

September 27, 2012

Dear Friends and Colleagues,

I am writing you all with the hopes that you will write to our Developmental Disabilities Service System Task Force urging them to expand the use of the facilities at our states Intermediate Care Facilities for those with Intellectual Disabilities (ICF/ID or RHC).

As some of you are aware, we are lacking in available services with our Division of Developmental Disabilities (DDD) and there have been extreme cuts in services – services which directly affect our families. The unfortunate part is that our RHCs have been blamed for the lack of services in the community and have been looked at for consolidation and closure.

There is a long history of inaccurate information which has partially led to some closures and we have been trying to inform our legislators and public of a picture that is more realistic with regards to the needs of our loved ones, the intensity of their support needs and the cost of care.

It is well documented that the RHCs are cost effective for those with the highest support needs. It is stated in both the US DD Act and the 1999 US Supreme Court Decision *Olmstead* that people should have a choice of an institution (RHC) or community and that for some, the institution may be the least restrictive environment. What is happening though is that people are not allowed to have choice and this goes against both of these landmark decisions.

Washington State has instituted legislation which became law which now prohibits youth under the age of 21 to access these services. This alone is unconscionable given that for some of these youth there are NO safe or appropriate alternatives for care.

I am working with a family now who has an 18 year old at Fircrest. His care is very intense and his Individual Education Plan (IEP) states he needs total 1:1 support. The school he attends uses 4 instructional assistants who rotate “shifts” of 1-2 hours throughout the day since his care is so exhausting for caregivers.

It was not this family’s first choice to have their son placed at Fircrest on a short term respite stay but once there, with the appropriate supports; he has stabilized and made gains. The family has looked at no less than 10 community placements – none of which would be safe for this young man. They have asked for permission for him to have a long term placement at Fircrest and the family has just received a denial of services from DDD. The reason is SSB 5459

which passed in 2011 which denies those under 21 safe and appropriate services at the RHC. There are NO alternatives for youth such as this young man so our state has legislation in place which is discriminatory - denying available supports and services to those in desperate need solely based on age. This legislation directly conflicts with both the US DD Act and *Olmstead* as stated above.

But, the state has offered an “exception to rule” and said that they would get a house for this young man and staff it with 1:1 caregivers. There are so many things wrong with this option and I find it incomprehensible that anyone would suggest this as an alternative. Aside from the concerns we have about safety for this young man and caregivers in this arrangement, how would this save our state money? In my opinion this suggestion by DDD is ludicrous – particularly when the family has specifically stated that they would like long term placement at Fircrest.

What many who live and work with those who are much higher functioning fail to realize is that living in a “community” home for those who are totally dependent on others to even go outside the house is tantamount to being in a prison cell. This is particularly true for those who need to be moving about and need the stimulation of being “out in the community” amongst other people.

This is one reason that the RHC is the least restrictive environment for many of our loved ones – this young man is one example and my son is another example. The campus community not only serves as a safety net and back up support but also as a social community in safe surroundings. People are free to come and go as they desire, people are free to walk outside their homes and know they are on in a safe environment. There are no fences and locks which restrict the residents.

It is a wasteful shame that we have these services and they are not being utilized due to philosophical reasons to push deinstitutionalization without regards to cost or safety. Senator Kline was absolutely correct when he spoke about the inefficiencies of the RHCs. He is wrong about the reason though – the real reason is that our state, legislators and DD Advocates have not allowed the RHCs to run efficiently and support those in the community. There has been a planned obsolescence program in place at our RHCs which promotes “deinstitutionalization with no regard to the cost” policy which our state has endorsed. This must change. Senator Kline is also correct in the fact that people should be outraged at this. I am - because I see this as planned scheme to promote deinstitutionalization and force people out of their homes which will only increase the crisis for those in the community. I fully support community supports but deinstitutionalization with no regard to cost is not the way to go about this.

When I hear Lance Morehouse of The Arc of King County talk about people with very high support needs who live in the community, he is absolutely correct. What I don't understand is that when he also says that his son was able to be home and in the community with the support of 19 hours a day of 1:1 nursing care from the DD HCBS Waiver that he does not realize the cost of care for those with high support needs in the community is great. The cost is much higher than the same care in the RHC. So, if people cared about cost, as they say they do, they would take a much more critical look at the deinstitutionalization movement which forces people out of their homes

It is one thing to talk about deinstitutionalization but without safe and appropriate supports in the community, this type of advocacy endorses neglect and risk for our most vulnerable citizens.

There are great benefits to having an RHC community – not only for those who need that level of support but for those in the community to be able to access services, respite and for a safety net. People are free not to use the services at the RHC – no one is forcing anyone into using these services but our state has taken it up as their duty to force people out.

Please, I urge you to write to the DD Task Force and tell them if you support a continuum of care, a continuum that will look at the RHC as a resource for the future, as a place to build from to support those living in community settings. We need to use the resources we have first while we build more community resources rather than tearing down what we have only to create a larger crisis in community care.

Please let Senator Kline know that his plan to consolidate and close our RHCs is not a wise choice for our state and our states' most vulnerable citizens and their families. You can write to the DD Task Force at this address:

DD Service System Task Force

c/o Brittany Yunker

Brittany.Yunker@leg.wa.gov

Brittany Yunker
Senate Committee Assistant
Cherberg Rm. 466
PO Box 40466 ~ Olympia, WA 98504
360.786.7407

DD Service System Task Force Website:

<http://www.leg.wa.gov/JointCommittees/DDSSTF/Pages/default.aspx>

Next Meeting is October 9.

Thank you very much,

Cheryl Felak, RN, BSN
Family Advocate
Because We Care – Beyond Inclusion

www.becausewecare1.com