

From: [Sunset Advisory Commission](#)
To: [Dawn Roberson](#)
Subject: FW: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)
Date: Wednesday, June 25, 2014 4:35:04 PM

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

From: sundrupal@capitol.local [<mailto:sundrupal@capitol.local>]
Sent: Wednesday, June 25, 2014 2:30 PM
To: Sunset Advisory Commission
Subject: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)

Submitted on Wednesday, June 25, 2014 - 14:29

Agency: DEPARTMENT AGING AND DISABILITY SERVICES DADS

First Name: Leslie

Last Name: Phillips

Title: Parent Advocate

Organization you are affiliated with: National Autism Association, Katy Autism Support

City: Katy

State: Texas

Your Comments About the Staff Report, Including Recommendations Supported or Opposed:

I am the parent of three sons, two on the autism spectrum. My oldest son, diagnosed with Aspergers Disorder, is an incoming sophomore at Texas Tech and with supports we pay for at the University, is doing well.

My youngest son is 14 years old and was considered moderate to high functioning when he was younger. Beginning about second grade, we placed him in private school due to significant behavior challenges that resulted in restraint practices that injured him, and unwillingness on the part of the school district to change services or placement. Rather than filing due process (normally not successful for families in Texas), we chose the private placement which we funded.

About a year ago, my son's behavior suddenly worsened. He has episodes of rage that are unpredictable and despite rigorous behavior analysis, seem not to have an antecedent. These episodes escalated in January to the point where we needed to consider temporary out-of-home placement or treatment.

Despite the fact we have fairly good health insurance for general medical needs, long term residential placements are not an option. In one emergency situation, we took our son to West Oaks Hospital for inpatient treatment where we were denied admittance because of his autism. They told us he could not benefit from group therapy and the milieu, therefore they could not serve him. We called three other area psychiatric hospitals who told us the same thing.

We were prepared to place him in Meridell, but once they met my son, despite receiving extensive information from his school and psychiatrist, they determined he was too low-functioning for them to help. They referred me to Bayes Achievement Center. Bayes told me their residents are funded by school districts (many from out of state because Texas schools very seldom pay for this placement),

CPS, and less than one percent private pay because of the \$15,000 per month cost. They did not accept insurance.

Texas NeuroRehab Center did accept my son. After four weeks of residential treatment, he came home and behaviors, within a few days were much worse than before the treatment because of their lack of knowledge of autism.

We are currently awaiting assessment to see if he qualifies for the Behavior Treatment Training Center, but meanwhile must deal with these situations ourselves. In the past several months, my son has destroyed three televisions, an Ipad, two doors, put holes in the wall, and bitten, kicked, hit and pushed me down. This is despite aggressive psychiatric treatment that is sedating him and causing dangerous side effects but not curbing the episodes.

Recently, for the first time I called 911 because I felt I was in danger. The Ft. Bend County Sheriff, Ft. Bend Fire Dept. EMS and a Crisis Intervention Team for mental health crises responded. No hospitals we called would accept my son because of his autism. Our only option was to transport him ourselves to Harris County Psychiatric Center and take him as a private-pay walk in. After nine days he returned home, again no better than when he was admitted.

Because I live in Ft. Bend County, only a couple of miles from Harris County, there were no wrap-around services available when he was discharged. The only discharge resource was to tell us to take him to his private psychiatrist soon.

Texana of Ft. Bend County has been helpful in providing a BCBA for crisis, but her visits are limited to 8 times. There are NO respite agencies available. When I have asked nursing agencies or HCPC about how to PRIVATELY HIRE AND PAY OURSELVES for a trained psyche tech to help me in the home, I'm told such people don't exist.

When I asked about doing a medication wash out because the side effects were becoming intolerable, I was told the only facility that would provide that for pediatric was Austin State Hospital, with no beds available. Texana could not confirm that we could be eligible for this anyway. Even the SSLC's have a long waiting list, if you have to make the agonizing decision for a longer term out of home placement.

It is hard to say whether my son has a dual diagnosis of autism and a psychiatric disorder, or whether the encephalopathy, mitochondrial dysfunction and gastrointestinal disturbances have caused these rage episodes. But it is CLEAR that there are no options available for an adolescent with significant autism and serious behavior concerns.

Autism rates have exploded in the last 25 years, and it is completely clear that better diagnosis cannot account for the number of children affected. Individuals with autism who have severe behavior challenges need effective, intensive and humane care to determine medical, emotional or mental antecedents and provide appropriate treatments with the least risk of side effects, particularly long term serious side effects from overmedication due to inappropriate interventions.

Any Alternative or New Recommendations on This Agency:
Wrap -around mental health services should be available in all counties in Texas.

For individuals with autism, medical services should be expanded to diagnosis and treat underlying biological contributors to behavior challenges. Simply medicating these individuals without rigorous investigation of medical underpinnings is unethical, wastes money by not treating conditions that could improve health, behavior and long term prognosis, and violates the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment by failing to investigate causes of pain for individuals unable to reliably communicate, thereby unethically withholding pain treatment

Emergency out-of-home respite should be available to any Texas family in a similar crisis to avoid tragic outcomes for both the child and other family members.

My Comment Will Be Made Public: I agree