HB576 V. Susan Villani, M.D. 103 Longwood Rd. Baltimore, MD 21210 Position: SUPPORT

Our daughter, who had a serious mental illness, died in 2022 at the age of 37, the result of a fall down the steps of a boarding home where she was residing. Her father and I are both board certified child and adolescent psychiatrists with connections to the Maryland mental health system. Although we could ensure that she got to the hospital when needed, without assisted outpatient treatment she would relapse. Her illness prevented her from recognizing the need for continuing treatment in the community. She was unable to adhere to needed medications on her own and unwilling to accept existing services. For her, AOT could have been life saving. It would have encouraged her treatment adherence and required providers to consistently encourage engagement and provide services.

When she 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 was 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. Although concerned about what her symptoms possibly meant, we were confident that with the help of professionals, she would learn to manage her moods, and build a happy adult life.

We were wrong. Her mental illness got worse and worse through her adolescence and her 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 ordered 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 would surround her, make sure she took her medications, and work 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 and had to call 911. 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 into 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 that was not enough to engage her in treatment. 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. I am certain she would have respected the order of a sympathetic judge to engage with a treatment team and adhere to treatment. 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 you will give HB576 a favorable report to provide AOT for the citizens of Maryland who suffer with serious mental illness. I do not want anyone else to unnecessarily lose a loved one because the state has not added this service to the mental health care system.

V. Susan Villani, M.D. Board Certified Child and Adolescent Psychiatrist February 11, 2024