

From: [Sunset Advisory Commission](#)
To: [Dawn Roberson](#)
Subject: FW: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)
Date: Tuesday, June 03, 2014 1:45:17 PM

-----Original Message-----

From: sundrupal@capitol.local [<mailto:sundrupal@capitol.local>]
Sent: Tuesday, June 03, 2014 11:47 AM
To: Sunset Advisory Commission
Subject: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)

Submitted on Tuesday, June 3, 2014 - 11:46

Agency: DEPARTMENT AGING AND DISABILITY SERVICES DADS

First Name: Louis

Last Name: Heard

Title: Pastor

Organization you are affiliated with: Grace Baptist Church

City: FORT WORTH

State: Texas

Your Comments About the Staff Report, Including Recommendations Supported or Opposed: I read a lot about care facilities and the cost it takes to operate one. Yet, most caring family members aren't looking for impatient care, we just need medical assistance as we keep our child(ren) at home with us, which is much more cost effective for the state. What is being done about that? It's the "waiting lists" for MDCP and CLASS (and others) that is bogging down the system to provide help. How can the time on these waiting lists be eliminated (or at least shortened) so that families can get the help needed? I suggest addressing this issue more diligently, for it may decrease enrollment in care facilities, which could save state money. Maybe there could be another agency created just for more severe/genetic disorders to get their needs met more rapidly? Though everyone feels their medical issues are important (which I understand), there are some more severe cases that can't be ignored for years while they wait on a list. Please address this. Thank you!!

Any Alternative or New Recommendations on This Agency:

This isn't a new recommendation, but it's just an emotional appeal to act. I feel compelled to provide a few comments for the sake of so many parents (like myself) who have the extra challenge of raising a child with special needs. Before moving to Texas in May of 2012, we lived in Arizona, where disabled individuals were well-cared for. In the state of Texas, however, I am shocked at the disregard for children (and adults) who need state assistance but cannot receive it in a respectable amount of time.

Currently, my daughter, who has a rare chromosome abnormality called Alfi Syndrome (9p minus) cannot even be considered for state assistance until she gets to the bottom of the Medically Dependent Children's Program list (MDCP) that is currently 27,745 individuals long. I signed up my daughter 2 years ago (May 2012), and I was told then it would take about 6 years to get to the top of that list. Well, two years later, she is still about 6 years away from getting any assistance. I'm puzzled at how can that be acceptable in a great state like Texas. I should also mention that I have her on the CLASS list too, but it's a 10 year waiting list! Many kids and adults with these kinds of needs could die before they ever receive help.

I understand there is a complicated process to make changes, but I'm seeking to find a legislator willing to fight for those who most of the general public ignore because these issues don't deal with them. Some of these kids (and adults) needs are costly, so I understand the financial burden upon the state. But I know there must be a better way to handle this waiting list issue. But who will stand? That I don't know.

I wish policy makers could meet my daughter. I believe it would compel them to act. Her voice (along with many others with special needs) is very quiet in the noisy world we live in, so that's why she needs an advocate in our government. Please make some changes soon.

My Comment Will Be Made Public: I agree