



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
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The Honorable John Carney
Governor

John McNeal
SCPD Director

June 4, 2020

Via E-mail

The Honorable Governor John Carney
Secretary Kara Walker, DHSS
Dr. Karyl Rattay, Division of Public Health

Re: DHSS Agencies Opt-Out of Mandatory COVID-19 Testing

Dear Governor Carney,

For several weeks the State Council for Persons with Disabilities (SCPD), partnering agencies and advocacy groups have openly shared our concerns regarding the disproportionate number of COVID-19 cases and deaths of people with disabilities that have occurred in long-term care facilities throughout our state. On April 15, 2020, Delaware Online posted a headline, *Carney bears down on Delaware nursing homes, as COVID-19 cases increase in them* (Newman). According to that article, there were 21 deaths attributed to the COVID-19 virus at long-term care facilities across the State. At that time, however, the Administration did not provide any real explanation as to what steps would be taken to help define what "bears down" meant. Less than two months later on May 29, 2020, it was reported by the Division of Public Health (DPH) that the number of deaths in long-term care facilities related to COVID-19 had risen to 228. That number accounted for 65% of all reported COVID-19 deaths in the State. In short, in less than 8 weeks from the date that Delaware Online published the article "Carney, bears down...", the deadly count of persons with disabilities in long-term care facilities increased by over 1000%.

From the beginning of this pandemic, scientists from around the world provided warning that the aging community and those with underlying conditions (people with disabilities) would be the most vulnerable populations to be impacted by the deadly virus. On May 22, 2020 you took action to require long-term care facilities within the State to perform mandatory testing of staff, effective June 1, 2020. It would have been so easy to applaud that action, if not for the inaction that took place from the time that it was made obvious to the world that people with disabilities in congregate settings were in clear and present danger from this virus. The most haunting date is May 5, 2020. That was the date that your office announced that the Division of Public Health would provide testing support at long-term care facilities for staff and patients. Unfortunately, the testing within those facilities was deemed voluntary. To those of us that know the history related to the lack of value that many long-term care facilities have for the lives of people with disabilities, it came to no

surprise that very few facilities took advantage of this life saving tool. As of May 5, 2020, there were 102 lives lost in Delaware long-term care facilities due to COVID-19. The disabilities community is haunted by that date, because it is clear that DHSS knew that testing was the most effective means for reducing the spread of the virus and implied that the resources were available to fulfill that commitment. Between the dates of May 5, 2020 through May 29, 2020, 126 individuals with disabilities had died. I think it is completely fair to contemplate how many people with disabilities would be alive today, if there had been the bold commitment to make testing for COVID-19 in long-term care facilities mandatory. This was a need that was obvious. If there is an explanation that the Administration, the Department of Health and Social Services and/or the Division of Public Health can provide for that decision, SCPD, member agencies, advocates and peer organizations would be very interested in knowing.

The SCPD was pleased to hear that that the Administration had made the May 22, 2020 decision to require COVID-19 testing at long-term care facilities throughout the State. However, SCPD was bewildered when it was informed that that the Division of Substance Abuse and Mental Health (DSAMH), which oversees the Delaware Psychiatric Center (DPC) had chosen to opt-out of testing. DSAMH offered a few reasons for opting out (see attached). None offer a convincing argument for those of us that know the facts. The most disturbing fact is that DPC has had as many or more COVID-19 deaths (3) as 13 other long-term care facilities in the State, which are now required to do weekly mandatory testing. Unfortunately, the count of those infected and may have died do not represent all “clients” under the oversight of DSAMH. There also has several clients and staff that are in group home settings that are under their oversight of DSAMH. We know that infections and deaths do occur in group home settings as well. DDDS can account for 44 people have been infected with COVID-19, with (6) deaths of clients (people with disabilities) within group homes for which they have oversight of. Group homes that provide housing for people with disabilities deserve the same standards of protection as those living in other forms of congregate living. DDDS has also decided to opt-out of mandatory testing in group homes.

In an email from Director Romero, she explained that one of the reasons that DPC has opted out of testing is because she has concluded that DPC does not have the same population as long-term care facilities. We have to question that reasoning. First, DPH in its reporting identifies DPC as a long-term care facility. Further, as previously noted, DPC has one disturbing common denominator with the State’s other long-term care facilities, they have reported multiple deaths in their facility. She reported that DPC did do early testing and has identified that 21 patients have been diagnosed with COVID-19 and “several” are still recovering. She also reported that over 40 staff members were tested and “many” have returned to work. Director Romero stated that “the prevalence of COVID is low” at DPC. SCPD believes that the terms “several” and “many” to describe the number of patients and staff infected by COVID 19, is more indicative of a high prevalence of COVID 19 at DPC. The patients at DPC deserve the same required protections against the virus, as all other vulnerable populations in long-term care facilities, especially as it is a State operated facility.

There is a long history in society of stigmas and stereotypes of individuals with behavioral or mental health disabilities that has led to discrimination and disregard. Unfortunately, the State of Delaware knows this all too well. The same can be said for those with intellectual/developmental disabilities (I/DD), which is why SCPD is concerned about those under the care of DDDS. We should be past the semantics of defining the meaning of a long-term care facility. DPC is not far removed from

providing the same kind of congregate care as the Division of Services for Aging and Adults with Disabilities (DSAAPD), which is requiring staff to be tested at long-term care facilities (Governor Bacon, Delaware Hospital for the Chronically Ill). We understand that a long-term care facility under the oversight of DDDS, the Stockley Center is also requiring testing of staff.

Finally, since the onset of COVID-19, some DHSS agencies have been less than cooperative with requests for data and information. SCPD, partnering agencies and advocacy groups understand the magnitude that this pandemic has had on resources for all state agencies, but especially DHSS. However, the SCPD and many of our partnering agencies are required to inquire about the programs and policies of state agencies. SCPD is statutorily mandated to “make recommendations to the Governor (you), the General Assembly and all state departments and agencies respecting ways to improve the administration of services for persons with disabilities and for facilitating the implementation of new or expanded programs”, [[29 Del. Code § 8210 \(b\)\(3\)](#)]. This is how we serve the State of Delaware, as well as you, the Governor of our great state.

To that, the SCPD is aware of **Executive Order 39**. We applaud the development of the *Pandemic Resurgence Advisory Committee*. However, SCPD cannot understand how any groups or individuals representing a direct understanding of the needs of persons with disabilities have been left off this committee. It is obvious that people with disabilities have been disproportionately impacted by this virus, thus far. SCPD believes that any effort to prepare for a resurgence of COVID-19 should have representation from people with disabilities. SCPD is concerned that again, an important tool is being left in the toolbox.

Per the SCPD’s mandated responsibility to provide you with recommendations, we strongly recommend the following:

1. Add representation from the disability community to the Pandemic Resurgence Advisory Committee.
2. Make recommendations to DHSS to incorporate mandatory testing of all staff and direct support providers, as well as voluntary testing of patients and clients in congregate settings:
 - a. Group homes under the oversight of the Division of Substance Abuse and Mental (DSAMH);
 - b. Group homes, under the oversight of the Division of Developmental Disabilities Services (DDDS);
 - c. Delaware Psychiatric Center (DPC)

Your consideration is greatly appreciated.

Sincerely,

A handwritten signature in blue ink, appearing to read "John McNeal".

John McNeal
Director, State Council for Persons with Disabilities

Cc: The Honorable Lieut. Governor Bethany Hall-Long
The Honorable State Senator David McBride; President Pro Tempore
The Honorable State Senator Nicole Poore, Senate Majority Leader
The Honorable State Senator Bryan Townsend, Senate Majority Whip
The Honorable State Representative Gerald Hocker, Senate Minority Whip
The Honorable Senate Catherine Cloutier, Senate Minority Whip
The Honorable State Representative Pete Shwartzkopf, Speaker of the House
The Honorable State Representative Valerie Longhurst, House Majority Leader
The Honorable State Representative John Mitchell, House Majority Whip
The Honorable State Representative Daniel Short, House Minority Leader
The Honorable State Representative Timothy Dukes, House Minority Whip
Dir. Yrene Waldren, Division of Healthcare Quality Assurance
Dir. Kristen Harvey, Developmental Disabilities Council
Dir. Wendy Strauss, Governors Advisory Council for Exceptional Citizens
Laura Waterland, Esq., Community Legal Aid Society Inc.
Todd Webb, State Council for Persons with Disabilities, Chairperson
Terri Hancharick, State Council for Persons with Disabilities, Vice Chairperson
Lisa Furber, Nursing Home Residence Quality Assurance Commission
Margaret Bailey, Nursing Home Residence Quality Assurance Commission

Enclosures: (1)