

Karen Newman, testimony to House Human Services Committee

My name is Karen Newman, and I am from Burlington, VT, where I live with my husband, almost 15 year-old daughter and almost 13 year old son. (spring birthdays). On behalf of our team, which is, for lack of a better name, the "Crisis Committee" of the Autism Task Force, I want to thank you for honoring families like ours on Autism Awareness Day by hearing our testimony.

We want to bring your attention to an issue within the autism community that is both hidden and hideous. It's the fact that as a state we are failing to support children and families who are not receiving the community support they desperately need. You'll be relieved to hear that it's not related to a lack of money. It comes from a culture that doesn't want to embrace institutionalization and likes to think that everyone can be seamlessly integrated into our Vermont Communities, because we value things like Least Restrictive Environment, Child-Centered Care, and Supporting Families.

The problem is, the children who qualify for the most support aren't able to access the supports due to a dysfunctional funding stream where professionals don't understand how to code things properly. The fear of violating medicaid regulations is so intimidating, that they opt to withhold the services all together. Lately I've been attending the autism planning meetings of the Integrated Family Services initiative. They are charged with creating a long-term plan for meeting the needs of our rapidly growing population of children on the autism spectrum. I learned there from a representative from Medicaid that there is a huge surplus of funds. Every one of the thirty or so people at that meeting would vehemently agree that this is not due to lack of need. And the biggest need of all is FUNDING REFORM: We need flexibility in funding delivery so that the creative solutions that are out there can be put into place NOW. Every minute we wait while meetings are scheduled and rescheduled and then held without any resulting action steps is a minute that families are suffering. Every dollar we spend paying state employees to their webpages is another minute that we are contributing to gross negligence.

In the meantime, I've included in your handouts a graph that depicts an alarming trend: the steep increase in the number of children who have been sent out of state to receive the proper support. What this graph doesn't show is the wreckage created by our lack of capacity for delivering wraparound supports.

Today you are going to hear from three families. We will attempt to share glimpses of our situations so that you can truly start to grasp how broken our system of care is.

All society needs a continuum of care. Think of it like a train track (see handout.)

Brief explanation.

The train track needs to go both ways. I want my child to travel back to the realm of less support. But he can't get there without transitioning through a gradual step-down of support. Last year we tried to bridge this gap by creating our own program designed with our family and a private consultant. The problem was that in the end our backup was a dysfunctional crisis response system. There is no safety net for us. My son is ready to leave, but the community is no more ready to receive him than they were three years ago.

Thank you.