Oral Public Comments

IACC Full Committee Meeting

January 29, 2013

List of Oral Public Comments

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

Amy Lutz

January 29, 2013

Good morning, my name is Amy Lutz and I am the president of EASI Foundation: Ending Aggression and Self-Injury in the Developmentally Disabled. We support autistic individuals with dangerous behaviors and their families through our resource guide, our research projects and our advocacy – speaking, as I'm doing now, on behalf of parents who can't stand before you themselves because their children require constant supervision to ensure they don't hurt themselves or others.

I'm sure you already know that aggression and self-injury are prevalent in the autistic population – studies suggest that up to 30% exhibit these behaviors to some degree. But because these behaviors generally isolate families and preclude their children's participation in the community, I wanted to show you what they actually look like. This is my son, [PII redacted], pounding himself in the face when he was ten years old; and this is a Colorado boy whose self-injury landed him in the hospital. And these cases aren't as rare as you might think: I just don't have pictures of the young woman who blinded herself after repeated blows to the head, or the teen who had to wear arm stays that literally kept him from bending his arms so he didn't do the same, or the young man who spent years in five-point restraints in a state hospital because his aggressive rages required six trained professionals to manage. To give you an idea of the scope of the problem, there are 11 specialized inpatient hospital units in this country for kids with developmental delay and dangerous behaviors, and that isn't enough; many of these have waiting lists months long.

Research shows that aggression and self-injury are highly correlated to restraint, abuse and institutionalization – and most obviously, a very low quality of life for afflicted individuals and their families. Yet this population is severely underserved. I'd like to leave you with three action items I hope you will consider as you shape your strategic plan for the future:

- First, simply recognize in the strategic plan that this underserved population of severely disabled autistic individuals exists and has completely different needs from high-functioning adults who can speak, work and self-advocate at meetings like this one. And it's not a small group. Fully 50% of the autistic population also have intellectual disability, 20% are non-verbal and, as I already mentioned, up to 30% suffer from aggressive and self-injurious behaviors. These symptoms are all highly correlated, resulting in thousands of individuals who fit all three categories.
- Second, investigate treatment options that target this profoundly disabled group. One promising area is the use of electroconvulsive therapy (ECT) to treat the co-morbid affective and catatonic disorders that often drive aggression and self-injury. My own son is living at home today and not in a highly restricted residential facility because of the remarkable stabilization he achieved through ECT, and he isn't alone. There are many case studies in the psychiatric literature of young people with developmental delay and dangerous behaviors whose rages have been stopped by ECT – including, by the way, the young woman who blinded herself; unfortunately for her, her parents found this treatment too late to save her sight.
- Finally, expand both in-patient and out-patient psychiatric services to treat autistic individuals with dangerous behaviors. EASI Foundation is working to establish a best practices guide for treating this population,

Dena Gassner

January 29, 2013

My name is Dena Gassner and I am a licensed and University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) trained social worker providing direct hand-over-hand systems navigation support to teens and adults with Asperger Syndrome and Pervasive Developmental Disorder not otherwise specified (PDD-NOS) for the past six years.

Thank you for allowing me to address two significant needs. First, I have grave concern that we are not engaging in longitudinal studies to explore the emotional and physical implications of a lifetime of disenfranchisement from community resources and supports. In my professional experience, the later the diagnosis, the more likely it will be complicated with co-occurring mental illness. Many states deny services via the below 70 intelligence quotient (IQ) standard, resulting in this segment of the community being without services until co-occurring mental health issues develop. Mental health providers are not properly prepared to address the unique needs presented by this population. Lastly, I am seeing increased incidence rates for physical issues such as scoliosis, fibromyalgia, lupus and other autoimmune issues in our unsupported adult population. Our community must realize that their intellect is no remedy for these very real disabling issues.

Secondly, we must address the massive denial of services to women with autism spectrum conditions. My practice ratio is 1-1, women to men. Colleagues in the nation working directly in human services support confirm no more than a 2-1 differential in gender representation. Despite statistics suggestive that a 2-1 ratio is more accurate, we continue to operate under a gender bias that includes dependency on the male phenotype for the "expression" (Attwood) of ASD.

Of the women I have served via my practice and in national training, I have not met a single woman who has not endured emotional, physical and sexual abuse. Not one. Some experienced abuse but were unable to fully and accurately report the assault, stating it wasn't "rape because he didn't hurt me."

With astonishing frequency these vulnerable women are subjected to relationships with partners who have abusive natures. Thus, the woman becomes the unsupported primary caregiver to children, many of whom also experience autism. These mothers are revictimized as they attempt but often fail to navigate the social politics required to insure schools give their children what they need, thus the cycle of instability continues. Unplanned pregnancies, domestic violence and poverty occur at astronomical frequencies and no one is noticing. I can tell you this scenario is the rule rather than the exception. There is no research being done to substantiate what my colleagues and I see. But the damage is multi-generational and needs to be addressed.

While I respect continued efforts with employment and education, I can state with confidence that no one in my practice (40 ongoing clients aged 19-63) is prepared to address either option. We are not addressing autism in my practice; we are dealing with PTSD and undoing abuse. The focus on employment and education is moot without undoing the emotional trauma instilled upon us from late diagnosis.

As such, I am asking that the IACC name a professional woman to its panel—a woman who has an autism condition who is also highly qualified and trained—with educational training comparable to that of the other professionals on this panel. There are many women with Asperger Syndrome who have human

services backgrounds who could meaningfully and intentionally contribute. Please consider this need moving forward.

Sincerely,
Dena L. Gassner, LMSW
Director
Center For Understanding

Dawn Loughborough

January 29, 2013

Subject: Autism is Medical

My name is Dawn Loughborough. I am the mother of a child with autism. I am here today to convey medical concerns and Autism. As a coordinating agency, IACC should work to coordinate medical concerns in Autism. What families would like is a physiological model for Autism as a special patient population.

Coordinating such an approach will help ready hospitals and clinics in the mainstream medical practices for patients with Autism, improve quality of care, and lower costs of autism treatments. It would help physicians and staff to better serve the autism patient population on concerns that impact delivery of care such as emergency room care metabolic considerations for medicines and anesthesia.

We desire an Integrative Autism Medical Care model similar to St Jude's Hospital quality of care approach to children's cancer where the finest teams work together to facilitate clinical treatments that inform mainstream medical institutions. If we are going to continue to deny and ignore the environmental and vaccine causation concerns, we need to put medical care in place to manage the resulting health outcomes and be responsible for these families' quality of life.

Quite often, our children have massive inflammation which alters the immune system and the nervous system both. These children cannot detoxify well. They have sensitivities and sensory problems.

It is very hard to say vaccine injury is happening without huge industrial-political back lash, but in reality, all science starts with observation. And the overwhelming observation coming from parents is that their children are changing after vaccines. Whether it is a genetic predisposition, illness, quality of vaccine, or sensitivity to one or more vaccine components, children are having adverse events and it is causing Autism. Federal awards from the NVICP should inform IACC further. Fifty percent of Americans are vaccinating on alternative schedules because they have lost faith in the national vaccine program.

The relevance here is that IAAC exists to coordinate Autism. Autistic children are physically ill and require accurate diagnosis and appropriate treatment and quality of care. How do we know what to do if they have never been tested for things like mitochondrial disorder? Continuing to treat autism from a psychological model denies basic medical care to a generation of children. In addition to appropriate medical treatment, integrative services such as speech therapy, occupational therapy, well being and social development interventions are imperative.

Here are some general concerns that come from not talking about this and not coordinating medical solutions:

1. Intake Analysis Lacks Collection of Medical/ Physiological Data
Medical intake diagnostics for regressive autism are missing from mainstream medicine. We have psychological intake, but we do not have physiological intake. Caregiver observations need to be accounted for and pathways for appropriate medical treatment discussed.

2. Medical Management of Adverse Events

Flu shots are known to sometimes trigger Guillain-Barre Syndrome which affects the nervous system and can paralyze patients, but physicians can now treat GBS early on with steroids and help patients avoid or recover faster… but childhood vaccines aren't identified in this manner which impedes knowing the signs of vaccine injury that may lead to chronic illnesses, like autism, when not treated.

Emergency room staff and pediatrician's offices need to be trained to recognize vaccine reaction so that they may start interventions immediately.

3. Medical Screening Needs to be Developed
Mitochondrial disorders are not rare, but rather a common issue with regressive autism. Our children should be screened for mitochondrial disorders. Additional screenings can be developed in future.

4. Seizures are Underdiagnosed
60% of autistic patients have seizure disorder or abnormal brain activity often affecting speech and movement and social disorders. Many children do not have their seizures detected because they are not referred to a neurologist for an electroencephalogram (EEG) to look at their brain activity. All children with autism and speech or movement problems should be presented the opportunity to have a 24 hour EEG.

5. Gastrointestinal and Immune System Problems are Disregarded
Severe Gastrointestinal symptoms occur in a large percentage of autistic children. These children can have bowel disease, malabsorption, nutritional deficiencies, severe pain, inflammation, bleeding, diarrhea, constipation and immune dysfunction. Many children exhibit self-injurious behaviors in response to this pain. Proper investigation of and diagnoses is rarely made and most of our children are sent off with laxatives as their only intervention later in life leading to motility issues such as Hirshsprungs disease. This lack of investigation is nothing short of medical neglect. Endoscopy and colonoscopy are the standard that would be applied to any other patient presenting with the same persistent, severe symptoms. Autistic children and adults suffering, some for many years, when treated appropriately, drastically improve.

Faulty immune systems cause many symptoms and illnesses in the autistic child. All children should be baseline tested prior to receiving multiple vaccinations at once.

Many children who have autism have overloaded immune systems and are highly sensitive with extensive allergies to foods like gluten, casein, corn and soy, and other additives used in medicines including but not limited to dyes, glutamate, artificial sweeteners, and actual constituents themselves.

6. Detox Mechanisms are Sub Par
Children with Autism are terrible at detoxifying. They need system supports to assist with proper detoxification such as comes from [vitamin] B12 shots or glutathione. They are not effective excretors. They have a lot of metals in their systems. There are novel and emerging medical therapies to help with excretion.

7. Current Infectious Disease Management is Not Specific to Individual Needs
Policies currently in place by pediatric associations and individual practices exclude the very patient population that requires extensive coordination of care by a medical home and primary pediatrician. Parents who care for children with severe illness of injury following vaccination are told they must continue to vaccinate their child or they are forced from the pediatrician's practice. This results in children going without appropriate medical care.

I hope this shines some light on some of the very basic issues families are dealing with. Since 1998, I have had parent mentoring conversations with these families and this is our reality. We are everywhere. Thank you for this agency's time.

Jake Crosby

January 29, 2013

Hello, my name is Jake Crosby, for those of you who don't know me. I am an MPH candidate studying epidemiology at GW School of Public Health and Health Services and a contributing editor to Age of Autism: Daily Web Newspaper of the Autism Epidemic. The views I am about to express here are my own.

In the previous months following my last public comment to IACC, my general opinion of this committee has not changed; it is merely a tool of a federal agency, the NIH, implicated in covering up the causal role vaccines play in the autism epidemic. It uses this tool to distract and deflect away from that cause by taking the autism community down the garden path of what the "real" causes of autism could be.

This was abundantly clear in my conversations with several key federal members of IACC, particularly the NIH director Dr. Francis Collins and the IACC Chair Dr. Tom Insel. I asked Francis Collins if he thought it was wise that Marie McCormick, chair of the 2004 Institute of Medicine (IOM) report aimed at whitewashing a vaccine-autism link, had made up her mind about the vaccine-autism link before looking at any evidence for-or-against when she said on January 12, 2001, "we are not ever going to come down that autism is a true side-effect."

First he told me he didn't think she made up her mind and then he changed his story to claiming that he didn't think her statements had much of an impact. Didn't have much of an impact? This is the chairwoman of the panel that produced the scientific con-job held up as the "scientific consensus" that vaccines don't cause autism for the IOM, which Collins himself agreed has global influence. He also admitted that if IOM is corrupted, then that would corrupt the whole scientific process. Yet he would not admit IOM is corrupt. So the director of the NIH does not thing coming to a preconceived, evidence-free conclusion is corrupt. If that is not corrupt to him, what would be?

When I asked him I was thrown out of NIH and dubbed a "stalker" by vaccine industry spokesman Paul Offit after I corrected his faulty reasoning behind claiming that all autism begins prenatally, Collins told me "you must not have been very diplomatic in your approach. Before that, I wrote a letter to his office inquiring about my removal, for which I received no response.

I wasn't any happier following my conversation with Tom Insel. Even though he holds a tremendous conflict-of-interest with his brother having developed a vaccine with the mercury-based neurotoxic preservative thimerosal, which plays a causal role in the autism epidemic, his big response that this happened before I was born. Therefore, it's not a concern. Well, of course it happened before I was born. I was born at the beginning of the autism epidemic, so the development of any vaccine that contributed to the epidemic would have had to have taken place before my birth!

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Megan O'Boyle/Geraldine Bliss

January 29, 2013

[Photo Redacted]

My name is Geraldine Bliss. I have a 14 year old with autism and epilepsy, caused by a partial deletion of the SHANK3 gene. I chair the research support committee of the Phelan-Mc Dermid Syndrome Foundation.

Phelan-McDermid Syndrome is caused by deletions of 22q13 and mutations of the SHANK3 gene. Phelan-McDermid Syndrome is highly associated with autism. 50% of people with Phelan-McDermid Syndrome meet strict criteria for autism and 80% fall on the autism spectrum. Approximately ½%-1% of all cases of autism are caused by deletions of 22q13 or SHANK3 mutations. While that might not seem like very much, SHANK3 protein plays an important and central role in synaptic structure, learning, and memory in autism. It interacts with many other proteins critical to neurological functioning, and many of these proteins are also implicated in autism.

I volunteer my time with the Phelan-McDermid Syndrome Foundation because I believe that one day we will have cures for Phelan-McDermid Syndrome and other genetic causes of autism. There's definitely a degree of hopeful thinking involved – my son needs a cure. But there are also objective reasons to believe that a cure is within reach. One need only look at Fragile X to see how breakthroughs there are forging new paths for autism research.

In the Phelan-McDermid community, we are very excited about a number of different SHANK3 knockout mouse models. These mice are some of the most important resources for hastening scientific research. Because it is impossible to look into the brains of people with autism to understand what is happening at a molecular level, these mouse models allow scientists to study how genetic mutations cause molecular changes in the brain. These mouse models are also important because they can be used to identify and test new drugs.

My greatest hope is that my son's life will be improved by new drugs – not in a dozen years, but in the next few years. There are many projects that will need to be done, and they depend on well-validated model systems to be made **widely available** to the scientific community.

Unfortunately, there are systemic and institutional barriers that are slowing down the process of finding cures. These barriers are creating real problems for scientists, who have failed to reproduce findings in many mouse models of autism. These inconsistencies could stem from many different factors: differences in genetic background, subtle differences in behavioral assays or the way data are analyzed, real phenotypic variability, compensatory mechanisms, environmental differences, or other factors.
Many of you on the IACC know these problems really are NOT insurmountable.

First, we need uniformly backcrossed lines, so the role of genetic background in phenotypic variability will be minimized.

Second, we need mouse models to be disseminated quickly to the scientific community. It's not okay for investigators to keep their mice for years and not make them available to other scientists – especially those mice that have been funded by the federal government. These are important national resources.
Third, we need programs that can ensure mouse models of autism undergo behavioral and electrophysiological phenotyping that is done in a standardized fashion to minimize various sources of bias.

Fourth, we need more scientists conducting replication studies. Industry representatives have repeatedly cautioned me about the need for mouse findings to be reproduced before they are willing to make investments in drug development. This is a real barrier to translating basic science into therapeutics, but without incentives for investigators, I don't think there will be too many investigators who would be willing to make replication studies a major focus of their work, other than as a necessary precursor to other projects.

Fifth, we need to make sure the findings from replication studies are published somewhere. We know that occasionally scientists do repeat the studies of their colleagues, but the findings, whether positive or negative, aren't likely to be published in a high impact journal, so they are not submitted for publication anywhere.

I urge you to look at what the Simons Foundation has begun to do. Simons [Foundation] has a few initiatives that will address some of these systemic problems. So far, though, Simons' plans include only a few mouse models. I'm extremely grateful that SHANK3 mice are among the prioritized mouse lines at Simons, but the autism community will need more than a few mouse models.

As I've gotten more involved in science through my role with the Phelan-McDermid Syndrome, I've grown very concerned about what these barriers will mean for the autism community. While it's important that we continue to have projects that are exploring new veins of research, we also need to make sure we are cultivating the most promising areas of research in ways that will translate into effective therapeutics for patients.

As you develop the strategies for our nation's research portfolio for 2013 and beyond, I urge you to consider how we can systemically make well-validated mouse models widely available to the scientific community.