

01/04/16

1 Of 8

Carl Young

Representative Hogan, members of the committee, guests, my name is Carl Young. I am a mental health advocate. Not because of any of the boards and committees that I am a part of, rather because of my role as a parent to a child with mental health issues. It is in the role of parent that I speak to you today.

A brief history.

In 2001 my family met a little boy who had been abandoned at birth by his parents. He was placed in foster care. His first Christmas we participated so that it wouldn't be just him and his foster mom.

In 2002, at Christmas our adoption application was approved and he was placed in our home.

In 2003 for his second birthday the adoption was finalized. As an adoptee, I know how important family is.

In the years since then we have experienced a roller coaster of joy and sadness. This little boy has done nothing to deserve his lot in life.

We knew early on that he might have mental health issues due to his birth history and the birth mom's drug use. At first it was just accelerated levels of energy. Extreme ADHD is what we it was called. Severe ADHD is another term. In the first five years of his life, we learned to lock things up if we didn't want him to take them and destroy them. Nothing was sacred. Initially we thought it was curiosity driven.

About five years ago his mental health began to take a turn for the worse. He attacked a teacher who tried to search him for a stolen deck of Go-Fish cards. That started us on the path of seeking mental health care for him, and the rest of the family.

Initial placement in a PRTF level facility came in Bismarck. A Godsend we stated. We could see him every week, we could do home visits. We could participate actively in his care. During discharge planning, a care plan was established with the cooperation of the school. The local community school where we live in Garrison, ND. On the first day of his return, he was denied access. This was January

2013.

We home schooled our son for almost ten months. We did this so that we could continue therapy and psychiatric care. And because we felt we weren't given any other choice in the matter.

All that year things escalated. Frequent calls to 911 were made. Many hospitalizations were undertaken in the acute psychiatric care unit in Minot. We made the decision in conjunction with his Partnerships Care Coordinator to seek placement in a facility. Marc staying awake for 72 hours at a time was taking its toll on the family.

During the time leading up to his placement in a facility in Minot, ND, we had to undergo a full medication change roughly every six weeks because of our son's ability to adapt to the new medications. Most of the times, medicine is hit and miss when it comes to treating mental health.

His stay in Minot would last 15 months. From October 2013 to January 2014, our son achieved a moderate level of success at the facility. It is documented that the staff thought he needed long term residential care. In 2014, we transferred him to a facility in Billings, MT. This was done because the facility wanted our son to continue to receive care, but there was some question as to how long the CON would continue to be approved.

The facility staff told me on a number of occasions that typically CON's were not approved beyond one year. When I asked why that was the case, I was told "that is just the way it works."

I personally made frequent trips out to Billings to see my son.

Prior to his stay in Billings, we saw him every week and at holidays. We could make an effort to stop and see him when we were in Minot for other reasons. We could participate in school parent teacher conferences.

While he was a resident in Billings, we did family therapy via telephone. He was moderately successful. He had behaviors. In December 2014, I received a phone call to let me know of an emergency situation that had come up.

It seems our son was angry, and broke a window. During the resulting behaviors, he got cut on his knee. Upon seeing this cut, he made the wound larger by pulling on the cut with his fingers. Thus causing a wound that required a bandaid to become a wound that required stitches. It seems he was upset about a slight that occurred in the residence.

I saw my son every two months while he was there. Our whole family rented a tow trailer and went to spend a week with him for his birthday the summer he was there. He was 13.

Doctors and staff alike have regularly stated that our son needs long term psychiatric care.

In January, I received a call from the counselor at the facility. His CON had been denied, but they appealed the decision to deny.

A couple of days later, another call, CON denied. "We are going to lodge another appeal" I was told.

That Friday, I was called one more time. All appeals have been exhausted, you have 72 hours to come and get your son.

That Monday I travelled to Billings to get him. No aftercare plan was established. No transition care plan was established. I was given medications, discharge paperwork, my son and his belongings.

Followed by a "good luck."

Initially upon return things were okay. We figured the behaviors that we saw were part and parcel of being a teenager. We fought to get him into his last psychiatrist that he saw before placement. Because he hadn't seen her for more than two years, initially they wanted to treat him as a new patient. When I explained the necessity of early rather than late, they put me on a call list. I was able to get him in to see the psychiatrist before we ran out of medications.

We fought to get paperwork from the facility to continue his care. We fought to get him into public school again, and arrangements were made for our local district to provide transportation to a school in Minot. We did this for the rest of the year.

In April the behaviors started up in earnest. Stealing. Arguing, fighting. In May, he threatened to hurt

me if I didn't give him the right snack. He pushed an 8 foot long oak table across a room trying to hit me because he wanted oatmeal and at bedtime, he gets a granola bar. I made the decision to take him to the hospital, as this had been a culmination of behaviors all day.

If you remember, May 2015 saw the last major snow storm of the year. We had near zero visibility when my son, myself and my daughter left home to make the 50 mile trek into Minot and the hospital. Shortly after leaving home, his behaviors escalated. In that he started opening and closing windows and doors on the family van. Just south of Max ND, he tried to take the keys out of the ignition while we were driving. I fended off his blows, and kept the vehicle on the road. My daughter was in the second seat, recording video of the event as it happened. He played with switches on the dash in attempt to distract me, then would reach over and try to shift out of drive or take the keys. He kicked the passenger side door until it broke. North of Max, I pulled off the road onto an approach. I called 911. I was assured that help was on the way.

A quick background. My son has an evening snack when he gets his evening medications. He gets the medicine before he gets the snack. About half an hour later, he was calming because the medicine was taking hold. So I called 911 back and told them they could cancel the call for help. They did so. We carried on into Minot. 6 hours after our arrival, he was placed in psychiatric care.

Kids get at most 5 days of care at the acute level. I'd like someone to define acute care. Five days after arrival he was discharged from the hospital.

We were given a couple of scripts from the hospital to get filled at our local pharmacy. Since my son was a special needs adoption, he gets state Medicaid as mandated by the judge who issued the adoption decree. I dropped those off at the pharmacy and asked to be notified if there were any issues. I was called an hour later. Insurance requires preauthorization and that takes three to five days. This was on a Friday. No medication available. I called the hospital. Doctor has left for the day, and they don't know what to tell me.

Four days after he was discharged from the hospital psych unit, the doctor finally submitted the preauthorization forms. One week after his discharge I posted a note to the facebook wall of the insurance company, and they called me. Medicaid it turns out is the secondary payer. It took over a ten days to get him the medication to help calm his mental health. We muddled through.

At the end of May, our son stole a riding lawn mower from the neighbor.

In June, our son forged checks on our family account at the local auto store.

Because of the threats against me and the family we made the decision to seek placement. The way placement in a residential facility works is you fill out something called a universal application. That gets submitted through the Care Coordinator to facilities in state. What we have seen is that when one facility denies, all will deny, so we prepared to apply out of state. Our son was accepted into a facility in Butte, MT. We prepared him and ourselves to make the trek over the July 4th holiday.

A few days before we were to leave, I called to confirm what time we should arrive. Only to be told that there was a problem with the Certificate of Need and they would get back to me.

When they got back to me, I learned that the CON was denied because we hadn't done enough for our son at home. The letter that we received from the people responsible for the CON was different from the one that the facility received. I called Ascend Management Innovations, the company who does the CON's. I wrote about them on my blog. They commented and gave me a contact name and telephone number to discuss the situation.

It seems that the reason for the two letters was because on an IT glitch.

I asked if they let computers make human decisions and never got a response.

In July, our son was confronted numerous times for stealing. He was hospitalized many times. Over the 8 months he was home this year, he was hospitalized 12 times for an average stay of 5 days.

When he cussed out his mom, she washed his mouth out with soap. The hospital turned us in to Child and Family Services. The result "no services required."

He threatened to kill me with a shovel. Even had the shovel in his hand and was swing wildly.

He threatened to beat me with a stick.

We have had law enforcement make many stops at our house. Sometimes it can take an hour more more for the Sheriff to respond because they are on the other side of the county.

We placed him in the hospital in September, and were again referred to Child and Family Services.

I was accused of slamming him face first into the sidewalk by our home. I was accused of exploiting him by writing about him on my blog and speaking about his care in front of people such as those who are on this committee.

The decision? "No services required."

In the past year, our son has been charged with unruly, destruction of property, assault and theft. In only one instance did the charges result in a hearing and that hearing occurred when our son was in the hospital. When asked by the CFS investigator the Sheriff stated "the family asked not to have those charges pushed through." We never made any such request.

We have had psychiatrists tell us we need to bring him into the emergency room and just tell the people we can't care for him .

Our son is currently in a facility here in Bismarck. We see him as often as health and he will allow. He is manipulative. He likes to tell stories about things that he says happened to him or near him.

Typically these are things he has learned in therapy with other kids. He does this to manipulate his world. He refuses to eat. He is disruptive and disrespectful to staff. He thrives in the facility in all other aspects.

They are talking discharge in March.

CON is up for renewal in February.

We are again being told that we need to give up custody of our son so that he can get the care he needs.

Why can't he get the care he needs without our giving up custody? He has already been abandoned

once in his life, why would I willingly subject him to that again? Sure it's not the same thing that his birth mom did, but how does he know?

When we finally received a copy of his chart from the facility in Billings, it is full of notes such as “this child needs long term care.” and “being discharged against the advice of doctors.”

What am I asking for?

I would like to see the DD System mirrored over to the mental health community. Daily support in the community. We have it on record from his current facility that he needs daily support of 2 – 3 hours after school every day, at least eight hours a day on the weekend and throughout the summer.

It costs roughly \$230,000 a year to keep him in a facility. This doesn't include medical care.

When it comes time to place in a facility, decrease the barriers. One of these times, our son will follow through on his threat to harm someone. When he is in a facility, leave it to the team to determine the length of stay. Letting insurance companies say things like “since there has been no change or little improvement, send him home.” Don't let insurance companies dictate length of stay.

As we close, I want to remind the committee of a couple of important facts. The Schulte Report opens with the line “the North Dakota mental health and substance abuse system is in crisis”. No where is that line more adequate than when we look at my son's case. And the following statistics

16- The greater multiplier of risk that Americans with severe mental illness will be killed during a police encounter compared with the rest of the US population.

23- Number of states increased spending on mental health services in 2015 including South Dakota, Minnesota and Montana.

11- Number of states decreased spending including North Dakota!

Data from Modern Healthcare, December 21/28, 2015 edition.

My son has one identifiable factor. Above all else that makes me fear for his life. Am I saying that he will become a statistic? Am I saying that I will become a member of a community whose sole cost for membership is the loss of a loved one because he was suffering from his mental illness, someone didn't understand what they were seeing and shot him? No, I am not. What is that one factor?

My son is African-American.

I write a blog. <http://www.fightingforanswers.com>

<http://fightingforanswers.com/2015/05/seeing-david.html>

<http://fightingforanswers.com/2015/07/differing-letters-of-denial-from-ascend-management-innovations.html>

<http://fightingforanswers.com/2015/12/how-can-we-change-it-relinquishing-custody-to-get-mental-health-care.html>