

Testimony before House Committee on Health Care, March 11, 2015

(1) Good afternoon, Chairperson Greenlick, Vice-Chairs Hayden and Nosse and 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 partnership council for behavioral health, a member of the new Oregon state Young Adult Suicide Prevention Steering Committee, and co-author of the Oregon Psychiatric Physician's Association suicide prevention checklists which you have previously been provided by committee staff, ~~I believe~~. But I'd like to make clear that today I am not testifying as a representative of any group, but as a grieving parent.

(2) Please let me take a moment to tell you about my daughter. 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 she also was afflicted with mental illness. Between her junior year of HS and her junior year of college, she saw a variety of providers in Hood River, Portland and Eugene. She was very proud of being accepted into the Honors College at the U of O with a Presidential Scholarship, 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. Her discharge plan was minimal. The only follow up appointment the hospital made for her was with a psychiatrist 30 days after she left the hospital. One month after her discharge, and one day after missing that appointment, she took her life.

(3) I am here today because I am hoping to spare others the pain I live with each day of my life. I want to make you aware of 3 things which might have saved my daughter, which might save others in the future, and which are encapsulated in HB 2948, 2022 and 2023.

The first item would be much greater communication between providers and the caregivers (by blood or affinity) of their patients. Even where the patient has signed a release, many providers are just not accustomed to communicating with families. At a minimum, providers must be encouraged to seek authorizations to communicate with appropriate supporters of the patient and then actually communicate. HB 2948 attempts to do this. There is ample literature indicating that extensive communication is a best practice for therapy and suicide prevention. But ample communication is not standard procedure. Why? I believe that is because many, perhaps most practitioners have a misunderstanding of HIPAA which has both blinded them to the need to communicate as well as to the legal and ethical strictures that encourage communication.

I'd like take a few moments to outline what HB 2948 does, and as importantly, what it does not do, as some persons may be misinterpreting the bill.

1. HB 2948 does not modify HIPAA in any way. The exceptions to confidentiality contained in Section 2 (b) are already in HIPAA, and were emphasized in both the letter of federal HHS Secretary Leon Rodriguez in 2013 and in the Office of Civil Rights guidance on HIPAA of Feb. 2014, both of which have been provided to the committee.
2. The bill does not require anything. But like HIPAA, it permits providers to breach confidentiality where the exceptions apply in the interest of preserving the life and health of the patient.
3. It does neither require nor even suggest that communication must be made to a patient's family or other blood relation. Disclosures may be made to, quote: "a family member, other relative, a close personal friend or other person identified by the individual." If one or more of these persons are part of the problem, then of course it would be inappropriate to communicate with them. This bill encourages providers to seek early on to learn from the patient whom they trust and who would be likely to support them.
4. The types of communication mentioned in Section 3 are cited as best practices by a variety of national organizations, and are encouraged by the National Strategy on Suicide Prevention adopted by SAMSHA two years ago. Virtually every major national professional association has an exception for communicating with family under certain circumstances; harm to self is always one of those circumstances.

5. The immunity from civil suit in state courts contained in Section 3 (2) would encourage greater communication, analogous to that currently in ORS 109.680, but in no way mandates anything. And of course it does not, and could not, purport to grant immunity in federal courts.

The second issue that might have saved Susanna's life concerns discharges and is the purview of HB 2023 and the proposed amendments to it drafted by Legislative Counsel on March 9.

Discharges from hospital care must be much better coordinated with the resources in the community and with whatever support system the patient has. 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 done 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 in order to 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. The point is, communication must become robust, rather than ignored, and the patient's support system engaged in the discharge process. HB 2023 is a giant step in that direction.

The last item is coordination of care or case management. A report from the Suicide Prevention Resource Center in 2011 stated that "as many as 70% of suicide attempters of all ages will never make it to their first outpatient appointment." It continued on to say, "scheduling the first outpatient appointment within 48 to 72 hours of discharge and making reminder phone calls are among the successful strategies identified."

When Susanna left the hospital, 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. So we left it up to the professionals, and frankly, they failed. There could be a solution for this by requiring coordination of care and payment for case management to facilitate the smooth hand-off between providers. This would result in both lower costs ultimately, and more importantly, fewer deaths.

(4) Sadly, my story is not unique. I speak with numerous parents across the state, and this melancholy situation is more common than not. We can work together to improve the situation, to save the lives of those we love. I for one am devoting the rest of my life to help make that come true. Please join me. Thank you.