

From: [Amy Trost](#)
To: [Dawn Roberson](#)
Subject: FW: Sunset DADS Testimony
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From: Clay Boatright
Sent: Wednesday, June 25, 2014 11:05 PM
To: Alternate ID Sen. Jane Nelson; Four Price; Dan Patrick; Brian Birdwell; Juan Hinojosa; Charles Schwertner; Cindy Burkett; Harold V. Dutton; Larry Gonzales; Richard Raymond
Cc: Ken Paxton; Van Taylor; Amy Trost
Subject: Sunset DADS Testimony

Hello. Thank you so much for taking time today to hear from the public on the recent Sunset reports. I flew down early this morning to testify on the DADS report, but I had to leave at 6:30pm to return home and care for my twins with disabilities. If you don't mind, below is the testimony I had planned to share.

Thanks again for all your hard work, and I appreciate your consideration on the issues I describe.

Take care - Clay

Hello, my name is Clay Boatright. My wife and I live in Plano with our three teenage daughters, including identical twins who have severe intellectual disabilities, autism, and are prone to what can only be described as apocalyptic meltdowns.

As Senator Nelson pointed out Tuesday evening, Sunset staff recommendations to close some of the state supported living centers, improve the minimum standards for community-based programs, and strengthen DADS ability to penalize violators are intricately related. As a father, I believe this has nothing to do with where a house is located, but rather with the fear associated with every aspect of our disability support system.

For the last five years my family has stayed together due to support from a Medicaid-waiver program. Eight weeks ago one of my biggest fears came to fruition when I was told my children no longer qualified. I immediately filled out two applications for them to live in a state supported living center, but had to deal with the fear of that decision, given the news stories on abuse and neglect. For what it's worth, I would have filled out those applications if there were 13 or 7 state schools. We were soon pointed toward another program which will enable my children to stay at home with us, but as my wife and I are going to completely run out of gas within the next few years, I'm already dealing with the fears that Representative Dutton described on the potential quality of group home and community day programs.

Our situation is not unique. Every single disability family deals with these fears. While I support all the Sunset staff recommendations, I urge this committee to focus on modernizing our support system by alleviating the fears families face. I also believe addressing these fears will make this entire consolidation issue easier to deal with. I would like to offer two ideas:

1. The number of families who have members with strong behavior challenges is growing at an accelerated rate, due in part to the growth in autism. We need services to give caregivers significant relief, such as respite which lasts longer than four hours on a Friday night or a week at summer camp. Extended respite can significantly reduce the risk of institutionalization and could be one of the services offered by a state supported living center as described in Recommendation 2.3.

2. CMS in Washington has implemented new rules defining the community-based housing they will support. For people with more significant needs, we need options beyond institutions, 3 bed group homes, or living with mom and dad until they're dead. To use the word Representative Raymond used on Tuesday, families deserve a MODERN solution. I ask that you encourage DADS to partner with local organizations in developing residential options that meet the letter of federal law while providing practical solutions that people need.

Thank you for your time.

Clay Boatright

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Clay Boatright Comments
DADS Sunset Advisory Commission
June 2014

Hello, my name is Clay Boatright. My wife and I live in Plano with our three teenage daughters, including identical twins who have severe intellectual disabilities and autism. Though they are fourteen years old, my twins are nonverbal, unable to bath or use the bathroom on their own, and are prone to apocalyptic meltdowns. I'm the past president of The Arc of Texas and a former volunteer at the Denton State Supported Living Center. In 2011, I was appointed by the President of the United States to a two year term on the President's Committee for People with Intellectual Disabilities and last year I was appointed Chairman of the Texas Intellectual and Developmental Disability Redesign Advisory Committee which was created by Senate Bill 7. Please know that the testimony I'm about to give is my own personal perspective and does not represent the positions of any organization or committee where I am serving or have served in the past.

As a physically, emotionally, and financially exhausted parent of two children with very few options, these issues are in integral part of my family's life. In addition, we call ourselves a DADS "sandwich" family, because for the last six months we have also been learning the system for supporting the elderly in Texas. In addition to caring for our children, my wife has had to coordinate her mother's entry and exit from nursing homes along with their related Medicaid nuances and community-based options.

Much of the Sunset report focuses on our state supported living centers, the home to thousands of people just like my daughters. When I'm changing the blood-saturated pull-up on a nonverbal teenage girl while she's having a meltdown, I empathize with the parents forty years ago who placed their children in our state schools because there were no other options. The state made an agreement with those families to care for their children for the rest of their lives, an agreement that cannot be forgotten.

Volunteering at a state supported living center helped form my perspective. First, our state institutions are a family's option of last resort. Having dealt with many crises with my own children, the state supported living centers are an option I have considered for my daughters. When being attacked by two children who don't know their own strength, a parent needs an option of last resort. Nonetheless, this option becomes difficult to swallow when walking through the crumbling barracks at our SSLCs. I'm really not surprised compliance with the DOJ settlement is so low, as no one would ever spend more than the bare minimum necessary to maintain the place of last resort.

The state must honor it's obligation to care for these citizens for the rest of their lives, but it is not obligated to do so in specific buildings which are impossible to maintain. Our state institutions are a money pit costing three times more per person than they should. In 2011 the Legislative Budget Board recommended a plan for consolidating our state supported living centers for these same reasons, a recommendation which was ignored and has cost the taxpayers of Texas tens of millions of dollars since. This year's Sunset recommendation to close six of our institutions in a thoughtful manner respectful of their residents is the right thing to

do, and is long overdue. The concern over job loss when an SSLC closes is overstated as most of the direct care positions will follow the residents into the community through private providers who are always in search of qualified staff. I urge the commission to implement all three recommendations associated with Issue One.

That said, families of those living in the state supported living centers have every reason to be scared about moving their family members into the community, as the Sunset report highlights what I believe is the dirty little secret of community-based programs. Before I could volunteer at the Denton State Supported Living Center, I had to undergo an extensive background check. With the exception of financial disclosure, that background check with significantly more involved than the one required for a Presidential appointment. Meanwhile, there are no consistently mandated background checks required for people working with our loved ones in community-based day habilitation programs, nor are there consistent requirements for basic safety precautions. Today I take comfort that my teenage daughters attend a public school that meets state and federal license requirements, where all employees have been thoroughly screened, and the school has documented procedures for handling an emergency.

Here is a conundrum many parents face when their children with disabilities transition out of high school. Do they send their child to a state supported living center where all employees have had extensive background checks, yet documentation shows abuse occurs nonetheless, or do they send them to unlicensed community-based day programs where there are no reporting requirements on treatment by employees who may not have been screened at all? Think about that for a minute. We have a line of sight into neglect at places where the staff is screened and paid more, but no perspective on potential abuse at places by people who are unscreened and paid less.

Providers of quality programs will not object to meeting standards because, by definition, true quality already surpasses minimum standards in an effort to set the bar high. In my opinion, a provider unwilling to make improvements to meet a minimum standard is no better than a state institution unable to meet a DOJ requirement. I strongly urge the commission to implement all recommendations associated with Issue Three. In addition, I support the adoption of all recommendations in Issue Four enabling DADS to more aggressively pursue and penalize providers who routinely violate protection standards for our citizens.

As I alluded to earlier, I can relate to families who find themselves in crisis situations and need immediate help. The Sunset report indicated these situations will rise as people transition out of the closed state supported living centers, but they will actually increase at a much faster speed due to the growing rate of children and adults being diagnosed with severe behavior needs. To avoid regrettable events at home, please pursue the recommendation in Issue Two and expand crisis intervention teams across the state.

Finally, I would like to ask the Commission to consider a recommendation not included in the staff report. While the issues and recommendations addressed here are sound, they amount to putting a Band Aid on a heart attack. The core problem is that Texas currently meets the federal Medicaid entitlement requirement with crumbling and excessively expensive institutions, which fewer families are willing to accept. While the state institutions may have been a reasonable solution in 1974, they are inadequate for the task in 2014. I request that

this commission instruct DADS, through legislation similar to Senate Bill 7, to develop a plan for evaluating the risks and advantages of moving the Medicaid entitlement from institutions to community-based services. The current effort behind managed care may provide the mechanism for that entitlement shift, funded largely by reduced costs achieved through consolidating the state institutions. Said another way, we can lower the cost of care and serve more people BEFORE they get to the point of needing an option of last resort.

Thank you for your time.