

From: [Sunset Advisory Commission](#)
To: [Dawn Roberson](#)
Subject: FW: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)
Date: Monday, June 02, 2014 12:38:50 PM

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

From: sundrupal@capitol.local [<mailto:sundrupal@capitol.local>]

Sent: Monday, June 02, 2014 12:04 PM

To: Sunset Advisory Commission

Subject: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)

Submitted on Monday, June 2, 2014 - 12:03

Agency: DEPARTMENT AGING AND DISABILITY SERVICES DADS

First Name: Cassie

Last Name: Myers

Title:

Organization you are affiliated with:

City: Houston

State: Texas

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

- We would need the same individualized care plans provided by the SSLC's from private ICF's.
- Penalties for safety violations in private ICFs have no consequences. Why?
- Inspections of private ICFs are not comprehensive and don't ensure the safety and welfare of our loved ones. We need inspections that mirror the SSLC requirements.
- Day Habilitation Programs are poorly organized, staffed by people with little or no training to support the disabled, offer little in the form of vocational skill development, are frequently conducted in unsafe environments, and are not individually focused to support varying disabilities.
- Private ICF homes are not required to provide high quality community interaction activities.
- The Commission's cost data is faulty. Private ICF costs don't reflect medical services provided and paid by Medicaid. We want them to reexamine this data with a more critical eye. We want apples to apples evaluations, not apple to orange evaluations.

Any Alternative or New Recommendations on This Agency: Inform families who have loved ones with special needs about the living centers. It took our family YEARS before we even heard about RSSLC. Had we known help was available, my brother would have had the care that he needed much sooner.

My Comment Will Be Made Public: I agree

Cassie Myers

Written Testimony for the Sunset Advisory Commission Hearing

June 25, 2014

Submitted by Cassie Myers

Sister of Blake Myers

Resident of Richmond State Supported Living Center



Blake, enjoying his favorite pastime, reading Dr. Seuss books
at Richmond State Supported Living Center.

My name is Cassie Myers, I am the sister of Blake Myers, resident of Richmond State Supported Living Center. Blake has been a resident at Richmond for over 4 years. During his time there, Blake has made friends, experienced new things, and has grown healthier.

Blake lived at home with my parents and me until he was 20 years old. During his time at home, we were in constant battle with the school system and doctors to make sure Blake had the best quality of life possible. Over the years Blake has been diagnosed with Autism, Alternating Hemiplegia, Osteoporosis, High Blood Pressure and a multitude of other ailments. We were constantly running into issues with Blake's healthcare. Doctors were not willing to treat Blake and those who were could not adequately treat him because of the difficulty and/or inability to take blood samples. Also, they could not communicate with Blake regarding his symptoms. The fact that Blake is non-verbal and cannot express pain was a huge issue for them. When we took Blake to the Texas Children's Emergency Room, we quickly realized the hospital was not equipped to handle a child such as Blake. After an entire week of testing, their suggestion was to take him to the Harris County psychiatric ward. We knew this was not in Blake's best interest. As a family, we were at a loss as to what to do for Blake. After the visit to the ER, we had a follow up visit with Blake's General Practitioner at which time the doctor told my mother that she had decisions to make and he would no longer treat Blake. The medical care offered to Blake was progressively getting worse. We reached out to our Advocate, Louis Geigerman, who found us another General Practitioner in Pasadena, Texas who was willing to treat Blake. When we spoke with the new doctor, we explained that all we wanted for Blake was good health, safety and a quality of life that everyone deserves.

As Blake grew in age, his seizures and the aggressive behavior associated with his seizures worsened. The School District decided that Blake's medical needs were beyond what they could handle and suggested we find placement for Blake. Being without medical care to help the situation, my family made the decision to find a home for Blake to ensure his safety and as well as our own. We wrote a list of needs that we felt were required of the facility. The following are those needs that we felt should be addressed:

1. Strictly Controlled Diet

A craving of carbohydrates is a side effect of the medication that Blake takes, leaving him hungry all the time. At our home it was virtually impossible to monitor and control his diet. We would lock the pantry and guard the refrigerator. Even then, maintaining portions was a difficult task.

2. 24/7 Supervision by a Trained Professional

Blake has insomnia and can stay awake for 24 hours at a time. Blake cannot be alone without supervision so my parents and I would take shifts to stay awake with him.

3. Immediate Access to Medical Attention

Blake requires access to doctors and medical staff immediately if needed. Any fluctuation in behavior or sign of illness needs to be assessed and addressed if needed. Wait times for specialists in the private sector can be up to two hours. This wait time is far too long for anyone with special needs.

4. Strict Regulation of Medication

The medications that Blake takes require that they be given at the exact same time each day. Strict regulation of dosage and time given is extremely important. Also, the changing of medication requires strict supervision. When Blake was in the private sector, his neurologist would frequently change seizure medications. He would add or drop medications with only a seven day transition period. When Blake went to Richmond and began receiving proper care, the medication changes took six weeks. The doctor would wean him off one while slowly adding the new medication. This kept Blake comfortable, reduced the risk of seizures and kept aggressive behaviors to a minimum.

5. Structured Environment/ Daily Routine

Blake has a tendency to overstimulate on TV. Keeping him busy with arts and crafts, class, work, outings and new experiences is critical for his mental and physical health.

We visited a list of private care facilities that the district provided. During this time, we contacted a private home in Pasadena, Texas. This home just lost a patient and had an opening that needed to be filled. My mother explained the situation and the home quickly agreed to take Blake as a resident - sight unseen. My mother asked how they planned to care for Blake properly when three adults are struggling to do it on a daily basis in our home. She was told that a psychiatrist comes in once a week to evaluate the residents, implying that the residents are medicated to stay calm. My mother explained that Blake was in need of medical care, not psychiatric care. This group home called multiple times attempting to get us to agree to enrollment in their home. When my mother finally said it simply isn't going to happen, the calls stopped. This situation is a prime example of why we do not want our loved ones placed in group homes. They will not receive adequate care. The main goal of these homes is to keep their beds full for monetary gain, they do not have our loved ones best interests at heart.

Only one facility, Shiloh Treatment Center in Manvel, Texas was even remotely capable of meeting Blake's needs. We inquired if residential placement at Shiloh was a possibility for Blake. Shiloh declined placement because the facility was not suitable for Blake's many medical problems. We reached out to Mental Health and Mental Retardation Authority for help, they visited our home and stated there were many families in much more difficult situations than ours. Desperate to find help, we asked our Advocate, Louis Gigerman, for any ideas he might have. Louis put us in touch with Ileene Robinson. She immediately took action, putting us in contact with Richmond State Supported Living Center (RSSLC). This center was never provided to us as an option for placement from the school district. We were not even aware that it existed. The RSSLC carefully reviewed Blake's situation and ultimately made the decision to allow him to become a resident. As difficult as this decision was, it was the best decision we could have made for Blake. When he became a resident of RSSLC, he was overweight, his renal numbers were in the danger zone, his seizures were out of control and his behavior had progressed to the point where we could not keep him safe. Now, his weight is under control, his seizures have decreased, kidney function is good and his overall health has greatly improved. When Blake arrived at Richmond, he was on 3

medications all of which were given to control his behavior. He now takes several medications, all prescribed for specific medical reasons. This is yet another example of why I feel the State Supported Living Center (SSLC) is the best option for my brother. He even has access to dental care. When we see Blake now, he looks like he always should have... Genuinely happy, healthy and smiling.

RSSLC has been a blessing to my family. If more education about the Living Centers were given to families like ours, I know residential placement would increase. There are so many families in crisis and have no idea where to turn. The SSLC's could alleviate so much of the stress that these families endure. Knowing that your loved one is being cared for in a capable facility is a relief like no other.

In closing, there is one more thing I would like to address. As a family member of a special needs person, I make it a point to vote for elected officials that I feel will make the right choices on their behalf. I, under NO circumstances, agree with having an appointed commission make decisions that will determine the course of my brother's future. That is not the form of government we have in this state. Please hear me when I say this, I, nor my family, want an appointed commission overseeing these decisions. These decisions should be reserved solely for elected officials who are not swayed by avaricious providers and their professional lobbyists.

The closure of the state supported living centers should not and cannot happen. The State of Texas will not save money by closing these centers! The closure would send the residents of the SSLCs and their families into crisis. Why cause more pain by closing the centers? Why not alleviate the pain by allowing access to families that need it, and are not aware of the existence of a facility like the SSLC's?

I will leave you with this last thought; if my brother was capable of being in a home, he would be at my home, with my family and in our care. Thank you for allowing me the time to speak on my brother's behalf. I hope you consider all that I have said and make the right decision and keep the State Supported Living Centers open and available to those who need them.