Vermont Developmental Disabilities Council

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Thank you for the opportunity to speak briefly today about payment reform for the Developmental Disabilities Service System (DDS). For the record, my name is Kirsten Murphy, and I am the Executive Director for the Vermont Developmental Disabilities Council (DD Council).

Whenever I testify, I give this disclosure: The Council is a public board established in federal law and funded by Congress. Sixty percent of our members are Vermonters with intellectual or developmental Disabilities or family caregivers. While we sit administratively in the Agency of Human Service, we have a unique set of assurances that allow us to engage in advocacy and systems change work independent from the typical approval process at AHS. So today I am speaking on behalf of our Council members and the people they represent, Vermonters who use the Developmental Disabilities Service System.

As noted in the brief prepared by Nolan Langwel, the DD Council has advocated for both conflict-of-interest free case management and payment reform since 2014. We believe these changes are in the best interest of people who receive services. However, today I was asked to focus on concerns. I do so in the context of general support for the goals of these system innovations.

I want to focus on two things that our constituents have told us are the most important to them.

1. **Self-Advocates and family members want their hours to be filled. Period. Hard Stop.**

   DAIL's Report indicates that the statewide rate at which Designated and Specialized Services Agencies (Das/SSSAs) fulfilled these hours for non-residential services in SFY'24 was 55%.[1] A reasonable goal is 80%. Further, there are five agencies below the statewide rate. One agency was only able to fill 38% of the hours that its service recipients had been

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[1] DAIL Report, Table 1, page 5.

assessed – through a rigorous assessment process – to need. This same table also shows that rates vary widely across the state, from 38% to 85% -- a 47-point spread. This is not an indicator that we are moving in the direction of bringing greater uniformity to the DS System, which was one of the stated goals of payment reform.

The Director of the DS Division has said in open meetings that the SFY'25 data is on track to be roughly the same.

This is unacceptable.

Context is important here. Agencies will tell you that this is not the full picture and that's true. These are not all the service hours that many people receive. Agencies deliver residential services (for example, the support of a home provider or staff at a group home) at close to 100%. However, for people living with their family, which is 39% of all service participants, it is all the paid support they receive. It is the core of what they rely on, because they don't receive residential services.

Understand that what we are talking about are the hours that support a fundamental part of Home and Community Based Services (HCBS). These are the support hours that people depend upon to leave their home for work, for recreation, to see and sustain friendships, to run personal errands, to get to doctor's appointment. These are the things that anyone typically expects to be able to do.

This problem is likely not a small one. Simple math suggests that although the data are de-identified, the statewide rate is low (55%) because there are larger agencies in the cohort below the statewide rate. This means that this problem is impacting a lot of people in the DS system. It is not surprising that a survey by an organized group of families last spring found that 18% of parent caregivers surveyed said their adult son or daughter was receiving none - 0% - of the hours s/he had been assessed to need.

I am not talking about this to blame agencies. Workforce challenges are real and represent forces beyond the easy control of providers. However, a state system that cannot reasonably meet the needs that the State itself has determined to be necessary, that system is not a quality system. That is a broken system. It is ultimately the State's responsibility -- in partnership with agencies, lawmakers, advocates, and service participants -- to fix that system.

The individuals and families that the DD Council speaks with daily, tell us that they do not want to delay changes to the DD System because they hope that Conflict of Interest Free Case Management – Independent case management -- and a new payment structure will give us new ways to see what is broken and to fix it.

The DD Council asks that the State and the Legislature monitor utilization rates carefully, with an eye toward using all the tools at their disposal – rate setting, budgeting, etc. – if they remain unacceptably low and continue to show wide disparities across the state.

2. **Self-advocates and family caregivers want quality services provided by well-trained staff.**

   It is important the State guard against an unintended consequence of payment reform. If filling more hours is the path to higher prospective payments, agencies may be driven to cut corners when it comes to hiring practices. This would be deeply problematic, even potentially life threatening.

   With budgetary support from the legislature and leadership from the House Human Services Committee, the Division for DDS has been able to enhance and improve its quality assurance team. That needs to continue.

   What the State has not yet supported is a return to using the National Core Indicators (NCI). NCI is a set of metrics used widely across the United States to assess whether the services delivered to people with I/DD are having a meaningful, positive impact on their lives. It's not a chart review or a cursory survey or a checklist of compliance indicators. NCI is a thoughtful structured conversation with a randomly selected set of service participants.

   NCI asks questions like: Do you have friends who are not staff or family members? Can you see friends when you want to? Are you able to contact your case manager when you want to? Does our service plan include the things that are important to you? Are you able to get places when you want to do something outside of your home?

   These are not trivial questions. These are questions about the rights that people have when receiving services and about the things that make a life --- any life -- meaningful.

   Vermont used the National Core Indicators in 2017-18 and again in 2018-19. Then it was discontinued because of the pandemic. At this important time, when we are radically changing how DDS are delivered, the State needs to return to using quality metric that illustrate whether we – including you the legislature that provides the funds – are getting a strong return on investment: Meaningful lives in the community for this group of often overlooked Vermonters.

   Thank you for your time and for considering these comments.