

Transcribed by Anne Dachel

<https://autismmedia.org/>

## **Autism: The Missing Piece**

*In November of 2017, the Centers for Disease Control and Prevention, Health and Human Services and the National Center for Health Statistics put out a report showing that the rates of autism were now one in 36 children.*

*What was alarming was that the rates had increased between 2014 and 2016 by more than 23 percent, yet the report indicated that there was not a statistically significant increase in the rates of autism.*

**Michael Smith:** *I feel like the autism logo should really be a loud siren, sounding the alarm, letting people know that this is a crisis of huge proportions.*

**Slide: People with autism who have seizures: 33%** 1:46

**Donald Trump (CNN clip):** *Autism has become an epidemic. Twenty-five years ago, thirty-five years ago, you look at the statistics, not even close. It has gotten totally out of control.*

**Slide: Children with autism that cannot speak: 40%**

**Smith to Marcus Molinaro, 2018 Republican candidate for Governor of NY:** *Do you believe we're in the middle of a public health epidemic right now with autism?*

**Molinaro:** *It is without question that we are living in a time where the diagnosis and assignment of autism and autism spectrum disorders is growing at such a rapid rate, affecting so many people that we are in the midst of a crisis of kinds.*

**Slide: Mean age at death for people with autism: 36.2 years** 2:24

**Smith:** *For the public health authorities to not recognize that this is a crisis, and for policymakers to not realize that this needs to be a legislative priority is of great concern.*

**Slide: Unemployment rate of adults with autism seeking employment: 86%**

**Molinaro:** *Because we have to be able to provide the help and support that these individuals need and we are not able and we are not focused and we are not adequately doing so now. That is a crisis in and of itself.*

**Slide: Intellectual disability among people with autism: 44%** 3:03

**Speech pathologist Sheri Marino:** *It's a public health crisis because at the rate we're going, we're not going to be able to sustain this. This is a bubble that's going to burst.*

*We can't afford, as it is, the educational needs and the therapeutic needs and now we have the medical needs on top that we're just [now] understanding.*

**Slide:** Within the next decade the projected annual cost of autism will exceed annual cost of social security in the United States 3:33

**U.S. Rep. Dan Burton:** *It is worse than an epidemic. It is an absolute disaster.*

**Barbara L'Italien:** *The big jump in diagnosis from one in 10,000, when my son was diagnosed in 1990, to now one in 36, many people think, oh that's just better health care, better diagnosing.*

**Dr. Walter Zahorodny:** *I'm always struck by the fact that people think the prevalence is increasing because we're just getting better at identifying subtly affected children.*

*That's definitely not the case.*

*Autism is going up and has increased significantly across every group that we look at: boys and girls, black, white, Hispanic, Asian, all up significantly. Children from rich communities and poor towns, up significantly.*

**L'Italien:** *While it may be true that some of the folks on the milder side of the spectrum may not have been diagnosed 30 years ago, it does not in any way account for what is a public health epidemic.*

**Zahorodny:** *Interestingly enough, we've seen the widest or the broadest increase among the children who have the highest level of impairment of autism, not the subtle, mild levels of impairment.*

*So I do consider escalating autism prevalence to be a public health crisis.*

*The cliché now to me, epidemic is a cliché. People talk about it in many different ways. The public's not sensitive to that term anymore.*

*If there's a stronger term, I'd be in favor of using it.*

*But when we saw autism prevalence go from one to two percent, nobody objected or seemed concerned, and now we've gone from two percent to three percent, and I also see no significant concern or urgency.*

*On the other hand, we're seen autism escalating very progressively in the last 10 and 15 years, and I'm a little bit concerned why nobody really sees this tsunami right there in front of us.*

*We saw a very significant rise in prevalence between the 2012 and 2014 cycle. It was over 25 percent in a 2 year period. That's very significant.*

**Smith to Zahorodny:** *Do you think most pediatricians are aware of this increase?*

**Zahorodny:** *Definitely.*

**Smith:** *And they're seeing it?*

**Zahorodny:** *No doubt about it. I attended the New Jersey Academy of Pediatrics meeting last spring, and that's a very frequent comment, spontaneous comment by many, many pediatricians.*

*The teachers and the doctors don't have the luxury of not seeing reality.*

*Reality is there in the classroom and in the consulting room every day.*

**Slide: Co-occurring medical conditions 6:35**

**Marino:** *I'm Sheri Marino, and I am a speech pathologist. I specialize in autism, and I started out early on during college actually when I was at Rutgers University. I had an internship at the Douglas Developmental Disability Center. This was probably back in the—probably 1990, and at that time, Douglas Developmental Disability Center was the school to be at for autism.*

*Of course, back then, we didn't hear of much autism, so we were the only school in New Jersey. So as a behavioral speech path, I specialized in ABA and really saw the power of that and how we can really influence learning.*

*But over time, I also realized there were a lot of limitations to that. We understood better what the sensory system was and how important occupational therapy was, so I got involved in early intervention where I can work with OTs and PTs and speech pathologists with children on the spectrum.*

*It really gave me a great understanding of the body and how the body is connected and how you really have to look at the whole child and not just isolate the mouth as a component of speech and language.*

*But even over time, I would say really, early 2000s, we started hearing how sick kids are who are on the spectrum.*

*They're not just developmentally disabled; they don't just have sensory challenges and behavioral issues, they're but they're sick.*

**Smith:** *A growing number of practitioners are really starting to understand these complex medical conditions.*

**Marino:** *So really looking at what is going on medically that is exacerbating these autism symptoms? Not treating from a behavioral level, but first looking deeply and within to find out what is going on internally.*

**Smith:** *Some of the more common co-occurring medical conditions associated with autism include gastrointestinal issues, food allergies, epilepsy, oxidative stress, metabolic abnormalities, and mitochondrial dysfunction.*

*We visited one of the largest autism research facilities in the world that studies and treats these co-occurring medical conditions.*

**Dr. David Amaral:** *My name is David Amaral, and I'm the research director at the MIND Institute, UC Davis MIND Institute.*

*I'm a professor in the department of psychiatry. My training is in neuroscience initially, but in 1998 I was asked by families here in Sacramento who were, who all have children with autism, to help develop the MIND Institute.*

*MIND stands for Medical Investigation of Neurodevelopmental Disorders.*

*From their vision we developed buildings and then we invited scientists and clinicians to come to California, to Sacramento, and we built the MIND Institute, which is dedicated to understanding autism and other neurodevelopmental disorders to the point where to the point where we can have better targeted treatments that decrease disability.*

**Smith:** *What are some of the basic things you would like pediatricians to know about autism and younger kids as far as some of the health related issues?*

**Amaral:** *I think those are very, very important. You're right that a lot of pediatricians, even to this day, aren't appreciating that some of the medical components of autism are real. They're not psychological. It's a medical condition.*

*So gastrointestinal problems really are one of the major issues for parents of young children with autism.*

*Kids with autism have either chronic constipation or diarrhea or some, you know, acid reflux condition that is really painful. It's really debilitating, and it's treatable. To say, that's just that child's autism, nothing we can do about it, is ridiculous.*

**Slide: Deaths in individuals with autism increased 700 percent in the past 16 years and were three times as likely as in the general population to be caused by injuries 10:36**

**The average age at death for individuals with autism was 36 years younger than for the general population, 36 years of age compared with 72**

**Amaral:** *We used to say that people with autism have a normal life span. It turns out now, we've done research on that, and they don't. They die earlier.*

*Why do they die earlier?*

*If you look at what kinds of things are affecting these people with autism, it's not only the GI problems, but virtually every disorder, whether it's cancer or diabetes or whatever. People with autism are being affected by those diseases more.*

**Marino:** *We have these children who are medically complex on a variety of levels, whether it is that 30 percent of children who are on the spectrum have epilepsy, 40 percent of children on the spectrum have food allergies and 70 percent have gastrointestinal disorders.*

*All these different disorders require a different specialist, but if those specialists aren't talking to each other, and there isn't any collaboration, you're going to walk away with multiple plans of care, and then who is the quarterback? –The parent, with no medical education.*

**Slide: Medical Collaboration 12:04**

**Marino:** *Our [Autism Think Tank, NJ] founder, Dr. Abend, has a son on the spectrum, who is a teenager, and he wasn't doing very well medically. He had uncontrolled seizures, he was severely self-injurious and aggressive towards others. He had a hard time finding local doctors that understood how to treat these medical issues or how to even identify them. For his own son,*

*he brought Dr. Buie, who is a gastroenterologist, Dr. Margaret Bauman, who is a pediatric neurologist. Dr. Chuck Henry is a psychiatrist and psychopharmacologist, and then the other three doctors are from UCLA.*

*Dr. Raffi Tachdjian is an allergy immunologist. Dr. Lonnie Zeltzer is a pediatric pain specialist, one of the only ones in the country, and Dr. Talin Babikian is a neuropsychologist.*

*So together we use this service now for children all across the U.S. and even overseas, where we'll bring all our specialists together in a video conference with the family and that family's treating physician.*

*So if your child is seen primarily by a pediatrician, that pediatrician is involved in this video conference with our doctors, and together, through this collaboration, we develop a cohesive plan of care.*

*So a family has one plan of care to follow as opposed to six different plans of care from six different specialists who never communicated.*

**Amaral:** *In fact I think some of the major areas of flack I get from parents who work with us in the research programs is that we're not doing enough to educate the physicians that they see.*

**Rick Rollens, former Secretary of the CA State Senate:** *I've spent the last two and a half decades educating the California legislature and staff and governors and our administrations about that co-morbid situation, where our kids are sick.*

*How can a child who's suffering from chronic constipation or chronic diarrhea make progress in a behavioral program unless you address those conditions.*

**Marino:** *A motto that we use in the Autism Think Tank is that "Not all behavior is behavior."*

*Behavior is sometimes medical, and you can't treat medically based behaviors with behavior modification. You have to uncover what is going on medically.*

**Amaral:** *When the children come in after they've been diagnosed, [we] do a really comprehensive analysis of those children. So a medical workup, a psychological workup, do an imaging of their brain to see how their brain is developing, take a blood sample so that we can look at their genetics and look at their immune system.*

*Our hope was that we would be able to come up with subtypes that would be based on real biological or behavioral and biological factors.*

**Slide: CDC Research, Autism and Developmental Disabilities Monitoring Network (ADDM) 14:50**

**Zahorodny:** *I've been involved in autism research and autism clinical care since 2000. My colleague and I, Frank Desposito and I, were among the first people to secure the CDC grant to do autism surveillance in our state.*

*That was in 2001, and I've been involved with that continuously from 2001 to the current date.*

**Smith:** *Is there anything in the methodology that quantifies the functioning level of these kids like the amount of kids who are non-verbal or the amount of kids with co-occurring medical conditions such as epilepsy?*

**Zahorodny:** *We do very careful abstraction of all the medical and educational information. We review to establish prevalence. We know for each individual with autism what his or her co-occurring medical or developmental problems or conditions are.*

*We know what interventions they're receiving through the school system. If they're receiving psychopharmacology for something, we know about that and we record that, and we do a very careful job of characterizing the broad expression of autism.*

*Each child with autism is dramatically an individual, and there are wide differences between the abilities and the limitations of children with autism. So it takes a very comprehensive approach to figure out what the child is good at and what the child's limitations are, and then to assemble an individualized portfolio of educational services or behavioral interventions or comprehensive care.*

*Everything is unique and requires a highly individualized approach, and that's, I'm sure, very complicated for both the school systems and the health networks in our region. It's not like there's one approach that helps everybody.*

**Slide: Behavioral Therapists and a Lack of Recognition of Co-occurring Medical Conditions** 17:04

**Smith to Amaral:** *Do you find that there's a disconnect between a lot of the ABA therapists and their understanding of these co-morbid medical conditions?*

**Amaral:** *I think that's just part of our training. I'm a psychologist, but I'm also a neuroscientist; so I have both biology and psychology. I was fortunate to be able to do both.*

*Most psychologists who do ABA or practitioners who do ABA are so embedded in psychology that they haven't really been exposed to the biological features of autism. So one of the things that we did at the MIND Institute here explicitly is we appreciated that we need to have psychologists who are talking to immunologists and microbiologists to, you know, psychiatrists and whatever.*

*So I think if the MIND Institute has been able to accomplish one thing, it's we realize it really does take a village to understand a complex disorder like autism—in a village of clinicians and scientists. And really what it was, people like Rick Rollens and the other founding parents that realized that clinicians alone aren't going to solve the problem, scientists alone aren't going to solve the problem. It really takes the collaboration of both.*

*We have students now coming out of the MIND Institute who do behavior therapy, you know, early intervention. They've heard about the brain and autism, and they've heard about the immune system and autism, and they're very open to the idea that there are these medical problems as well.*

*So I'm encouraged that the next generation of practitioners are going to be much more aware of the kinds of problems that you're talking about. The people who only sort of have blinders on that you know they can solve everything by, you know, by operant conditioning and ABA, you know, those people are sort of, you know, they're the past. They're not the future.*

**Marcus Molinaro:** *I know in my case, we've experienced a multitude of digestive concerns and issues, of course the seizure disorder, sleep related issues. So I don't know that there is enough understanding, but that's also a matter of advocates educating a bit more and elected officials listening a little bit more.*

**Slide: Autism Services 19:26**

**Michael Smith:** *In New York State where I live, early intervention services are not even occurring in many parts of the state. I mean we have these kids who are in need of intensive therapy at the time of life when that therapy can do the most amount of good, and they're put on waiting lists.*

**Rick Rollens:** *California is really under the gun. We've now established waiting lists for services, which has never happened before in our state, because we can't pay providers the rate that they need to stay in business to serve this very challenging population.*

**Barbara L'Italien:** *The rates that are being paid at least here in Massachusetts right now for the really severe students— young people that are transitioning—are flat, and we may actually see some of the best providers that provide the most intensive treatments, closing up shop for adults. That's really worrisome.*

**Molinaro:** *If you live with someone with a disability, you know firsthand the value of these services. But if you don't, you begin to say, well, you know, we already spend enough on taxes. Why do I have to spend more? And it creates a very adversarial and competitive situation. It's why, by the way, the education system isn't sufficient. [It's] because it's adversarial by nature.*

*It says, if you need the help, you have to come in and ask for it. You have to fight for it.*

*By the way, because of the finite, because a property tax base is finite, school districts of all different sizes sometimes are already at their max when it relates to property tax levy. Shouldn't the state be providing that assistance so that small districts are not overburdened by the cost.*

*I remember as a state assemblyman, I remember families who said they were almost bullied in public because the others knew that theirs was a kid that cost 50, 75, 150 thousand dollars a year in a small district. That's heartbreaking.*

**Slide: Think Differently 21:20**

**Molinaro:** *New York is unique in that it requires county governments to be the deliverer of many of its services. We call these unfunded mandates, but in New York the delivery of Medicaid service and most of the developmental disability programs are, at least the initial point of contact, at the county level.*

*So as we looked internally to county government to change the way we do business, we launched ThinkDifferently.net, which is an intuitive website to kind of help people navigate through the*

*system to find resources. It was clear to me that the one place we could affect substantial change without having to take on a bloated bureaucracy was to focus on the county level. That's really where most families make their first point of contact. Maybe it's early intervention services or special education pre-k or some interaction through your department of health.*

*So for me it was, you know, look internally and by seeing how broadly we can impact change on the county level. It was clear that the association as a whole could embrace this, and that we counties, all 26 of us across the state of New York, have the ability to affect change for a whole population that continues to grow, continues to live with great challenges.*

*When we brought it to the New York State Association of Counties, it was embraced immediately, Republicans, Democrats, upstate, downstate because we recognize that we're the ones, at the end of the day, who are delivering that frontline access to service.*

*It's a matter of ensuring that all of state government recognizes that an individual on the spectrum can live independently or may need significant. So that broad spectrum needs to be accommodated in all that we do, all of the agencies. And there needs to be greater integration and coordination.*

*In this state, we outsource most of those services to local governments which are stretched pretty thin because of the burden of property tax, taxes on families.*

*So the state needs to confront that. I think the State of New York should be paying for Medicaid in its entirety to ensure one, integrated delivery of service, which would provide savings, new resources that could be invested in service. And at the same time, be sure that you're not stuck, as an individual, having to traverse all these individual agencies to get help.*

**Slide: Adult Transitions and Lifespan Issues 23:37**

**L'Italien:** *What happens when you become an adult is a huge, huge issue. For many kids, it really is, once the federal standard under IDEA goes away, those who've had very intensive supports, perhaps going out-of-district, their families are shocked to find that where they go when they transfer over into the adult world frequently is not equivalent in terms of the intensity, in terms of the duration, in terms of the placement. We have to come to grips with that.*

**Thomas Abinanti:** *And then when a kid gets out of school, where do they go? There's something that we call transition. There really isn't a transition program. Where is the transition program? There really isn't one.*

*And if they're supposed to transition to adult life, where are they going to find that adult life?*

*We've stopped building group homes. We've stopped setting up opportunities for people who've now gotten out of school.*

*We have Special Act Schools where some kids with some little additional difficulties are supposed to be helped. We're not properly funding them.*

*And we're finding that the kids, who are over 21, are still in Special Act Schools, in violation of the law because there's no place else for them to go and they don't have families to take care of them.*

*So we look around now for housing; we're not building any housing. So we have people who are 80 years old taking care of their kids who are 55 and 60.*

*Where are we going? What about Day Hab, programs for people during the day? Working environments, we're not setting any of those up. We've basically decided, in this state, that we're only going to help some people. The new New York is not a place that is hospitable for some of the vulnerable people who are our families, and who deserve to be able to have a life like the rest of us.*

*So we're here today, if for any reason at all, to call attention to the fact that New York has abandoned our most vulnerable people*

*If you take a look at all of the different programs, this budget doesn't do anything to help, nothing at all. People with special needs are not in any of the press releases.*

**Molinaro:** *Make the actual delivery of residential options for those with disabilities a priority. Maybe it's housing where both the parent and the child can live in a supportive setting. Maybe it's housing where we provide opportunity for the service providers to be integrated right into the residential setting. Then maybe it is some sort of full care, a residential setting.*

*But in all of those cases, the state needs to make clear that that is a priority, and we're going to provide both the tax credit and the investment to help both the private sector make that kind of housing commitment and then the public sector support it through providing resourced to make it open and accessible.*

**Smith:** *One of the biggest problems we have right now is these lifespan issues and this transition to adulthood.*

*Right now we have over a hundred thousand adults that are on waiting lists for housing. When a child reaches 21 years of age as a young adult, that well-elaborated support system that they have in the public school system goes away.*

**L'Italien:** *My son is 27. He's at home with us. A lot of the work I do now is for that post 22 age, is focused on where they're going to live and what they're going to do.*

**Abinati:** *All these years you're spending time and effort, hard-earned tax dollars and private money to help your child through behavioral intervention, medical intervention—all of these things, and then age 22 comes. As I use to say at all the conferences I spoke out for all these years, you're a child in your lifeline, if your lifeline is this long, you're a child about this long and you're going to be an adult about that long.*

**Slide: Insurance Coverage for Autism 27:41**

**Charles Fuschillo, NY State Senator:** *My interest in autism advocacy awareness legislation stems from a neighbor of mine outside my house one day, a gentleman walking by my house, off the train. We started a conversation. He was telling me he's expanding his house, and he had to refinance his house and that's second or third time he had to refinance his house.*

*So we started to get into a discussion. The expansion of his house was because of his, he has two children. One of them is autistic, a young boy at the time. He needed to expand the house to create a recreational, therapeutic room because all the therapy was done at home.*

*But he was telling me the expense associated with caring for a young child, individual with autism. I said to him, why aren't you getting insurance reimbursement? He said we don't get insurance reimbursement for it.*

*He said I felt we've been discriminated with hospital coverage, with insurance coverage. New York State does not require insurance reimbursement, so we dip into our pocket anywhere from 50 to 75 thousand dollars a year.*

*I was devastated when I heard those numbers, and I knew I needed to do something, but this all started from a gentleman on Long Island and Merrick on behalf of their son, Nicholas.*

**L'Italien:** *As both a mom and a policy maker, that was why we did the medical insurance coverage that we did in 2010. We tried to be certain that it did not have age caps or restrictions, dollar restrictions as some states have had to do. We tried to make sure that it was written broadly for the entire spectrum as long as it was medically necessary.*

*People marveled that we got this done in 18 months, but they don't understand it was eight years of really talking to my colleagues, bringing in families, organizing sort of the grassroots that the families, the practitioners, the folks that lead the specialty schools.*

**Laura Cellini, IL autism advocate for legislative policies:** *Subsequently I worked on the Illinois Autism Insurance Mandate in which we mandated insurance coverage for treatment for autism and that included things like behavioral therapy, speech therapy, occupational therapy.*

*Perviously, before we passed our mandate in 2008, those things were not covered and families were often maxing out credit cards. We heard horror stories of families even taking out second mortgages or selling their homes and moving into apartments to pay for therapies.*

**Smith:** *We saw a lot of these autism insurance bills around the country where it provided coverage up to an artificial age. Usually the best one was like 21, up to 21.*

*So as you were saying, we have all that blood, sweat and tears, and ABA and all that, and what do you do now? You get a higher functioning person with autism, they get a job in the public or private sector or they obtain health insurance only to be told that they can't have what is medically necessary, i.e. ABA, because the legislature has put a law in place precluding them from getting what is determined to be medically necessary.*

*That seems to be a problem we're seeing in the adult world as well.*

**Rollens:** *You're absolutely right, and in most states that's the case. We saw that coming, and we advocated and were successful here in California on the bill that was carried by our president pro tem, our autism insurance mandate bill. to do two critical things. There's no age limit in California, so if it's medically necessary, it doesn't matter if you're two or 92, you can access ABA services. And there's no cap on benefits, a yearly cap on benefits. It's the strongest mandate bill in the country.*

**Smith:** *While working to pass the New York State autism insurance bill in 2006, we knew that we weren't going to get everything that we wanted in that bill, and we know we were going to have to build on it in subsequent years. But we did get a bill passed that banned discrimination against people with autism by insurance companies, and it was a good bill and it was a solid bill. It helped thousands of families across the State of New York.*

**Fuschillo:** *So we may not have gotten everything we wanted in the first piece of legislation or the first step, but we kept building and building and building from it.*

*It resulted in New York State being, I think it was the 28<sup>th</sup> state in the nation that required the insurance reimbursement for the treatment, diagnosis and therapy.*

*But it all stems from the public support, and that's critically important, whether you were nervous [the] first time in your journey of visiting the capitol and going to the legislative office building. Whether it was you or countless other families or individuals, you all had a common goal, and the common goal was to get this done.*

*And when you started educating myself and when I started working with all of the groups and educating other legislators, it just kept rolling and rolling. The ball kept rolling, rolling, rolling to the finish line.*

**Slide: Albany Times Union photo and story: Governor signs bill mandating insurance for autism care. 32:41**

**Slide: The Autism Financial Crisis That Is Upon Us**

**Smith:** *The growing financial demands of the autism epidemic are leading to the type of budget and policy decisions that are reducing essential services such as early intervention, special education services, and even areas such as physical therapy so that kids with autism can live a pain-free life.*

**U.S. Rep. Danny Davis:** *The Harvard School of Public Health has estimated that it can cost \$3.2 million to care for an individual with autism over the course of a lifetime.*

[See Harvard Press Release, April 2006 <https://archive.sph.harvard.edu/press-releases/2006-releases/press04252006.html>]

**Rollens:** *Take the human decency element out of it, about caring about another human being in their life's plight, just look at the dollars. What happens when that happens?*

*You have a situation of unemployment, you've got government programs that are being taxed because food stamps, all kinds of programs, because of the downstream effect of having this happen to families.*

*You know, I talked about the eighty, eighty-five percent divorce [rate]; there are thousands of families out there right on the edge of that.*

**Marino:** *In 2015 autism cost our nation \$268 billion*

**Davis:** *Although insurance covers some of these costs, intensive behavior therapies, often paid out-of-pocket, can cost as much as \$60 thousand per year.*

**Marino:** *If the trajectory of autism continues as it has over the past decade, then we're on track for autism to cost our nation one trillion dollars by 2025.*

**Zahorodny:** *We're headed toward a gigantic, whatever you'd call it, resource bust or a services bust, because all these children that we identify at age eight, [the] vast majority of them continue to have autism and some degree of impairment throughout adolescence into adulthood.*

**Rollens:** *Let me tell you that by not addressing the needs and keeping families together and supporting people with autism, the cost, the downstream costs in divorce, in public social service programs, and everything else that would be accessed, not only by the child with autism, but the parents themselves. We need to do something to stop that snowball effect.*

**Smith:** *As for funding and providing services throughout the lifespan, we are simply not prepared for the onslaught of service requirements that we have upon us. And we're not going to solve this issue without a really serious focus and collaboration from the public and private that values the civil rights of people with autism.*

35:50

**NY Assemblywoman, Melissa Miller:** *A friend of mine, who just this weekend because it was Autism Awareness Month, she posted something on Facebook, and I thought that is was very compelling and moving.*

*"April 1<sup>st</sup>, the first day of Autism Awareness Month. This beautiful face, my beautiful boy has autism. What does that mean?"*

*"Truly I can never put into words what autism has taken from him.*

*"To give you a peek into his life and how he struggles, I can tell you that on Tuesday he needed anesthesia just to get cavities filled because he can't keep his mouth open to get them fixed, because he doesn't know what a cavity is, because he doesn't understand, because he is scared.*

*"I can tell you that on Thursday he spent an hour hitting himself and me, and I don't know why. All I can do is try and keep him safe until it passes.*

*"I can tell you that yesterday we drove around in the car watching Sesame Street videos because we needed a way to pass the time.*

*"I can tell that this weekend he has no plans, no karate, no band, no practice, no activities, no friends at 15.*

*"I can tell you that on Tuesday he will have surgery again because his heel cords are so damaged due to significant sensory issues and an inability to stand with his foot flat on the ground. His feet have not grown in years because he stands only on his toes. He is 15 years old and wears a size 4.*

*“He has calluses and cuts all over his hands and knuckles because he rubs them constantly and cannot stop.*

*“This is autism. It sucks. It causes problems in all areas of life and in ways you would never imagine.*

*“My son was robbed of what his life should be. It is not fair to him, and it never will be. Yet he preserves.*

*“He wakes up with a smile. He forgives me for when I am not my best. He hugs so hard that you can feel how much he loves you even without words.*

*“Jackson is the best, most admirable, most inspiring person in my life. He has guided the way for me, and I hope he knows that I am so proud of him.*

*“So I will try every day to make a difference in his honor. I encourage everyone to do something during the month of April to help an individual with autism because, trust me, they need it.”*

*This is the mom of a 15 year old who’s still battling with this every single day. We need to do more.*

**Slide: Autism Policy 38:29**

**Cellini:** *What science has shown is that autism really is a whole body disorder.*

**Marino:** *There is a push now. There are some other activists and bills being written to address a medical workup for children on the spectrum.*

**Cellini:** *As a matter of fact, I worked on a recent law in Illinois that we passed in 2016, and that is called the Autism and Co-occurring Medical Conditions Awareness Act. It’s quite a mouthful. One of the efforts we were trying to address in our state was to make more physicians aware that there are a lot of co-occurring and underlying conditions that go along with autism.*

**Marino:** *You have an individual, say that is self-injurious, maybe they’re nonverbal, so they’re not able to communicate, my belly hurts.*

**Cellini:** *So that law recognizes those conditions which range from allergies, autoimmune issues, gastrointestinal dysfunction, immune dysregulation, oxidative stress, neuroinflammation, and seizure disorders, along with mitochondrial and metabolic abnormalities.*

**Marino:** *It’s very difficult to get these services covered if you don’t have the evidence to support why you’re going to order something like a scope.*

**Cellini:** *So what we’re trying to do is to get doctors to recognize that when they see a patient with autism, and that patient, maybe their parent is saying, I’m concerned that my child has this symptom and maybe this symptom is associated with something that’s gastrointestinal.*

**Marino:** *They can’t express these things verbally and so you can go to the doctor,*

**Cellini:** *-- and physicians say, oh that’s just autism, then don’t look further.*

**Marino:** *How does a doctor translate that into coding for insurance to get a scope covered?*

**Cellini:** *When they actually do evaluate them and find that there maybe is something that is treatable, what's amazing is that sometimes when we treat these co-occurring and underlying medical conditions appropriately, we see the symptoms that we associate more with autism actually ameliorate and reduce.*

**Smith:** *When these kids get adequate medical treatment, they feel better and they can learn better in whatever educational program is being offered to them.*

**Cellini:** *So I think we do need a paradigm shift in understanding. It's not that while we see symptomatology that looks social and behavioral in communication, what we're really seeing in the, when we look medically is a whole host of co-morbid and co-occurring medical conditions. That's occurring really in some cases, on a cellular level.*

**Smith:** *We're literally denying many of these kids a pain-free life because we're not giving them the medical treatment that they deserve and that the scientific community knows that they need.*

**Cellini:** *When we look at policies, we really have to take a very comprehensive approach and at different life stages.*

*So, for example, what we're considering for early intervention is going to be different from what we're considering for somebody who's aging out of the school system. So we need to adapt our policies to reflect the needs of each community at each stage of life.*

**Molinaro:** *So I think, the government, at all levels, if given the latitude, could be a much better employer. The civil service requirements are so complex that it's hard enough to get people into jobs in government of any ability.*

*So government needs to be a leader in that, and then the state needs to create a labor policy that allows employers to make similar accommodations.*

*Because again, a single job could be carved up into four or five responsibilities if we can give an individual with a particular skill set access to income. And there may have to be waivers for minimum wage requirements, and there ought to be considerations for salaries and structure, and at the same time make sure that there's transportation and housing opportunities. Because without those things—you know, having a job without having a home or having a job without being able to get there isn't of anybody's benefit.*

*So creating those avenues for employers, private sector employers, to make the appropriate accommodations, I think is important. Again that's a focus of the state government changing labor practices to make it easier for individuals to work.*

*The other is, I would say, there is nothing wrong if the most integrated, the most integrated setting is some sort of workplace for multiple individuals living with disabilities. That's acceptable.*

*It shouldn't be where we put people because we don't want to provide help, but closing these work environments across the state is a mistake.*

*There's an opportunity for those who maybe this is the most integrated setting that they can live and work in. Give them that job and provide that resource and that opportunity, because having that is just, it is just so powerful to an individual and to a family.*

**Smith:** *Why should his be a priority for legislators right now?*

**Rollens:** *Well, because it's the number one public health crisis in our country. There's no doubt. It's at this level that when we're adding one new child every 42 minutes in the State of California with autism, something has got to be done.*

**Smith:** *There's just no doubt we have an onslaught of service requirements that is upon us. A lot of people have described it as a tsunami. The wave is hitting it now; we're seeing it with the budget busting school budgets.*

*There are state services that are supposed to be serving the disabled, that are the laws, that are on the books, that are simply not occurring.*

*I know that Assemblyman Abinanti has addressed this repeatedly at press conferences.*

**Abinanti:** *When you take a look at what we're doing with the money that is being appropriated, you see we're growing the bureaucracy and shrinking the services.*

*I just went through a process to apply for services for my son. He'll be 18 this week. I decided to wait until the last minute because we didn't need the services. We were providing the services ourselves and through insurance.*

*But I heard so many complaints from constituents that I subjected myself and my family to this rigorous, absurd process which is designed to stop people from getting services.*

*It took us the better part of a year just to get what's called a Medicaid waiver, which is the first step towards getting the services. And when we finally got the Medicaid waiver, the departments that were dealing with this couldn't talk to each other.*

*They were asking the same information on different forms over and over again.*

*You go to OPWDD [Office for People With Developmental Disabilities], then you go to social services, then you go back to OPWDD. Then we get a letter from social services saying, we can't give you the Medicaid waiver because you haven't filled out such-and-such a form, when in fact, they already issued the Medicaid waiver and we had the card to prove it.*

*So I now personally understand all of the stories that I've heard from my constituents who've been going through this for years.*

*I subjected myself to our two hour class. They told me absolutely nothing and told nobody in the classroom anything other than, there were no service coordinators available in Westchester County at this time. And you needed a service coordinator before you can move forward and use any of the services.*

*When I contacted service coordinators, they said, "Well, you need to have a Medicaid plan, and there's five available."*

*I said, "Tell me what they are."*

*They couldn't tell me what the plans were about or what type of services they provided.*

*So you're dealing with a stumbling block, a major wall for the parent who's already gone through a very traumatic experience in trying to raise a child who faces very significant challenges, whether it's autism or any other type of developmental disability.*

*The State of New York is standing in the way of people getting the services that by law they're entitled to get.*

**Molinaro:** *I would look to an entire review of the way in which we provide these services and integrate and demand greater efficiency in the delivery of those services, everything from early intervention prenatal, right through early intervention, right through residential and housing opportunity. And integrate the public education system in that decision making.*

*Again what happens is early intervention becomes a county health department responsibility. Education from K to 12 is a public education responsibility.*

*And then the rest is in many ways, fend for yourself because you're out there, you know, on a cliff.*

*So you've got to get the private sector, you've got to get the public sector, you've got to get all areas of government focused on this.*

**Abinanti:** *It's up to the policymakers to see these numbers and to recognize that the services that we used to provide and the money that we used to provide, which has kind of remained flat or gone down, is not enough to deal with all of the people we have.*

**Molinaro:** *If you invest early enough, the lifetime cost is less. If you invest in the services at the right point in time, the lifetime cost is less, and you make a more impactful investment.*

*In this state, because we have so many layers of government within the state government, it is a very wasteful and bloated bureaucracy that just needs to be confronted.*

**Slide: Autism Awareness Campaigns 47:52**

**Smith:** *Autism awareness, if I don't smile, I'm going to cry.*

*It's a great source of frustration for a lot of parent advocates I know.*

*We're aware. I think a lot of people are aware that the numbers have been going up, and yet we're not seeing enough in terms of action. We need action. We need funding. We need to stop the reduction in services that we're seeing across the country.*

*I just kind of wonder if these awareness campaigns and the millions of dollars that have been spent that have been spent on them are actually doing anything.*

**Smith to Zahorodny:** *Do you think that better awareness has resulted in earlier diagnosis?*

**Zahorodny:** *Ironically, we took a look at that question a few months ago, and we found that better awareness of autism, age of your autism diagnosis has not changed between 2000 and 2014. In spite of all the campaigns, better awareness, media attention, the age at which a child is getting diagnosed with autism has not changed has not changed or improved.*

**Slide: Legislative Advocacy 49:13**

**Smith:** *Positive change will only occur when there is a true collaborative, grassroots advocacy movement and collaboration between the public and private sectors that makes autism the legislative priority that it needs to be.*

**Rollens:** *I've seen it personally both inside the legislature at the highest level when I worked in the senate and now for the last 21 years outside as a lobbyist who represents the developmental disabilities community and autism organizations.*

*If you're not there doing grassroots day, meeting legislators, keeping the issues, trust me, there are thousands of other organizations out there who are doing that and you quickly become a memory and not forcing people to confront what again is the number one public health crisis in our country.*

**Smith:** *If more parents do not get involved in legislative advocacy, we're simply not going to see the changes that need to occur.*

**Rollens:** *We're all stressed, there's no doubt. I mean, you know, families of children with autism. Studies have been done about just how hard it is to raise a child with autism. We all are under siege every day.*

**Smith:** *So if we had just a small percentage of parents that redirected one percent of the time that they spend on social media to actual legislative advocacy, we would see positive policy change.*

**L'Italien:** *We can only get the government only get the government that we deserve if we inform our legislators on what's needed.*

**Rollens:** *To be able to cobble together some time and some effort to advocate for programs that help our kids is hard, it's tough, but it has to be done or nothing's going to change.*

**Smith to Molinaro:** *How important is it for parents and self-advocates to make legislative advocacy a priority? It's well known that many people are, just they're intimidated by it. I mean, you're a nice guy, I'm not intimidated by you, you know.*

*But seriously, I've talked to a lot of parents. They'll talk tough on social media, but at the end of the day, they will not go in and meet with their elected officials*

**Molinaro:** *Every advancement in policy for those living with disabilities has come because a parent of a child has been the advocate. No one is going to advocate for your child better than you are. I understand the steep slope. I understand the intimidating factor of having to do, and it's unfortunate that we have to.*

*In order to get people who don't understand or have a thousand priorities to focus in on the real need here, we have to be those advocates because if we're not, you cannot be confident someone else is going to be.*

**Cellini:** *You know at the end of the day, we're all human. Legislators are not different. They deal with the day-to-day struggles. While maybe it's not autism, some of them may have somebody else who's ill in their family, and they've had some experience there. Most legislators, I have found, are very compassionate and kind people when they really have the time to understand your issue.*

**Molinaro:** *I remember as a state assemblyman arguing for the expansion of insurance services for those living on the spectrum, I just told my story, and I think more of us just need to do that.*

*I've often hesitated to be the legislator that advocated for something because it's personal to me, but in this line of work in this realm or this area of service, we need more people stand up regardless of their background, and say, this is my story and this is why it's valuable.*

**Rollens:** *Families are really so important in the advocacy. Things change because of family involvement. Our system here in California would have never happened unless families of people with children with developmental disabilities got together in the late 1960s, and said we can't do this anymore.*

*We have two options as parents back in the ...all the way up to the late 1960s, either keeping our kid at home, and in fact, in California, you couldn't even send a child with autism to public school until 1972. So you had your child at home, no supports, no education, nothing, or get on the waiting list to have your child institutionalized in one of the large state developmental centers.*

*So those families got together, and they changed the world. They created the Lanterman Act here in our state which now serves over 300,000 individuals and their families with autism and cerebral palsy, epilepsy, and intellectual disabilities.*

**Abinanti:** *It is important to have one-on-one contact. They spent a lot of time advocating for their kids whether it be with teachers, whether it be with school officials, whether it be with people who provide services. It's the same skill.*

*It's going to one of your neighbors who happens who happens to have been elected to office and telling that neighbor, here's the problem I have. I need you to help me fix it. You have the tools of government at your disposal; direct some of them this way.*

**Smith to Fuschillo:** *A lot of autism advocates have a different view. They don't always agree with one another.*

*There's often infighting. Can you explain how important it is for them to try to come to mutually agreed positions ahead of time before going into legislative offices so that when they go in, they don't have a legislator saying, hey, I've got three different autism groups who want three different things.*

*I can't help them. They throw their hands up.*

**Fuschillo:** *And by the way, that's the way it generally happens with many other issues. You could have 20, 30, 40, 50 people around the room, all different personalities, come from different walks of life in this state. We know that there is a social and economic difference in every avenue of this state.*

*When they came to my office, we said to them, we have this one opportunity to do something that's right for your family.*

*Right now you're not getting insurance reimbursement for the diagnosed treatment and therapy*

*All of you have different views on how to do this. We have a piece of legislation with so many co-sponsor in the senate. We have an assembly partner that was terrific, who had the support in the house, in the assembly.*

*Let's join together. Put all the advocacy groups together for one common cause and one common goal, and it worked. We made them put their differences aside and said, let's start with this.*

*If we have to build in later years, we'll do that. But we need to get this legislation passed, we need to get it signed into law, and we need to ensure that you're not going to be continually going into your pocket for 50, 60, 70, 80 thousand dollars of your own money to provide the kind of care that you want to provide to your child or your loved one.*

**Cellini:** *I think, first of all, it's important for parents to meet with our legislators back home in their district where the legislators have more time and, you know, an opportunity to really have a more casual and intimate conversation with them. So I do encourage parents to make those appointments back home in their districts when they're not in session.*

*I think the first thing that they need to do is just sort of educate the lawmaker on what their day-to-day life is like and what their struggles are.*

**Rollens:** *You don't have to always travel to the state capitol. Every legislator has a district office where you can meet them in their district.*

**L'Italien:** *I would say, having spent years teaching parents about how to be an effective advocate, that their power is in their story and sharing their story.*

*Every year when budget time comes around, I tell them don't just, you know, send off a cut and paste email. Contact your legislator and tell them what funding for a particular program would mean for your child.*

**Rollens:** *There are many issues that impact and families with autism, but the way you get that elevated is through organization and passion and basically just really hard work.*

**L'Italien:** *I always caution people that advocacy isn't a one and done. People who flood into the statehouse once a year with their list of demands aren't going to get the same reception as someone who takes the time to get to know their house member, their senator. Meet them perhaps for coffee, particularly out in the district.*

*Everyone of us has office hours. People will agree to meet you at any coffee shop, sit down, get to know the person in an unrushed and undisturbed situation and really share your story. Emphasize to the legislator that you can be a source of information for them.*

**Rollens:** *Put yourself in an elected official's shoes for a moment. Here's someone who's responsible, regardless of what state or what legislature, what responsibility all the way down from city council, all the way up to the President of the United States.*

*The myriad of important issues that they have to deal with and make decisions on, they seek out information. They want to know...what people think about these issues, and you have to work as an advocate to get your issue elevated above all others. And that is the challenge.*

**L'Italien:** *One of my favorite stories is that the current speaker of the house in Massachusetts, Bob DeLeo, was the ways and means chair, and I tried to pass something in the budget, and he didn't fully understand that it was a spectrum disorder, and so he didn't want to do it.*

*So I asked him if I could have my son and 10 of his classmates come in from his out-of-district school. He had lunch with them for over an hour, and he saw in that amount of time the incredible richness of thought, the strengths, and he saw the glaring challenges. He began to understand that this was a spectrum disorder.*

*From that point forward, I would say, anything that I tried to do in legislation with regards to autism, he was on board. That's critical because then you have someone who you've got here, right? You've got his heart, and then you are being trusted as the leader. So because it's not just having great ideas in policy, it's getting it passed and getting it funded.*

**Smith:** *One of the things that's very troubling is that there is no fulltime lobbyist in Washington on autism issues.*

**Cellini:** *It's quite shocking that we don't be quite honest because when you think of conditions such as Alzheimer's or ALS or other medical conditions that are impacting many people, they do usually have representation in D.C. and across the states.*

**Rollens:** *It is criminal if there is not a voice fulltime there in Washington advocating for our kids.*

**Cellini:** *Those of us who've been in the process understand the good that a lobbyist can do and what they can achieve, and how sometimes the impact that a lobbyist can have can translate into policies which could serve thousands.*

### **Slide: Why Autism Epidemiology Should Be a Legislative and Public Health Priority. 1:00**

**Smith:** *One of the most important things that I think legislators should be doing is active cause surveillance and monitoring or basic autism epidemiology.*

*It's really hard for policy makers to make intelligent decisions on an issue that they can't even measure.*

**Smith to Zahorodny:** *Why should states that are not already doing so make epidemiology a priority?*

**Zahorodny:** *These children are there, and they'll become adolescents and adults, and they're not invisible. They need, and they deserve both high quality educational services and medical interventions*

**Smith:** *Most states cannot even count the number of kids with autism. The policymakers and their staff don't have the accurate data that they need. They cannot make intelligent policy decisions.*

**Rollens:** *It's really the basis for your ask, and clearly the competition for your state and federal tax dollars is brutal. There's no doubt. There's so much need out there with so many different programs that you really have to establish a baseline of need for a population.*

**Zahorodny:** *You can't understand what has to happen for these children unless you know how many are affected.*

*And this is the beginning. This is the way that you appreciate the scope of the problem.*

*We know, we do surveillance in Essex, Hudson and Union Counties. They're part of the New York metropolitan region, and if our rate is three percent, I would bet that the rate in all of your suburban, urban New York counties would be the same.*

**Slide: Centers for Disease Control and Prevention 1:01:51**

**Smith:** *One of the most compelling epidemiological studies that I've seen in recent history is the study from Dr. Zahorodny in New Jersey showing that 4.4 percent of the boys in the State of New Jersey now have an autism spectrum disorder.*

*What is troubling about that study is the fact that we know that not all of these kids are diagnosed by age four, and the real rates could be as high as six percent.*

*If we look at the fact of how many of these kids have an intellectual disability or nonverbal, we could be looking at a situation in New Jersey right now where three percent of these boys are going to grow up to be non-verbal and have an intellectual disability, the term we use now instead of mental retardation.*

*So that's very troubling, and I'm really concerned why other states are not making epidemiological studies a major priority so that they can manage the crisis that they have upon them in their states right now.*

**Zahorodny:** *For some reason, the CDC has been very effective in massaging the message in the last few years, and whatever the CDC offers as a bullet point or two, invariably winds up being repeated almost verbatim in the leading press reports, and then everybody else copies those.*

*I find that there's very little independent investigation by the media.*

**Smith:** *Do you think the CDC is afraid or concerned about reporting on the actual public health crisis that autism is?*

**Zahorodny:** *Yeah, my impression is that they don't really know how to address the problem. I'm certain that people there understand the magnitude and the scope of the crisis, but if you don't have any way of explaining it to the public, it's embarrassing to come forward and say, we've seen autism, a significant developmental disorder, rise 200 percent and we don't know why that is.*

*I can say that because I'm not a public health authority, but if one of my main responsibilities was trying to project a sense of confidence and authority, I wouldn't be repeating that I don't understand why an important problem is occurring.*

**Smith:** *Is the methodology going to be changing at all?*

**Zahorodny:** *Yeah, we were surprised, or at least I was surprised a week or two ago when we had a webinar with the CDC during which all the investigators that are going to continue doing surveillance were notified that the methodology is going to be changing and changing, I'd say, rather dramatically.*

*Instead of really doing active case finding going forward, the CDC now wants us to only identify children who have already received an autism diagnosis by age eight.*

*That's a lot simpler. It's a lot more efficient, but it's going to give us no information about the expression of autism, and it will certainly suppress the estimate of autism prevalence.*

*My co-investigator took a look at this a few days ago, and she found that if we used the new, the proposed methodology in 2014, instead of the traditional active case finding methodology, our rate wouldn't have been 29.3 per thousand, it would be 21 per thousand.*

*So there's a gigantic difference between two percent and three percent.*

**Smith:** *If the rates are going to be suppressed by 20 to 30 percent under the new methodology, can we expect the CDC to issue press releases next year saying, that the prevalence rates of autism are going down when we know that they're actually still going up, but they've just changed the methodology?*

**Zahorodny:** *I'm not so sure that the public health authorities really grasp this even in New Jersey and probably not in New York.*

*I don't think that they really appreciate the magnitude of the health crisis, but something has to wake those people up because they're the ones who can pass the laws and shift the policy decisions so as to be ready to help.*

**U.S. Rep Dan Burton:** *But sometimes I think that outside influences have too great an impact on the scientific research that's necessary to find cures for major problems.*

**Slide: Going Forward** 1:06:42

**Molinaro:** *It's often been said that it takes special people to raise an individual with a special need. The truth is, it's the other way around.*

*I want people to understand in the big debate about what causes, how do we prevent and how do we help those living on the spectrum, we need to think differently and understand that at the end of the day, we need to invest in those things, but these individuals are so special they remind us in many ways of our own humanity.*

*It would be nice if, as a society, we kind of toned it down, focused on providing the help that these individuals need, but also see the very special, very authentic, very genuine humanity that exists.*

*The small successes that we experience are so major, so important, so valuable, it reminds that we're all in this together.*

**Smith to Rollens:** *What would you like to see the federal government doing right now that you think is achievable?*

**Rollens:** *I think from the administration, the Presidency and all the way down into Congress and in all levels of government, there needs to be a focus on this issue.*

*We've got a lot of smart people, dedicated people who would come to the forefront and be involved in real true planning, meaningful planning and following that up with the money and the funding it needs to address the many issues that our families face every day.*

**Zahorodny:** *But after awareness there should be action. Parents need to take actions to get the best care and services for their children.*

*Teachers and educators need to make plans to accommodate more children coming for services.*

*Doctors have to understand the complexity of this disorder. It's not one issue that you're going to be trying to help with.*

*There could be better public health actions that could affect people across the country.*

**L'Italien:** *And as far as legislators go, whether you have a child like I do or you're related to a child, at this point, if you've been involved in politics, you know of constituents, you know of people who are affected by autism. It's so pervasive now that there's no way that you don't know someone affected by autism.*

*Use the power that you've been given for good.*

**Amaral:** *I do think that where we're heading is that in 10 years or maybe sooner, when you're diagnosed with autism, besides having a behavioral diagnosis, people are going to take a blood sample, people are going to look at the immune system, they're going to take a fecal sample, they're going to look at the microbiome.*

*And they're going to say, your type of autism is associated with GI problems, it's associated with a certain imbalance of metabolites and the best possible treatment for this profile is such and such.*

**Zahorodny:** *The other thing that I would emphasize is that more states should be doing more active case finding surveillance the way we do in New Jersey, and that requires the cooperation of both health authorities and educational authorities.*

*In the atom network, as strange as it sounds, there are some sites which never gained access to the education records in their surveillance region.*

*Without access to your education records, you're not generating a reliable estimate.*

*The thing that's in the way in some states is how they interpret a FERPA, Federal Education Privacy Law.*

*If the Department of Education at the federal level decided that public health surveillance of autism was important enough, they would wave and allow access by investigators to go public health surveillance or monitoring.*

*The CDC is an important preeminent, probably public health organization in the world.*

*If they wanted to do something, they could accomplish some of these things.*