

Jerry Gabay Testimony

September 2014

Senate Interim Committee on Health Care and Human Services

House Interim Committee on Human Services and Housing

(1) Good morning, Chairperson Anderson/Tomei, Vice-Chair Kruse/Olson and Gomberg, esteemed members of the committee. My name is Jerry Gabay. I am a member of the NAMI Oregon state board of directors; co-chair of Providence Health System's collaborative council for behavioral health, and co-author of the Oregon Psychiatric Physician's Association suicide prevention checklists which you have previously been provided by committee staff, I believe. Dr. Stewart Newman and I received the Oregon Psychiatric Association's Access Award for 2013 for creating these documents.

Most importantly, I am the father of a daughter afflicted by mental illness.

(2) Please let me take a moment to tell you about her. Susanna was delightful from the moment of her birth. Pretty, cheerful, with a smile that was truly infectious. She loved to travel and was fluent in Spanish. She was a semi-finalist at the 2006 Oregon State Speech and Debate Tourney; a pole-vaulter and sprinter on the track team, and valedictorian of Hood River Valley HS in 2007.

Yet early in her junior year of HS, she came home after having listened to a guest speaker in her health education class and asked us to take her to a counselor. She was diagnosed with clinical depression and given meds that did not ever seem to work well. In December of her senior year, her counselor called us to say Susanna had been cutting herself and might be suicidal. The counselor arranged for her to be admitted to the secure adolescent psychiatric unit at Providence in Portland.

Her 10 days in the unit appeared to help greatly. She returned home very much the same ebullient child she had earlier been. But even though we requested some sort of partial hospitalization or intensive outpatient program that would enable her to continue the group

sessions and individual psychiatric visits that had been so helpful for her, no such program was available to us then, nor is it today.

Back in the Gorge with very few mental health resources available, she slowly regressed. She was very proud of being accepted into the Honors College at the U of O with a Presidential Scholarship for full tuition, room and board, but there she seemed to retreat more and more into herself. In the spring of 2010, just after her 21st birthday, she suffered a psychotic episode which resulted in her being placed in the secure psychiatric unit at Sacred Heart Hospital in Eugene. One month after her discharge, and one day after missing the only appointment with a psychiatrist which the hospital had made for her, she took her life.

(3) So why am I here today? Because I want to make you aware of 3 things which might have saved my daughter's life, and which might save others in the future. The first would be much greater communication between providers and the families (by blood or affinity) of their patients. The problem is more than just HIPAA...even though some providers cannot think outside that box. Providers are just not accustomed to communicating with families, largely due to a misunderstanding of HIPAA. Providers must be encouraged to seek authorizations to communicate with appropriate supporters of the patient and then actually communicate.

I'll give you one quick example of this problem. Susanna did sign a release for Sacred Heart to communicate with us, as she always had before. Her mother and I spent 8 days down at the hospital during Easter Week 2010. We asked the staff when Susanna would be released and told them we wanted to be present, and participate in the discharge planning. They told us they didn't know when she would be discharged, so we told them we would be going back home to our jobs after visiting with her on Easter Sunday, but would come back for the discharge conference. The very next morning, Susanna's mom got a call from the hospital saying that they had already discharged her- without our participation or involvement, despite the authorization. They discharged her without ensuring that she had an informed and present support system to help her transition and keep her alive.

A second issue is continuity of care...the availability of step-down programs that can continue the successes of more restrictive environments, as I mentioned above from Susanna's stay at

Providence Portland during her senior year. Right now, for many children in this state, there are no good alternatives, and as I indicated, parents are not sufficiently involved by professionals so that they know what to do. We need incentives for the provision of care at levels higher than outpatient level but less intense than hospital setting.

The last item is coordination of care or case management. Susanna left the hospital and we, her parents, were provided no resources, no referrals to support groups, no information on her high risk for suicide. Training at the medical practitioner level for this could be improved, whether it be for primary care doctors, ER doctors, or actual mental health therapists and psychiatrists.

Like many other rural teens, Susanna saw at least 8 different professionals in 3 different cities over 4 years. There was no one to coordinate her care so she didn't drop through the cracks. Her mom and I might have, had anyone taken the time to communicate with us in depth as to the nature of her illness, the warning signs and risk factors, and the actions we could take to promote her recovery. We were the only ones with either the time or the level of concern to do this, but we were ignorant of what to do, as are so many other parents. We were well-educated parents in responsible professional positions, but we were not educated in this field. Mental illness knows no socioeconomic or educational distinctions.

(4) Sadly, my story is not unique. I speak with numerous parents across the state, and this situation is more common than not. There are many small acts which the legislature could take to improve the situation, and we'd be happy to work with any of you who are interested. For now, I'd just like to say that although I am sad every single day of my life, I am also profoundly grateful for having had this brilliant, delightful child in my life. I hope that each of you, and everyone else in a similar position, may keep these lights in their lives...and I'm devoting the rest of my life to help make that come true. Thank you.

