

Lisa Wesel

LD 2009

I am Lisa Wesel from Bowdoinham, and I strongly oppose LD 2009. If this bill had been law when my daughter had her first seizure, I could have lost her, not to the epilepsy that has taken over our lives, but to the state. I had to refuse to leave Maine Medical Center in order for her to get the care she needed; imagine having to decide between getting life-saving medical care for your child vs. losing custody of her.

Let me explain.

The first epilepsy medication my daughter took was Keppra – a very common drug for kids with seizures. It also can cause psychosis. Keppra transformed my funny, happy daughter into a terrifying, dangerous, unrecognizable person with superhuman strength. First she became agitated and unable to sleep; then she started screaming in an other-worldly voice, non-stop, for hours. Then she became violent – she tried to kill our cat. We had to send her little sister away to keep her safe. Her adrenalin-fueled strength was such that we could not restrain her safely, so I called 911. My 110-pound little girl sounded so violent that the dispatcher said she would send an ambulance, but she would also send two sheriff's deputies to protect the EMTs.

But the ER doctor at Parkview Hospital sent us home. She decided the minute my daughter walked in the door that she was having a “behavior issue” that we should be able to handle at home.

My daughter, I learned later, is a GOMER, a term coined over 50 years ago in the medical literature – it stands for Get Out Of My ER. It's reserved for the people that ER doctors just do not want to deal with: People who are mental ill, drug addicted or homeless. And, it turns out, people with intellectual disabilities experiencing a mental health crisis that is commonly dismissed as a behavior problem.

Her neurologist said the Keppra would wear off in 72 hours. All I wanted was for the hospital to keep her safe for 72 hours. Instead, Parkview discharged her, and my daughter tried to jump out of the car on the way home. We went back, and they again refused to treat her, ignoring a mountain of evidence that this was not just a misbehaving teenager: Her neurologist, her case manager, even a behavior specialist from Sweetster that the hospital brought in – all told them she had no history of behavior issues. The Mayo Clinic – a pharmaceutical resource trusted by doctors – lists psychosis as a rare but documented side effect of Keppra, particularly in people with I/DD. No amount of medical evidence would convince the ER that my intellectually disabled and now psychotic daughter was worth their time.

The neurologist eventually advised us to somehow get her to Maine Medical Center, where the ER doctors conceded that she was indeed suffering from a drug reaction, but they said there was nothing they could do for her and discharged her. That was the end of my rope. I told them that I refused to leave until the drug was out of her system. If she had a seizure, someone would know what to do. If she became violent, someone would be forced to care. Then they magically remembered that they had ER beds specifically for psychiatric patients.

Under this law, Maine Med could have called Adult Protective Services at that point to take my daughter away. This law would penalize me for advocating for my daughter and done untold harm to her. I could have lost custody of my child for insisting that the ER treat her. That is beyond cruel, and it fails to solve the real problem of inadequate support services for people with disabilities.