Planning to Reopen Services for People with Intellectual and Developmental Disabilities (I/DD) and Behavioral Health Clients

Front-Line Human Service Employees: “Essential Today, Essential Every Day”

Introduction

The Ability Network of Delaware (A.N.D.) is a statewide association of agencies under contract with state government and managed care organizations for the provision of I/DD and behavioral health services.

On March 22, 2020 Governor Carney issued the fourth and fifth modifications to the Coronavirus State of Emergency plan, which included instructions to maintain “at least six-foot social distancing from individuals.” This order instructed Delawareans to stay at home whenever possible, unless serving in an essential business function. All I/DD services and behavioral health services were deemed essential. However, services that were delivered in group settings, such as day programs for individuals with I/DD and group therapy for people with substance use or mental health disorders had to be discontinued to comply with the governor’s social distancing instructions, to slow the spread of the coronavirus.

On April 27, 2020, during a phone conference with the Deputy Secretary of State Courtney Stewart, A.N.D. was asked to participate in the development of a plan for non-profit agencies to “reopen” as the restrictions imposed by Governor Carney’s emergency orders are lifted. In response to this request, A.N.D. sent the attached list of questions to the member organizations that provide I/DD services and held two focus group phone conferences with these members on May 6, 2020 to discuss the input that was received. A focus group discussion was also held that day via phone conference with the behavioral health members.

Services Currently Being Provided to People with I/DD

For the 1,170 people with I/DD who live in residential settings funded by the Delaware Department of Health and Social Services Division of Developmental Disabilities Services (DDDS), Governor Carney’s stay-at-home order resulted in provider agencies assuming responsibility to serve them on a 24 hour/7 day a week basis. Adding daytime staffing to these Neighborhood Group Home and Supported Apartment settings was challenging to provider agencies that were already experiencing staff shortages due to competition in the local and regional labor market with other industries able to pay higher wages.
of the Direct Support Professionals (DSPs) who had been working in day programs were able to go to work for the residential providers, while additional DSPs had to be recruited with mixed success. Much of the work being done now is performed by DSPs working overtime.

I/DD providers have had to restrict visitations between service recipients and their family members and have discontinued community activities for the recipients. The restrictions on these visits and outings has significantly reduced the exposure of service recipients to the virus. As of May 7, 2020, DDDS reported that only 31 people served in residential settings had tested positive for COVID-19, 5 of whom died. Initially, DSPs had been using improvised Personal Protective Equipment (PPE), like cloth masks and goggles, if non-woven masks and face shields were not available to care for those diagnosed with COVID-19. However, more appropriate PPE has been made available for DSPs to use with people with I/DD diagnosed with COVID-19 and although 35 DSPs have been diagnosed with the illness, there has only been one death so far.

DDDS has been successful working with the Division of Medicaid and Medical Assistance (DMMA) in obtaining additional federal funding through Appendix K emergency funding that was made available under the Home and Community Services waiver authorized by the Centers for Medicare and Medicaid Services (CMS). This additional funding is being used to pay retention payments so that day programs can maintain capacity to serve individuals with I/DD as the restrictions are lifted. It is also being used to ensure funding is available for the reimbursement of PPE purchases being made by the residential providers. Other funds are being used to provide some support to the hundreds of families whose loved ones remain at home instead of going out to a day program every day.

**Behavioral Health Services Currently Being Provided**

Most services provided by behavioral health providers have continued, although the volume of some services has been greatly reduced. The professionals providing these services are also at risk of contracting the virus and they were also using home-made cloth masks before other PPE became available.

Medication Assisted Treatment for opioid use disorder continues, with some individuals being permitted under federal guidance to receive 28 days of take-home doses of medication, while others still need to receive daily doses in person.

Some group therapy and assessments for substance use disorder are being delivered via telehealth, although the participation rate for both therapy sessions and residential treatment has dropped off significantly in part because of disruptions in the referral network (i.e., services are no longer being ordered by the courts, which are not in session, and other referrals sources have declined) or because of the difficulty of engaging people in a group process via the telehealth modality. The loss of this revenue threatens the continued operations of these programs.
Assertive Community Treatment (ACT), Intensive Case Management (ICM), and residential homes for people with severe and persistent mental health disorders continue their operations more or less as usual, although with some issues caused by staff absences due to illness or caregiving responsibilities. The personnel who are providing ACT and ICM services in community environments are putting themselves at risk for contracting COVID-19 every day, because face-to-face contacts still need to be made to ensure continuity of services and the mental health of service recipients.

By contrast with the efforts made by DDDS and DMMA to secure emergency funds, the Division of Substance Abuse and Mental Health (DSAMH) and DMMA have not yet found a funding mechanism to offer retention payments to behavioral health providers to ensure their continued operations after social distancing requirements are eased or to reimburse them for PPE purchases, cleaning supplies, disinfectants, and the “deep” cleaning expenses that exceed typical operating expenses.

A.N.D. has communicated with the DSAMH and DMMA Directors about the need for state government assistance to maintain the capacity to meet the behavioral health needs of Delawareans. This situation is not unique to Delaware, however, as A.N.D. is aware of issues in mobilizing federal support for behavioral health services in other states with funding that needs to come from the U.S. Department of Health and Social Services through CMS or from other federal agencies. Nonetheless, a solution needs to be found.

Reopening Day Programs for People with I/DD

The main concerns expressed by both day program and residential I/DD providers have to do with their ability to maintain social distancing and the potential for increased transmission of the virus due to the characteristics of the population they serve.

Most day programs are facility-based. People with I/DD are transported from their group homes, supported apartments, and family homes to a facility, where they are served in groups of various sizes, making social distancing difficult. Community-based day programs have similar problems with social distancing because they typically begin the day by having individuals meet at an initial gathering place before they head out to various activities. Additionally, both types of programs have an emphasis on providing activities in typical community settings, like malls, libraries, or recreational sites such as ballparks. None of those options are currently available and even when they open up, they may present risks to service recipients.

The ability to maintain social distancing while in transit and at the facilities is especially problematic, given the capacity of paratransit and agency-operated vans. To solve the problem of social distancing will require an extensive amount of planning and cooperation between DDDS, the Delaware Transit Corporation/DART, and the provider agencies. If social distancing is not possible during transit to day program facilities, the guardians of people with I/DD will need to be asked to give informed consent for the return of individuals to the day program in recognition of the risks involved. As a corollary to the need to obtain informed consent for those returning to day programs, it would also be
important for guardians to be able to opt-out of returning individuals for whom they are legally responsible to their day programs.

The day programs that have begun planning for resumed operations are carefully examining the space they have available and how many people can be safely served in the space, given whatever recommendations are in place for limitations on group size. Some are considering the option of bringing people back in phases, with priority being given to people who are the least vulnerable to adverse outcomes of a COVID-19 infection and those who are best able to maintain social distancing and the wearing of masks. Some may also begin by offering services to a limited number of people on certain days of the week or during certain hours of the day instead of serving them on a full-day, Monday – Friday basis. Another consideration is whether some people can come back with transportation provided by their families, although the drop-off and pick-up process would become another management concern.

The Divisions of the Department of Health and Social Services that administer Medicaid regulations and reimbursement will need to clearly define what social distancing requirements should be followed so that day programs can judge what size gatherings will be permitted given the space they have available during the reopening phases. These Divisions may also need to waive certain nondiscrimination requirements related to who must be served, in order to permit a more gradual reopening by providers who could begin reopening by serving those who are best able to maintain social distancing and mask-wearing protocols.

Day program providers are planning to provide guidance on regular hand washing for all staff and service recipients on proper hand washing, as well as guidance to their staff for the disinfecting and sanitizing procedures for all frequently-touched surfaces. This would include specific training for both staff and service recipients on proper methods of handwashing. Some providers also said they will post signs in their buildings to remind staff and participants to wash their hands frequently, as well as what symptoms of illness should be reported and who to notify if symptoms are observed, as well as instructions to stay home if these symptoms are experienced. To the extent that supplies are available, providers will also make hand sanitizer available throughout their facilities.

A residential provider that is beginning to plan for the reopening of their day program said they will use the same process for the day program staff that is currently in place for their residential DSPs who are required on every shift to complete an Employee Health Attestation form that includes a symptom review checklist, as well as to have their temperature checked. This was seen as a best practice for all programs to implement, although there was some concern expressed about the accuracy of readings obtained with “no contact” infrared thermometers. Another provider suggested that an expectation to screen individuals before they are sent to the day program be communicated to all caregivers. By taking responsibility for screening for symptoms of illness displayed by service recipients at their home prior to their departure to the day program, caregivers would help assure multiple levels of screening take place, in case anyone is missed, thereby putting the entire group of service recipients at risk of contracting the virus.
Concerns Expressed by Residential Providers about the Reopening of Day Programs and with Resuming Family Visits & Community Activities

Providers that operate residential settings are proud of the efforts they have made to keep the transmission of the virus very low among the people they serve. They are fearful that the relaxation of social distancing measures and the resumption of day program attendance, community activities, and family visits will result in an increased incidence of infection and death of their service recipients. They urge the state to adopt a “take-it-slow” approach to permitting family visits that are currently restricted, reopening day programs, and resuming community activities.

One provider suggested communication between day and residential providers could be enhanced by doing a daily review of the service recipients’ compliance with social distancing protocols to help identify any breakdowns that could lead to a potential exposure, as well as when either day program staff or service recipients that attend the program have been diagnosed with COVID-19.

Some of the things that residential providers would want to see day program providers do to keep the rate of transmission as low as possible include:

- Disinfection of frequently-touched surfaces at the day program location.
- Strategies for maintaining the distance between each individual while at the program.
- Adoption of CDC guidelines, including a requirement that all day program staff wear masks.
- The process for checking on whether the staff and participants are experiencing symptoms of illness.

As it relates to family visits, one residential provider said they would want to receive assurances from the family via an attestation process of some sort that the family member would limit the exposure of the individual during the visit by assuring that they will only be visiting the family home and will not be taking the individual out to multiple homes and stores during the visit. They would also likely limit the resident’s visit with their family to a maximum of 48 hours initially. Another suggested that parks or open areas would be good places for families to start visiting for short periods of time with service recipients, along with encouraging clear and open communication between DSPs and families during the entire process. They also suggesting that the DSP on duty when the service recipient is picked up for a visit review the CDC recommendations about use of masks, symptoms of illness, travel, etc., for the family as well as for the benefit of other staff members service recipients.

To date, DDDS has been supportive of the restrictions on family visits that providers have put in place for the protection of everyone they serve. Residential providers felt it would be helpful for DDDS to issue an additional clarification to family members when family visits resume about the rights and responsibilities of service recipients and their families.
with respect to helping to keep the rate of transmission as low as possible by following the CDC guidelines and cooperating with limitations placed on visits by providers.

When community activities start up again, providers will require individuals to wear masks and will not allow community outings at places where social distancing is not feasible. The focus will be on planning community outings to places that limit exposure while still providing an opportunity to leave the home and get out and about.

While waiting for day programs to open, family visits to resume, and community activities to start up again, residential providers said they will continue to use PPE in the homes at all times, require social distancing, and require DSPs and residents who leave the home for work or doctors’ appointments to wear masks. They also plan to continue to follow disinfectant procedures and to check daily on the health and symptoms of employees and service recipients. They are all attempting to maintain supplies of PPE through continuous purchasing as their supplies are depleted.

**Increasing Capacity of Behavioral Health Providers**

As stated above, most of the services delivered by the behavioral health providers have continued in one form or another. The assurance that the general public receives about their safety personal safety by seeing media coverage of the state’s success in its efforts to increase testing and contact tracing will increase the motivation of individuals to participate in group therapy and to obtain treatment. The reopening of the courts will help increase provider revenue by increasing referrals for court-ordered services, as will follow-through by Probation and Parole officers who check on the compliance of individuals with these orders.

In the meantime, because the utilization of behavioral services has declined significantly, providers are at greater risk of financial failure due to lost revenue. This may result in the need to lay off staff who will be hard to bring back if they have skillsets that enable them to find other employment. Therefore, it is imperative for state government to find a way to keep these organizations intact through making retention payments, reimbursing providers for PPE and other expenses that exceed normal operating costs, redetermining the adequacy of rates for services that have to be offered in smaller groups now and in the future, and other initiatives.

As cited in a recent New York Times op-ed, every 1% increase in unemployment leads to a 3.5% increase in opioid addiction. Behavioral health providers that were already underfunded will be relied on more during the economic downturn caused by the pandemic, so they need to remain open in Delaware and functioning properly to continue to meet the mental health challenges that will be faced by the citizens of the state in the months to come.
Additional State Actions that Could Help Providers

Public recognition of the efforts being made by providers to continue services and the role DSPs are playing by putting themselves at risk to serve vulnerable population would be invaluable, whether that would take the form of a tribute from the governor, lieutenant governor, or cabinet secretaries; a Tweet recognizing their efforts; or a video expressing appreciation specifically directed to an audience of service employees such as the April 24th message to DSPs from Pennsylvania Secretary of Human Services, Teresa Miller. Any or all of these actions would be a huge morale boost to the provider agencies and their employees.

Employees of provider agencies under contract with DDDS, DSAMH, or the Medicaid-funded Managed Care Organizations should be identified as essential health-care workers who need access to the same kind of PPE and testing as health care workers in hospitals or long-term care facilities. This would alleviate a lot of the stress that providers are experiencing in trying to deliver services without the benefit of the kind of supports that other health care providers may be receiving from the Delaware Emergency Management Agency, the Division of Public Health, or the general public.
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Reopening Discussion Guide for I/DD Providers

1. For day programs, how will you decide when to bring your participants back into program and how will you begin to do so?
   a. If Governor Carney’s order is amended to permit groups of 10 to gather, for example, would this allow you to invite some participants to return?
   b. Is it possible for you to implement social distancing or other ways of minimizing potential exposure to COVID-19?
   c. Will you require participants and your employees to wear masks?
   d. What regular hand-washing or other hygiene protocols will need to be implemented?
   e. Are there populations that you will exclude from services initially, due to their heightened vulnerabilities? Are there other factors that may influence how would you prioritize the ability of your program participants to return to a regular schedule?

2. For day programs, how will the availability of public transit (regular buses and DART) affect your reopening plans? Are there any work-arounds that you can implement for an initial reopening?

3. For day programs, what steps will be necessary to reduce the chances that your employees (DSPs, bus drivers, etc.) will expose their co-workers or participants to COVID-19?
   a. Is it possible for you to put screening protocols in place to reduce the chances that employees with obvious symptoms do not come to work?
   b. Will you notify employees of expectations regarding their health status?
   c. Will you create a pool of employees to replace those who must take sick leave when they begin showing symptoms of COVID-19?
   d. If there is a valid serological screening test for COVID-19 antibodies, will you require employees to obtain the test and provide you with the results?

1 This set of discussion questions was sent to I/DD providers in advance of the focus group meetings held with them on May 6, 2020.
4. For residential programs, what steps would need to be taken for you to allow family members to take residents out and return them to their homes?

5. For residential programs, what steps would need to be taken for you to begin sending residents to day programs?
   a. Are there assurances from the day programs that you would need to receive regarding potential exposures, etc.?
   b. Are there any enhanced communication strategies that could be implemented with the day program staff members to boost your confidence in the safety of having residents return to the day programs?

6. For residential programs, what steps will you keep in place or add to your current protocols to reduce the likelihood that your employees will expose their co-workers or residents to COVID-19?
   a. Are you requiring employees to wear masks? Are you requiring residents to wear masks?
   b. Have you already put screening protocols in place to reduce the chances that employees with obvious symptoms do not come to work?
   c. Have you or will you notify employees of expectations regarding their health status?
   d. Have you or will you create a pool of employees to replace those who must take sick leave when they begin showing symptoms of COVID-19?
   e. If there is a valid serological screening test for COVID-19 antibodies, will you require employees to obtain the test and provide you with the results?

7. For residential programs, what steps will you take to protect residents from exposure during community outings?

8. For all programs, are there other considerations that you think should be added to Ability Network of Delaware’s response to the Secretary of State’s office for a general reopening plan? Should we add expectations related to the state’s reopening orders or support you need to the plan?