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Re HB 4088.

As the mother of a 34 year old man with profound developmental disabilities who functions like a very young toddler, this bill frightens me. My son experienced a catastrophic brain injury in infancy (his neurologist's words, not mine), and he is blind, has autism, cannot speak, and has the terrible cognitive disability. The little bit of vision he does have AND his hearing desert him when he is upset.

Despite all these years of helping him through every step of his life, he has not been able to learn how to communicate reliably through any means other than behavior. By behavior I mean grabbing, pulling, pushing, shoving, spitting, whacking, etc. It was hard enough when he was a young child, but now he has the strength of a man but the cognitive understanding of a young toddler. Ian lives in his own home on our land in Southern Oregon, and he has 24 hour care by a team of highly trained staff plus additional 2:1 IADL hours, 2:1 community hours, and 2:1 seizure support hours. Many of our staff have been with us between 15-30 years and know him well.

My Ian cannot just go to the doctor and get treated. He cannot have blood drawn without being completely restrained. (I cannot recall when the last time was that his blood was drawn or his blood pressure was taken or a doctor looked down his throat.) He cannot sit in a dentist's chair and open his mouth, and if by chance he does open his mouth for a second, he will clamp down hard on the first thing that is put into it. He cannot obey what a stranger tells him to do.

It is his disability, not his choice.

In order to get dental work done, Ian has to be knocked out in the hospital, and we have had to go through that several times. We also had to go through two foot surgeries at Shriner's Hospital when he was in his teens. What it means for us is that we have to have a minimum of two, preferably three people who KNOW Ian well and

know how to support him through stressful moments. The only thing that works is for the hospital to allow US to get dressed up in scrubs and walk him into the surgery and help him lie down. We know how to secure him without traumatizing him, and once he is out, we leave and the surgery can begin.

Hospitals are NOT interested as a rule in allowing parents/caregivers into their operating rooms. It takes a tremendous amount of energy to get them to allow us to do it. Two times, they did not. The first time, Ian was about 6 years old, so certainly not as strong as an adult, but they sent a woman out to walk him in. She insisted on putting a bracelet on him, which he fought. By the time they had walked 2-4 steps, he had ripped off the bracelet, ripped off his hospital gown, ripped off the cap she had forced onto his head and was starting to rip off her gown, tearing at her arms. We had to just stand there, helplessly watching as our son was dragged away from us. As soon as they got him through the doors, they had 4 or 5 men come and hold him down so that they could get him anesthetized. It was extremely traumatic.

That same day, when his dental procedures were done, they called us into the recovery room, as we had requested, so that he could hear our familiar voices and have his best chance to remain calm. However, they had placed an IV in his arm, and he was obsessed with ripping the IV out of his arm. The nurse stood there and said to him, "You stop that. Leave that alone. I said 'stop that.'" I couldn't take it and said to her in a loud voice, "IF HE COULD DO THAT, HE WOULD. HE DOES NOT UNDERSTAND." She looked at me, turned on her heels, and stormed out of the room. We held Ian as best as we could, securing his arms and hands so that he could leave the IV in. It was a major struggle, even for us, even though he was only 6 years old. He was fighting for his LIFE and was very strong. In a few minutes the nurse was back with a little arm board, and we helped secure him while she secured his arm with the IV onto that board and wrapped it up.

Shortly, she actually removed the IV and then Ian was able to settle down. I took him for a walk, and she came out of the nurses' station and said, "I owe you an apology. It is ALL OVER his chart, but I hadn't read his chart carefully enough." That helped, but really, the damage was done. It had been traumatic for all of us, including her.

Fast forward to several years later at his next dental restoration procedure in the same hospital. Despite my spending the day before the procedure in the hospital and getting an agreement that we would do it differently, they balked at the last minute. However, the anesthesiologist was willing for us to suit up and walk him

down to the surgery, which we gladly did. We helped him get onto the table. We helped him lie down, we sang to him, and they placed the mask over his face and was out like a light. No trauma for anyone.

They also put the IV into his foot, and he was unaware of it, and they called us into recovery right away. It was a much better experience.

Next, he had to have two foot surgeries at Shriner's hospital, one at a time, so two separate trips to the hospital. We thought we had everything arranged, but then while we were talking to the nurse, his caregiver raced to find us because someone had come to take Ian to surgery and they were not willing to wait. When we got to him, he was standing on the gurney and the gentleman was telling him in an exasperated voice to "SIT DOWN!" I was so angry. We were working so hard to have a non-traumatic time, and it was all spoiled.

With the foot surgery, they felt they had to keep him in the hospital for 5-6 days afterwards, and that was also a very challenging thing. One of us stayed with him in his room, while the other two went to rest. It took all three of us to keep him calm during those next days. After 2 days, I said to his doctor, "we are in a motel about 5 miles from here. Let us take him there and then he will actually be able to calm down, just being around the people who love him, having the food he likes, having his special things. We will stay in the motel as long as you think we need to, and then we'll come in before you discharge us and you can give us the go-ahead." They took us up on this offer and it was so much better.

The second one was different, and they remembered, thankfully. No one wanted to repeat the incidents of the first surgery. They allowed us to go into a room with him and they came in there and administered medication to knock him out while his dad held him. Then they did the surgery and had us spend the first night. Then they released us to the motel again, and it was successful.

These things all happened while he was much younger than he is today. Today he is in a man's body and is much stronger and more capable of inflicting damage. He still has his "child mind" because of his disabilities, and that is not his fault. We cannot just tell him he must do something and have him obey. He is incapable of working like that. We are concerned about how we are going to manage his dental now. His long time dentist retired, and it took us a year to find someone new, and that was wonderful: he would just do the procedures in his office and knock Ian out there. We

could be involved. They supported our involvement. And now, just when our appointments were just coming up, the practice was sold and the new dentist will pull teeth but not do dental restorations in the office OR the hospital.

We have just learned that at this point, there is only 1 dentist in Oregon who will do "special needs" patients. That dentist is in Albany, and we are feeling so discouraged. He works out of a hospital in Salem, so again, we have to travel away from home and try to make arrangements with a brand new hospital who has never seen us before. People just don't really understand what the risks really are and how traumatic the whole experience is, for Ian, for his family and caregivers, and for THEM.

Ian is vulnerable and is at risk of being aggressive and hurting someone, even us. He hurts us on a regular basis, but we know him. We know how to speak with him. We know what he is trying to say when he is flailing his hands and arms around, his versions of sign language. We know what every grunt and sound means and how to respond to it. We know how to touch him so that he does not feel assaulted and how to secure him safely. We have been trained how to safely restrain him in medical settings.

It doesn't HAVE to be so hard. There just needs to be some flexibility and a lot of compassion.

This proposed new law is terrifying to me. Ian doesn't want to be mean. He doesn't want to hurt someone. But he also cannot handle being restrained. He cannot handle people talking to him who don't know his language, and he WILL lash out, fighting for his life. It just doesn't have to be that way.

Thank you

Mar Goodman, Ian's mom