My Daughter Could Light Up a Room

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ABSTRACT

A mother describes her daughter's experience of trying to be "seen" by clinicians due to her developmental abilities. She eventually finds a new way to communicate. This narrative describes the experience of a mother and daughter whose care improves when clinicians stop looking past a child with developmental differences.

My daughter could light up a room. She is vivacious, expressive, and always had an opinion. By the quirk of her eyebrow or the expressions on her face you always know where you stood. She laughed easily and was quick to kick her brother in the shins when he made her mad.

But something happened when we were in the hospital. My daughter became invisible. Not because she was sick, but because my child had multiple disabilities. Her intellectual disability rendered her less than human in many medical professional's eyes.

My daughter was no slouch. She knew people were ignoring her. It infuriated her. She was also not one to be a passive wallflower about it. Once a physician came in doing rounds. He spoke over her to his students droning on about how she couldn't understand things and how hard it was to work with "children like her." My daughter's eyes sparked fire. As he moved closer to her, I said, "she doesn't like being touched." The physician assured me that she didn't understand. Meanwhile my daughter had a low throat growl going on, a sign of danger. As the physician leaned over to poke her, she lunged and latched on to his hand, sinking her teeth into him.

I wish I could say that this happened one time and then magically we never had any problems with medical professionals again, but this happened over and over. Clinicians would walk in, glance at my child, and then talk over her like she isn't even there. Watching your child's face fall and spirit droop repeatedly is heartbreaking as a parent. I have been told often that I am my daughter's voice. I would like to go on the record saying I am *not* her voice. I am her microphone. A microphone can only echo and magnify what its user is saying.

As my daughter's condition began to deteriorate, tough decisions needed to be made. Specialists came and began to want to have discussions about how far we were willing to go to and what measures we wanted in place for our child. I once again felt the familiar frustrations rise up in me as everyone talked around her but no one talked to her.

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Once, as they left the room I heard a little sob come from her bed. So I did what I always did and began to explain things to her. I told her how brave she was and how proud of her I was. That the doctors were trying to figure things out to help her. At that point she started rolling her eyes at me, so I quit while I was behind.

As I sat there holding her hand, I thought about a favorite book of ours, *Out of my Mind,* by Sharon Draper. In the book the main character, Melody, has cerebral palsy and is unable to speak. Everyone downplays what she can do until she is given a voice. Then people began to see her potential. Although it still wasn't easy for her, more people began to listen and she felt valued.

I needed my daughter's team to see her as the most important member of the team. They needed to take her seriously when it came to decisions involving her body, to recognize that she could have a voice. She found this voice through alternative access communication (AAC) with pragmatic organization dynamic Display (PODD).

AAC gives her a voice. PODD is a specialized book that contains words and symbols to support and facilitate communication between people with complex needs and their communication partners. She was able to hit a yes or no button as we scanned through her book. Each page held words or phrases to get her message across.

Using this voice, she told the next specialist that visited her, "Go away, bad doctor." Clinicians now couldn't ignore her. I don't think they took that really well, but I think we were all pretty frustrated at that point. After talking things over as a family, we decided that it was really important that everyone was on the same page and respected my daughter's thoughts on what was happening to her.

Things did improve once we started working together as a team. When you begin to look past the disability and focus on my daughter's ability you see possibility. When she talked about pain, clinicians paid attention. She had the nurses slowing down on the pokes. Was it a perfect system? No. Did we still have people who didn't listen to her? Yes. But Rome wasn't built in a day.

Seeing the surprise on clinicians' faces as she showed them how much she understood what was going on, and the interactions that occurred from that, made us so happy.

For the first time the hospital saw my daughter. They looked at her first instead of me. They talked with her and engaged her. She was included, and that was powerful. Her underlying conditions were still there, but due to a boosted spirit, she started improving.

We saw her old spunkiness returning and the delight in her eyes as she started ordering nurses around and telling the physical therapist to "Go fly a kite." Seeing the surprise on clinician's faces as she showed them how much she understood what was going on, and the interactions that occurred from that, made us so happy. For once, the tables were turned and I was the invisible person in the room.

As a careprovider it's important to provide your patients with the best care. It's also equally important to make sure that their voices are heard. Allowing children with disabilities the chance to partner with their team to the best of their abilities is a win-win situation for both parties.