



Vermont Developmental Disabilities Council

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Thank you Madam Chair and Committee Members for the opportunity to testify on H. 720.

Introduction

For the record, my name is Kirsten Murphy, and I am the Executive Director of the Vermont Developmental Disabilities Council.

For context, there is a developmental disability council in every state and territory. Councils were created in the 1990's by the federal Developmental Disabilities Assistance and Bill of Rights Act to ensure that citizens with intellectual and developmental disabilities live lives characterized by self-determination, the greatest degree of independence possible, full community inclusion, and the ability to make meaningful contributions to society. I report to a public board that is 60% individuals with I/DD and their families. We are entirely federally funded. To carry out our mission, we have a memorandum of understanding with the Agency of Human Services, of which I am an employee, that permits me to provide testimony on behalf of the Council. This is different from the rules that other AHS employees must follow regarding legislative testimony.

H. 720 is an important piece of legislation that attempts to address longstanding challenges faced by the Developmental Disability Services System. I divide the bill's prescriptions into three categories.

H. 720, Section 2, Rescinding Procedural Changes to the System of Care

The first of these categories performs necessary housekeeping. This includes rolling back the provision that certain parts of the System of Care Plan for Developmental Disabilities Services go through rulemaking. This procedure has proved cumbersome and does not enhance public input. The provision was something the DD Council – under previous leadership -- sought roughly seven years ago in the hope that it would bring more oversight and accountability to the DD System. That intent remains important and is still needed, even while rulemaking was not the right approach to achieve this aim.

H. 720, Sections 4 and 5, Service Supported Housing

The second category in H. 720 is set out in Sections 4 and 5. These measures address the critical need for more service-supported housing options for individuals with I/DD. Legislative direction regarding housing options has come about because of significant parent advocacy. I am sure some, if not all, of you have heard from these parents, who are genuinely – and not unreasonably -- alarmed that their son or daughter will have no appropriate place to live when they as parents can no longer provide a home.

The Developmental Disabilities Services Division (DDSD) has recognized the need for housing alternatives for a long time. This need is highlighted in the Division's own System of Care Plan written well before the pandemic in 2017 under "Special Initiatives" (page 44). However no concrete action has been taken.

H. 720 lays out a path forward so that DDSD can work with stakeholders to identify appropriate options. It sets up an advisory group and provides resources for the initial phases of this work, including a limited-service position for someone with expertise in housing. The Council fully supports these provisions in Sections 4 and 5.

Requested Revision

In section 5(a) the Vermont DD Council is named. We respectfully request a revision to this section. This suggestion was received favorably by the House Human Services Committee but was lost in editing. Specifically, section 5(a) reads:

“The Department of Disabilities, Aging, and Independent Living shall work with the Vermont Developmental Disabilities Council and a statewide self-advocacy group to [insert text] review housing models in other states for the purpose of informing the pilot planning grants developed pursuant to subsection (b) of this section.”

Where text can be inserted, we request that the phrase “quantify and describe the service-supported housing needs of Vermonters receiving Home and Community Based Services through the Developmental Disabilities Service Division and to” be added.

It is the Council's desire to work with DDSD to ensure that the full range of supported housing needs are explored. The Council has offered funding for this assessment, and we are aware of complementary funding, potentially from the Housing and Conservation Board and/or the F-Map bump. To help ensure that first steps are taken expeditiously, the Council is anxious to be part of this process.

Continued

H. 720, Section 6, Quality Assurance Measures

The third and final category of provisions under H. 720 is related to quality assurance in the DD system. These measures are found in Section 6 and a portion of Section 3 . To understand these sections of the bill, it may be helpful to consider two events that took place in 2014.

The first of these is the promulgation of new rules by the Centers for Medicare and Medicaid (CMS). Several years in the making, this initiative was the first time that CMS defined what it means by “living in the community.” In fact, the genesis of these rules stems all the way back to the Supreme Court’s Olmstead Decision in 1999, where the court found that states must provide to people with disabilities an option to live in the community rather than in an institution. CMS began funding more community placements, but it took more than a decade to define how it would define these services.

What did CMS say about community living? The 2014 rules have two sections. The first was put in force 60 days after the rules were published. This is the person-centered planning section of the rules. The second, known as the “settings rule,” will not come on-line until March 17, 2023.

It’s the first part of the rule to which I want to call your attention. This is the section that includes the requirement that case management services be provided in a manner that is free from potential conflicts of interest. In developmental services, Vermont has a vertically integrated system in which a single agency is responsible for all an individual’s services. This includes the initial clinical evaluation, the service planning process, and ultimately the maintenance phase where a service coordinator oversees a beneficiary’s day-to-day supports. What is of concern here, is the fact that by providing all these services under one roof, there are fewer checks and balances. The agency may, for example -- unconsciously even -- steer an individual toward services that are more convenient or lucrative for the agency to provide; or conversely, the individual may feel beholden to their agency - - even fear reprisal -- if they raise an issue about the quality of their services or adherence to their person-centered service plan.

The Council has believed since 2014, that the intent of the CMS rule is sound and necessary. In fact, we are aware of many instances where conflict of interest has worked to the disadvantage of beneficiaries. We have provided extensive public comment to this effect.

Vermont chose not to move forward with the CMS rule. Instead, the Agency of Human Services tried several strategies to see if it could maintain its current vertically integrated system either through exemption or a special agreement with CMS. Vermont has effectively pushed implementation of the CMS conflict of interest rule out more than eight years. Last fall, CMS gave Vermont a final ruling, and DDS now has a plan of correction awaiting CMS approval. The Plan would add as much as five more years to the process.

The second important event in 2014 was a review of the designated agency system by the State Auditor. There was much that the auditor determined to be sound about agency financial practices. However, the auditor did find that the reporting mechanism between the State and the agencies were not sufficient to ensure that a dollar intended to support, say, John, did, in fact, go to support John and not Mary. This finding is in large part the impetus for payment reform.

Notice again, that we are eight years from 2014. Payment reform has moved very slowly. Anxiety among beneficiaries and their families remains high. I believe Rep. Wood has characterized the atmosphere as one where trust needs to be restored.

In this context -- where the State is under a plan of correction and recipients of service, both self-advocates and families, are distrustful and anxious – it is understandable why H. 720 would seek greater legislative oversight of both conflict free case management and payment reform. The Council believes, however, that legislative approval goes one step too far, crossing well established boundaries between the legislative branch and the executive branch. We ask that H. 720 be revised such that the legislature may continue to receive regular updates about changes in DDSD; but stops short of the legislature needing to approve these changes.

Finally, we have in Section 3 a provision which calls for at least annual “on-site quality assurance and improvement visits.” The Council believes this is a commonsense measure that merely restores oversight and accountability to the level that was the norm for our system until around 2007. When onsite inspections were reduced to once every two years, the DD System was serving about 3000 people. Our system now serves more than 1.5 times as many people for a total of around 4600. At this volume, why would the State do anything less than insist upon annual inspection?

The State is ultimately responsible for the wellbeing of the individuals in service and for the provision of services that meet the standards set out by CMS. CMS has set a high bar. In fact, more than health and safety is required. It is the expectation of CMS that people will have individualized plans and that those plans will be honored. Frankly, we hear too often from self-advocates who describe a service development process that does not represent best practices in person-centered planning. We hear people concerned that their service plan is not adhered to. We have been hearing these concerns since long before Covid and the current workforce crisis.

The Council recognizes that restoring annual review has implications for staffing. Still, we fully support this measure and trust that leadership at AHS will find a way to support these quality assurance activities.

Thank you for considering my testimony and for your work on H. 720.