



# The Impact of the COVID-19 Pandemic on People with Disabilities in Delaware

*Disproportionate Risk. Devastating Impact. Emerging Resilience.*



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# INTRODUCTION

## *Disproportionate Risk. Devastating Impact. Emerging Resilience.*

This report explores the experience of people with disabilities in Delaware during the pandemic caused by the COVID-19 virus from January 1 to December 31, 2020.

One in four adults in Delaware have a disability according to the Center for Disease Control and Prevention's (CDC) 2019 Behavioral Risk Factor Surveillance System. The 198,284 individuals living with a disability in Delaware were disproportionately at risk from COVID-19 during the past year.

To capture the Delaware experience, it is essential to understand the context of the pandemic both nationally and globally. It is also critical to recognize that the profound impacts of the pandemic on our day-to-day lives were felt by all Delawareans, those with and without disabilities. This story, then, is necessarily broad to capture the larger context, but it also is very focused with a lens on the impacts felt by the disability community within the state.

The lives of many people with disabilities are interconnected with support systems to ensure independence. These support systems are fragile and susceptible to disruption when threatened. Shakespeare et al. (2021) suggest that the disproportionate impact of COVID-19 on people with disabilities is a case of triple jeopardy.

“People with disabilities have been differentially affected by COVID-19 because of three factors: the increased risk of poor outcomes from the disease itself, reduced access to routine health care and rehabilitation, and the adverse social impacts of efforts to mitigate the pandemic.”

This report outlines the findings from delving into a limited number of data sources, listening sessions, and discussions with individuals involved in the COVID-19 response. An online story map is also available to review the findings at <https://arcg.is/19XLqD>.

A myriad of **risk** factors aligned during the COVID-19 pandemic that made people with disabilities among the most vulnerable segments of the population. The **impacts** resulted in a devastating loss of life, threatened independence, extended isolation, and disrupted service delivery. As the pandemic comes under control with increased knowledge about transmission and the availability of vaccines, it is possible to look back and identify the fault lines in service systems that exposed people with disabilities to increased risk and the threads of community **resilience** that emerged to fill in the gaps to protect the most vulnerable.

As Delaware policy makers and community leaders look forward, there is an opportunity to learn from the past year and weave these threads of emerging resilience into a stronger system that will decrease the vulnerabilities and disparities in the system of care and support and make strides to fully protect people with disabilities in future public health emergencies.

# ABOUT THE PROJECT

In July 2020, the Freedom Center for Independent Living issued a Request for Proposals to conduct a study on the impact of the COVID-19 pandemic on people with disabilities within Delaware, set against a national backdrop.

The Freedom Center for Independent Living is a resource and advocacy center located in Middletown, Delaware, that works to promote dignity, self-determination, independence, and full participation in community life for people of any age that experience a disability. The Freedom Center's mission is to empower persons with disabilities by enabling them to gain effective control and direction over their own lives. The Center assists individuals with navigating the bureaucratic system so that they can acquire the support and services they need to achieve and maintain a dignified, independent lifestyle within the community. The Center promotes a growing sense of empowerment, self-determination, self-esteem, and self-direction within persons with disabilities by providing, at a minimum, advocacy, support, and training services.

The Center for Drug and Health Studies at the University of Delaware was awarded the contract and began work on the project in January of 2021. The project was initiated with two specific goals.

- Explore and document the impact of the COVID-19 pandemic on the community of individuals in Delaware living with a disability during 2020 using available data sources.
- Provide data and documentation that will support the Freedom Center for Independent Living in its mission to empower persons with disabilities and to provide advocacy, support, and training.

## **Methods**

The project's dates of interest were from January 1, 2020, until December 31, 2020. Data collection was undertaken in January 2021 and continued through June 2021. Researchers were

initially searching for reports, news stories, and social media posts to determine what, if any, data was available to quantify what was happening in the Delaware disability community relative to COVID-19.

The first type of data collection was undertaken with online sources, including social media, using the keywords “COVID,” “coronavirus,” “pandemic,” “disability,” “intellectual disability,” and “developmental disability.” Stakeholders in the state also sent articles of interest to researchers if they believed they fit the parameters of the project. Searches were conducted using LexisNexis, an online news database accessible through the University of Delaware. Further, the News Journal, a Delaware based news publication was searched for articles regarding disability and COVID-19. Some known sources for this project included media outlets that specifically cover disability related stories such as DisabilityScoop.com and AARP.com. Data collected from online sources were read, summarized, and coded based on 25 different life domains.

A second method of data collection were listening sessions. These were held via zoom and were not recorded. It was decided to reach out to people in the disability community as key informants on what data may be available or known to be in the process of being collected. Individuals were put onto an email invitation list in consultation with members of the disability community who knew of individuals and organizations that were working with people with disabilities in relation to COVID-19. Emails were sent to individuals throughout Delaware inviting them to join one of three listening sessions. These sessions were held on different days and times to allow participants to select the most convenient time to attend. The sessions were open to any member of the Delaware community, including those who did not initially receive the invitation. Confidentiality and autonomy were not able to be maintained, so all participants were told at the beginning of the session that they may be quoted or referenced in any final, finished material.

Participants were asked if they knew about any data regarding disabilities and COVID-19. Further, participants were asked what their organization typically does during normal operations within the context of the disability community and how that changed because of



COVID. Specific questions and prompts were used as follow-ups depending on responses to the initial questions.

A third data collection strategy was to follow-up with participants of listening sessions, those who were unable to attend, and individuals referenced as possible key stakeholders during listening sessions in order to explore specific topics brought up in the zoom calls. These were typically handled by setting up a zoom or phone call with the participant. Further, these follow-up discussions usually provided additional contacts to query about data on disabilities and COVID-19. Eleven additional conversations were conducted, via zoom or email, to glean information on pre-identified domains as well as potential areas with data.

### **Limitations: Things to consider as you review this story.**

**The impact of COVID-19 on people with disabilities is not yet fully known and is still emerging.** This report was originally planned to cover 2020, but the pandemic continues to develop. We have tried to include relevant events from early 2021 (e.g., vaccines) and capture early observations but there will be more to this story.

**This was not designed as an exhaustive inquiry.** The focus on existing reports leaves the possibility that key elements of the challenges of people with disabilities were not identified. The inclusion of agency representatives aimed to help fill this gap; however, these statements are not representative of the entire disability community in the state.

**Disability status is not being routinely collected with COVID-19 case forms.** The CDC case form does not include fields for disability status or type (CDC, 2021a). While the focus of this report is on Delawareans with disabilities, please note that for many of the key areas of impact Delaware-specific data was not available. In these cases, we have illustrated the impact of the pandemic on disability populations using available data. In some cases, the data is from another state. In other cases, it may be limited to a sub-population of disability (e.g., individuals with Down syndrome). The intent is to reveal the disparate impact on this population and point to opportunities to explore further the true impact on Delawareans with disabilities. This data gap reveals the challenge of finding critical reporting from other states such as disparities in

outcomes for people with disabilities in hospitalizations and death rates without being able to report Delaware equivalents because of lack of data collection on disability status.

**There is a significant lack of data on the Delaware disability community's experience with COVID-19 being captured.** The ever-evolving nature of the pandemic meant that often people were too busy responding to the needs in their communities that they did not have time to quantify many of the needs they saw or the actions they, or their organization, took. Individuals were able to speak anecdotally about what they knew was happening in the disability community but did not necessarily record dates that different events occurred, or the way needs were met. It was accepted that the situation was untenable for many individuals in Delaware, but looming problems often brought the requirement for immediate solutions rather than time to reflect and document. Health concerns easily overshadowed other pressing issues such as food insecurity or educational challenges. Other issues affected by health appeared to be less tangible than prevalence and death rates and thus more difficult to explain with the lack of tracked, written data. Moreover, as the pandemic is still ongoing, there are no existing after-action reports to cross reference.

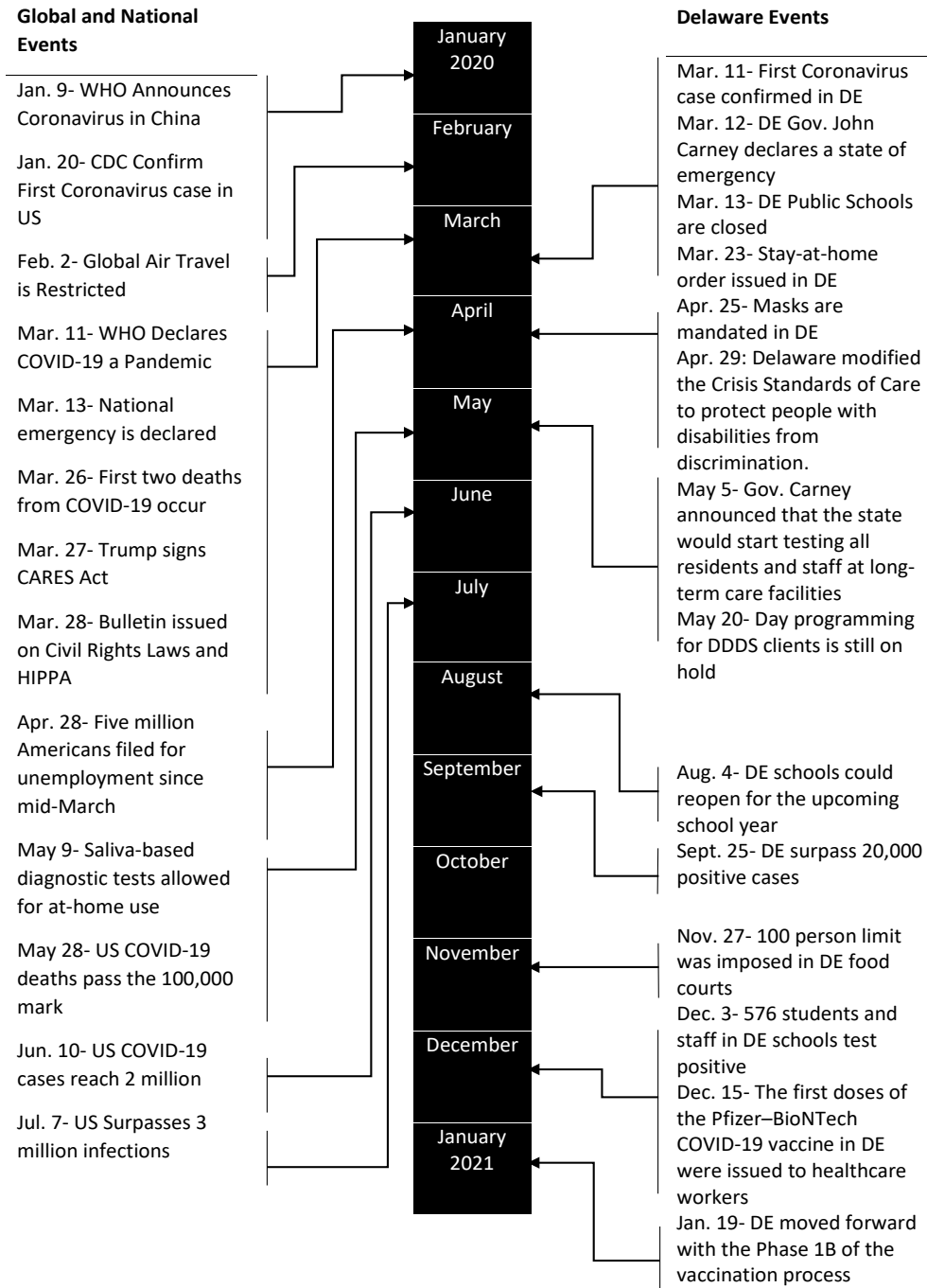
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An interactive map of Daily New Confirmed COVID-19 Cases per Million People beginning January 28, 2020 is available at: <https://ourworldindata.org/explorers/coronavirus-data-explorer>.

# TIMELINE OF COVID-19

An interactive version of this timeline is available in the online story map at

<https://arcg.is/19XLqD>.

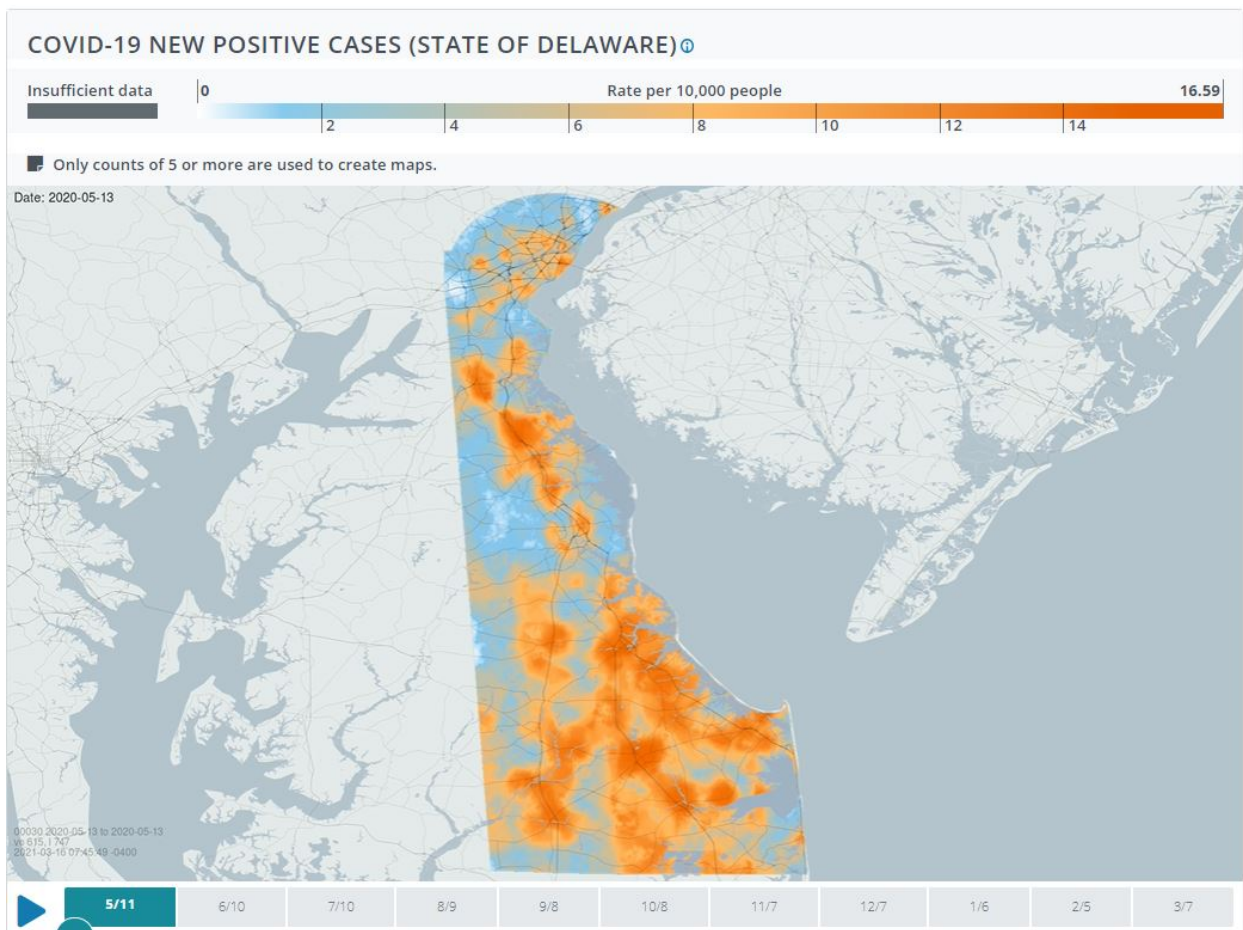


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**Delaware New Positive Cases Map:** This map reflects the cases in Delaware at the end of December 2020.

An interactive version of this map is available at

<https://myhealthycommunity.dhss.delaware.gov/locations/state.>



# DISPROPORTIONATE RISK. DEVASTATING IMPACT.

A constellation of risk factors aligned during the COVID-19 pandemic that made people with disabilities among the most vulnerable segments of the population. These are factors that contributed to the disproportionate impact.

## **People with disabilities have higher rates of chronic conditions or comorbid conditions.**

People with disabilities are more likely to have certain conditions that can increase risk of death due to COVID-19 and complications related to delayed or interrupted care. In a review of more than 400,000 claims records from privately insured patients from a five-month period in 2020, researchers found that having comorbid conditions increased the odds of dying from COVID-19. Eighty-three percent of the patients included in the claims analysis had a pre-existing comorbidity. As the patient’s number of comorbidities increased, so did the odds of dying from COVID-19 (Makary, 2020).

Adults with disabilities experience health disparities that amplify their risk for severe outcomes from COVID-19. The 2019 Center for Disease Control and Prevention’s (CDC) Behavioral Risk Factor Surveillance System provides data that confirms the higher rates of these conditions in adult Delawareans with disabilities (CDC, 2020b).

<b>Rates of conditions increasing COVID-19 risk in Delaware adults by disability status</b>		
<i>Source: 2019 BRFSS</i>		
CONDITION	Without disability	With disability
Have obesity	31%	44%
Have diabetes	8%	18%
Have heart disease	3%	10%
Smoke	13%	28%

Having certain types of disability may increase risk as well. The Fair Health study found that across all age groups people with developmental disorders (i.e., developmental disorders of speech and language, developmental disorders of scholastic skills, central auditory processing disorders) had the highest odds of dying from COVID-19 and were three times more likely to die than those without developmental disorders (Makary, 2020).

Although specific data for Delaware is unavailable for risk associated with disability type, there is evidence that individuals with developmental and intellectual disabilities were more likely to contract the virus and more likely to die from it.

In June 2020, NPR reported disparities in death rates for Pennsylvania and New York related to disability status. In Pennsylvania people with intellectual disabilities and autism who tested positive for COVID-19 were twice as likely to die from the virus as other Pennsylvania residents who contracted the virus. In New York, people with developmental disabilities were dying at a rate of 2.5 times the rate of others who contracted the virus (Shapiro, 2020).

In March 2021, the [Delaware Journal of Public Health](#) published an issue focused on [Diversability](#), and included a report on the COVID-19 outcomes for individuals receiving services from the [Delaware Division of Developmental Disabilities Services](#). The mortality rate in Delaware's long term care facilities was reported at 29 percent, nearly fifteen times the overall State rate, and deaths among facility residents account for over half the State's total.

While there was some fluctuation in the disparity in case rates and mortality rates early in the pandemic, the disproportionate burden of those with IDD was constant. When data are available for comparison, residents with IDD are getting infected, and are dying, at significantly higher rates than the general population (DAM/DJPH, 2021).

Adults with intellectual and developmental disabilities have higher odds of having pneumonia contribute to their death than adults without IDD. "Specifically, compared to adults without IDD, the probability of having a diagnosis of pneumonia at the time of death were 2.9 times higher for adults with intellectual disability, 3.5 times higher for adults with cerebral palsy, 3.9

times higher for adults with Down syndrome, and 1.9 times higher for adults with other rare developmental disabilities (Landes et al., 2020b).”

### **People with disabilities are more likely to be living in congregate settings than those without disabilities.**

According to the 2019 American Housing Survey (AHS), approximately 38% of all U.S. households in multi-person homes (34 million households) were not prepared to keep one person completely isolated if required to because of COVID-19, meaning those homes did not have at least two full bathrooms and enough bedrooms for isolation (AHS, 2020).

For individuals living in congregate settings - nursing homes, long-term care facilities (LTC), group homes, or assisted living facilities - isolation or quarantine may be even more difficult and the risks from COVID-19 significantly increased. In Delaware, it is reported that 6.84 percent of people with disabilities over age 65 reside in nursing homes (ADA PARC, July 2020).

A striking statistic nationally shows that residents of long-term care facilities constitute less than 1 percent of the U.S. population, yet 43 percent of all COVID-19 deaths through June 2020 occurred in those places (Hochmad, 2020b). During the first two months of the pandemic from March 23, 2020, through May 30, 2020, nursing homes surveyed reported issues with securing personal protective equipment (PPE) and having adequate numbers of staff (Office of Inspector General, 2020) which likely affected the number of people being infected with the virus.

In a review of cases of Californians receiving IDD services compared to the larger California community, researchers found that outcomes for individuals receiving IDD services varied by type of residence and skilled nursing needs. They found higher rates of diagnosis in settings with larger numbers of residents and higher case-fatality and mortality rates in settings providing 24-hour skilled nursing care (Landes et al., 2020f).

Distribution of COVID-19 outcomes for Californians who were/were not receiving IDD services as of October 2, 2020. SOURCE: Landes et al. 2020 (f)				
	Population	Case rate per 100,000	Case fatality rate	Mortality rate per 100,000
Californians not receiving IDD services	39,157,583	2085	.019	41
Californians receiving IDD services	354,640	831	.055	46
Receiving services in own home or family home	315,650	523	.028	15
Receiving services in Community Care Facility	23,722	2,268	.043	97
Receiving services in ICF/DD Habilitative (ICF-DD-H)	3,739	5,590	.062	348
Receiving services in ICF/DD Nursing (ICF-DD-N)	2,163	4,392	.158	693
Receiving services in ICF/DD Developmentally Disabled (ICF-DD)	557	19,031	.047	898
Receiving services in Skilled Nursing Facility	1,031	27,546	.204	5,626

Delaware’s chapter of the American Civil Liberties Union (ACLU) called for protection for individuals living in congregate settings through oversight to ensure supports are in place (e.g., investigating abuse or neglect complaints, support for families providing care, etc.), transparency surrounding infection rates, and higher compensation and support for the employees at care facilities because of the volume of people they interact with every day in close quarters (ACLU of DE, 2020). Nationally, residents and worker deaths are higher in LTC facilities, and Delaware’s COVID-19 death rate is attributed to LTC facilities, at a rate of over 60 percent (ACLU of DE, 2020), as living in an institutional setting increases the risk of infection and death (McMullin-Powell, 2020).

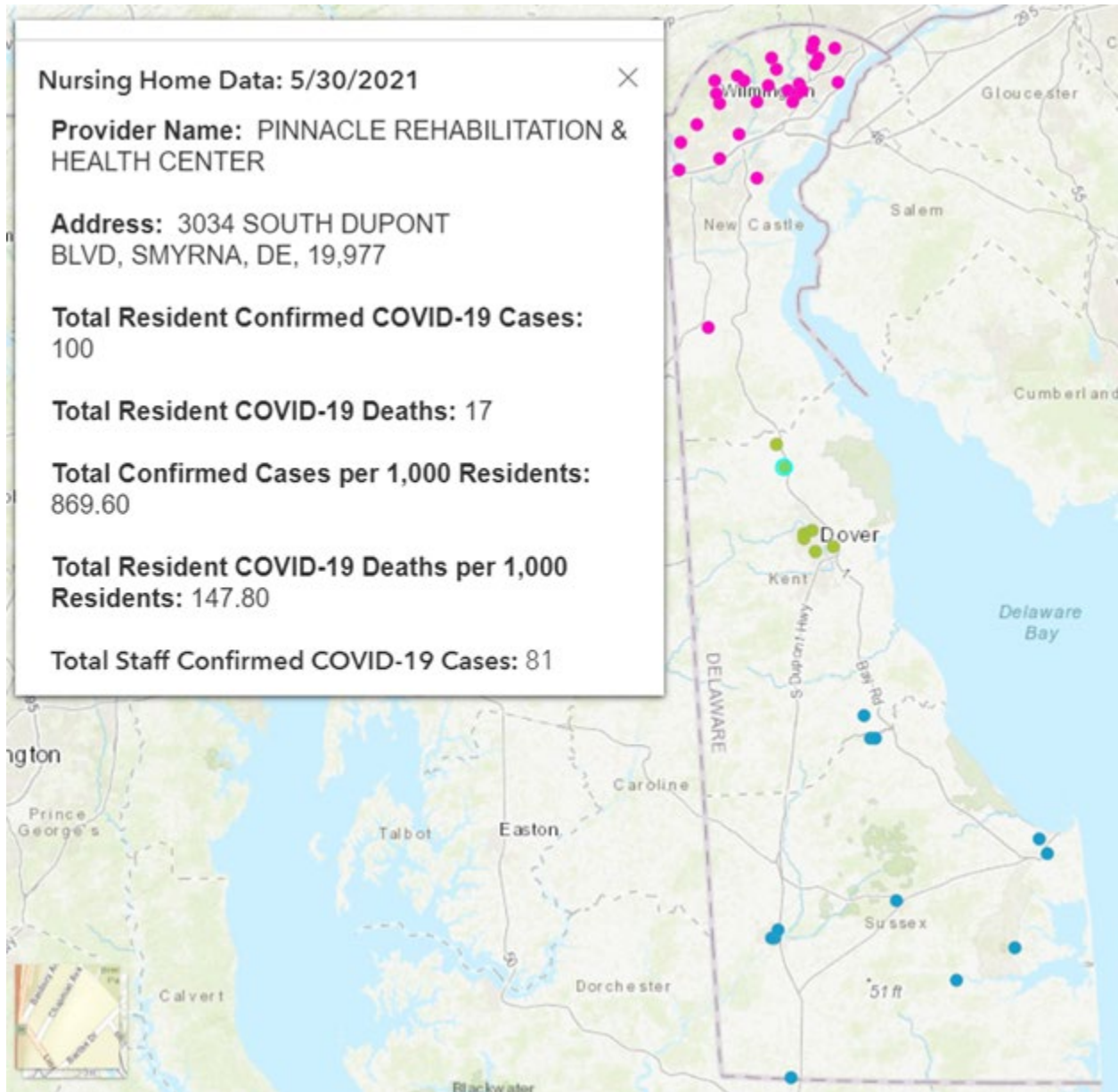


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Map of Delaware nursing home locations with resident and staff COVID-19 cases and deaths.

An interactive version of this map is available online in the partner story map

(<https://arcg.is/19XLqD>) and provides detail for each facility.



## **People with disabilities often rely on in-person services for independent living and many experienced interruptions in service to closures and social distancing.**

Supports, often delivered in-person, are key to maintaining independence for people with disabilities. This one-on-one care enables people with disabilities to navigate daily living skills, to attend school or work, and to be engaged in the community.

Covid has severely limited much of the day-to-day care that people with disabilities utilize to maintain independence and has made it difficult for individuals to maintain a normal routine or to even count on care from others. This is because it is generally unsafe for people to be coming in and out of the home or care facility. However, this creates situations where it may be dangerous for there to be no help and extremely risky to receive help from anyone not living in your home (Sy, Jackson and Kuhn, 2020).

One study found that more than 70% of people with IDD living in the community had a direct care worker to provide care in the home during the pandemic. Among those, 76 % continued to receive those home services while 24% were no longer receiving services. For those who were receiving services from direct care workers, only half reported that they were able to maintain safe distance from their direct care worker (Drum, 2020).

Educational support professionals often provide one-on-one support to students receiving special education services. In a study of staffing patterns in Delaware schools, it estimated that nearly 3,000 paraprofessionals work with students (Kelly, 2019) in Delaware. School closures left many students at home without the one-on-one support they need to fully engage and learn.

The impact of the closure of schools was more severe for students who rely on support professionals. 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. The value of in-person coaching also extends to job training programs and supported

employment. Another aspect of education impacted by the restrictions on in-person activities was the process for students to get assessed and determined as eligible for services, and to plan for transition from school to employment following graduation (Constantino et al. 2020).

“Identifying autism is something that would typically be done face-to-face, it’s been hard for families to get medical diagnosis and to get medical support and paperwork for schools. In adult services, programs were closed or not able to expand what they were doing to serve more people. It is a struggle at the student level going to transitional services and for families ... families don’t want to expose their loved ones to work right now, there’s also work options that have been shut down (Meisel, 2021).”

### **Individuals with disabilities living in the community, along with their caregivers, were at increased risk.**

Although congregate settings were the hotspots of COVID-19 infections, individuals with disabilities in community settings, along with their caregivers, were not without risk. The presence of chronic or co-morbid conditions, potential exposure through health care workers coming to the home, and interruptions in health care and services created elevated risk for this population, even though they were living in the community.

Those who are providing in person support also experienced increased burden. Family caregivers, who provide unpaid care to a spouse, parent, child, other relative, partner, or friend to help them take care of themselves because of an illness or disability, were also impacted by the pandemic. A 2020 survey of family caregivers and noncaregivers conducted by the University of Pittsburgh found that family caregivers reported more negative effects from the COVID-19 pandemic than noncaregivers.

Family caregivers were more likely than noncaregivers to make behavioral adjustments due to COVID than noncaregivers. They were less likely to visit a doctor than noncaregivers (5% vs. 64%). They were more likely than noncaregivers to cancel out of home activities such as pleasure travel (63.5% vs. 59.0%), work or school activities (39.3% vs. 31.7%), or doctor’s appointments (57.0% vs. 42.9%). Family caregivers were more likely than noncaregivers to:

- Worry more about their financial situation compared to prior to the pandemic,
- Worry about having enough food and being able to pay for food since the pandemic,
- Report higher levels of anxiety on the PROMIS anxiety score (9.1 vs. 8.3) and the depression score (7.5 vs. 7.1), and
- Report higher levels of fatigue, sleep disturbance and pain interference in the last seven days (University of Pittsburgh, 2020).

A University of Connecticut survey of caregivers of children with and without disabilities also found the mental and emotional well-being of caregivers impacted by the pandemic. Caregivers of children with developmental disabilities experienced significantly higher caregiver burden, depression, anxiety, and stress (Chafouleas, 2020).

Delaware's disability advocacy agencies collectively sought to bring awareness of the risk of individuals with disabilities and their caregivers to the attention of the governor, public health administrators and the medical community (L. Waterland, personal communication, 3/31/2021). Advocates successfully petitioned for direct support professionals and family caregivers, along with care recipients living in the community, to be included in the first tiers of vaccine eligibility.

Caregivers also reported that employment was impacted by the pandemic. For those who were no longer working after the pandemic non-caregivers reported it being related to COVID-related shutdowns while caregivers were more likely to report no longer working being related to having to provide care for their family (University of Pittsburgh, 2020).

**The economic position of people with disabilities that may make them more susceptible to negative impacts - low income, working part-time or not working, or working in service positions that put them at risk or resulting in unemployment.**

Services in the community for IDD that provide day services or assist with employment were curtailed in March 2020 to stop the spread of COVID-19 but may have lasting impacts.

Nationally, a survey of 191 organizations that serve people with developmental and intellectual disabilities in areas related to employment services and day programs found that 77% discontinued or shut down programs due to COVID-19 related challenges. Of those that curtailed services, 16% of organizations do not anticipate reopening (Diament, 2020a). This dearth of services may be further exacerbated by the census being ended two weeks early on October 15, 2020 rather than October 31, 2020 which may have caused an undercount that will consequently result in funding cuts for programs in the disability community (Diament, 2020b).

### **Health promotion and educational materials related to COVID-19 that may be inaccessible or not available to people with disabilities.**

Accessibility to media is a longstanding issue for people with disabilities. The health promotion messages related to COVID-19 were constant, evolving with scientific understanding and often confusing for the general population. Regular channels of receiving information were interrupted as medical appointments were delayed and schools were closed, and information mediums shifted to mass and social media for information.

One survey of individuals with disabilities found that television was the most important source of information about COVID-19 (31%), followed by the internet (24%) and health care providers and health systems (both at 15%) (Drum, 2020).

# EMERGING RESILIENCE

*Extraordinary ways that people came together to transform service delivery.*

The response to COVID-19 was dramatic. It shut down life as we knew it. Travel was banned. Schools closed. Businesses sent employees home indefinitely. Religious groups were unable to congregate. The community organizations that structure social life were closed: only “essential businesses” were allowed to continue operation, and only with severe restrictions. Knowledge about the virus was emerging and guidance was limited, changing and confusing.

The system did not work well for people with disabilities during the pandemic. The need for in-person supports collided with the attempts to control the virus. The closures of services, the stay-at-home orders, and social distancing left people with disabilities isolated and bereft of critical services. The nature of the public health crisis revealed cracks in the system that allowed people with disabilities to be among the most vulnerable and most ravaged by the fallout of the crisis.

In response to the gaps laid bare as the pandemic rolled on, there was a creative, flexible initiative that emerged to continue the work of meeting emerging needs: community resilience.

Community resilience is a concept that captures the sustained ability of communities to withstand and recover from adversity. Elements of community resilience include social connectedness for resource exchange; effective risk communication for all populations, including at-risk individuals; integration and involvement of government and non-governmental entities in planning, response, and recovery; physical and psychological health of the population, and social and economic well-being of the community (US DHHS, 2021).

The resilience of Delaware residents generated extraordinary measures taken to protect life, ensure human connections, and sustain social structures. Policies were changed and community agencies learned to do things in new ways that kept residents safer and provided care for those most in need.

**Access to food** was essential and access quickly became limited for those who had lost jobs and income, for children who relied on school-based meal programs, and for seniors and people with disabilities who are receiving home-delivered meals or attending community meal sites.

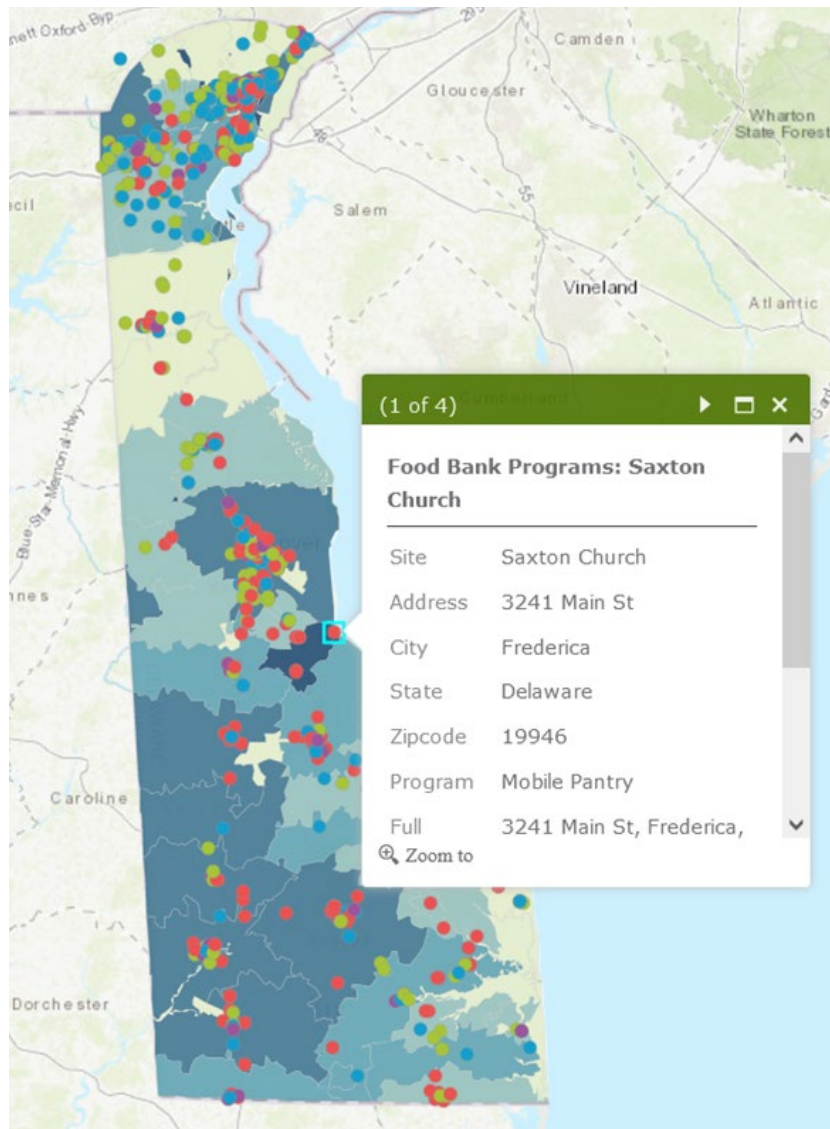
A Census Bureau COVID-19 Household Pulse Survey on food security found that of Medicare beneficiaries (under 65) with disabilities only 44.3% reported having enough of the foods that they wanted to eat during the pandemic (United States Census Bureau, 2020).

State agencies, community agencies and local businesses collaborated to redistribute food supplies quickly. Facebook and other social media posts helped alert the community when food pantries were mobilized. Many agencies, including the Division of Services for Developmental Disabilities (DDDS), the Division for Services for Aging and Adults with Disabilities (DSAAPD), the Delaware Emergency Management Agency (DEMA), and the Delaware Department of Transportation (DelDOT), were actively supporting and promoting these events.

The Food Bank of Delaware engaged in a massive effort to meet the urgent need. More than seventeen million pounds of food was distributed to the community through Food Bank programs. Homeless individuals living in motels received 353,009 meals and snacks. 167,726 backpack meals were distributed to kids in need and 33 drive-thru food distributions served 42,847 households (Food Bank of Delaware, 2021).

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The Story Map contains an interactive resource for information on food resources in Delaware. The map was created by the University of Delaware Institute for Public Administration. Each dot represents a point of distribution. Visit the interactive map to explore details for each site: <https://arcg.is/Pvbzz>.



To respond to the closing of senior centers and meal programs in 2020, the Division of Services for Aging and Adults with Disabilities (DSAAPD) supported senior centers in a shift to home-delivered meals and curbside pick-up and provided more than 1,000,000 meals to 6,172 Delawareans over age 60 (J. Devlin, personal correspondence, March 25, 2021). Providers in the state, St. Anthony’s, Modern Maturity, and Cheers as well as Meals on Wheels Lewis and Rehoboth, among others, were instructed that the last in-person meal they could serve would be Friday, March 8, 2020. On Monday, providers would need to be able to begin to deliver meals. DSAAPD believed that providers truly stepped up and it made a difference for the



individuals they serve. Meals were delivered to participants via the providers throughout the state and when needed, DSAAPD had a grab-and-go area at the Adult Day Center for individuals who were able to come by to pick-up a meal.

The Delaware Department of Education received a waiver from the federal government allowing school nutrition programs to continue providing meals even though schools are closed (DDOE news release March 16, 2020). In late March of 2020, school districts and other organizations began to provide Delaware students with breakfasts and lunches during the closures. School buses continued their routes and delivered food to families who rely on school nutrition programs.

**Recognition that direct care workers and caregivers were essential supports for people with disabilities.** In the early days of the pandemic, restrictions on visitors in hospitals were enacted to control the spread of the virus. There were heartbreaking stories of people dying without families at their side and goodbyes facilitated over FaceTime on a device.

For people with disabilities who rely on a direct support professional for assistance with activities of daily living and to enable their independence, this restriction was devastating, and functionally denied them access to the same level of service.

In May 2020, the National Council on Disability issued a statement encouraging state and local agencies to issue rules and guidance allowing for visitation by direct support professionals (DSP) for patients with disabilities admitted to the hospital for COVID-19. The statement cited the lack of training that hospitalists have with disability and the key role that DSPs play in relaying patient history, translating body language and diffusing anxiety (NCD (b), 2020)..

With prompting from disability advocates in Delaware and in response to a bulletin from the HHS Office of Civil Rights, in May the Delaware Division of Public Health released hospital guidance confirming that it does not consider “support professionals for individuals with intellectual or developmental disabilities to be visitors” (DHHS, Hospital Guidance, May 2020). A later revision also addressed and allowed family caregivers to remain with individuals with intellectual disabilities or cognitive impairments as a reasonable accommodation.

**Telemedicine restrictions were eased**, and legislation enacted to facilitate access to health care when in-person visits were not possible. In March 2020, Governor Carney included a temporary lift on certain telehealth restrictions in his modification to the emergency declaration. On 7/17/20, he signed legislation (HB348) that suspended restrictions on telemedicine related to provider requirements, the location of the patient in Delaware, and the requirement that the patient first see the provider in person. In addition, insurers waived or reduced copays for telemedicine visits.

**Medicaid waivers eliminated barriers to care** for Delaware residents under the Medicaid Disaster Relief State Plan Amendments. Delaware Division of Medicaid and Medical Assistance sought waivers to ease requirements for timely processing of applications and/or renewals, eliminate deductibles, copayments, co-insurance, and other cost sharing charges, eliminate waive or suspend enrollment fees, premiums, or similar charges in Medicaid and CHIP. This effort also eased restrictions on access to prescription medications (i.e., allow for early refills, waive, or extend prior authorization requirements), payment changes to increase state plan payment rates, authorize telehealth payment variations and/or include ancillary telehealth costs, and temporarily increase payment for COVID-19 vaccine administration to 100% or the Medicare rate (KFF, 2021).

**Expanded access to communication devices and internet access** allowed many people with disabilities to stay connected and access services that otherwise may have been delayed or cancelled. Organizations across the state used federal funds to provide technology - laptops, tablets, or phones - to people with disabilities to ensure they could stay connected.

Schools across Delaware deployed devices to students to allow for remote learning and facilitated access to Wi-Fi with internet providers for families with limited resources (<https://www.doe.k12.de.us/Page/4273>). The DDOE invested federal Elementary & Secondary School Emergency Relief (ESSER) funds to provide students with access to educational and popular digital books that will be available to schools and their 144,000 students. The digital collection is available for students to borrow and read on any device inside the classroom, at

home and anywhere 24/7. Families received their sign-on credentials through their students' schools.

DSAAPD was instrumental in providing technological devices via Senior Centers. DSAAPD received CARES funding that was used to support various programs, and one of the ways funding was used by DSAAPD was to accept applications from Senior Centers throughout Delaware to support virtual programming. The Senior Centers submitted applications with a wide array of requests: funding to buy technology, teach people how to use the technology, and virtual programming including Zumba classes, bible studies, yoga classes, as well as others. It was reported that Senior Centers saw hundreds of participants access virtual programming to stay connected during the course of the pandemic.

In a Culture of Health blog post in September 2020, Russo named broadband services, as well as affordable gas and electricity, as one of three services crucial to health equity. Internet access is essential for employees working from home, for students learning remotely, for patients to connect with medical providers for routine and acute medical care, and to foster social interaction (Russo, 2020).

Libraries boosted the pre-existing wireless signals from their buildings in order for people to sit in the parking lots on their devices to access the internet. Libraries have also purchased or in the process of procuring additional hotspots for patrons to check out in order to have access to the Internet.

Libraries expanded their hours of operation to better serve patrons. Curbside pick-up was started at all sites so that patrons could call in and request material or use the library catalogue at home to decide on what material they wanted to take out. As libraries were fully closed to the public for months, one library in Bethany used their kids room window to put books on display for individuals to look at new material and put in requests. Libraries also started reaching out to some of their patrons that were known to be homebound or those that regularly used the library services and were known to the staff. The Laurel Library kept in touch with their patrons during COVID-19 by sending cards for major life events and calling when they

had not seen one of their known-to-them patrons for a while. If phone calls were not successful in reaching the patron, officers would go with a library staff member out to do a home check on the patron.

The concept of 'homebound' expanded because of COVID-19 due to the need to shelter-in-place. Pre-COVID at one of the downstate libraries, only 2-3 patrons were homebound in the traditional sense but that increased dramatically when programs were shut down and people were told to remain at home.

# COVID-19 IMPACT ON LIFE DOMAINS

Life domains is a concept that emerges from the LifeCourse framework. It approaches life as a connected and integrated set of six life domains. The next section looks at the impact of the pandemic on specific domains.

## **Healthy living**

This domain focuses on managing and accessing health care and staying well — medical health, mental health, behavioral health, developmental stages, wellness, and nutrition.

## **Disability status and co-morbid conditions**

The CDC has identified certain groups of people who may get severely ill with COVID-19: older adults, people from racial and ethnic minorities, and people with disabilities. People with disabilities are more likely than those without disabilities to have chronic health conditions, live in congregate setting, and face more barriers to healthcare. Studies have shown that some people with certain disabilities are more likely to get COVID-19 and have worse outcomes (CDC, 2021a).

Individuals with intellectual and developmental disabilities (IDD) have a slightly higher rate of contracting COVID-19 and a substantially higher rate of dying from the virus. This report also identified patients with intellectual disabilities and related conditions had the third highest risk of COVID-19 death.

## **Living arrangements/Congregate living**

Elaine Ryan, AARP's vice president of government affairs for state advocacy: "Early on, there was a lack of prioritization for nursing homes. Hospitals were seen as the epicenter of the crisis — but the epicenter of deaths was nursing homes. It was stunning to see that at the start of the pandemic, there was quick action to dismiss college students from campuses, to close down

basketball games because these were congregate settings. Yet nursing home residents were ignored. No one suggested moving them.”

Center for Medicare and Medicaid Services (CMS) Director Seema Verma saw it differently: “Nursing homes were always high priority. Originally, states weren’t necessarily getting PPE out to the nursing homes, which is why we changed that strategy. FEMA [the Federal Emergency Management Agency] started directly sending supplies to the nursing homes, and I think that made an incredible difference” (AARP, 2020).

People with developmental disabilities are much more likely, than even elderly people, to live in a setting with roommates and staff like group homes where two or four or 10 or more people live together. About 13% to 20% of people with developmental disabilities live in such settings, Landes notes, compared with only about 6% of people over age 65 (Shapiro, 2020).

### **Disruptions and delays in care**

The World Health Organization (WHO) Pulse Survey reports that health services were hit across the board. Based on reports from key informants, countries on average experienced disruptions in 50% of a set of 25 tracer services. The most frequently disrupted areas reported included routine immunization – outreach services (70%) and facility-based services (61%), non-communicable diseases diagnosis and treatment (69%), family planning and contraception (68%), treatment for mental health disorders (61%), cancer diagnosis and treatment (55%).

Disruptions were caused by a blend of demand and supply side factors. Reductions in outpatient care attendance owing to lower demand were reported by 76% of countries, with other factors such as lockdown (48%) and financial difficulties (33%) also mentioned. The most commonly reported factor on the supply side was cancellation of elective services (66%). Other factors reported by countries included staff redeployment to provide COVID-19 relief (49%), insufficient personal protective equipment available for health care providers (44%), unavailability of services owing to closures of services or health facilities (33-41%), and interruptions in the supply of medical equipment and health products (30%) (WHO, 2020a).

The American Association on Health and Disability (AAHD) conducted a survey of 2,469 adults with disabilities in spring of 2020 to assess the impact of the pandemic on health care and other areas of living. Respondents were asked if they were able to get regular health care treatment (such as physical therapy, dialysis, bloodwork, etc.) during the COVID-19 outbreak. Thirty-six percent of respondents did not receive regular health care. Among respondents who did, 56% reported access had been disrupted and 44% reported that access had not been affected (Drum, 2020).

**Death rates**

According to the Delaware Environmental Public Health Tracking Network (<https://myhealthycommunity.dhss.delaware.gov>), as of June 30, 2021 there were 1,695 COVID-19 related deaths reported in Delaware. This is a mortality rate of 13.7 per 10,000 people. Eighty-three percent of those deaths were residents aged 65 or older. Seventy-one percent were White, and 95 percent were non-Hispanic.

Having certain types of disabilities appears to increase the risk of death. Individuals with IDD have a slightly higher rate of contracting COVID-19 and a substantially higher rate of dying from the virus.

<b>COVID Event Rates, DDDS Residential Rehabilitation Service Recipients (through 1/31/2021)</b> <i>Source: Data Courtesy of Delaware Division of Developmental Disabilities Services (via Ashford et al. 2021)</i>			
	% Positive	No. of 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

In March 2021, the Delaware Academy of Medicine published a report on the COVID-19 outcomes for individuals receiving services from the Delaware Division of Developmental Services in the [Delaware Journal of Public Health](#). The mortality rate in Delaware's long term care facilities was reported at 29 percent, nearly fifteen times the overall State rate, and deaths among facility residents account for over half the State's total.

While there was some fluctuation in the disparity in case rates and mortality rates early in the pandemic, the disproportionate burden of those with IDD was constant. When data are available for comparison, residents with IDD are getting infected, and are dying, at significantly higher rates than the general population (Ashford et al., 2021).

Adults with IDD have higher odds of having pneumonia contribute to their death than adults without IDD. Specifically, compared to adults without IDD, the probability of having a diagnosis of pneumonia at the time of death were 2.9 times higher for adults with intellectual disability, 3.5 times higher for adults with cerebral palsy, 3.9 times higher for adults with Down syndrome, and 1.9 times higher for adults with other rare developmental disabilities (Landes, 2020a).

In an October 2020 report on the COVID-19 and Down syndrome T21RS Survey, researchers compared people with Down syndrome from this survey who had been hospitalized for COVID-19 to a group from the UK ISARIC4C survey of the population, including a subset with Down syndrome, of similar age, gender and ethnicity hospitalized for COVID-19. Notably, patients with Down syndrome age 40 and older have a similar risk of death as patients without Down syndrome age 80 and older. Rates of death after hospitalization were higher for patients with Down syndrome across both comparisons (T21RS, 2020).



<b>Deaths after hospitalization, comparing patients with Down syndrome to UK controls of similar age, gender, and ethnicity. Source: T21RS, 2020</b>			
	With Down Syndrome		Without Down Syndrome
	T21RS Survey	UK Survey	UK Survey
Younger (< age 40)	6%	12%	3%
Older (> age 40)	43%	49%	17%

**Mental Health**

Adults with disabilities, compared with those without disabilities, experience more mental distress and are more likely to experience factors associated with a higher occurrence of mental disorders, including poverty and limited health care access. Nationwide, an estimated 17.4 million adults with disabilities experience frequent mental distress, 4.6 times as often than do adults without disabilities. Adults living below the federal poverty level report mental distress 70% more often than do adults in higher income households (Cree, 2020).

The presence of COVID19 has exacerbated mental health issues for many people with disabilities. Data are from the U.S. Census Bureau’s Household Pulse Survey administered from August 19 to November 23, 2020. Nationally, 11.1% of adults reported unmet mental health treatment needs in the most recent period (Nov. 11-23). Adults with children in the household consistently reported higher rates of unmet mental health treatment needs compared to those without children in the household. Rising rates of unmet mental health treatment needs suggest a worsening crisis, especially for adults with children in the household (U.S. Census, 2020b).

Addressing mental health needs presented issues as well. The AAHD COVID-19 & Disability Survey addressed anxiety and depression during the pandemic. Seventy-six percent of

respondents feeling anxious or depressed had emotional support or services. Twenty-four percent of respondents were without emotional support or services (Drum, 2020).

And for those who are recovering from COVID-19, little is known about how long-haul COVID syndrome might affect them. Early reports indicate that symptoms can resemble chronic fatigue syndrome and can include depression, anxiety, aches and pains and sleep problems. There are no set treatments for the impact of inflammation and immunological responses on emotions and mental health that may be linked to this syndrome (Moreno, 2021).

A small study tracking youth with autism spectrum disorder (ASD) found that during the pandemic physical activity decreased, screen time increased and no change in sleep behavior was observed (Garcia, 2020).

## **Daily life and employment.**

This domain looks at what a person does as part of everyday life — school, employment, volunteering, communication, routines, life skills.

### **Employment**

Individuals with developmental disabilities (IDD) often find employment in fast food restaurants, cleaning services, warehouses, and grocery stores - areas that during the pandemic employees were deemed essential workers. These same workers were also at higher risk of contracting and having negative health outcomes due to COVID-19 (Thompson and Nygren, 2020).

### **Financial Status & Security**

Individuals with disabilities faced additional threats to their employment because some programs that assist in finding employment have closed down during COVID-19 and are not expected to reopen. In a national survey of organizations that serve individuals with IDD, 77% of 191 organizations had to discontinue or shut down programs because of COVID-19 and 16% of those are not expected to re-open (Diament, 2020a).

## **Education**

The sudden school closures in March 2020 caused districts to rethink how to bring lessons and accommodations to students with disabilities. Technology, if available to districts to give out to students, was often the first line of communication to get students back into virtual classrooms. However, this alone may not be enough for students with intellectual and developmental disabilities (Constantino et al., 2020) and more services may be necessary to ensure students are able to access curriculum (Jeste, Hyde, Distefano, Halladay, Ray, Porath, ... & Thurm, 2020). One of the more innovative ways to engage with special education students during COVID-19 happened in Austin, Texas by way of a school district using school buses to bring in-person learning to students to enhance virtual learning (Osborn, 2020). When schools were beginning to re-open in the fall of 2020, parents of students in Baltimore public school special education classes struggled with the options they were given to accommodate their children. Although it was speculated that these students would be among the first to go back to in-person learning some parents were concerned about their student's health due to the student's higher susceptibility to COVID-19 (Reed and Roberts, 2020).

## **Transportation**

When the State of Delaware declared a State of Emergency in March 2020 the Department of Transportation (DelDOT) continued Paratransit services during normal operations and rides could be arranged through the reservations call center (DelDOT, 2020). Curtailing ride sharing also occurred downstate through an organization, Village Volunteers, that ordinarily pairs community participants, many with disabilities, with community volunteers to get to and from destinations in the community for errands and medical appointments. Only individuals who needed to appear in-person for medical appointments were able to reserve a ride with one of the volunteers. Throughout the state, people who utilize Paratransit stopped traveling unless absolutely necessary.

DelDOT provided additional guidance on what transportation assets were going to be doing on June 8, 2020, in their phased reopening plan. For Paratransit, customers and bus operators

needed to wear face coverings and there was a cap of three customers per bus. To decrease contact between vehicle operators and riders, DeIDOT billed riders for their trips on Paratransit if they did not have a DART Pass (DeIDOT, 2020). As the state began expanding transportation services to expand services Village Volunteers followed the state's guidance and began allowing volunteers to drive participants to locales other than medical appointments.

## **Community living**

This domain looks at where and how someone lives — housing and living options, community access, home adaptations and modifications.

### **Congregate Settings**

Between the years of 2016 and 2018, high priority nursing home complaints were not investigated within in timeliness thresholds by 21 states (US Department of Health and Human Services, 2020). While not overlapping with the COVID-19 pandemic, knowledge that unmet standards in nursing homes establish a precedent for the types of conditions that may be found and exacerbated by COVID-19. There is support by advocates that because congregate care settings can be expensive, there are benefits to individuals staying in their homes and bringing services to them (Sun Sentinel Editorial Board, 2020). Indeed, Medicaid officials support Medicaid recipients using more community-based resources versus residing in nursing homes especially in light of the pandemic that has caused disparate impacts in congregate settings (Diamante, 2020f).

A striking statistic nationally shows that residents of long-term care facilities constitute less than 1 percent of the U.S. population, yet 43% of all COVID-19 deaths through June 2020 occurred in those places (AARP Bulletin, 2020). In one egregious case, a nursing home in Pennsylvania had such filthy conditions in which COVID-19 was spreading so rapidly, the death rate came to the attention of the Federal Bureau of Investigations which launched an investigation (Stelloh, 2020).

During the first two months of the pandemic from March 23, 2020, through May 30, 2020, nursing homes surveyed reported issues with securing personal protective equipment (PPE) and having staff (Office of the Inspector General, 2020) which likely affected the number of people being infected with the virus.

In Delaware, June, July, and August of 2020 had some of the highest rates of new cases in long term care (LTC) facilities, while nationally new cases in community settings did not spike until December 2020 (Chidambaram and Garfield, 2021). Other state trends for LTC are similar to those found in Delaware. For instance, in New York state, individuals residing in group homes with intellectual and developmental disabilities (IDD) had COVID case rates of 7,841 per 100,000 of severe illness compared to a state rate of 1,910. Death rates were similarly unevenly distributed for people with IDD compared to the general population (Landes, Turk, Formica, McDonald, & Stevens, 2020). California congregate settings posed a similar risk to IDD as there were higher rates of COVID in those environments and varying levels of care (Landes, Turk, and Wong, 2020). Overall, people living in congregate settings were much more likely to test positive and those with intensive nursing had an increased risk of death (Wong and Landes, 2021).

### **Housing & Homelessness**

There is a lack of affordable housing nationwide in the United States. For individuals with disabilities that may require modifications in the housing structure to maintain independence there is even less housing stock available. To address this need, the US Department of Housing and Urban Development has allocated millions to public housing through agencies or mainstream funding vouchers and separately to fund the development of more rental housing for people with disabilities (Heasley, 2020b).

The final report by the Delaware Pandemic Resurgence Advisory Committee (2020) also highlights the need to discuss with non-profit organizations that work with homeless populations how to best use funds. This becomes more pressing as the need for housing for individuals experiencing homelessness is a critical concern throughout the state.

While housing is undoubtedly a problem, there is also concern regarding the general costs of daily living, especially during the interruption of employment for so many individuals with disabilities during COVID-19. The Robert Wood Johnson Foundation (2020) compiled a national poll series to determine key findings. One takeaway of the poll series was that “more than 1 in 3 households that include anyone with a disability report facing serious financial problems, many experiencing difficulty affording utilities and food.”

### **Long-Term Services and Supports**

Long-term services and supports (LTSS) enable people with disabilities to live independently and live longer by receiving the broad range of paid and unpaid medical and personal care assistance that people may need when they experience difficulty completing self-care tasks (Reaves, 2015). Since March 2020, states have applied for LTSS waivers to increase provider payments and modify provider qualifications. Delaware has applied for a waiver for behavioral health and managed long-term services and supports. However, individuals who use LTSS continue to be disproportionately affected by COVID-19 (HCBS Innovation During COVID, 2020).

Individuals with developmental disabilities (IDD) are more likely to have experienced a cataclysmic disruption in community, home, and health services that put undue pressure on informal and formal support networks that are, under normal circumstances, facing incredible daily challenges to meet needs (Nygren & Lulinki, 2020). Some disruptions facing IDD both on a state and national level is also occurring globally. For instance, in the Netherlands, many employees providing direct support services have been concerned about the communication regarding COVID from their employers as well as being a possible vector for taking COVID-19 home to their families from their work locations (Embregts, Tournier, & Frielink, 2020). This concern was borne out in other areas where research shows that caregivers, especially in long term care and congregate settings, had a higher risk of contracting COVID-19 and subsequently taking it home to their families (McConnel, 2020).

## **Political Participation**

The General Election held on November 3, 2020 added a layer of complication to an already complex situation dealing with the COVID-19 pandemic. In previous years, exercising a constitutional right to vote would have entailed, for many people, going to their polling location, casting their ballot, and then departing. This year, there were the additional thoughts of personal protective equipment (PPE), the possibility of early voting, utilization of an absentee ballot, and perhaps attempting to go during uncrowded times. Understanding that COVID-19 was transmitted through aerosolized droplets prompted many people, especially those at high risk of infection, to request absentee ballots in Delaware. The Delaware Division of Developmental Disabilities Services began posting on April 15, 2020 on their Facebook page information from the Delaware Department of Elections on how to request an absentee ballot beginning with the Presidential Primary Election.

A second way that people were able to politically participate was to complete the 2020 US Census. However, the census was supposed to continue to count individuals until October 30, 2020 but it was curtailed early. Ending early may have caused some individuals to miss being counted which may have detrimental effects on the programs offered in the disability community through a reduction in their funding (Diament, 2020b).

## **Safety and security**

This domain focuses on staying safe and secure — emergencies, well-being, guardianship options, legal rights, and issues.

## **Emergency Management**

The Delaware Emergency Management Agency (DEMA) is the coordinating entity in Delaware during disasters. During a public health emergency, the Division of Public Health's (DPH) Office of Preparedness is the lead agency in response. In the early days and months of the pandemic, personal protective equipment (PPE) was in short supply (AARP, 2020; Office of the Inspector General, 2020) both for the general population and for long-term care (LTC) facilities. When

facilities, both medical and LTC, require PPE during a public health emergency, the entity would put a request through DEMA to have it fulfilled. An additional issue that hospitals faced during surges of COVID-19 patients was the need to have ventilators. DEMA and Bloom Energy refurbished ventilators before moving them to a DPH warehouse to await requests from hospitals (Delaware Division of Public Health, 2020a).

DPH was also tasked with setting up COVID-19 testing sites throughout the state, especially at social service centers that serve specific zip codes (DPH Office of Preparedness, 2020). In this way, people should have been familiar with where they were, and the centers should have been accessible by public transportation.

Beginning on March 9, 2020, DPH stood up and staffed the State Health Operations Center (SHOC) (DPH, 2020b). Within the SHOC, there is a Functional Information and Support Center branch staffed with personnel who have expertise on and with disabilities and access and functional needs (AFN). For people who called into the SHOC and required information on a disability or AFN resource or service, individuals were able to answer questions and direct them to resources.

### **Civil Rights**

During March 2020, many institutions hastened to shut down facilities and curtail services and resources. Schools, running the educational gambit from primary schools to universities, sent students home, with plans to continue lessons online as bringing people together was discouraged. Sporting events were canceled as they were considered congregate settings. However, nursing home residents did not have alternate plans made to move them to safer locations or address the possibly unique needs of keeping them in place. This suggests that there may have been ageism present that placed residents of nursing homes, the majority of whom are older, at disparate risk of COVID-19 compared to their non-institutionalized counterparts (AARP, 2020). In a Qualtrics survey about general well-being of American adults with and without disabilities, concerns regarding receiving care and difficulties at home were evident (Dobrinsky and Hargittai, 2020).



As the pandemic affected more and more people in nursing homes, resources to address the emerging need became scarce. States were tracking availability of personal protective equipment, ventilators, and intensive care unit (ICU) beds. These resource allocation discussions have been troubling for people with disabilities who have historically been discriminated against on misguided criteria of utility, quality of life, and life expectancy. The National Council on Disability (NCD) report on Medical Utility and Disability Bias explored this issue in its Bioethics and Disability Series (NCD (a), 2019).

The Delaware Disabilities Law Program advocated successfully for revisions to the state Crisis Standards of Care (CSC). The CSC is guidance for providers in medical decision-making during public health emergencies or crises when resources and normal practice standards may be challenged.

Access to the full range of medical care is a matter of immense importance to people with disabilities, whose lives have been historically undervalued, especially by the medical community. State officials made a number of very significant positive changes to the CSC, guidance that offer protections for the disability community. They took out language calling the policy "utilitarian" in both the Executive Summary and in other places. Language was added referencing anti-discrimination laws and disability, and indicating that laws related to reasonable accommodations remain in effect. Prohibitions on potentially discriminatory criteria were noted, including consideration of intermediate or long-term survivability (life expectancy) and quality of life assessments. The revision also added disability to a list of protected classes (L. Waterland, personal communication, April 14, 2020).

## **Social and spirituality**

This domain is about building friendships and relationships, leisure activities, personal networks, and the faith community.

## **Social isolation/ Leisure and Recreation/ Relationships**

Social isolation is considered a risk to health. The pandemic upended all areas of life around the world, ranging from the ability to work to attending school to what people do in their free time. The loss of human connection and increased social isolation is real. There has been growing evidence that lack of connections and loneliness can impact health. The stay-at-home orders and social distancing of the past year due to the pandemic have amplified concerns about what isolation means for health. About one in four (24 %) of Americans aged 65 and older who live in the community are considered to be socially isolated. Feeling lonely is more widely reported with 35% of adults aged 45 and older and 43% of adults aged 60 reporting this. Social isolation has been associated with a significantly increased risk of premature mortality from all causes and has been associated with an approximately 50% increased risk of developing dementia. Poor social relationships (characterized by social isolation or loneliness) have been associated with a 29% increased risk of incidence of coronary heart disease and a 32% increased risk of stroke (NASEM, 2020).

One article found that, among young people with Autism Spectrum Disorder, physical activity and screen time were negatively affected (physical activity went down; screen-time went up) by COVID-19 (Garcia, J.M., Lawrence, S. Brazendale, K., et. al. 2020). Another article found that people with Intellectual and Developmental Disabilities (IDD) were more likely to have experienced “massive disruption in health, home, and community services” (Nygren and Lulinski, 2020).

In some cases, entire programs were affected, like the Easter Seals day services which had originally closed due to COVID-19 and did not reopen until January 2021, and even then services were offered in limited capacity (Easterseals, 2021a). As of February 2021, Easterseals was offering virtual programming and was planning for summer programming (Easterseals, 2021b).

Most facility-based day programs for persons with IDD in Delaware made the decision to close in the early days of the pandemic. Approximately 2,200 persons in Delaware with IDD have

been receiving day services and had to adjust to life without those key connections. Not only do program participants miss the services and spend more time without socialization but the impact on families, who may need to leave or reduce employment to provide care, may be severe (Olson, 2020).

DSAAPD also worked with the Delaware Aging Network to conduct routine check-in calls and deliver essential goods. Participating community members receive weekly calls to check-in on them. Participants can request delivery of groceries or other essential items. During the past year, 4,471 people received check-in calls and 444 had essential goods delivered to their homes.

### **Advocacy and engagement**

This domain is about building valued roles, making choices, setting goals, assuming responsibility, and driving how one's own life is lived.

### **Community participation**

Organizations and agencies charged with day-to-day services within the disability community continued to reach out and connect with their members. This included providing information via phone, social media platforms, and drop-in visits when safe to do so or when it was possible to mitigate risk of transmission. For instance, the Division of Developmental Disability Services (DDDS) regularly reached out to individuals and families they serve within the community to pass along information on what was occurring statewide and what precautions and activities DDDS was undertaking to ensure families were having needs met. The Department of Services for Aging and Adults with Physical Disabilities (DSAAPD) also assisted in supporting community organizations such as senior centers to enable the centers to provide more virtual programming to ensure people remained connected during times of isolation.

During the initial shutdown and closure of state agencies, it became apparent to community organizations that the needs of their community members were no longer being met, as well as a large number of emerging needs being brought to the fore. COVID-19 closures exacerbated

the already tenuous living situations many community members experience daily. While there was a dearth of toilet paper to be had at stores and food staples were selling out at some markets, the Delaware Emergency Management Agency (DEMA, 2020) posted that there was no supply chain interruption. Rather, the lack of food supplies was due to buyers not being judicious in purchasing.

For individuals who the purchasing of food was an economic hardship, many families and individuals relied on food pantries throughout the state. Often, the disability community is economically disadvantaged, living on fixed incomes that do little to adjust to the cost of living. Therefore, organizations and agencies, such as DDDS, the Delaware Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), and the Delaware Department of Transportation (DeIDOT), publicized or, indeed, in the case of DeIDOT hosted, drive-thru food pantries.

One business in Sussex County affiliated with the Cape Community Coordination for COVID-19 (CCC4COVID), a coalition of community and civic organizations that created a network of nonprofits, faith communities, chambers of commerce, public libraries, educators, city officials, and healthcare providers with response capabilities serving the Cape Henlopen School District, used their Kudos Project bus to drive food to individuals' homes and set up mobile pantries. This business also had a large, empty warehouse space that was used to store donated supplies for distribution.

Village Volunteers, a nonprofit organization that assists older individuals many of whom have disabilities related to aging, participated in CCC4COVID, and became a drop center for supplies before they were taken to the warehouse. One of the items that were in high demand were disinfectant wipes that everyone needed but were not an eligible purchase on an electronic benefit transfer card. Village Volunteers also had to curtail services when COVID broke out. During normal operations, approximately 450 rides are provided a month for medical and non-medical appointments as well as activities including person-to-person visits and activities, like yoga, dinners, and book clubs to avoid social isolation. In March 2020, all rides were suspended unless a member of the Village community needed to have an in-person medical appointment.

When state requirements changed in July 2020, there was a surge of requests for rides for activities that while not medically necessary, were necessary for people to feel that they were getting back to normal: the beauty parlor, for example. Volunteers also kept in contact with community members by being on the phone and watching shows together. This enabled homebound individuals to maintain connections with others.

### **Cultural Diversity**

Researchers have speculated and found COVID-19 has affected different populations of people differently. For example, one study found that women, notably Black women, were more likely to be laid off during COVID because of the jobs that they primarily work in (i.e., hospitality, government, healthcare). It is estimated that single mothers in the US will be the most severely affected by COVID-19 due to difficulty finding childcare and the challenges of maintaining a job during COVID-19 (McConnell, 2020). A separate study confirmed this, finding that working class women and people of color are more likely to lose jobs and have a more difficult time finding new jobs during the pandemic (Long et al., 2020). Rural counties specifically have experienced major challenges due to limited access to medical care. Black and Hispanic people have suffered the most from this as they were found to be disproportionately more likely to get COVID-19 (Cheng, Sun, & Monnat, 2020). Outside of rural communities, the overall death toll for 2020 was higher than average, notably in communities of color. This is believed to be because of underlying health issues—or medical discrimination—as well as working high-exposure jobs (Bernstein, 2020). In addition to getting sick at higher rates, populations who are disproportionately affected are also the least likely to be vaccinated. Recent data suggests that those who are getting vaccinated are not those most at risk of getting sick (Besser & Morita, 2021). Some organizations are working toward solutions, including putting out toolkits like the Center for Medicare and Medicaid Services did to emphasize treatment and “diverting people from segregated settings” (Diamante, 2020f).

## CONCLUSION AND IMPLICATIONS

### *Enhancing Resilience*

There are lessons to be learned from the pandemic of 2020. Lessons that, if applied and integrated into planning and service implementation before the next public health disaster, could protect people with disabilities, could improve the quality of life for them and their caregivers, and could enhance the service systems that support them. It is critical that Delaware develop contingencies and strengthen policies that will maintain essential services, supports and mitigate disruption of daily living in future public health events.

To protect people with disabilities within the context of their increased risk, the following actions are essential for Delaware policy makers and advocates to pursue.

**Create more inclusive planning initiatives that will ensure that people with disabilities are engaged in planning in a strategically meaningful way.**

The risk associated with living with a disability was revealed during the pandemic. In some cases it was confounded by the risk of living in a congregate setting but people with disabilities and advocates continued to educate public health officials about the risk of chronic conditions, the need for in-person supports and the need for protections from discrimination. People with disabilities can participate and inform policy that will serve the community more safely and appropriately.

*“The one thing that we've learned, and I think the big challenge that we still have, is that decisions are still being made without people who are directly impacted being at the table. The agencies, and many times leadership, doesn't learn that lesson. I think what we have learned is, if you don't have the right people at the table, the people who know best what they need, it's not just a matter of convenience, but it's a matter of life and death.” (McNeal, personal communication, May 4, 2021)*

**Implement routine data collection of disability status as a demographic variable for state service delivery to improve tracking and addressing of disparities in health care outcomes.**

Tracking population health outcomes and disparities requires data collection, surveillance and analysis. While Delaware has focused on addressing health equity, the focus has been on race, ethnicity and place, and this effort has often overlooked the disparities experienced by people with disabilities. The devastating impact on people with disabilities during the COVID-19 pandemic warrants a renewed look at expanding the equity lens to include disability.

Previous initiatives laid the groundwork for establishing surveillance systems in state service delivery through routine data collection of disability status (DHSS, Policy Memo 70, July 2015). Renewed focus and support for this effort would better prepare the state for prevention and protection of the disability population in future public health events.

**Accelerate the shift from institutional settings to home and community-based services to minimize risk and provide services where most people want to be.**

*"I think one of the big challenges that we're going to have in the coming future is identifying how home and community-based services are provided, how home and community-based services were impacted. And how those who are living utilizing home and community-based services were directly impacted. ...Our challenge is to get that data. Finding the data that we need to find out how we can better do things. (McNeal, personal communication, May 4, 2021)*

**Preserve and expand the protections for people with disabilities added to the Crisis Standards of Care enacted in 2020.**

The threat of discrimination in medical care based on disability status is real and should be addressed. The willingness to amend the Crisis Standards of Care to protect and provide guidance in crisis situations is a step toward extending these protections during non-crisis situations. Medical providers, hospital systems, and public health officials need to engage with

people with disabilities and advocates to ensure a full understanding of the implications of using archaic, discriminatory criteria for resource allocation decisions.

**Maintain legislative and policy changes accelerated by COVID-19 that supported enhanced or expanded services and participation.** These changes include:

- Telehealth expansion to broaden access to health care;
- Easing administrative requirements for insurance coverage and minimizing financial burden (i.e., reductions in copays and premiums); and
- Permitting virtual meetings for official business to encourage participation by people with disabilities in local and state government.

**Restructure and strengthen the workforce that supports people with disabilities.**

Home health care workers, hospice care workers, direct support professionals and family caregivers are an essential element of a system that maintains health, independence, and quality of life for people with disabilities. The critical role of these professionals and family caregivers during the pandemic revealed a discrepancy between the contribution they make, and the value ascribed to that contribution.

**Build robust contingency plans for services that are delivered in-person.**

These services are essential for people with disabilities and provide alternatives to closure of the programs that led to isolation and diminished quality of life. Plans for alternative service delivery should be in place for:

- Students receiving special education services who require in-person supports and contact;
- Facility and home-based services so that home health care workers, hospice workers and direct support professionals can provide assistance with activities of daily living in both settings; and
- Day programs that serve people with disabilities.



**Preserve the gains in accessibility in technology that broadened access.**

Electronic communication became the norm and there were significant improvements developed (i.e., captioning, normalizing zoom meetings, ASL delivery) during the pandemic that should be sustained. Ensuring access to the internet by expanding broadband into low-income and rural communities will be vital to strengthening access to technology, including devices, for all through schools, libraries, and community sites.

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This retrospective look at the impact that the COVID-19 pandemic had on people with disabilities in Delaware is a catalyst for reflection and action. People with disabilities were among the most vulnerable segments of the population facing disproportionate risks related to comorbid conditions, congregate settings and reliance on in-person services to support independence. The disability community experienced devastating loss of life, severe challenges to the structures that support independent living, extended social isolation and disrupted service delivery across life domains.

The resilience of this community, and the actions that were taken in the darkest points of the pandemic to protect and ensure a chance to thrive, provide a path forward to enhance systems for the future. Building on the actions of the past year will decrease vulnerabilities and disparities, and move Delaware forward to fully protect people with disabilities in future public health emergencies.

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# RESOURCES

1. Center for Disease Control and Prevention (CDC): Centers for Disease Control and Prevention (CDC) is regularly updated with information about Coronavirus. This resource can guide users to vaccines, precautions, and other materials for people with disabilities. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>
2. American Association on Health and Disability (AAHD): American Association on Health and Disability (AAHD) conducted an online survey from April 17th – May 1st. Research products include a summary report, disability-specific products, and comparisons across disability groups. The summary report is available at the following link. <https://aahd.us/dissemination/covid-19-disability-survey/>
3. Special Olympics: The Special Olympics website shares resources for Healthcare Providers, Athletes, Parents, and Caregivers about the risk of Covid-19 on people with intellectual disabilities including resources such as fitness videos and stress-reduction challenges to help them stay active. [https://www.specialolympics.org/our-work/covid19/covid-19-risk-for-people-with-intellectual-disabilities?gclid=CjwKCAjwwqaGBhBKEiwAMk-FtCziYG0iFVnaTRp4rppmem4NRQJiYIUvjm08FOZESh4coi8VcvYxKR0C3YIQAvD\\_BwE](https://www.specialolympics.org/our-work/covid19/covid-19-risk-for-people-with-intellectual-disabilities?gclid=CjwKCAjwwqaGBhBKEiwAMk-FtCziYG0iFVnaTRp4rppmem4NRQJiYIUvjm08FOZESh4coi8VcvYxKR0C3YIQAvD_BwE)
4. World Health Organization, Disability considerations during the COVID-19 outbreak: The World Health Organization provides a list of actions that can be taken by key stakeholders to mitigate the impact of Covid-19 on certain populations such as those with disabilities. <https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1>
5. State Councils on Developmental Disabilities COVID-19 Report - Council Activities, Initiatives, and Impact: This report is intended to describe the ways Councils responded to and are involved in pandemic-related activities. <https://seureservercdn.net/198.71.233.87/718.d58.myftpupload.com/wp-content/uploads/2020/09/COVID-19-Report-2020.pdf>

6. Disability Impacts Delaware: This resource is an infographic describing the number of individuals in the state of Delaware with disabilities.

[https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/pdfs/Delaware\\_Disability.pdf](https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/pdfs/Delaware_Disability.pdf)

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