

Oral Public Comments

**IACC Workshop on Under-
Recognized Co-Occurring
Conditions in ASD**

September 23, 2014

List of Oral Public Comments

Casandra Oldham.....	3
Eileen Nicole Simon	4
Megan Davenhall	5

Note: Personally Identifiable Information (PII) has been redacted in this document

Casandra Oldham

September 23, 2014

Thanks for the opportunity to speak today. Although I 'm speaking based on my experience I know that my facts are similar to a number of parents. 2-3 minutes and limited number of speakers is insulting particularly when we are part of a population and problem that don't feel like we are being heard. I personally judge if people hear me based on their actions and it is clear that this committee doesn't recognize the urgency of the issues that are occurring in autism based on the inaction.

First, I need to address the fact that my children are treated like fifth class citizens. Here are three examples, 1/ My nine year old lost the top of his finger when he fell at special needs hockey. Virginia hospital center said because he has autism it wasn't worth reattaching! 2/ My six year old was put in a "box" by TSA agents because he set off sensors and then couldn't follow verbal commands and 3/. I was told by three therapists that a worker was abusing one of my children. I called CPS and the police and even though I had three witnesses, no charges were filed because my child couldn't describe what happened and he "didn't look traumatized". The abuse and trampling of basic human rights for these human beings makes me ill.

Now the numbers continue to rise with little being done to find the cause or cure. My children acquired autism via toxins. We know based on medical tests the toxins were vaccines. Something needs to be done to prevent other children from such injuries. My children have no future. They are extremely affected. It was brought to my attention that some of the studies that this committee uses to base certain opinions were falsified and corruption was taking place. People need to be held accountable because children continue to be harmed.

Also any of the numbers you read on vaccine injury don't include my boys. Any numbers you read on autism rates don't include my boys. And with studies being eschewed to benefit a few, this should make everyone question anything produced by people with things to gain of conflict of interest. I was personally asked to remove my son from a study at KKI with [PII redacted] because my son was negatively affecting the findings. During that time period a genetist at Hopkins who studied my boys told me he was not publishing some papers on autism out of fears. I was told certain key aspects of my sons medical condition were being omitted from my child's medical report because he did not know who I was going to show them to.

Not only do my children not count. They suffer for the benefit of the "greater good" but you committee members treat us as if we are grasping for false answers and looking to blame. I wish I had the luxury to go to bed with the peace that my children were born with autism. That it was like Downs Syndrome but I know better. I didn't seek a mitochondrial diagnosis; I walked in to the hospital with a child that regressed. They told me toxins caused it. Now I know better and I must do something. I wonder as I look at you all where your moral compass is at or when it broke because you have the power and authority to move forward on change and I don't see any action to change these children's future.

Eileen Nicole Simon

September 23, 2014

My first two sons suffered trauma and oxygen insufficiency at birth.

Pediatricians reassured us that our children would outgrow their developmental delays. They did mostly; but problems with language development remained as a serious impediment for cognitive growth.

In my written comments I discussed auditory processing deficits, and problems with speech production.

I also described research with monkeys on asphyxia at birth. Damage was most prominent in nuclei of the brainstem auditory pathway. But then, maturation of the cerebral cortex did not proceed normally.

Autism is the result of many different causes. In my written comments I pointed out some of these, and why all are likely to affect subcortical sites.

Nuclei in the brainstem auditory pathway are susceptible to damage by all of autism's known causes, during gestation, during birth, and from some neonatal interventions.

Please discuss the possibility that co-occurring conditions in autism may all result from: Injury of brainstem sites, and subsequent disruption of maturation.

Please discuss also any evidence that language disabilities and co-occurring conditions might be mere differences on a spectrum of "neurodiversity."

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Conrad Simon Memorial Research Initiative

To seek understanding of brain system impairments in autism.

<http://conradsimon.org/>

Megan Davenhall

September 23, 2014

My name is Megan Davenhall, President of The Thinking Moms' Revolution.

What I am here to say is nothing this committee hasn't heard before, because parents have been screaming this to you for years. There is a huge subset of individuals with the label 'autism' that were not born with autism. These children, young adults and adults were born as typically developing, healthy children and then regressed into autism. This is NOT the autism that you see in our highly functioning adults that participate in committees such as this one. It is not the autism that manifests as a quirky personality, some limited social capabilities or rigid thinking. This autism is an entirely different experience for these people. It is pain. It is bowel disease. It is mitochondrial dysfunction. It is immune deficiency. And it is in many cases silent pleas for help through head-banging, self-injury and aggression.

Parents have been treating these co-conditions for years. YEARS. We've had to pay out of pocket because insurance won't cover the staggering cost of healing the many physical ailments our children suffer from. Our kids who fall into this model of autism, the one where the healthy become urgently ill, need to be treated with respect and like human beings who are sick. Their physical symptoms need to be addressed by medical professionals in the same ways that they would in a person without autism. Never again should a parent have to hear from a doctor or a psychiatrist that a physical problem, such as diarrhea, or constipation is 'just part of autism.'

Parents have been screaming for years that there was some trigger that sent their healthy child into a physical and developmental tailspin. They watched this happen to their kids. Yet you ignore us. You ignore our first hand, eye-witness accounts of damage to our children. You have these meetings that accomplish NOTHING and give us the mic a few times a year and we scream at you, "AUTISM IS MEDICAL! Our children get better when we treat the medical problems they have! Their behaviors that landed them on the spectrum in the first place improve when they get healthier!" And you don't hear us. You give us 15 minutes of your day, and interrupt parents who travel on their own dime to get here if they go over their allotted 3 minutes so you can get home by 5 o'clock. It is disgraceful.

The committee NEEDS to start getting serious about vaccines dangers, pesticide exposure, antibiotic overuse, chemicals in our food supply, and a medical system that is run by pharmaceutical companies who don't care one bit if our kids are healthy or not. This committee needs to start WORKING with our government to lessen the toxic burden our children are exposed to, instead of twiddling your thumbs and congratulating yourselves on the good work you are doing, because the parents are watching and we don't see you doing much of anything. Stop patting yourselves on the back for a job well done when the autism numbers continue to climb with no end in sight.

This epidemic and the US governments inaction has created a vocal, intelligent, passionate army of loved ones that has reached a critical mass in number and will not back down. The time is now to act. We want to hear what you are going to do about these co-occurring conditions that we've been shoving in your face for the last 10 plus years. What will you do? I think you owe us some answers.