Via Email

July 29, 2020

The Honorable Doug Ducey
Governor of Arizona
1700 West Washington Street
Phoenix, AZ 85007

Dear Governor Ducey:

In honor of the Americans with Disabilities Act's (ADA) 30th anniversary and in light of the lessons learned from COVID-19, the American Civil Liberties Union (ACLU) of Arizona, The Arc of Arizona, Arizona Center for Law in the Public Interest, Arizona Center for Disability Law, Native American Disability Law Center, and Living United for Change in Arizona write to ask the Governor's Office to work with stakeholders to institute measures that will save the lives of some of the most at-risk members of our communities and the people who care for them.

Since President George H.W. Bush signed this important civil rights law, people with disabilities have seen improved access to important programs and services, and many have successfully advocated for their rights. However, despite all of our success as a nation, people with disabilities still experience discrimination, especially those living in nursing homes and assisted living facilities.

We urge the Governor's Office to swiftly enact policies to safeguard the health and safety of residents within institutional settings, to reduce the number of people in nursing homes and other congregate facilities for people with disabilities by transitioning them into community life, and to support and protect essential workers who care for seniors and people with disabilities regardless of setting. In order to achieve that critical transition from institutions to the community, Arizona must also prioritize efforts to support healthcare workers, paid care givers, and other essential employees who sustain people with disabilities who rely on home and community-based services.

In this letter, we outline the following steps that will help achieve these goals and urge you to implement these actions as soon as possible:

- Further strengthen and prioritize community-based services by:
  - Continuing to prioritize and expanding home and community-based services programs;
  - Assessing the status of residents in psychiatric inpatient facilities;
  - Granting advocacy organizations access to facilities;
  - Supporting family members providing care.

- Protect residents in nursing homes and other large congregate facilities by:
  - Expanding data collection and transparency;
  - Conducting on-site monitoring for abuse and neglect.

- Support direct service professionals and workers in congregate facilities by:
    - Providing personal protective equipment for workers;
    - Providing paid leave to workers in all settings;
    - Increasing worker pay and providing alternative housing.

These action steps are needed more than ever because of the pandemic. COVID-19 is raging through nursing homes and long-term care institutions across the country and recent reports indicate that more than 54,000 residents and workers have died as a result,[i] accounting for more than 40 percent of all deaths in the United States.[ii] These statistics have shocked not only the healthcare community, but individuals and loved ones who live and work in these facilities. Arizona has not been spared; we have seen at least 471 deaths among nursing home residents, and many COVID-19 deaths in the state are attributable to long-term care settings.[iii] As of the date of this letter, there are 812 congregate setting facilities across the state with cases of COVID-19, with many occurring in Assisted Living Facilities and Long-Term Care Facilities.[iv]

Segregated institutions are dangerous and unhealthy for both residents and staff, and the pandemic's impact on nursing homes reaffirms that without certain protective measures and enforcement, many vulnerable individuals are at risk. This view applies with equal force to other congregate institutions — intermediate care facilities for people with developmental and intellectual disabilities, psychiatric hospitals, and large group homes — for which we have insufficient data but where workers' and residents' risk of infection and death may be just as high. Because of the intimate nature of the work required in many congregate settings — assistance with feeding, bathing, dressing, and toileting — social distancing between staff and residents is impossible, and social distancing is impossible between residents who share a room. As a result, frontline workers, who are disproportionately women of color and immigrants, are at high risk of contracting COVID-19 and spreading it within their families and communities, which makes this issue not just a disability rights issue, but a race and gender issue as well. By taking the following crucial actions, you will help to safeguard the lives of people with disabilities, the workers who care for them, and the many Arizona families of both residents and staff.

A. Further Strengthen and Prioritize Community-Based Services

Arizona has a history of committing to Home and Community-Based Services (HCBS). When the pandemic began, the Arizona Health Care Cost Containment System's (AHCCCS) Medical Director was at the forefront and applied for numerous waivers to prepare for the care and treatment of those who would be affected by the pandemic. However, additional waivers would further combat COVID-19 and improve outcomes for people with disabilities.

Given the longstanding obligation under the Supreme Court's *Olmstead* decision to move people from institutions to the community,[v] and given the heightened public health hazard that these congregate settings are proving to be for residents and the workforce, the state must step up its efforts to reduce the number of people in

nursing homes and congregate facilities for people with disabilities. We urge the Governor's Office to take the following steps.

1. Continue to Prioritize and Expand HCBS

According to the latest available data, Arizona devotes 70 percent of its Medicaid Long-Term Services and Supports expenditures on HCBS, more than nearly every state.[vi] It is clear the state recognizes the importance of HCBS programs in helping people with disabilities and seniors live in their homes and communities, rather than institutions. HCBS services are especially important during and after the pandemic, which has made the dangers of institutional life even more clear. These funds are necessary to sustain the workforce that supports people with disabilities, the service providers that employ that workforce, and the people with disabilities who rely on those services to live safely in their homes and communities. States across the country, including Arizona, have sought approvals from the U.S. Centers for Medicare & Medicaid Services (CMS) for section 1915(c) waiver Appendix K changes that have made it easier to access home and community-based services. However, Arizona did not take full advantage of these flexibilities, including increasing payment rates. It should do so. Other options, such as Community First Choice waivers, alternatives to hospitalization like "Hospital at Home" programs,[vii] emergency personal assistance registries, and cohorting in alternative housing while transitioning to the community,[viii] should also be used to supplement HCBS in order to reduce the institutional population.

Additionally, to assist Arizona in providing HCBS services, you should encourage the state's U.S. Senators to support Federal Medical Assistance Percentage (FMAP) increases in the next COVID-19 relief package that Congress will likely pass, including an HCBS-specific FMAP increase in order to defray the cost of these programs and avoid cuts in the future.[ix]

2. Assess the Status of Residents in Psychiatric Inpatient Facilities

Aggressive action is necessary to reduce the number of people confined in inpatient facilities across the state, including the Arizona State Hospital (ASH), which, according to recent reporting, has not adequately prepared for COVID-19 and consequently suffered an outbreak.[x] Earlier this month at ASH, 114 cases of COVID-19 were reported with one death.[xi] Officials at ASH and other inpatient facilities should require the facilities to certify and report immediately that they have engaged in an individualized assessment and re-evaluation of residents under their care in order to assess who can be discharged and what supports are required to live in the community. Officials should also ensure adequate supplies of PPE and verify that all staff members have adequate training.

Our recommendations on inpatient facilities include any facilities that house juveniles as well, such as Mingus Mountain Academy (Mingus) which "is the site of one of the largest outbreaks at a child rehabilitation center in the country."[xii] Mingus is a licensed residential facility that provides mental and behavioral health treatment for teenage girls. In mid-May more than half of the children housed at Mingus and at

least 20 staff members were infected with COVID-19.[xiii] Patients, family members, and staff deserve immediate action to improve the current situation at inpatient facilities at every level in Arizona.

The federal government's Substance Abuse and Mental Health Services Administration (SAMHSA) has urged, with respect to admissions, that "[b]ecause of the substantial risk of coronavirus spread with congregation of individuals in a limited space such as in an inpatient or residential facility… outpatient treatment options [should] be used to the greatest extent possible. Inpatient facilities should be reserved for those for whom outpatient measures are not considered an adequate clinical option, i.e., for those with mental disorders that are life-threatening, (e.g., the severely depressed suicidal person)."[xiv] This standard must be applied in all psychiatric inpatient facilities until testing of patients and staff is widely done and safe isolation practices and social distancing protocols are in place.

Additionally, discharges should be accelerated. To facilitate a decrease in the psychiatric inpatient population, the state should increase its support of community providers of outpatient mental health treatment. Restrictions on telemedicine have largely been lifted. However, community providers, already strapped before the pandemic, need additional funding and greater access to technology and PPE. Ensuring robust community-based crisis treatment, community supports, and integrated housing settings will reduce the need for psychiatric hospital and other inpatient facilities admissions and enable more patients to safely return to their communities, which is also in line with the ADA and the *Olmstead* decision to eliminate segregation and to provide the most integrated setting based on an individual's needs.[xv] Moreover, in many cases, families will offer to temporarily house and care for relatives being discharged from or not admitted to an inpatient facility. More families will do so if support is available from community providers.

Given the urgency of the situation, we ask that your office provide an expedited public report on the steps that have already been taken or that will be taken to address these concerns on behalf of people confined at inpatient facilities throughout the state.

3. Grant Advocacy Organizations Access to Facilities in Order to Assess Residents' Ability to Transition into the Community

Many nursing homes have instituted lockdowns that prevent family members and advocacy groups from gaining access to residents. While this measure may be necessary to limit transmission of infections, Arizona should not block Protection and Advocacy agency staff who have access authority to investigate and monitor settings with people with disabilities.[xvi] The state must grant immediate access to Independent Living Center staff, members of the Long-Term Care Ombudsman Program, and others with expertise in transitioning people from institutions to the community, so that they may speak directly to all residents in congregate facilities, either in-person (with appropriate PPE provided) or via videoconference, to offer assistance for relocating and an assessment of each person's desire to move to a safer location, either temporarily or with the option to make a permanent transition to the community.[xvii]

4. Support Family Members Providing Care

Family caregivers play a central role in helping seniors and people with disabilities live in their homes and communities, rather than institutions. For instance, 80 percent of people with an intellectual or other developmental disability live with a caregiver who is a family member.[xviii] And more than 40 million family caregivers provide unpaid care each year.[xix] But the economic, logistical, and health challenges faced by caregivers are only exacerbated by COVID-19, especially as infection spreads and creates new caregiving needs. While Arizona has elected in its Appendix K waiver request to allow spouses and parents of minor children to provide personal care services, it should expand the ability for family members other than spouses and parents to be paid for caregiving responsibilities.

B. Protect Residents in Nursing Homes and Other Large Congregate Facilities for People With Disabilities

5. Expanded Data Collection and Transparency

We recommend improved reporting so that those affected by these issues can make better decisions to control and limit COVID-19 infections and prevent deaths. The recent CMS rule requiring collection and dissemination of information from nursing homes was a great step in the right direction.[xx] That mandate, however, was incomplete. It only requires reporting from May 2020 forward, and excludes the preceding months when COVID-19 was officially declared a pandemic. We need data about all deaths and for all reasons from the start of the calendar year. The CMS data collection also does not mandate reporting on other types of congregate settings for people with disabilities, including assisted living facilities, of which Arizona has more than 2,000.

Arizona's state-run data collection and transparency effort with regard to congregate settings needs improvement, displaying on its Data Dashboard a total number of settings with confirmed COVID-19 cases, broken down by county, setting type (including an unexplained "other"), and cases by week. There is no facility-level data, nor data on the number of cases and deaths among residents and staff, or any type of demographic data. The Division of Developmental Disabilities (DDD) is reporting cases and deaths for individuals in Licensed Residential Setting, with no other detail. There is no public information about the status of COVID-19 in ASH and other psychiatric inpatient facilities.

Across the nation, disability rights and workers' rights groups have been sounding the alarm about the lack of attention and resources devoted to residents and workers in these facilities[xxi] and we join them in expressing grave concern. Nationally, available data suggest that case fatality rates in intermediate care facilities for people with developmental disabilities, group homes, and psychiatric facilities are also far higher than for the general population.[xxii] The hundreds of people in ASH[xxiii] and psychiatric inpatient facilities, Intermediate Care Facilities,[xxiv] and approximately 1,500 ICF/IDD recipients living in group homes for more than four people[xxv] are at

heightened risk. The crisis requires more public data, transparency, and swift and concerted action by government leaders.

Therefore, we urge the Governor's Office to enact the following measures: release to the public the state's plan to address COVID-19 in long-term care facilities, ensure that all nursing homes are complying with required data collection, require all congregate facilities for people with disabilities, *not just nursing homes*, to report to the Arizona Department of Health Services (ADHS) information about facility COVID-19 policies/protocols/plans, testing, PPE supplies, staffing levels, discharges and evictions, positive cases and deaths of residents and workers in each facility.[xxvi] Failure to require comprehensive data conceals from the public the full scope of the problem, and thwarts critical attempts to design and implement policies that will protect seniors, people with disabilities, and the people who care for them.

Data for all these facilities must be publicly available and posted on ADHS' COVID-19 dashboard, and include demographic breakdowns by race, ethnicity, sex, primary language, disability status, and age for infections, deaths, discharges, and evictions. As of today, Arizona data on race and ethnicity is "unknown" for 48 percent of reported infections across the state.[xxvii] This must be addressed as well.

The effect of COVID-19 has landed disproportionately on people with disabilities, women, and Black, Indigenous, and Latinx people. Recent reporting shows that while about 14 percent of nursing home residents nationally are Black and five percent are Latinx,[xxviii] nursing homes with predominantly Black and Latinx residents — regardless of government rating, size or location — "were twice as likely to get hit by the coronavirus as those where the population is overwhelmingly white."[xxix] Race and ethnicity data that we do have for Arizona underscores this point, particularly for Indigenous people. In Maricopa County, for instance, they are hospitalized at more than twice the rate of any other group.[xxx] And while race and ethnicity data is not known for about 10 percent of the state's deaths, 18 percent have been Indigenous people,[xxxi] which make up about five percent of the state's population.[xxxii] Notably, the Navajo Nation once had the highest infection rate in the country,[xxxiii] and its 441 confirmed deaths[xxxiv] are more than have occurred in 16 states.[xxxv]

All nursing home residents are people with disabilities, and nearly 70 percent are women.[xxxvi] As we detail below, the workforce in Arizona caring for people in nursing homes and other congregate settings for people with disabilities consists disproportionately of women of color. More robust demographic reporting is needed to determine how COVID-19 is disproportionately affecting these overrepresented populations.

6. Conduct On-Site Monitoring for Abuse and Neglect

Residents of nursing homes and other congregate facilities for people with disabilities face a heightened risk of abuse and neglect during the pandemic, when their families and friends outside the facility cannot maintain the same level of in-

person contact they would ordinarily enjoy. However, preventing the spread of COVID-19 should not mean that we ignore abuse and neglect. Your recent new grant program to help facilities purchase videoconferencing devices[xxxvii] is helpful in this regard, so families can see the physical condition of their loved ones and have a better chance to know when abuse and neglect is occurring. But we urge you to do more. Specifically, we urge state agencies like DDD and Adult Protective Services (APS) to conduct routine, on-site monitoring of facilities, with appropriate PPE provided. Granting advocacy organizations access, as described above, will help deter and uncover abuse and neglect when it occurs.

C. Support Direct Service Professionals and Workers in Congregate Facilities Who Care for Seniors and People With Disabilities

Arizona must do all in its power to meet the needs of essential workers who, at great risk to themselves, their families, and their communities, are showing up every day to care for and assist vulnerable seniors and people with disabilities. Nationally, nearly 90 percent of nursing, psychiatric, and home care aides in the United States are women[xxxviii] and 23 percent are immigrants.[xxxix] Black women are over-represented in the congregate care workforce.[xl] And overall, the majority of women working as home health and personal care aides are women of color whose economic security is already precarious due, in part, to systemic racism that has long devalued caregiving[xli] and fueled poverty-level wages.[xlii] In Arizona, these figures are similar: 9 in 10 home-care workers are women, more than half are people of color, a third are Hispanic or Latinx, and a quarter are immigrants. Their median annual earnings are $14,600 and nearly half rely on public assistance.[xliii] All workers in the state deserve greater workplace benefits and protections but during this pandemic, the state should step forward and prioritize the needs of these essential frontline workers.

1. <u>Provide Personal Protective Equipment for Workers</u>

Arizona must ensure that direct service professionals providing HCBS *and* workers in congregate facilities have the necessary supply of PPE including gowns, N95 facemasks,[xliv] gloves, hand sanitizers, and eye protection (i.e. face shields or goggles).[xlv] The PPE shortages experienced by nursing homes have been well documented[xlvi] but the situation facing workers in other settings is dire[xlvii] and must be prioritized. Without innovative and aggressive action to procure PPE, seniors, people with disabilities, and workers and their family members will be at grave risk of infection, illness, and even death.

2. <u>Provide Paid Leave to Workers in All Settings</u>

Arizona should provide at least two weeks of guaranteed paid sick leave to allow workers to care for themselves or family members for the duration of the public health emergency. The spread of COVID-19 has highlighted the health and economic consequences faced by working people when they lack access to paid sick days and paid family and medical leave. In the United States, 33.6 million workers lack access to paid sick days.[xlviii] While 93 percent of the highest-wage workers have access to paid

sick days, only 30 percent of the lowest wage workers do, including the men and women who care for seniors and people with disabilities in facilities and in communities. Too many workers must choose between risking their own health (and that of their families and communities) and risking the loss of a paycheck or job. No one should face this choice, let alone during an unprecedented public health emergency.

3. Increase Worker Pay and Provide Alternate Housing

Arizona should increase workers' pay and offer alternative housing to workers, as other states have done, especially those in COVID-positive facilities who do not want to return home and risk exposing their families to COVID-19. As stated above, our state should use CMS waivers or state plan authorities to pay overtime rates to workers at congregate settings during this crisis as hazard pay or compensation for dangerous working conditions. We should also seek authorization for temporary supplemental pay increases to direct service professionals providing HCBS and for overtime pay by lifting caps on the number of hours workers may provide HCBS. Protecting workers by providing PPE, paid sick leave, increased hazard pay, and alternative housing is smart for Arizona families, our communities, and our economy.

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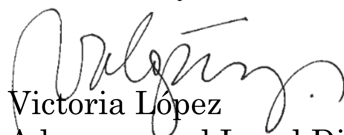
Arizona and our nation are facing unprecedented challenges. In this moment, we have been called to come together against a pandemic that has taken the lives of many, but also against long-entrenched biases that warehouse people with disabilities and against systemic racism that has deeply wounded and killed more than we will ever know. In these instances, people with disabilities and Black, Indigenous, and Latinx people have have paid a steep price. We can begin to strike a blow against these scourges by implementing the policy proposals outlined in this letter. These recommendations will not only help to protect the lives of seniors and people with disabilities, but also greatly benefit the Black and Brown workers (and their families) who comprise the majority of the workforce in congregate facilities and HCBS programs.

Thank you for your consideration. We welcome the opportunity to discuss these proposals with you and members of your administration.

Sincerely,



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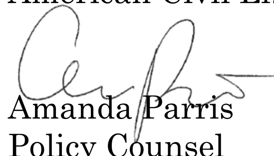

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[i] The New York Times *Coronavirus in the U.S.: 43% of U.S. Corona Deaths are Linked to Nursing Homes* (June 27, 2020), https://www.nytimes.com/interactive/2020/us/coronavirus-nursing-homes.html. According to data published by the U.S. Department for Health and Human Services (HHS), at least 29,497 residents and staff of nursing homes in the United States have died of the coronavirus. CMS, *COVID-19 Nursing Home Data* (last updated June 18, 2020), *available at* https://data.cms.gov/stories/s/COVID-19-Nursing-HomeData/bkwz-xpvg (including data submitted as of week ending June 7, 2020). This figure is almost certainly an undercount because under the reporting guidelines adopted by the Centers for Medicare and Medicaid Services (CMS), nursing homes are not required to report deaths or cases that occurred before May 8, despite the fact that the first reported nursing home outbreaks occurred in February.

[ii] Kaiser Family Foundation, *State Reports of Long-Term Care Facility Cases and Deaths Related to COVID-19* (as of June 18, 2020), *State Data and Policy Actions to Address Coronavirus* (last visited June 18, 2020) https://www.kff.org/health-costs/issue-brief/state-data-and-policy-actions-to-addresscoronavirus (reporting 50,185 deaths in long-term care facilities from 41 states); *Coronavirus in the U.S.: Latest Map and Case Count*, N.Y. Times (last visited June 20, 2020), https://www.nytimes.com/interactive/2020/us/coronavirus-us-cases.html; Jon Kamp & Anna Wilde Mathews, *As U.S. Nursing-Home Deaths Reach 50,000, States Ease Lockdowns*, Wall Street Journal (June 16, 2020).

[iii] https://www.azfamily.com/news/continuing_coverage/coronavirus_coverage/arizona-assisted-living-death-toll-higher-than-federal-data-shows/article_2b4f0da6-af95-11ea-86ec-8f92c20ad15b.html.

[iv] Arizona Department of Health Services, *Data Dashboard* (Congregate Settings with Positive

COVID-19 Cases data as of July 28, 2020), *available at* https://www.azdhs.gov/preparedness/epidemiology-disease-control/infectious-disease-epidemiology/covid-19/dashboards/index.php.

[v] *Olmstead v L.C.*, 527 U.S. 581, 600-01(1999) (recognizing that "unjustifiable institutional isolation of persons with disabilities is a form of discrimination"…that "confinement in an institution severely diminished the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment"…and that such confinement "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.").

[vi] Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports in FY 2016,* Medicaid Innovation Accelerator Program (May 2018), *available at* https://www.medicaid.gov/sites/default/files/2019-12/ltssexpenditures2016.pdf.

[vii] Sarah Klein, "Hospital at Home" Programs Improve Outcomes, Lower Costs But Face Resistance from Providers and Payers, The Commonwealth Fund (last visited June 22, 2020), *available at* https://www.commonwealthfund.org/publications/newsletter-article/hospital-homeprograms-improve-outcomes-lower-costs-face-resistance.

[viii] Silvia Yee, *DREDF Policy Recommendations for Reducing COVID-19 Nursing Home Deaths Through Innovative HCBS* (May 21, 2020), *available at* https://dredf.org/2020/06/04/dredf-policyrecommendations-for-reducing-covid-19-nursing-home-deaths-through-innovative-hcbs/.

[ix] Letter from The Disability and Aging Collaborative & Consortium for Citizens with Disabilities to Sens. Mitch McConnell and Charles Schumer (June 15, 2020), *available at* http://www.c-c-d.org/fichiers/National-and-State-Sign-on-COVID-19-Senate-Letter.pdf.

[x] Dave Biscobing, *State hospital struggles to contain COVID-19,* ABC15 (June 29, 2020), https://www.abc15.com/news/local-news/investigations/state-hospital-struggles-to-contain-covid-19.

[xi] ASH employees reported "protocols were not effectively communicated" and a lack of personal protective equipment (PPE). Additionally, symptom screenings were completed by non-medical staff. *See*, Dave Biscobing, *State Hospital has first COVID-19 death, 144 cases,* ABC15 (July 6, 2020), https://www.abc15.com/news/local-news/investigations/state-hospital-has-first-covid-19-death-114-cases.

[xii] Jerod MacDonald-Evoy, *COVID-19 outbreaks in AZ child detention centers worry advocates*, AZ Mirror (July 8, 2020), https://www.azmirror.com/2020/07/08/covid-19-outbreaks-in-az-child-detention-centers-worry-advocates/; *see also*, Lily Altavena, *About 30% of teens at an Arizona treatment center infected with COVID-19. Their families are worried*, Arizona Republic (May 7, 2020), https://www.azcentral.com/story/news/local/arizona/2020/05/07/mingus-mountain-academy-arizona-has-42-teens-covid-19/5172243002/.

[xiii] Vyto Starinskas, *Coronavirus outbreak escalates at Mingus Mountain Academy*, The Verde Valley Independent & Campe Verde Bugle (May 14, 2020), https://www.verdenews.com/news/2020/may/14/coronavirus-outbreak-escalates-mingus-mountain-aca/.

[xiv] Substance Abuse and Mental Health Services Administration, *Considerations for the Care and Treatment of Mental and Substance Use Disorders in the COVID-19 Epidemic* (March 20, 2020, revised May 7, 2020), *available at* https://www.samhsa.gov/sites/default/files/considerations-care-treatment-mental-substance-use-disorders-covid19.pdf.

[xv] U.S. Dep't of Justice, Civil Rights Division, *Olmstead: Community Integration for Everyone, available at* https://www.ada.gov/olmstead/.

[xvi] The Arizona Center for Disability Law is the designated Protection and Advocacy agency of Arizona and has authority to monitor facilities and investigate allegations of abuse and neglect. 42 C.F.R. § 51.42(c) (Protection and Advocacy for Individuals with Mental Illness Act regulations, authorizing Protection & Advocacy access for the purpose of "monitoring compliance with respect to the rights and safety of residents"); 45 C.F.R. § 1326.27(c)(2)(ii) (Developmental Disabilities Assistance and Bill of Rights Act of 1975 (DD Act) regulations, authorizing the same); 29 U.S.C. § 794e(f)(2)) Protection and Advocacy for Individual Rights Act, granting same authorities as set forth in the DD Act.

[xvii] We recognize Protection & Advocacy agencies (P&As) have access authority pursuant to 42 CFR 51.42 (access authority for protection & advocacy agenicies for individuals with mental illness) and 45 CFR 1326.27 (access authority for protection and advocacy agencies for individuals with developmental disabilities). P&As and facility staff should work together to ensure effective monitoring while recognizing and staying compliant with federal, state, and facility safety guidelines.

[xviii] The Arc, *New Data Reveals Our Nation Is Failing to Support People With Intellectual and Developmental Disabilities* (June 12, 2018), *available at* https://thearc.org/new-data-reveals-nation-failing-support-people-intellectual-developmental-disabilities/.

[xix] National Council on Aging, *Issue Brief: Support Family Caregivers and Home and Community-Based Services* (March 2016), *available at* https://d2mkcg26uvg1cz.cloudfront.net/wp-content/uploads/IB16-Family-Caregivers-and-HCBS-March.pdf.

[xx] Centers for Medicare & Medicaid Services; Medicare and Medicaid Programs, Basic Health Program, and Exchanges; Additional Policy and Regulatory Revisions in Response to the COVID-19 Public Health Emergency and Delay of Certain Reporting Requirements for the Skilled Nursing Facility Quality Reporting Program, 85 Fed. Reg. 27550 (May 8, 2020).

[xxi] Holbrook Mohr et al., *Thousands sick from COVID-19 in homes for the disabled,* Associated Press (June 11, 2020), https://apnews.com/bdc1a68bcf73a79e0b6e96f7085ddd34?.

[xxii] *See, e.g.*, Joseph Shapiro, *COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities*, NPR, (June 9, 2020), https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higheramong-those-with-intellectual-disabili; Ill. Dep't of Human Servs., COVID-19 Confirmed Positive Cases (last updated June 19, 2020), *available at* https://www.dhs.state.il.us/page.aspx?item=123651.

[xxiii] Arizona State Hospital, Dep't of Health Services, *Program Summary, available at* https://www.azleg.gov/jlbc/psdhsash.pdf.

[xxiv] Stephanie Innes, *Hacienda HealthCare patient rape case prompts federal legislation,* Arizona Republic (Feb. 13, 2020), https://www.azcentral.com/story/news/local/arizona-health/2020/02/13/rape-hacienda-healthcare-az-has-inspired-congressional-bill/4729869002/.

[xxv] National Residential Information Systems Project, *RISP Profile FY 2016: Arizona, Institute on Community Integration (UCEDD), University of Minnesota* (Feb. 14, 2018)*, available at* https://ici-s.umn.edu/files/4ne4KRniJq/arizona-risp-2016.pdf.

[xxvi] We recognize that the Maricopa County Superior Court recently ruled against news organizations seeking public release of aggregate state data on the impact of COVID-19 in nursing homes, concluding that state privacy laws applied and rendered this information not publicly disclosable under state public records law. *See*, https://www.azcentral.com/story/news/local/arizona-health/2020/05/29/judge-rules-arizona-nursing-home-covid-19-records-private/5283835002/. We disagree with this decision, and recommend the state legislature take action to ensure the public has access to information critical to understanding the impact of COVID-19 and other potential pandemics, and for making decisions to control and limit its effects.

[xxvii] Arizona Department of Health Services, *Data Dashboard* (Demographics data as of July 28, 2020), *available at* https://www.azdhs.gov/preparedness/epidemiology-disease-control/infectious-disease-epidemiology/covid-19/dashboards/index.php.

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