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RRF: COVID-19 and the Field of IDD

**Editorial**

**COVID-19 and the Field of Intellectual and Developmental Disabilities:**

**Where HaveWe Been? Where Are We? Where Do We Go?**

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**Author Note**

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**Abstract**

The coronavirus (COVID-19) pandemic has affected, and will continue to affect, every aspect of the Intellectual and Developmental Disabilities (IDD) community. We provide recommendations to (a) support people with IDD and the broader of field of IDD during the course of the pandemic, and (b) place the IDD community in a strong position when the health threats associated with the pandemic abate and post-pandemic social and policy structures are formed.

**Key Words: COVID; pandemic; community; field; health**

The coronavirus (COVID-19) pandemic has affected, and will continue to affect, every aspect of the Intellectual and Developmental Disabilities (IDD) community. As we write this editorial at the end of May of 2020, it is striking to us that only a year ago any thoughts about how the field of IDD might respond to a pandemic were far from the forefront of people’s concerns. A quick word search of the 2019 AAIDD conference program and issues from the three AAIDD journals published during 2019 shows that, although emergency preparedness and disaster preparedness were topics of research and discussion, there was no mention of policies, services, or supports that would be needed in response to the spread of a highly contagious and deadly virus that human immune systems had never encountered. The COVID-19 pandemic caught the world off guard, and people with IDD and the human service system that supports them were no exception.

Daily life prior to December of 2019, when the first cases of COVID-19 appeared, no longer exists. By the third week of January, 2020, the first fatalities from the virus had been reported in Wuhan, China, and this city of more than 11 million people had been placed on lockdown. By February’s end it was clear that the infection could be transmitted from asymptomatic people, and significant outbreaks in South Korea, Iran, and Italy revealed its capacity to spread exponentially through a community. The vast majority of people in the United States. and in much of world were under either mandatory or voluntary stay-at-home directives by mid-March. This entailed large swaths of the workforce working from home or becoming unemployed, as retail stores and restaurants shut down, colleges and universities closed their campuses, and schools moved from face-to-face to online instruction. Pleas to the public to venture out to public places only when absolutely necessary (such as to get food or medicine) and to maintain a safe social distance when there, as well as reminders to wash hands regularly and avoid touching the eyes and face became ubiquitous. AAIDD’s annual meeting, scheduled for Pittsburgh in June of 2020, had to be cancelled for the first time in the organization’s144-year history.

Although most people were asked to stay home, workers deemed essential were asked to put themselves at risk by continuing to work. Many of jobs held by essential workers required them to interact with people outside of their households and put themselves at greater risk of infection and contracting COVID-19. Some essential workers voluntarily inserted themselves into especially dangerous situations, and the bravery of physicians, nurses, and other hospital staff has been widely and deservedly celebrated.

The contributions of other essential workers, such as those involved in food production/distribution and those providing janitorial/cleaning services, have also been acknowledged. However, the public accolades for these workers have not been commensurate with the value of their contributions. It is noteworthy that a significant number of these essential workers include people with IDD. Data from diverse sources over multiple decades have shown that people with IDD often find employment in warehouses, fast food restaurants, grocery stores, and cleaning services (e.g., Hiersteiner et al., 2018; Newman et al., 2011). Although their numbers are unknown, it is indisputable that many people with IDD have significantly contributed to the health and safety of society during this challenging time.

Also, among the everyday heroes who did not have the privilege of working from home were direct support professionals (DSPs). They continued to go to work, at the risk to themselves and their families, in order to assure that people with IDD remained safe and healthy. Although they have traditionally been the most poorly compensated professionals in the field of IDD, evidence for the importance of their work has never been more apparent.

Speculating how everyday life will proceed two and a half months from now (when this editorial comes into print) is fraught with difficulty. As Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases, has reminded the public multiple times, the virus will set the time table to resume pre-December, 2019 life activities. How long will it take for the infection curve to fully descend? When will effective treatments for those infected become validated? When will a vaccine become available? These are but a few of the unknowns about what the future holds. And, it is the ongoing uncertainty that fuels much of the worry and anxiety that so many are feeling.

**Recommendations**

Despite the uncertainties, there are actions that can be taken to address the most pressing needs of people with IDD during the COVID-19 pandemic, and to assure that they are not left behind as COVID-19 restrictions get eased and daily life gradually returns to normal. The purpose of this editorial is to call on members of the IDD community to:

* **Insist that children with disabilities have full access to educational opportunities no matter what the mode of instruction.** With many schools closing their doors and suspending face-to-face instruction as a means to combat the spread of COVID-19 during the 2019-20 school year, the shift to online instruction has been massive, unprecedented, and without preparation. It was reasonable to allow educators and school systems some grace as they were asked to quickly learn new technologies and implement new ways of instruction, but it is important for the growing pains that inevitably accompany new ways of schooling not be used as an excuse to indefinitely deny students with IDD (as well as other disability populations) their right to a free and appropriate public education. Without vigilance from the IDD community, it will be too convenient for educational authorities to rationalize that the needs of the majority of students outweigh the needs of students with disabilities. The choice between educating some or all students has always been a false dichotomy, and it remains one regardless of the mode of instruction. Any suggestion that COVID-19 justifies releasing schools from their obligation to adhere to legal protections afforded to students with disabilities must be soundly rejected. Educational leaders at the federal and state levels must ensure full compliance with the Individuals with Disabilities Education Act (IDEA) for this and future school years, and there must be sufficient public resources dedicated to fully monitor and enforce IDEA requirements. Moreover, it is critical that educators have to access to the technical assistance and professional development they need to deliver meaningful instruction.

**Assure that a community IDD service infrastructure is supported.** The shift from institutional to community-based supports has been dramatic over the past 50 years. The establishment of a network of community service provider organizations has provided people with IDD an increasing range of opportunities for community engagement through residential, employment, recreational, and other supports. Self- directed models of support have further expanded the ability of people with IDD and their families to access individualized supports that meet their needs as they strive to engage and contribute to their communities as well as to prepare for and address crisis situations. Many IDD provider organizations operate on tight budgets during the best of times and are completely dependent on public funding to maintain their operations. As the nation strives to recover from the economic ramifications of the public health crisis, it is imperative that policymakers are made fully aware that community-based provider organizations that do not receive the funding needed to keep delivering their services will be forced to close, and there are no substitutes readily available. Platitudinous calls to “tighten the belt” and “do more with less” are empty rhetoric to organizations that operate without profit or operational reserves. Funding delays and cuts will not only result in people with IDD having fewer choices and less opportunity to exercise self-determination in regard to where and how they live, as well as how their supports are delivered, but will eventually place the health and safety of people at risk.

* **Assure that the public service infrastructure is maintained.** The significance of IDD provider organizations should not overshadow the importance of public services to the quality of life of people with IDD. People with IDD need a vibrant network of public services (e.g., public transportation, libraries, community health care, legal aid offices, schools and adult education, public recreation) in order to fully participate in community life. For example, access to affordable and dependable public transportation is critical for many people to get to jobs, visit the doctor, go to school, and/or maintain connections with others. When public transportation is undependable or limited (e.g., busses come and go only twice a day) or too expensive, people with IDD become at risk for increased isolation and exploitation. To someone who is unable to secure reliable transportation to their workplace, news of businesses rehiring and reopening will be cold comfort to the many people with IDD who lost their jobs during the pandemic because their employers had to retrench. Public services are a lifeline to the community for people with IDD and they must be maintained.
* **Compensate DSPs appropriately.** Although this particular call to action has been applicable since community-based services began, as we enter the recovery phase of this health crisis there may be a unique opportunity to enact public policies that will support a stable and competent DSP workforce. The high rate of DSP turnover is well-documented, as are the contributing factors; however, it is obvious that low pay and poor benefits are the primary drivers (e.g., see Houseworth et al., 2020). Society needs DSPs who are skilled community facilitators, have strong interpersonal skills, are excellent collaborators and team members, and who spend enough time in their positions to develop deep insights into the personalities and competencies of the people they support. As mentioned earlier, the value of DSPs as an essential lifeline for people with IDD has perhaps never been more apparent. Over and over again, they have demonstrated dedication to the people they support and their employers during the COVID-19 pandemic. At a minimum, DSPs deserve to work within a human service system that supplies them with living wages, access to good health insurance, and a career path that rewards the knowledge, skills, and competencies that increase with years of experience on a job.
* **Address disparities in health care for people with disabilities.** Compared to the general population, people with IDD are at much greater risk of serious health problems (e.g., diabetes, cardiovascular disease,) and experience significant disparities in health care access (e.g., preventative medicine, treatment for acute and chronic conditions; Krahn & Fox, 2014). In the wake of this pandemic, governments will be rebuilding their health, social service, and other infrastructures that promote optimal outcomes among people in their jurisdictions. Since a majority of people with IDD in the United States. are already using Medicaid and/or Medicare programs, the most logical path to decreasing discrepancies in health outcomes and assuring equity in health care access is to expand these programs and institute reforms that increase their effectiveness. As the United States. begins to enter what will surely be multiple reckonings on deciding how to proceed in in the wake of COVID-19, it is essential to build on the foundation of current Medicare and Medicaid services.
* **Continue your alliance with AAIDD** **and its partner disability associations.** Althoughencouraging continued membership in AAIDD may appear to be self-serving advice from the Association’s Executive Director and an Editor of one its journals, we believe that the importance of the field of IDD uniting and speaking with a consistent voice has never been greater. We live in a time of political divisiveness. There is a consistent cacophony of opinions from all corners that tend to drown out individual voices. This is a time for those committed to ensuring good lives for people with IDD to stick together and speak with an expert, passionate, and united voice that cannot be ignored due to the sheer number of people with a breadth of experience and a depth of knowledge. So, keep your AAIDD membership current, and continue to support our sister disability organizations as well. Together we are better and far more powerful, and this is a time for the IDD community to work together to advance policies and practices that are based in evidence and support people with IDD to have the highest possible quality of life. If we are not willing or able to provide a united leadership, directions for policy and services will be set by others, and possibly by those who do not share our values or possess our knowledge and expertise. Additionally, membership in AAIDD and other organizations maintains our connections with one another and provides access to accurate information. Being connected to others and staying informed with accurate information is a winning combination for all who are striving to cope in these unprecedented times.

**Supporting Others: The Key to Surviving the Pandemic**

Recently, in an article appearing in *Forbes*, Remy Blumenfeld (2020) announced that his immunity had been compromised and he was self-isolating for the next 12 weeks. He pondered how he could continue to make a difference in the world during his time in isolation, and was inspired by a story involving the American anthropologist Dr. Margaret Mead. A student asked Dr. Mead what she considered to be the first sign of civilization, and she made no mention of any of the obvious artifacts of early civilizations such as tools, art, or religious relics. Rather, she claimed the first evidence of civilization was a fractured femur (the bone connecting the hip to the knee) from 15,000 years ago. This bone had been broken and then healed, a process that takes at least six weeks. It would have been impossible without the support of others. Mead explained that no person could have survive a broken leg 15,000 years ago as it would prevent escaping from predators, gathering food or water, or engaging in other activities needed for survival. The healed femur was evidence that somebody had decided to not abandon their injured companion, but to share their survival interests with another and help their fellow human recover. Perhaps it was the first case of someone embracing the philosophy of enlightened self-interest, the idea that acting in a way that furthers the interest of another ultimately serves one’s own interests (e.g., if the injured person recovered, they could return to contributing to the welfare of the group; if a group ethos to help members who in need were to take hold, then someday help from others will be available to oneself when needed). Or, maybe these healer(s) were simply acting out of love for their injured friend. Whatever the reasons, Dr. Mead was quoted as saying, “Helping someone else through difficulty is where civilization starts. Never doubt that a small group of thoughtful, committed citizens can change the world; For indeed, that is all who ever have. (para. 1)”

The COVID-19 pandemic is a global event and the world’s survival response will be evaluated by future generations. What will the future IDD community say about us? Did we meet the challenge of our day, or did we come up short? In writing this editorial our aim was to encourage everyone to take or support actions to help the field of IDD emerge from this pandemic in a strong and promising position. We will close by extending our encouragement to all who are striving to assure that the human rights of people with IDD are protected. And to applaud all of those among us who, despite the times, continue to dream of a future where all citizens are able to fully realize their capabilities and value.

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