2/6/14

Testimony in support of bill S.287

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I have been berated for stating my relationship to my family member so now refer to him as Milo for *mentally ill loved one.*

Thank you for giving me an opportunity to speak to you again this year after I was too stricken by a virus to do so during the public testimony last Thursday.

I was able to see the on-line video of the testimonies and feel somewhat superfluous after the many heart-wrenching and compelling testimonies of the family members who spoke. I'm not sure I have much to add to what they said in addition to what I told you when I testified in support of S.137 last year.

I understand that there are probably going to be some changes to the bill, but I don't fully understand them at this time. My comments are about the initial iteration and the intent.

I will give a quick review our story, less than last year, and then elaborate more on some topics that have come up in the testimonies of others. I'm forcing myself to only address issues relevant to this bill, though could address many related topics, such as medication. I understand the bill is only about the duration of judicial proceedings, or what I call wait times.

Quick refresher: Milo suffers from childhood-onset schizophrenia, we started taking him to child psychiatrists in elementary school but the diagnosis was missed, he had a clear psychotic break on the day of his 18th birthday and then received the formal diagnosis, but we could not get any care for him since he was then a "legal adult" and could not perceive he needed any medical care due to anosognosia.

In 2006 at age 20 the disease caused him to commit crimes including felonies while in the excited phase of a severe catatonic state, which resulted in him being sent to jail without treatment as soon as he emerged from the subsequent catatonic stupor, though still unable to speak or move. The jail transferred him to VSH and then began our ordeal with the VT system of "justice." First he had to endure repeated criminal court appearances which included being transported by sheriffs in metal handcuffs and shackles to the court in Burlington. Eventually I found a private lawyer who convinced the prosecutor he was not guilty due to his insanity.

Meanwhile at VSH, extensive attempts were made by many providers and me to explain his condition to him and the reasons why he needed to be in the hospital and why medication was recommended. He became progressively ill and finally got his day in court for a commitment hearing approximately 2 months after admission. Initially the thought of medicating him against his will was not even part of my thinking and providers were not suggesting it because involuntary treatment is a last resort. However, by the time of the hearing I realized that was not going to happen because he was incapable of understanding his own needs in addition to reality in general. I nearly lost it when I realized that he still couldn't be treated after that hearing; that there would be another wait for a medication hearing and his intense suffering would continue.

By now he's been hospitalized 17 times, all but 2 in VT. With the very different laws in those states, he was only hospitalized in them for about a week. We have been through the protracted ordeal of the two hearings, replete with delays, many times.

Waits have ranged from over 60 to 88 days. The 88 day wait was not during his first admission and by then it was established that medications, one type in particular, did help him, though certainly were not close to a cure. The benzodiazepines keep him out of severe catatonic states and are probably lifesaving. He wants to take those by now.

He was hospitalized for 1.5 years for the admission where he waited 88 days to get treated.

I'd like to spend the rest of my time developing some key points.

1. "Involuntary medication" (IM) in the context of this bill is entirely different from "emergency involuntary medications." (EIM) The terminology is similar and thus confusing. IM refers to ongoing actual treatment with a medication(s) that often brings long term reduction of symptoms and relative relief. EIM is when a patient who is often not on chronic meds, is given short acting injections to control an imminently dangerous situation. They are given for their sedative properties and usually cause the patient to fall asleep. ***This does not require a judge's order***. EIM does not have any ongoing therapeutic effect. It is not treatment or medication in this context. It is indeed a form of chemical restraint. This bill does not change the laws about EIM.
   When Milo has been held without actual treatment he has been repeatedly subjected to this trauma, which undoubtedly has made him additionally sicker and more wretched. This is one of the main reasons I don't want him to go for extended periods without ongoing treatment. Some of the traumatic experiences described by other testifiers about being subjected to what they called "forced drugging" sound much more like EIM than court ordered medication to me.

When not receiving ongoing treatment, Milo was also subjected to a device called "belt and wristlets" for 3 days.

2. Milo has always taken medication without being restrained once it has been court-ordered to the best of my knowledge. He, like most, *has* been put in restraints for the legal EIM.

3. It is key to understand that Milo cannot be "heard" when he cannot talk. Time is not on his side when he suffers from such extreme distortions of reality that he thinks a nurse taking his blood pressure is attacking him and thus punches her in the face causing injury.

4. It is wonderful that others who have suffered from serious mental illnesses are now well enough to testify before you. For the most part Milo has barely been able to mutter for years. He cannot advocate for himself. We must do that for him.
   He is among the approximately 0.1% of people with a serious mental illness Dr. Bob Pierattini refers to in his extremely clear and accurate My Turn piece in last Sunday's *BFP*. What I call "the sickest of the sick." These are the people S.287 is about.

5. I want Milo to be treated humanely as much as others who have testified want to be thusly treated. That's a huge part of why I support S.287. It is inhumane to prolong his misery when he is unable to make decisions in his best interest, severely psychotic and often unable to verbalize and sometimes barely able to move from the catatonic features of his disease.

6. I want Milo to have civil liberties and rights, but he has been robbed of them by his severe schizophrenia. He was much better able to make decisions in his own best interest as a very young and intelligent child than he has been since his 18th birthday. His turning 18 did not cause us to love him less and stop defending his best interests.

   S.287 should speed up his right to receive the best medical care currently available to him, though it would still take way longer than it does to initiate treatment for most patients direly ill from other illnesses.

7. I agree with another testifier that there is some difference between a first admission for severe psychosis and subsequent ones. He needed more time the first time around to be thoroughly educated and have time to think about his plight than for all the subsequent admissions. However the literature indicating that there can be toxic effects of protracted untreated psychosis on the brain still concerns me.

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   Before stopping I will briefly indulge in going off-topic to make sure you all understand that, contrary to some testimony you have heard, we have not abused Milo. We never even spanked him. Nor was he abused by our parents or siblings, all of whom also loved him and did everything they could to help him. Families are not a root cause of schizophrenia except through the DNA we unknowingly harbor when conceiving our children.