

From: Cheryl Felak
Sent: Friday, April 14, 2017 10:25 PM
To: Keiser, Sen. Karen
Cc: Minich, Jennifer
Subject: Re: Factual cost information for DD community costs

Dear Senator Keiser,

I'm a little taken aback by your response and am really not quite sure how to respond. Yes, I am well aware of the costs and that community and RHC costs for high acuity residents are higher than the "average" reported and used for budget purposes. In order for an average to be relevant it needs to reflect the population. In this case, the average used does not reflect the Level 5 and Level 6 types of clients who reside in the RHCs and community settings but includes the greater number of clients who are Levels 1,2, 3 and 4.

Again, my concern is the issue that "average" is used when it is not really a good reflection of the type of client that we are all talking about when moving RHC residents from the RHC. You state that we have moved "hundreds of RHC clients" to the community and you have real data on this. I don't doubt that but what I have concerns about is the acuity of those people who were moved and when they were moved and where they were moved to.

Many of the hundreds of residents you may refer to transitioned from the RHC years ago - many are residents who should never have been in the RHC but were placed there as the thing to do at the time. People who can speak in sentences, sit still and follow directions, who can dress themselves and do personal care or know how to direct someone else to do it are a different type of person than the majority of current residents.

The people remaining in the RHCs tend to be those with higher acuity levels and support needs and are not similar to the many that left our RHCs when deinstitutionalization was initiated and in full force. Many of those people do not need the level of support that the current residents do and while my son's costs are only his they do give a good representation of the current level of support needed for the current residents of the RHCs.

The issue of providing data for my son is extremely relevant to this issue, it is factual and accurate. I provided the exact documents that were provided to me by DDA so if for some reason they are inaccurate, that is an issue that needs to be addressed with DDA. I would be more than glad to provide you with the same information.

Also, the Certified Cost Reports are documents provided by DDA. Community costs are itemized on these reports and if you believe they are not factual, that is an issue to be taken up with the agencies and DDA. All I did was access the reports that for some reason had been ignored by others.

I understand the references to the DD Audit but there are problems with the data they used - particularly only using 3 of the 6 (now 7) acuity levels used to assess the clients. It is also important to

note that when a person is high in more than one area that adds to the support need. The audit looked at Behavior, Medical and Activities of Daily Living but did not address Interpersonal Supports, Mobility or Protective Supervision. A 7th assessment area of Caregiver Risk Level has now been added to the assessment. Of note, in order to "score" high in Medical, one needs to have a tracheostomy, continuous tube or IV feeding, dialysis, or severe seizure disorder.

Regarding the DD Audit, it also needs to be noted that they ONLY looked at DDA costs for these clients. They did not address any other DSHS or other State agency costs that are used to support these clients in the community. Since the state pays for these services I think that it would be important to get a more comprehensive view of the costs not just the DDA silo.

The fact alone that it took 15 months to get my son moved from Fircrest to the community is something that should be looked at. He was denied by about 8 agencies before Alpha agreed they could support him. Once a house was identified that would be appropriate for him it took 3 more months to hire and train staff. My son is not aggressive at all but does need one on one support while awake and has several medical appointments he needs to attend each week and needs nurse delegation services. My assumption is that those who are more aggressive or destructive would require higher person hours or support costs to safely have them live in the community.

Of an extra note there is the issue of having other community services involved. For instance, I know that Shoreline Police have been called to my son's house about 4 times since he moved there last year. This is due to the fact the agency was following regulations that any injury to a head area or other certain body areas needs to be reported to the police. The specific issues that the police were called to my son's house were just accidents that can happen when two adult sized men who have the intellectual and emotional capacity of toddlers interact and try to grab for the same food or other items they may want. There was no malicious intent or aggressiveness other than typical toddler like behavior with no one at fault. But given the regulations these incidents were reported to police and residential care services and there were a couple investigations done which were deemed "unfounded" (rightly so). These issues add cost to community care - both for local law enforcement agencies and DSHS which increased investigations needing to be done.

The whole issue is extremely complex and unless one has been in the presence of people like my son and others for even a few hours and understanding that the care needs to be constant, it is hard to understand particularly when one sees self-advocates testify who have abilities far advanced of my son and others.

My concern is about safe care provided in the appropriate setting and that there is an understanding of the complexity and rhetoric and ideology that may or may not be pushing budget decisions.

As a Registered Nurse I view this as an ethical and moral issue and a professional responsibility of mine to advocate for our vulnerable citizens and their families, provide information and allow people to make informed choices.