

April 4, 2016 – Increase wages for Direct Support Professionals

Dear Susannah,

Thank you for taking the time and effort to do an investigation of the Developmental Disabilities System in our state. My hope is that there is some clarity that will become evident with a full disclosure of cost distribution, services and the choices of the families and people who live with intellectual disabilities.

As a parent of a young man with profound developmental disabilities and a mental health illness (dual diagnosis) and as a healthcare professional working with many in this population, I understand there is a huge variation in support needs of this population. There are many reasons why a person/family may choose to live in a campus based community versus scattered homes in the community at large.

I also know from having had my son in both of these settings and from extensive research from the Certified Cost Reports required for each agency to submit annually to DDA, CMS reports, Certificate of Evaluation reports and academic research journals, that the costs analysis used in this series is incorrect.

It is a fact that those with higher support needs have a higher cost to their care than those who may not need as much support. This is true regardless of the residential setting. The difference in cost is deceptive due to the fact that only one budget (Developmental Disabilities Administration) is looked at.

When a person lives in a supported living home or other home in the community at large the cost of rent, food, medical, employment support and other supports come from other budgets. Subsidized rent, food stamps, Apple Health Care, Behavioral Health Care, Vocational support, transportation subsidies are just an example of the different budgets that help support residents in the community. These costs are not included in any of the cost comparisons of community homes to RHC costs.

Typically, the cost one sees attributed to care in the community is only that of the Direct Support Professional (DSP). This cost of care for those with high support needs can be much more than the same DSP cost in the RHC given that lack of ability to share staff and resources in scattered homes throughout the community.

Another issue concerning the deception in cost reporting is the use of the "average" cost of community care in reporting the RHC costs more than community care. What we do know is that for those with high support needs their care costs for direct support only can be as high as \$750.00 day for an individual's direct support care. In the community each person's cost of care is known since the agency negotiates with DDA for each contract. The RHC does not have individual costs applied to each resident and so an average cost must be used.

That being said, we do need to be able to pay the DSPs a higher wage. This is hard (although rewarding) work and takes a toll on one's body. There is a high turnover of staff mainly due to the lack of supports for the DSP – healthcare, short staffing and high use of overtime and a baseline pay that is not enough for one to live on without working 2 or 3 jobs.

We do have a shortage of providers but the reasons are not due to the RHC – they are due to limits put on bed usage and pay by the legislature.

We cannot let neglect become the standard of care by underfunding these critical services.

April 5, 2016 – Supported Living Agencies

Dear Susannah,

I am writing today with information regarding supported living and the residential habilitation centers. Your series "The Last of the Institutions" has sparked much interest in the programs and services for our citizens with intellectual and developmental disabilities.

It needs to be clarified that there are quality programs and services in both the community and habitation center options – and there are problems in both scenarios too. It is unfair to focus only on the good in one situation and the undesired in another situation and then compare them.

I know from research (Reviews, Evaluations, Cost Reports, and community discussions) that two of the agencies you highlighted (Provail and Alpha Supported Living) are two of the quality programs in our area. In fact, my son utilizes services from both of these agencies and I believe he has the dream team working for him. They hold high standards and have integrity. They are both non-profit agencies. Unfortunately, not all services and programs hold these high standards.

For instance SL Start, a supported living agency in our state (for profit) has had issues with safety in the homes of their supported agency clients. One recent Certificate of Evaluation report cited faulty lighting fixtures hanging by duct tape with unprotected lightbulb as the source of light. Other issues were holes in walls and no working curtains on bedroom windows. One young man I know has a 1:1 caregiver and enjoys going out but the caregiver only sits on the couch and refuses to take this young man out. The mother has complained to her case manager and the response that she hears over and over is "we are doing the best we can."

Ambitions, another for profit agency, has a home in Shoreline. There have been multiple incidents at this home involving police. A woman who needs 24 hour supervision often leaves and the caregivers are unable to go after her since they are alone and there are others to care for in the home. This woman has been seen getting

into strangers vehicles and driving away, going barefoot on cold, wet days, has been reported as being lost only to be found at Northwest Hospital ER and recently had a foot infection. She often calls 911 or an ambulance demanding that she be taken to the hospital that she wants to leave. There were over 10 incidents at this home in 2014 and they became well known to the sheriff and Fire Department EMS.

The officers are well acquainted with the residents of this home and have advised the house and/or management team the many false calls were a misuse of public emergency services and have encouraged them to develop a better plan.

You report that residents of the RHC are segregated but in talking to the families of the residents this is not their impression of the campus communities. I do not recall you speaking with any residents about their choices and why they love living at the RHC. I know for a fact that the residents are not segregated – cut off from the community at large. It is a fallacy that the residents are locked away against their wishes. This myth is reinforced by comments of those who have not even set foot on the campus or worked with the residents and/or their families. It is also perpetuated by the continued reference to the atrocities of the past as if those practices are still in play today. We have a very different system in place now.

We need to understand that there are quality services and really poor services in both community and RHC settings. It is critical to look at the quality services, figure out what they are doing right and cite the programs that are not meeting standards. We need to pay the providers for the work they do and stop the quota on allowed beds.

We need to build services where the people live and where they want to be served. We should not force them to move to another city/county because that is where the “bed” in the community is. We hear of choice in the community but in reality the residents do not have a choice of housemates or homes and there is a limit of spaces allowed by the legislature. There is a huge need for more services but the agencies are limited in what they can provide. The rules look at vacancies – not necessarily where those vacancies are or if they are appropriate for resident compatibility. Is this really choice?

Thank you,

April 6, 2016 – Residential Alternatives and Intentional Communities And Unions

Dear Susannah,

I have some additional comments and concerns regarding the issues that you have raised in your series “The Last of the Institutions.”

It appears that there is a consistent theme of attacking the RHCs for having union employees. It needs to be pointed out that all the Individual Providers under contract with DDA are members of SEIU 779. Also care givers from First Choice and ResCare

have also joined this union. What is the motive for the attack on the union employees? Is it because they have benefits? If so, why is that so bad?

There is a national movement among families and people who live with intellectual disabilities to support campus communities and intentional communities. I urge you to read "[Who is my Neighbor](#)" and "[Intentional Communities](#)" for more information on residential options that many advocates are developing. We need to have more options not less and closing the RHCs reduces many of the options and also reduces the availability of crisis supports. See **#ChoiceFirst** and **#increaseoptionsdecreasebarriersnow** for more information on the nationwide movement to promote alternatives, campus living and intentional communities.

You and others speak of segregation without realizing that many families and individuals are segregated in their own homes and apartments. Not having the ability to go out, to work, to meet with other friends because they are locked inside their homes with no support. This is real segregation that needs to be highlighted. There is no such segregation such as this occurring at the RHCs.

Catering to the vendors is not the same as advocating for people with intellectual and developmental disabilities. There is a major conflict of interest when some of these advocacy agencies gain much of their income from providing residential services. Is this an advocacy agency which is really looking out for the people or for issues of its own gain hidden behind the cloak of advocacy?

Please feel free to publish.

April 7, 2016 – "too disabled" to live in the community

Dear Susannah,

I also wanted to add one additional issue that is often misunderstood. One of the arguments that is heard is that people who advocate for RHCs say that their loved ones are "too fragile" or "too disabled" to live in the community. It is not the medical fragility or disability that prohibits the person from living in the "community" but the cost of care and restrictions to the family when there is a person with extremely high support needs.

For instance, during the Developmental Disabilities Task Force meetings that were held in 2012 this very issue was raised. Lance Moorehouse, then The Arc of King County Parent Coalition Coordinator spoke about having his disabled son living in their family home as proof of the fact that those with high support needs can live in the community. Mr. Moorehouse then stated that his son had 19 hours a day of 1:1 nursing

care for 17 years that was provided by the Home and Community Based Service Wavier. The cost of this care is great – certainly much higher than the same care in the RHC yet there was no one telling Mr. Moorehouse that he needed to move his son to what they believed was a less expensive option or one that was against their personal choice. Mr Moorehouse was not being condemned as being evil or selfish by taking more than his share and therefore making it impossible for others to have any services. Yet this is the treatment that families of RHC residents receive from so-called advocates. The choice of families such as Mr. Moorehouse' are honored (as long as there are providers) just as the choice of families who choose to have their loved ones live in a campus community and share services and costs should be honored.

The Arc of King County (the agency which employed Mr. Moorehouse at the time of the DD Task Force) is one such agency which advocates for closure of the RHCs based on costs. It is clear just from this one example that the cost of care for some of the people with high support needs is something that needs to be looked at more closely. The cost of care for these individuals is well above the "average" cost reported and used as a cost of care analysis for moving RHC residents to scattered community settings. Continuing to use the average cost of care gives a very skewed representation of the actual costs that would be needed if such an endeavor to close the RHC was undertaken. If we based the budget on this average it would mean disaster to services and supports for those who live with intellectual and developmental disabilities.

The advocates who support the RHCs and campus community settings do so for many reasons. They are also being more realistic in what can be accomplished financially in community at large settings for those with high support needs. If we were to advocate for all people with very high support needs to live in a family home, the cost of care would be astronomical. In theory all people, no matter what their support level, can live in a community home. In reality, this goal is unattainable and cost prohibitive.

I am including links to three letters that I wrote in 2012 to the Developmental Disabilities Task Force. These same issues continue to be current. When I heard that you were doing an investigative series I had hope that these issues of a monopoly, conflicts of interest and biased reports would be exposed. I'm sorry to say that the series was more of the same and an advertisement for The Arc and their viewpoint.

See these links for more information:

[Letter to DD Task Force](#)

[Letter to DD Task Force about Least Restrictive Environment](#)

[The Arc and Parent Coalitions](#)

Please feel free to publish this letter. Thank you for your interest.

April 8, 2016 - Cost of Care for people with developmental disabilities

Hi Susannah,

I realize that I have sent you several letters in the past few days. Please, if you have any questions about any of the information I would be more than happy to answer them.

One last issue that I would like to pass along for the sake of transparency and that is concerning the cost of care. As you may recall, my son has just recently moved out of Fircrest into a supported living home. The information on the cost of his care is just starting to come in and I am not surprised at all. I knew that it would be expensive for his care in the community and I am right. But, then again, the care is better and of a higher quality.

Thomas lives in a supported living home. The agency receives \$418.15 a day for his care. The nurse delegator receives \$26.58 per day. These two expenses come to \$13,786.65 per month or \$165,439 per year. On top of this, my son needs to pay his own rent from his Social Security (a rent that is subsidized by HUD), buy his own food (but he will receive food stamps). He will utilize his medical and mental health care providers in the community – billed to our insurance and Apple Health and his medications and incontinent supplies will also be paid for by Apple Health. Adding all these costs up his annual cost of care in the community will be greater than that of the cost of care in the RHC.

Interesting to note is that the Shoreline Police have already been called to his home due to being hit by another resident. There was no fault but only caused by the excitement of two adult sized men who have the emotional maturity of 2 year olds and often their communication involves swinging of the arms or hitting. My son was hit in the head and had a bruise on his ear. It was not a serious injury at all and there was no blame but it is the law that the police are notified and a report is filed. In all honestly this was much less of an issue than some of the injuries he had while at the RHC but I am not aware if the police need to be notified of all injuries for client-to-client "assaults". At any rate, this does show the increased cost to the community when other agencies need to respond and support these folks.

I am writing this to you so that you are aware that it is not LESS expensive for those with high support needs to live in the community. The care is better, the health care meets standards, the providers work with the guardians and include them in correspondence and collaborate - to me that is worth the extra cost of care.

We need to be honest about what the real story is. If the RHCs closed and others (many with higher support needs than my son) moved to the community there would be a huge cost increase. To report otherwise is misleading and negligent.

Thank you again for the work you did on the series.

