



SPEAKING UP FOR US OF MAINE

Maine's Self-Advocacy Network

... every time we speak up for ourselves we make Maine a brighter place

December 11, 2012

RE: Comments on MaineCare Redesign Task force
Recommendations

My name is Eric McVay and I am from Bangor. I am a member of Speaking Up For Us (SUFU), Maine's statewide self-advocacy network for people with developmental disabilities.

We thank the redesign task force for their work and are here to provide comments.

In particular, we appreciate the use of the term Intellectual Disability (ID) in discussion and the report, but want to ask you to continue to use the correct terms to describe people with disabilities, not only in writing, but verbally as well and as a way to educate others about legislation passed last spring.

Much has been made in the press about Maine ranking fifth in the nation for amount of monies spent on people with Developmental Disabilities (DD). SUFU self-advocates do not see that as a shame but as a source of pride. Unlike many other states, Maine has closed its institutions and serves its people in the community through waiver services for about \$66,000 per person annually. Compared to that, the national average for people who are in institutions elsewhere in the country is \$191,000 per person. We thank Maine for doing the right thing and saving the state money in the process.

The MaineCare Redesign Task Force concedes that particularly the cost of the top 5 % (and 20%), influenced their long-term strategy. Those are people with DD ages 18-44 and who receive waiver services and have more significant service needs. The statistics of a

small percentage of people requiring the largest portion of services is not unlike other health insurances.

Some savings could be realized by people with intellectual disabilities living in Shared Living (SL) as opposed to staffed group homes. SL resembles much closer family living and community inclusion than does any other staffed housing model. The yearly cost for an individual in a group home is around nearly twice as much as for those who are in SL. Self-advocates from SUFU who are in SL situations, appear to be happier than those in group homes. They often feel less segregated, more included in the SL provider's family life and feel as if someone cares about them. On the other hand, group homes are often associated with strict rules and guidelines and as a place where relationships between staff and clients is discouraged.

If SL were to be adopted as a housing model of the future in Maine. SUFU self-advocates would ask that quality assurance, independent oversight and "work to be performed," such as providing transportation, be part of a contract. SUFU would also ask that SL providers receive on-going training.

SUFU self-advocates also like the idea of using technology to help them manage their lives more independently. SUFU is in the process of providing more information to self-advocates through presentations from MaineCite.

We also commend the task force for its wisdom to not look at a quick fix through short-term savings, but to look towards the future in redesigning MaineCare. We too are looking towards the future. In that vision, we see thousands of young people at home and isolated. We see parents who had to quit their jobs to ensure the safety of their young son or daughter with disabilities who is on the wait list for waiver services. If nothing changes, that number will rise dramatically as we are looking toward the number of children who are currently identified with autism, 1 in 88 nationally. So, just making sure that people get off the wait list is not enough. We also cannot add any more as the number of people needing supports increases. The investment that the state has made through very expensive early intervention and special education should continue with helping people to get employment, and the supports they need for independence, instead of people falling off a cliff. Having the

waitlists means that individuals may be losing skills that were learned, and experience more physical and emotional health issues from stress, boredom, and isolation. Some parents will be forced to stop working to stay home to make sure their children are safe.

We are therefore recommending that all or part of the \$8.6 million savings identified for Targeted Care Management in 2015 be used to get people off the wait list by providing services designed to move people to independence. This would mean minimal support needs, and free up services so more people could be served.

People with disabilities can and want to work. Employing them in small businesses is a way to save money while at the same time doing the right thing. We must make sure that we create a climate in Maine that values the contribution of persons with DD in the work force. Employing them in small businesses is a way to save money while at the same time doing the right thing.

Whatever happens to savings in targeted case management and managed care, we must ensure quality standards and evaluations to make sure that not only peoples' needs are met but met with quality.
The value must always be on the individual!

Sincerely,

Eric McVay
SUFU Self-Advocate,
On Behalf of Speaking Up For Us