



Complex Child E-Magazine

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You Don't Have to Yell: Handling Inappropriate Comments

by Janis C.

There are a lot of people out there to educate about interacting with kids with special needs, or in this case, dealing with the moms of special kids like me. I get it. Not everyone has grown up around other-abled kids, and not everyone knows what to say or do.

Here is a hint: act normal. Period. That's all you have to do.

You don't have to stare or point...you don't even have to avert your eyes. If you have a question, ask it. But, for goodness sake, don't yell at me across a crowded hospital waiting room.



A Personal Situation

When you have as many ongoing medical issues as my son Austin does, you may find yourself spending a lot of time in and out of doctor's waiting rooms. Occasionally, you may meet someone who is genuinely curious about something, whether it's the feeding

tube, the BAHA (surgically placed hearing device) or the Trach. Some are drawn to his Microtia (deformity of the outer ear) or the Oxygen tank. It varies. We deal with it. I am all about being open, hence the reason that I blog.

I often approach other moms and start conversations in the typical mom-to-mom fashion, "Oh how cute...I love that sweater...How old is he/she?" This is me acting normal.

Recently we were in the Radiology waiting room at our children's hospital, which was uncharacteristically full. I spotted a little girl, about three years old, with Unilateral Microtia. Normally, I would go and speak to her parent about her diagnosis, swap stories about doctors or that sort of thing. But I could not determine who her parent/caregiver was because it was so crowded and she was playing in the middle of the room.

Later, just outside that same waiting room, her mom approached me in the hallway to ask about Austin. I quickly answered her questions, because I was heavily into a conversation with someone else. She asked questions like, "How old is he? How long has he had his BAHA? Does he know sign language?"

I returned to my previous conversation and apologized for the interruption. A few minutes later, she is shouting at me from across the room over the noise of kids, TV and the Wii. Seriously! She wants to know what kind of BAHA Austin has. It looks different from her daughter's BAHA. And the headband where did we get that? She only has the red one.

Um. OK. Awkward.

I raise my voice back over the din and answered her questions: "He wears a BAHA Intenso, it's a newer model, I guess, and pretty powerful. The headband was one of the choices. Thanks, we think it's fun and like it too."

Then she shouts back. No lie.

"Oh that's nice, well at least he isn't Deaf anymore."

WHAT?

Excuse me?

It took all I had to remain composed. I am pretty sure I shot her a look, as did the other fifteen or so parents in the waiting room.

So many things were swirling in my head that I didn't say:

- You are incredibly rude.
- How about keeping your voice down?
- Why are you yelling stuff across the room?

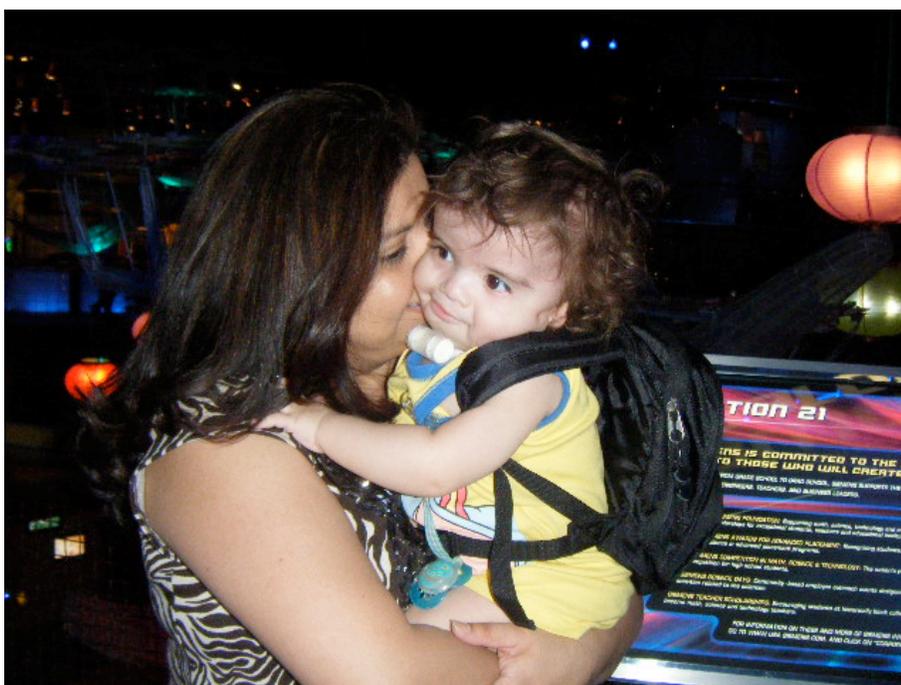
- Your child has the same congenital anomaly. How about a little sensitivity to my son who CAN hear you?!

But mostly it was something like this: What is your problem?!

I mean seriously, what do you say to that? I was not bothered so much by what she said, although I think she should have known better. It was just how she yelled it out. Does the entire waiting room need to hear this? Do I? Did I give you permission to share my son's medical history with everyone in the room?

I am pretty sure the look on my face said it all. She clammed up.

Like I said, I am all for educating people about Austin. I would rather he be understood than feared or pitied. But I was seriously at a loss for words, and that, my friend, is NOT easy!



When Asking Questions to a Parent

When you run across a child who is different than your child, think first and foremost, do you really need to know the answer? How will the child feel about me asking that question about him/her? Are there siblings there who might feel ignored or left out if I focus my attention and questions on that one child? Is it possible that this child wants to be recognized for something beyond his medical condition? Remember that this is a child and a family who deserves some peace and privacy.

Many parents with children who have special needs are willing to answer politely phrased questions. You don't have to raise your voice at that parent or child to be heard and not every parent has the time or desire to educate you. Respect all types of families with your questions and your attitude in asking them. Treat the child as a child first and not as a disease or disability.

And, for goodness sakes, you don't have to yell!

Janis is a busy single mom and personal assistant to Austin, an adorable, G-tube fed, Trached and BAHA-wearing toddler. Austin, born at 36 weeks, is diagnosed with Branchio-Oto-Renal (Melnick-Fraser) syndrome. At quick glance, his medical chart is likely to include the following terms: Bilateral Microtia, Aural Atresia, Hemifacial Microsomia, Dysphasia, Micrognathia, GERD, Chronic Lung Disease, Obstructive Sleep Apnea, Hypotonia and Macrocephaly, to name a few.

Janis is looking forward to the day when they can ditch all the doctors, nurses and therapists; in the meantime, she blogs about Austin's life at Sneak Peek: Raising a Special Child [<http://sneakpeekatme.com>].

September is Craniofacial Acceptance Month. For more information on Craniofacial differences visit:

- <http://www.ccakids.org/>
- Atresia/Microtia Yahoo group:
<http://health.groups.yahoo.com/group/AtresiaMicrotia/>
- Craniofacial (ccakids) Yahoo group:
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