

From: [Sunset Advisory Commission](#)
To: [Dawn Roberson](#)
Subject: FW: closure of Austin SSLC
Date: Tuesday, June 24, 2014 4:05:03 PM
Attachments: [06-24-2014 Testimony of Erica Luckstead for DADS final1.pdf](#)

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

Sent: Tuesday, June 24, 2014 12:38 AM
To: Sunset Advisory Commission
Subject: closure of Austin SSLC

The ASSLC should not be closed. Community homes are NOT a better alternative for this fragile population, and they should not be geographically separated from family. See attachment.

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 24, 2014 4:05:08 PM

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

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

Sent: Tuesday, June 24, 2014 12:17 AM

To: Sunset Advisory Commission

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

Submitted on Tuesday, June 24, 2014 - 00:17

Agency: DEPARTMENT AGING AND DISABILITY SERVICES DADS

First Name: Erica

Last Name: Luckstead

Title: Ms.

Organization you are affiliated with:

City: Austin

State: Texas

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

Testimony of Erica Luckstead

Introduction

I am Erica Luckstead, sister of Lee Luckstead, an Intellectually Developmentally Disabled (IDD) resident of the Austin State Supported Living Center.

Lee lived at home until April 1971, when at age 8, he was too much to handle because of his size and impulsivity. Even now, Lee has been described as having the emotional resources of a toddler and an IQ of between 20 and 50.

He does not speak, although he emits expressive noises. He is very impulsive and quick. He is also very large. When he was 8, I was the eldest sibling at 16, and Lee was as tall as I was and could outrun me if he so chose. Lee is now 6'5" and a healthy 200 pounds. Additionally, he stands on his toes, a brain-generated trait we cannot correct. He has poor fine motor ability and no ability to speak words, probably from a touch of cerebral palsy. He is nearsighted and stares at people.

Need I say that Lee has poor social skills? With no verbal ability, he cannot introduce himself. He does not observe, or probably understand, physical boundaries with others and he stares. He needs help—an intermediary--with all social interactions. Lee has been diagnosed as autistic. Between the autism and the toddler level of emotional development, he is low in empathy.

But this does not mean he forms no emotional bonds. Lee has very close bonds with his family of origin, bonds with caretakers, and sometimes has friends in his dorms.

I will illustrate my points with examples about my brother Lee, because he is the IDD person with whom I am most familiar. Family has fairly consistently visited Lee every two weeks since the over 40 year separation.

I. "Consolidation" will separate IDD from family, which is nearly always very bad all around.

For years now, families had to show no community home would take their IDD member to qualify for placement in an SSLC. All of a sudden, these same folks who were refused before are supposed to find

community homes, some with only a few months' notice. Few will have changed so much that they are now accepted in a community group home (and how many nearby vacancies are there?). This means MOST will end up in other SSLCs far from family. They will not understand when family, who have jobs and homes they cannot easily change, and money and time constraints, cannot visit as much as before.

A. Family gives meaning to our lives and theirs. Separation or abandonment issues are difficult and damaging. Aside from the psychological damage, behavioral regression and other problems are foreseeable results of reducing the contact between family and the IDD resident.

B. Family is a communication bridge and care assistant. I recall attending appointments with Lee in which private care doctors and their assistants showed visible fear, and did not want to approach or examine Lee, because of his size, despite my holding his hand. He is not aggressive, and only stares because his eyesight is poor and his social graces even more lacking. Family always tries to be there for medical care. I recall for example putting two sets of eye drops in each of his eyes, even though they stung. I was truthful that they would not feel good and apologized; then, he allowed me to do it.

However, moving Lee hundreds of miles from family means none of us could be there often, especially on a weekday when we work. And, if he did make it into a community home, appointments would not be grouped as on campus. Thus, a separate visit would be required for each exam or procedure, rather than sequencing these events in a single afternoon to use one dose of anesthesia.

C. Family involvement improves quality of care. Often family will bring attention to a problem the IDD person cannot articulate, or propose unique solutions tailored to their loved one.

II. Not all IDD people are better off in the community.

It is wrong that more interaction with the community is always better for the IDD person.

I believe that as ability level falls, this becomes less true; for my brother, forays into the community must always be managed and involve risks. There should be choice to place the IDD person in either a group facility in the community or in a dorm in a closed campus setting, depending on the abilities and characteristics of the individual.

I am not at all against community homes and opportunity for those who can benefit from this. I am happy that many IDD are able to enjoy meaningful employment and socialize largely like normally intelligent people, given support.

However, a significant number of IDD individuals can never achieve independent participation in the community, however much training and support is offered. Training cannot prepare someone like Lee for all of the variables of the real world. His impulsiveness and fascination with machinery and food, his inability to judge danger and avoid moving vehicles or machines, his lack of respect for personal physical boundaries and of ownership, and his lack of social skills and speech can add up to disaster very quickly. Moreover, he is easily lost on his own and has no skills to deal with it. Lee must always be accompanied in the community, by someone he trusts and will obey.

In Lee's case, the dormitory is the safe and supportive environment that allows him to be at his best. A goal to integrate every IDD person fully into the community is unachievable, and harmful to many. My brother is not violent, but cannot be taught to move freely in society.

Here is a true story of Lee escaping into the community around age 7, when he still lived with family. One evening at dinner, some controversy arose and we were momentarily distracted from watching Lee. He may have been upset over my Dad's raising his voice to quell the arguing. Anyway, suddenly the front door slammed and Lee was gone! Mark and I, the two eldest siblings, immediately ran out after Lee. It was almost dark. I told Mark to circle the block one way while I went the other. Each of us called for Lee and began to walk rapidly, peering between cars and into hedges as darkness fell.

Soon I found Lee. I heard an angry woman's voice threatening, "If you come one step closer I'll sick my dog on you," and "Go away, git." I could see her in a garage which had a light on, and cowering in the corner was Lee, sobbing with fright and moaning. The woman was holding a dog and motioning that she would throw it on him, trying to run him off. She seemed totally oblivious to his retreat, his fear, his tears. A big guy was in her garage and she saw a potential robber, rapist or whatever. I ran to him and tried to explain, leading him out, that he was a lost child and had only entered the garage because of the light. Even as I led him away from the garage by the hand, she continued to holler threats.

Now imagine Lee today, at fifty years old and 6'5", entering a garage because there's a light on and he's lost. He can no more communicate or find his way home than when he was seven. But today that woman would probably have a gun.

III. Community homes are not immune to neglect and abuse issues.

My brother was in a private group home at one point, and the family came to disagreement with its management over issues of abuse and neglect. As we were researching our options to move him, they tried to cover their butts by claiming Lee was violent and they had to treat him as they did. At that

point they wanted him out, maybe fearing we would report them. But unfortunately, while statistics on state-run facilities are kept, and abuses are tracked, there were no records kept for private facilities. We got him out and did not fight with them or try to report them. The fact that statistics about community homes are not kept does NOT mean that abuse and neglect cannot/do not take place in such settings.

IV. The level of care needed for some IDD persons is more efficiently delivered in a campus/dormitory setting than in scattered, small community group homes. Forcing some IDD persons off campus could result in their care being much more expensive, if quality of care remains a goal.

I cut this down tremendously and apologize that it is still too long.

Any Alternative or New Recommendations on This Agency: Please allow the Austin State Supported Living Center to remain open and available to those for whom it is the best fit, indefinitely, or find a closed campus setting geographically similar in location to avoid separating this fragile population from family.

My Comment Will Be Made Public: I agree

Testimony of Erica Luckstead

Introduction

I am Erica Luckstead, sister of Lee Luckstead, an Intellectually Developmentally Disabled (IDD) resident of the Austin State Supported Living Center.

Lee lived at home until April 1971, when at age 8, he was too much to handle because of his size and impulsivity. Even now, Lee has been described as having the emotional resources of a toddler and an IQ of between 20 and 50. He does not speak, although he emits expressive noises. He is very impulsive and quick. He is also very large. When he was 8, I was the eldest sibling at 16, and Lee was as tall as I was and could outrun me if he so chose. Lee is now 6'5" and a healthy 200 pounds. Additionally, he stands on his toes, a brain-generated trait we cannot correct. He has poor fine motor ability and no ability to speak words, probably from a touch of cerebral palsy. He is nearsighted and stares at people.

Need I say that Lee has poor social skills? With no verbal ability, he cannot introduce himself. He does not observe, or probably understand, physical boundaries with others and he stares. He needs help—an intermediary—with all social interactions. Lee has been diagnosed as autistic. Between the autism and the toddler level of emotional development, he is low in empathy. But this does not mean he forms no emotional bonds. Lee has very close bonds with his family of origin, bonds with caretakers, and sometimes has friends in his dorms.

I will illustrate my points with examples about my brother Lee, because he is the IDD person with whom I am most familiar. Family has fairly consistently visited Lee every two weeks since the over 40 year separation.

I. "Consolidation" will separate IDD from family, which is nearly always very bad all around.

For years now, families had to show no community home would take their IDD member to qualify for placement in an SSLC. All of a sudden, these same folks who were refused before are supposed to find community homes, some with only a few months' notice. Few will have changed so much that they are now accepted in a community group home (and how many nearby vacancies are there?). This means MOST will end up in other SSLCs *far from family*. They will not understand when family, who have jobs and homes they cannot easily change, and money and time constraints, cannot visit as much as before.

A. Family gives meaning to our lives and theirs. Separation or abandonment issues are difficult and damaging. Aside from the psychological damage, behavioral regression and other problems are foreseeable results of reducing the contact between family and the IDD resident.

B. Family is a communication bridge and care assistant. I recall attending appointments with Lee in which private care doctors and their assistants showed visible fear, and did not want to approach or examine Lee, because of his size, despite my holding his hand. He is not aggressive, and only stares because his eyesight is poor and his social graces even more lacking. Family always tries to be there for medical care. I recall for example putting two sets of eye drops in each of his eyes, even though they stung. I was truthful that they would not feel good and apologized; then, he allowed me to do it. However, moving Lee hundreds of miles from family means none of us could be there often, especially on a weekday when we work. And, if he did make it into a community home, appointments would not be grouped as on campus. Thus, a separate visit would be required for each exam or procedure, rather than sequencing these events in a single afternoon to use one dose of anesthesia.

C. Family involvement improves quality of care. Often family will bring attention to a problem the IDD person cannot articulate, or propose unique solutions tailored to their loved one.

II. Not all IDD people are better off in the community.

It is wrong that more interaction with the community is always better for the IDD person.

I believe that as ability level falls, this becomes less true; for my brother, forays into the community must always be managed and involve risks. There should be choice to place the IDD person in either a group facility in the community or in a dorm in a closed campus setting, depending on the abilities and characteristics of the individual.

I am not at all against community homes and opportunity *for those who can benefit from this*. I am happy that many IDD are able to enjoy meaningful employment and socialize largely like normally intelligent people, given support.

However, a significant number of IDD individuals can never achieve independent participation in the community, however much training and support is offered. Training cannot prepare someone like Lee for all of the variables of the real world. His impulsiveness and fascination with machinery and food, his inability to judge danger and avoid moving vehicles or machines, his lack of respect for personal physical boundaries and of ownership, and his lack of social skills and speech can add up to disaster very quickly. Moreover, he is easily lost on his own and has no skills to deal with it. Lee must always be accompanied in the community, by someone he trusts and will obey.

In Lee's case, the dormitory is the safe and supportive environment that allows him to be at his best. A goal to integrate every IDD person fully into the community is unachievable, and harmful to many. My brother is not violent, but cannot be taught to move freely in society.

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Soon I found Lee. I heard an angry woman's voice threatening, "If you come one step closer I'll sick my dog on you," and "Go away, git." I could see her in a garage which had a light on, and *cowering in the corner was Lee, sobbing with fright and moaning*. The woman was holding a dog and motioning that she would throw it on him, trying to run him off. She seemed totally oblivious to his retreat, his fear, his tears. A big guy was in her garage and she saw a potential robber, rapist or whatever. I ran to him and tried to explain, leading him out, that he was a lost child and had only entered the garage because of the light. Even as I led him away from the garage by the hand, she continued to holler threats.

Now imagine Lee today, at fifty years old and 6'5", entering a garage because there's a light on and he's lost. He can no more communicate or find his way home than when he was seven. But today that woman would probably have a gun.

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From: [Sunset Advisory Commission](#)
To: [Dawn Roberson](#)
Subject: FW: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)
Date: Friday, June 27, 2014 4:50:26 PM

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

From: sundrupal@capitol.local [<mailto:sundrupal@capitol.local>]
Sent: Friday, June 27, 2014 2:02 PM
To: Sunset Advisory Commission
Subject: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)

Submitted on Friday, June 27, 2014 - 14:02

Agency: DEPARTMENT AGING AND DISABILITY SERVICES DADS

First Name: Erica

Last Name: Luckstead

Title:

Organization you are affiliated with:

City: Austin

State: Texas

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

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I cut this down tremendously and apologize that it is still too long.

Any Alternative or New Recommendations on This Agency: I recommend that no campus close, that campus living (SSLC) be continued as a side by side alternative to community homes, that equivalent monitoring be required of ALL group homes, that no resident should be required to move more than 2 hours'

drive from their guardian while living on a campus, that campus living should be given equal promotion and open admission to families who could choose community settings, and that funding should be adequate to renovate buildings as needed and to pay staff in accordance with the private market for their tenure and education.

My Comment Will Be Made Public: I agree