

Testimony and Statements
Nancy D. Hernandez
Legal guardian, Darla K. Deese

TO: Texas Health and Human Services Commission
RE: SSLC Long Range Planning Report

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My name is Nancy Hernandez, I am the legal guardian of Darla K. Deese, who is 59 years old and lives at Richmond State Supported Living Center.

Darla's sister, Esther Hobbs, was my best friend. She died on Sept 29, 2011. Esther's death was a traumatic experience for Darla and me.

I spent that night with Darla in the king size bed that the sisters shared. I continued to live at Esther's house with Darla, sleeping in the king bed and caring for her with the help of many others until a transition plan was fleshed out in early December of that year.

I also became Darla's legal guardian.

I knew Esther did not want her sister returning to Richmond State Supported Living Center. There is a long history with Darla surrounding this issue, but I won't go into that here. With the help of Darla's provider, we finally found a residential group home in Rosenberg, TX, and a new provider in Fort Bend County. My core team of Esther's friends and supporters all thought it was a good fit.

Problems arose immediately. Bruises appeared on Darla's body. I noticed a passiveness in one of the caregivers. Not all of the direct care workers were used to, or prepared for, the hands-on care Darla needed. They were used to caring for a 19 year-old who was mobile, simply needed meals prepared, meds administered, rides to and fro, and to perform more sitter-type duties.

It was while attending a state-required adult daycare facility where staffing oversight failed Darla a month into her Rosenberg residency. She fell forward out of her wheelchair trying to pick something up off the floor. She hit her head on the linoleum floor and two weeks later became ill with a subdural hematoma, which required emergency brain surgery at Methodist Hospital.

This medical event required a second brain surgery one week later to evacuate blood that wouldn't clot. She was in ICU for three weeks and another week in a regular care room, which now required private care sitters to be at Darla's side.

There was a feeding tube, a tracheotomy tube, and Darla with the IQ of a 2-3 year old kept trying to pull them out. There was the recovery from two brain surgeries, the

trauma it created and months of nursing and caregiving with private-pay sitters around the clock. She was in the first nursing facility for more than six months.

Thank goodness for the fine people at St. Dominic Rehabilitation and Nursing in Houston. They agreed to take Darla and continue her care. She was there for over two years, again with private sitters full-time, then later part-time, but the facility finally asked Darla to leave. She had reached her recovery baseline, regained the weight she had lost and was now becoming disruptive with staff and other residents. St. Dominic's was not staffed to take care of someone with Darla's profound intellectual disability.

Darla will always need 24/7 oversight and hands-on medical resources.

The attempt at community based residential living with the adult daycare component, and without the eagle eye of her sister 24/7, or others you hope would be on top of things, turned into a disaster for Darla.

I struggled deeply with the issue of considering Richmond State Supported Living Center for Darla because of her history there and her sister's strong feelings about it. Darla lived there from 1968 to 1994 and there were problems. I looked into other options and visited another recommend residential home, but was taken aback by what I saw. None of these places are perfect, but community based residential living for individuals like Darla is not a good fit.

In the end as her guardian I was called to do what was best for Darla. So I went and looked at the Richmond campus. I had heard good reports about improvements since the Justice Department got involved and how clean the residents are when they show up at the hospital for medical care. I knew this was the right arrangement for Darla as much as I regretted how Esther might feel about it and took action to apply for her return to Richmond.

The application process was difficult and extremely frustrating. It's as if there is a concerted effort to thwart those who want to apply or get referred to a State Supported Living Facility. My experience with MHMRA of Harris County was dreadful. After going through all the steps it took to complete and submit the application package it went missing. It took many calls and prodding, and finally a month and a half later someone found it.

Helping families and individuals learn about SSLCs, where and how to apply and getting good information is imperative. Why does it have to be so difficult? The channel to the Local Intellectual and Developmental Disability Authorities (LIDDA) for admissions is flawed and needs improvement. This process needs reviewing. Please look at how you can help people get connected and plugged into SSLCs who need them the most.

How difficult was it for all of those "Involuntary Regular" admissions to occur? Could you have, or can you make it easier?

We have a moral and ethical responsibility to have good care facilities like State Supported Living Centers. The need is not going away, in fact there is probably more of a need now than ever. There has been a dramatic rise in childhood autism, birth defects still occur, there is an opioid crisis damaging children and adults who will need long-term care. Also, the community based residential living arrangements are not working out as well as some people would like us to believe.

Mahatma Ghandi said “A nation’s greatness is measured by how it treats its weakest members.”

What we need to do is work together to improve these facilities and help those who are the most fragile and who cannot advocate for themselves.

Instead of trying to peck away around the edges trying to downscale the SSLC facilities in hopes of closing them through top-down initiatives and other tactics, let’s work together to raise them up and turn them into something we all will be proud of.

In respect to the Long Range Planning Report, how do you plan to share and integrate the stated vision and mission so it reaches into the day-to-day lives of employees and creates a meaningful outcome for residents and workers?

I would like to see a more robust engagement with families, guardians and external communication with the public through emails, correspondence and communication.

Empower the SSLC’s mission and vision though marketing and public relations. Reverse the negative impressions people have of SSLCs.

Regarding initiatives intended to improve services and supports. Besides the nine month evaluations and monitoring by the Health and Human Services Commission, what else can be done?

I see a profound ongoing need for qualified and trained staffing. The direct care staffers churn through the system and these are the same employees who are hands-on with our loved ones every day. When I visit on weekends the dorm my loved one resides in is regularly understaffed because someone has not come to work for some reason or there is a staffing shortage. Let’s pay them a better working wage. Raise them up. Train them.

Are midlevel managers and long-term staffers performing and carrying their weight or impending progress and working the system? Perhaps they need engagement and uplifting to do a better job. Why do some executives retire, go on hiatus for several weeks and return as contract workers? Where does management need refreshing?

How do you identify individuals and families who need information about IDD services and eligibility? Who communicates with them and aggregates the information?

How does the SSLC system plan to improve their services and supports for persons with severe and profound IDD and those individuals who are medically fragile or who have significant behavioral health needs?

Are projections for transitions to the community based on false assumptions and reasoning or a bias towards scaling down SSLCs?

I believe referrals and transitions into SSLCs have slowed down because there has been a top-down initiative and far-reaching culture created for this occurrence.

There wouldn't be a decline in the census if you didn't want a decline. Why would you want a decline? Do you really want a decline in the census? That's self-defeating. A pivot in approach and thinking about this needs to take place.

A push for referrals to the community should not be a priority end goal as I have experienced personally. Where it makes good sense, yes, but unilaterally, no. Too much emphasis on community transition is underpinned on reducing census numbers and not necessarily the best interest for the individual or the community. Exemplary caregiving should be the foundation and end goal.

A top priority of maintenance should always be about improving the space the residents live, dine and function in.

How can the community help you with goals and achievements? Why not try to cultivate benefactors, architects and community leaders to help you execute and solve problems. Creative solutions are there if you seek them. People want to help. A much more external approach and outreach may net you a bounty of results.

Long term cost projections look too low. Please don't undercut what's really needed for sustainability.

Becoming a hub for clinical services and supports for individuals living in the community is a great idea. Figure out what services are most needed for this population and a business model that makes sense to help with a global sustainability of the SSLCs and care for the individuals.

What is done now for those who have transitioned out into the community?

The assumption that the SSLC census will continue decline is a very negative self-fulfilling projection not based on a true ongoing need in the population.

Let's work together to change this attitude.

Thank you for letting me present my thoughts today.

Nancy D. Hernandez, June 7, 2018