

Julie Magers Testimony – September 2014

SENATE Interim Committee on Health Care and Human Services Sept 15th, HR C

Good morning Chairperson Anderson, Vice Chair Kruse, esteemed members of the committee.

HOUSE Interim Committee on Human Services and Housing Sept 16th, HR D

Good morning Chairperson Tomei, Vice Chairs Gomberg and Olson, esteemed members of the committee.

Suicide is not easy to discuss because it touches our pain centers so deeply and profoundly. I know because I talk to a lot of people about it as an employee with NAMI Multnomah, on multiple consumer advisory councils, and in the role I've taken on as an advocate for families. I am impassioned about this topic because there are implications and consequences that families and young people experience as a result of us not being willing to earnestly explore doing better than we're currently doing. [I want to thank Senator Gelser and others who are pushing this topic forward in our state]. Thank you all for your time and attention on this topic. As Senator Gelser stated, "Unless we can talk about it, it's very hard to find solutions to it."

My name is Julie Magers, I am the mother of two young adults who are thoughtful, kind, talented, and ambitious. My son is 23 yo and a masters student at UofO with a bright future in physics ahead of him. My daughter just turned 20, works full time at a veterinary clinic and just got a promotion to Vet Technician. She's gifted in working with horses and she has a bright future ahead of her. Her ambition is to return to college and to work as a psychiatric nurse.

3 ½ years ago, when she was 16 years old, she had been spiraling downward with anxiety and depression. In 5th grade she struggled with social anxiety, in middle school she was withdrawing into darkness and cutting herself, and by her junior year of high school, her only strategy left to relieve her pain and anguish was suicide.

She had not been entirely "untreated." We were seeking guidance from many people to help her meet the day-to-day expectations of school, home, and social life and to address her health challenges: Primary care, exercise, nutrition, acupuncture, extra help at school, consequences to behaviors, counseling, tighter rules, looser rules – most everything that parents try in order to teach their children what they need to know and to do so that they become successful young adults we were trying.

I heard concerns expressed by teachers and doctors: "I'm really concerned about your daughter," "Your daughter seems depressed and withdrawn," and "If she works really hard

this term, she can catch up...” – however there were many barriers to getting the right care at the right time and with the right knowledge by providers.

The night my daughter swallowed 3 bottles of acetaminophen, ibuprofen, and OTC cold medicine, enough to destroy her kidneys and liver and to stop her heart from beating, I came to the hard realization that I was the only person who was going to act on the concerns and fight to ensure her needs would be met.

At the ER, they stabilized her “medically,” and then, without psychiatric assessment, told me they were preparing paperwork to discharge her back to home. I insisted on more intensive care and pushed back enough that they found a bed in acute care at Legacy Emanuel’s Adolescent Psychiatric unit. In her 11 days there, they stabilized her, put her on a trial of new meds, and after a checklist of tasks she completed with ease, they discharged her back to my care. They didn’t do IMO a reasonable evaluation of her, and they definitely did not prepare me realistically for her increased risk of suicide. Two weeks following that discharge, she had an explosive psychotic episode and a second suicide attempt. We returned to the same acute care, where they stabilized her, weaned her off the meds, and prepared yet again for a discharge without adequate evaluation or a longer-term, coordinated care plan. This time, I was unwilling to yield to the protocol to move her to the “least restrictive setting,” and the barriers to a clinically appropriate step down treatment plan. They found her a placement in a residential setting, where I insisted on a thorough evaluation, as well as my involvement in her treatment process. 30 days later our entire team created a comprehensive care plan that considered: her clinical, educational, and social needs; family supports; formal services; and informal community-based services. A year later, my daughter walked with her classmates and graduated high school with a regular diploma.

We were not free of more ups and downs in the years that followed, but what we did have were plans, strategies, tools, and resources to overcome any challenges that arose.

You may be asking yourselves, “How did I know what to ask and how to ask for it so that our needs would be met?” I can tell you that, with my child’s life on the line, with 2 suicide attempts within one calendar month, I pulled together everyone I knew who might play a role in helping us. In the years preceding, I’d been working for The Archimedes Movement, the non-profit organization founded by Governor Kitzhaber to build public awareness and civic engagement around health reform. I worked for a woman who was very well versed in case management and the pitfalls of a broken health care system, who just 2 years prior, had been immersed in the same children’s mental health system with her own teenager. I had a highly skilled therapist who was willing to work out a generous repayment plan for the dramatic increase in services I needed from her. I had a natural support system accessible to me that helped me learn what to say to whom and what to do at each juncture. They helped me through the most frightening and traumatic experiences of my life – and without them, I’d be telling a different story today.

With their help, both my daughter and I have learned how to advocate for reasonable and clinically appropriate care, to engage professionals, and to navigate the system. And as you all know, very few families are in a position to tap similar resources.

I have numerous details of what was helpful and what was harmful in how we've been treated over the past several years and I tell these stories to motivate change. **I tell the stories of what worked for us because I want that for others.** If my daughter had not survived, you'd be hearing another tragic story and we would all perhaps wonder helplessly, "what DO we do?" **My daughter's and my story shows what CAN be done -- and that's why I keep telling it.**

As legislators, you hold some power to shape the stories for families and young people to look more like mine, rather than that of my colleague, Jerry's --- **Stories of hope, rather than despair.**

The things that Jerry stated that might have made a difference for his daughter DID make a difference for my daughter, inasmuch as I, the parent, was successful at insisting they be implemented:

- Greater communication between providers and families,
- Continuity of care with clinically appropriate step down treatments,
- Meaningful inclusion of family preparation at discharges,
- Comprehensive and integrated, longer-term care planning approach.

These best practices saved my daughter's life. However, very few parents know what these best practices are, nor have the natural supports or perhaps the personality to aggressively persist with a system that is not implementing the best practices of their trade that produce positive health outcomes.

We believe what's called for is a genuine and in-depth dialogue that explores the implications of us doing the same things we're doing, as compared to what is possible if we commit ourselves to creating real change.

There are many people who are living these experiences and are willing to help inform the policy changes that can make a real difference for families in our state. Again, I sincerely thank you for your attention on this topic and for listening to us today.

