

HB823, House Health and Government Operations Committee

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Position: SUPPORT

When our daughter was a young child she was delightfully creative, played soccer, took piano lessons, and on Mother's Day made me cards telling me how much she loved me. She became moody as an adolescent, worried about her weight, and anxious about her relationships with peers. We thought she was going through a tough developmental phase and sought help for her through the best child and adolescent psychiatrist we could find. Her father and I being both being child and adolescent psychiatrists, although concerned about what her symptoms possibly meant, were confident that with the help of professionals, she would learn to manage her moods, and build a happy adult life.

We were wrong. At the age of 37 this past summer our daughter fell down the steps of the boarding house where she was living and died. Her mental illness got worse and worse through her adolescence and young adult years. She had residential treatment out of state in a well-regarded treatment facility which probably saved her life, however, when she returned to Maryland she had aged out of transition to adult-life programs and went into the adult system of care. Again, my husband and I thought that certainly with all our professional knowledge and connections within the mental health system, she would surely get back on track, learn a trade or skill to be able to construct a life and be able to move forward.

Again we were wrong. She bounced in and out of hospitals with over 50 hospitalizations, multiple medication trials, and ECT. She would get better only to be discharged and be unable to take care of herself. Living with us was untenable due to her wanderings at night, inability to comply with basic requirements of living with others, and a developing hostility towards us and her younger sister. She was inconsistent with taking her medications, would sleep all day, and refuse to be involved with recommended therapy, be it individual or group. She was becoming severely and persistently chronically mentally ill before our eyes, but as an adult she was allowed this as her choice. It did not matter that her brain was deteriorating. We could see her losing cognitive abilities, but she could not be forced to take her medications or be in any meaningful treatment.

As time went on, she became increasingly paranoid, argumentative, and hostile towards us. This would get better when she was taking her medications, but she did not like them and unfortunately saw little connection between taking them and the positive effects. She denied that they helped and saw us as interfering parents trying to control her. She could not give a reliable history when she showed up in ER's, and those caring for her were fearful of violating her confidentiality so did not seek information from us. Being knowledgeable health care professionals we understood that our giving information was in fact not a violation of HIPPA and so we often used this knowledge to work our way into being involved with her care.

But our love and our persistence was not enough to save her. She needed a system of mental health care that provided beyond what parents can do. She needed a treatment system that surrounded her, made sure she took her medications, and worked through her paranoia

and self-sabotaging behaviors. During her last year of life my husband and I each found her in her apartment near death. She was hospitalized over and over, each time discharged back to the apartment near our house that we helped fund, even though we told the inpatient teams she could not manage there. We finally had to say she could not go back there. After one prolonged hospital stay at Johns Hopkins, she was less paranoid and seemed to be developing some insight to needing to take her medications. But without AOT within a few weeks she began to deteriorate once again. A group home with medication supervision was the best there was to offer. But she had the right to refuse her medications and her participation in other treatment was optional as well. She was her own worst enemy and there was nothing we could do.

I am convinced that if Maryland had AOT our daughter would be alive. There would have been another tool in the toolbox to help us help her with her struggles. At our daughter's memorial service I spoke about her struggles and mentioned that 47 other states have AOT and Maryland does not. Many in attendance were shocked to hear this and shook their heads in disbelief. It is my hope that the legislature will move forward to adopt and sign into law AOT for the citizens of Maryland who suffer with serious and persistent mental illness. I do not want anyone else to unnecessarily lose a loved one because the state has refused add this service to the mental health care system.

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