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Jill Escher at TEDx: Five Things You Must Know About Autism — Reality Check Edition

April 15, 2023

On April 14, 2023 NCSA's president **Jill Escher** gave a TEDx talk in Cupertino, California focused on #AuthenticAwareness of major issues in autism. Video:

A Reality Check on Autism | Jill Escher | TEDxMontaVistaHighSchool



Below are the notes on which she based her talk (which varies from what's below, as the talk was improvised based on the notes), along with presentation slides.

TEDx

5 Things You Must Know About Autism

Reality Check Edition

Jill Escher
President, National Council on Severe Autism
Past President, Autism Society San Francisco Bay Area
Founder, Escher Fund for Autism

TEDx Monta Vista • March 14, 2023

The slide features a light blue background. At the top left is the TEDx logo. The title is in large, bold black font, with 'Reality Check Edition' in a smaller, red, italicized font below it. The speaker's name and credentials are listed in black text. To the right of the text are three small portrait images: Sheldon Cooper from 'The Big Bang Theory', a young man with brown hair, and a woman with short black hair wearing a yellow jacket. At the bottom right, the event name and date are displayed.



Twenty-four years ago I gave birth to our second child. He was a handsome, healthy guy. But then as he developed something was amiss. He was irritable, wouldn't sleep, had no interest in toys, never developed language, he would flap his hands and stare at ceiling fans. At age two we took him to a neurologist for an evaluation — **autism**, he said, and I quote "he has it in spades."

Autism, a term I hardly ever heard or thing I had ever encountered growing up — had somehow struck our son.



Some years later, we had another child, this time a beautiful girl. But as she grew, again something was amiss. She too failed to develop speech, she never played with toys, she couldn't imitate, and like her brother she met none of her cognitive milestones. And again, the diagnosis— autism.

To this day, Jonny and Sophie remain profoundly autistic, nonverbal, and dependent on others 24/7 for nearly every aspect of their lives.

And then, as now, no doctor could give us any reason for **these extreme outcomes, these unfathomably severe disabilities.** They have no genetic errors, I had no risk factors in my pregnancies. There was no autism or anything even close to autism up our family trees.

But for some reason, my family was part of this rising tide of autism, which I saw growing all around me. There were so many questions. What was causing it? How can we meaningfully treat it? And most distressing of all, what happens to all these special but very disabled children when parents can no longer provide care?



Deeply concerned about the fate of families like mine, and wanting to serve my community, I have been intensely involved with autism ever since. I now serve as president of the National Council on Severe Autism. I am past president of Autism Society San Francisco Bay Area, where I remain active. I run a philanthropy that supports cutting-edge autism research looking at novel questions regarding causation. And I provide low-income housing for adults disabled by autism and other disabilities. **Through it all I've had two decades of a front-row seat to everything autism.**



And hey, it's April! It's Autism Awareness Month! Celebrate! Party! And I do, I enthusiastically celebrate our children, our families, our community not just this month, but every month, every week, every day really.

But I think **April should also be a time for some serious reality-checking.** Because autism is a massive and rapidly growing crisis for families, and for our entire country. Yes there is much feel-goodism about autism, but I'm concerned that the sugary media narratives of autism simply do not match our increasingly dire reality. So in the spirit of #AuthenticAwareness, I want to share with you five key things you really must know about autism — the reality-check edition.

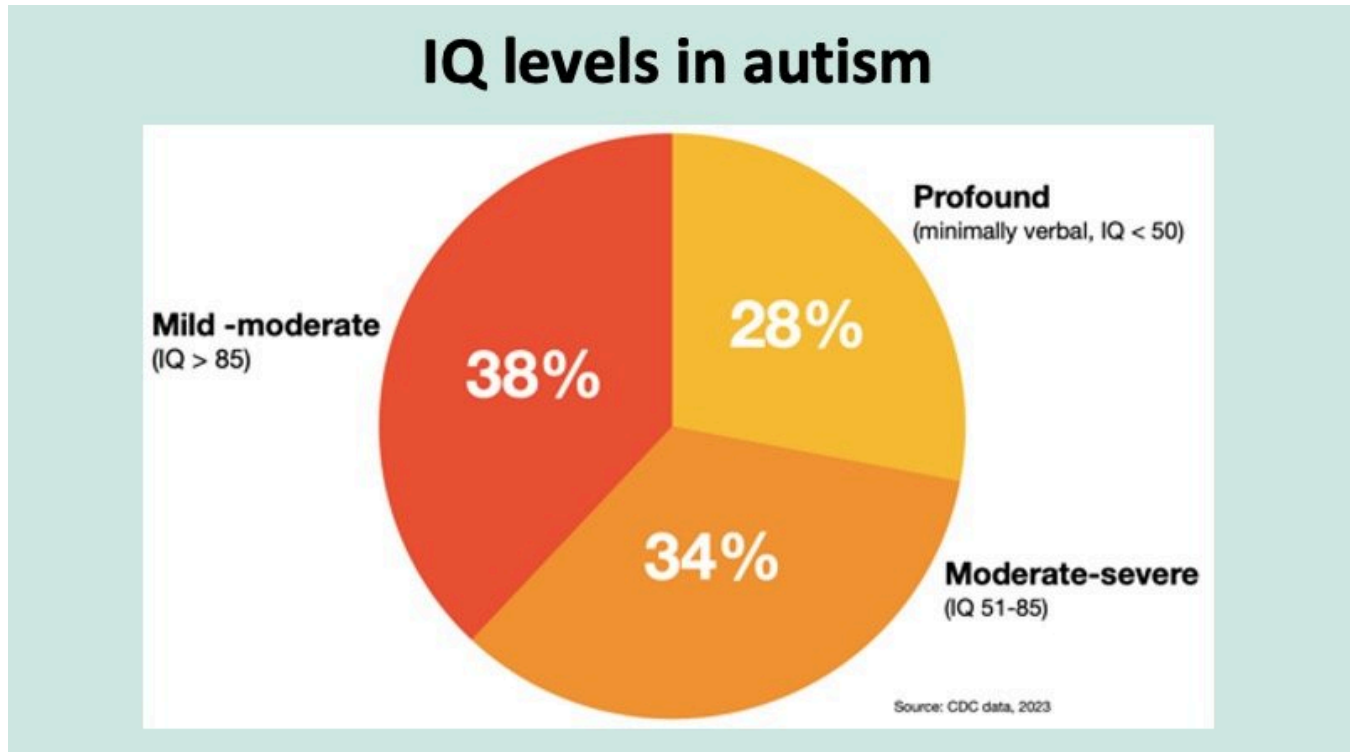
1. Autism is not a superpower



ONE. Autism is not a superpower.

If you watch hit TV shows or spend time on TikTok, or even the TEDx archive, you will often hear that autism is a strength, a gift, a superpower! A mere neurodiversity or divergence, and not a disorder.

And perhaps for a subset that is true. Certainly on TV it's true. But autism is by definition a **mental disorder, involving significant impairment that interferes with basic functioning**. People with autism must exhibit significant social communication challenges and abnormally repetitive behaviors. And beyond that, most have other very serious impairments. These can include challenging behaviors like aggression and self-injury, property destruction, pica, elopement/wandering, seizures, sleeplessness, irritability, debilitating anxiety and much more.



Here is a graph based on some very recent CDC data on children. You can see that nearly a third have what is termed "Profound Autism" with IQs below 50, and minimal if any language. They have very limited daily living skills and usually require 24/7 supervision, for their whole lives. My kids fit into this slice of the pie.

Next to that is another third— those with some language and skills but still very dependent and vulnerable. Many don't graduate high school and cannot hold jobs. Finally, only over a third have an IQ over 85, some people call this group "high functioning." But for the most part I don't think autism is ever "high functioning" — despite their relative cognitive strengths, this group tends to have many serious challenges, including isolation, depression, anxiety, difficulty with inference and abstraction, and difficulty with independent living.

No, for the vast majority, autism is not a mere "neurodiversity," it's disabling, it's life-limiting, it greatly reduces functioning and quality of life.

2. Autism is rooted in dysregulation of early brain development

(It is in no way, shape or form related to vaccines)



Which brings me to number TWO. On a physiological level, autism is not some magical neurodiversity or benign difference. It's biological, rooted in abnormal development of the brain. Neuroscience research, much of it conducted here in California at UCLA, UCSD, UCSF, is showing autism rooted in marked abnormalities of early brain development. Specifically we see disruptions in the way neurons are born during fetal development, how these baby neurons fail to properly proliferate and migrate to their expected posts and perform their duties. We see failures of connectivity and function, particularly in this outer shell of our brains called the cerebral cortex, the seat of much sensory processing and higher-order thinking.

Autism is hard-wired from birth, even before birth. It's a very intractable condition because it's baked into the child's brain, it's innate. And it's definitely not caused by vaccines, let's please forever bury that hypothesis.

3. Autism rates are truly skyrocketing



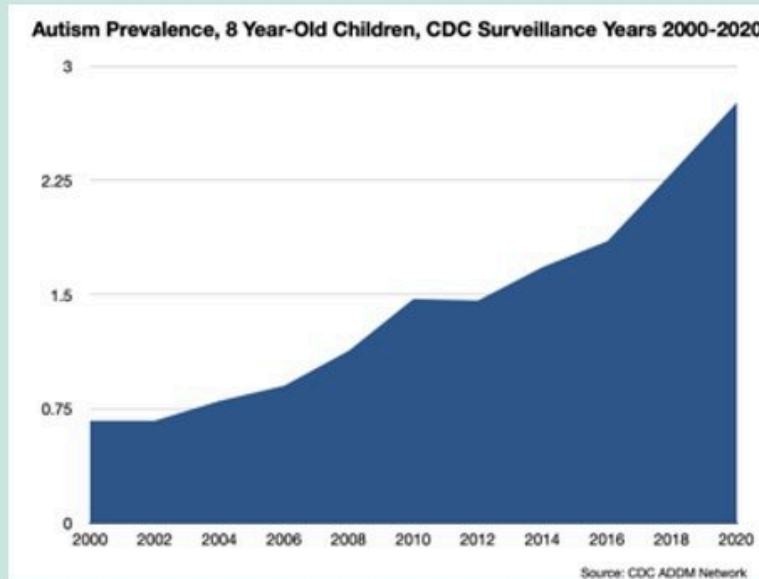
THREE. Autism rates have truly skyrocketed. There's an old saying If you tell a lie big enough and keep repeating it, people will eventually come to believe it.

I believe one of the most dangerous lies of our time is the oft-repeated notion — you have probably heard this numerous times — that autism is a mere “epidemic of awareness,” that the numbers aren't really growing, that we're just noticing it better, we're using different labels, expanding the diagnosis.

Nothing could be further from the truth. There is overwhelming evidence that rates of abnormal neurodevelopment we call autism are truly surging.

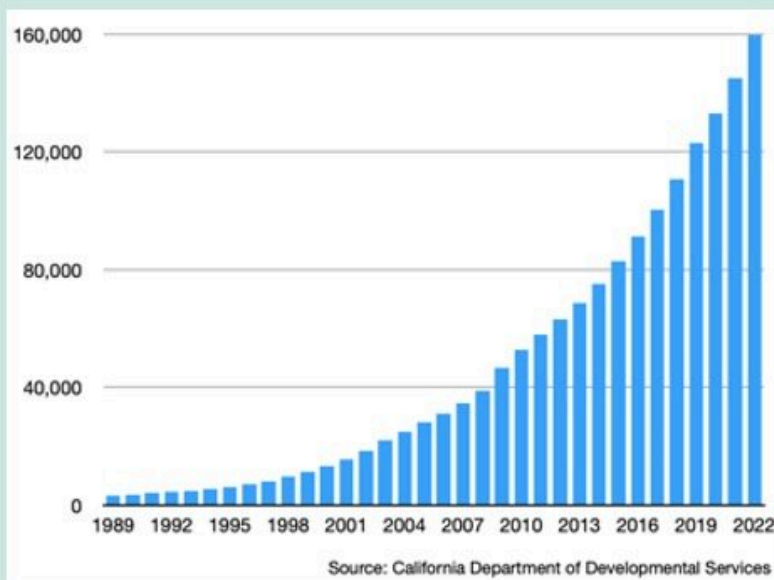
The CDC recently reported that autism rates among children had jumped again, now affecting an estimated **1 in 36** 8 year-olds. This is **almost 3%** of U.S. children. It's 4.3% of boys and, for the first time, more than 1% of girls.

Autism prevalence: clinical definition, 2000-2020 (CDC)

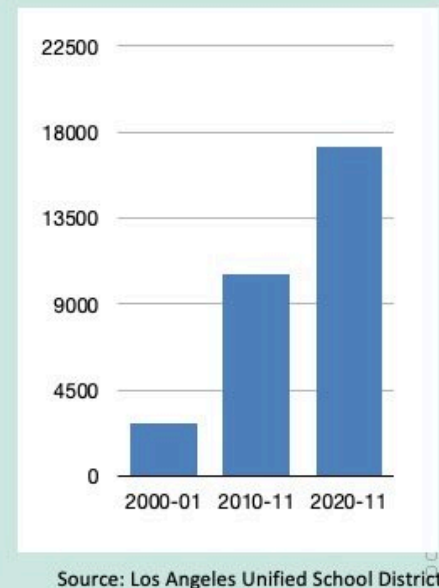


Over just 20 years, CDC studies show a 4-fold increase in the rate of autism in children. From 1 in 150 to 1 in 36 children. And this is not all high-functioning children. Increases have been seen across all functional levels.

Autism cases, 1989-2022 (California Dept of Developmental Services)



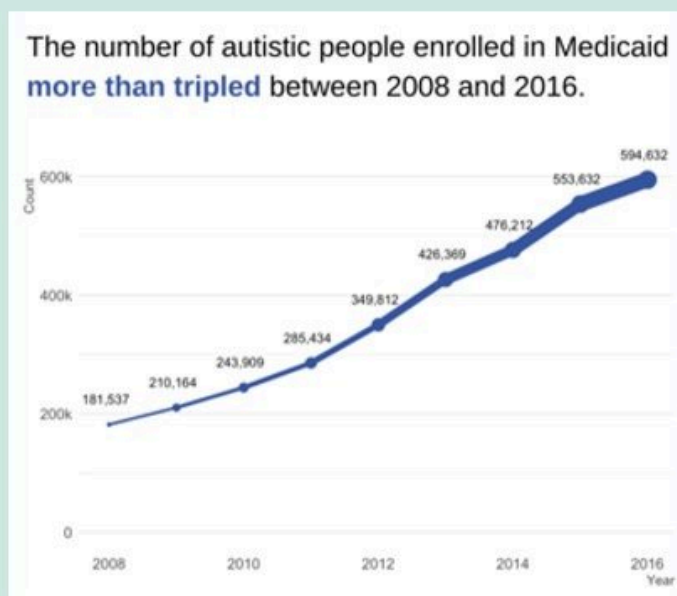
Autism cases, 2000-2020 (LAUSD)



Now if we switch to our state of California, which has long kept the best records on autism in the country, you can see over a longer time horizon. When I was your age in the early 1980s, California counted about 3,000 cases of autism in its Developmental Services system. But today it's 160,000. From 3,000 to 160,000! Nothing remotely subtle in the California data. And these cases are more **severe** than the clinical definition — these are developmental disability cases, a much higher bar. And the legislature has not expanded the definition, it made it more stringent in the early 2000s.

In school districts across the country, the numbers of students requiring special education services due to their autism has also skyrocketed. Here you can see just one example, in Los Angeles Unified — despite the district having overall declining enrollment — autism cases over 20 years have surged more than 6-fold. This is a trend seen throughout our state, and indeed throughout our country. Again, this is not just anyone with a label of autism, these are students with autism who required special education services.

Autism cases: Medicaid definition



Now using an even stricter definition of autism — let's look at our federal Medicaid system — largely limited to those in need of what they call an "institutional level of care." The system has seen a 3.3-fold growth over just 8 years, 2008-2016.

I could go on, I could show you dozens, even hundreds of graphs just like these, from many systems and countries. What I can't show you — because *this data does not in fact exist* — is that these increases are due to “awareness” or other external factors. Maybe a bit of that at the high end of the spectrum, but no data anywhere to even suggest that these tremendous surges are artifacts of different labeling.

“Autism prevalence has increased significantly and broadly across every group, type and category, across US regions, since 2000.

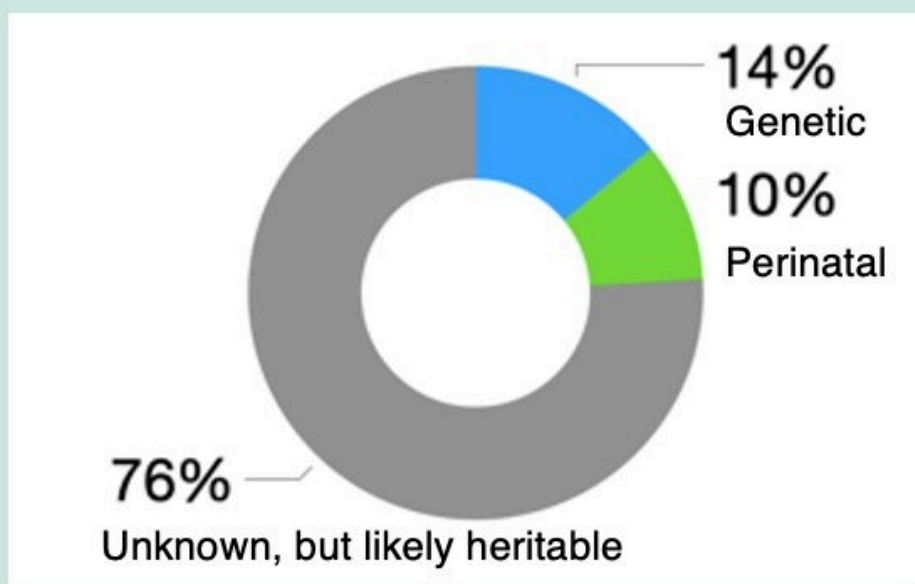
“The surge in autism cannot be explained by broadening of criteria, diagnostic substitution or other rationalizations reflecting the hypothesis of better awareness.”

— *Walter Zahorodny, PhD, Rutgers University*
Epidemiologist, New Jersey CDC investigator



As Dr. Walter Zahorodny, a CDC investigator for the New Jersey study site, has commented: “The surge in autism cannot be explained by broadening of criteria, diagnostic substitution or other rationalizations reflecting the hypothesis of better awareness.”

4. We still don't know what causes autism



FOURTH, and alarmingly— we still don't know what's causing it. Now, I hate to say this because I'm a huge supporter of autism research, but in this dimension, autism research has been a colossal failure. Despite billions poured into research, using the most robust and advanced technologies and methods, we know very little about the root causes. Only about 14% of cases can be attributed to genetic mutations — maybe depending on the study 8%, 10%, or even 20% if you count just more severe cases — but 14% is a fair estimate. And these very rare mutations for the most part are not handed down ancestrally, they are mostly *de novo*, or newly occurring in the child, or more likely the gametes that made that child.

And perhaps something around 10% may have roots in perinatal factors such as prematurity, or rare adverse exposures in the womb, such as drugs like some anticonvulsants or high maternal fever. But for maybe 75-80% of cases, despite billions spent on research — **we still don't know**. My kids are in there in the grey swath — most of the kids I know are in there.



But one thing we have learned as that autism is strongly heritable, even though it is not strongly genetic, but it's only heritable in a weird way. There is no evidence it is heritable through ancestry, the evidence for heritability is based on high recurrence rates in twins and siblings. Recurrence in the new generations. Look at my own children — we certainly had a high recurrence of autism.

This bizarre pattern of course raises the question about a phenomenon called non-genetic inheritance, or intergenerational epigenetic inheritance — a topic on which I am a very vocal superfan. With esteemed colleagues, I've published many papers in prestigious scientific journals about this phenomenon and why it's extremely relevant to the autism question. But we have no time for genetic toxicology or molecular reproductive biology today.... Please geek out on Google Scholar or PubMed if you are interested. My only point here is that there is a vast continent of questions about autism's origins that still remain completely unexplored.

5. Autism parents can't die



AND FIVE — No matter what is causing it, the bottom line is this: We have an unprecedented population in need of often-intensive lifespan care. And the strongest support system on the planet for those with autism— that's us autism parents — we are just temporary.

But, our system is so broken, so completely unequipped to handle the long-term care needs of the burgeoning autism population, that really, autism parents simply cannot afford to die.

Our system is **already past the breaking point**. We are already beyond crisis. We have waitlists, mindless bureaucracy and suffocating red tape, the shuttering of services, the defunding of options. We lack outpatient care, inpatient care, crisis care, we lack case management. And it's nothing compared to what's coming down the pike. It's not a question of if — it's a question of when. Autism parents will become incapacitated and die. It's already starting to happen — the parents in the leading edge of the autism bubble are now in their 70s.

The inevitable demise of the autism parent generation is a massive issue looming over our fragmented care systems. Parents are the unsung heroes of the autism world. They are the Swiss Army Knives of autism. In one package, a mom and/or a

dad you have people doing countless different, often very difficult jobs, to support their children and adults.



When we lose parents, this is what we lose:

The housing provider
 The 24/7 supervisor
 The program manager
 Guardian
 Trustee
 Financial manager
 Benefits manager
 Advocate for services
 Protector from abuse and neglect
 Cook
 Driver
 Hygiene manager
 Housekeeper
 Launderer
 Medical and dental supervisor
 Medication dispenser and monitor
 Recreation provider
 Interpreter

iPad fixer

Handyman

And of course the source of LOVE and nurturing.

It's the equivalent of a more than a dozen jobs, if not more — plus jobs that money can't buy. Did you know that when an autistic adult moves out of the family home and into the community it can easily cost \$100,000 to \$400,000 per year to provide all the necessary services? Can you see how much parents are truly worth?!



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So what's the answer? What are we going to do? We have never faced **anything** like this before. But **we have no plan**. Unless that plan is to stay in denial and hit the snooze button on reality, over and over again. Will siblings take over? Sometimes, but usually not. And no one wants to return to this. No one wants warehousing and neglect like days of old. I believe people genuinely want adults disabled by autism to have a high quality of life.

Sure it's great that we closed inhumane institutions. But we have utterly failed to provide the necessary alternatives, in any close to the quantity we need.

We have an ever-larger population in need of intensive supervision and care, with wrap-around services and protection, **in need of housing and staff**.

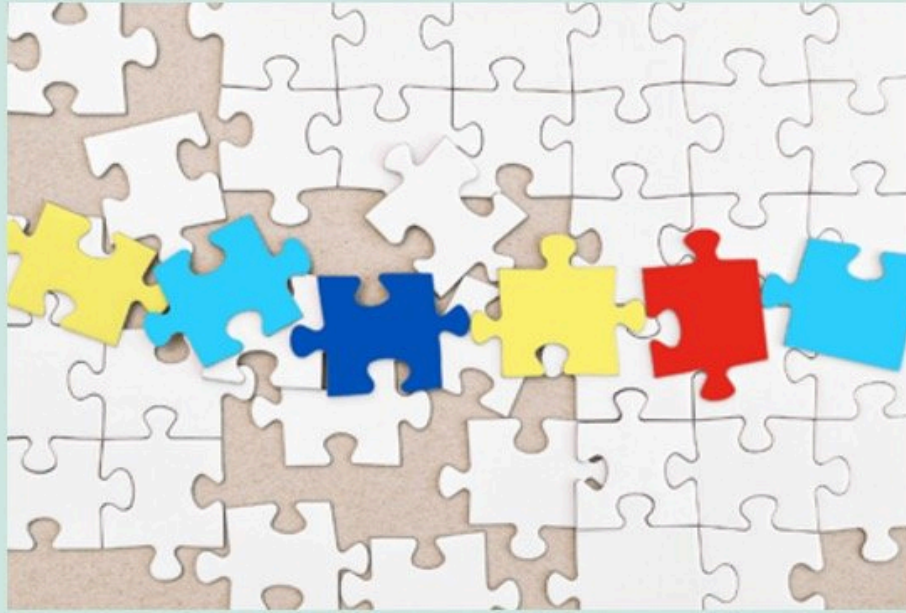


We hear daily from families across the country desperate for these necessary services that do not exist.

There's no way around this. We need to turbo-charge our policies to ensure proper care and housing. **We need all the alternatives:** apartment projects, group homes, farmsteads, co-ops, adult foster care, shared living, and much more.

All the awareness and acceptance and feel-goodism in the world means nothing if we lack options for SUPERVISION, HOUSING and STAFF. We will need a vast new workforce. We must provide training and adequate compensation. We need our immigration laws to align with our desperate need for care workers as we are now experiencing a massive deficit.

But to get there we must be honest about the vast scope of our autism crisis — we cannot legislate what we cannot see, what we cannot define. We must dispel the myths.



I know I may sound pessimistic — autism is a terribly complicated, costly puzzle. But I also have reason for optimism. We are quickly heading to a time when autism touches most families in the U.S, and all these families will demand change. And it's also the great nonpartisan issue — it crosses all races, ethnicities, education and income levels, religions, all political persuasions. We are all in this together.

It's time for us to move past "Awareness" and into "Action." Meaningful action that promises long-term care for all the adults disabled by autism. They can't do it themselves. The Jonnys and the Sophies of the world are entirely dependent on us to create systemic change. They depend on us to get this right.

Thank you.

Jill Escher is president of the National Council on Severe Autism.

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