Oral Public Comments

IACC Full Committee Meeting

January 12, 2016

List of Oral Public Comments

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

Lanny Edelsohn **January 12, 2016**

Thank you for the opportunity to offer some of my insights regarding persons on the Autism Spectrum to the IACC. My name is Lanny Edelsohn. I wear three hats. The first hat and the most important one is the hat of a father of a 43-year-old son with a significant intellectual disability. He cannot add 3 + 3, cannot shave himself and needs supervision with most of his personal care. However, I enjoy reading his frequent, poorly spelled, joyful, 3 or 4 word e mails with smileys daily. My second hat is that of a neurologist and Clinical Professor of Neurology, a hat I have worn for 43 years. Wearing this hat I have cared for thousands of persons with Intellectual Disabilities including adults with Autism. My third hat is that of President of Homes For Life Foundation, a not for profit foundation that my wife and I established in honor of our son [PII redacted]. My wife has single handedly, as a volunteer with no paid staff, raised approximately 10 million dollars over the last 25 years, and has designed, built and furnished 25 group homes and 2 apartments for those with Autism and other intellectual disability disorders. One hundred and four persons with a variety of intellectual disabilities now have a safe place to call home.

My comments today, although brief, will focus on three issues – Capacity, Community and Choice.

The first is capacity. As a neurologist I see patients who clearly fit the definition of an intellectual and developmental disability as Federally codified in the Developmental Disability Assistance and Bill of Rights. (42 U.S.Code § 15002).

One of my many patients is a [PII redacted] man with severe autism and epilepsy. Let me call him Joseph. Joseph has no speech, minimal comprehension, has self-abusive behavior, sometimes will strike out at relatives and aides and lives at home with his father, his disabled mother, 2 brothers with severe autism and a neurotypical sister. His future is grim unless we recognize that his capacity is that of an eight year old and he should be protected in life as we would always guide and protect someone with a capacity of an eight year old. I will address his ability to choose later in my presentation. Suffice it to say at this point that he is a man in stature but an 8 year old in behavior. However, there are those in positions of power and influence who stress self-advocacy and who paint all those with Autism and other IDD disorders with one brush, with a single color, regardless of their capacity. "Nothing about us without us" is the familiar mantra. Joseph's ability to self-advocate is clearly limited. Ari Ne'eman the founder of ASAN on the other hand is a brilliant, articulate man who writes an extensive blog, testifies frequently and alleges that because he has a mild form of autism he can therefore speak for all those with Autism and others with significant disabilities. Mr. Ne'eman has a right to speak for himself but not for Joseph or my son. Mr. Ne'eman does not have an intellectual disability according to the federal definition and clearly has capacity. Joseph has a clear intellectual disability, is vulnerable and has the capacity of an 8 year old.

The second is community. Ms. Sharon Lewis, the former HHS Commissioner, and others have decided to redefine the meaning of community under the Administration for Community Living (ACL). Those with Autism and other intellectual disabilities needing Federal and State support can only live in communities consistent with the ACL's definition and now CMS's definition of community. With the new regulations it is assumed that the community will embrace those with IDD, help with their care and even invite them over for parties, barbecues, sporting events etc. Having built 25 group homes in beautiful Delaware communities over the last 25 years I can assure you that #1- NIMBY is the first rule we have had to overcome. #2- No-one, let me repeat, no-one has ever invited any of the 104 very nice people living in our Homes For Life homes to an event despite the fact that we host an open house whenever WE move into a neighborhood to introduce the neighbors to our special needs adults. Three of our homes are on the Campus of the University of Delaware. No students, faculty members or neighbors have ever embraced the people living in these beautiful homes. Therefore the premise that the neurotypical community wants us in their neighborhood and will embrace us is not only faulty but also naive.

Lastly, let me address choice. All of us have chosen where we live. It is an absolute right under the constitution. Why is it that those with Autism and IDD cannot have that choice? Imagine the outcry if Chinese-Americans, African-Americans, Jewish-Americans, Italian-Americans and other ethnic groups were limited in their choice of community. We have all enjoyed experiencing the culture, food and camaraderie found in culturally identified communities of many of our major cities such as China Town and Little Italy. Persons with similar interests and backgrounds often choose to live together and thrive together. Our loved ones with Autism and IDD are entitled to choice as well; but the outcry related to a violation of their civil rights is merely a whisper. They deserve better. They deserve a voice. Some may choose to stay with their families assuming that the families, as they age, can continue to care for them. Others may want to choose an apartment, condo, group home, farm, intentional community or other arrangement. The menu of choices should be expanded, not limited to ensure a meaningful quality of life.

Let me return briefly to Joseph. Despite his many challenges, Joseph likes to prepare some simple meals. In fact, much to the chagrin of his parents, he frequently awakens at 2 or 3 AM to prepare an early breakfast. He chooses the ingredients and he chooses the time. I can imagine a future for Joseph in an environment where his skills are embraced and his disabilities accepted. Perhaps he would thrive in a farm community where he could be taught to grow his vegetables, milk a cow and prepare a meal for his new friends and staff. I can also imagine a life of isolation and loneliness should he be forced by regulation to live in an apartment in a community that is unwilling to accept him. The defining principle should be quality of life not geography.

Capacity. Community. Choice. Three critical issues that need to be addressed.

As a father, physician and advocate for those with disabilities I strongly urge you to use your voices to protect those with Autism and other intellectual disabilities by remembering the three C's.

Thank you.

Sincerely,
Lanny Edelsohn MD

Christiana Care Neurology Specialists
Newark, DE
Clinical Professor of Neurology
Jefferson Medical College
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Lisa Wiederlight **January 12, 2016**

Subject: Addressing the Urgency of the Autism Crisis Through Collaboration with Relevant Stakeholders for the Development of Public Policy Recommendations

Lisa M. Wiederlight, MPP
Executive Director, SafeMinds

My name is Lisa Wiederlight. I am the mother of a 15 year old son with autism, and executive director of SafeMinds, a national nonprofit organization whose mission is to end the autism epidemic by promoting environmental research and effective treatments.

In November, I asked this Committee to form **four workgroups** to address the urgency of the autism crisis. I am told that you must begin to formulate a Strategic Plan immediately, and so I ask that these workgroups are established today, to inform the Strategic Plan document. The four workgroups are: (1) Environmental Factors that May Underlie the Rise in Autism Prevalence; (2) Co-occurring Conditions with Autism; (3) Autism and Wandering; and (4) Caregiver Support.

Workgroup 1: the Environment. Autism is an urgent issue for this country—in terms of the safety, health, and welfare of people with autism and the skyrocketing costs to American taxpayers. As you know, **autism prevalence has increased from 1 in 88 in 2012 to 1 in 45 in 2015,** according to the U.S. Centers for Disease Control and Prevention. With a number of potential environmental causes tentatively identified scientifically but no policy in place to utilize these findings for prevention, it is unlikely this number will cease its downward spiral anytime soon.

A UC Davis study published last year in the *Journal of Autism and Developmental Disorders* found that **the total costs for caring for all people with autism spectrum disorder in the US for 2015 were $268 billion, and this number is forecasted this cost to rise to $461 billion in 2025.** One of the study authors remarked that the current costs of ASD are more than double the combined costs of stroke and hypertension, and are on par with the costs of diabetes. A UC Davis news release stated that "If ASD prevalence continues to grow as it has recently, the costs will likely far exceed those of diabetes in 2025." Where is the urgency to address prevention from modifiable environmental risk factors?

Workgroup 2: Co-Occurring Conditions. According to a study published in the November 5, 2015 issue of the *British Journal of Psychiatry*, **people with autism are more than twice as likely as their peers in the general population to die prematurely.** The study found that the risk of suicide in individuals with mild autism is about 10 times higher than in the general population. The most common cause of death among people with severe autism is epilepsy, which affects up to 40 percent of people with autism. Approximately 49 percent of people with autism wander from safe environments, as this Committee knows. Sadly, in addition to the over 30 people with autism who wandered and died in 2015, the autism community learned on January 2nd that a five year old child with autism wandered and drowned in Allentown, Pa. Serious co-occurring conditions are REAL and they can be DEADLY.

Workgroup 3: Wandering. We cannot wait to solve the problems that families facing autism address every day, especially when there are seemingly simple things that can be done to affect change. In November, SafeMinds asked that the IACC coordinate with the legislative affairs offices at HHS and the U.S. Department of Justice to support Avonte's Law Act of 2015, S.163, which provides funds to support law enforcement training on autism and wandering. If you have not already done so, please do this today. There are many opportunities for cooperation and collaboration among persons with autism, parents, educational professionals, autism service providers, and public safety practitioners related to addressing the wandering issue. A workgroup on wandering is a sound mechanism to coordinate Federal response to this critical need.

Workgroup 4: Caregivers Support. For many families, the past two months since the November IACC meeting were not easy, slow, or uneventful, especially those families facing autism. There's the autism parent whose child had his second seizure and now has epilepsy, which does not run in the family. There's the autism parent whose child was extremely aggressive with her as a result of a bad reaction to a medicine, and who had the police at her house three times in four days—except that the police did not have any training in addressing autism, and try as they might, they could only put a band-aid on the problem. There's the autism parent who, while working full-time as a single parent, had to prepare for, and advocate for her son at a school IEP meeting and then give feedback on a behavior intervention plan by herself. And what if I told you that "that autism parent" was **the same parent who endured all of what I described in the past two months since the IACC last met**? That family, unfortunately, is one of too many. Caregiver support is ESSENTIAL.

We are one-third of the way to reauthorization of the Autism CARES Act of 2014, and HHS has not yet fulfilled its legal requirement to designate an existing official within the Department to oversee, in consultation with the Secretaries of Defense and Education, national ASD research, services, and support activities. Consequently, the IACC is now the Federal government's only autism policy-related body.

A great majority of what the IACC has supported in the past is academic research—very little of which has helped families facing autism every day, including my own. We need public policy making and best practices research now, more than ever.

Today you are faced with a great opportunity—because, the autism crisis demands urgency, and, as my mentor Ellen Camhi used to say, "Democracy is not a spectator sport." One tenet of effective public policy development is consulting with relevant stakeholders in the formulation of public policy.

Workgroups provide a mechanism to involve subject matter experts from outside of the IACC to make the most effective policy recommendations to the HHS Secretary, including, but not limited to, people with autism who are not able to participate regularly in IACC meetings due to the characteristics and/or the severity of their autism, caregivers across the country, environmental health experts, toxicology specialists, gastroenterologists, and public safety professionals.

We are hopeful that the workgroups will be established today, so that significant, measureable, and positive changes in the lives of people with autism and their families will occur as soon as possible.

Thank you.

Josh Mazer **January 12, 2016**

Subject: Low Cost, Effective Strategies to Potentially Enhance the Ability of Individuals on the Autism Spectrum to Access Educational Curriculum- A Case Study

Thank you for the opportunity to address the Committee. Welcome to incoming Acting Director Dr. Cuthbert and wishing him success during his tenure on this Committee.

I live in Annapolis, Maryland. I hold a BS in Environmental Biology from Tulane University. My wife teaches special education in Anne Arundel County. I would like to share with the Committee our experience in helping school age children become better able to access educational curriculum.
The basis for our strategy starts with an article I read in the Journal Pediatrics November 2012 Volume 130 Issue Supplement 2 Gastrointestinal Conditions in Children with Autism Spectrum Disorder: Developing a Research Agenda Coury et al. According to this article "The reported prevalence of any GI disorder in children with ASDs ranges from 9% to 91% (see Fig 1), abdominal pain or discomfort ranges from 2% to 41%, constipation from 6% to 45%, diarrhea from 3% to 77%, and persistent diarrhea from 8% to 19%3,9,11–21. Although all the studies have significant methodological limitations, they collectively indicate unusually high rates of GI disorders or certain GI symptoms in children with ASDs and higher rates in all but one study when a control population was used."

On the basis of this data, I will present the case history of a male child currently age 14 years 4 months who underwent evaluation and treatment for gut disorders. The case is representative of the possibility for an improvement in the overall health and mental ability of children on the spectrum who have undiagnosed gut problems when their gut disorders are recognized and treated. History, evaluation, diagnosis, and resultant changes in measured levels of neurotransmitters, body mass index, and prescription medications will be discussed.

The child John Doe was born with normal Apgar scores and progressed through all developmental milestones through age 14 months. At that time, he lost all language, stopped eye contact, and began behaviors indicative of autism. Age 36 months he was diagnosed at Johns Hopkins with autism.
Age 18 months he began periods of episodic diarrhea with yellow, loose, foul smelling stools forcefully expelled. There was an average of four copious bowel movements per day. Child Doe exhibited signs of stomach discomfort by guarding his stomach; molding his stomach against furniture, and clutching his stomach. He refused most foods except milk and highly processed, easily digestible foods such as chicken nuggets, French fries, and pasta. His stomach was noticeably distended and guarded when probed. Parents took him to pediatrician who checked for helicobacter pylori with negative results. Over the ensuing 10 years, parents continued routine pediatric visits. Child Doe was in 5th percentile for height and 90th percentile for weight with a BMI in the 27 to 30 range. His diarrhea suddenly stopped age 5 after a course of Vancomycin and Nystatin. His stomach was still bloated and he still showed signs of gastric distress.

Age 11 child was seen by board certified family health doctor. Doctor recommended CAT scan of child stomach as the negative effect of the radiation exposure was offset by the value of the diagnostic knowledge. The CAT scan revealed prominent mesenteric lymph nodes in the ileocolic region and retroperitoneal left periaortic; suspect these lymph nodes are post inflammatory reactive; spondylolysis at L5 with grade I spondylolisthesis of L5 and S1; and moderate stool within the ascending and transverse segments of the colon.

On the basis of the CT scan, the child was worked up for gut issues. Chymotrypsin, intestinal lysozyme, and gut flora were assayed and determined to be abnormal. A concurrent neurotransmitter panel was run and showed: serotonin: 20th percentile of normal range; GABA 2.5th percentile; Glycine 50th percentile; Glutamate 80th percentile; Histamine 80th percentile; PEA 25th percentile; Dopamine 58th percentile; Norepinephrine 70th percentile; and Epinephrine 15th percentile.

Child Doe underwent further gut evaluation by board certified pediatric gastroenterologist involving Prometheus Test (negative for IBD); pill cam, endoscopy, colonoscopy, and 19 biopsies of areas of intestinal tract. Initial findings are: 1) Distal esophagitis; 2) Antritis with erythematous LNH; 3) duodenitis (WSLs with erythema; 4) terminal ileum moderately lymphonodular with mildly erythematous line; 5) colonic mucosa diffuse mild LNH; 6) hypertrophied nodules of the rectosigmoid demonstrating halo erythema; 7) white spot micro erosions; and 8) multiple apthous ulcerations in the proximal jejunum. The biopsy resulted in a positive diagnosis of mild chronic inflammatory bowel disease.

Once the diagnostic process was completed, Child Doe was placed on a standard regime to treat IBD. This included a three month course of budesonide followed by non steroidal anti inflammatory Pentasa for a further 6 months.

During the course of treatment, parents reported that Child Doe’s gut distress was visibly reduced. The obvious gut distension that had been a feature of the patient for over ten years ameliorated. Patient’s BMI dropped from 29 at start of treatment to 18 after nine months. Intestinal lysozymes declined from 160 to 5. All neurotransmitter levels reset to ranges within 80th to 110th percentile with no medication or supplementation. Patient experienced a concurrent growth spurt and two years after initiating gut intervention height is 40th percentile and weight is 50th percentile.

The Pediatrics article discussing undiagnosed gut issues in children with autism is a relevant and important starting point to begin the process of helping these children become more able to access academic curriculum. As Patient Doe improved medically, he became better able to focus and learn. In addition, it was found that his dose of Focalin could be reduced from 15mg XR down to 5mg, or 10 mg XR, with same result as the higher dose, possibly due to better absorption through healed gut.
The Pediatrics article referenced above suggests that about 50% of children with ASD have undiagnosed gut issues. It is relatively simple, inexpensive, and noninvasive to do initial screening for potentially treatable gut issues in these kids. If we make it standard medical practice to do gut evaluations on ASD kids, they can be treated. As their stomachs are healed, they are better able to focus and access scholastic curriculum.

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Amy Lutz **January 12, 2016**

My name is Amy Lutz, and my son [PII redacted], 17, is severely autistic. For most of the past two years, I have been immersed in the debate gripping our community over the type of housing that will be available to [PII redacted] and his peers when they become adults, a project that culminated in my article "Where Should Autistic Adults Live?" which was published by *The Atlantic* in May. This piece discussed the push by organized self-advocates for small, dispersed, integrated housing as the only acceptable model, and the regulations that have been accordingly proposed in several states drastically restricting the size and setting of housing available to waiver recipients. It's this problem I'm asking the IACC to address today.

There's no doubt that autistic adults who choose full community integration should be supported as much as necessary to achieve that goal. But it isn't the most important goal for everybody. Parents of severely autistic children in particular have an entirely different set of priorities. Doors that can be locked by residents, freedom of mobility and free access to food – all policies demanded by self-advocates – pose significant danger to individuals with compulsions to elope or eat themselves sick. Rather, parents whose children have profound behavioral or medical challenges remain focused on the safety, security and structure they feel will maximize quality of life.

But congregate settings aren't just appealing to parents; in a 2013 survey by Autism Speaks, almost 30% of autistic individuals surveyed identified intentional communities as their "most preferred housing style." After traveling around the country for the Atlantic piece, I understood why. I saw farmsteads that allowed residents to pursue agricultural, artistic and commercial enterprises in peaceful, bucolic environments, like Camphill in my own state of Pennsylvania, and intentional communities designed to facilitate the development of strong peer relationships among adults who had never in their lives had real friends, like the Arc Village in Jacksonville. The fact is, many neurotypical people choose to live with their peers in gated communities – my mom lives in a retirement community in Florida. It's baffling to me that autistic adults should not have the same right everyone in this room enjoys to choose where and with whom they live.

The courts and federal agencies have always recognized that the broad range of impairment in the autistic and I/DD populations requires a similarly broad range of housing options, but inclusionists have persistently misinterpreted their rulings. The 1999 Olmstead decision, which is frequently cited as a mandate for community integration, is actually a mandate for choice, including congregate settings; the justices noted there is no "federal requirement that community-based treatment be imposed on patients who do not desire it." Similarly, the CMS Final Rule, released in January 2014, set no size limits, no density restrictions, and no proximity rules. Rather, it looked to "establish a more outcome-oriented definition of home and community-based settings, rather than one based on a setting's location, geography or physical characteristics."

However, confusion over the Final Rule arose from the guidance CMS issued two months later, which did cite farmsteads, gated communities and clustered group homes as potentially isolating. Afraid of running afoul of CMS and the Department of Justice, and under pressure from organized self-advocates who claim that any setting larger than four people is an institution, many states have since proposed rules that would eliminate congregate settings entirely. I am asking the IACC to review and investigate this concerning trend, particularly its impact on our most disabled adults, and to advise Secretary

Burwell to direct CMS to issue clearer guidance, in keeping with Olmstead, re-emphasizing the importance of choice and quality outcomes – goals that we've seen can be achieved across all settings, and goals which are intended for ALL individuals with disabilities under Olmstead.

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Mark Olson **January 12, 2016**

Good afternoon Committee members and public guests.

My name is Mark Olson. I am here on behalf of my daughter, [PII redacted], who is 20, nonverbal and autistic. I am her only parent, and legal guardian.

I believe that [PII redacted], and other adults with autism, have the human and civil rights to live, work, play, socialize, recreate, live, learn and worship in the settings and manner of their choosing, with the support of family, friends and caregivers.

While [PII redacted]'s abilities are many and largely undiscovered, her disabilities are significant enough that they may likely keep her from living completely independently. They may also make it very difficult for her to earn enough money to be free of government funded supports. To what extent federal and state regulations permit her to direct her own supports will ultimately enable or restrict her self-determination.

We are very active in our community and she has traveled with me extensively to conferences, site visits to housing and employment settings, and meetings with other adults on the spectrum and their families. She has walked Capitol Hill in Washington DC to meet with Congressional staffers and appeared in front of the Nevada Legislature to speak up for insurance reform, expansion of workforces who can provide the supports she'll need, and for the right to have her choices respected.

Today as she and I engage in the process of person-centered planning for the next 5, 10 and 20 years of her life, we are optimistic, but also deeply concerned.

We're optimistic because we have seen and met with creative, inspired people developing innovative, promising housing and employment opportunities all over the U.S. [PII redacted] is a unique individual with diverse interests. A "one-size-fits-all" approach to where she will live and work and enjoy her life won't work for her. And if she is anything like her father, she is likely to change residences and jobs several times in her lifetime. [PII redacted] should have the broadest range of opportunities and settings from which to choose, and the least red tape and fewest barriers to choose them.

We're deeply concerned because some of the legislation and regulations meant to enhance the outcomes and experiences of her choices, and some of the efforts of state and federal agencies and private advocacy organizations, are having the unintended (or perhaps intended) consequences of limiting or eliminating her options and her rights to choose. Efforts by people who have never met [PII redacted], making judgements about settings and opportunities they've never seen, that put limits on her autonomy are wrong. Enabling people with disabilities to make their own choices, even if you think they are making the wrong choices, or different life choices than you would make, is a true measure of diversity.

I'd like to finish with two quotes. The first is from Brittany Dejean, founder and executive director at AbleThrive, writing on LinkedIn.com last month: *"People with disabilities and their families are responsible for making their own choices about disability and have their own views and narratives, all of* *which deserve to be equally respected and represented in society and in mainstream media. Let's let people make their own decisions and accept and respect the diversity that comes with it."*

The second is from Micaela Connery, an inclusion advocate and founder of the Unified Theater, writing in the *Huffington Post* last June: *"...we have to put the risks, fears, challenges, and uncertainty aside in favor of choice. Choice is closely aligned with respect, dignity, happiness, and independence -- things each of us seek daily. Funding alone won't likely fix the problem. The challenge isn't new, but the solutions will need to be."*

Thank you for the opportunity to speak before you today.

About Mark L. Olson
Mark L. Olson is the only parent and legal guardian to his daughter, [PII redacted], who is autistic. He is President & CEO of LTO Ventures; chair of the Adults and Aging Subcommittee for the Nevada Autism Commission; appointed member of the Nevada Governor's Task Force on Integrated Employment; and, a co-founding member of the Coalition for Community Choice.

About LTO Ventures
LTO Ventures is a 501(c)(3) Nevada nonprofit corporation that develops live/work/play intentional communities for adults with Autism Spectrum Disorder and related developmental disabilities. More information is available at: www.ltoventures.org

About Coalition for Community Choice
The Coalition for Community Choice is a national nonprofit alliance of individuals with disabilities, their families and friends, disability rights advocates, professionals, educators, and housing and service providers which aims to increase options and decrease barriers to housing and employment choices for all individuals with I/DD. More information is available at: www.coalitionforcommunitychoice.org

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Dr. Linda Varsou **January 12, 2016**

DEVASTATING EFFECTS OF CHRONIC PARENTAL DENIAL IN AUTISM

It is for the 6th time that I am bringing to the IACC meetings the serious, widespread and devastating issue of **"Chronic Parental Denial"** (*non-acceptance or non-resolution*) of their child's autism and/or denial of the extent of its severity, having detrimental effects to the child (or adult child), who becomes the definite and ultimate victim. Advocates, professionals and parents active in the field of autism, have the tendency to ignore or to underestimate its existence because by definition they are not in denial themselves. As the prevalence of autism is on the increase, the same applies to the issue of chronic parental denial, increasingly reported in blogs, autism awareness groups and societies, where parents are desperately seeking help on this issue. Although parental **"Denial"** is part of a normal mechanism within the "*grievance*" process that follows the diagnosis of autism (*whereby parents' reaction can be one of shock, denial, anger, bargaining, sadness, shame, guilt, depression, fear, anxiety and narcissistic trauma, eventually leading to adjustment, reparation, and acceptance*), **"Chronic Denial"** from a substantial number of parents (*usually from fathers, rarely from both*) could be characterized as a psychopathological trait. This type of Denial (*which is not a… river in Egypt*), is the most devastating issue, only second to the diagnosis of autism. This permanent resistance of acceptance, or the attitude of "*flight instead of fight*", is the negative side of the latter. Based on the deleterious site-effects and consequences of the chronic parental denial:

- Children miss out on the crucial early intervention therapies and decisive earliest positive professional help and advice.
- Collaboration between parents and professionals, which is of undeniable and utmost importance, fails.
- Any amount of services and funding provided for autism cannot prevent a parent's denial and the child doesn't get their benefits.
- The parent who recognizes all the implications of autism has the additional heavier burden of having to deal with the other parent's denial, and the child with autism pays the price of the family's conflict (*family dramas due to divorces, abandonment, lack of support, lack of collaboration between parents, still blaming "refrigerator mothers" as causing autism, etc*.).

The reasons of the widespread high prevalence of chronic parental denial especially in autism in many countries worldwide could be explained (*besides the disability's stigma, prejudice, lack of awareness, stereotyping, discrimination, etc.)* also by the fact that autism is characterized as an "*unseen*" disability compared to other disabilities, often parents belong to the Broad Autism Phenotype themselves, and by the impact of raising a child with autism has on the family.

Furthermore, parental denial compromises the quality of published data and articles, with conflicting, misleading, non-reproducible results. Depending on who gives the information to researchers, i.e. the parent in denial or not, the data are in total disagreement. Autism professionals estimate the prevalence of obvious chronic parental denial close to 45% in the US and close to 50% in Europe, but not official research data are available (not counting rare cases of filicide). Besides some dissertations and an original paper from Israel reporting the prevalence of chronic parental denial specifically in autism as high as 53% (*"Resolution of the Diagnosis Among Parents of Children with Autism Spectrum Disorder: Associations with Child and Parent Characteristics", J Autism Dev Disord (2010) 40:89–99*), relevant scientific literature is sadly wanting. Even the above mentioned comprehensive study from Israel, has the bias of the voluntary nature of parents' participation, i.e. those not in total denial, expecting the actual prevalence to be much higher.

Because children with autism should not be made to pay the cost of a parent's ignorance or chronic denial, I would propose **low-cost, fast and easy research protocols**, and a meta-analysis, to investigate the issue of denial, its extent and consequences, as well as measures to deal with the problem and prevent family dramas, as follows:

1. From now on, any type of research on autism must include and evaluate the factor of chronic parental denial in each individual case. There are already available protocols and questionnaires from previous research on denial, easy to apply to autism.
2. For all ongoing research protocols, there is still time to incorporate the evaluation of the factor "*chronic parental denial*".
3. For past, older or longitudinal autism studies, if access to data is still available, it is possible to go back and add the factor of denial, leading to a new updated publication. It is possible that denial could be a "confounding factor" altering the previous results.
4. A meta-analysis could give an accurate estimation of the prevalence and degree of chronic parent's denial in the US.

Based only on solid scientific data, IACC and Autism Organizations could propose the much needed mandatory changes at all levels. These results can be used to enforce social awareness, to every service, school, agency, State and Government, including judiciary changes to Family Court legislation, considering "*denial*" as serious as "*child abuse*" and the act of abandoning a child with autism as a crime, and also to promote ***"An Autism Friendly Society which will benefit us all"***. A similar study is going to start soon in Greece and Europe; why not in the US as well?

In conclusion, it is time to see the IACC addressing scientifically this particularly devastating issue of "*chronic parental denial*", so as to show its support and commitment to every family and person struggling with autism in the US.

From Dr. Linda (Angeliki) Papadimitriou-Varsou, PhD, MPH, DABCC, Immunologist, Assistant Professor. *Mother and legal guardian of a 30-year-old college student with autism; advocate for the Rights and Strengths of People with Autism, a fervent supporter of the concept: "**An Autism Friendly Society will benefit us all**". SHORT BIO: Long-standing member of different autism related organizations and scientific societies in the US. Founding and board member of the Greek Society for the Protection of Autistic People and founding member of the Greek Scientific Autism Network. Long-standing member of "Autism-Europe" and elected member to its Council of Administration. MSc in Biochemistry and postgraduate studies, Paris University; Specialization in Immunology, Paris Institute Pasteur, France; MSc in Public Health with honours; Diplomate of the American Board of Clinical Chemistry; Two PhDs in Diagnostic Laboratory Medicine; Research Associate at the University of Maryland School of Medicine, Faculty member at Johns Hopkins University School of Medicine where I studied neurosciences and initiated the "**fever study in autism**". Current position: Assistant Professor at the University of Athens School of Medicine in Greece, responsible for teaching 3rd year Medical students and graduate students in three MSc Programs at the Departments of Biology, Chemistry and Clinical Pharmacy -a position which allows me to spend more than half of the year in the US with my son, while continuing my teaching online.*

Katie Walsh **January 12, 2016**

Good afternoon. My name is Kate Walsh, and I'm a proud mom of a child on the autism spectrum. However, my son isn't the impetus for my address and plea to you today. The recent disappearance of Jayliel Vega Batista captured my attention, and his death broke my heart. I'm confident you've shared in the same emotional responses to this tragedy. I'm ashamed to admit it required the glare of the local spotlight on Jayliel's disappearance and preventable death to recall my attention to the ways in which we're continuing to fail these children and their families.

In the state of Pennsylvania, Jayliel's wandering incident didn't warrant the broadcast of an Amber Alert, and like many others within the region, I learned of his disappearance through social media. The day before his body was recovered, hundreds of online followers demanded an Amber Alert be issued in efforts to bring him home. After his confirmed death, public support for alerts issued for missing children with autism also, ironically, disappeared. Entirely inappropriate and yet not wholly unexpected, a faction of the general public's response moved instead to pass judgement on his family and their supposed culpability. Internet trolls were quick to assign blame and question how his loved ones could have momentarily looked away…

And what struck me is the irony that I too, am responsible because I had looked away. His death happened on my watch, and it happened on this committee's watch. We share in responsibility for Jayliel's death, because like his caregivers regrettably did in that brief, tragic moment, we've taken our eyes off him too, and other children like him…

I'm embarrassed to further confess that it was only after his death that I became aware of the appalling statistics. Forgive me if I'm redundant, as I'm sure you're already well-versed in the following, but these bear repeating:

- Nearly half of children with autism engage in wandering behavior.
- Wandering occurs across all settings, under every type of adult supervision.
- Increased risks are associated with autism severity.
- Half of families report they have never received advice or guidance about wandering from a professional.
- Accidental drowning accounts for approximately 90% of lethal outcomes. Sixty-eight percent of these deaths happened in a nearby pond, lake, creek or river.

I was stunned to discover: a new medical diagnosis code had been approved by the Centers for Disease Control. Implemented in October 2011, the code is listed as "Wandering in Diseases Classified Elsewhere". Is this really how prevalent wandering is, to necessitate a medical diagnosis? So I ask you: what are we doing to combat this?

Wandering dangers include Drowning; Exposure; Dehydration; Hypothermia; Traffic Injuries; Falls; Physical Restraint; Encounters with strangers; Encounters with law enforcement. Roughly half of children with autism attempt to elope from a safe environment, a rate nearly four times higher than their unaffected siblings. More than one third of children with autism who wander/elope are never or rarely able to communicate their name, address, or phone number.

Conditions like Alzheimer's and dementia are supported by federal dollars to counter very similar wandering incidents, yet autism-related wandering initiatives do not yet receive federal support or funding? Again I'm asking: are we watching this, or have we looked away?

This Committee's expressed mission is to provide advice to the Secretary of Health and Human Services on matters concerning autism spectrum disorder. You've been tasked with the responsibility to facilitate the efficient and effective exchange of information on autism activities among the member agencies in order to enhance coordination of autism-related programs and activities. To this end, and in efforts to satisfy your mission, you must take the following action steps:

First, immediately reinstate the Safety Subcommittee. IACC's Subcommittee on Safety was dissolved in 2012. IACC has since been petitioned multiple times to reinstitute a Subcommittee on Safety, but to no avail. Since 2012, the avertible deaths of Jayliel Vega Batista, Avonte Oquendo, and dozens of children might have been prevented through the findings and actions of an IACC Subcommittee on Safety. To efforts to illustrate this point, I attempted to research and determine the precise number of children with autism whose lives have been lost in wandering-related fatalities, but this data, if recorded anywhere, isn't easily available. I suspect, if I had wished to quote for you the exact number of children without autism who were abducted or endangered in the US since 2012, this data could be easily generated. And I ask you: which is more prevalent? This committee has both the ability and the obligation to respond to call to action in reinstituting the Safety Subcommittee, rather than continuing to effectively "look away".

Second, the reinstituted Safety Subcommittee must provide directives for mandated reporting and data collection of incidence and prevalence of wandering, bolting and eloping, as data proves critical to effective advocacy efforts and resource mobilization, program development, policy implementation and monitoring of interventions. Data must be aggregated and collated on a number of important elements, such as the prevalence and incidence of wandering and eloping, and the costs and consequences related to such incidents, especially loss of life. Develop and immediately implement a standardized format for recording and reporting data that can be centralized from the local, to the state to the national level. Institute systems management for regular data collection and analysis to involve partnerships between government organizations, civil society and academic or research institutions at both the national and sub-national level, then gather data from entities, such as:

- law enforcement
- hospitals and health care facilities;
- social work agencies and child protective services;
- schools and child care centers;
- and, parents and caregivers of children with autism. Eliminate stigmas and apprehensions endured by parents and caregivers when their autistic children have wandered or eloped. The reality is that we simply don't have enough accurate, timely, and serviceable data on the issue of wandering. This committee can help us get the information we need. You can change this. If you won't do this for us, who will?

Finally, and perhaps most importantly, Congress must be called upon to pass the stalled Avonte's Law Act. US Senator Chuck Schumer of New York State has twice put forward legislation that will go a long way into addressing the issues regarding the safety and recovery of wandering children with autism. If passed, Avonte's Law will provide federal funding for tracking devices, resources for families, and training for first responders that can aid in reducing incidents, particularly those resulting in tragedy.

Upon introduction of the bill, Senator Schumer remarked, "Thousands of families face the awful reality each and every day that their child with autism may run away. Making voluntary tracking devices available will help put parents at ease, and most importantly, help prevent future tragedies like Avonte's." Senator Schumer's statement is even more profound today, three hundred and sixty four days later; but unfortunately for Jayliel and his family, the stalled bill is many days too late.

This committee faces monumental tasks. You are hearing numerous calls to action, and at times, you are presented with conflicting priorities. I implore you to value the safety of our nation's autistic and special needs children as your highest priority. In reinstating the Safety Subcommittee, in providing increased research and opportunity to report, record and amass data of these incidents, and in vigorously advocating for the passage of Avonte's Law, this committee can satisfy your most important mission.

Thank you.

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

Desiree Kameka **January 12, 2016**

MADISON
HOUSE
AUTISM
FOUNDATION

Desiree Kameka, Director of Community Education & Advocacy, Madison House Autism

My name is Desiree Kameka, and I am a professional who has focused my career in improving the lives of those on the autism spectrum, specifically in regards to identifying and comparing housing and support models. I feel that I bring both a national and personal perspective to the IACC committee. It is timely that a presidential candidate is highlighting the needs of autistic adults by releasing a public plan to improve and expand services.

Last time I spoke here in April 2014, I shared a story about a friend of mine who was living in a homeless shelter in Seattle. He had lost his waiver supports and affordable housing voucher because someone whom he considered a friend said they should move out of state together. That “friend” took control of his finances, leaving him homeless and without access to any of the supports he previously had. Stories like this are not uncommon. Based on a national survey in 2012, the Disability Abuse Project concluded that 67% of autistics have been victims of abuse.

Thankfully, my friend has since moved to a supportive housing community, an apartment building created specifically to meet the lack of affordable housing and offer immediate supports to those who are chronically homeless due to a disability. He has control over his life, pays rent and can access supports as needed from on-site coordinators. This intentional community of 66 peers with various disabilities has made a huge difference for him. He still gives money to almost anyone who asks, but at least he has trustworthy neighbors to whom he can easily introduce his new friends.

I am extremely concerned that changing policy and regulations, without basis in research, would one day force him and many others to leave their homes in order to continue accessing essential life supports through the HCBS waiver in order to continue accessing essential life supports through the HCBS waiver. Unfortunately, even if the waiver recipient can clearly communicate that he or she wants to live or work in a particular setting, if the state determines through its assessment tools that the setting does not meet its Home and Community-Based criteria, that waiver recipient will be forced to move or forgo waiver funding. Restricting people’s access to waiver supports because they choose to have other autistic people as neighbors or coworkers is discrimination and wrong.

Policy and related assessment tools should be based in current research that helps shape policy into a direction that honors person-centered plans and preferences as well as ensures barriers to one’s quality of life are being identified and addressed.

There are three national trends of utmost concern for the future of autistic adults:

1) **States do not have strategic plans to prevent the forced institutionalization or crisis placements of autistic adults living with aging caregivers.** One million individuals with developmental disabilities live with a family caregiver over the age of 60, yet nationally only half a million people with developmental disabilities live and have supports in a setting outside of their family home. I continue to get desperate calls from mothers and fathers in their 70's and even 80's all seeking the answer to one question: What will happen to my son/daughter when I am no longer able to provide care?

2) **States are creating barriers to the local development of planned communities without regard for the demand of these settings nor a plan to provide a sustainable housing solution.** The goal of planned communities is to prevent the forced institutionalization or displacement of adults with disabilities from their hometown because the only "open bed" is hours away or affordable housing is inaccessible. These planned communities provide an additional housing choice for those on a fixed income, yet without basis in research, are being stigmatized as isolating and segregating. As a neurotypical, I experienced a huge expansion of personal growth and independence when I left my family home. Why should we expect anything different from autistic adults? How does staying in one's family home for decades of adult life influence their self-determination, confidence, independant living skills, ability to navigate their community, and build friendships? How would living in a supportive housing community influence these outcomes?

3) **States are promoting adult-foster care (sometimes called 'shared living') with limited outcome measurements.** Research findings by National Core Indicator study show that adult foster care settings have the highest rate of reported loneliness by individuals with developmental disabilities at 51%. Surprisingly, the setting with the lowest rate of loneliness is actually an I/DD institutional setting at 37%. Further research is needed for autistic adults to be more meaningfully informed when deciding if living with a host home is a good fit. How many times does one move from host homes in their lifetime? How do these moves impact one's quality of life and relationships? Do individuals understand that they will need to move if the host family relationship changes? Are accountability standards and outcome measurements sufficient? Will they be put at the bottom of the waitlist to access affordable housing and supports after realizing adult foster care is not a good fit?

Part of my job is to visit and profile residential and employment models across the country and around the world. I have visited 100 communities in nearly half the states. In a planned community in North Carolina, a man by the name of [PII redacted] told me, "In my other apartment, I could go to a neighbor and ask for sugar. They would give it to me. But here, I can go to my neighbor with my hurts and tears, and they will stay with me." He is not isolated, but has found a community within the greater community. His choice of home and community should be protected.

As a federally-funded interagency entity, IACC can speak with authority and dictate research into areas that should be shaping policy to meet the needs of autistic citizens throughout their lifespan.

Research is needed to determine if and how supportive housing communities, farmsteads, or other forms of intentional communities are creating barriers or enhancing community access and the quality of life of individuals with autism.

Please consider researching outcomes and why people choose to spend over $50,000 a year to live in private pay intentional communities and/or post-secondary residential schools.

Please consider setting aside funding to develop effective strategies for identifying abuse of autistic victims and improving person-centered, quality of life assessment tools to reflect what matters most to people;

Thank you for your commitment to those on the autism spectrum. Please don’t hesitate to contact me if Madison House Autism Foundation, or I can provide assistance or insights to the IACC committee.

Madison House Autism Foundation is a public 501 c 3 non-profit, national organization working to eliminate barriers and increase opportunities for the rapidly growing numbers of adults with autism. Its immediate priority is to address the near total lack of flexible housing options for adults with autism. Its programs and philosophy are based on the belief that sustainable, replicable solutions must engage all sectors including public and private sectors, non-profits, families and advocates.
For more information, visit www.madisonhouseautism.org.

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

Albert Enayati **January 12, 2016**

Treatment and Biomarker Focus of a Co-Occurring Conditions Workgroup within the IACC

Testimony Presented By

Albert Enayati, MSME

Research Scientist, Senior System Engineer

Father of [PII redacted], who regressed into autism after his childhood vaccinations

E-mail: [PII redacted]

Before the
***Interagency Autism Coordinating Committee** (**IACC**)*
Tuesday, January 12, 2016

Bethesda, MD

My name is Albert Enayati. My son [PII redacted] regressed into autism after receiving seven vaccines in the space of two days.

Today, I would like to expand on the SafeMinds recommendation to establish a workgroup under the IACC to investigate co-occurring conditions. Many of the most disabling or fatal features that are present in a person on the spectrum are co-morbid conditions. These conditions are amendable to treatment. There is an urgent need for a workgroup to follow promising treatment leads, shepherd existing treatments through clinical trials and facilitate FDA approvals and/or mainstream acceptance. This group would require membership from within the committee as well as significant representation from the broader autism advocacy and research communities. An example is Isaac Kohane, MD of Harvard Medical School[1] who was invited to speak to the IACC in the past and who has the knowledge to advise IACC on this topic.

Over the history of the IACC, there has been no coordinated effort to develop treatments for people on the spectrum. Despite 1.6 billion dollars in spending, parents still have few options that have been proven effective. Risperdal and Abilify are only appropriate for certain symptoms and have significant side effects. We can and must do better.

In 2015, researchers at Johns Hopkins University Medical School in collaboration with Massachusetts General Hospital for Children determined that chemicals extracted from broccoli sprouts may help ease autism symptoms[2]. In another published paper, researchers at Stanford University found that symptoms of autism can be caused by a gene mutation that both blocks the body's natural production of endocannabinoids and also interferes with the way cannabinoids communicate with the brain[3]. These leads need immediate follow-up and there is currently no mechanism to ensure this.

There are existing medications such as antibiotics, pioglitazone (Actos), and naltrexone that need further study in autism. In addition, there are vitamins and supplements such as folinic acid, melatonin, methyl B-12, carnitine, folinic acid, probiotics and tetrahydrobipterin that have preliminary evidence of efficacy, but need further study. Lastly, many psychiatric medications are prescribed off-label for those with autism despite lack of properly controlled clinical trials and long-term safety studies in this population. A toll-free number and the IAN surveys should be used to collect community input on treatments to be investigated and to report side effects as a way to include the broad community's input. All of these areas need the concentrated attention of a dedicated workgroup to move the research forward.

Perhaps most importantly, this workgroup should play a key role in identifying the biomarkers associated with various comorbidities, assessing what treatments might help, and shepherding these treatments through clinical trials. For example, someone with a co-occurring phenotype of PANDAs and tics will have an underlying immune problem (biomarker) and can be treated with an existing and validated intervention (IVIG) for PANDAS. Or, someone with co-occurring irritability and glutathione imbalance can be helped by N-Acetyl Cysteine treatment. We need to investigate broadly what differentiates the biology of people with autism compared to controls and pursue treatments that make sense.

Related to all of this, I must draw attention to the fact that the IACCs database of published research in autism is now ridiculously out of date [4]. The web tool which is designed to allow analysis of IACC's research only includes articles through 2010. The 2011-2012 Portfolio Analysis Report has been "Coming Soon" for two years now.

In 2016, it is imperative that the coordination and availability of research funds have oversight. A 2013 report by U.S. Government accountability office (GAO) [5] concluded" Eighty-four percent of the autism research projects funded by federal agencies had the potential to be duplicative." Of the 1,206 autism research projects funded by federal agencies from fiscal years 2008 through 2012, 1,018 projects were potentially duplicative because the projects were categorized to the same objectives in the IACCs strategic plan. While some replication is necessary, you, the new committee, have the responsibility for making sure that the tax dollars entrusted to you are spent in ways that will benefit our loved ones.

People with autism and their families cannot wait for the glacially slow rate of progress that has characterized autism treatment research. They also cannot afford to try 10 things that may or may not work. To help those with incapacitating anxiety, severe pain, refractory seizures or other medical problems that severely impact quality of life, we must create a roadmap of simple testing, and validated treatments. And it must be done now – not 20 years in the future. Our children need help today.

Sincerely and respectfully,
Albert Enayati, MSME

1. https://www.hms.harvard.edu/dms/neuroscience/fac/Kohane.php
2. http://www.iflscience.com/health-and-medicine/chemical-extracted-broccoli-sprouts-may-help-ease-autism-symptoms
3. http://www.cell.com/neuron/abstract/S0896-6273%2813%2900225-0
4. https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects
5. http://www.gao.gov/products/GAO-14-16