



Testimony about 1.2 million in cuts to family managed respite under DAIL budget January 21, 2015

I am Kathy Holsopple, Executive Director for the Vermont Federation of Families for Children's Mental Health, and also a parent of a young adult with significant disabilities. I am speaking for the families that we and the Vermont Family Network represent and support.

The definition of respite from the Vermont 2001 respite summit is: personal services and supports that help maintain children and adults in their homes over time, by providing flexible support to caregivers.

Respite is an important service for families of children with mental health/behavioral needs. One of the original intents of respite was to help families keep their kids at home. That intent has not changed. We do not want our kids in hospitals or institutions unless absolutely medically necessary. Families need respite to provide a break from the intense needs, to prevent burnout, and to enable the parents to regroup and come up with renewed energy and creative strategies to continue parenting their children. The child also gets a break, and the time away can interrupt the pattern of negative behaviors and needed responses. By providing respite we help prevent crisis, hospitalization, residential care, and lower the need for emergency beds.

Respite, planned breaks, sooner could prevent or put off the need for higher cost residential programs. Combine respite with services that are flexible to meet the real needs of families, and we have a much better chance of keeping our kids at home and in our communities.

Finally, it is very important that families be involved in deciding the best use of any new dollars being put into respite services. A core value of the Vermont System of Care for children's mental health is that families are the experts about their needs, and the services to meet those needs must be defined by the family and implemented with the family's total involvement. Working with individual families to decide the services for their own children is important.

Over the years, families have voiced their need to have respite services. When the state changed the rules regarding children's personal care services (CPCS), and how the determination of medical necessity is being made, DVHA transferred \$8.2M to the Designated Agencies (DAs). The DAs were asked to divide that funding into 4 categories:

1. Mental Health Fee for Service so that children with Developmental needs could have access to the full array of services available at a DA, if those services are determined medically necessary
2. To increase the Bridge Case Management
3. DA managed and provided respite
4. Family managed respite that would be facilitated through the DA but paid through ARIS with the family able to hire their own provider (after passing background checks)

One of the reasons for unspent funds is: the state delayed the implementation of all the changes to personal care. This new assessment process is now happening and some families will find that their child no longer meets the medically necessary EPSDT definition of CPCS and therefore will likely need respite. A lot of families like the family managed because it is easier and quicker to find someone to provide care for their child.

Currently or soon, 150 -200 children per month are being re-evaluated for CPCS. Approximately 25%+ will no longer qualify and need some respite and other services. If that begins in Feb, 187-250 families will be looking for respite to help support them as they transition off of children's personal care. At least a portion of the 1.2M family managed respite funds being proposed to cut will be needed to ensure a smooth transition for these families. VFFCMH and VFN believe that families need to have sufficient information to make informed decisions for their children and family. Most of this information has been held within the agency and not available to families, as a general rule. Often families do not know they can access DA funding.

We were also assured that this funding could be used for families who need respite, but are not transitioning from CPCS. We have had several calls from families in this category across the state about their need for respite. When these families asked the DA about respite, they have been led to believe none was available. We believe that information about respite funding needs to be clearer, that we all should be helping families understand what resources are available to them, and that we should be enhancing timely access to respite to ensure good outcomes.

