

## **Inestimable Harms:**

### **COVID-19 Vulnerability Among Delawareans With Disabilities**

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## **Introduction**

On April 6, 2020, the Delaware Psychiatric Center confirmed its first case of COVID-19. From the beginning of the COVID-19 pandemic, the hospital had been taking every precaution to try to protect clients and staff. Leadership made surgical and other masks available to staff and clients, and encouraged their use. Handwashing was encouraged. Traffic in and out of the hospital was curtailed. But a client in the geriatric psychiatry unit experienced a high fever and had quickly become short of breath, and on that day, it became clear that the dreaded pandemic had penetrated the hospital. As was playing out throughout the world, COVID-19 would spread—quickly, thoroughly, and relentlessly.

The infection at the Center eventually would be contained, but as the pandemic progressed, as infections and deaths escalated in Delaware’s long-term care facilities, as the mortality rate climbed among the residents of the State’s group homes for people with intellectual and developmental disabilities (IDD), it became fair to ask whether Delaware’s disabled citizens were bearing the brunt of the pandemic. Were Delawareans with disabilities suffering disproportionately – were their rates of infection, of morbidity, of mortality, especially high?

A fair answer to those questions, it evolves, must contain two truths. First, we don’t know for certain: the data is too limited, in Delaware and elsewhere. Second, what we do know very strongly suggests that the pandemic has indeed had an especially lethal impact on people with disabilities, including disabled Delawareans.

Following is a brief summary of the available data on COVID events among people with disabilities, and an attempt to gauge vulnerability based on the prevalence of known risk factors among Delawareans with disabilities.

## COVID Events among Delawareans with Disabilities

### Data Generally

Data on COVID-19 event incidence (infection, hospitalization, mortality) for people with disabilities is sparse. While Congress has required that the federal government include race and ethnicity among the demographic data in its COVID analyses, the Act containing that mandate (April's "Paycheck Protection Program and Health Care Enhancement Act") did not include an explicit requirement for disability. A subsequent request to specify "disability" as among the "other relevant data" required by the Act, tendered by letter from a congressional group to the Secretary of the United States Department of Health and Human Services (HHS), was to no avail. The Centers for Disease Control and Prevention (CDC) did amend its case reporting form (the "Human Infection with 2019 Novel Coronavirus Person Under Investigation and Case Report Form") to add "Disability" to its list of "underlying medical conditions," but neither the CDC nor any other federal agency has reported disability data.<sup>1,2</sup>

Nonetheless, the limited direct impact evidence that is available strongly suggests that the pandemic is having an especially lethal impact on people with disabilities. A comprehensive study of death records in the United Kingdom released in June 2020, for example, determined that fully one-third of all COVID-related mortalities were people with disabilities.<sup>3</sup> Subsequent updates in September and in February 2021 confirmed the disparities: according to the last release, "in England, the risk of death involving the coronavirus (COVID-19) was 3.1 times greater for more-disabled men and 1.9 times greater for less-disabled men, compared with non-disabled men" and "the risk of death was 3.5 times greater for more-disabled women and 2.0 times greater for less-disabled women, compared with non-disabled women."<sup>4</sup>

In the United States, meanwhile, limited data started to emerge in late spring. In June, National Public Radio (NPR) released the results of a study on COVID mortality rates among recipients of IDD services:

In Pennsylvania, numbers obtained by NPR show that people with intellectual disabilities and autism who test positive for COVID-19 die at a rate about twice as high as other Pennsylvania residents who contract the illness. In New York, the state with the most deaths from COVID-19, people with developmental disabilities die at a rate 2.5 times the rate of others who contract the virus.<sup>5</sup>

A subsequent study of New York group homes seems to confirm this understanding. The study found that case rates for people with IDD in group homes were roughly four times the overall state rate, and the case-fatality percentage roughly doubled (and overall mortality rate, as a result, is almost eight times the overall state rate).<sup>6</sup> A follow-up report released in September utilizing data from the New York Disabilities Advocates (NYDA) COVID-19 Survey of Providers noted that the case rates disparity disappeared in early summer, while case-fatality rates remained around two times higher for people with IDD living in group homes.<sup>7</sup>

Finally, a study of IDD service recipients in California published in December concluded as follows:

Compared to Californians not receiving IDD services, in general, those receiving IDD services had a 60 percent lower case rate, but 2.8 times higher case-fatality rate. COVID-19 outcomes varied significantly among Californians receiving IDD services by type of

residence and skilled nursing care needs: higher rates of diagnosis in settings with larger number of residents, higher case-fatality and mortality rates in settings that provided 24-h skilled nursing care.<sup>8</sup>

California compiles and publicly reports COVID-related data for IDD service recipients; the data is updated twice weekly.<sup>9</sup>

### **Delaware data**

Disability data for Delaware comes from two sources: the record of the outbreak at the Delaware Psychiatric Center, and data maintained by the Delaware Division of Developmental Disabilities Services (DDDS) for recipients of Residential Habilitation Services, euphemistically residents of group homes for people with intellectual and developmental disabilities.

### **The Delaware Psychiatric Center**

The Delaware Psychiatric Center is a 120-bed state run mental health inpatient facility, consisting of four civil units and two correctional units. The COVID outbreak at the facility began on April 6 on the geriatric psychiatric unit: the infected client and his roommate were both transferred to the hospital's newly purposed COVID unit. Over the next two weeks, every resident of the geriatric unit was diagnosed with COVID-19 and transferred to the COVID unit.

Of the 22 clients on the geriatric psychiatry unit, ten required hospitalization at nearby Christiana Hospital for declining respiratory function. Four required intubation and mechanical ventilation. In total, three clients died from COVID-19 during their hospitalization.

In the initial weeks, the hospital was challenged by the same shortage of personal protective equipment (PPE) that affected health care workers nationwide, forcing hospital staff to reuse masks and gowns for an extended period. Among hospital staff, the nursing staff bore the brunt of the outbreak, with additional responsibilities and pressure to keep clients safe, and with rising COVID infection rates themselves. Due to the dwindling number of available nursing staff, the Delaware National Guard was called in. Guard members arrived on April 17, 2020. Through the infection control efforts of dedicated hospital staff and the National Guard, the outbreak was contained.

After the April outbreak in the geriatric unit, the hospital experienced only occasional infections: from June through November, just 12 additional clients contracted COVID-19. None of the 12 experienced significant symptoms or required hospitalization.

Despite the challenges that a deadly pandemic has placed on long-term care facilities throughout the world, the inpatients at DPC have fared well. The psychiatry faculty report no significant challenge to their ability to achieve a satisfactory mental health outcome.

### **Division of Developmental Disabilities Services**

The Community Services unit of the DDDS oversees the provision of, among other things, Residential Habilitation services to eligible Delawareans with IDD. Throughout the pandemic, the unit has collected data on COVID events among its service population, and has reported data to service providers, and to service recipients and their families.

At any given time during the period, roughly 1270 individuals were receiving residential habilitation services, typically in residences with a maximum of three or four service recipients. Through the end of October, the COVID positivity rate among service recipients was seven percent, compared to an overall State rate of four percent; the mortality rate, however, was 13

percent (11 total deaths), compared to an overall State rate of two percent (777 deaths). The ratios shifted dramatically with the fall surge. Between October 31 and January 31, the cumulative positivity rate for the State doubled, from four percent to eight percent, while for service recipients it tripled, from seven percent to 21 percent. Fortunately, the mortality rate saw a very different change: while the State rate held steady at two percent, the mortality rate among service recipients was more than halved, dropping from 13 percent to six percent (17 total deaths, see Table 1).

The one constant in the DDDS data throughout the pandemic has been the fact of disparity: as in every other state with reported data, residents with IDD are getting infected, and are dying, at significantly higher rates than the general population.

Table1. COVID Event Rates, DDDS Residential Habilitation Service Recipients

	Percent Positive	# Deaths	Percent Mortality
RHS Recipients	21	17	6
Total State	8	1195	2
Long Term Care Facilities	n/a	627	29
RHS Recipients (through 10/31)	7	11	13
Total State (through 10/31)	4	777	2

Data Courtesy of Delaware Division of Developmental Disabilities Services, and through January 31, 2021 unless otherwise specified.

One final note on Delaware data: the mortality rate in Delaware’s long term care facilities stands at 29 percent, nearly fifteen times the overall State rate, and deaths among facility residents account for over half the State’s total. These numbers are also consistent with the trends in other states. As residents of the facilities are likely to have disabilities – age-related and otherwise – they are also a part of the story, though the lack of disability-specific data makes it impossible to determine to precisely what extent.

## COVID Vulnerabilities among Delawareans with Disabilities

By itself, this data might not support generalizations about COVID event rates among Delawareans with disabilities. But they are consonant with the hypothesis that Delawareans with disabilities experience higher rates of COVID cases and higher COVID mortality rates, and that these reflect disparities in vulnerability. This is so, because Delawareans with disabilities are at greater risk of exposure and infection, and are more likely to be disadvantaged by the comorbidities and other risk factors that portend poor outcomes in COVID cases.

### Infection Risk

Although fomite and other mediated modes of transmission for the novel coronavirus remain theoretically possible, the dominant (and perhaps exclusive) modes of transmission now appear to be through person-person contact or aerosolized spread. Absent immunity to infection, the persons most at risk of infection are those most likely to be exposed to other people, and as such, the risk would be impacted by a number of factors highly relevant to people with disabilities: shared or congregate living arrangements; contacts with caregivers, aides, and support networks; and the lack of suitable personal protective equipment for people with disabilities and their caregivers.<sup>10</sup>

These factors alone make mitigation difficult. And for a limited number of people with disabilities, masks present a special problem. Cory Ellen Nourie, MSS, MLSP, Director of Community Services for the Delaware DDDS, notes that “a lot of our service recipients cannot wear a face mask, and that’s either because of an underlying health condition, or because from a behavioral standpoint, they would not be able to maintain wearing it.”

“That’s one of the reasons,” she explains, “that we advocated so strongly to make sure that our service recipients have access to the vaccine, because otherwise the mitigation strategies that you think of being that three legged stool – mask wearing, maintaining social distance and extreme hand hygiene, some of those three legs they don’t have access to in their daily life.”

### **Morbidity and Mortality Risks**

Some biological risk factors for COVID morbidity and mortality are now fairly well-established, including a variety of comorbidities. Among the risk factors currently listed by the CDC, diabetes, kidney disease, hypertension, cardiovascular disease, obesity, and pulmonary disease seem most prevalent in the literature on comorbidities.<sup>11-15</sup> Most of these unequally burden people with disabilities.

Some of these comorbidities are not merely correlated with disability, rather the relationship is definitional: if the condition is severe enough, it is itself disabling. Federal regulations, for example, recognize as “disabilities” for the purpose of Social Security Disability benefits: diabetes (regulations do not distinguish among the types), kidney disease, pulmonary diseases (including COPD), and a variety of cardiovascular diseases.<sup>16</sup> In these cases, people with disabilities are at risk solely by virtue of their disability.

Moreover, whether or not they are disabling, the COVID comorbidities are more prevalent among people with disabilities.

According to the 2019 Behavioral Risk Factor Survey, 12.8 percent of Delaware adults have been diagnosed with diabetes, but that percentage is nearly doubled – to 23.2 percent – for adults with disabilities. Nearly half – 46.4 percent – of Delawareans with diabetes report having a disability.<sup>17</sup>

A logistic regression analysis of data by the Delaware Division of Public Health determined that disability status was “consistently associated with coronary heart disease and angina in Delaware during all years from 2011 to 2015”; disability was also correlated with heart attack and stroke.<sup>18</sup>

Data from the 2017 Behavioral Risk Factor Surveillance System (BRFSS) reveal high blood pressure among 26.8 percent of U.S. adults without disabilities, and 42.9 percent among adults *with* disabilities; in Delaware, high blood pressure was reported by 29.2 percent of adults without disabilities, and 45.1 percent of adults with disabilities.

The same survey data yields similar results for obesity: obesity was found among 25.3 percent of U.S. adults without disabilities, and among 39.6 percent of adults with disabilities; in Delaware, obesity was reported by 26.3 percent of adults without disabilities, and 41.4 percent of adults with disabilities.

The CDC has also identified among its risk factors a behavioral determinant: smoking. According to the 2017 BRFSS, 14.6 percent of US adults without disabilities smoke, a proportion more than doubled – to 30.6 percent – for adults with disabilities. In Delaware, 17.6 percent of adults without disabilities smoke, compared to 33.3 percent of adults with disabilities.<sup>19</sup>

## Immunities

The immune system is the body's natural defense against all pathogens, including viruses, such as COVID-19. With the immune system functioning normally, pathogens are typically dispatched without the individual noticing; illness occurs when the immune system is not properly equipped to handle an infection. There is thus at least a theoretical basis for the need for a strong immune system in the prevention and treatment of COVID-19.<sup>20,21</sup>

There is evidence to suggest that immunity can be enhanced by specific behaviors: that exercise is positively correlated with immune function, and can reduce the incidence of respiratory illnesses<sup>22</sup>; that adequate nutrition is critically important to proper immune functioning<sup>23</sup>; and that the human immune system and sleep are associated and mutually influenced.<sup>24</sup>

But exercise, nutrition, and sleep all can be problematic for people with disabilities. Exercise opportunities are subject to both physical and environmental limitations, thus data from the BRFSS indicates that 24.3 percent of U.S. adults without disabilities are “inactive” (and 25.2 percent in Delaware), while the percentage of adults with disabilities who are “inactive” is nearly doubled, at 43.0 percent (and 42.6 percent in Delaware). Nutrition may be compromised by food insecurity: a 2013 study by the United States Department of Agriculture found “a strong association between disability and food insecurity,” as one-third of U.S. households with a working-age adult unable to work due to disability were food insecure, and one-quarter of households with other disabled working-age adults were food insecure, compared to 12 percent of households with no disabled working age adults.<sup>25</sup> And sleep problems are disproportionately common among people with disabilities, both with physical disabilities<sup>26</sup> and intellectual disabilities.<sup>27</sup>

## COVID Testing, Treatment, and Prevention.

Testing, treatment, and prevention measures—including vaccines—need to be both available and accessible. Too often they are neither. The Federal Emergency Management Agency notes that “People with disabilities may not be able to access COVID-19 testing sites which include, but are not limited to, community-based drive-through testing sites.” “Drive-through testing,” FEMA observed, “is especially inaccessible in urban areas, where fewer people have access to cars.”<sup>28</sup>

Access to testing, treatment, and vaccines can be especially problematic for homebound or institutionalized persons. Transportation and other accessibility issues help explain why people with disabilities are more likely to report delayed or unmet medical care needs.<sup>29</sup>

In the case of vaccines, availability is a particular concern: in spite of the overwhelming evidence that they are at risk, people with disabilities have struggled to get vaccination priority.<sup>30</sup> Marissa Band, Managing Attorney for the Disabilities Law Program (DLP) of Community Legal Aid Society, Inc. (CLASI), says that “demand is really exceeding supply, and people with disabilities are not as far up the list as we’d like them to be.” The Division of Public Health, she notes, did move people with serious mental illness and with intellectual and developmental disabilities, as well as those living in group and congregate care, higher up on the list than they were previously. “Those are steps in the right direction,” she concludes, “but it’s still not yet the ideal.”

Treatment may also be limited by another critical factor: discrimination, including through medical care rationing and Crisis Standards of Care. The SARS-CoV-2 pandemic has resulted in record levels of hospitalizations, creating scarce resources in hospitals across the country, and prompting state agencies and hospitals to implement crisis standards of care policies.<sup>31</sup> According to disability and aging advocates, many of these policies include official guidance which would result in the rationing of medical treatment “based on discriminatory assumptions about the life worth of people

with disabilities.”<sup>32</sup> In some cases, policies overtly discriminate based on disability<sup>33,34</sup>; other policies rely on “neutral” criteria like the patient’s Sequential Organ Failure Assessment (SOFA) score, which may disproportionately harm people with disabilities “due solely to their underlying condition and not their actual prognosis.”<sup>35</sup> Many of these policies were modified after disability rights organizations filed complaints in court, with state agencies, or with the federal Health and Human Services Office of Civil Rights.<sup>36</sup>

Well-conceived policies, however, and well-crafted guidelines, are essential tools in preventing discriminatory treatment based on deeply rooted biases and assumptions about disabled lives. Without guidelines and accountability, individual discretion drives treatment decisions, a hazardous route when 82.4 percent of US physicians report that “people with significant disability have worse quality of life than nondisabled people,” and only 40.7 percent feel “very confident about their ability to provide the same quality of care to patients with disability.”<sup>37</sup> Care decisions made behind closed doors may well be disproportionately adverse to people with disabilities (and to older and heavier adults, and people of color),<sup>38</sup> and people with disabilities “have expressed concern that crisis triage protocols have not adequately prioritized their lives when determining how to allocate access to life-saving health care resources.”<sup>39</sup> It is of significant concern, then, that twenty-two states have no crisis standards of care publicly available, or simply no plan in existence at all.<sup>40</sup>

At the start of the SARS-CoV-2 pandemic, Delaware was relying on a pandemic flu plan originally created in 2008 to guide medical crisis standards of care. The original plan made no mention of specific practices to prevent the discrimination of people with disabilities. While the 2008 plan did not use discriminatory SOFA score criteria, it also did not include any specific criteria for ways to prevent discrimination when rationing lifesaving care in emergency situations.

In April 2020, CLASI’s DLP sent a letter to Governor John Carney and state officials, calling on the state to take “specific steps to ensure that life-saving care is not illegally withheld from Delawareans with disabilities ... due to discriminatory resource allocations or altered standards of care.” Shortly after, the Delaware Health and Social Services Division of Public Health released the Crisis Standards of Care Concept of Operations. The updated guidelines adopted a number of anti-discrimination policies, including orders to maintain the anonymity of triaged patients “to ensure no biases are introduced into the process;” that medical care rationing should “prioritize the number of patients who will recover over the number of life-years saved;” an insistence that “intermediate or long-term prognosis or survival may not be factors in determining priority for emergency lifesaving treatment;” and that vulnerable populations receive the same “resource allocation strategies as all other populations without differentiation as a result of disabilities or vulnerabilities.”

## Conclusion

The available data on COVID events all indicates that people with disabilities are getting infected more often than people without disabilities, and are dying at much higher rates. This is true in Delaware as it is elsewhere. And that limited data is consistent with everything we know about the situation of people with disabilities, and the determinants of COVID risk: people with disabilities are necessarily exposed to greater interpersonal contact and thus to COVID infection; people with disabilities have higher prevalence rates for the comorbidities that predict poorer outcomes in COVID cases; people with disabilities may be less able to bolster their immune systems in ways that might protect against COVID; and people with disabilities confront distinctive barriers to

COVID testing, treatment, and prevention. In short, the evidence is overwhelming that people with disabilities are distinctively vulnerable to the ravages of the COVID-19 virus.

The precise nature and extent of their vulnerability is made difficult to gauge by the relative paucity of data; that in turn makes it difficult to formulate and implement preventive, mitigating, and remedial measures. “It’s problematic,” observes Marissa Band, of CLASI’s DLP, “that we really don’t know the prevalence in the state, and where it’s hitting the hardest, to really help us make decisions.” And, she notes, “it’s the people with disabilities living in the broader community that are likely to be missed when they’re not collecting that data.” “That data,” she concludes, “would be very useful.”

In the interim, we are left to record the suffering:

“Right after the Thanksgiving surge,” recalls Cory Nourie, of Delaware’s DDDS: “I was on my provider phone call on Thursday morning, and we had gone, I think, eight hours without anyone sending me an email with a new positive case. And I was getting ready to celebrate that it had been eight whole hours. And then the emails started coming through, and on that call. Now the providers send me emails and a lot of them preface it with, “I’m so sorry to have to tell you this.” And I’m like, “no, please. I don’t mean for you to take on my sadness here,” but the fatigue is real, it’s real. And every time a new positive comes in, my heart just sinks a little lower because it’s real. And I think about all of the staff who are trying so hard and their leadership of the provider organizations, and it’s just really, really difficult.”

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