

nhcorrespondence,

From: Beverly Skinner <beverlyskinner91@gmail.com>
Sent: Tuesday, March 12, 2013 1:54 PM
To: Haley, Nikki
Subject: TREY/CC Suzanne Cooper
Attachments: Courage-My Son.docx

RECEIVED

MAR 11 2013

referred to LS

answered me

Governor Haley and Suzanne Cooper

My son's safety, health and happiness is the most important thing to me as I know it is to all who have children. The question still to be answered is where can a young adult with this illness receive the health care and safe environment and program that he needs in our community and/or in SC? I hope that whatever answers are given to you that you will visit the place personally and look at it through a parents eyes as if it were for your own child.

Sincerely,
Beverly Anderson

log # 310425

“WHATEVER YOU DO, YOU NEED COURAGE. WHATEVER COURSE YOU DECIDE UPON, THERE IS ALWAYS SOMEONE TO TELL YOU YOU ARE WRONG. THERE ARE ALWAYS DIFFICULTIES ARISING WHICH TEMPT YOU TO BELIEVE THAT YOUR CRITICS ARE RIGHT. TO MAP OUT A COURSE OF ACTION AND FOLLOW IT TO THE END, REQUIRES SOME OF THE SAME COURAGE WHICH A SOLDIER NEEDS.”

RALPH WALDO EMERSON (1803-1882)

Dear Mr. President, Senator Glenn Reese, Governor Nikki Haley

I am a desperate mother seeking help for my son. My son Trey(nick name) is a beautiful young boy. He has a heart of gold. His smile can light up the world. He has never been in any trouble. Everyone loved him. Trey played baseball in elementary school and was the valedictorian in 6th grade. He continued to exceed expectations through high school in Math and Science. He was in honors classes through high school and was a drummer in the marching band. He did so many things well. I hate to brag but my child was an all around beautiful child. Some nights I would lay in bed and just pray and thank God for blessing me with this beautiful and unusual child. In the 12th grade he decided he wanted to major in the science field and was accepted to the College of Charleston, by choice, because he loves the ocean and it wasn't too far from home. We were all so excited about Trey's future and looking forward to his graduation in 2009 from Chapman High School, Inman SC.

Trey began doing things out of the ordinary in February 2009. He told me he felt depressed. We took him to his family physician. They put him on an antidepressant. Trey did not want to take this because he said, "Mom you know I don't like medication because I like my body to work its own magic." Trey continued to change so quickly we could not keep up with it. I remember one morning he just looked at me with his big beautiful eyes and begged me to help him. He said, "Mom something is going wrong with my brain and I can't stop it!" My child was begging me for help. I took him to the hospital. The physicians started a treatment where he was diagnosed with depression. To make a very long story short, he continued to progress with unusual symptoms and left home. We began searching for him. We received a call from the Canadian border where our son was trying to cross because he said he was" going to Alaska to live off the land." We finally got him back but not in time for graduation. He missed his graduation and did not graduate because he did not finish 2 credits in government which is a requirement for graduation, even though he exceeded all other requirements and was an advanced student all through school. This was a heart break for us and him. I remember crying for weeks. Trey's illness continued. He was diagnosed with bipolar and bipolar quickly turned into paranoid

schizophrenia. If you have not researched this illness then you should before you pass judgment. We have lived with this horrible illness for years now, begging for doctors, hospitals, anyone to PLEASE help us. He has been in and out of numerous hospitals and seen numerous doctors.

We are an average middle class working family. I was a teacher but I have started back to school as a nurse thinking it would give me more time to help and understand my child's illness.

We do not know what else to do. Trey's illness causes him to be paranoid of medication, going to the doctor and getting his blood taken. We have struggled many times. We have had to watch our sweet boy being put in hand cuffs just to get him to the hospital where he can be helped. Can you imagine watching your only son having to suffer through this. It is like having your heart ripped out of your chest while someone stomps on it.

This is just a little piece of what our family goes through daily. I am begging someone to help us. We have no money for expenses to help him get further treatment. He is on Medicaid but that is limited and there are things that are in his requirements to keep him on the medication that cause him to slip backwards, because he is required with this illness to continue getting blood work and seeing doctors. He refuses because of his illness to see doctors or get his blood taken over and over the health professionals will not give him his prescriptions, which causes him to go in and out of the hospital and us to be tortured over and over. It is a reoccurring vicious cycle and they will not help us. We try to explain to the doctors he can't come to you because of his paranoid sickness and they can't understand. Unless you have actually lived with someone that has this illness you really cannot understand. Even a doctor who studies for years cannot know. He is too big to pick up and force to go to the doctor. So the viscous cycle continues over and over. Our hearts are broken over and over. It hurts more than I can explain to watch your child get eaten up by this horrible illness. Some days it takes everything in you to move.

We also have major problems with him being sick and no one to watch him. He is on SSI but getting to the office to answer their questions is a task and they start

the cycle all over again every time he gets put in the hospital. This is NOT like a physical illness. IT IS SO MUCH WORSE. So we have no money to help with his expenses. We have to continue living and to live we must work. But this illness has also caused this to be a difficult task. We have a difficult time with the requirements of a job and taking care of a sick child.

We are begging for someone to help us find healthcare for our child! We have looked for a place that is descent for him, but the only places around here are nursing homes for older people. Our child is young, 21 and needs a place he can be with young people like him. He wants so badly to have someone his age to talk to. He is lonely and has no more friends. We are concerned that he will end up accidentally hurting himself. I have tried to get help by his Medicaid paying for someone to be with him while we work but I have not received any help.

I wish we could find a place where he could be happy but there is nothing for young adults his age with mental illnesses. Please help us. We are so afraid we are going to lose him. We want our child to be happy and safe and close to us. What would you do if this was your child and you did not have a lot of money? Where would you turn? What would you do if you woke up one morning and your child was sick? If you give me advice I will take it but remember if this is what is good enough for your child then and only then will it be good enough for mine. Please visit the places around our area and see if it is somewhere you would place your child. Look into what the care is like for them. I have seen things I cannot believe. Please help us and most of all our beautiful Trey. He is waiting for help. If you can help us please email me or call 864-978-0559. We will continue praying and hoping that God will send someone to help him.

Sincerely,

Beverly Anderson

Where can my son go?

There are no young adult homes or rehabilitation to meet the needs for people with severe mental illnesses on MEDICAID and or insurance in South Carolina. ONLY privately owned in another state-Cash and Credit Card. Price range 14,500 a MONTH

Choices (2)

- Midway Residential Care Facility Duncan, SC
 - Funded partly by the government and non-profit
 - COST-1132 dollars plus mental health money (I don't know exactly what that is?)**
 - This money comes from disability from patient and OSS eligibility (Medicaid) Medicaid pays the remainder and extra from mental health**
 - 5 units (95 beds) **FULL**
 - 2 beds in each tiny bedroom-barely enough space to walk
 - Small living room-looks like old furniture-small TV
 - Small dining room with as many tables crammed in as possible
 - 1 Big room where they do there group meetings
 - Extremely close to a 4 lane highway (no gate/fence)
 - 3 Small bathrooms
 - Lots of people packed in small houses

NEEDS

- MUCH MORE SPACE
- A gate/fence
- A descent yard with grass, perhaps a garden
- An activity room
- Much more help/care givers
- More bathrooms
- Better program

REQUIREMENTS TO GET IN

- Available Space
- Must attend the **TLC program**- Towards Local Care at the department of mental health which pays extra money to the facility for patients to go there. They are required to get up very early and get on a bus to go to the group or class. The program is from 8:30-12:00 and sometimes after lunch because they go out to lunch sometimes. They teach life skills. Patients must be able to go to this program or they will not be accepted to the facility. This is how they manage behavior because they do not have enough people there to help. They are partners with Spartanburg Mental Health, which give them money.
- must be able to wash clothes and take care of yourself

QUESTIONS AND CONCERNS

Why should old and very sick patients be required to attend the TLC Program?

Why should they be made to go somewhere to receive therapy?

Why can't someone come to them?

Why should someone that is on an extremely powerful medication be required to do these things until they are ready?

Have you ever taken the medication?

Do you know how it makes you feel?

Why aren't these sick people given more help?

Why do we have all sorts of treatment, research, for people that have cancer who do things like smoking knowing that this is a risk and they choose to do it and nothing for people with severe mental illnesses that do not choose this?

Why do we have nursing homes for elderly people where the sick can be locked up for their safety because they have dementia and none for young severe mentally ill who take the same medication for similar but much more severe and serious illnesses?

- Patrick B. Harris Mental Hospital-Anderson SC
 - Funded by the government
 - Big Hospital-similar to a jail
 - Locked facilities (a good thing when a patient is trying new medications and is non-compliant to the medication and understanding the mental illness)
 - Length of stay is 3 Months even if you are not well
 - Lots of men locked in a unit
 - Living room, Long Tables and Ping Pong all in one room with a glass room in the middle and a speaker for them to come speak through if they need something. (Very intimidating for a young 21 year old boy)
 - Beds **FULL**
 - Long Drive**
 - A whole part of the hospital shut down and not being used because they said not enough money for staffing and doctors.**

NEEDED

- More help
- More doctors per patients to receive better treatment
- More homey environment
- Longer length of stay if needed

BIG PROBLEM

- There is nowhere for a young adult to go that has reached the limit of stay at the hospital. If he cannot take care of himself such as requirements for Midway but is well enough to leave Patrick B. Harris and still needs to be helped and monitored on his medication where can he go?

- He will be in between both places which is a stage of recovery if he is able to recover from this illness and if not he will need help for the rest of his life.
- Parents are not capable of caring for their children that are on a medication such as this and have to work and worry about the thoughts and safety of their child and others around them if a child has continued to be noncompliant to the medication and are not capable of taking care of themselves.

IDEAS TO FIX THE PROBLEM

- Build a new facility based on a program used at the private facilities such as COOPER RIIS for severe mental illness. <http://www.cooperriis.org/>
- ADD to the program based on Community Hope in New Jersey where they have 3 stages to their treatment program.
 - Stage 1-** The patient enters the locked facilities and the medication is given and tweaked until it is the best that it can be. The patient is evaluated every 90 days until they are ready for the second stage. The patient is not moved to the second stage until he/she is ready. (Trial and Error). It is a very scary process to see your child go through. I cannot begin to tell you the suffering. The side effects and permanent damage that can be caused is enough to make you sick.
 - Stage 2-**When they are ready for the next stage it is an unlocked facility where they begin to take care of themselves. They are still monitored but a little less. They are watched to see how they can handle things on there on.
 - Stage 3-** If they are able to master stage 2 then they are helped with housing and a job but still monitored weekly for any problems or changes. <http://www.communityhope-nj.org/>
- Build a new and much improved rehabilitation hospital for severe mental illness out in the country with all 3 components and bring the patients from Midway that can fit in the program.
- Get as much help from the government and community and resources to make it happen.

I have confidence in our leaders of SC that you can and will make this happen. Where there's a will there's a way. I am willing to fight and work however I can and whatever you need me to do. My son... our children need your help now. As the saying goes..."Do not let one bad apple spoil the bunch." When someone says we can't show them that WE CAN AND WE WILL.

"Whatever you do, you need courage. Whatever course you decide upon, there is always someone to tell you you are wrong. There are always difficulties arising which tempt you to believe that your critics are right. To map out a course of action and follow it to the end, requires some of the same courage which a soldier needs." Ralph Waldo Emerson (1803-1882);

“It always seems impossible until it’s done.”
Nelson Mandela (born 1918);

What is Schizophrenia?

Schizophrenia is a brain disorder that affects how a person thinks, feels, and behaves. The illness usually strikes in late adolescence or early adulthood but can strike at any time in life. The signs and symptoms vary from individual to individual but all the people with the disorder show one or more of the following symptoms.

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| 1. Delusions: These are beliefs that are not true, such as feeling people are following or trying to hurt them, believing other people can read their minds, or beliefs that they have special powers or abilities. |
| 2. Hallucinations: This usually takes the form of hearing voices that are not there, but people with schizophrenia may also see, smell, taste, and feel things that are not there. |
| 3. Bizarre behavior: This can be expressed in many different ways. In short, the individual behaves in ways that seem inappropriate or strange to other people. |
| 4. Disorganized speech: The individual speaks in ways that are hard to understand. For instance, sentences might not make sense, or topic of conversation changes with little or no connection between sentences. Sometimes speech is completely incomprehensible. |
| 5. "Negative symptoms": This includes lack of motivation or interest, diminished cognitive functioning, and decreased emotional expression. Individuals may lose interest in attending to their own personal hygiene, have little interest in interacting with others, and rarely seem to feel or express strong emotions. |

In addition to these above symptoms, people with schizophrenia suffer a decline in their level of functioning; for instance, they may not be able to work at a job that requires the same level of skill or concentration as the job they held before they became ill required, or they may lose all ability to withstand the pressures of the working world. They may show a decline in their ability to attend to household chores or all the demands of raising their children, and/or they may not be able to have a full social life anymore.

Sometimes schizophrenia is a chronic condition, and the individual afflicted is constantly experiencing hallucinations or other symptoms of the disorder. Other people have periods of time when they are relatively symptom-free but have periods of more acute psychosis. Every individual is different, and every person with schizophrenia experiences the disease in a different way.

What treatments are currently available?

Just as different people with schizophrenia can experience different symptoms, the effective treatment for each person is different. Each individual's treatment program can include one or more of the following:

Medication: Finding the right medication can be difficult, and a trial-and-error process may have to occur. It is important to be open with the psychiatrist, reporting what symptoms and side-effects are occurring, so the doctor can help to find the best medication to meet individual needs of each patient. It is also important to learn the contraindications of certain medications, such as the effects of alcohol or sunlight on the effectiveness of the medication.
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Education: The person with schizophrenia and his or her family members can benefit from learning all they can about the disorder, including how to diminish stress and conflict, which can sometimes help spark a relapse. It is also important to learn what resources are available in the community for treating mental illnesses.

Individual, group, and family therapy: This can help with problems that arise day to day, as well as setting realistic goals and defining strategies for reaching those goals.

Hospitalization: This is required during some acute phases of the illness or sometimes in order to make changes in medication in a well-controlled, monitored environment.

Support groups: These can be very important for those with schizophrenia and for their family members and friends. See below for a list of support groups.

Residential, day-treatment, and vocational programs: These programs can help the person with schizophrenia reach his or her highest potential and greatest level of independence. Staff in these programs become well-acquainted with their clients and can help find living arrangements, work, and recreational activities that are well-suited to each client's needs.

We only have a TLC program at the Mental health facility that I am aware of. But you must be well enough to get up and go there, which means that you must only have a mild case or a case that can be treated.

Although, these are great organizations that offer a wealth of information and help for parents this can be misleading. While you think we have help, we do not have a place that meets the needs of a severe mentally ill young adult.

Organizations and their websites:

NAMI (National Alliance for the Mentally Ill)	www.nami.org
Mental Health Net	www.mentalhelp.net
NARSAD National Alliance for Research on Schizophrenia	www.narsad.org
Open The Doors	www.openthedoors.com

These organizations offer information about the illness but there is no list of places for your son or daughter/loved one to get treatment on Medicaid or insurance other than short term. They are moved from hospital to hospital over and over just to receive treatment.

THE ONLY FACILITIES AVAILABLE ARE PRIVATELY OWNED AND COST ABOUT 14,500 a MONTH. They will take cash or credit card ONLY.

Facts About Schizophrenia

- Schizophrenia affects an estimated one percent of the world's population.
- Symptoms usually appear between the ages of 15 and 35.
- Schizophrenia affects males and females equally, although symptoms often appear earlier in males.

- In the U.S., about 2.5 million people have this illness.
- About 80 percent of people with schizophrenia can live either full, productive lives or relatively independent lives with treatment.
- The other 20 percent of sufferers will require long-term, structured care.
- People with schizophrenia have a higher rate of suicide than the general population. Approximately 10 percent of people with schizophrenia (especially younger adult males) commit suicide.
- Schizophrenia accounts for about 40 percent of all long-term hospitalization.
- Schizophrenia can run in families. The risk for inheriting schizophrenia is 10 percent in those who have an immediate family member with the illness, and 40 percent if the illness affect both parents or an identical twin.
- Heredity does not explain all cases, however. About 60 percent of people with schizophrenia have no close relatives with the illness.
- Early treatment of schizophrenia and newer treatment options may control the illness in up to 85 percent of individuals.

Did you know?

- Schizophrenia is NOT the result of any action or personal failure by an individual. Nor is it caused by childhood trauma, bad parenting, or poverty.
- While stress does not cause schizophrenia, it has been proven that stress makes the symptoms worse when the illness is already present.
- Schizophrenia is a medical illness, like other better known medical illnesses such as diabetes or heart disorder.
- Schizophrenia affects 1 in 100 people worldwide-in all races, in all cultures and in all social classes.

Resources (facts about schizophrenia taken from these websites)

<http://www.hopkinsmedicine.org/epigen/szwhatis.htm>

<http://ehealthmd.com/content/what-schizophrenia>

<http://www.wfmh.org/PDF/schizophreniayoungadults.pdf>

<http://www.cooperriis.org/>

<http://www.communityhope-nj.org/>

NEEDS OF MY SON

- Safe structured environment
- Locked facility until he is compliant with medication and safe for himself or others
- Homey environment
- A place where parents are welcome and can visit anytime
- A place where we can take him to lunch or dinner or he can spend special time with his family
- Excellent healthcare professionals-medications and weekly blood work are crucial for him to live
- 24 hour watch until he is better even if it takes longer than 3 months, 6 months, 1 year or the rest of his life. (We will not always be here.)
- Help doing daily routines
- Cared for even if he needs help washing clothes and reminding things he needs to do.
- Activities a 21 year old would be interested in
- Freedom to go outside-He loves the outdoors and riding his bike
- Friends his age
- Happiness, Love, Hope