

Oral Public Comments

**IACC Full Committee
Meeting**

April 19, 2018

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Thank you for having me here today. My name is Debra Cordone, I'm from Buffalo, NY. I'm the mother of James, a 12-year-old autistic child with severe SIB and Aggression.

Before I start, I'd like to say that I am not here to lessen the struggles of anyone with autism. I am the founder and Executive Director of Fantastic Friends of WNY. A not for profit for all individuals with special needs, regardless of age, abilities or behaviors. 99% of our members are autistic, from very high functioning to very severe, some so severe that they require 4 staff with protective equipment at all times. Therefore, I am aware of and do understand the struggles they all face.

When I speak publicly on this topic I use visuals such as photos and videos. Since I am unable to do that here, I stand before you dressed in what far too many parents wear in their homes to protect themselves and their autistic children with severe SIB and aggression. For myself, arm guards and jeans to protect from bites and gouges, a ball cap to prevent getting my hair ripped out, a blocker for when my son comes at me, a call button that goes directly to my sister and/or police department and a bottle of Haldol in my pocket. This is not occasionally but on a daily basis, sometimes several times a day. At times my child requires 4 trained adults to restrain him. I'm sure this is unimaginable to most, if not all of you.

There are far too many families living in crisis on a daily basis. Sibling suffering from depression and anxiety due to their home life. We are failing them.

The worst nightmare, for parents like myself is needing to take our children to the hospital. The lack of training being the main reason. James was hospitalized twice before finally getting him to The Kennedy Krieger neurobehavioral unit, where we remained for 9 months. One of a handful of inpatient units in the United States that can assess and treat a child like James, with waitlists 6 months to 2 years.

The reason for James' hospitalizations was safety, we couldn't keep him safe at home by ourselves any longer. The hospital is an extreme last resort. The length of stay for James was 13 days and 7 weeks. They could do nothing but sedate him, I stayed with him because no one was trained to appropriately care for him. These lengths of stays were actually short in comparison to other autistic children with severe SIB and aggression. Many are hospitalized 6 months, a year or longer in hospitals and psychiatric units where they can do nothing for them other than mechanically restrain and sedate. My husband and myself both required multiple surgeries due to injuries sustained while protecting James from himself.

While one mom is searching for a sensory friendly movie for her autistic child, there is another mom struggling to keep her child from biting her tongue off.

While a mom is searching for a restaurant with food that her autistic child will eat, there is a mom and dad on the floor struggling to restrain their autistic child from putting his head through the wall.

While I am speaking, there is a 21-year old man having his 30th ECT treatment.

These individuals are being left behind and the parents in crisis crying for help are being ignored. The individuals I speak of are not even being advocated for by large, national and worldwide autism organizations.

Respite, non-existent for families like ours, no camps, no after school or vacation programs. We are on our own.

This needs to change and quickly. Funding for research, resources and more in-patient units is desperately needed. How can this crisis be happening in our country?

I started a Facebook page, Fight for James 2 years ago to raise awareness and support other families. It breaks my heart that I get messages almost daily from parents across the country asking for help and guidance. They have nowhere to turn. Doctors that can treat these individuals are far and few between. I beg you to help these suffering children and their families. They deserve better. I also ask that the parent of an autistic child with severe SIB and aggression be added to this committee. They cannot advocate for themselves. They deserve a voice.

Inclusion of Autism Means We All Assume The Burden

Imagine a scene. A 5-year-old boy holding his mom's hand heads into a packed auditorium to see an Elmo show. Suddenly and without warning, he breaks into a full-body tantrum, he starts shrieking at high pitch, pounds his head with both fists, and rams his skull into the floor. Everyone is watching, horrified and afraid, *this kid obviously does not want to go into that show*. And just as they expect them to leave, his mother leaps on top of him full force, pins him to the ground and drags him inch by inch towards the show, obviously against his will.

This child - my child - has autism and an intense fear of unfamiliar places. But he can make it into that show, and when he does, he will have made a small step to changing the course of his life. But it will require what I call "burden-shifting."

The burden begins with me, the parent of the autistic child, to disclose his disability. "My child has Autism, I'm working with him to overcome his fears." That's it, that's all I owe you. And notice that I am not apologizing for his Autism, simply identifying it. Many parents of autistic children will resist this idea: "why should I have to explain anything, my life is already hard enough!" Because a tantrum is an opportunity to educate. I believe we advocate best for our children when we put their autistic behaviors in context rather than let others assume the worst. We advocate best if our words are not angry or defensive, just factual, "My child has Autism, I'm doing the best I can." Because we are not seeking to punish the people who might be our greatest allies, if only they understood.

But now the burden shifts to you, general public. All you bystanders who don't know what to do when you witness the unthinkable. The answer is tolerance – you have a duty not to comment cruelly, not to insist we leave. A duty to temporarily tolerate the screaming even if it makes you uncomfortable. Because if you're uncomfortable for 20 minutes, imagine how it feels for the parent who lives with it.

Given our numbers, public tantrums should be happening daily, hourly. But they are not – because we parents feel so ashamed of tantrums we keep our children locked up at home. In my humble opinion – this has to stop. Because there is no substitute for real world exposure. A child with Autism who's kept at home cannot engage with the world. And if he can't engage, he can't practice overcoming his fears to participate. So if we want people with Autism to become productive and contributing members of society, it must start here. If we want true inclusion, we're all going to have to be uncomfortable for a little while, as we all accept our burden.

Autism Uncensored: Pulling Back the Curtain

Whitney Ellenby

#1 Amazon New Release in Mentally Disabled Education

"...an unflinching exploration of a mother's emotional—and, at times, physical—struggle for the dignity and humanity of her autistic son. A brave book."

—Ron Suskind, Author of *Life, Animated: A Story of Sidekicks, Heroes, and Autism*

DESCRIPTION

"And when in the grips of a public tantrum, amidst the horror and humiliation of him shrieking and splayed out on the floor while strangers recoiled in shock, my mind lurched towards an inescapable truth—that I want out from this nightmare.

I want out from this child.

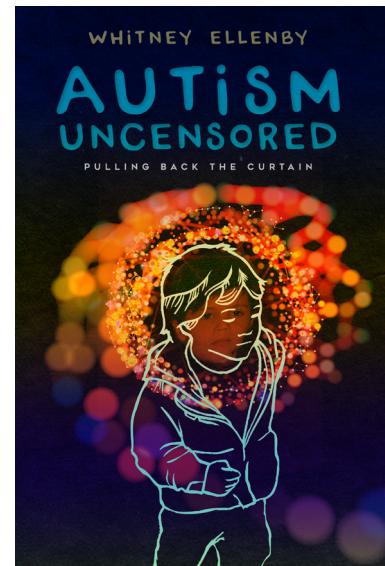
So begins the turbulent ride of one parent's decision, crafted in despair and desperation, to abandon traditional interventions for her autistic son in favor of a "hands on" approach of repeatedly exposing her son to real-world settings. *Autism Uncensored* is an unrestricted portal into the mind of someone who had no intention of sacrificing her career or life for Autism, unaware of the many ways it would irreversibly redefine both. As she clarifies at the outset, "this is not the story of a miraculous breakthrough or recovery," Zack is still very much autistic and always will be. It is instead the true, real-time account of her decision to allow Zack to indulge in the very behaviors that formal therapies sought to extinguish, to disclose Zack's diagnosis in public settings, and to repeatedly expose him to real-world situations and override his tantrums regardless of public ridicule or scorn.

Autism Uncensored goes where no other book dares—revealing the private disgrace and self-blame about having a "defective" child; the near disintegration of marriage; the failure of the traditional behavioral interventions; and the mercenary way in which service providers prey on parents' desperation for a cure. It is a personal manifesto about how a socially integrated life is attainable regardless of whether a child overcomes the major limitations of Autism, sparking a new conversation which goes beyond simply accepting persons with Autism for who they are, but considers pushing them beyond their comfort zones to learn who they are capable of becoming. An unstoppable ride with jolting twists and turns, *Autism Uncensored* will leave you exhilarated, informed and still gasping for air.

AUTHOR BIO



Whitney Ellenby is a former US Department of Justice, Disability Rights attorney whose writings have been published in *The Washington Post*, law review periodical and the U.S. DOJ website. She is the author of "Divinity vs. Discrimination: Curtailing the Divine Reach of Church Authority," *Golden Gate University Law Review* (1996)), as well as an amicus brief on behalf of the U.S. DOJ Disability Rights Division regarding discrimination against mobility-impaired individuals in violation of the Americans with Disabilities Act (ADA). She is the proud parent of a son with Autism and founder of "Autism Ambassadors," a charitable venture through which she runs exclusive recreational events for over 600 families impacted by Autism in the Washington, DC/Maryland area. She is an expert on Autism and has testified before the Maryland Senate, and serves on the University of Maryland Autism Spectrum Disorder Advisory Board. Whitney's expertise is steeped in her extensive disability law background and over 10 years of serving children, teens and adults with Autism through her "Autism Ambassador" events. Her "Ambassador events" have been featured in local t.v. news, *The Washington Post* and *Bethesda Magazine*. Whitney was most recently honored with a "Community Leader" award for her advocacy and dedication to the disability community of Maryland. She has what she describes as a "healthy obsession" with all things Autism.



Publisher: Koehler Books

Distributor: Ingram

PUB DATE: 4/15/2018

SOFT COVER: \$19.95, 978-1-63393-413-9

HARD COVER: \$29.95, 978-1-63393-415-3

EBOOK: \$4.99, 978-1-63393-253-1

TRIM: 6"x 9", 338 pages

FAMILY & RELATIONSHIPS: Autism Spectrum Disorder

AUTHOR WEBSITE:

whitneyellenby.com

AUDIENCE

- Parents, grandparents and siblings of persons with Autism
- General public who are often bystanders to tantrums but have a life-changing role to play
- Pediatricians and diagnosticians who require a parent's perspective
- Special education teachers at all levels who teach about Autism or to students with Autism

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KEY SELLING POINTS

- Autism has captured the national zeitgeist, appearing in Netflix and t.v. series and movies, as autism rates continue to soar to 1 in every 60 children are born
- Book speaks candidly to national thirst for the unguarded truth about how Autism truly looks and feels
- Unflinching candor about subjects most parents are afraid to say aloud including devastating impact of Autism on self-worth and marriage, this providing an outlet for guiltless honesty
- Only non-fiction story that advocates public disclosure of a child's Autism across all social and educational settings
- Only non-fiction story to tackle the mercenary nature of unproven medical interventions
- Demonstrates how to enlist general public in struggle for social inclusion of child with Autism in his community

MARKETING & PR:

- The author's over 600 "Ambassador families" will purchase and review book on Amazon, post on social media and blogposts
- Author is taping essay reading for PBS television to be posted on PBS website and featured on PBS Newshour.
- Book already received major endorsements and currently seeking media reviews from *The Washington Post*, *The Atlantic* and *Bethesda Magazine*; also being submitted to National Writing Contest for non-fiction.
- Author has personal contacts for distribution to: Autism Speaks; Autism Society of America; Autism Science Foundation; JCC inclusion centers; National Institute for Health (NIH); Kennedy Krieger Institute (KKI); Montgomery County Public School System; Special Ed Department at the University of Maryland; local and federal politicians in Maryland; and U.S. Congressional members of the Autism Caucus in Congress.
- Author has secured commitments from six local Indie bookstores and chains; book will be featured in Amazon bookstores in Bethesda, MD and Georgetown, DC, as well as Barnes & Noble bookstores.
- Author will retain professional publicist for greater outreach nationwide.
- Book available for preorder in December 2017 but set for release in March 2018 before Autism Awareness Month in April.

Susan Jennings

April 19, 2018



ORAL TESTIMONY

Interagency Autism Coordinating Committee

April 19, 2018

Hello, my name is Susan Jennings, the mother of a dearly loved young man who suffers with autism, intellectual disability and schizo-affective disorder, named Joey. I am a founding member of KIIDS—Keeping Individuals with Intellectual Disabilities Safe, a grassroots organization of parents, families and friends of the severely and profoundly disabled residents in the Intermediate Care Facilities of Pennsylvania’s Developmental State Centers.

My son, like so many thousands of autistic adults, displays severe self-injurious, aggressive and disruptive behaviors that make living in a family home, an adult foster-care living arrangement, and even a community group home dangerous and unmanageable. His behaviors are unpredictable, physiological in nature, and often preclude him from participation in the greater community vocational, residential and educational settings for his own safety and the safety of others.

Because of a current ideological bias against “institutions” by the powers that be, my son was offered the “community” group home or no services at all. In the short space of four years he was discharged by three different community group homes and thrown into 5 different psychiatric wards (for up to 6 months at a time) under Section 302. In the psychiatric wards, he was forced onto 21 different psychotropic medications in varying combinations that did not resolve his maladaptive behaviors but did result in permanent Parkinsonian-like tremors, Serotonin Syndrome, development of female breasts, insomnia, pre-diabetes, and episodes of psychosis.

Joey was always isolated and segregated in a one-person community “group” home with two staff because the group home would not be able to keep other residents safe with him. He was so lonely he phoned us up to 18 times per day. In one group home, on more than one occasion, Joey would elope into the nearby busy street from the apartment risking serious injury and death.

In one community group home, staff members also called 911 so frequently that I was told the police warned the group home that the police are “not part of your behavioral program” and if the group home staff continues to call police, “the community group home will be fined”. Poorly paid, minimally trained, and poorly supervised staff took him to see the sadistic pornographic movie “50 Shades of Grey” and that deeply distressed him.

Joey was denied access to the community swimming pool because of the potential of behavioral outbursts that community group home staff could not handle in public settings.

The behaviorally challenged are a particularly hard clientele for community providers to handle safely. It is where over-medication, abuse and a shifting burden to local emergency responders can often be found. The trauma and chaos in the life of the severely autistic adult in the revolving door between community services and emergency services cannot be overstated and the financial cost to the taxpayer for the community police, hospital, and psychiatric ward services is exorbitantly high.

In a February, 2017 study in the Journal of Autism and Developmental Disorders, researchers from Pennsylvania State University found that young people ages 12 to 21 with autism are four times likelier to go to the emergency room than peers without autism. They also are 3½ times more likely to be admitted to a hospital floor — at which point they stay in the hospital nearly 30 percent longer.¹ Young autistic adults languish for months in psychiatric wards and hospitals because they have no safe place to go.²

Intermediate Care Facilities (ICF's) can offer the stable, structured specialized care that severely autistic adults need. These congregate care Centers have a therapeutic value. When multiple forms of care are provided in the same building, professionals, stable, justly compensated frontline caregivers, clinicians and nurses work together to solve medical and behavioral crises quickly and safely. Also on-site supervision provides accountability, oversight and safety for the residents.

In the ICF of White Haven State Center, apartments are therapeutically designed with thick walls to withstand the force of behavioral outbursts and minimize sensory triggers of light and noise. There is safety furniture Joey cannot throw and break.

The campus environment is stable, structured and safe and appropriate for Joey. On-campus workshop, swimming pool, gymnasium, chapel, café and other facilities, scheduled parties, dances and events provide a wonderful quality of life for residents. Residents have the fellowship of other residents with similar challenges and opportunities for friendship.

Any plan dependent on the ability of aging parents or adult foster caregivers in family homes or direct service personnel in community group homes to provide round-the-clock care for big, strong adults — often with aggressive, self-injurious or other dangerous behaviors, such as elopement or property damage — will end in predictable tragedy and crisis.

Without Intermediate Care Facilities, where will our loved ones end up? The jails? The psychiatric wards? The hospital emergency rooms? The streets? The chaos and suffering in the lives of severely autistic adults will be unimaginable, the taxpayer costs will be too high to bear and the inhumanity of denying our loved ones the care that they need is unworthy of a civilized society. There needs to be a place to go - when there is no place to go.

I implore the IACC to advocate for a full continuum of residential services to include the badly needed Intermediate Care Facilities and other forms of specialized congregate care like farmsteads, so our loved

ones who are on the most profound end of the autism spectrum can choose the residential services that they need to have a safe and happy life.

Sincerely,

Susan Jennings

Mother and Co-guardian of Joey, White Haven State Center, PA

KIIDS – Keeping Individuals with Intellectual Disabilities Safe, www.thekiids.org

1. Adolescents with Autism four times more likely to visit Emergency Department

<http://news.psu.edu/story/453233/2017/02/28/research/adolescents-autism-four-times-more-likely-visit-emergency>

2. Nowhere to go: Young people with severe autism languish weeks or longer in hospitals

https://www.washingtonpost.com/national/health-science/nowhere-to-go-young-people-with-severe-autism-languish-weeks-or-longer-in-hospitals/2017/09/23/25333dfc-997c-11e7-b569-3360011663b4_story.html?utm_term=.2ae0d2622e34

See Also:

Autistic Man, 21, Abandoned By Family, Has Spent 5 Months at Manchester Hospital As State Declined Responsibility

<http://www.courant.com/news/connecticut/hc-ct-news-disabled-man-languishes-manchester-hospital-1223-story.html>

Autistic Man, 21, In Group Home After Languishing For 5 Months In Hospital Emergency Department

<http://www.courant.com/news/connecticut/hc-news-disabled-man-languishes-manchester-hospital-folo-20171226-story.html>

Autistic Man Dropped Back At Hospital Emergency Room By Group Home

<http://www.courant.com/news/connecticut/hc-news-manchester-autistic-man-back-emergency-room-1228-story.html>

Autistic Man's Abandonment In Hospital Emergency Room Is Tip Of Deepening Problem

<http://www.courant.com/news/connecticut/hc-news-autistic-man-abandonment-statewide-crisis-1229-story.html>

An Intermediate Care Facility was the solution for my severely autistic adult son, Joey.

EXCEPTIONAL PARENTING MAGAZINE - Joey Jennings Story

<http://reader.mediamobile.com/epmagazine/issues/202487/viewer?page=40>

"THE LEAST OF THESE" Video

https://drive.google.com/file/d/1By-LwXbDkr-H3nKSc7MVbMn-Ti_6_uc2/view

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Cheryl Smith

April 19, 2018

Autism and Aggressions

Cheryl C. Smith

April 3, 2018

I am Cheryl Smith from Salt Lake City, Utah. I am very involved with autism in Utah – we have a non-profit called the Autism Council of Utah, I'm on several boards and committees, and I'm involved with educating legislators and helping to create policy. I suppose what makes me a real expert on at least one person's autism is my son, Carson, who is considered to be on the severe end of the autism spectrum.

Every day, in thousands of homes everywhere, there are individuals who have autism who have episodes of explosive emotional overload when they physically hurt themselves, and those around them, as well as destroy property. These individuals are delightful for the vast majority of the time, but when something triggers them, the level of violence they are capable of is frightening.

Parents in the middle of these situations involving aggressions usually don't talk openly about it because of shame or fear. We go through life trying to get people to accept our children, to hire them, to be their friend, to give them a chance at a regular life -- not to be afraid of them. The world can be cruel and unforgiving to people who are different. Add aggressive behavior into the mix and it is taken to a new level.

Because physical violence and aggressions are rarely talked about, policy makers and providers may not understand the scale of the problem. When things are hidden away services aren't funded and developed that may address the issues properly. Funding sources do not take into consideration emergency placement or respite when families are in danger, giving them no options for immediate help. Aggressions can make it virtually impossible for a person with severe autism, or his family, to function well in typical settings like school, the grocery store or the doctor's office, and can limit access to treatment and services, and increase need for medical interventions.

According to some researchers, the extreme behaviors seen in severe autism are very often the result of frustration, sensory overload, or physical pain. Because people with severe autism have such a hard time communicating their needs verbally, they may find expression in behaviors that can be scary. If the behaviors can't be addressed or managed, they can actually be dangerous; in many cases it becomes impossible for parents or siblings to live safely with a severely autistic teen or adult.

Carson is 19 years old, weighs 300 pounds and is about 6 feet tall. I describe Carson as 95% teddy bear, and 5% tiger, and you never know when the tiger side will appear.

Stephen M. Edelson, Ph.D. said, "When I speak to parents and professionals on treating behavioral problems, I typically say up front that there are no easy and quick fixes to reduce or eliminate severe behavioral problems, which include: self-injury, aggressiveness, severe tantrums and destructiveness." Sadly, this statement is true. Not only are there no easy fixes, but rarely a fix at all. Carson's doctor has prescribed medication for his outbursts. The problem is that they don't kick in for about an hour, after

the meltdown is over, then they just make him tired for a few days. We have also been doing behavioral interventions since his diagnoses at 2 ½ with some, but little results.

Carson has intense meltdowns causing severe injury to himself or others, usually me. He bites himself ripping flesh. He actually had to have surgery to graft skin onto his hand where he continually bit himself. We had to watch him 24/7 so that he didn't reinjure it by pulling out the stitches or re-biting it. He then moved to the other hand and up his arm.

The first time he bit me I reached up from the back seat of the car to avert him from jumping out. I didn't go to the doctor. I was afraid of what they would say when I told them how it happened. I was afraid of the unknown, would they take him away? That wound got infected and ultimately I had to go into the hospital to get IV antibiotics for three days. I have had to return to the ER on several occasions for stitches and antibiotics. I now know they just shrug and stitch me up.

He will bash his head on the floor and the wall, breaking off teeth and making holes in the sheetrock. Worse than the holes is the damage he causes to himself. Some times he will lie on his back and roll his head under his body. It looks as though he will break his neck. He pinches, screams and cries, and destroys property as well when he is out of control.

What is more sad to me than being hurt and even seeing him hurt himself, is what must be going on in his head to make him act out that way. It breaks my heart to see him in so much mental anguish. After his meltdown he always pets the floor where he hit his head, the furniture, my arm, saying "soft". He has few words, but he will say, "Sorry mom, sorry Carson." He doesn't want to meltdown, and he is very sorry afterwards, but he just can't help himself.

There is no way to predict the meltdown, causing us a kind of PTSD. We are exhausted and worried all the time. We avoid community outings, and anything that may set him off. He had a meltdown shopping at Sams when he bit a shopper trying to help and hit his head several times on the cement floor. Once at a restaurant he tipped over the entire table raging and biting himself. Our grandkids are afraid of Carson; we cannot have our other children over if he is at home or awake unless someone stays with him in another room. We don't take him to other people's houses, and don't have people over to ours. Now that he is so big, I live in fear that law enforcement will be involved and misinterpret the situation resulting in a horrible outcome, like incarceration or even death.

Recently we took Carson to Disneyland where he reached out and pinched a girl's arm. They did call the police. I don't blame the family for being afraid or concerned. The officer took all our information. Luckily Carson was calm so no intervention was required. My husband and I take Carson and a helper to Disneyland each year, it's his trip and he loves it, having us write the dates on the calendar and looking forward to it all year. He has never aggressed toward others there before. I know he cannot hurt people, so what is the answer? Do we keep him locked at home with us?

The ultimate dread for us, and for every parent of a special needs adult, is no one will love and take care of him like we do. Where will he go? Who will care? Where will his safe shelter be?

We are currently working on a life-skills, day program through the Pingree Autism Center of Learning in Salt Lake City for those adults on the spectrum who require more supports. Along with behavioral supports, the program will consist of a number of activities to promote skills in the areas of pre-vocational, vocational, and daily living using evidence based curriculum and therapies in these areas:

- Academics
- Library
- Culinary
- Agriculture
- Arts & Crafts Studio
- Fitness Education
- Home Living
- Vocational Training (general)
- Social and Leisure Skills

Individuals will learn and practice skills in the Center in order to use them in the community. For instance, they may learn to use exercise equipment for fitness education and go on to use the community recreation center, or learn to grow vegetables in the green house in order to sell their produce at the farmer's market, or make meals with it.

Research on adults is sparse, programs for adults are hard to find, and quality programs for adults who require significant supports and have behaviors is virtually non-existent. This program will allow our adults a safe place to go and continue learning with trained professionals who will help them with their behaviors.

We would also like to include housing with this project, however the Medicaid Settings Rule has made that impossible for the time being. The Settings Rule makes sense for the higher functioning adults, but not for our population. These adults on the spectrum who are considered severely affected need more supports, may never be employed or make independent decisions, and need safety measures in place. It's extremely frustrating to try and serve this underserved group with roadblocks like the Settings Rule.

Autism never sleeps. It doesn't go on vacation, it's there on Sunday's and holidays, it never takes a day off. Autism never takes a break, therefore, neither can we.

I appreciate you letting me share my story. Thank you for continuing to look at ways to improve the lives of people with autism and their families.

Cheryl C. Smith
[PII redacted]

In trying to determine how many adults requiring more supports in Utah would benefit from our day program at Pingree, URADD provided this information.

The Utah prevalence rates as reported by the Utah Registry of Autism and Developmental Disabilities are as follows:

- Identified **10,375** individuals aged 15-61 in Utah with ASD
 - 61 is the oldest person we have identified in Utah with an ASD diagnosis
 - Conservative estimate is that 1/5 of these folks have co-occurring ID then **2075** people in Utah have ASD + ID
 - Recommended range for ASD with co-occurring ID is probably **2075-3458** (a fifth to a third of adults with ASD)

- Identified **4,392** individuals aged 15-61 in SLC with ASD
 - Conservative estimate is that 1/5 of these folks have co-occurring ID then **878** people in SLC have ASD + ID
 - Recommended range for ASD with co-occurring ID is probably **878-1464** (a fifth to a third of adults with ASD)

<http://utahautismregistry.org> Utah Registry of Autism and Developmental Disabilities

https://www.autism.com/all_steve_edelson_bio Autism Research Institute

<http://foa.sagepub.com/content/early/2013/01/18/1088357612472932> Sandra Hodgetts

Living with Autism as a Parent, Scientist, and Advocate

Daniel J. Fairbanks, Ph.D.
Dean of the College of Science and Professor of Biology
Utah Valley University

We excitedly anticipated the birth of our third child. My wife's pregnancy was excruciatingly difficult, much of it spent in bed with pain, weakness, and never-ending nausea. The thought of welcoming a lovely baby into our home helped soothe her suffering. Late at night, on June 12, 1992, the labor began, and our son Michael was born the following morning. From the start, things did not appear right. During his first wellbaby visit, just a couple of days after his birth, our physician was concerned that his testicles had not descended, and his left kidney was swollen and palpable. As loving parents, we were worried about our child's health. Little did we know then that these health issues would become the least of our worries. Within a few days his testicles descended normally. A pediatric urologist, an expert who had published extensive research on the kidney condition my son had, diagnosed him with hydronephrosis; a kinked ureter was causing urine to back up in his left kidney. But it was not serious, and it could wait. Two years later, major but nonetheless routine surgery corrected the condition. He fully recovered and he has never suffered from it since. In fact, throughout his life his physical health has been excellent. He is now twenty-five years old: tall, fit, strong, and able to outrun most everyone.

The earliest signs of some sort of cognitive disorder began to appear quite soon, unlike many autistic children whose symptoms appear when they regress after several years of normal progress. He did not cry like most babies, and was not as alert as it seemed he should be. We reported our concerns to our physician, who assured us that each child is different and that he would catch up. He didn't. As he grew older, he could not hold a bottle like most babies his age, and when it came time for him to crawl, he did not. We put him on his hands and knees, and while I moved his legs, my wife moved his hands, forcing him to crawl. Day after day, week after week, and month after month, we persisted until he finally learned how to crawl on his own. But he never was much of a crawler. At that age of two, he still could not walk. Again, I held him up while my wife moved his feet. Finally, by age three he was walking, clumsily. He did not play with toys like other children his age. He simply held them and stared at them. By the time his peers were speaking in cute sentences, he had yet to utter a single word. Late in his third year, our physician diagnosed him with PDD: pervasive developmental delay. We sought help through the school system and enrolled him in an early intervention program. It was not long before PDD was no longer his diagnosis, and the word autism became a part of our daily vocabulary. Most of the time, he was pleasant, usually confined to himself, running sand or water through his hands for hours at a time. Each day, however, brought at least one tantrum and some sort of uncontrolled behavior. We were devastated.

My wife and I were both university professors with doctoral degrees, and highly devoted to our careers. Now, our child became our principal and unending focus. We gave what we knew we had to give to keep our careers going, but were severely restricted. Our two older children suffered from parental neglect as all of our parenting time was devoted to Michael. My mother was deceased; my father had remarried and was managing a new family in another state. None of my siblings lived nearby. My wife's parents wanted us to institutionalize Michael from the start, not realizing that institutionalization was not an option, even if we had wanted it, which we did not. A few hours with my son, and even the most well-meaning family members and friends gave up on helping us. No one was willing to create family activities that included him. The tension and criticism from extended family at our inability—perceived by them as unwillingness—to participate in routine family activities added to the stress that had overtaken our lives. We sought government assistance, and were placed on a waiting list—years long we were told, correctly as it turned out. We spent much of our own income hiring caregivers to provide some respite. Friends and family were willing to be with us, as long as Michael was not present. We faced our constant challenge alone.

By the spring of 2008, Michael was almost sixteen. He could speak about thirty garbled and barely uttered words that only we could understand, a few nouns and adjectives. But most of the time he was entirely non-verbal. His IQ was estimated at 47 and on the scale of autism, he was classified as being in the lowest one-percent in terms of functioning. He is still at that severely low level. Although most of the time, he was happy and pleasant, he could be dangerously violent. He would on rare occasions attack my wife because he found her screams of terror to be hilariously funny. He was entirely innocent, incapable of feeling empathy or remorse. The violence became severe enough that we began to look for residential options. I considered finding an apartment and moving out to live with him alone to protect my wife and our son who was a couple of years older than he was.

There were no options for residential care in Utah, where we lived at the time. My oldest son was employed full-time at a residential school for autistic teens in Massachusetts, and it seemed to be a remarkably good option for us. I began applying for positions at universities in Massachusetts, and accepted an offer as a professor and department head at the University of Massachusetts–Amherst. It appeared that our dilemma would be resolved, and my son would receive the residential care he needed. By then I was an academic dean at a university in Utah. I resigned my position and moved to Massachusetts with my son. It was August of 2008.

The great recession, economic downturn, or whatever pejorative name we might call it hit just as we moved, and government support for people with disabilities evaporated even in states considered to be the best in the country, Massachusetts among them. I will not go into detail, but our experience was a nightmare. We hired an attorney, and for a while it looked like we might succeed. But in the end, all opportunity faded. After many

telephone calls, and interventions by attorneys, a possibility for residential care opened up in Utah. Another university in Utah, not the one where I had been previously employed, offered me a position. I drove my son across the country and placed him in residential care, not certain that the funding would last. We eventually worked out an arrangement whereby we paid for part of my son's care, and a combination of Medicaid waivers, state funding, and the school system paid for the rest. It was January of 2009.

By then, we had sold our home at a loss, due to collapsed real estate values, and lost all of our equity built over twenty years. All of our savings had been depleted. We withdrew retirement funds, paying a penalty for early withdrawal, and my father-in-law provided some financial help. But finally, my son was in excellent care, and in a good situation. Though we still have problems with violence, danger, and frustrations, he has been with loving and capable caregivers for the past nine years. He now lives with a young couple who are large and strong, and love him like we do. He visits us every Sunday, and is living a happy life. He is almost twenty-six years old, but functions at about the level of a two-year old. He cannot work, has minimal cognitive ability, requires 24-7 supervision, and will undoubtedly be that way for the rest of his life. We continue to advocate for him through legal means, with the support of his caregiving family, and a dedicated and knowledgeable support coordinator.

His situation works because he has funding from a mixture of sources. We meet regularly with state officials, his caregivers, his support coordinator, our physician, and others to ensure that his care continues. It remains the principal focus of our lives. With good employment and careful resource management, it has taken us nine years to return to some sense of financial stability. The nightmare is mostly over, for now. We hope it will never return, but the lingering fear that it could, should an accident happen, or if his support is curtailed, continues to haunt us. Our son's autism will continue to be the principal focus of our lives, probably until we die. In fact, preparing for his future after our passing is now the major consideration of how we are planning for our family's future.

His autism has had surprising and unexpected benefits. I speak at events, give art demonstrations, and consult with experts around the country on autism. My wife and I are both professors at Utah Valley University, which recently established a Center for Autism, much of it based on our input and involvement. I am a geneticist, and have directed some of my research toward human genetics and autism. I carefully follow advancements in the science of autism, and in the development of promising medical treatments. As a scientist, I am encouraged by what I see and read as promising discoveries that are unraveling the mystery of autism are progressing at an astounding pace. The professional conversations I have with colleagues who are on the front lines of research give me great hope that, based on a better scientific understanding of this condition, we may be able to better treat the symptoms of autism, and, importantly, reduce its incidence in the future and perhaps, someday, defeat it. I fear that our country, which has been the world's leader in autism research, could fall behind. I am hopeful in

the worldwide scientific and medical effort to discover its causes and genetic and physiological basis, and to find effective treatments informed by cutting-edge science, and not by fad or anecdote.

For adults with autism, we must fight on several fronts. We must support scientific and medical research. As a professional scientist, I have never been more hopeful for achievements on this front. We must support sufficient and loving care for those with autism as they grow older, and as their families lose the ability to adequately care for them. Long waiting lists, inadequate funding, and legal obstacles devastate countless families. Though we suffered, we emerged into a functional and workable situation, with government employees who truly care about our son and help provide for him, and sufficient resources to see to his needs. I shudder to think of what might have happened had we not had the level of education and financial stability that allowed us to emerge from what could have been absolute ruin. Lastly, we must continue to raise awareness of autism, what it is, what it is not, and advocate for not just acceptance but loving embrace, support, and inclusion of those who are now entering adulthood. My son will never be gainfully employed. Thankfully, most who are on the autism spectrum can lead productive lives with employment, if managed and administered appropriately. I am proud to be a parent, a scientist, and an advocate for those with autism. I remain optimistic in the face of the greatest challenge I could ever imagine facing that we will continue to make progress on all fronts.

Jalynn Prince

April 19, 2018



MADISON
HOUSE
AUTISM
FOUNDATION

Oral Comments

Meeting of the Interagency Autism Coordinating Committee - April 19, 2018

Respectfully submitted by JaLynn Prince, President & Founder Madison House Autism Foundation

Date: April 10, 2018

Three years ago, Madison House Autism Foundation (MHAF) moved forward with marking April 21 as Autism After 21 Day, having it noted in Congress, state legislatures and many local governments.

Our awareness of the need for this day to be designated during national Autism Awareness month came after hearing two phrases over and over again, first from the parents, "***What will happen to my adult child when I am no longer around?***" and second, when people in the community, locally and nationally, learn about the mission of Madison House Autism Foundation, they often comment, "***I've never thought about adults having autism.***"

After working in the arena of adults with autism for the past decade, as one of the few organizations looking at lifespan needs of adults on the autism spectrum, we saw the need to take a step back and educate the country, community by community, that there are valuable individuals in their neighborhoods, their communities, their places of worship and their workplaces whom they may walk past every day but may not see, let alone know how to engage. No two people on the spectrum are alike, just like the general population, and they have unique talents, abilities and challenges much like everyone else.

We hope to bring each community into an understanding that adults with autism have a wide range of capabilities and a wide range of needs. Many people want to help others, but if you don't realize people with such needs exist, how can you open your world and lives to include them?

We shine a light on the lives of adults with autism so we can make a place for them in our communities and workplaces. Many employers tell us how much it has enhanced their businesses and employee culture when autistic adults are successfully on-boarded in their workplaces. Others tell us how they have developed more patience with clerks, servers and others when they have been made aware that some of these individuals may be on the autism spectrum. Other people have seen autistic adult relatives or next door neighbors in a new light and this new understanding has relieved anxiety all the way around.

April 21 is their day and we hope that all of the days to follow will be filled with greater inclusion and understanding.

Video:

Here is the link to the video: <https://youtu.be/Nq5YY6q7vsY>

Joe Joyce

April 19, 2018

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Joseph Joyce is the Chairman of the Board of The Autism Society of America.

[PII removed]

David Joyce is 19 years old. Thank you to the IACC for giving him time to tell his story. Elise Joyce, and I, Joe Joyce, will assist David in articulating his public testimony.

David has autism. He has severe self-injurious behaviors, and he is Non-Verbal.

Despite these challenges, David has become an ambassador to raise awareness and acceptance for autistic individuals. He recently became a member of the Autistic Self Advocacy Network (ASAN).

Elise and I are committed to David being his own self-advocate, in his own unique way. David, Elise, and I have worked tirelessly to learn how to communicate with each other as effectively as possible. We would not be standing here today if we did not fully believe that David wants us to help him to tell his story on his behalf. David respects, and is more patient, with people who sincerely try their best to communicate with him. Unfortunately, too many people fail to even acknowledge him.

David has lived a life full of obstacles, and he continues to strive each and every day to overcome these challenges.

David has brought an immeasurable level of awareness and acceptance about autism to countless number of people, and has become a tremendous source of inspiration to many. My employer, Keystone Insurers Group, adopted Autism Awareness and Acceptance as the corporate cause in 2009, in honor of David. Since that time, Keystone has held numerous fund-raising events across the country, and has raised approximately \$1 Million for local schools, Autism Society Affiliates, and The Autism Society of America. More importantly, David allowed me to speak at each event to tell the story of David's journey. Not being an autism professional, I spoke from the heart, and as a result, countless numbers of people became exposed to autism, and became advocates in their local communities. The level of acceptance of autism was raised throughout the country, and this young man, David Joyce, is responsible for making it happen.

Here is David's story:

At an early age, David began a frightening degree of Self-Injurious Behaviors (SIB's). Elise and I were terrified of potential permanent damage that he could bring upon himself. Through full-fledged fist strikes to his head, David inflicted bloody nose, swollen eyes and ears, and severe bruising to his face, despite our best efforts to help him and prevent such damage.

David's SIB's averaged 8,000 per day.

In addition to his own fists, he would bang his head into walls, windows, and his own shoulders. He would bite his hands until his skin was raw. Of course, Elise and I would always attempt to intervene, and would often get in the way of David's self-inflicted activities. As a result, we have suffered many injuries, bites and bruises ourselves, which we refer to as loving wounds and warrior badges.

The truth of the matter is, David never “wanted” to do these things. They were uncontrollable. Back in the days before assistive technology became prevalent, David communicated his desires through his eyes and facial expressions. David has the most beautiful and expressive blue eyes that you will ever see. While in the midst of a meltdown, David’s eyes would lock with ours, and his eyes would be pleading to us to find help for him.

And help him is what we did.

At age five, Elise Joyce began taking David on a 180 mile round-trip to Kennedy-Krieger Institute (KKI) for treatment in their outpatient unit two times per week. Unfortunately, the severity of David’s situation continued to worsen. It was no longer safe for us to drive him anywhere without another person in the back seat with him.

KKI then recommended that David be admitted to their inpatient unit. KKI, part of Johns Hopkins, is the most renowned neuro-behavioral unit in the world for autistic individuals with severe self-injurious behaviors. As such, there was a frustratingly long waiting list.

Finally, at the age of 7, David was admitted to the KKI in-patient program. The goal was for David to reduce his Self-Injurious Behaviors (SIB’s) by 90% from 8,000 per day to 800 per day. The projected timeline to accomplish this goal was six months.

KKI then embarked on a lengthy series of behavioral treatments and medication trials. Unfortunately, nothing was working, and David’s behaviors continued to escalate. We desperately wanted David to return home and live with our family, however, we were extremely concerned about his personal safety.

Finally, after 18 months in the inpatient program, KKI recommended that ECT be utilized to help David. We were extremely reluctant to attempt this strategy. We then spoke with Dr. Max Fink in New York, who assured us that ECT is far less hazardous than the medications that David has been putting into his body over the past four years. We prayed, and we also discussed this idea with David. David communicated to us through his eyes and facial expressions that he wanted us to help him. We realized that we had no other option. David wanted a solution. He did not want permanent damage or death resulting from his severe SIB’s. He wanted to safely come home and live with his family. We therefore made a collective decision based on the available information at the time, and the advice of professionals.

KKI and Dr. Wachtel literally saved David’s life through these treatments. In the days following these treatments, David’s daily SIB’s changed from thousands, to almost zero! David was cleared to return home at age 9. He continued receiving the treatments until age 13, when he had a physical condition (unrelated to autism) called SCFE, where his femoral bone became detached from his growth plate. David still walks with a pronounced limp today from that experience. It became impossible to continue to transport David for his ECT treatments, and we discontinued the treatments.

Since coming home from KKI, David’s case has been under the care of Dr. Richard Foxx. Dr. Foxx assembled a team of Therapeutic Support Staff, BCBA’s, and educators that enabled David to live at home and continue to thrive.

David began learning to communicate with the Picture Exchange Communication System (PECS). This process was modernized in the past few years where David now uses an I-Pad to communicate. He has

it with him today, and takes it everywhere he goes. David uses the I-Pad to communicate his wants and needs. He is also learning to convey emotions with the I-Pad. This ability to communicate has reduced his frustrations from an inability to communicate. Today, David's SIB's usually average less than 100 per day.

David is here today with us because he is a Self-Advocate. We discussed this with him, and he wants to be out-front in the community, raising acceptance for all those with autism.

You will notice that David wears protective equipment. This equipment was prescribed by his doctor. He wears arm protective devices that he calls "stays." David decides when he wants to wear the stays. We do not decide that for him. By using his I-Pad, David will tell us that he wants "Stays ON" or "Stays OFF". We then follow his instructions. He often wants to wear his stays because they help him to self-regulate. When he is ready to remove the stays, he informs us accordingly.

David also has a helmet that is prescribed by his doctor. David usually only wears the helmet when he is experiencing a meltdown and a severe burst of self-injurious behaviors. Once his behaviors begin to slow down, he will request through his I-Pad "Helmet Off." We will then use a visual timer, and advise David that this timer is for his request for "Helmet Off." David then uses the timed period to calm down, and when the timer goes off, and David remains calm, the Helmet is removed as David has requested.

In closing, I would like to also say that, in my present volunteer role as National Board Chair for The Autism Society of America, we work every day to help to improve the QUALITY of Life for ALL autistic people and their families. David traveled today to this IACC meeting, to help to spotlight the issues that he faces in being a non-verbal and self-injurious self-advocate. Hopefully, more focus on people like David can help to bring the resources and support services necessary throughout the Lifespan. However, all autistic individuals across the entire spectrum face equally compelling challenges on a daily basis, and my objective as Chair of ASA is to help all autistic individuals achieve the greatest quality of life possible, and have a life of dignity and respect.

We are very proud of David. He has made amazing strides over the past 15 years. David has had many IEP meetings. For David, IEP stands for Integrity, Energy, and Pride. David is very proud of himself and his accomplishments. He is very social and loving. He loves to meet people. As mentioned previously, David is an ally for everyone on the autism spectrum, and he is a strong Self-Advocate. I would encourage all those on the panel and in the audience today who are Self-Advocates on the autism spectrum to please come up and introduce yourself to David. He would love to meet you, and I can guarantee that you will be happy to get to know him.

Thank you.

Sincerely,

David Joyce

Joe and Elise Joyce

Harrisburg, PA.

Upon sitting down to write this, many emotions surface. Anxiety, frustration, anger, and sadness to name a few. The past several years of my parents life and James' have been an absolute nightmare.

My brother, James Cordone, was adopted at a very young age by my parents. They were so kind to take him out of a very bad situation and bring him into their loving and nurturing home. They were older, past the age of raising children, however they saw the need to give James the love and care he needed.

Fast forward a couple years later, aggressive behaviors including head banging through walls, windows; biting, hitting, punching etc sadly became part of every day life. My parents had no business restraining James, my Mom needed knee surgery (she had a history of several back surgeries) and my Dad had neck and arm surgery (as well as a history of Lymphoma). My parents were prisoners in their own home. Their grandchildren could not go to their home because of this dangerous environment. My parents could not go to family functions or even have time to themselves, because taking James out of the house was incredibly risky. And no, I'm not exaggerating. It was absolute hell. Forget family holidays, we weren't able to be together as a family. I recall Thanksgiving 2015 being away from my 2 year old son so I could help my parents as they had no aid to help with James. Luckily I was there, as it took three of us to restrain him from punching and biting himself, as well as doing the same to one of us. Thankfully, there was a relative in the area who could quickly get to the house to administer the Haldol into his mouth to calm him. That was the only option as there was no possibility of one of us letting up on restraining James. These words cannot begin to convey how heartbreakingly tragic this was. It was devastating to see bruises and teeth marks on my parents, sad to know this was their every day struggle and the anxiety that came along with it. It was painful to witness James endure these episodes, come out of it, and hug us. Everyone suffered, James, my parents, my siblings and I, and our children.

The most devastating moment, and I still have this clear in my mind was Christmas Eve 2015. We were so fortunate to have one aide so my family and I could spend some time together. Everything was going well and then James spiraled out of control with a need for five of us to restrain him. Yes, five adults to restrain this child. This went on for some time, with finally the only option being an ambulance to the hospital. When we arrived at Childrens Hospital, it still required five of us, the ER doctor, the nurse, myself, my sister and my Mom. No one knew what to do with this poor child. The scene could be comparable to something out of the Exorcist movie and again, not an exaggeration. That evening, I recall my Mom standing in that hospital hallway crying, on Christmas Eve. This was the most heartbreakingly tragic moment of my life to see my Mom crying with no end in sight. It was devastating to see James suffer through this, not knowing what is going on in his mind. Being a PA, I thought, how are the meds not controlling this, how is this so severe every day? I don't understand why this can't be controlled. We need help. This poor child sat in that hospital for seven weeks before finally getting a bed at Kennedy Krieger. To have to fight with insurance on top of it was mind blowing. How sad to think there are so many children waiting for a bed and there are not nearly enough. I've seen first hand that the hospital staff do not know how to care for these individuals, however this is not their fault, there needs to be more training. Thankfully, James has been blessed with an excellent Psychiatrist, Dr. Michael Cummings, who has been an incredible advocate for him, my family and the autism community. Autism has a spectrum, mild to severe, therefore all medical professionals, first responders etc. need to know how to manage all individuals on that spectrum. There are not nearly enough services to help these families.

that are struggling every single day. These families are barely making it through their day, there needs to be more support, with in home staffing and hospitals like Kennedy Krieger. My hope is people become more aware of the range of the autism spectrum, especially the most severe, with anticipation that more services become available to assist these individuals and their families. Thank you for your time.

Sincerely,

Danielle Augustino PA-C

(Autism Sibling and Physician Assistant)

Lisa Wiederlight

April 19, 2018



**Public Comment
Provided by Lisa Wiederlight, Executive Director, SafeMinds
April 19, 2018**

It is my pleasure to speak to the you and the members of the IACC on behalf of SafeMinds, a national nonprofit organization focused on ending the autism epidemic by promoting environmental research and effective treatments. A group of parents dedicated to identifying the environmental causes of the autism epidemic started our organization 18 years ago, and we remain dedicated to increasing the safety, health, and independence of people with autism and their families.

The problems facing the autism community are very serious and require urgent responses. Since the IACC' was created, it seems the problems facing people with autism and their families have worsened. Autism prevalence has increased with no identified cause. We also don't have any widely-recognized causes of autism, either.

It is imperative that the IACC focuses on urgency and accountability. Given the size and scope of the autism crisis in the United States, I was dismayed to find that the only strategic research plan available from the IACC is from 2016-2017. Do we not have a plan for this year? We're in the second quarter of the year already. Don't the taxpayers and other stakeholders deserve to know how we are going to affect this situation this year moving forward?

There are 23 new objectives in the 2016-2017 Strategic Research Plan, which recommends doubling the research budget from \$343 million in 2015 to \$685 million in 2020. Unquestionably, more must be spent on research, services, supports, and the like, but what justification is given? Why does the strategy fail to identify and quantify outcomes that can be measured and compared over time? We need a research plan that will support policies and programs that will ultimately make a significant difference in the everyday lives of people with autism and their families.

By way of example, one of the 2016-2017 Strategic Research Plan's objectives is to "reduce disparities in early detection and access to services." Reduce by how much? From what level to what level, over how much time? In which populations? Other terms used in the strategic research plan include, "understand" and "explore."

Another example is, "What is the biology underlying ASD" and then the objective is to "support research to understand the underlying biology of co-occurring conditions in those with autism." How is "Supporting research" measurable? Perhaps "Identify 'x' many biological factors that would contribute

to the development of seizure disorders”, or gastrointestinal disease, or suicidality, or wandering, or sleep disorders?

If the IACC instead coordinated research that supported the policy goals of an Autism Strategic Plan, or the goals of participating agencies, our community would see significant changes. For example, one goal could be to reduce mortality rates by X percent in the next five years. The research supporting that measurable goal would identify the causes of and treatments for suicidality and seizures, which are the main reasons for higher autism mortality rates. Then, the agencies responsible for addressing them could measure the effects of policies and programs designed to reduce autism mortality over time. The IACC could also coordinate research into the gaps in knowledge and roadblocks to achieving that goal.

The same can be said for autism prevalence data. How can this data be used, if at all, toward informing policy objectives toward a measurable goal? For example, how many people with autism are over the age of 18 who can be employed? How many are employed, and what services are needed to decrease unemployment rates among people with autism by five percent in the next three years? What should and could that percentage be? How do the agencies represented in the IACC collaborate with the members of the IACC to formulate policies, programs, and metrics toward a stated goal that will positively affect our community’s safety, health, and independence?

This is the necessity of our times, in which

- The majority of people with autism experience gastrointestinal disease.
- A higher percentage of people with autism have seizure disorders than in the general public.
- People with autism are nine times more likely than their peers to ideate suicide.
- The unemployment rate among people with autism is at 80 percent.
- Autism is costing our country \$500 billion.

Those are only a few examples of the unintended policy consequences of ignoring the urgency of the autism crisis facing our country, while not taking a measured response with accountability. SafeMinds hopes that the IACC presents a more accountable, effective, and outcome-based response for now and the future of our great nation.

Thank you.

Tara McMillian

April 19, 2018

Hello, my name is Tara McMillan and I have a son who is impacted by Autism. More specifically he developed encephalitis after his “catch-up” vaccinations at 17 months of age. This medical emergency was not treated as an emergency but a neglect. Yet because we were not informed, and not educated my son suffered brain damage without treatment. Following this brain damage, he lost all ability to speak.

He is now 12 and he does not speak. He can communicate in other ways, but his abilities are few because of what happened to him in that doctor’s office. Do we have compensation—no- do we have help? Only because a mother and father don’t give up. I am here today to speak about the recent article in Time magazine discussing the study published in JAMA claiming that children with autism were unprotected from vaccine preventable diseases.

The problem with this discussion is that the children with autism were vaccine injured. Parents of children with autism are not going to continue to go back to the very thing that caused their child’s brain injury.

Instead of funding a study to better understand why parents refuse to put their children in danger of ACIP guidelines—scientists should be asking what is different in the families of children with autism. Why are they not vaccinating? That is the question that should be asked—and the answer should be pursued without prejudice from the scientist.

Cause and effect in science can be documented. We have documentation of our children’s vaccine injuries. Thousands of children have been injured by vaccines, and therefore the parents no longer vaccinate. I implore you to seek out the reasons why vaccines harm instead of seeking to make our children the scapegoats for the failures of the vaccine program in The United states. We are a shame to other countries because we are the most vaccinated citizens among children, and one of the sickest. This is proof that the vaccines are more harm than good to our children.

In a recent ACIP meeting I watched with horror as a new hepatitis B vaccine was added to the schedule even though there is no data to show safety among newborns. With the lack of safety studies and no liability for damages from vaccines, our children are sitting ducks when it comes to these shots. We have no idea what will happen, and when the bad does happen there is nothing anyone can do. Parents are smart. They follow what other parents are telling them. If one child is injured and medically neglected, you can bet ten parents will know about it. It is the failure of The CDC and all those that tow their agenda that has caused this tragedy. Instead of helping the parents and the child studies are conducted to “better understand the dissent”

If the CDC continues to state that vaccines don’t cause autism—there will be thousands and thousands of children not getting vaccinated. You don’t have to thank Andy for that, or Jenny. It is the parents who see their children disappear after shots. They only want to keep their child safe from more harm. Nothing good could ever come from a needle that once did harm to that child.

Thank you for allowing me to speak today on behalf of my son and others like him because vaccines took away his voice.