

September 25, 2012

Dear Ms. Yunker,

After listening to Lance Morehouse talk today about the parent coalitions, I thought it would be critical for the DD Task Force to know that these Parent Coalitions (all or almost all are actually Arc groups as are the online list serves for support), the Community Advocacy Coalition, Disability Rights Washington, The Developmental Disabilities Council and The Arc have all censored and blocked communication to their groups by advocates who support a continuum of care.

I have addressed this with The Arc of King County (both Sylvia Fuerstenburg and Lance Morehouse), The Arc of Washington (Sue Elliott and Diana Staddon), the Developmental Disabilities Council (Ed Holen and Leslie Smith) and Disability Rights Washington (Mark Stroh). They are aware of it and I have also heard that there has been a directive from Sue Elliot to all Arc Members to not respond to any letters that I may send. I have contacted the Community Advocacy Coalition (Scott Livengood) regarding membership and have been denied even though they say "nothing about us without us" and I fully support community advocacy. These meetings are all focused on closing the RHCs yet they do not allow those who support a continuum of care to be members or attend meetings.

How can these groups state that they speak for those in the community? They do not allow useful and accurate information to be disseminated and by doing this they are making the choice for the people since they are not giving them information so that they may make informed choices. I find this practice extremely detrimental to the DD Advocacy movement and very isolating for those families who may support a continuum of care. In order to find out information about a continuum that is accurate, they must go through great lengths since the information is not shared by the people who say they speak for people with DD in the community.

I am out in the community all the time, with my job and with our son, who happens to live at Fircrest. I am continually supported by those in the community and I find that there is quite a bit of support from those, even in The Arc chapters, who do support a continuum of care. Yet, because The Arc does not endorse any form of congregate care, no matter what the cost, members of The Arc cannot speak publicly about their support for a continuum of care.

So, until this moratorium on information which is accurate and not coming from the clouded lenses of The Arc position is lifted, the legislature will not know nor will the public know that many, many of these families do want and support a continuum of care. Talk to Dr. Chuck Cowan or Dr. Gary Stobbe from Seattle Children's, talk to people at Tavon or Tessera or Autism Society of Washington about their support of a continuum of care and you will get a very different picture than the one which you hear from those who you regularly hear from.

I find it so disrespectful of these groups to not allow useful and accurate information to be shared. Even when the issues that I write about to support community (such as the newly formed Shoreline Community Lifelong Learning PTA) are submitted, they are blocked because they come from me. Why won't they allow the public to have accurate information and make informed choices? Personally, I'm tired of hearing spokespeople from The Arc Chapters talk as if they are the experts. They are not and it would be greatly beneficial for them to allow the public to have better access to accurate information.

These comments are not only mine but comments that I hear from others in the community who have had contact with The Arc Chapters. I support the work that The Arc has done in helping build community supports and many breakthroughs in DD Advocacy but I cannot endorse them with the censorship and lack of ability to pass on truthful information to the public and legislators who look to them as the voice of the DD Advocates.

I hope that you are able to pass this message on to the DD Task Force Members. It is important for them to understand why those who do support a continuum must work extra hard to be able to advocate for a continuum of care.

Thank you,

Cheryl Felak