



Providing support and information for families of children with disabilities, chronic illness and other special health care needs

If an older mom can interject here

Marsha Earley, TxP2P Volunteer, Austin

NOTE: This article came from an email listserv for TxP2P Volunteers - it was so powerful we decided to share it with everyone. Hope you enjoy it! Editor

If an older mom can interject here, without any real answers to any of the specific problems described, which are certainly not trivial - if you can all just step back a bit and enjoy your children in small moments when you can. Embrace their 'difference' because that is what makes them their own very special person, and realize that this problem will pass, and other problems will take its place - but your child will BE WATCHING AND LISTENING as they grow up with a stressed out mom who wants to 'fix' her child as best she can. Or a mom who works so hard to make their lives a little more tolerable - even in kindergarten - where every child should enjoy fun time and recess and every other wonderful things their teachers can think of to do with them. Relax on yourselves AND YOUR CHILDREN, Mom!

When my child was little, like yours, I also ran around every place she went and tried my best to 'move the beast' of autism to my way of thinking. Meanwhile she was growing up and pretty much ignoring everything I did in her honor. Probably most of it she didn't even know about. And you know what? None of it mattered in the long run. The schools didn't change much, and the lobbying I did fell by the wayside and the politicians didn't even remember my name the next day!

But I still had my little girl, and now she's 25 years old, and has her own life (which I helped create) where she is just herself, and is accepted as just herself, with all the trappings of life as she can handle. I am very proud of the life I helped mold for her, and she does seem to enjoy herself, but in the long run, for me it's an empty victory. TO ME. All that work. All those tears. All those meetings. All those fears. All that pain and suffering - that really just went on in MY mind! I wanted things MY way - not hers. I really just wanted to have her not be autistic, and in that is the crux. For her - autism is reality; but it's HER reality, not mine. I have never spent one day autistic. A little attention deficit for sure, but autistic - no.

And at this point, when they have finally grown up - we need to let things be the way they are - and maybe they aren't so bad! They may not be what we expected, or what our Mom's might have expected, but it really isn't THAT bad, either! It just is. My daughter just has autism and it's OK! She's OK, and people still love her and like her, she still has a rich life, she will outlive me, and she is in a good place. What's not to like? It's all good in the end.

Texas Parent to Parent

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She's in a place I helped put her so she wouldn't be lost if something happened to me. A place where she would be taken care of instantly if something happened to HER! And that is also key. Someplace where they will always care for her. And she's as safe as I can make her in my absence. And you know what? I'm tired now, and I need to focus on me and not on her anymore. It's been hard leaving all that passion and energy behind. Feeling so important because I did something today that made a difference, even if it was a very small difference. Those feelings of victory that were so important before, but I don't need them anymore.

I grew out of it while she grew up to it! It's HER life now, after all. When our children are small, just out of our womb, mothers tend to have a sense of ownership of how our children come out of us and how they will grow. When they are small, we feel the need to keep adjusting them as they grow. But once they are grown, and our job is done, we need to let go and let God!

You will get to this place too - at a point far in your futures. But when you do get here, enjoy it! Enjoy your victory - for however our kids turn out - mothers need to only feel victorious. We got them to adulthood, and that's enough. So ladies - enjoy your ride. It will be over long before you are ready. Because none of us want to let go of our babies hands. Maybe we need to let go of OUR baby's hand so we can open it up for our GRANDCHILDREN's hand!

Now THAT's a whole other story! Read the story of Dr. Temple Grandin. It's such a great story of success they are making a movie about her now. People with autism have a place in this world - either as super-smart like Dr. Grandin, or so attention deficit they can't focus for more than 1 minute. My little grandson has some little bits of autism and I can guarantee you that he can name EVERY car you pass by, be it in a parking lot or on the road - and he's invariably right! At 4 years old! How could that happen?! But it did. What a wonderful car salesman he will make! Or maybe he'll build his own car! They say Albert Einstein had autism and I believe them. Only a true autistic could focus on the complexity of the universe and actually make sense of it and then figure out string theory as a side line! What? Oh yeah - people with autism DO have a place in this world.

You know, this world wants everyone to fit in that round hole - but I think it's all the square pegs who figure things out. They have to - to figure out where they fit into this world that thinks they are odd or crazy or stupid or whatever. Those tags don't mean a thing. They told me I was fat when I wasn't. They told me I was stupid when I wasn't. They told me I was ugly when I wasn't. They will tell my big grown up girl stuff but she won't hear them - she's too busy figuring out string theory to bother with ninnies like them! Tata for now girls - I'm going for a walk ALL BY MYSELF AND JUST CAUSE I WANT TOO!

Another Mom of a beautiful girl with autism.

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