



June 1, 2020

Dear Director Snyder, Director Christ, Director Wisehart and Acting Assistant Director Ramadan:

The Arizona Developmental Disabilities Network and The Arc of Arizona recently conducted a survey of individuals with intellectual and developmental disabilities (I/DD) who require support, their families, and the organizations that serve them. The purpose was to discover how this group is adjusting as life returns to normal after the end of Governor Doug Ducey's stay at home order. Attached are the key findings of this survey. The full report is also available by request. In addition, we conducted a meeting with community members on May 26 to discuss COVID-19 issues related to cultural and linguistic competency. Key findings of both of these activities follow:

- The vast majority of the I/DD community is uncomfortable with returning to their everyday routines. Their biggest concerns are people not social distancing, thereby placing individuals with disabilities at greater risk of exposure to COVID-19.
- There is a fear that people will be forced to resume routine activities outside of the home when they still do not feel safe. They ask that expanded options currently available (e.g., telehealth, 720 hours of respite, paying family members to serve as caregivers of children) continue until the pandemic is over.
- Most have said they will wash their hands more frequently and practice social distancing as a result of COVID-19. Others felt that there weren't enough guidelines given in plain language for families to teach their children and adults with I/DD how to stay safe and reinforce best practices.
- There continues to be a lack of clarity for how day programs should resume operations and residential programs should operate when members become ill.
- The majority of our sample routinely interacted with more than 10 people at a time before COVID-19. Individuals and families were concerned about the availability of testing and the rising number of cases and fatalities. With a lack of COVID-19 data currently available on individuals with I/DD or any disability, it is difficult to trace or track how effective current prevention efforts are for an already compromised group. Individuals were fearful due to so many unknowns.
- Currently, the only consistent method of communication from state agencies for families are weekly town hall sessions from the Division of Developmental Disabilities (DDD) conducted via teleconference calls. Participants asked for

quicker and better communication, from DDD in particular, and greater enforcement overall to ensure public health guidelines are followed.

We have also been told that deaf members with I/DD are not consistently able to access certified deaf interpreters. It is important that these options always be offered to deaf members, as some don't understand American Sign Language (ASL). In addition, members who are blind have greater anxiety about returning to public settings in the event others don't social distance; however, there are social networks available online to support this community.

Finally, we continue to struggle to ensure people with I/DD and family members receive information in an understandable format and in their native languages to make them feel safer or help them follow guidelines to make others feel safer. Some families do not have the internet or the knowledge to find needed information on agency websites or social media platforms.

A recent international [study found](#) that COVID-19 appears to present a greater risk to people with I/DD, especially at younger ages. It is critical we work together to develop and share more frequent information in plain language and other accessible formats on topics requested by our community to keep them safe. These subjects could include any changes to agency policies or practices, keeping yourself safe, what to do if others you talk to are sick, what to do if your loved one can't follow guidelines, and what to do if you or your loved one is feeling unsafe, overwhelmed or anxious. Having a solid communication plan to reach our entire community will not only help throughout this pandemic, it will also help set up a communication blueprint for future emergencies.

We thank you for the work all of your agencies have done so far. This situation is unprecedented and none of us has all of the answers. But at a time of great uncertainty, we hope you consult with us to ensure no one is left behind. We look forward to your response.

Sincerely,

Erica McFadden, Executive Director, Arizona Developmental Disabilities Planning Council

J.J. Rico, Chief Executive Officer, Arizona Center for Disability Law

Wendy Parent-Johnson, Executive Director, Sonoran University Center for Excellence in Disabilities, University of Arizona

Kelly Roberts, Executive Director, Institute for Human Development, Northern Arizona University

Therese Yanan, Executive Director, Native American Disability Law Center

Jon Meyers, Executive Director, The Arc of Arizona

cc: Christina Corieri, Senior Policy Advisor, Office of the Governor