

**Pennsylvania House Health Committee Hearing
May 2, 2023
Testimony of Erin Gabriel
Pennsylvania Health Access Network**

Good morning Chair Frankel, Chair Rapp and members of the Health Committee. My name is Erin Gabriel and I am here representing the Pennsylvania Health Access Network. PHAN is Pennsylvania's only statewide consumer-driven organization working to expand and protect access to high-quality, equitable, affordable healthcare for all Pennsylvanians.

Thank you for having me here today to discuss the need for the Patient Safety Act.

I am the government affairs representative for PHAN and the mother of 3 children with disabilities including my youngest daughter, Abby, who also has complex medical needs.

Abby loves helping Daddy drive his big red tractor around the yard, anything Disney, traveling, camping, and just exploring her world. In addition to being the coolest kid in the universe, Abby is also a non-speaking Autistic, DeafBlind wheelchair user with an extremely rare, progressive neurological syndrome, which means we spend more time in the hospital than most kids her age. Access to high quality medical care is critical to keeping Abby and people like her healthy, safe and thriving. And at PHAN, we hear from families like mine every day.

Abby has intellectual and developmental disabilities and is unable to communicate with hospital staff. In order for her to be safe in a hospital, she needs someone to be continuously checking on and monitoring her. When Abby is in the hospital, nurses monitor her pain levels, her seizures, her breathing and her color. They also ensure that she gets the correct dose of the correct medication at the right time. We rely on nurses to keep Abby safe when she is in the hospital.

We hear from parents of children with complex medical needs like Abby all the time. Those with children who have tracheostomies (a breathing tube in their throat) need nurses to regularly suction and monitor them to ensure their airway is clear and they are getting enough oxygen. Many have children who require IV nutrition or medication delivered through a central line and nurses are the ones who ensure that every procedure is done correctly so as not to introduce a potentially fatal infection into an already vulnerable child's body. In fact, at home many of these children have a dedicated home care nurse with them around the clock. These kids are especially vulnerable in the hospital because there are just so many extra germs floating around. These types of procedures require time, patience and a level of alertness that simply cannot be achieved when a nurse is overtired or distracted. In other words, fatigue in a nurse can literally kill one of our children.

When we drop our kids off at school there are government mandated ratios of teachers and students and those mandated ratios vary based on the type of classroom. For my daughter, in a special education setting, that ratio is one teacher for every 8 students. That's the minimum and it can be adjusted upwards by the individual school district or with an individual education plan (IEP). There are no such mandated ratios for her in the hospital. I'll say it again, because I couldn't believe it myself. There are no government mandated staffing ratios for patients- including children, in hospitals.

The impact of staffing levels on patient safety affects families and caregivers as well. As parents, many of us will stay in the hospital with our kids to keep them safe. To be clear, the ability to do that is a privilege not all parents can afford. But for all of us, our goal is for our kids to grow up and hopefully outlive us. So what then? What happens with the children who cannot have their parents or caregivers with them in the hospital? And what happens when these patients are adults with all of these same needs and no caregiver to stay with them?

In Potter County, Richard's family told us of how much they worried for their elderly father's health when he simply could not leave his wife's bedside when she was hospitalized with Alzheimers and Epilepsy, staying with her in the hospital for 6 days because he was afraid that the nurses could not monitor her appropriately and she might fall or have a seizure. Richard did not believe his wife would be safe in the hospital.

Think about that for a moment- the reason that any of us is hospitalized instead of being sent home is so that we can have continuous monitoring and intervention by trained professionals. That so many families feel that they cannot leave their loved one in a hospital alone out of fear for their physical safety should be a giant red flag for all of us.

Add to that, the level of fatigue that comes with being a bedside family caregiver in a hospital is almost unimaginable, as I can tell you from personal experience. It puts a great deal of physical stress on caregivers who should be using the hospitalization time to rest and recharge in order to be ready to receive their loved ones home when they are discharged. Stress that often leads to other health issues for these caregivers.

My daughter, like many patients, requires frequent bed changes and can tangle herself up dangerously in the mass of wires, tubing and IV lines that comes with a hospital stay. I frequently am the one to change her bedding and continuously untangle those lines, and watch for seizures. This really does mean I can't leave her bedside. The simple mission of getting a cup of coffee, or even using the restroom yourself while your child is admitted is one that parents like me time out with all the detail and precision of a Navy Seal operation, trying to find a time that is both between rounds so we don't miss the opportunity to speak with the medical team, but also not during a shift change when the nurses are extra busy, and hoping that nothing happens while you're on that 5-10 minute coffee run to the cafeteria. I remember during one hospital stay, when I was on day five without a

shower, I managed to arrange with the nurses for a volunteer to come in and sit with Abby during her nap, while I snuck downstairs to the Ronald McDonald House to grab a quick shower. Even though her room was only 10 feet from the nurse's station with a camera on her, we knew she wouldn't be safe without someone in the room with her to not only ensure she didn't fall or get tangled up on equipment, but to watch for seizures or any other events while we were carefully adjusting her medication.

These fears that family members have are not unfounded, nor are they limited to those with multiple disabilities like Abby and Richard's wife.

Nora, a healthy 34 year old woman, fell while she was at work and broke her ankle. She was taken by ambulance to the hospital and the broken bones were set in the emergency room. When she asked for assistance to get to the restroom, there was no one available. She waited as long as she could and then tried to make it to the restroom herself. She fell, rebreaking her ankle far worse, requiring immediate and multiple followup surgeries to reset and place pins in the bones. This resulted in a weeklong admission to the hospital, where she found the same situation repeating itself- her pain medications were due, but there was no one available to deliver them on time, often missing doses by an hour or more, leaving her in substantial pain immediately after bone surgery; she would call for a nurse or aide to assist with toileting and be forced to wait for 2 hours or more. After she was discharged, she was not able to return to work for over 8 weeks because of the severity of her injury.

Maybe toileting doesn't seem like a high medical priority, but we have to ask ourselves, if we can't get someone into a patient's room to assist with something for several hours, what else are we missing? What are we not monitoring? Patients are expecting high quality care in hospitals and at a minimum deserve to feel safe and have their basic needs attended to.

I know these days with all the high tech we have, some might ask about electronic monitoring. When my daughter is hospitalized for epilepsy, there are cameras and monitors on all the patients at all times recording in case of a seizure, but the nurses don't have the time to have their eyes on these monitors at all times, especially when they are helping other patients. While cameras are a helpful tool, they simply cannot substitute for the in person eyes and ears of a trained nurse watching for subtle changes in these patients. In the worst case scenario, nurses are the trained professionals who need to be there at my daughter's bedside immediately if she starts to crash. They are the ones moving quickly to intervene and save lives. They can't do that if they are also attending to another patient in crisis. Cameras simply can't substitute for staffing.

Patients have the right to expect that they will be receiving a high level of care in a hospital setting- not that they will simply be warehoused and checked on every few hours. Patients deserve the dignity of having their needs addressed in a timely manner. A husband deserves to be able to trust that a hospital will keep his wife safe so that he can go home when visiting hours are over. A mother

should be able to trust that the nurse injecting medications into her child's vein is not so hurried and overwhelmed that they have miscalculated a dose or introduced an infection. Families deserve to know that their child, spouse, sibling or parent will be well cared for and safe when they are in the hospital.

You're going to hear from a lot of experts here today. But I'm going to ask you to keep kids like my daughter Abby, hard working adults like Nora, and our aging parents like Richard and his wife centered in all of this. Whatever solutions you come up with here, we must focus on patient care and safety. Our families- your constituents deserve nothing less. Thank you.