



Green Mountain Self-Advocates
2 Prospect Street, Suite 6
Montpelier, VT 05602
www.gmsavt.org
1-802-229-2600
nicole@gmsavt.org
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H. 728 - An act relating to Developmental Services' System of Care

I'm Nicole LeBlanc from Montpelier. I am the Advocacy Coordinator for Green Mountain Self-Advocates, a disability rights organization. I'm on the Autism Spectrum and I get Developmental Services. I managed my own services.

I am here today on behalf of Green Mountain Self-Advocates to talk about the how the Developmental Services System has changed since 1996 when the DD Act was passed. We are serving close to twice as many people and are spending more than double the amount of money. But one thing that has not doubled is the number of state workers checking on the quality of services. In the 90's there were 12 full time state workers reviewing the agencies and monitoring quality. But the state made cuts and today less than 5 full time equivalent positions are doing the job of checking up on services.

This makes us nervous. Many Green Mountain Self-Advocates have a strong voice and have learned to speak up for themselves to make sure they get services that meet their needs. But we have so many brothers and sisters with developmental disabilities who either lack the confidence to speak up if someone was hurting them or don't know how.

There are other reason why we are concerned.

The nature of how services are delivered has changed since the DD Act was passed in 1996. Then, the majority of staff providing community supports and respite services were employed by Designated Agencies. Since then to save money in response to pressure from budget cuts, providers have reduced the number of people they employ and directly supervise. Now upwards of 2,000 independent support workers carry out DAIL's mission for developmental services. This can be problematic because typically there is a greater degree of training, support and supervision when a staff person is employed by an agency. This practice of having services provided by independent support workers is referred to as "wrap" services. Let me give you an example: Susan is 55 years old and is now getting services because her parents died. The agency sub-contracts with a shared living provider so Susan has a place to live. The shared living provider is then responsible for hiring and supervising independent support workers who are with Susan during weekdays and for respite. We worry about agencies moving farther away from directly supervising the people who are actually providing services. Reportedly DAIL encourages the use of contracted services as a way to save money. This trend seems to be the opposite from recent calls from AHS for more accountability. Unfortunately, quality assurance procedures have not been implemented to address this issue.

There is more.

In the past service coordinators were required to make in-person home visits once a month for individuals receiving residential services. DAIL has

allowed this standard to be reduced to once every 2 months. As I mentioned many people have “wrap” services which means all of their staff are contracted workers (home providers, respite workers, community support staff). Our concern is that in situations where a person has no direct support staff employed by an agency it increases vulnerability since they may only meet with their service coordinator 6 times a year.

Another overall system concern is that in the past a person’s service plan has been written every year. But now the state is allowing them to be written every 2 years. In an age when agencies have less in-person contact with the people they serve, reducing the number of meetings to discuss, plan and evaluate how services are provided seems like a bad idea.

Now do we know lots of people who get excellent services? Yes, we do. Many people live amazing lives and are very pleased with their services. Our point is that we are worried about the erosion of quality standards and monitoring. The FY2015 budget for Developmental Services is more than a \$180 million dollars. We can’t imagine that our legislators want a program this large hardly able to check on quality. H.728 improves quality assurance.

H. 278 also provides legislative oversight. Last year we were concerned because on 3 different occasions DAIL attempted to make changes to the System of Care Plan which would have resulted in significantly reducing public comment. Most other state benefit programs require legislators to approve any changes. This is not so for Developmental Services. Legislators need to have a say. H. 728 says that legislators must approve any changes to the System of Care Plan.

Finally, H.728 increases the likelihood that a comprehensive assessment of unmet and met needs will be done every 3 years. Last year the state reported that the number of people meeting a funding priority for Developmental Services had more than doubled. Most agency directors describe the people starting services as having more intense needs than in the past. Over 70% of the people who are eligible for services, do not getting any. We wonder how they are doing. The state does not have a clear picture of what life is like for those who do not get services.

This is not a practical way to run our state. Planning for the future begins with knowing what is needed and what works. H.728 makes it clear when the Agency should report to the legislature and what their annual report should include. The Agency should be required to consider the needs of individual who are eligible for services but not receiving any and how this is impacting their lives and their families.

I want to thank the committee members for listening to my testimony. Being able to speak about the services people get is a great way to spend Disability Awareness Day. Thank you.