

The Next Thing You Know Ellen Notbohm



Notes, news, perspectives and possibilities

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“We cannot always build the future for our youth, but we can build our youth for the future.”

~ Franklin Delano Roosevelt

Confronting the Ominous New Age of Autism Awareness

I don't think we were naïve, back then. I think the consciousness surrounding autism has fomented, for better . . . and not.

For many years, we plunged into the cause of autism awareness believing that once people became aware of autism, they would understand autism and be moved to take action to help people with autism.

Those compassionate, community-minded people do exist, and the effort to reach them will always be worthwhile and necessary. But amongst them stand people who form a different by-product of autism awareness. They're aware, but not sympathetic. They reject our message. They're unwilling or unable to empathize. They may even take obstructive action. So we no longer have the luxury of saying we'll just focus our efforts on those who are willing to help and disregard those who aren't. The naysayers' numbers are too large and their capacity to do damage, whether through direct action or through inaction, is too great.

We've entered an ominous New Age of Autism Awareness. It requires that we name, then reframe, its challenges.

Aware, but don't care. *You were dealt a bad hand, sorry. Don't expect support (“handouts”) from lawmakers, school boards, insurance companies, employers.*

There's no argument for withholding services to children with autism that holds up over the long run because, barring catastrophe, children inescapably become adults. Contrary to wishful thinking, children with autism don't “outgrow” it. Like all adults, they'll require housing, food, medical care and a source of income. Those who haven't been adequately prepared to live as independently as possible don't evaporate upon high school graduation. Some remain within the care of their parents—for a while. As autism

parents are acutely aware, we aren't always going to be around to see to our children's care.

So we have to force a change in attitude and focus from “drain on resources” to “return on investment.” The meanest bean counters in the world are the ones who should most strenuously support robust interventions. Childhood services are infinitely cheaper than supporting a dependent adult through a 60-year span. That's not “special education;” that's common sense, third-grade arithmetic.

Aware, but resentful. *Special education, paraeducators, therapies and accommodations take resources away from “regular” kids and that's not fair.*

There's no argument for withholding services to children with autism that holds up . . . oops, did I already say that? Let's meet the “not fair” argument on its own turf. What's really not fair is to “regular” kids is for adults to fail to prepare their children's autistic peers to take their place in the community to the fullest extent possible. That failure hands off to those “regular” kids-turned-adults the responsibility for providing public services through a lifespan. What's “fair” to “regular” kids is to ensure that *all* their peers have their best shot at becoming the workers and citizens they want to be, i.e. taxpayers and voters contributing to community health, safety and well-being.

Aware and sorry, but . . . *“Our hearts go out to you” or “Our thoughts and prayers are with you.”*

These are kindly reactions, but rarely a prelude to action or assistance. “I named my cats Thoughts and Prayers,” reads one barbed meme, “because they do nothing.” I'm no fan of assumptions, but we're probably not far off if we assume many people simply don't know how to help and may be very willing to do so if we offer them simple, concrete ways. “Do you think you could _____? It would really help him to _____.”

Aware, but don't accept. *Your kids are misbehaving weird on purpose to get attention. If you were stronger parents, your kids would shape up. They just need a good smack. Teachers need to try harder. There didn't used to be any autism, so why all of a sudden now?*

The answer to all of these is, “Incorrect.” Or, if you must elaborate, “The facts do not support your opinion. Get some.” But some people aren't ready to hear the truth and aren't worth your lung power—yet.

Aware, but suffering compassion fatigue. *April is Autism Awareness Month—and also awareness month for Alcohol, Child Abuse, Irritable Bowel Syndrome, Minority Health, Occupational Therapy, Sexual Assault, Oral Cancer, Infertility, Meningitis, Air Quality, and Distracted Driving.*

And that's just April. There are countless worthy causes and every person has only so much money and time to go around. The onus is on us to craft our message, actions and requests so that they rises to the level that not just grabs but *sustains* attention, all year.

Aware, and exploiting. *Buy now and show your support! Get your autism awareness t-shirts, jewelry, key chains, phone cases, sneakers, beach balls, stickers, puzzles, candy, pencils, picture frames, balloons. Magnets, rubber duckies, water bottles, bandanas, garden flags, bags, backpacks, nail decals, plush toys, leggings . . .*

Those items all came from a single Internet search, and they wouldn't be available were vendors not making a profit. Can we agree that overmining our kids is just as bad as undermining them? Encourage people to support kids, not commodities, by giving their money to local organizations that directly benefit families living with autism in their communities.

The ominous New Age of Autism Awareness calls for a blend of empathy, facts, and irrefutable common sense as we work to expand perspective from compassionate accommodation of children to thorough preparation for adulthood for all our kids, not just those with “amazing gifts.” We have to anticipate blowback arguing that we can’t afford full investment because not all kids with autism will become independent adults. That’s true—and it is the very reason for community to give its maximum effort. “We cannot always build the future for our youth,” said Franklin Roosevelt, “but we can build our youth for the future.” The New Age of Autism Awareness means we firmly answer every “can’t” with one of the most powerful words in the autism vocabulary—“yet.”

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Your story

Starting with this issue, I’ll include a writing prompt or two. Tell your story, even if it’s only to yourself. If you do feel like sharing, send me your thoughts for possible inclusion in future newsletters. (Hateful and/or profanity-laced material will not be considered.)

This month's prompts:

You get to name the streets in a new subdivision designed for families of children with autism. List at least twenty street names.

Ask your child to describe the items in your jewelry box, tool chest or junk drawer. Write about how his perspective resembles or differs from yours.

Your question: Do we squelch echolalia . . . or not?

We’re just learning about echolalia and find it fascinating. Our child has always done it. How do you think children with autism match an appropriate phrase to the situation so quickly and smoothly? What kinds of things did you employ to try to stop your child from using echolalia?

Echolalia is fascinating. Once understood, you’ll be able to view it as an admirable step on a child’s road to conversational competence. Many children with autism, my own included, are stunningly clever in their appropriate use of delayed echolalia. They’ve identified a personal strength—the ability to memorize large blocks of dialogue or text, and to search those “files” and instantaneously retrieve relevant passages. They then employ this strength to compensate for a deficit—expressive language skills not yet developed enough to formulate the instantaneous original response expected of them. In that context, echolalia is the marvelous accomplishment of a brain that processes language in a particular way, and it is the gateway to learning originate the expressive speech required for conversation. . . [Read more](#)

Got a question you’d like to see answered in my newsletter or blog? [Tell me about it.](#)

Translations

[Polish translation of Ten Things Every Child with Autism Wishes You Knew](#) is now available from Wydawnictwo Uniwersytetu Jagiellonskiego.

Arabic and Turkish translations of *Ten Things Every Child with Autism Wishes You*

Knew are in the works. I'll announce publication on my website and social media.

Both of my *Ten Things* books as well as *1001 Great Ideas for Teaching and Raising Children with Autism or Asperger's* are available in audio editions, through [Audible](#) or [Amazon](#).

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