

Written Public Comments

**IACC Workshop 2018:
Addressing the Health
Needs of People on the
Autism Spectrum**

September 27, 2018

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Lauren Agoratus, M.A.

September 27, 2018

There is a need for training of medical professionals to work with patients with developmental disabilities. This includes everything from primary care to specialty care, preparation for medical procedures, and oral health. There is also a lack of providers who treat those with a dual diagnosis of developmental disabilities and mental illness.

Lauren Agoratus, M.A.

State Coordinator-Family Voices NJ

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

Eileen Nicole Simon, Ph.D., R.N.

September 27, 2018

Comments on Health Needs of People on the Autism Spectrum

For the IACC Workshop, September 27, 2018

Eileen Nicole Simon, PhD, RN

Conrad Simon Memorial Research Initiative

[PII removed]

1. Autonomic Problems

The IACC should investigate autonomic functions like gastro-intestinal problems, reported by many parents of autistic children into adulthood.

Respiration, heart rate, intestinal peristalsis, spatial equilibrium, and sensory vigilance are controlled by brainstem centers that are continuously active. These brainstem sites have higher blood flow and metabolism than any area of the cerebral cortex. This was described in the seminal paper by SS Kety, 1962 (which is free online), and in papers reporting use of the deoxyglucose method of Sokoloff.

The autonomic centers are affected in the bilaterally symmetric hemorrhagic damage of Wernicke's encephalopathy, brainstem injury caused by alcohol, drugs, and many environmental poisons. Impairment in these subcortical sites can lead to loss of balance, diminished level of consciousness, decreased oculomotor activity, gastrointestinal problems, respiratory distress, and cardiac arrest.

WF Windle described an ischemic form of Wernicke's encephalopathy in monkeys subjected to asphyxia at birth (Scientific American, October 1969). Birth complications and low Apgar scores have been reported in many papers on autism. Wernicke published his description of brainstem injury from chronic alcohol use, and in one case of attempted suicide by ingestion of sulfuric acid in 1881 (137 years ago). His findings have been confirmed many times over; see <http://conradsimon.org/V-BrainstemDamage.html>.

2. Language Difficulties

The IACC must address the lifelong language problems of people who were diagnosed with autism in childhood. My son suffered head trauma and asphyxia at birth. His difficult birth may have led to injury of the brainstem auditory pathway as described by Windle (Scientific American, October 1969). Windle's findings have been too long neglected.

My son finally learned to speak normally just before age 6. But now at age 55 he continues to have trouble comprehending rapid streams of speech. As he puts it, "I can't deal with people who talk a mile-a-minute." He tends to isolate himself, and at times covers his ears when he can't keep up with a conversation. He thus appears rude and uncooperative in many situations. This is not a "social disorder," but an ongoing problem understanding spoken language. Isn't this similar to the isolation observed in older people with hearing loss?

3. Metabolic Syndrome

The IACC should investigate the disorder known as "metabolic syndrome." In the past two to three years I have attended many meetings where this problem has been discussed. More and more mentally ill adults are suffering from obesity, type-2 diabetes, and diminished physical endurance. This has also been described as "50 is the new 70," whereas the opposite is true for adults who have maintained good health.

Metabolic syndrome should be investigated as the result of long-term administration of anti-psychotic and anti-anxiety medications. Are these medications disrupting aerobic metabolism? What enzymes in aerobic pathways are affected? During drug development were long-term effects looked for? Too many mentally ill people may have been treated for too long with these drugs.

Comment on Health Needs of People on the Autism Spectrum

For the IACC Workshop, September 27, 2018

Eileen Nicole Simon, PhD, RN

Conrad Simon Memorial Research Initiative

[PII redacted]

Community Care

The IACC should set supervisory standards for care givers who work in community group homes. After his special education ended, my son Conrad was placed in a group home. At that time he was a little younger than staff. The staff were also young. Most were in college part-time, and they did not work for more than a year or two in the group home. By age 30 Conrad was older than all of his care givers, and he was not happy. He was strong and staff were frightened by his angry outbursts.

A psychiatrist prescribed Thorazine and other medications to control his behavior. What a shock it was when we got the phone call that Conrad was dead, at age 31. More details are on conradsimon.org, the website I setup in his memory.

Cause of death was a lethal blood-level of Thorazine. An investigation revealed that the psychiatrist increased the dose of Thorazine at the request of staff who told her he needed more to control his behavior. The psychiatrist did not see Conrad before prescribing additional Thorazine.

Grieving staff members attended Conrad's memorial service. How unfair that these young people had so little guidance from the psychiatrist or other medical professionals.

Family Involvement

The IACC should mandate family involvement in putting together treatment plans for health, education, and ongoing development of community group home residents.

"Trauma-Informed Care" is a concept I have heard too much of in courses I have attended to obtain continuing education units (CEUs) for renewal of my nursing license. Staff at my son Conrad's group home aimed a lot of criticism at me, and I was ordered not to visit him.

My husband advised that I should stay away, for awhile anyway.

"They won't kill him," he said.

But they did, by obtaining a doctor's order for more Thorazine.

Yesterday was the 56th birthday of Conrad's brother. He too is a resident of a group home where staff have been treating me with disdain for 15+ years. He was placed in this group home in 2003 after being discharged from Westborough State Hospital.

Over the years since closure of the state hospitals, I have met other parents who feel abused by young staff at group homes. I recently took a CEU course on the importance of family involvement, but this is not happening for my son, now regarded as another old man who simply needs housing for his remaining years. This appears to be the case for other families as well.

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

Kim-Loi Mergenthaler

September 27, 2018

Hello, I am interested in more research on autism and co-occurring mental health conditions, including anxiety, depression, PTSD (and whether this is linked to compliance-based therapies such as applied behavior analysis), and the increased suicide risk (and decreased lifespan) in autistic adults. Please devote more resources to these crucial topics. Thank you.

[PII redacted]

Parent and homeschool educator of an autistic child

Gilda Sanchez

September 27, 2018

Dear IACC:

For the research and healthcare topics in those with ASD, I would like to see more research (translational) focus on Deep Brain Stimulation (DBS) for those that have severe OCD comorbidity. Current medication has not always improved OCD symptoms, but perhaps allowing DBS to be a priority treatment that doctors may be allowed to perform? Can we get research trials on this started now? Spectrum has already published a post on this here: <https://www.spectrumnews.org/features/deep-dive/rebooting-beckys-brain/>

Please discuss the importance of the possible application of DBS or other means of neurostimulation to treat severe OCD. My 15 year old son with ASD has not improved on currently prescribed medications that are indicated to treat OCD.

Thanks,
Gilda M. Sanchez

Marie Ciriello

September 27, 2018

I'm interested in the links and co-relations between ASD and Congenital Heart Defects. Especially differences in treatment and approach.

Angie Hughlett

September 27, 2018

The gastrointestinal health of the adult with autism must not be downplayed or ignored as being just a part of the autism.

Jaqueline Murphy

September 27, 2018

There is an incredible lack of psychologists with expertise in ASD. Specifically, persons with ASD have a much higher rate of depression and anxiety than their typical peers. There are very few pediatric psychologists and even fewer with expertise in Autism Spectrum Disorders. The result is a high rate of hospitalizations and children and adults who fail to thrive or live independently as the result of their mental illness.

Maureen Callahan

September 27, 2018

I would like to express my concerns about two main issues.

First is that autism is not sufficiently understood by medical professionals in hospitals so that appropriate consideration is given to persons with autism in triage situations. This occurs not just in the ER, but also in other areas where testing for serious medical concerns may be delayed due to unexpected circumstances. We had two such situations at a prominent Boston hospital.

The first situation is that our son was scheduled for an EEG to detect seizures. Due to his sensory issues, a multitude of people involved in his care had spent a significant amount of time and effort to prepare him so that this testing could be successful for him. An unexpected delay in availability of a room led to our family being left in a waiting room with our son having leads on his head for over three hours before the testing ever began. No one checked in on us, no one offered to take the leads off and reapply closer to when the test could begin, staff saw us having difficulty and ignored us. My son finally could no longer tolerate the leads were on his head and ripped the leads off. As we struggled to prevent him from doing so, the doctor entered the room and said "Why even bother?"

The second situation is that my son required an MRI for a knee injury. The doctor had told us that the MRI would show if my son needed surgery and that there was a window of time within which the surgery if needed would be effective. My son needed to be sedated to tolerate an MRI. Because of the need for sedation, there were no appointments available within that window of time. The surgeon told us not to bother pursuing an MRI, as it would be useless information outside of the surgical window. So if a surgical intervention was required, my son would not have that option available to him solely because he required sedation to tolerate an MRI.

In both of these situations, my son was denied effective access to appropriate care because of his disability. This is unacceptable.

My second issue for your consideration is my son's intellectual disability. He cannot read or write, nor can his limited speech be understood by unfamiliar listeners. Access to health care cannot be predicated on individuals being able to understand or communicate in order to gain such access. More consideration needs to be given to such issues so that laws designed to protect the rights of the general population do not inadvertently restrict or limit access to effective care for our community members with intellectual disabilities.

Thank you for your listening.

Sincerely,
Maureen Callahan

Ben Furlow

September 27, 2018

I have concerns about health issues related to Autism.

Public Comment Submission September 20, 2018

To Dr. Joshua Gordon IACC Chair and Committee Members:

It is extraordinarily difficult for myself, as a layperson, to compose a comment on the area relating to autism that I am most concerned about. To make sense of the limited research available regarding the intersection of autism, intellectual disability, and epilepsy is a task that I am struggling with immensely. That said, what I have learned regarding the bi-directional effects of these co-morbid conditions strikes me as a matter of dire public health importance and one that should receive significantly more attention. The more I learn, the more concerned I become that a dramatic shift in focus to those individuals with ASD who also have epilepsy & intellectual disability is necessary to reduce the disturbing rates of excess mortality among this population.

Regarding ASD and mortality, we know that:

*"elevated mortality risk associated with ASD in the study cohort appeared related to the presence of comorbid medical conditions and intellectual disability"*¹

*"Mortality and patterns for cause-specific mortality were partly moderated by gender and general intellectual ability"*²

*"Associated medical disorders (including epilepsy with cognitive impairment) and accidents accounted for most of the deaths, and it was not possible to determine whether autism "per se" actually carries an increased mortality risk."*³

*"Analysis of new data from the California State Department of Developmental Services is consistent with past reports showing that there is a higher than expected rate of mortality in individuals with autism and epilepsy than autism alone."*⁴

Regarding epilepsy:

*"evidence suggests that people with intellectual disabilities and epilepsy do have a substantially increased risk of mortality, particularly where seizures are ongoing"*⁵

Regarding sudden death:

*"SUDEP accounts for approximately 5.3% of sudden deaths from any cause in individuals aged between 18 and 64. Death certificates underestimate the burden of sudden death in epilepsy, attributing only 1.5% of sudden deaths to seizures or complications of seizures."*⁶

*"Accurate and consistent classification of cause of death among individuals with epilepsy remains a dire public health concern. SUDEP is likely underestimated in national health statistics."*⁷

"People with epilepsy face a significantly increased risk of death from direct effects of seizures as well as indirect effects of epilepsy and its treatment. Sudden death is approximately 25-fold higher among people with epilepsy compared with those in the general population, with the greatest risk due to sudden unexpected

death in epilepsy (SUDEP). Despite intensive research leading to animal models as well as epidemiologic and clinical studies to better define mechanisms and risk factors, SUDEP continues to be the leading cause of epilepsy-related death.”

Regarding research for those with intellectual disability and epilepsy:

“Fewer than 2% of presentations at epilepsy conferences specifically related to the ID and epilepsy group compared to 15% relating to children with epilepsy. Similarly only 1.4% of the research presented at major ID conferences related to those with people with epilepsy and ID. About 5% of published research in the field of epilepsy related to those with ID as compared with 24% for children with epilepsy.”⁹

The medical complexities of autism with co-morbid conditions, given the amount of what is still unknown in excess mortality of those with ASD, is an area deeply worthy of significant further investigation.

Thank you for your time and consideration as well as for your effort and dedication to improving the lives of people with autism and their families.

Sincerely,

Denise Lombardi

¹Bilder D, Botts EL, Smith KR, Pimentel R, Farley M, Viskochil J, McMahon WM, Block H, Ritvo E, Ritvo RA, Coon H. Excess mortality and causes of death in autism spectrum disorders: a follow up of the 1980s Utah/UCLA autism epidemiologic study. J Autism Dev Disord. 2013 May;43(5):1196-204.

²Hirvikoski T, Mittendorfer-rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. Premature mortality in autism spectrum disorder. Br J Psychiatry. 2016;208(3):232-8.

³Gillberg C, Billstedt E, Sundh V, Gillberg IC. Mortality in autism: a prospective longitudinal community-based study. J Autism Dev Disord. 2010;40(3):352-7.

⁴Pickett J, Xiu E, Tuchman R, Dawson G, Lajonchere C. Mortality in individuals with autism, with and without epilepsy. J Child Neurol. 2011;26(8):932-9.

⁵Robertson J, Hatton C, Emerson E, Baines S. Mortality in people with intellectual disabilities and epilepsy: A systematic review. Seizure. 2015;29:123-33.

⁶Chen S, Joodi G, Devinsky O, Sadaf MI, Pursell IW, Simpson RJ. Under-reporting of sudden unexpected death in epilepsy. Epileptic Disord. 2018;20(4):270-278.

⁷Devinsky O, Bundock E, Hesdorffer D, et al. Resolving ambiguities in SUDEP classification. Epilepsia. 2018;59(6):1220-1233.

⁸Devinsky O, Ryvlin P, Friedman D. Preventing Sudden Unexpected Death in Epilepsy. JAMA Neurol. 2018;75(5):531-532.

⁹Shankar R, Rowe C, Van hoorn A, et al. Under representation of people with epilepsy and intellectual disability in research. PLoS ONE. 2018;13(6):e0198261.

Cynthia Reed

September 27, 2018

Please advocate for improving statewide data for people with ASD and comorbidities. Improved data is essential to states to plan for long term health care and housing for this cohort. Data will also help parents and advocates change the basic qualification requirements and training for group home workers who are not currently providing adequate care. Increasing qualifications and training will create an option for families who now must keep their family member at home until the caregivers are incapacitated or die. The complex medical needs of these family members is under-represented at the state level as so many families keep members home due to fear of inadequate care in group homes or other facilities.

Question: Is there a better way to provide routine checkup (eg blood tests etc) by mobile unit to a group home or an adult day hab program rather than having the individual go to a health care facility. Less trauma for person with ASD.

My thanks to you, the members of the IACC, for your work on behalf of autistic people of all ages and abilities.

I am writing to you as the parent of a seventeen-year-old high support autistic son, whom I love with all my heart. (There is no 'but' after that statement.) I am also writing to you as an advocate deeply engaged with autistic people, their families, autism professionals, and autism researchers, in my role as editor of Thinking Person's Guide to Autism.

I am certain the Committee is aware that autistic people as a community are badly served by the current state of health care and supports. Both formal research, and autistic people's own reports, clearly show that autistic health concerns, including mental health issues, are too often dismissed or misunderstood, and that autistic people are also more likely than the general population to have co-occurring health conditions.

I have to believe that the Committee shares my opinion that it is unconscionable for our autistic community members to receive improper and insufficient health care. I have to believe that you recognize why the current approach is also financially irresponsible, as the proactive and appropriate health care autistic and disabled people currently *aren't* getting is demonstrably more cost-effective than the reactive or emergency care they tend to get instead.

Based on both my personal and professional experience, I have some recommendations on how to improve health care matters for autistic people.

If nothing else, I would like to see more autistic-informed health care policy. It is only through participatory autism research that we have become aware of matters like the crisis-level rates of suicide and suicidal ideation in autistic people, while studies of commonly self-reported but poorly studied and understood co-occurring conditions like hypermobility or Ehlers-Danlos syndrome are only now emerging. If we are going to properly support autistic people of all abilities to achieve best possible health outcomes, our health care initiatives need autistic guidance.

I would like to see more of this autistic-informed policy integrated into autism education for medical professionals, for matters like accommodations during patient-professional interactions. We need more medical personnel to understand why autistic people, even those technically capable of holding a conversation, can have a debilitating fear of needles, may have difficulty with sensory-intensive procedures like MRIs or EEGs, may have trouble answering questions or self-reporting accurately due to processing, alexithymia, or interception issues, and may have meltdowns when overwhelmed. We must develop strategies for ensuring those autistic individuals are accommodated, so they can receive the care they deserve without being written off as "difficult."

I would like to see more medical professional awareness about the sensory needs of autistic people both in general, and in medical environments. When my son was recently in the ER at Stanford University, he was given access to a lovely sensory 'Imagination Station,' and in addition the flickering fluorescent lights in his room were turned off. Many autistic adults who heard about my son's experience reported that they too would like access to these kinds of sensory accommodations, but such options, even when available, are usually reserved for children.

I would like to see more outreach to medical schools and other training programs about the need for more neurologists, behavioral psychiatrists, developmental pediatricians, and registered dietitians both in general, and who understand autism specifically. The scarcity of these specialists makes accessing health care even more difficult for autistic kids and adults.

I would like to see investment in 'health passports,' like those developed by the UK's National Autistic Society, to improve autistic people's hospital and medical experiences. I would like to see encouragement to adopt and support models like the autism and healthcare toolkits and resources developed by AASPIRE and UCSF's Office of Developmental Primary Care, in delineating compassionate, respectful, and useful best practices for patients with developmental disabilities.

I would like to see all autistic people, including those with intellectual disabilities, treated with more respect by medical professionals. Autistic people must be able to trust the professionals taking care of them if they are to tolerate anxiety-provoking medical environments, yet too often autistic people are not even addressed during in-person conversations about their own health, or they are spoken in a manner more appropriate for speaking to A Very Good Dog (as happened to my son while getting his flu shot just this week). In worst-case scenarios, dismissive attitudes can lead to tragedy, as with the recent death of 18-year-old Oliver McGowan. These attitudes must change, because my son's life and those of his autistic community members are valuable, and should be treated that way.

I would like to see more awareness in medical professionals (and documentation in research) about autistic people's increased likelihood of atypical or paradoxical reactions to medication. I have learned about this tendency from autistic community self-reports as well as specialists like Dr. Glenn Elliott at Children's Health Council in Palo Alto, and have also observed it first-hand many times with my son, including an ER visit in which he was given a medication that was supposed to stop his grand mal seizure, but instead sent it into overdrive. Yet not one medical professional who has prescribed medications to my son has ever mentioned such reactions to me, not unless I bring the topic up, and even then, many were not aware that atypical or paradoxical medication reactions are "a thing" for autistic people.

I would like to see more outreach from medical professionals to autistic individuals and families about the side effects and unpredictable outcomes of routinely prescribed FDA-approved antipsychotic medications like Risperdal, which can cause liver damage, diabetes, and unavoidable weight gain, and the lifestyle changes people can make to at least partially offset those effects.

I would like to see outreach campaigns about the ongoing (and illegal) use of medications as chemical restraints for people with behavioral difficulties. I would instead like to see more medical professionals helping families to understand how health, sensory, processing, and communication difficulties may be underlying the 'unmanageable' aggression, and that in many cases accommodations and health care, rather than (or in addition to) medications, are what is needed.

I would really like to see more emphasis on why co-occurring health conditions like GI troubles or epilepsy are not caused by autism, and why treating those conditions is not the same as 'treating' autism.

I would like to see the IACC take a firmer stance on pseudoscience medical approaches to autism, as these approaches dupe autistic people and their families into pursuing expensive, bogus "cures," diverting both funds and focus from legitimate approaches to optimal autistic health and wellness. The

organization TACA (Talking About Curing Autism) is holding its annual conference in California next month, and is featuring autism 'health' seminars on topics that have not only been debunked by mainstream science, but which encourage parents to subject their children to potentially dangerous treatments. Examples include 'The Importance of Detoxification' and 'The Relationship Between Heavy Metals, Parasites, and Symptoms in Your Child.' Yet somehow this conference is eligible for Regional Center (Medi-Cal) reimbursement. This is a waste of both private and public funds, especially for families or individuals with limited access to resources.

Finally, I would like to see recognition that health care access gaps are even more pronounced for autistic kids and adults who aren't male, autistic people of low socioeconomic status, and autistic people of color, due to well-documented barriers including accessing formal diagnosis, and thus receiving proper care and accommodations. We need investment in easy-read and multilingual autism and health care information. Ideally, we also need investment in "community ambassadors" who can translate and/or advocate for people who may have multiple barriers to resources, and thus to effective self- or family advocacy.

I need the Committee to understand that while this list may seem excessive, it is in actuality neither comprehensive nor sufficient; I am hoping other commenters and discussants will address my oversights. However, tackling these issues would be a welcome start to helping more autistic people lead the happiest and healthiest lives possible.

Thank you,

Shannon Des Roches Rosa
Redwood City, California

I am the mother of a 30 year old young man, Daniel, who carries a diagnosis of PDD-NOS (and with regressive autism).

First, some background on Daniel. As a child Daniel had years of recurrent strep (as did his father) and was on antibiotics (amoxicillin/augmentin) almost continuously for several years. As an adolescent and adult he appeared generally healthy and required little medication for his general health.

Daniel has a brother, David, who is 20-months older. David was diagnosed with Celiac at age 20 after initial negative test results; Daniel's mother (me) asymptomatic other than unexplained low bone density, was diagnosed with Celiac in her late 40's -- a couple of years before David. Although Daniel's serology has repeatedly been negative, as a child and adolescent he often alternated between diarrhea and constipation and was at the time and since considered to have GI upset of unknown cause.

I have detailed this personal medical because it may have relevance to a larger population (and may not be an unusual history for families of individuals with autism) and to possibly offer some worthwhile thinking about management suggestions of early health 'differences' in autism:

: STREP. When he was a child, Daniel qualified based on history and examination, for IVIG at Boston Children's Hospital. The timing and state of the treatment were not suitable and so he did not receive this new intervention. In the meanwhile, believe that earlier and long courses of antibiotics reeked havoc in his GI, with chronic consequences.

Q: Is there some alternative treatment that is recommended today?, if antibiotics remain the best choice, can they be paired with something to neutralize their indiscriminate effect -- like probiotics, cod liver oil (not a science person here, trying to present a concept).

: GI. Many inoculations for serious diseases are given to a baby and toddler, with the presumption that he has a generally robust immune system. However, there may be subtle deficiencies or irregularities present, like a nutritional deficiency passed on from an undiagnosed/untreated Celiac (or other GI, autoimmune (thyroid?) disease mother -- many of which remain undiagnosed for many years for women for decades.

Q: In Africa I believe they pair Vitamin A with inoculations to bolster the immune system. Is this something that is done here in the US or that we should be thinking about?

: VITAMIN D, bones. When Daniel was 24 months old, he gently rolled down a small slope. He didn't cry much or seem to be in pain but it was a drop, a fall nonetheless, and we felt that a visit to the doctor was necessary. To our surprise we learned that, in fact, he had sustained a hairline fracture in his arm. He was put in a cast and soon recovered.

Q: What is the status of bone density of young people with autism; if there is a density issue, what does it suggest -- are they deficient in vitamins such as Vit D and why at this young age? Would supplementation help and what kind of impact or outcomes might there be?

: BONES. Now a 30-yr old adult, Daniel enjoys being active and is in generally good shape. However, his posture is terrible -- stooping like a much older man. Yes, he has been on several medications for 6 years now and that could be part of the story here.

Q: Is this issue something that is medication/environmental or part of a long and chronic bone density issue? Can it be measured, addressed? (We are now trying different exercises as a partial solution.)

I could go on, but I'll end here for now and with 2 short tales. (Though there are many, many heroes out there always room for tweaking.)

PATIENT-PROVIDER RELATIONS, 1. Many years ago, when Daniel was about 10 years old we visited a (endocrinology) specialist at one of the esteemed medical centers in the NE. After waiting months for the appointment, and then hours in the waiting room and then examining room to see the doctor he finally comes to the doorway, stands there for a minute or two, and from a distance never even touching or examining Daniel states very matter-of-factly: "it's just autism. The symptoms you are concerned about are because he has autism, they are part of his autism."

COMMENT: Individuals with autism have the same, and maybe more numerous and complicated, medical issues as everyone else.

PATIENT-PROVIDER RELATIONS, 2. When Daniel was a boy, I attended a conference where a savvy mother of an adult with autism spoke. I found her words inspiring and helpful and walked up to her after, asking if she had any advice for families with younger children as they moved forward on this wobbly and challenging road. She answered: "go with your gut.?"

COMMENT: And so I say that when clinicians perform intakes, they should carefully and seriously consider the information and opinions of the family. Each child has so much individuality, labs and other tests are often inconclusive. This can be a precious trove of information and insight.

With many thanks for your great initiative, valuable attention and good work,

Marian Dar

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

Dr. Linda (Angelique) Papadimitriou-Varsou, PhD, MPH, DABCC

September 27, 2018

WRITTEN COMMENTS FOR THE IACC WORKSHOP OF SEPTEMBER 27, 2018

Addressing the Health Needs of People on the Autism Spectrum

September 20, 2018

Based on my written comments for the October 26, 2016, IACC Full Committee Meeting, I am adding 10 more FACTS specially related to the health needs of people with ASD.

- 1) The rate of the prevalence of people with ASD is expected to increase dramatically. Therefore, there is an urgent need to address preconception and prenatal parents' health condition, the environmental pollution and epigenetic factors.
- 2) The only certain prediction is that children with ASD become adults with ASD while remaining childish. Nevertheless, all healthy adults with ASD, with special training can play a productive role in society and join the workforce by developing and applying the unique and very special hidden strengths which all possess.
- 3) Although the first cause of death in US youngsters is suicide, its prevalence is much higher in people with ASD. As suicide is the tip of the iceberg, mental health services and socialization, but not poisonous drugs could prevent it.
- 4) The Health System, Hospitals, Emergency Rooms, etc. fail or refuse to treat adequately ASD. A human approach, understanding and compassion are also missing. IACC could implement detailed directions and protocols on how to treat a patient with ASD and enforce every health facility, hospital or ER to strictly follow them. If not, legal actions must be taken against them.
- 5) It is clear that doctors, nurses and medical practitioners have not enough education about ASD, and the only approach is usually strong medication, followed by the accumulation of side effects, deleterious for the child's wellbeing.
- 6) The medical system never uses a functional, integrated, and holistic approach regarding the treatment of ASD, while a wealth of evidence shows the efficacy of such a medical approach. For instance, doctors receive minimal or no education at all about the role of microbiome, nutrition, soft exercise, grounding, breathing techniques, sensory stimulation, yoga, etc., so effective and with no side effects at all.
- 7) Despite the ASD's high comorbidity, the holistic approach better helps the treatment/therapy of the ASD person's condition by minimizing the side effects. A medication could be beneficial during a crisis but not on a daily basis. But the crucial factor is the close and constant communication among health specialists, the family and the child with ASD.
- 8) Many diagnostic interventions and tools (for example brain MRIs, fMRIs, etc.) have deleterious effects on a brain already compromised. The same applies to all the gadgets emitting EMF radiation, etc. Many blood drawings have a traumatic effect to the child with ASD instead of using other body fluids with no invasive techniques.
- 9) ASD is the disability with the highest rate of "parental denial" which has detrimental effects on a child's health. In 50% of families, at least one parent (usually the father), remains in chronic denial of his child's ASD, with the attitude of "*flight instead of fight*", or even "*freeze*", therefore, neglecting or postponing any early therapeutic interventions. Therefore, parents also need medical intervention and counseling as well. (Regarding the dramatic issue of chronic parental denial, please read my detailed written comments of 1/12/2016).

10) Poverty has a negative effect to everyone, but in case of ASD it becomes devastating. In a period of economic crisis, I am not asking for more federal money (SSI, Food stamps, etc.), but rather to implement measures to avoid poverty. Poverty afflicted families having a child with ASD, is the worst mirror image of any civilized society.

In conclusion: All the above 10 FACTS are “common sense” and mandatory for the health of people with ASD. But based on my concept that **“An Autism Friendly Society will benefit us all”**, if we use the “autism friendly” health approach, the same approach will benefit everyone.

Note: *For all the above mentioned facts and solutions, I have a huge amount of documentation, photos, witnesses, websites and experts and I am willing to present them to any forum or federal NIH committee. Furthermore, I would be glad if I could use my experience and expertise in order to help the IACC’s working group.*

From Dr. Linda (Angelique) Papadimitriou-Varsou, PhD, MPH, DABCC, Immunologist, Hygienist, Clinical Biochemist, Associate Professor in Medicine. Mother and legal guardian of a 33-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, resigned in May 2018. MSc in Biochemistry and postgraduate studies, Paris University; Specialization in Immunology, Paris Institute Pasteur, France; MSc in Public Health with honours; Diplome 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, Department of Neurology, where I studied neurosciences and initiated the “fever study in autism”. Current position: retired Associate Professor from the University of Athens School of Medicine in Greece, where I am still teaching a graduate course, a position which allows me to spend more than 9 months per year in the US with my son, while continuing my teaching online.*

[PII removed]

American Academy of Pediatrics

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345 Park Blvd
Itasca, IL 60143
Phone: 630/626-6000
Fax: 847/434-8000
E-mail: kidsdocs@aap.org
www.aap.org

September 20, 2018

IACC Health Outcomes Working Group
National Institute of Mental Health
National Institutes of Health
6001 Executive Boulevard
Room 6184
Rockville, MD 20852

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Re: Interagency Autism Coordinating Committee Workshop: Addressing the Needs of People on the Autism Spectrum

Dear Health Outcomes Working Group:

The American Academy of Pediatrics (AAP), a non-profit professional organization of more than 67,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety and well-being of all infants, children, adolescents, and young adults, appreciates the opportunity to provide comments regarding the upcoming Interagency Autism Coordination Committee (IACC) Workshop: Addressing the Needs of People on the Autism Spectrum. As the leading pediatric health organization in the United States, the AAP is uniquely positioned to provide support and evidence-based guidelines to pediatricians caring for children and youth with Autism Spectrum Disorder (ASD).

The AAP's Council on Children with Disabilities (COCWD) is comprised of nearly 600 members who care for and have an interest in children and youth with special health care needs. The COCWD Autism Subcommittee (ASC) serves as the main point of contact for the Academy on issues related to care of children and families with ASD. Over the last decade, the ASC has successfully implemented multiple activities and initiatives designed to educate pediatric clinicians on how to address co-occurring health needs of children with ASD. These initiatives include but are not limited to the following:

- Publication of two clinical reports on the identification, evaluation, and management of children with ASD;
- Development of numerous educational sessions at the AAP National Conference & Exhibition on caring for children with ASD; and
- Development of a clinician toolkit focused on caring for children with ASD and their families.

The COCWD ASC is currently revising the two previously published clinical reports on the identification, evaluation, and management of children with ASD. These two reports will be published as one comprehensive clinical report. The COCWD ASC is planning multiple educational initiatives that will launch when the revised clinical report is published. These initiatives include the revision of the ASD clinician toolkit and the development of a Continuing Medical Education (CME)/Maintenance of Certification Part 2 course. The AAP is a leader in providing CME programming.

Please see below a list of examples of outstanding programs at the National Conference and Exhibition in the last five years:

2018:

- Autism Spectrum Disorder in the Medical Home: Identification, Diagnosis, and Management

2017:

- Screening for Autism in Young Children and Next Steps
- Schools, Rules, and Therapies: School-age Children with Autism Spectrum Disorder

2016:

- Autism Spectrum Disorder: Behavioral Challenges of the Higher Functioning Child
- It's Not Always Autism
- Autism: From Diagnosis to Transition and Beyond

2015:

- Decisions, Decisions: Navigating Treatment Options for Children with Autism Spectrum Disorders
- Treatment of Typical Medical Problems in Children with Autism: Eating, Sleeping, and Pooping


2014:

- Autism Spectrum Disorder: DSM-5 and Diagnosis in 2014
- Common Behavioral Problems in Autism and Intellectual Disability
- Evidence-Based and Alternative Treatments for Autism Spectrum Disorder
- Ensuring Nutrition in Children with Autism Spectrum Disorder: Too Much and Too Little
- MCHAT and Beyond: Overcoming Barriers to Screening for Autism in Primary Care

The IACC has identified several important topics for this upcoming workshop, and the AAP appreciates the efforts to select appropriate speakers. However, the AAP believes it would be advantageous for IACC to explicitly engage primary care providers in this discussion, and therefore promote the care of people with ASD and all disabilities in the medical home. It is crucial that the medical home be emphasized as a critical element of coordinated and high-quality care for children, youth, and adults with ASD. The AAP would be glad to partner with the IACC to specifically engage providers on these topics.

The AAP appreciates the opportunity to provide feedback on the IACC's upcoming workshop on the needs of people with ASD. Going forward, we hope to be an active participant in these workshops and other meetings by contributing the provider perspective. If you have any questions, please contact Allyson Perleoni in our Washington, DC office at 202/347-8600 or aperleoni@aap.org.

Sincerely,



Colleen Kraft, MD, FAAP
President, American Academy of Pediatrics

CAK/arp

Elizabeth Moffit

September 27, 2018

I wanted to bring to your attention that children in Alameda County, CA are not getting speech services. The only clinics that medicaid will cover are 30-40 minutes away, and if you can get an appointment, you have to wait months for an intake.

As a registered nurse in the emergency department of a rural hospital, I do occasionally see patients who are on the spectrum display variations of spectrum-specific behaviors, which are frequently interpreted by other staff and physicians as a symptom of various psychiatric disorders. This often leads to false diagnoses of psychiatric disorders. I think improved exposure to those who are on the spectrum, or at least visual based education for those pursuing careers in the healthcare field is highly important.

I never had any contact, to my knowledge, with anyone on the spectrum until my daughter was diagnosed at the age of 10. For the first ten years of her life, I never knew I was in the presence of someone on the spectrum- an RN with 15 years experience in the healthcare field and she flew right under my radar because I had no training in autism. If I could miss the signs in my own daughter, how many children and adults have passed before me in my work and missed having a health professional detect the need for testing? How many patients have I mistaken for having a psychiatric disorder?

Education is the greatest asset we have in properly confronting autism spectrum disorders, and I feel a greater push for education would benefit our populations greatly.