

## Disability as a Determinant of Health:

### Lessons from the Pandemic

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### Introduction

The COVID-19 pandemic brought infections with coronavirus, hospitalizations from the illness, long-term disorders still not fully catalogued or understood, and in many cases—almost 1200 in Delaware—death. And for Delawareans with disabilities, it brought these things in grotesquely disproportionate numbers.

But it brought more, too; more ways to harm our health. The virus, and our necessary responses to it, closed businesses and schools and government offices; disrupted programs and services and routines; stole jobs, savings, and security; left us confused, anxious, and, too often, alone. These things, too, it did with a particular vengeance to disabled people.

What follows is a brief attempt to describe some of the ways the pandemic has challenged us: some of the ways it has visited its harms unequally, the ways in which—beyond COVID—the pandemic has been distinctively harmful to the health of disabled Delawareans. The hard data suggests that Delawareans with disabilities are especially vulnerable to such harms. Qualitative data—including the voices of Delawareans—suggests they have suffered those harms, are enduring them still, and that the challenges remain ours to meet.

### Health Care Services

From the outset, the pandemic caused substantial disruptions of support services for people with disabilities, as resources were diverted, programs suspended, and care providers were excluded from contact or themselves became ill. Substantially similar issues were reported for educational services. Combined with the economic impacts of the pandemic, the result for many Americans with disabilities has been increased need, new barriers, and greater isolation.

The health consequences of these changes can be substantial, and quite directly so when it is health care services that are disrupted. The evidence to date is largely self-reported, through interviews and surveys: it consistently shows that the COVID-19 pandemic has substantially exacerbated existing health inequities, as well as created new ones. In a survey of roughly 2500 adults with disabilities by the American Association on Health & Disability, for example, nearly one-fourth of the respondents (23%) reported that they had lost critical care services as a result of the pandemic, while over half (56%) reported a disruption of regular health care services.<sup>1</sup>

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For those with a disability, it's been really difficult to access any kind of health care. I know for myself, telemedicine can be problematic; for individuals with disabilities, it has to be heart-wrenching and difficult.

And for individuals with disabilities that live in the community, home health care has been especially difficult. There's already a shortage of nurses and direct support personnel, and with the pandemic has come a greater shortage. So sometimes families might go for days without having a nurse coming in to do the home health care that they need. And the lack of nursing in home health care has really hit those individuals and their families hard.

Keep in mind that nurses that do home health care, they haven't gotten a pay raise in quite a few years, and now they're working harder, and working in really hard conditions, too. And then you have individuals getting sick with COVID, whether it's in the family or whether it's the nurse direct service providers themselves that are getting sick.

What can we do? I think it's really important that we make sure that our society, our community, our doctors and healthcare providers, and our legislators, do what is appropriate to ensure that our families get the services that they need. We also need to ensure that our children get the services that they need. That means, for a start, that nurses are paid adequately, so we have enough of them to go into the homes, to provide the care that's needed, to keep our constituents safe, and in their community, versus being in institutions.

It's a matter of respect for the people that need care. And we have a very bad habit sometimes of being disrespectful, of treating people as though they are "less than," especially people with disabilities.

## **Access to Care**

Home care, in private homes and group homes, has been substantially disrupted, as the already short supply of nurses and direct support personnel was diverted to emergency care, or was prevented from providing in-home assistance by social distancing mandates, the lack of personal protective equipment, or by infection. In a survey of 556 Developmental Disabilities (DD) nurses early in the pandemic, the top expressed concern was obtaining an adequate supply of personal protective equipment (PPE) and sanitizers. It is not an abstract concern: in Delaware, among the direct support personnel providing services to Delawareans with IDD in group homes, 350 have tested positive throughout the pandemic (as of January 31) and at least five have died. "The pandemic," the national survey concluded, "has left DD nurses feeling stressed, fearful, depressed, and burned out, and simultaneously wishing they could do more to help."<sup>2</sup>

Care outside the home has been problematic for a variety of reasons. Evidence suggests that roughly 70 percent of people with disabilities limit their regular travel because of their disabilities; 15 percent of the people with travel-limiting disabilities—a total of 3.6 million Americans—do not leave their homes at all.<sup>3</sup> And travel takes longer for people with disabilities, even after controlling for transportation mode.<sup>4</sup>

All of which has been made worse by the pandemic, when safe transportation—from public or private services, or from friends or relatives—may be harder to come by. Some Delawareans with disabilities avoid travel due to increased anxiety brought on by the pandemic; others avoid leaving home because their disabilities make them more vulnerable to severe COVID outcomes. Those Delawareans with disabilities who do not self-manage their transportation rely on caseworkers, peer specialists, and others to give them rides to medical and other healthcare appointments, as well as to help with logistics to make those appointments. If those supports and services are not available and accessible, then people with disabilities—who otherwise use health care more often than people without disabilities—simply miss out on the care they need. And because people with disabilities are more likely to be out of the labor force, or if they were employed, to have lost their job during the pandemic, paying for the transportation is often not an option.

Telemedicine, meanwhile, presents its own challenges, as it requires broadband access, technological skills, and accessible platforms—platforms, for example, that interface properly with video relay service or ASL interpreters. And something else can be lost in the transition from in-person care. “In some ways,” notes Cory Nourie, Director of Community Services for the Delaware Division of Developmental Disabilities Services (DDDS), “telemedicine has helped because people can access care.” At the same time, she notes that it’s also difficult for people with IDD to maybe understand and utilize telemedicine the way somebody who doesn’t have IDD uses it. For some individuals who are part of our system, they have a rapport with their provider, and the provider knows the secret way to convince the person to open their mouth, to let them look inside: they remember “when I tickle your neck, you’re going to open up and show me your tongue.” And through telemedicine, you can’t establish or maintain that rapport; it just doesn’t work the same way through a screen.

### **Access to Support Persons**

At the outset of the pandemic, Delawareans with disabilities who were hospitalized were often denied access to caregiver support persons. As a result, people with significant disabilities who needed a support person—who required support from a family member, personal care assistant, or trained disability service provider in order to communicate with their care team or make healthcare decisions—were effectively denied access to services.

In May, however, Division of Public Health Director, Dr. Karyl Rattay issued a new guidance on hospital visitation policies. That guidance, amended in September, noted that “hospitals are permitted to restrict visitors during a pandemic or infectious disease outbreak,” but declared that, for patients with intellectual or developmental disabilities, or cognitive impairments, the Division of Public Health “does not consider support persons to be Visitors.” Advocates praised the decision, noting that the new visitation policies were crucial to ensuring that Delawareans with disabilities have equal access to medical care, and are consistent with the mandates of federal anti-discrimination law.

## Wealth determinants of health

### Poverty correlates

Poverty is significantly correlated with disability in Delaware: in 2018, the poverty rate of working-age people without disabilities in Delaware was 9.7 percent; the poverty rate of working-age people *with* disabilities in Delaware was nearly triple that, at 28.6 percent. And wealth and poverty impact health in many ways.

COVID comorbidities, for example, are significantly correlated with poverty. Nationally, socioeconomic status is strongly associated both with chronic kidney disease and with end stage renal disease progression<sup>5</sup>; with risk of diabetes<sup>6</sup>; with an increased risk of hypertension<sup>7</sup>; and with COPD.<sup>8</sup> The Behavioral Risk Factor Surveillance System (BRFSS) confirms these trends for Delaware: each morbidity is much more prevalent among low-income Delawareans. Meanwhile, general health and immunity boosters—nutrition, rest, and exercise—are unequally distributed based on wealth: according to the 2018 American Community Survey (ACS), just 5.4% of households with an income-to-poverty ratio of 1.85 or greater are food insecure, but for households with a ratio under that, the percentage soars to 29.1%. And, according to the BRFSS, low-income Delawareans are less likely to get adequate sleep and exercise.

Unsurprisingly, poverty compounds the disadvantages experienced by people with disabilities during the pandemic. Participants in a web-based survey of 5,378 people living with Parkinson disease reported that during the pandemic they had experienced “disruptions in health care, social engagement and exercise, as well as a worsening of motor and non-motor symptoms.” And the impacts were worse for respondents with lower household incomes: they were less likely to attend telemedicine appointments, had greater difficulties obtaining medications and were less likely to find alternative means of exercise than participants with a higher household income.<sup>9</sup>

### Job loss

People with disabilities have long been excluded from the workforce. In 2018, the labor force participation rate for working-age people without disabilities in Delaware was 80.0 percent; the rate for working-age people *with* disabilities in DE was 37.7 percent.<sup>10</sup> And that was before the pandemic.

Nationally, the labor force participation rate for working-age people without disabilities decreased from 77.4 percent in January 2020 to 75.5 percent in January 2021; for working-age people without disabilities, the labor force participation rate also decreased, and by roughly the same proportion, but from 33.6 percent in January 2020 to 32.8 percent in January 2021.<sup>11</sup> Meanwhile, for those in the labor force, according to the Current Population Survey, from February 2020 to September 2020, the total number of employed persons with a disability declined by approximately 670,000—from 5.92 million in February to 5.29 million in September, a 10.6 percent decline in employment.<sup>12</sup> And in addition to the job losses occasioned by business closures, caregivers of people with disabilities have lost employment because they cannot secure enough nursing coverage for a dependent family member with disability, to allow the caregiver to work outside the home.

### Homelessness

Homelessness is a massive problem anytime, but it is of special concern in a pandemic: homelessness leaves people very vulnerable to infection, and makes it very difficult to contain the spread. Indeed, the Centers for Disease Control and Prevention (CDC) has issued a “declaration

determining that the evictions of tenants could be detrimental to public health control measures to slow the spread” of the virus.<sup>13</sup>

And homelessness is a distinctive problem both of, and for, people with disabilities. It is, first of all, especially difficult for people with disabilities to manage their disabilities when experiencing homelessness. Consider the challenges in testing and responding to fluctuating glucose levels, and hygienically utilizing injectable insulin, for a homeless individual with diabetes. Or imagine trying to follow a prescribed medication regimen when the medication requires refrigeration. And consider the challenges for homeless people with mental illnesses: estimates are that least 25 percent of homeless people are seriously mentally ill, and that 45 percent have some mental illness,<sup>14</sup> and there is an unhealthy synergy between mental illness and homelessness, as homelessness may contribute to psychiatric vulnerability.<sup>15</sup>

The risk of homelessness is also greater for people with disabilities. Even before the pandemic, there was not enough supportive housing for people with disabilities: there are waiting lists for many different types of subsidized housing, as well as housing designed to support people with disabilities, like neighborhood and group homes. And without subsidies, people with disabilities—who are disproportionately poor, who are disproportionately excluded from work, and who may have special housing needs—are especially vulnerable in the housing marketplace. The pandemic has only heightened their economic vulnerability. While the eviction moratorium provides temporary security, rents still accrue, and when the moratorium is lifted, a crisis awaits.

## Disruption, Isolation, and Stress

In addition to the direct impact the SARS-CoV-2 infection has on health, the COVID-19 pandemic and subsequent policy responses have resulted in unprecedented disruptions to daily life activities, access to health care and supportive services, and social connection. The nearly inevitable result is increased stress among people with disabilities.<sup>16,17</sup>

American respondents to the COVID-19 Disability Rights Monitor reported loss of access to personal assistance, assistive technologies, rehabilitation services, therapies and development interventions, and more.<sup>18</sup> That, alas, is consistent with the Delaware experience. Delawareans with disabilities have lost access to a wide range of programs and services, either because they have become remote, or because they have closed altogether. These include recreational and group programs, a major social outlet for many participants, as well as day programs designed to develop independent living or vocational skills. In all cases, the loss of the programs means that the relevant skills—cognitive, communication, social—will not be enhanced, but may in fact be diminished. And at least as worrisome, the loss of the programs means a disruption of routine, a severing of connections, and, perhaps, a lost sense of progress, of independence, and of belonging.

*Maria Olivero is the mother of a twelve-year old student in the Brandywine School District. Her daughter, Francesca, AKA Franki, who has Down syndrome, was learning on-line in the spring and during Extended School Year in the summer, and is now back in the classroom part-time in a hybrid format (see Figure 1). Before the pandemic, Ms. Olivero notes, Franki was making real progress with her social skills.*

Franki had to learn social skills. We worked very hard on it. She was learning to take turns. She was learning to be a friend. She was learning to say hi. With the pandemic, all of that went away. Now we are back to, maybe not square one, but close.



And it's not just school that is affected. She loves to go shopping. I don't know why, because I hate shopping. She keeps asking me, she signs, to go shopping and I'm like, "we can't go shopping." So it's been a year since she's been really anywhere, in a group of people to talk to, and that's just going to further inhibit her. So the socialization that we worked so hard for, just kind of goes away.

We've fought so hard for inclusion and acceptance in our communities. And now we are once again forced to segregate our children. And I realize we all are, not just the special needs community, but it impacts our children differently and they really don't understand. They think they are being punished, that they did something wrong.

It truly takes a village, and somehow the village is working in a lot of ways: I don't know how it's working, but it is working. The new normal is different than our old normal, so it's not getting back on track. We can't think of it that way. It's figuring out the new track. It's figuring out the new path, figuring out how we're going to navigate all of this going forward.

And we need to keep this in mind: there are different levels and there are different abilities for all of us. To compare kids, even within the special needs community, does no good to anybody. So I don't compare her to her peers in our community, or to other kids at school. Because she is Franki. She is her own little person and she's doing things her own little way. And comparing only keeps you from appreciating the little things that do come along that can bring so much joy, that you may miss otherwise. Because after all, comparison is the thief of joy.

The same, of course, may be happening in the schools. In a survey of more than 1,000 parents of Delaware school children, 61% of parents of students with disabilities reported that changes to their

routine were “very disruptive” to their children, 50% higher than the figure for parents of students without disabilities.<sup>19</sup> Remote learning presents the same technological challenges as telemedicine, compounded by the need to maintain a connection—internet and interpersonal—with a child, and for hours at a time. And some learning may be nearly impossible: it may be hard, after, to secure all the benefits of inclusion, while isolated at home.

The cumulative emotional impact of service disruptions—disruptions of health care services, social services, educational services—is undoubtedly substantial, both for the people with disabilities who participate in them, and the families who have come to rely on them. At the very least, the disruptions have contributed to the already overwhelming stress caused by the pandemic.

The detrimental effects of acute and chronic stress have been extensively documented in existing research.<sup>20</sup> Exposure to a variety of different types of trauma and social stressors over time has been shown to activate a complex stress response system that can result in structural and functional changes and impairments across numerous body systems and the exacerbation of existing vulnerabilities.<sup>21</sup> Impacts of chronic stress can include impaired or disrupted brain function (e.g., memory, cognition, learning, and mental illness),<sup>22,23</sup> immune response,<sup>24,25</sup> cardiovascular functioning,<sup>26,27</sup> and gastrointestinal functioning,<sup>28,29</sup> among others.<sup>30</sup> Furthermore, the harmful consequences of chronic stress and trauma can be intergenerational, resulting in poor birth outcomes and increased risk of mental and physical health conditions across the lifespan.<sup>31–33</sup>

During the COVID-19 pandemic, a wide-range of interrelated social and structural stressors, also commonly identified as harmful health determinants, have been experienced by people with disabilities and people with chronic disease. Using transportation during the pandemic as only one example, the myriad factors leading to increased stress become clear: a qualitative study in the San Francisco Bay Area revealed that people with disabilities had so many transportation concerns, they often simply abandoned the effort, resulting in less health care, and also greater social exclusion.<sup>34</sup>

Meanwhile, a separate study found that people who perceive themselves to be highly vulnerable to COVID-19—a group that is not limited to, but almost certainly includes, people with disabilities—reported more COVID-19 worries, higher social isolation, and higher traumatic stress than people who perceived themselves less vulnerable to COVID-19.<sup>35</sup>

While the true impacts of the increased stressors experienced by people with disabilities and chronic illness during the pandemic are yet to be known, an early example of one alarming consequence that may be related to increased stress and social isolation is the increase in overdose death rates in Delaware and nationwide.<sup>36</sup> In June 2020 compared to June 2019, there was a nearly 20 percent increase in overdose death in Delaware.<sup>37</sup>

DDDS’s Cory Nourie offers this:

We have no idea the long-term consequences of isolation, of loneliness, of depression, of lack of connectedness to other people. I think there's going to be long-term consequences that we haven't even thought about yet, from how this all plays out when it's eventually over—both for the general population at large, but also specifically for DDDS service recipients. It's just really hard for people who oftentimes have a harder time understanding information as it's presented to them, to now go back into a place where they haven't gone to their job or seeing their friends for 10 months.

*Emmanuel Jenkins is a member of the State Council for Persons with Disabilities, and of the Employment First Oversight Commission, was*

*a Community Resource Officer for the Delaware Developmental Disabilities Council, and is the Founder and CEO of We Stand 4 Something, a non-profit organization that helps individuals with disabilities accomplish their goals. Like many Delawareans, with and without disabilities, Mr. Jenkins has been affected by COVID-19 in more ways than one.*

Whether you use a wheelchair or not, or have any form of disability, you have to learn how to adapt, because this world is not set up for people like us. People with disabilities have always known how to adapt. We just needed the rest of the world to catch up with us. It's the same with the isolation. People with disabilities have always dealt with social isolation. And now, for the first time in my 37 years of living, the world is getting a glimpse of what I feel.

So things are harder now. For example, for people with disabilities, community-based services have always been at a disadvantage, because there is a lack of resources. We could add resources, if personal care attendants got paid more than \$10.75 an hour. People say, "well, that's the job they chose." You know why they might've chose that job? Because they have a heart, they have a mind, they have a need, and they have a desire to serve people.

And when we talk about community-based services, there are great things. You become part of the community, you're not only affecting your life, you're affecting people's lives that you come around, you're connecting them. That's what community based is all about: building relationships, connecting with people, being involved. And as long as we don't have the resources, that is always going to be a struggle.

And it's hard without supports. As a parent with a disability during the pandemic, it's like a magic show and I am the juggler. There are so many new roles now. You have to be the guidance counselor; you have to be the principal; you have to be the cleaner; you have to be the psychologist; you have to be there at the table. So now you have to juggle all of these things. And my son has probably been getting away with murder, because he knows I'm working, and I cannot go running into his room every couple of minutes, because he's just going to hear my chair coming down the hall.

Overall, I think, the pandemic has shown people they need to take a moment, stop, and breathe. Because the ability to be free can be gone at any moment. And this pandemic, you know, unfortunately there's not a vaccine for the side effects.

## **Conclusion**

It seems that some of the lessons to be learned from the pandemic, are lessons that many Delawareans with disabilities learned long ago. That inclusion is better than exclusion, because isolation is hard. That we need one another, to lift us up sometimes, to move us forward sometimes, and at all times, to respect us. That we are at the mercy of one another, and we can hurt—and be



hurt—not only by malicious action, but by stubborn indifference and neglect. That we can make our world adapt when we are moved to, but we have to know, and we have to care. That our civil rights require protection, as Harry Truman once said, not only from the government, but by the government, because “equal protection” is an affirmative duty. That the things we take for granted—the people, the places, our abilities, our every breath—are in fact precious and fragile, and can be stolen in an instant.

There are other lessons, we are sure, and we can’t be certain of any of these. But we hope we are learning, and we are grateful to all the people—with and without disabilities—who have tried to teach us, throughout the pandemic, through their compassion and devotion.

“Nonetheless,” Albert Camus wrote, about another plague, the tale we tell “could not be one of a final victory. It could be only the record of what had had to be done, and what assuredly would have to be done again in the never ending fight against terror and its relentless onslaughts, despite their personal afflictions, by all who, while unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers.”

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