

Good and Bad Experiences

by Nicolette Aduama, a mother in Massachusetts

My daughter Nisah is five, and she has Down syndrome. I'd like to share one positive and one negative health care experience we've had.

The good experience happened when Nisah was three. She had to go to the hospital to get a tonsillectomy and adenoidectomy. The otolaryngologist also removed and replaced her ear tubes. Nisah hadn't had too many health issues up until then, so going in for these procedures was a bit scary for us.

Staff at the hospital were good at explaining each step of the process to me: how will anesthesia work, when will I go home, things like that. I was allowed to come see her right after it was done. And everyone there was caring and patient. That calms you as a parent. You realize, she's not the first one to go through this, and she won't be the last.

They also followed up with a phone call after we went home to make sure everything was OK. And they gave me a 24-hour number to call if I had questions. That was helpful for managing Nisah's pain.

The bad experience happened when Nisah was a newborn. In order to confirm the Down syndrome diagnosis, the doctors told me she needed a blood test. So we went to the phlebotomy lab at my primary care doctor.

While I was filling out the form for the blood work, the phlebotomy tech came in and looked at what I was writing. He said, "Why do you need this test done?"

I told him, "My OB-GYN requested it. They're pretty sure she has Down syndrome, but we need to confirm it with blood work."

The tech said, "But you're so young!"

I didn't know what to say to that. I know the stereotype is that only older women have kids with Down's. But plenty of younger woman do too.

When you're dealing with something out of the norm, the last thing you need is for someone to question your kid, or you, or why you're there. I never reported that tech's behavior, but it's always stuck with me.

Nurse's Reaction

This commentary is by a nurse who was asked to read and respond to Ms. Aduama's story.

In Ms. Aduama's first story, the hospital exhibited non-judgmental, holistic, empathetic care. For example, Ms. Aduama was allowed to see her daughter Nisah right after Nisah's procedure, instead of having to wait. And staff explained every upcoming step, so her mother could be prepared.



This type of care inspires confidence, trust, and respect from the patient and their family. These aspects are essential to healing.

In addition, Ms. Aduama described hospital staff as “caring and patient.” When patients feel that staff are emotionally supportive, they also feel as though the care provided is better.

The second story provides a stark contrast. The phlebotomy tech completely disregarded Ms. Aduama’s feelings. Asking her why Nisah needed this blood work done was a violation of HIPAA, and made the tech appear unprofessional.

Also, saying “But you’re so young!” was a judgmental comment. It implied that Ms. Aduama did something wrong to cause Nisah’s Down syndrome. This type of comment is unacceptable, and implies to the patient that the needs of hospital staff (in this case, to satisfy curiosity) are more important than the patient’s needs and privacy.

The tech’s rudeness leaves the patient in an awkward position: does she say something to a supervisor, and possibly create a more uncomfortable situation? Or does she just accept what the tech said, and try to move on?

Ideally, the patient should say something to a supervisor, and the employee should be spoken to about the lack of professionalism and respect for patients. However, no patient should have to make that stressful decision.

When we’re interacting with a patient, we must put our feelings, beliefs, and judgments on the back burner, and place the patient’s needs and emotions higher than our own.

Reflection Questions

- ▶ If you were the phlebotomy tech’s co-worker and overheard his comment, what would you have said to him?
- ▶ How do you help cultivate a respectful environment for your patients?
- ▶ Explain your response to this saying: “People won’t remember exactly what you do or exactly what you say, but they will always remember how you make them feel.”

Patient Story No. 2 • Good and Bad Experiences

Inclusive Health Care was developed by the Institute for Community Inclusion at the University of Massachusetts Boston and Boston Children’s Hospital. We have decades of experience in workforce training and specialized consultation related to disability inclusion.

