Testimony 1/2014

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Thank you for the opportunity to speak today. My 24 year old son was diagnosed in late 2011 with schizophrenia after a severe psychotic breakdown. The signs were there for many years. I sought help, but the unfortunate reality is that it is not until a crisis happens that help can be given. My son was hospitalized for 3 months. He was released twice, only to be readmitted shortly because he was suicidal and attempted suicide. He now lives in a shared apartment with 24/7 services.

Through this journey I have heard so many horrific stories from those who cannot speak out because they are in the throes of dealing with their loved one’s illness. I am here because of their stories. I also fear where my son would be without me.

I want to tell you a story about something that happened to me that I think highlights part of the problem. I came to give testimony at the mental health hearings about a year ago. I was waiting in line to sign in and there was a person in front of and behind me talking to each other that were from the mental health community. I am the type of person to strike up a conversation, it is a good way to gather information, and really I needed information at the time. So I said when my son got sick I didn’t know where to go. I was surprised at their reaction because it wasn’t what I expected at all. I thought maybe they could point me in the right direction. But what I got were blank stares. After a little more conversation I was asked if I called 211. I said how would I know to do that? At the time these were just innocent questions but now I realize the interchange pointed to a different problem. The lack of informational resources to help.

I think there are two segments of the mentally ill that are left out. Don’t get me wrong, I think CT has some great programs. However, if you are not in the system they are not available to you. The people I am thinking of are the untreated severely mentally ill. The other segment that gets left out is those “out of the system”.

Since my son’s diagnosis I have thought, I wish I had known the signs, who to call, what to do. Here are some ideas.

1. Education and Training: When my son was arrested for trespassing in a psychotic state and ran across town half dressed, showing up at my mother’s house with a silly grin on his face, I had no idea I should take him to the emergency room. The police didn’t suggest it. Police need more training.

I feel we need to educate the public on mental illness. What it is and what it isn’t. I think we can do a sensitive PSA that would both help parents identify mental illness as well as educate the general public. There needs to be a consistent message about the signs of mental illness that respects those with the disease as well as educates. Mental illness needs a makeover. Think of it as a brain illness not a mental illness. Mental has a horrible connotation.

2. Informational resources: When my son became ill I had no idea where to go. I googled, I called and here and there got information. Recently I had a need to find help for a person with mental illness who
was just let out of jail in New Jersey. I googled “NJ mental illness” and a website came up. http://www.njmentalhealthcare.org/ which is funded by the state. The website has a help number. When I called they pointed me in the right direction. It was great and easy, very different than my experience in CT.

3. Housing: Groups homes are either state or unaffordable private housing. My son did not get into a group home instead a shared apartment because he wasn’t on Medicaid, where he attempted suicide. All because of delayed paperwork getting him on state.

4. Assisted Outpatient Treatment: It boggles my mind that there is such push back on this because there are people who really needs it. I have a friend whose son goes off his medication and she has to wait until he so deteriorated that he is a harm to himself or others to get him to the hospital where there is a hearing and he is medicated. It becomes a vicious cycle in and out of the hospital. It is like you have to wait until your cancerous tumor gets big enough to treat. And we also know that each time this happens, the patient has to climb back out to recovery. As Judge Killian said, this only applies to 8-10% of those with mental illness. But these are the ones most likely to become homeless (and be a victim of violence), become incarcerated or worse be violent towards themselves or someone else. What about these people, what do you say to them and their families? Assistant Outpatient Treatment can help stop the vicious cycle of incarceration or hospitalization; we need to stop the cycle. What breaks my heart is knowing that jails are the asylums of yesterday. Without me, my son could be there.

I think everyone in this room knows the heartbreak of mental illness. I know firsthand the frustrations of getting help for a loved one. I’ve run up against just about every obstacle. I can’t even express to you how terrifying a journey this has been for my son and I. What is so sad is that I have felt my role as a parent was not respected. There were times when warnings about my son’s behavior were not heeded. When he was released from the hospital and I told doctor, he’s just not right and he attempted suicide. When I left message after message asking that he be seen by a therapist and my calls were not returned. Countless times I asked if I should be concerned about his dark, rambling poetry. No response. Thank god I called him as he was leaving to take a week long walk along the ocean. He had just come from the therapist. It is hard enough having your child sick but then having to fight to have him treated. That isn’t right. As a parent I am pleading that you look at the areas I have outlined. The families and their loved ones need help.