



Good morning. Thank you for giving me the opportunity to speak.

My name is Ellen Riley. I have a 16 year old son with Developmental Disabilities associated with Down Syndrome.

Last February I sat before this committee to speak about the importance of Children's Personal Care Service to my son and our family. These services were greatly affected by the new Functional Evaluation Tool (FET) the state was using to determine eligibility. In fact, my sons CPCS was terminated. The ability to address that issue was beyond the scope of this committee. Vermont Legal Aid initiated an appeal to the Human Services Board on our behalf and many others who had been adversely affected. In September 2013, VLA notified me that the cases have been "stayed".

During all this period, I am happy to report, we have been receiving CPCS. I expect that will continue until the appeal is settled. However, I received a "notice of decision" defining the CPCS units for the six month period from 1/1/14-6/30/14 in early January. Our allocation of units had been decreased. No explanation was received and no contact had been made notifying us of the decrease. While the allocated unit hours are more in line with our current need, no communication or consultation was initiated before the change was made.

This incident relates to the two major topics I would like to comment on today:

1. The Integrated Family Services changes for children and youth that have resulted in a lack of information and coordination about available services programs, and funding.
2. The importance of legislative oversight and review for policy decisions being made by the Developmental Services Division, Department of Disabilities, Aging & Independent Living.

1. Integrated Family Services and Bridge case management. In May 2013 I enrolled in the Bridges program at WCMHS, my Designated Agency. A care plan was developed by my son's case manger and me. My experience so far is that there is really no coordinated program available. I did approach my son's case manger last fall seeking funding for adaptive riding lessons, a program that would support physical and behavioral growth. That funding was approved.

I am concerned that there is case management, but no services to manage. I have no information about services that could replace lost personal care services, and no ability to use the funds in any kind of coordinated way for what Chris needs. In this time of fiscal constraints, my belief is that close review of programming and spending needs to happen.

2. Legislative Oversight of Developmental Services. My son is fortunate in that he lives in a stable and loving family that is dedicated to ensuring he is educated to the best of his capabilities and, that he is exposed to all the same opportunities as his peers. Since he is still fully matriculated in high school and we as parents interact directly with his educators, he requires minimal outside services. I want to ensure the same level of advocacy and exposure we provide will happen when he transitions to adult services. We are "aging"

parents and will at some point in the potentially near future, be unable to be as involved with his daily life. His neurotypical peers will be independent of their parents, he should be afforded that same independence (as should we).

I would like you to ensure that **quality** coordination and oversight of services, programs, work opportunities, and adult extended education is efficiently and effectively implemented. Communication and coordination is crucial.

The Developmental Services Division serves over 4000 Vermonters. Funding priorities continue to be narrowed as funds continue to be cut. When the Agency creates its System of Care Plan for developmental services every 3 years, who receives services and what services are provided is determined by the Department. Vermonters cannot turn to elected representatives to challenge and change the Commissioners decisions.

This past summer DAIL was proposing changes to its System of Care Plan. The proposed wording would have shifted even more authority for making changes to the Plan to the Department. Fortunately the public spoke out strongly against this change in wording. The Commissioner however had the authority to make the changes. Those who would have been affected would not be able to seek help from elected representatives.

H728 would remove the System of Care Plan's exemption from legislative oversight.

The needs of children with developmental disabilities vary greatly. Fortunately, at this time my needs center on support and supervision for limited periods time after school and during vacation. That will change when my son is no longer in school and transitions to adult services. Critical is identifying that he needs services, having a say in determining what services will be provided, and ensuring services are implemented.

I urge you to support H728 so that checks and balances are in place.

Respectfully,
Ellen Riley
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