Vermont Developmental Disabilities Council

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Testimony
Joint Hearing, Senate Education Committee & the Senate Health and Welfare Committee
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For the record my name is Kirsten Murphy and I am the Executive Director of Vermont's Developmental Disabilities Council. DD Councils exist in all states and territories with the statutory requirement of bringing the voice of individuals with developmental disabilities and their families to the policy making arena. I would also like to share that I am the parent of two young adults on the autism spectrum who received extensive special education supports during their school years.

I want to start off by acknowledging the tremendous work that you as legislators, my colleagues in State government, and our partners at school and community agencies are doing. As an advocate I am in the difficult position of having to share serious concerns while at the same time not wanting to appear to disrespect all that has been admirable in Vermont's response to the pandemic.

Over the last three weeks I have made it a point to reach out to as many self-advocates and family members as possible to find out what their experiences have been during this crisis. Their stories inform what I have to say today. Here are a few of them:

- One mother talked with me about an episode this past weekend. Her son, who is on the autism spectrum and has very limited verbal communication, had his school-based behavior therapy stopped abruptly when schools closed. Understand that this young man is a gentle, fun-loving teen. But without familiar routine and support, he assaulted his mother and sister, causing them to hide in a room in their farmhouse until the young man was removed from the home by another family member. There is no plan in place for this teen to resume the behavior therapy that he needs.

- Another mother in southern Vermont talked with me about having her son who is about 10 years old at home. She feels they are being well supported by her local designated agency. They are checked on regularly and they have worked with the agency to have a plan in place if someone in the household becomes ill. But because her son has underlying medial conditions that put him at higher risk, she cannot have people coming into her home for therapies or respite. A special educator herself, she is trying to prepare online learning for her own students while at the same time keeping her son safe and occupied – and that's before there are any expectations that her son make educational progress because general education has resumed.

- One family talked with me about what it is like to have 3 children with disabilities at home. Already stretched thin by their middle child's extensive medical needs, this family is now beyond the breaking point. Their chronically ill child needs dedicate care 24/7. Again, it is too dangerous to allow outsiders into the home. How are these parents supposed to implement special education for their children, all of whom have IEP's, and keep their medically fragile child safe?

In the special education arena, we have three immediate concerns.

- First, it would be very helpful if the AOE or perhaps the AOE in collaboration with a parent group could put its guidance for the delivery of special education during this period of school closure into plain language for parents. I have been communicating with maybe 30 parents over the last few days and very few of them even understand the basic timeline at work here – specifically that special education services are not required while schools are not delivering general education services, but will be a requirement once online general education resumes.

- Second, we are very concerned about the higher need special education students. These are already stressed families who have relied on schools for many services that are not easily delivered on-line. As wonderful as technology is, students with higher needs many not be able to attend to a screen for long periods of time and without one-on-one prompting. What used to be the job of a para-educator becomes the job of a parent, quite possibly a parent who is also trying to work from home and support the learning of other children in the household.

- Our third concern has to do with the future delivery of compensatory services. According to AOE's Continuity of Education Plan Guidance 2.1, IEP teams must consider several factors in deciding if a student is to receive compensatory services including:

> "Shall the team consider a deduction based on the student's reasonable recovery of progress once school resumes? Shall a deduction be made for exceptional / unreasonable conduct (ex: parent rejects services and supports offered; student places themselves or others at risk while an attempt is being made to offer the services)?
> If so, calculate and explain."

The document reminds educators to carefully document throughout the coming weeks if instruction and therapies have been refused and if so for what reason. We can imagine that parents working with a student that has high support needs may well have to refuse lessons and therapies that are not well suited for their child, if only because they have to be delivered-on-line. Should this be held against the child when seeking to regain lost skills later after the immediate crisis is past? The Council believes the AOE must be generous in awarding compensatory services when the crisis is past. Many special education students will regress and will need assistance reorienting themselves to their routines and learning goals.

I want to take just a few more minutes of your time today because members of the Senate Health and Welfare Committee are here. For the most stressed families in Vermont, the line easily blurs between what is education, what is medical care, and what is therapeutic support. I urge this group to consider some sort of emergency measure to help those families that cannot have outsiders in their home and where parents are struggling to be nurse, teacher, and therapist all at once. Our developmental services system has agreed to give home providers bonus payments because they are now delivering far more hands-on care than anticipated. As a temporary measure, the Council has recommended that financial relief be provide to these high need families who have often needed to reduce or entirely leave paid employment to deal with the care needs at home.

In preparing to speak with you today, the DD Council's Executive Committee asked me to share with you that – even as Vermont is doing a good job and people are trying their hardest -- the parents of people with developmental disabilities wake up every day terrified that they will lose a loved one either to Covid-19 or to the other risks that they have come to depend on staff to help avoid. Families are having conversations like this: "If our daughter gets the novel coronavirus, she will almost certainly die. If we take her to the hospital, she will be isolated and have to die alone. Better that we keep her here with us so she can die surrounded by family."