

# Testimony before the Insurance and Real Estate Committee

## March 6, 2018

### **S.B. No. 384 (RAISED) AN ACT CONCERNING MENTAL HEALTH PARITY, DATA REPORTED BY MANAGED CARE ORGANIZATIONS AND THE ALL-PAYER CLAIMS DATABASE.**

Good afternoon Senators Larsen and Kelly, Representative Scanlon and members of the Insurance and Real Estate Committee.

My name is Gail von Dwingelo, and I am a registered voter in Redding, CT; as well as a member of the National Alliance on Mental Illness.

I would like to testify in strong support of the proposed bill S.B. ~~297~~<sup>384</sup>, specifically as it relates to Mental Health parity.

Our son graduated from college in the spring of 2015. We were very proud and thought this marked the beginning of an exciting new chapter in his life. However, when he returned home he began spending the majority of his days on the couch. We became increasingly concerned as he seemed to become more and more depressed and unlike himself. This behavior continued for months as we tried to encourage him to look for a job and plan for his future, and as time went on and his behavior became more alarming, to get help. We became even more worried when he began abusing alcohol. Our formerly easy-going son started having violent rages; he spent large amounts of money, charged up his credit cards and engaged in dangerous, risky behavior. He incurred multiple traffic violations, had car accidents, obtained and lost jobs. He was also arrested. We felt helpless and didn't understand what was happening.

In early 2016, after a particularly alarming series of events, our son was hospitalized in an inpatient behavioral health unit and given the dual diagnoses of Bipolar Disorder and alcohol abuse. He was put on medication as it was determined his abuse of alcohol was an effort to "self-medicate" his mental illness. He was discharged home after six days and was referred to an intensive outpatient program.

His angry, risky behavior and drinking continued throughout his time in the IOP. After a few weeks he was terminated from the IOP due to his continued alcohol abuse and risky behavior. They recommended he move to residential treatment since he had already been hospitalized.

After his discharge from the IOP, we became completely overwhelmed when trying to navigate a mental health system that we knew nothing about. We began to research what services would both be best and available for our son. We were disappointed to find out that the answer was "very little". We searched Aetna's provider database for an appropriate residential treatment program, to no avail. We

also contacted several residential treatment programs on our own, only to discover that they cost \$30,000-\$40,000 for a 28-day program, with additional costs for treatment beyond the initial stay. None of which would be covered by our insurance.

We then found a program that would provide home based individualized treatment for our son, which included the services of a certified recovery advisor, psychiatric nurse, psychiatrist, therapist and family therapy; for a one-year period - at a lower cost than the residential treatment and follow up care.

We were disheartened when Aetna made the decision to deny coverage for the home-based services even though they were on par with services provided in residential treatment. We were told that our son was not "homebound," thus not eligible for home care services, and that these services were deemed "custodial."

We appealed Aetna's decision, explaining that the same services that would be provided by residential treatment could be delivered more cost effectively at home. We exhausted both levels of Aetna's internal appeal process (our health plan is self-funded, so we were told that we could not file a complaint with the Connecticut Insurance Department, but we did work with the Healthcare Advocacy program). Our appeal then went to an external review where it was again denied.

We ended up borrowing money to pay for the home-based services. When our son graduated from the program in early 2017, he was taking his meds, working a full-time job, and living on his own (having been sober for the entire year while in treatment).

Unfortunately, in the summer of 2017 our son made the decision, not uncommon for those diagnosed with mental illness, to stop taking his meds. What followed was months of depression – he lost close to 30% of his body weight, left his job and returned to his bipolar cycling of anger and violence. In January of this year, he was hospitalized and was restarted on medication. When he was discharged, he began another intensive outpatient program but soon exhibited symptoms of escalating bipolar disorder and began abusing alcohol again. He returned to the hospital but was discharged the next day. Within a couple of days, he was back in the hospital. All in all, in a 6-week period he was hospitalized 3 times and was in the hospital more days than he was out.

Currently our son is in an out of network residential crisis treatment program that we found on our own. Aetna has agreed to a "single case agreement" to cover this provider at our out of network rate. However, we plan to begin the appeal process again to request in network coverage for this provider as once more when looking for residential treatment through Aetna's provider network, there was nothing suitable available. In the 10 days since our son has been in the crisis treatment, he remains on his meds, is participating in therapy, learning self-care and doing well.

Needless to say, these last 3 years have been ones of incredible stress for our family as we struggle to find, and find ways to pay for, care for our son. We have struggled with feelings of helplessness and loss in trying to do what's best for him, compounded with our newfound knowledge that mental health parity does not exist in Aetna's provider network; including both a lack of in network psychiatrists and adequate treatment programs. We have watched painfully as our son has struggled with his mental

illness and what that means for his life but have also endured the added stress of searching for, obtaining and paying for his care. We know that with proper treatment, those diagnosed with mental illness can lead productive and happy lives. Alternatively, without proper treatment, they may endure endless revolving doors of expensive hospital stays, substance abuse and legal troubles. We are determined to fight for the proper treatment that our son needs in order to be in the former group. We are very proud of our son in that he has demonstrated time and again to be a true fighter as the last 3 years have resulted in incredible loss, challenges, and struggles for him as well. He continues to take steps to make a better life for himself, and we are fighting hard to support him in his battle.

Sadly, we often think that if our son had a medical illness, how different this would be. The stigma and lack of treatment options for mental health care vs medical care is disheartening. When we search Aetna's provider data base we see lists and lists of medical care providers that just don't exist when we search under behavioral health. It's hard not to think "if only he had a serious medical condition instead of mental health problems, then he would have access to the care he needs". This is a horrible thought, but unfortunately, it's the reality with the lack of mental health parity in health insurance coverage today.

In summary, we offer our plea in support of proposed bill S.B. 384 in order to ensure that those suffering with mental illness are afforded access to in network providers for the care they need.

Thank you for this opportunity to share our experience with you about what this would mean to our family, our son and the people we care about!

