From: Sunset Advisory Commission
To: Dawn Roberson
Subject: FW: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)
Date: Friday, June 06, 2014 8:17:42 AM

-----Original Message-----
From: sundrupal@capitol.local [mailto:sundrupal@capitol.local]
Sent: Thursday, June 05, 2014 11:13 PM
To: Sunset Advisory Commission
Subject: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)

Submitted on Thursday, June 5, 2014 - 23:13

Agency: DEPARTMENT AGING AND DISABILITY SERVICES DADS

First Name: Edmund

Last Name: Snuggs

Title:

Organization you are affiliated with: Denton SSLC Family Association; P.A.R.T.

City: Dallas

State: Texas

Your Comments About the Staff Report, Including Recommendations Supported or
Opposed:
My name is Ed Snuggs. I live in Dallas, and my step-son is at Denton SSLC. My wife Nancy and I are pleased with the care he receives, and believe that he is in the best available place.

The following is regarding the recommendations from the Sunset Commission report.

I am opposed to all 3 of the recommendations of Issue #1, as discussed below.

Here's a quick overview of our son's situation: he has the mental capacity of about a 6 to 9 month child. He does not talk,walk or even crawl. He has extreme osteoporosis, so is very prone to fractures, and is prohibited from weight-bearing activities . He requires seizure medication. He has a history of MRSA infections. If not closely monitored he puts his hand in his mouth; therefore, he must be closely monitored and frequently redirected or the saliva causes skin breakdown, and the hand gets infected. .

I wish to make clear to begin with that I am not opposed to group homes, community homes, etc.; in fact, I think they are a very good thing and can serve a significant portion of the intellectually and developmentally disabled (IDD) population. We need more of them. I do think that new capacity in group homes should be used for people who need the help and are currently unserved. I understand that there is a considerable waiting list for these facilities. Unfortunately, priority is given to people being moved out of SSLC's – people who are already being served. I see this as being a serious injustice to the unserved IDD population.

In Issue 1 of the DADS Sunset report, it is stated that the 2013 budget for the 13 SSLC's was $661.9 million, and that they serve about 3650 people. This works out to be about $181,000 per client. Shortly after, the report states

"Delivering services to a person for a year in an SSLC costs about $113,000 more than serving that person in an equivalent program in the community."
That computes to a cost of about $68,000 (in the same range as nursing home care, starting with the 2010 Texas average of $49,000 and using Genworth's figure of 23% increase in the last 5 years) to serve a person in the "equivalent program".I don't know of any 6-bed nursing homes – do you?
The term "economies of scale" is so common because almost everything can be done for less money if you do it on a larger scale. In my opinion the term "equivalent program" is being used very loosely. That's a bit like saying that all these people that are taken to the hospital could be served more economically in an 'equivalent program' of one of the urgent care clinics.
Now, if all you need is something to treat your cough or sore throat, then the urgent care clinic will be much less expensive than going to the hospital, but to call it an 'equivalent program' to the hospital is absurd.
So is calling a group home an 'equivalent program' to the SSLC. Just check your own experience – small, local facilities are more convenient, but can not provide complex services.

I challenge you to compare the training given to direct-care staff at the SSLC with that given to staff at a group home and tell me if it is equivalent. Or compare the availability of medical staff. Let me give some examples.

If our son develops a pimple, it is looked at by the LVN on the home and, because of the MRSA history, it would be looked at by the RN Charge Nurse. If it appeared questionable in any way, our son would be put on 'clinic' and the doctor would visit him on his rounds to make the determination of ordering a culture and whether to put him on an antibiotic. In my opinion he would not get any trained medical attention at a group home until the situation was out of control.

Our son takes several medications, which are administered by a LVN. He receives medication 5 times a day. Some medications have to be taken together; some have to be separated by a period of time; some have to be evenly spaced to keep the medication level constant; some have to be with food, some without. I would not be comfortable trusting this to the direct care staff, as I believe it would be in a group home.

It would be easy to go on with a dozen other non-equivalent comparisons, but I will end this point with this: by my observation a high percentage of the residents of the SSLC have complex and difficult emotional, behavioral, physical and medical problems that require frequent attention from professional disciplines that they would not receive in a community home..

I only have anecdotal evidence, but it seems too often when someone seems to be doing well at the SSLC and are moved to a group home, that we hear that "they died". I do not have access to the data to compare the mortality rates, but I think you do. Please take a look. Keep in mind as you do that the persons moved to the community are usually among those with the fewest problems.

As we are all aware, Texas is a big place. While 13 SSLC's seems like a lot, when you spread them out over the state they are pretty scattered. One of them seems to be not really the same type of facility, and serve a very limited area (Rio Grande, 3 counties.) For the other 12 SSLC's, the average driving distance to the county seats of the counties they serve is about 105 miles. The averages range from an average of 60 miles for the Brenham SSLC, which only serves 10 counties; up to an average of 137 miles for San Angelo, which serves 38 counties; and 142 miles for Lubbock, which serves 54 counties. Individual driving distances range up to 315 miles to get from Sierra Blanca in Hudspeth County to the SSLC in San Angelo.

Let's just imagine that your mom or dad needed a nursing home; how would you react if you were told that the closest suitable facility was 105 miles away?
(keep in mind that 105 miles is the average, not the maximum). Would you consider this to be an acceptable situation? How often would you be able to visit them? Is that good enough? We drive 42 miles to see our son each week, requiring about an hour's drive each way. If you were to set that as the limit of an acceptable distance for regular visits, you would have to conclude that more than half the state is currently unserved. It should be obvious that if you start closing the SSLC's, the average distance will go up, and the number of people who are within a reasonable range would go down.
With the drive up and back, taking our son out for lunch and a drive and meeting with staff as needed, our weekly visit usually takes 8 – 9 hours.
This has been going on for 37 years. We are in our 70's (among the younger parents at DSSLC). This is already a

burden – a much greater distance would be unbearable.

Regarding Issue #2, recommendation #1: I do not really understand the workings of the crisis intervention team, so don't have an opinion.
Recommendation #2, Yes. If a group home is to be suitable for typical SSLC residents. Recommendation #3 Yes. Making the services of the SSLC available to the community for a fee sounds like a good idea.

Regarding Issue #3. Recommendation #1Yes. Some day habilitation facilities are not satisfactory. Recommendation #2, Yes. Better oversight and reporting is needed.

Regarding Issues #4 through #7. No comment. Out of my area of interest or experience.

I think that if you implement all these improvements in the community program – adequate medical capability, adequate oversight and enforcement (comparable to SSLCs), and require that they meet the applicable DOJ standards (as SSLCs must) –i.e., make them truly an "equivalent program" - the community programs will be suitable for a lot of the people that currently require the services of a SSLC. And I think they will cost as much or more. The principle of economies of scale has not been repealed.

Let me conclude with this. Please give the families due credit.
Most families/guardians know their loved one better than anybody else.
Most families/guardians would like to have their loved one closer to them.
Most families/guardians know what is best for their loved one.
Most families/guardians would move their loved one if there was something "as good" closer to them.

Thank you for doing what is right for our loved one and for us.

Any Alternative or New Recommendations on This Agency: Consider the possibility of reducing the coverage area for Austin SSLC to the 9 counties immediately surrounding it, and reassigning each of the remaining 19 counties in its current coverage area to the SSLC closest to each. Perhaps you could then complete the needed infrastructure update on a smaller facility and avoid closing it.

My Comment Will Be Made Public: I agree