

Speaking My Truth

Written by Gayle Nobel

Friday, 06 November 2009 16:30 - Last Updated Friday, 06 November 2009 16:42

Here is something I wrote in response to a call for parents to speak out regarding their "take" on the Autism Speaks video.

I am a parent and author. I have seen the Autism Speaks video. In fact, I was supposed to share a table at the upcoming walk in Tempe, Arizona and have since told the company that so graciously invited me, that I can't in good conscience, connect myself with Autism Speaks.

I have lived with autism my entire life. Both my son, age 25 (living at home) and brother, age 49, (living in a group home) are on the low end of the autism spectrum.

I got to see first hand the way my mother was impacted by society's stigmas. Fortunately, we have come a long way in creating a more compassionate and understanding world when it comes to our children with autism. However, we still have a long way to go.

Frankly, I'm not surprised by the Autism Speaks video. It is the logical extension of making autism the enemy. They are all about the fight. The default position in life is to see autism in this way. It's sad that Autism Speaks has bought into this and is promoting this way of thinking.

I cringe as I envision a new parent seeing this video. They would be justified in a reaction of "Well, just shoot me now and get it over with." Is it necessary to paint such a grim picture of life with autism to go after the almighty dollar? What kind of awareness are we trying to raise anyway? The awareness of pity?

Why does Autism Speaks insist on making autism ugly? It's challenging enough to educate the public on how to accept, embrace and make room for our kids. What we need are more supports for our children, particularly as they become adults. Our kids don't need fixed- society needs fixed. As far as I'm concerned this video is damaging. It also distracts us from what families and children (and adults) really need from the world. It is certainly not a larger pity party.

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I look at my own life and believe I have very much triumphed as I have lived with a child extremely affected by autism. I have worked with the obstacles placed in my way, I have a happy marriage of 29 1/2 years, two compassionate children who are not on the spectrum, an amazing son who IS on the spectrum who has taught me in every way how to be a better human being! And I mean in every way! Living with autism asks a lot of us and I believe my entire family has risen to the occasion and beyond.

We only have one life. We can either make the best of it or the worst of it. We can embrace the children we have been given, love them "as is" without needing to fix them while at the same time doing everything we can to help them be the best they can be.

We need more supports for helping them be their best and helping US, as families, be our best, We don't need organizations such as Autism Speaks to reinforce stereotypes that we have worked so hard to eliminate.

It's sad that a national organization that is supposed to be "helping" is promoting this kind of mentality.

It's true. The high functioning adults do not understand our children or the stresses we live with. How would they?. They have their own stresses. However, I am grateful to them for speaking up. Autism Speaks would do themselves a favor by listening.

Fortunately, we get to choose the beliefs we decide to live by. These beliefs hurt children and they hurt families. Autism is not a battle we need to fight. It's another way to be a human being. It's all about supports that will help lift us up not ugly stereotypes that will drag us down.

I speak out for my son and my brother, who can't speak for themselves.

Gayle