



Vermont Developmental Disabilities Council

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March 22, 2020

Selina Hickman, Director
Division of Developmental Services
State of Vermont
Via email: Selina.Hickman@vermont.gov

Dear Selina,

Thank you for taking my call during this busy time. As we discussed, the Vermont Developmental Disabilities Council (VTDDC) would like to share some recommendations with the Division of Developmental Services and the Department of Disability, Aging, and Independent Living.

The Council is charged by federal law with assessing the welfare of all Vermonters who meet the federal definition of a “developmental disability,” which is broader than the definition used to determine eligibility for Developmental Services in Vermont. For this reason, these comments apply to recipients of Disability Long Term Services and Supports (DLTSS) in both the Developmental Services System of Care and in the Choices for Care Program, which serves some people with early onset disabilities that are primarily physical.

First, I would like to say that the Council recognizes and appreciates all the good work that AHS staff and community agencies are doing to address this unprecedented situation. It is very reassuring to see how quickly your team has been able to pivot and address a rapidly changing environment.

Second, I suggest thinking about the current situation in phases. The communication and expectations during the first two to three weeks of the crisis are likely to be different from the way the system operates if, as expected, the pandemic continues for weeks or months. The recommendations shared here target that second phase, when we have had a little time to plan and adjust to a longer period of disruption. The Agency of Education is using a similar framework: For the first two weeks there is no expectation that students make progress toward learning goals. However, after two weeks, online instruction will begin, and graded work will resume.

In the past week, I have had the privilege of speaking with most of the public members of the VTDDC and with many other self-advocates through Green Mountain Self-Advocates (GMSA). These conversations are the basis for the recommendations below. The Council is struggling like everyone

else to stay on top of the shifting landscape. These ideas are our best thinking at this time but may not be practical if the situation changes.

Communication

The State is to be commended for its agility in communicating to their contracting agencies and for how it has made timely information available to the public. As we enter the second, longer phase of the crisis, the Council sees a need for some additional direct communication in plain language and targeted to self-advocates and family caregivers. Social distancing depends upon goodwill and on clear expectations. Our observation has been that self-advocates and family members are confused about services and supports and even the virus itself. Communication by the State or by Vermont Care Partners (VCP) in collaboration with the State would be reassuring to DLTSS recipients. Unfortunately, some of what they are hearing in the media is anything but comforting. A common message has been that “*only* older people and people with underlying medical conditions will become seriously ill.”

This is an area where the DD Council and Green Mountain Self-Advocates could be very helpful, both in crafting plain language documents and in circulating and reinforcing the State’s message. We would welcome that opportunity.

Recommendations

- In collaboration with self-advocate or family groups, the State or VCP should create a bulletin in plain language that tells self-advocates and family caregivers what they can expect in terms of services and supports during the crisis. This is an opportunity to let people know important information including that: (1) they should expect regular check-ins by phone or Internet; (2) they should let their agency know immediately if they are not feeling well or if someone in the household is exposed or ill; (3) there are some temporary changes in the rules and what those are; and (4) who they can contact if the expectations outlined are not happening.
- As hospitals become more stressed, the Department of Health and the Governor should clearly and widely communicate to the public that healthcare providers will not discriminate based on age or disability status. Any policy for resource deployment will be based on objective medical criteria that do not intentionally or inadvertently lead to people with disabilities or older adults being disproportionately denied testing or treatment. If, in the worst case scenario, treatment is rationed, protocols must be transparent.

When services have been suspended

Gaps in services are inevitable during this emergency. We recognize that with limited resources, agencies must use their judgement in prioritizing people’s needs. The State has issued guidance for distinguishing between essential and non-essential service (3-17-20)¹ delivered in people’s place of

¹<https://dail.vermont.gov/sites/dail/files/documents/Final%20VDH%20Guidance%20on%20Home%20Based%20Service%20Delivery%203.17.20.pdf>

residence. Our understanding is that job supports and services in congregate community settings have been discontinued, but some technology-based interaction with direct support staff is occurring. The Council believes it is critically important that the State set a systemwide standard for checking on the status of each person enrolled in Developmental Services and those in Choices for Care who have disabilities and receive services in a non-institutional setting. While these types of checks were discussed at the State Program Standing Committee on March 19, 2020, the implementation of such checks does not appear to be uniform. We have spoken to self-advocates who receive services from various agencies, and some have not yet heard from their case manager. There is no mention of increasing the frequency of contact with one's case manager in the guidance issued to date.

Prior to the emergency, case management contacts were often initiated by the service recipient or a family member. This needs to change. The current situation is taking a toll on everyone's mental health. Self-advocates are understandably anxious and confused. We have also observed that many people with developmental disabilities need ongoing education about how to stay healthy and what social distancing means in practical terms. One of our members described being told by his case manager that his agency is closed, and he should "just send me an email if you need anything." This is too vague and passive when health and safety are concerned.

In addition, like other appeal rights, individuals and family members should have a way to contest an agency's decision that their services are "non-essential." While the State should retain the ultimate authority to make this decision, the State also has a vested interest in ensuring that a decision has not been made that could place someone in jeopardy. This is guidance appropriate to phase 2, not something we would expect to see in the first couple of weeks.

Recommendations

- The State should direct agencies to require that staff conduct phone/video conference checks with every person supported in DLTSS at least twice a week during this emergency; one of these contacts should be with the individual's case manager. Staff should ask about the individual's health and emotional status, answer questions about the virus, and check to make sure that the individual has food and other necessities. They can use the plain language guide to Covid-19 created by GMSA to reinforce messages about hand-washing and social distancing.²
 - These "telehealth" calls can be Medicaid reimbursable with appropriate permissions.
 - These calls should include checking on people whose only service is targeted case management.
 - Many individuals with developmental disabilities live with aging caregivers. Case managers should also check on the health status and wellbeing of family caregivers.

- The State should announce an expedited appeal process if an individual or a family caregiver feels that services have been discontinued inappropriately, thereby compromising the health and safety of the service recipient. It is important to note that Vermont has not yet implemented conflict of interest free case management, so self-advocates and family

²<https://ddc.vermont.gov/sites/ddc/files/documents/newsevents/Plain%20Language%20Information%20on%20Coronavirus.pdf>

members only recourse if a service has been determined to be “non-essential,” is to speak to the agency that made that determination.

When services are deemed essential

For some recipients of DLTSS, services cannot be suspended. The State has identified these to include medication management, clinical and nursing supports, assistance with feeding, daily living supports, assistance with maintaining a sanitary living space, and “ensuring human contact.”³ These are generally services that must be delivered in close proximity to the individual with a disability. The State needs to advocate that workers providing these supports are given resources to ensure they do not become infected or infect others. The Council was successful in advocating that language be added to H. 742 (draft 2.2) that would include Human Service workers who are unlicensed home-and-community-based providers among those who must follow “guidance from the Vermont Department of Health regarding use of personal protective equipment and other measures to address employee safety.” This language was supported by Vermont Care Partners and if adopted would be the basis for access to appropriate equipment.

The State should also try to mitigate incentives that may work against full disclosure by care providers when they have been exposed or suspect that they are sick. We are especially concerned that these requirements be communicated consistently across all agencies to home providers, service recipients, and family caregivers. If equipment like masks or thermometers would enhance safety in the home, these should be provided. The State should also use current flexibility in Medicaid rules to ensure that individuals who prefer to have a family member provide their necessary supports during this emergency can afford to do so.

Recommendations

- The Department of Health should give home care workers and direct support professionals the same level of priority for testing and personal protective equipment that is given to healthcare workers in institutional settings and hospitals. This would include priority access to testing, expedited testing results, and an epidemiological approach to follow-up when a homecare provider tests positive.
- A clear directive should be given to all home providers that they have an obligation to report to the agency with which they contract if they or another household member is exposed or becomes ill. This obligation should be communicated consistently across all agencies. It complements but does not replace other guidance regarding reporting to the Department of Health. Directly contacting the contracting agency is the fastest way to ensure that a case manager evaluate whether social distancing within the home is practical or if a service recipient needs to be temporarily moved to another home-based setting.
- The State should make additional respite funds available to designated and specialized service agencies. The State should clearly communicate to home providers and family caregivers that there this pool of funding is available. Home providers and family caregivers should not fear that they will deplete their respite budget if they report illness or suspected exposure to their

³ Memo from Megan Tierney-Ward, 3-17-20.

agency. If community support or job support hours can be converted to respite that should also be communicated clearly to providers and to recipients of services.

- Medicaid funds should be used to pay family members, including parents, when an individual chooses to have their services delivered by a relative or when workforce shortages make it necessary for a family member to provide essential services. Background checks and training requirements should be expedited or waived in these cases. The Council would not necessarily support paying parents to provide care during normal times; doing so should be temporary.

Maintaining our workforce and systems of care

The direct care workforce and our system of community agencies may be stressed to a breaking point if the crisis continues for as long as expected.

Some individuals and families will want workers to stay away -- even in the case of essential services -- because of the fear that a worker will introduce the virus into the household. This is one way that agencies risk a sharp drop in revenue, unless other Medicaid billable work can be found for staff. The DD Council is especially concerned about families and individuals that manage their own services and about respite workers. These groups do not have easy access to alternative work. Families and individuals will be in the difficult position of laying off workers who cannot afford to go without a paycheck.

Other direct care workers will not be able to work because of childcare needs or the illness of a family member. These vacancies will also stress community agencies that cannot bill Medicaid for unused hours. Our agencies have typically operated with dangerously low days-of-cash-on-hand and the current crisis makes it apparent how unsustainable this is.

The Senate Health and Welfare Committee let it be known during this week's review of H. 742 that they would support Secretary Smith in authorizing payment for DLTSS when those services go unused because the individual in services "declines service because of the Covid-19 pandemic, even if federal matching funds that would otherwise apply are not available, in order to sustain these providers and enable them to continue providing services both during and after the outbreak of Covid-19 in Vermont." (H. 742, §4a, draft 2.2). This language has since been removed from the bill, but it remains the committee's intent. It is not clear to us whether Secretary Smith can waive the prohibition against the use of Medicaid funds for undelivered service hours under his existing authorities or if an Executive Order is needed. This should become clear next week.

Our further understanding is that the Families First Coronavirus Response Act, which was signed into law last week, has made an enhanced federal matching rate (F-Map) available to States. The increase of 6.2% is estimated to provide Vermont with up to \$90 million in additional funds.⁴ Additional funding will be needed for many emergency measures. The Council feels that with schools closed and the high degree of stress created by the pandemic, respite should be a priority.

⁴ As estimated by the Center on Budget and Policy Priorities. See: <https://www.cbpp.org/blog/medicaid-funding-boost-for-states-cant-wait>.

Recommendations

- If granted authority by the legislature or by Executive Order, the Secretary should authorize payments for unused service hours when the cause of underutilization is related to Covid-19 in order to ensure the sustainability of Vermont's already limited pool of direct care workers and to provide financial relief to community agencies. These payments should include paying workers who are hired directly by families using a self and family managed care model.
- The State should move quickly to provide community agencies with additional funds for respite for families for whom this would be helpful, including families with children with disabilities supported by the very modest Flexible Family Funding.

Thank you for inviting us to share these recommendations. We would welcome further conversation, as I am sure would our partners at Green Mountain Self Advocates and Vermont Legal Aid.

Yours Sincerely,



Kirsten Murphy
Executive Director

cc. Governor Phil Scott
Secretary Michael Smith, Agency of Human Services
Commissioner Monica Hutt, DAIL
Commissioner Mark Levine, MD, Vermont Department of Health
Deputy Commissioner Megan Tierney Ward, DAIL
Julie Tessler, Vermont Care Partners
Max Barrows, Outreach Director, GMSA
Karen Topper, Administrative Director, GMSA
Nancy Breiden, Esq., Disability Law Project. Vermont Legal Aid
Senator Virginia "Ginny" Lyons, Chair, Senate Health and Welfare
Senator Jane Kitchel, Chair, Senate Appropriations
Representative Theresa Wood, House Human Services
Representative Diane Lanpher, House Appropriations
Representative David Yacovone, House Appropriations