortunately, if they cannot be adequately supported living in the community, they are at high risk of ending up in nursing homes, state institutions, and other congregate settings which have been at the heart of the disease spreading. Their caregivers, including both family caregivers and the workforce that supports them, provider agencies, are being stressed in many ways. Direct Support Professionals (DSPs) that work with people with disabilities supporting them at work, home and in the community are often providing supports that simply cannot be done from 6 feet away. DSPs face many of the same challenges and risks currently being experienced by health care workers, yet this vital workforce does not have access to the personal protective equipment (PPE) and the supplies needed to safely serve individuals with I/DD who are quarantined or sheltering in place.

As COVID-19 cases increase and spread throughout the country, U.S. health officials are predicting that there may not be enough ventilators, medical equipment, hospital beds, or health care personnel to meet the demand of patients with the virus who require intensive treatment. Some states and cities are already experiencing a shortage, and health care professionals and state officials have begun developing and updating protocols to determine who will and will not have access to life-saving COVID-19 treatment in the event care rationing becomes necessary. Disability advocates have expressed grave concerns that the plans being put in place discriminate against people with disabilities in violation of federal disability rights laws and place their lives at serious risk.

The Arc has gathered information from our constituents to better understand the challenges people with I/DD, their families, our chapters, and other provider agencies are facing.

**Major challenges** we have identified to date, include:

- The DSP workforce and service providers are struggling to find necessary Personal Protective Equipment (PPE) to keep staff and individuals with disabilities safe. Like healthcare professionals, DSPs are doing essential work, yet don't have access to needed supplies.
- Individuals with I/DD are struggling with a loss of services that support their being included in their communities. People with disabilities are being further isolated under circumstances they may not fully understand or manage without necessary physical, emotional, and behavioral support. Students with disabilities are struggling to participate in remote schooling, without necessary accommodation and supports. Increased isolation and stress also are contributing to a higher risk of violence and abuse.

- Day Supports – There are more than 620,000 adults with I/DD who receive day program and employment services, and thousands more that qualify but are not currently in service. In most states, all day programs are now closed; other states are likely to follow suit. People with I/DD are being isolated in their place of residence. This includes group homes for some, and the family home for many more. Chapters of The Arc and the DSP workforce are struggling to continue to support those individuals remotely so that they continue to have a meaningful way to spend the day and families are struggling to fill in the gaps for support, if they are able.
- Residential Supports – There are more than 680,000 adults with I/DD who live in some type of supported housing, more than 790,000 who live alone or with a roommate, and thousands more who are eligible for services, but are on waiting lists. For people with I/DD who live in a group home or other supported residence, as well as those living alone, they are now sheltering in place. Chapters of The Arc and other providers are struggling to serve those residents 24/7, including supporting their understanding of the pandemic, meeting their daily needs, including personal care, providing meals and providing for health and safety.
- Family Supports – More than 3.6 million individuals with I/DD live in their family homes. Due to the closure of many of the day supports and of schools, family caregivers are having to leave their jobs and stay home with their family members with I/DD who can't be left home alone. Many family members are struggling to provide adequate support without additional help and are unable to leave home to purchase groceries, pickup medications, or needed supplies. They struggle too with many of the same challenges and risks as the paid caregivers in group homes, in terms of safety, emotional and behavioral support, and meeting basic human needs. Family caregivers are also experiencing job loss and unemployment, undermining their financial capacity to provide care and support for loved ones with I/DD.
- Hospital Treatment – Many people with I/DD and their family members are afraid of how they will be treated if they are hospitalized. Given discriminatory provisions in state health department and hospital planning documents, they are concerned that in the event of shortages they may be denied access to ventilators, medication or other life-saving treatment. They have question about absence of supports needed to effectively communicate with their medical providers. Due to the need to contain the spread of the virus and the PPE shortage, family members, DSPs, and other similar disability service providers may not be allowed in the room with the patient to assist in communicating with medical professionals making critical treatment decisions.

**Major needs** identified from the field include the following:

- Access to Services and Supports
  - Additional workforce to support people with disabilities in their homes and communities, to prevent unnecessary institutionalization.
  - Virtual training opportunities for incoming workforce so that they can be informed and deployed efficiently.
  - Individuals with I/DD, families with low-incomes, and providers report need for iPads, laptops, and similar technology to allow remote supports and services, and communication between people with I/DD and caregivers

- Individuals with I/DD, families with low-incomes, and providers report lack of internet access needed for use of remote communications technology
- Need for quality, online, interactive programming to support and engage individuals who are isolated
- Need for resources that promote engagement and/or that relieve anxiety from social distancing and isolation
- Preventing Discrimination in Treatment Rationing
  - Need for education and advocacy directed to states and hospitals to understand their obligations under federal disability rights laws in creating treatment rationing plans.
  - Individuals with disabilities, their families, DSPs, and other disability service providers and advocates need to be educated about their right to receive treatment in a non-discriminatory way.
  - Need for access to lawyers to address discrimination against people with disabilities in rationing of ventilators, medications and treatment
- Workforce Safety and Adequacy
  - Agencies report impending shortages of Personal Protective Equipment (PPE) needed for direct support workers
  - Agencies report not having access to necessary medical supplies to safely quarantine individuals with disabilities as the need arises.
- Access to Food and other Grocery Items
  - Group home/supported living providers unable to secure sufficient groceries to feed residents and staff for 3 meals/day, and necessary supplies (e.g. food, including food for special diets, incontinence supplies, paper goods, supplemental nutrition products)
  - Family caregivers unable to pick up school meals from local authorities
  - Family caregivers unable to leave homes to obtain food, medication, or supplies
  - Family caregivers unable to secure other supplies (e.g. gloves, hand sanitizer, toilet paper, disposable underwear, blue pads, adult diapers, paper goods, supplemental nutrition products, specialized nutrition products)

To further illustrate these needs, issues and concerns, the following are links to select recent media articles:

Washington Post - [A time of unprecedented fear for parents of adults with intellectual and developmental disabilities](#)

ProPublica - [Intellectual Disability Service Providers Want to Protect Clients. The State Isn't Telling Them How.](#)

The Atlantic - [Americans With Disabilities Are Terrified](#)

Washington Post - [Low-income communities might fall through coronavirus stimulus package gaps](#)

Vox – [We're Being Punished Again](#)

New York Times – [‘It's Hit Our Front Door’ – Homes for Disabled See a Surge of Covid-19](#)

## The Arc and Disability Community Partners Respond

While these are extraordinarily difficult times, across the nation chapters of The Arc continue to advocate with and on behalf of people with I/DD and their families and to provide the services and supports they depend on to support their daily existence. We believe that the issues and needs described above can be successfully addressed through a combination of aggressive public policy advocacy at the federal, state and local level, inclusive grassroots organizing, increased investment in and expansion of program and services for people with I/DD and their families, and program innovation.

The Arc's federal policy, communications, organizing and mobilizing, media relations, and chapter relations teams have been working overtime advocating to Congress and the Administration, educating our constituents, and supporting our chapters to make sure that people with disabilities, their families, our chapters, and direct service providers are not left behind in this crisis. Our legal advocacy team is working to ensure that the rights of people with disabilities and the value of the lives of people with disabilities are respected in the face of this pandemic. State chapters of The Arc are advocating to their state Governors, legislators and developmental disabilities agencies on issues of state policy, program funding and implementation.

Progress is being made. The Arc has been instrumental in assuring the three Coronavirus relief bills enacted into law, which benefits all Americans, also include some provisions needed to address circumstances which are unique to people with I/DD and their families. Overall, however, the recently enacted stimulus bill largely overlooked many critical needs of people with disabilities, their families, provider agencies and the direct support workforce.

Given that the challenges faced by people with disabilities and their families received only scant attention in the initial legislative response to COVID-19, The Arc developed and launched the [#WeAreEssential](#) campaign to call attention to these unmet needs. The campaign includes a call for videos from people with disabilities, their families, the workforce and service providers so that the needs of the disability community are seen at the local, state and federal level. The campaign includes action alerts, several graphics and sample articles to be placed in local news. While developed for our chapter network, we have been pleased to see the campaign gain traction in both social media and traditional media.

On April 1<sup>st</sup> and 14<sup>th</sup>, respectively, The Arc and our partners scored major victories, successfully arguing to the Treasury Department to automatically issue Recovery Rebate payments to people with disabilities who receive Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits, abandoning the requirement that they file tax returns or other needless paperwork. Other important issues remain to be addressed.

The Arc, individually and as leaders in several large coalitions, is advocating for a 4<sup>th</sup> Coronavirus relief bill to include:

- **Funding for a Medicaid grant program** to support access to home and community-based services (to combat institutionalization) and to support the DSP workforce, provisions included in the proposed Coronavirus Relief for Seniors and People with Disabilities Act.
- **Personal protective equipment (PPE)** for direct support professionals. This is urgently needed to protect the health and safety of this critical workforce. Direct support professionals must be

designated as essential workforce so that they have access to the PPE and medical supplies they need.

- **Paid leave for caregivers.** As more people with disabilities lose their usual sources of care, family caregivers are scrambling and need access to paid leave and sick days to help their loved ones. Congress should include all family caregivers in the emergency paid leave provisions.

Outside the legislative arena, a major issue has arisen about equal access to healthcare for people with disabilities, as states, health systems and hospitals prepare for possible treatment rationing. The Arc's legal advocacy team, working in collaboration with other disability rights groups, has been instrumental in securing guidelines from the Office for Civil Rights of the U.S. Department of Health and Human Services clarifying that the nation's civil rights laws are not suspended during a pandemic. Hospitals, healthcare providers, and state governments, among others, may not discriminate against people with disabilities in the course of rationing of ventilators, medications, or other health care treatment.

On April 3rd, The Arc and our partners issued critical guidance to states and healthcare providers about how to avoid discriminating against people with disabilities if rationing access to COVID-19 treatment becomes necessary, which has since been endorsed by 90 national disability and health organizations.

At the state-level, The Arc's state chapters have been instrumental in advocating for the necessary flexibility and innovation in program funding and services to allow people with I/DD to continue to receive the services they need, to assure developmental disability provider agencies don't go out of business, and that a robust workforce is available to provide services. Local chapters, of course, continue to be on the frontlines, delivering services and meeting community needs, day in and day out.

Perhaps needless to say, this pandemic is not over and there still is a lot of work to do. Over the past several weeks, through our #WeAreEssential Campaign, The Arc has mobilized tens of thousands of people with disabilities and family members to implore their Members of Congress that when they return from the Congressional recess next month, they must address these unmet needs. We are going to have to be a lot louder in the coming weeks, as we face the grim reality of this virus spreading further, putting the health, wellbeing, and lives of people with disabilities, their family members, and direct support professionals on the line. We invite you to join with us.

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The Arc is the nation's largest and oldest nonprofit federation advocating on behalf of and providing services and supports to people with intellectual and developmental disabilities (I/DD). Our constituents include people with a variety of needs and conditions, such as Down syndrome, Autism Spectrum Disorder, Intellectual Disability, Fragile X Syndrome, Cerebral Palsy, Fetal Alcohol Spectrum Disorders, as well as the family members and organizations which support them. The Arc serves people with disabilities through our network of more than 600 chapters in 47 states and the District of Columbia. Our mission is to promote and protect the human rights of people with I/DD and actively support their full inclusion and participation in the community throughout their lifetimes.

Editor's Note: The Arc is not an acronym; always refer to us as The Arc, not The ARC and never ARC. The Arc should be considered as a title or a phrase.

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