

## Letters to the Editor

### The Impact of COVID-19 on Individuals With Intellectual and Developmental Disabilities: Clinical and Scientific Priorities

TO THE EDITOR: The goal of this communication is to provide clinicians and behavioral scientists with a scoping perspective on the diverse array of effects of the COVID-19 pandemic on individuals with intellectual and developmental disabilities in the United States. It is our hope that this will stimulate subsequent scientific and advocacy efforts to ameliorate the disproportionate burden of the pandemic on people with intellectual and developmental disabilities. We begin with the assertion that among noninfected persons in the United States, few are more adversely affected by COVID-19 than individuals with intellectual and developmental disabilities, given that a vast proportion require in-person care or critical therapeutic support within their living environments, with little backup or systematic coverage for prolonged interruption of services. Many have temporarily lost access to trained caregivers or community service providers and now face evolving threats to the return of baseline service, given uncertainties in state and agency budgets. Therefore, a first priority relates to restoration of in-person support services or comparable alternatives. There have been emerging guidelines on the safe care and support of individuals with intellectual and developmental disabilities during the COVID-19 pandemic (see Table S1 in the online supplement for a list of resources and documentation of the early success of such strategies). However, guidance is still evolving, has not permeated all reaches of the community where the information is desperately needed, and is not always presented in ways that can be fully comprehended by those with intellectual and developmental disabilities. It must be ensured that when in-person staff return to work, they are exercising techniques and participating in screening procedures that will protect their clients from infection with the novel coronavirus (1).

A second consideration is the likely disproportionate impact of mitigation efforts and social distancing on individuals with intellectual and developmental disabilities. For many, physical proximity to caregivers and loved ones is required to bridge gaps in intellectual and communication abilities and to make day-to-day life fulfilling, predictable, and manageable. People with intellectual and developmental disabilities were disproportionately isolated prior to the pandemic, and intensification of that isolation stands only to weaken the community for all citizens. Millions of people around the world are taking full advantage of screen-based technologies to mediate interpersonal connection, but this is

an impossibility for many with intellectual and developmental disabilities, for whom virtual interaction—even if accessible—is an inadequate substitute. Recovery efforts should be substantially guided by recognition of which individuals with intellectual and developmental disabilities can and cannot benefit from electronic substitutions for therapy, education, and social interaction. For those who can, attending to the “digital divide” (i.e., frank disparities in access to the technology necessary for virtual connectivity), as well as ensuring that Wi-Fi and usable devices are made available, is a pressing urgency; those who cannot benefit should be prioritized for the in-person services that they need.

A third and related domain is inequity in education across the lifespan. As summer school and summer camp programs were suspended, and as classrooms are being converted to virtual learning environments for the fall of 2020, the discrepancy in delivery of a free and appropriate public education (Individuals with Disabilities Education Act, Parts A–D) is pronounced between what is available to typically developing children compared with those requiring special education. Special education for youths with intellectual and developmental disabilities often requires nuanced physical contact and redirection, enhanced teacher-to-student ratios, interpersonal prompting, and close attention to the motivational structure of the environment. These educational considerations extend broadly to job training programs, supported employment for adults with developmental disabilities, and all elements of assistance that are required to sustain the integral role of individuals with intellectual and developmental disabilities in the national workforce. Support of students and trainees may require addressing physical positioning, toileting, feeding, and other needs related to activities of daily living. It is an inordinate burden to attempt to recapitulate the conditions of an “appropriate” education at home for most families and to avoid secondary consequences of individuals with disabilities falling further behind in academic achievement or training and suffering behavioral decompensation in the absence of the structure of a school or work day. Mobilizing qualified in-home personnel, clarifying which individuals with intellectual and developmental disabilities are more or less amenable to in-home virtual training and education—some children with autism-related disabilities, for example, are thriving in the relative absence of school bullying and overstimulation—and supporting newly unemployed parents to deliver education and/or developmental therapies are critical urgencies.

A fourth issue involves the emergent implementation of telehealth practice in clinical care. Telehealth has many

potential advantages, including expansion of access when transportation is a barrier and affording convenience and opportunity to observe patients in their own home environment. Exclusive reliance on telehealth, however, can leave gaps in critical aspects of the delivery of appropriate health care for some individuals with disabilities. Limitations in the capacity to adequately ascertain general physical safety and cutaneous manifestations of disease or neglect (e.g., for patients who cannot verbalize or adequately communicate pain or discomfort) can be significant drawbacks for those who are largely dependent on their own advocacy. Monitoring for adverse effects of medications, such as abnormal involuntary movements, oversedation, or dystonia, may be similarly compromised in many patients whose caregivers cannot reliably ascertain the presence of these physical states. Gaps in the capacity to communicate with a health care provider that are accentuated in the telehealth context must be recognized and incorporated into risk and benefit appraisals of prioritization for in-person clinical encounters.

Fifth is a set of concerns regarding access to testing for and appropriate medical care of individuals with intellectual and developmental disabilities infected with the virus. The pandemic has amplified hurdles related to transportation and the accrual of timely appointments and has raised serious ethical issues surrounding the allocation of treatment resources that are constrained or at risk during the pandemic. The American Academy of Neurology has issued a position statement on COVID-19 that includes attention to the fundamental obligations of physicians to individuals with neurological conditions in the community, including specific adaptations to treatment in both inpatient and outpatient settings (2). Mello et al. (3) recently raised attention to state policies that base triage decisions regarding intensive care on quality-of-life judgments or exclude patients with specific conditions that constitute disabilities. The authors suggested careful reexamination of these policies, urged the inclusion of disability rights advocates in policy development and dissemination, and issued specific recommendations to parameterize the prioritization of lifesaving medical treatments (e.g., ventilator support), which include avoiding the use of categorical exclusions, especially ones based on disability, perceived quality of life, or long-term life expectancy (i.e., over near-term recovery).

For all of these domains, as well as the longer-term biological, psychological, and social consequences of COVID-19 infection among individuals with intellectual and developmental disabilities, there are minimal scientific data on the degree of disproportionality of impact as a function of type of disability and socioeconomic disadvantage. Clinician scientists should be aware that the National Institutes of Health has issued NOT-OD-20-097, Notice of Special Interest Regarding the Availability of Administrative Supplements and Urgent Competitive Revisions for Research on the 2019 Novel Coronavirus and the Behavioral and Social Sciences, which thoughtfully articulates research priorities (see Table S2 in the online supplement). While the scientific community

appropriately entrains itself on research to end the pandemic, it is important to consider that the chronic public health burden of intellectual and developmental disabilities, which affect one out of every six Americans, remains considerable, such that there are balances that must be struck between optimization of safety and pressing on with the scientific enterprise of conducting intervention and other clinical research regarding individuals with these disabilities. Notably, this balance includes judicious consideration of resuming clinical trials and other critical human studies that have been suspended or disrupted by the pandemic.

We note that individuals with intellectual and developmental disabilities are subsumed under populations articulated by the World Health Organization and the Centers for Disease Control and Prevention to be at increased risk of infection with and complicated outcomes from the novel coronavirus. Adults with disabilities are three times more likely than adults without disabilities to have heart disease, stroke, diabetes, or cancer than adults without disabilities and have historically lacked equitable access to the level of medical care necessary to manage these conditions. Furthermore, a number of genetically based developmental disabilities are associated with features of health liability or immune function that may make them exquisitely sensitive to infection by COVID-19 (4), and the unique biological impact of COVID-19 on patients representing the diversity of rare genetic causes of intellectual and developmental disabilities is entirely unknown. This disproportionate toll must be offset by clarifying the extent to which preexisting health disparities are now accentuated by COVID-19 and by guarding against the compounding of inequity on the basis of limitations to in-person medical appointments and/or the rationing of intensive care (5).

Finally, there is the Herculean task stakeholders and advocates have to ensure that public decision making and the massive mobilization of relief funds by federal, state, and local governments are equitably responsive to the needs and interests of individuals with intellectual and developmental disabilities, who require representation in all decisions that affect the population in a public health emergency of this scale. Preserving equitable attention to the voices of individuals with intellectual and developmental disabilities, in addition to the already daunting enterprise of effective self-advocacy in the heat of a national crisis, creates inordinate challenges for people with limitations in communicative capacity to be heard effectively. In this context, advocacy therefore takes on unprecedented significance, given the consequences of oversight during such rapid mobilization of funds. Between March 6 and April 24, 2020, four COVID-19 emergency supplemental funding packages became law, and each has implications for individuals with intellectual and developmental disabilities (see Table S3 in the online supplement). The entities of the developmental disabilities system designated under the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 106-402), known as the University Centers for Excellence in Developmental Disabilities, each state's Developmental Disabilities Council, and the

Protection and Advocacy agencies nationally and in every state and territory, have pivoted to meet crisis-related needs and are continuing the critical work to advocate for the needs of people with disabilities in all parts of life—health, education, employment, and community living. Despite some provisions of the supplemental funding packages, major gaps remain for individuals with intellectual and developmental disabilities, and a chronic need accentuated in the current crisis is for Congress to expand home- and community-based services. These services pay for the workforce that supports people with intellectual and developmental disabilities to live as independently as possible in their communities, support training and access to adequate personal protective equipment, and ultimately keep people with intellectual and developmental disabilities in their homes and communities—and out of institutions and other congregate settings, where people are dying in greater numbers, ultimately, from increased exposure to the virus.

In conclusion, the strategy for supporting people with intellectual and developmental disabilities through the COVID-19 crisis extends far beyond the clinical consequences of infection. There are ways in which necessary measures for prevention and disease mitigation adversely and disproportionately affect individuals with intellectual and developmental disabilities, with severe consequences for a vast number of uninfected victims of the pandemic. Offsetting such secondary hazards in the domains of personal care, education, and workforce support are as important as managing complex decisions regarding the capabilities and limitations of telehealth, the ethics of allocation of lifesaving medical intervention, and the effective translation of infection control practices to the diverse circumstances of individuals with intellectual and developmental disabilities and their families. Attention to the manner in which each of these facets of the pandemic impinge upon an individual patient should guide the care provided by every clinician, and it is a new responsibility of all clinicians, scientists, and advocates to recognize and seek opportunity to offset these

unique and disparate aspects of the burden of COVID-19 on members of the community with intellectual and developmental disabilities.

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