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Senators: I am here to testify in favor of Bill 112-36.

On April 4, 2012, about 7:30 a.m., I brought my healthy, 24 year-old son, Matthew, to SDA for a comprehensive dental procedure under general anesthesia. ... In less than 45 minutes, he was dead ... on the operating table... from a cardiac arrest... He was resuscitated transported to GMH, and months later on August 5th, he was discharged ... Bedridden ... with a tracheostomy (to breathe from his neck), a feeding tube and a catheter. I took care of him for eight years and two months with only my husband as the after-work, self-mandated, part-time care-giver until my son passed away one year ago on June 9, 2020.

Frankly Senators, the thought of suing anyone was far from my plan of action. All the time he was hospitalized and while at home, my priority was to be there for his comfort and reassurance that I, his Mom, was there for him. You see, Matthew was not just blind; he was born without eyes. By the time he was 13 months old, he had a 6-word vocabulary, but he became non-verbal losing all those words by the time he was two years old. Before April 4, 2012, he was a healthy young man who needed dental work. And now he was bedridden, and required 24/7 care.

Matthew's simple joys were taken from him: He could not go out on Wednesdays with his step-dad, my husband, to Chamorro Village to enjoy his Shish Kabob, a soda, and to dance to the live music. He couldn't go to McDonalds with us, and he definitely could not enjoy the simple pleasure of going outside to swing for hours as he listened to Chamorro music from his favorite radio station 102.9.

So what happened?

First of all, I do not for one second imply that the physicians at SDA intentionally caused the injuries to my son. They sent him for a number of tests and numerous blood work and ascertained that he was healthy and able to withstand being under general anesthesia. He passed all those tests prior to the procedure. But, on the day of the procedure, the process went downhill. This is the sequence of events:

- That morning we were greeted by the anesthesiologist. We all discovered that I should have received a prescription medication to administer to Matthew two (2) hours prior to bringing him to the clinic for the procedure. I DID NOT get the prescription for a pill that was intended to relax Matthew.
- Then the anesthesiologist decided that a substitute tiny pill from the pharmacy with about 2 ml of water would suffice and instructed me to administer it to Matthew. She was confident that that would be sufficient to calm Matthew before the procedure. But, it did NOT calm him down.
- My older son and I were asked to escort Matthew into the operating room; there he was sedated moments before being put on the table. Minutes later, he suffered a cardiac arrest.
- About one week later (Matthew at GMH), she agreed to meet with me and my two adult children and explained to us that at one point, she noticed that Matthew was not getting oxygen; the oxygen concentration was dropping quickly. Why? How? She came to the conclusion that, "someone must have accidentally dislodged the oxygen tube," and ... that ... was ... that.

Months later while at home, only then did I start reaching out to a handful of lawyers. A couple said they don't accept these kinds of cases; a couple completely ignored my calls. Since Matthew was a person with developmental disability, I called the Protection & Advocacy (P&A) Office in Hagatna. They declined. Only one lawyer took the time to explain that Arbitration was mandated; that there is a fifty-thousand advance (\$50,000); that if I lost, I could continue to trial = more money; and that even if I won the case, there would be so little money left to use toward home care; that losing would involve MORE money. He didn't show confidence, and I accepted defeat before even trying.

SENATOR: (1) Because P&A is 100% federally funded, the Bill could include some local funding to them to assist the individuals with developmental disabilities proceed with the Pretrial process. (2) Funding for other families could be allocated to Guam Legal Services. Both entities could contract out these cases to the private lawyers. Senators, this Bill will give families a process, however imperfect, to present our cases.

But before I end this testimony, I must include some actions which lead to adding "Insult to Injury". Let me explain:

Before being discharged, I was told that the GMH doctors had recommended that once Matthew was discharged, I should get home health nurse support services. The referrals were sent to Public Health TWICE, (at the time Matthew only had Medicaid) and TWICE the requests were denied!! The doctors were stunned but ultimately, Matthew was discharged and, ... that .. was ... that. I had no support. He was discharged on a Sunday.

On Tuesday, I went to PH's Prior Authorization Office and pleaded with the manager to approve the request for a nurse to come to my home. Her response was, "I am not going to pay a nurse \$250.00 to take his temperature!" followed by, "You were at GMH long enough and should have learned to do everything by now." And that ... was ... that. Her decision showed complete disrespect for the doctors' recommendations; and definitely, she showed no empathy to me. **It was Insult to Injury.** If she had made a few phone calls and questioned me to explain my request, she may have changed her mind. But it appeared that she enjoyed being "in control". She didn't understand the reality between what was taught and the reality that my training was quite limited. As a summary, this is the training I received during "our stay" at GMH.

1. I was taught how to feed Matthew a doctor-prescribed concentrated formula via a feeding tube. **The reality** at home? Medicaid doesn't cover prescribed formula – it is a food, and therefore, I had to purchase similar formulas in cash from Kmart, from Big Navy or AAFB via friends – wherever a substitute was available. Oftentimes, I found mold within the plastic bottles!!
2. Also related to the feeding tube, I wasn't educated on how to respond to leakage from the sides of the tube, i.e. around the insertion site. I was horrified and terrified when I saw "stuff" coming out and called 911 more than once.
3. I was taught how to perform tracheostomy care **and** how to clear his airway with the suction machine and the suction catheter; however, I realized I had minimal practice on **how to clean** the tracheostomy at the hospital. I really didn't know what I didn't know. I thought I knew how to do it. **The reality:** I didn't have enough experience to do it. I was scared to do it. I called 911.
4. I never really learned to give my son a bath in bed. I was afraid to do it by myself for fear that I might rip out the catheter; for fear that I might infect the opening around his feeding tube; for fear that I might infect the opening over the trach.

At home, the complexity of caring for my son was intense:

- Teaching the occasional help how to follow the schedule; how to prevent pressure sores; how to interpret Matthew's facial expressions.
- Learning to use the machines instantly: I had to worry that the life-giving oxygen concentrator might break down. How to use the nebulizer over a breathing tube.
- Scheduling his feedings;
- Administering the medications and learning how NOT to plug up the feeding tube!

- Finding time to go to sleep!!! Matthew, was up during the night, 99% of the time!
- Respite Care Services: One of the most difficult aspect of home care is finding people who are willing to help out as short-term care-givers and willing to do it below minimum wage. It seems to me that anyone who loves to do this kind of work is already working full-time! They are scooped up by CSS and other private home-care services providers. The second problem is that whenever these providers are assigned, they are not allowed to perform any suctioning. They are not trained and they can lose their jobs if they are caught suctioning Matthew. So therefore, the reality in our situation is that, Respite Care services doesn't not allow me to leave my home while they are there to give my son a bath.!!
- Supplies: There is a constant concern with getting the needed supplies in a timely manner. Equally important is that, once the contract is signed, families can not switch to another medical supply store due to "no inventory because shipping is delayed" or any other reason. It is impractical to switch because it takes a couple months to do so and by then the supplies have arrived and the competitor medical supply store may be "out of stock" themselves!

Senators, I support the Bill 112-36 not to show revenge towards the doctors. I believe that most doctors do their best to take care of the people of Guam; however, when a mistake is made, it must be acknowledged by the doctor and/or the medical community, and families need to be able to be compensated. In my situation, money is not the issue. What I needed is an RN at least 10 hours daily to teach and to supervise me as I learn the best way to take care of my son. I needed an RN so that I could get some sleep!

Please feel free to call me regardless of the reason.

Sincerely,



Maria P. Espinoza