Oral Public Comments

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

September 27, 2018

List of Oral Public Comments

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

Shari Chase **September 27, 2018**

Hello all
I am a mom of two young men. One has Autism and is 22 and has fallen off the cliff since leaving high school last year. His days are not meaningful and he thrives when being creative and accomplishing meaningful jobs and roles . My son Alec is extremely bright young man but he is ruled by meltdowns. These meltdowns come in a moments notice and he sometimes has no control over them. We've been told by his doctor is that he has something called Sunct headaches And that these are secondary to Autism. His Neurologist stated that often people with autism end up pulling some of their hair out of her head hit their head and scream. These headaches last for 15 seconds to 15 minutes and never over 15 minutes but they are like an ice pick stabbed into your face. I have been hoping for years that we can find something that can detect some of his precursors that are non-obvious prior to even common meltdowns and the various biological symptoms that occur before the Sunct headaches occur. I have been searching for years to Find something that can give us a warning system prior to these headaches happening, so we can utilize some of the resources we have including breathing techniques removal from the situations etc. But until recently I saw no hope. My older son is a biomedical and is now completing his masters degree. He's devoted a great deal of his life to finding ways to help those people in the Spectrum that have meltdowns control them and give them back the ability to steer their own life and self advocate. He has done this through a device that is a wearable .
Excitement for this so needed device is shining bright light in the future for those people on the spectrum and those who suffer from anxiety and other meltdowns. it will be more than a life preserver it is a springboard to being able to rise to each person's fullest potential for often as is the case in my younger son Alec's life, the meltdowns prevent him from working or attending college which is what he so badly wants to do.

Next I want to alert that my son had a TBI and I have combed the metro DC area and no practitioner will treat a person with both Autism and a mild brain injury, this is an immediate area of need. Medicare and ASD must crack down on this void.

Finally, we need a national job training program for those with Autism. It needs to be visual for learning and a place where you learn your skills in a classroom then move it to practical application as a mentor and finally in an independent job. We can use our retiring work force as trainers and recreate the old vocational schools. It will be a win win situation. This can be further paired to a work,live and and play environment.

You must make sure these programs and the people who are willing and able to provide devices and therapies are covered by some of the social programs that we can offer. We can't leave people behind that can contributory citizens for that is not only a waste of life but it's a drain on society that does not need to happen. Let's work together to find social programs to help many find ways for individuals to control their meltdowns and other tics that prevent them from being completely employed and integrate into society . This way if one wants to utilize it they can, this could be a springboard for them to earn an income that makes them self sufficient, give him back the pride of control of their own body, it also takes eventually a burden off of society because these individuals that are on the spectrum that become contributory citizens l, can give back to help others who are in need . This can give those that do not have the ability currently, the right mind set to have vocational and behavior training modification. I'm not saying to be very clear that we need to a erase the characteristics of autism , what we need to do is to be able to give a hand to those that want the ability to be able to assimilate so that they can reach her own for potential. Finally I did not touch with housing Housing is extremely important I have been preaching the model of pairing individuals that are at retirement age with those people that have autism in a housing unit similar to a residential wonderful campus community. I believe you can bid jobs within the commercial businesses that are attractive. The workers who are retiring tmost likely will need more funds to enjoy their lifestyle and can pass expertise on that is second to none for hands on training usually is the most effective with individuals there on the spectrum. Just imagine a viable community where you live work and play with no ways to be locked in but only ways to springboard out and enjoy a full life and always feel welcome and excepted. Those people who are senior citizens eventually will be in need a physical companions and perhaps others to work with them on the cognitive level you now have an additional work for us on the property that bridges for now some of ASD community can be pre-trained by these individuals to assist the aging and become the heroes of those on the spectrum . We can further this by opening commercial and professional sites all through this campus and attracting therapists and medical practitioners of all types for localized medical care it is a win-win situation for everyone involved.

I ask you to take these very important needs that are not being met and make sure they are met in the most expeditious way. I do realize that many of these are or appear to be daunting tasks but they're not things that we can say we will have work committees think about these are task that must
be taken on ow and pushed forward mediately!!!

A question why do we not have current web sites talking about therapies that are used, drugs and supplements that are used that are very helpful so we don't have to remake the wheel on every day basis and also talk about what has not worked so we don't waste our valuable precious resources and time. We need to be more functionally coordinated and directive.

I thank you so very much and I hope that my son will come on and speak to you on details about what he is creating and has created for people on the spectrum it is a lifeline.
I spoke about to help those on the spectrum to regain their own self control and dignity and assist in being able to live up to their individual put fullest potential on a daily basis ! Let's get moving on this. My guess if you need more for soldiers most family members will help in whatever professional know how they have so let's get moving! I volunteer my services and let's see who else in the country steps up to do the same.

Shari Chase
[PII redacted]

Phelan-M c.Dermid Syndrome Foundation

September 14, 2018

To the lnteragency Autism Coordinating Committee:

We are writing to urge the committee to focus on a set of conditions with very high prevalence in the autism community: functional gastrointestinal disorders {FGIDs). FGIDs are defined by the Rome IV criteria,[!) which are international guidelines developed by gastroenterologists to define a wide variety of symptoms with a likely neurologic basis.

We are parents of children and adults with a rare chromosomal deletion called Phelan-McDermid Syndrome (PMS}, which results in a variety of developmental disabilities, including a severe form of autism. Many individuals with PMS are non-verbal or have profound communication deficits, and 74% meet criteria for autistic spectrum disorder, and 85% have some autistic features.[2] As such, most of our children suffer from an array of challenging FGIDs which are highly prevalent across the autistic spectrum, including functional constipation, gastroesophageal reflux disease, feeding dysfunction, cyclic vomiting, functional vomiting, rumination, and irritable bowel syndrome. Additionally, since autism commonly results in difficulties with sensory processing,[3] many individuals are unable to interpret neural input from their gastrointestinal tract and communicate these sensations to their caregivers. This sensory hypo-reactivity has been explored specifically in PMS,[4) and is a common concern for parents across multiple domains, but especially as it relates to stooling and the reporting of symptoms such as abdominal pain.

As the father of a two-year-old girl with PMS, I can attest first-hand to the enormous toll that gastrointestinal symptoms take on patients and their families, especially in those with communication deficits such as autism. As a pediatric gastroenterologist caring for a large number of children with autism, as well as multiple children with PMS, I have heard many parents echo these concerns. In fact, at our most recent Phelan-McDermid Syndrome Foundation conference, we had so many questions during the gastroenterology portion, that we had to schedule an *ad hoc* question and answer session that evening simply to accommodate everyone. This all speaks to the enormous burden experienced by PMS patients and their families in regards to FGIDs.

Our own data suggest that gastrointestinal symptoms are extremely common in PMS: 73% report problems with toilet training, 41 % constipation or diarrhea, 28% feeding problems, and 24% recurrent abdominal pain. This echoes the overall high prevalence of gastrointestinal complaints in autism. 45% of children with autism have diarrhea or excessively frequent stools (3 or more per day), compared with 15% of neurotypical siblings, and 23% have high stool variability, compared with 0-1% of neurotypical

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siblings.[5] Furthermore, the burden of frequent gastrointestinal complaints on families is tremendous. Constipation alone can account for thousands of dollars of additional healthcare costs to families,[6] but also a great deal of missed work and school days.

The gastroenterology community has recognized the need for an expanded body of research on FGIDs and autism[7J, yet few funding opportunities exist to explore this complex area. While considerable attention has been paid to the overlap between the human stool microbiome and autism,[8-10] and we applaud these efforts, a broader research approach addressing the many complex interactions between autism and the enteric nervous system are direly needed. Of the 1262 current open RFAs at NIH, only 54 of these have autism mentioned in the program announceme·nt, and Oare directed at gastrointestinal disorders (https:// grants.nih.gov/g rants/guide/search results.htm). Furthermore, none of these funding opportunities for autism are supported by NIDDK.

Now is the time to act, as we have the capability to marry the high volume of clinical data, progress in neuroscience, and vast genomic and microbiome data to create real clinical solutions for the many individuals and families affected by FGIDs in autism. We thank you for your consideration of this important topic area that has been woefully understudied and underfunded. Investment in research on gastrointestinal disorders in autistic individuals has the potential to vastly improve their quality of life for patients and their families.

Sincerely,

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1. Drossman, D.A. and W.L. Hasler, *Rome IV-functional GI disorders: disorders of gut- brain interaction.* Gastroenterology, 2016. **150(6):** p. 1257-1261.
2. Soorya, L., et al., *Prospective investigation of autism and genotype-phenotype co"elations in 22q13 deletion syndrome and SHANK3 deficiency.* Molecular autism, 2013. 4(1): p. 18.
3. Tomehak, S.D. and W. Dunn, *Sensory processing in children with and without autism:* a *comparative study using the short sensory profile.* American Journal of occupational therapy, 2007. **61(2):** p. 190-200.
4. Mieses, A., et al., *Brief report: sensory reactivity in children with Phelan-McDermid Syndrome.* Journal of autism and developmental disorders, 2016. **46(7):** p. 2508-2513.
5. Adams, J.B., et al., *Gastrointestinal flora and gastrointestinal status in children with autism-comparisons to typical children and correlation with autism severity.* BMC gastroenterology, 2011. **11(1**): p. 22.
6. Liem, 0., et al., *Health utilization and cost impact of childhood constipation in the United States.* J Pediatr, 2009. **154(2):** p. 258-62.
7. Coury, D.L., et al., *Gastrointestinal conditions in children with autism spectrum disorder: developing* a *research agenda.* Pediatrics, 2012. 130(Supplement 2): p. S160-S168.
8. MacFabe, D.F., *Short-chain fatty acid fermentation products of the gut microbiome: implications in autism spectrum disorders.* Microbial ecology in health and disease, 2012. **23(1):** p. 19260.
9. Mulle, J.G., W.G. Sharp, and J.F. Cubells, *The gut microbiome:* a *new frontier in autism research.* Current psychiatry reports, 2013. **15(2):** p. 337.
10. Rosenfeld, C.S., *Microbiome disturbances and autism spectrum disorders.* Drug Metabolism and Disposition, 2015: p. dmd. 115.063826.

Rick Walba **September 27, 2018**

Talking points for 2018 IACC workshop on health

Currently the conventional thinking on best-practices for high-functioning autism therapy is Cognitive Behavioral Therapy (**CBT**). But in fact this methodology is not even considered a best practice for neurotypical personal development, and especially should not be considered for HFA as it relies almost entirely on rote learning, an extremely inadequate means of personal development in general, and particularly inadequate for those on the Spectrum who typically suffer slow language processing and poor working memory. Only highly kinesthetic learning experiences are adequate here, and only the science-based use of Mental Imagery (**MI**) can provide a practical means of delivering and adequate degree of kinesthetic learning experiences, as the use of MI has scientifically been shown, in a completely validating array of studies, to provide such life-like kinesthetic learning experiences completely remote from the actual physical experience. Thus it can, in all cases and circumstances, provide an unlimited number of life-like learning experiences. Furthermore MI works to overcome the sensory processing deficits at the core of autism, and has even been used to recover patients from traumatic brain injury (**TBI**).

From this it should be obvious that any intelligent approach to autism remediation will absolutely have to incorporate the use of MI. Some examples covering major issues of autism, motor skills personality development and cognition: Absolutely every competitive athlete makes extensive use of MI to both develop and consistently perform the exceptional physical skills and abilities they demonstrate; And every successful actor also makes extensive use of MI, and likewise not just to create the complex personalities they often portray, but also using MI to express those personalities in real-time; Then there are the cognitive issues. Here we see that many great minds throughout history recognized the importance of MI, great minds such as Nicoli Tesla, Thomas Edison, Henry Ford, Andrew Carnegie, Alan Turing and Albert Einstein to name just a very few.

At this time there are just 2 examples of Interventions making significant use of MI. One is the work of Michelle Winner, the other is my own work, Adaptive Imaging Technique. Winner's work is unfortunately too simplistic and otherwise lacking in sophistication to adequate address the needs of late pre-teens to adults. Adaptive Imaging Technique, my own work, is unique in that it is not only the first and the only intervention created by someone on the Spectrum, but also provides a very sophisticated and in depth use of MI, along with essential related principles and concepts of cognitive-developmental psychology, that can meet the more complex and sophisticated needs of adolescents and adults. With these methods it is possible to transition significant numbers of those with HFA into adulthood seamlessly alongside their neurotypical peers. The full details here can be found in the book, 'Adaptive Imaging Technique.'

Mention here should also be made of the importance of bio-medical and dietary intervention, another all too neglected area. But all I will personally say here for is that the organizations TACAnow and the Autism Research Institute provide an extensive list of protocols and studies.

Sincerely,

Richard Alan Walba

Originator of Adaptive Imaging Technique, and the related works, The Scientific Study of Detrimental Antagonist Input and Dynamic Controlled Resistance Training.

Annie Acosta **September 27, 2018**

CONSORTIUM FOR CITIZENS WITH DISABILITIES

Statement for the Interagency Autism Coordinating Committee (IACC), Sept. 27, 2018

Thank you for the opportunity to provide comments today. My name is Annie Acosta and I am with The Arc of the United States. Today I am here on behalf of the undersigned Co-chairs of the Consortium for Citizens with Disabilities (CCD) Task Force on Developmental Disabilities, Autism, and Family Support to share some of our top priorities regarding the health care needs of people with autism spectrum disorder:

1) Mental Health Screening, Identification, and Intervention

Children and adults with ASD have much higher rates of anxiety and depression which can interfere with their physical health and adherence to prescribed treatments. A 2015 study published in the British Journal of Psychiatry found that people with autism and no intellectual disability are nine times more likely than the general population to die young due to suicide, making it the leading cause of early death for that population. The rate of suicide among people with autism and intellectual disability is also considerable.

Despite increasing recognition of the interplay of mental and physical health, practical application in health care settings if often lacking. Health care professionals need appropriate training in identifying and managing mental health problems in this population. Lack of training results in difficulty for practitioners and patients alike. For instance, providers who are unable to help calm a person with ASD are more likely to rely on over sedation for relatively routine testing such as EEGs.

We also encourage the committee to prioritize training for health care professionals and research efforts that examine health outcomes of people with ASD that includes social determinants of health such as employment, education, and social connections.

2) Reasonable Accommodations

Going to the doctor can sometimes be a stressful experience for people with ASD and elevated stress levels may trigger challenging behaviors. There are, fortunately, a few practices that can help mitigate such events, such as giving patients with ASD the first or last appointment of the day to avoid long wait periods in crowded rooms.

However, the most needed accommodation is additional time for appointments. Health care providers should anticipate the need for flexibility in scheduling. We encourage the committee to support research in efforts to improve public and private insurance reimbursement policies that allow for extended appointment times.

3) Transition from Pediatric to Adult Health Care

Autism is more than a childhood condition, it is a lifelong condition that requires appropriate supports and treatments which change as people move through major life phases. This includes moving from the pediatric to the adult health care system. This transition is critical to ensuring appropriate treatment for adults. Youth and young adults with ASD and their families need assistance in transition preparation, transfer of care, and integration into adult-centered systems of care that are less coordinated than pediatric systems. We encourage the IACC to prioritize efforts under “Strategic Plan Question 5: Where Can I Turn for Services?” to implement the Six Core Elements of Health Care Transition 2.0 developed by the Center for Health Care Transition Improvement with support from the Health Resources and Services Administration.

4) Decision-making Options for Adults with ASD

There are many incorrect assumptions made about the needs of adults with ASD for decision making support. For those who need support, guardianship is often treated as a default option for adults when a less restrictive one would suffice. Parents are often warned that, absent guardianship, they will be denied access to their adult children’s health information due to the Health Insurance Portability and Accountability Act (HIPAA). However, HIPAA allows the disclosure of protected information when a patient consents. However, parents will seek guardianship in order to go to appointments, schedule appointments, or access medical information.

There is a continuum of options that start with informal support. Other options include supported decision making, power of attorney and limited guardianship. We encourage the committee to promote health care practice guidelines that provide accurate information about the range of options for decision-making authority in health care settings.

Thank you for the opportunity to comment.

Annie Acosta
The Arc

Jill Kagan
National Respite Coalition

Erin Prangley
National Association of Councils on Developmental Disabilities

Dr. Xuejun Kong **September 27, 2018**

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

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Comments:

My son Raymond was diagnosed with severe autism at age four. I was a trained physician and I was entirely unprepared. I was also a mother who wanted to do all I could. My husband and I supported Raymond's intensive behavioral, speech, occupational and physical therapy, and array of special education services. We needed medical help. We engaged an array of specialists. Psychiatrists prescribed medicines. Neurologists ordered brain scans. Despite continued treatment, unremarkable scans, and 20 hours of therapies every week, Raymond's behavioral issues did not improve. His extensive behavioral problems prevented him from staying in public school. Care providers told us that little more could be done to help. I felt like they had given up on him and on us. With this news, my husband quit his job. I started to study autism as a primary care physician. We became Raymond's new care team.

Through our experience of caring for Raymond as a physician and parents, and interactions with other ASD families, we all feel deeply that the current care system is fragmented with the following major challenges. The increasing ASD population, the disease' complexity and co-morbidities, and a lack of effective treatments overwhelm the medical system: many physicians who care for ASD patients, both primary care and specialist providers, feel work-overload and may feel that they have little to offer ASD patients and families. Neurologists and psychiatrists caring for ASD patients experience difficulties managing medical co-morbidities without a systemic approach. As a result, families manage a large number of specialty provider appointments, often receiving conflicting clinical information and treatment plans for their child's comorbidities. Disconnections between the medical system and school supports also pose barriers to successful ASD care and rehabilitation.

To better address ASD comorbidities and respond to parents' needs to improve care integration, we call for a new approach to care. This approach will incorporate principles of chronic disease management and empower PCPs to address ASD patients' specialized and primary care needs. PCPs and primary care teams are well positioned to screen, identify, and address medical-comorbidities and coordinate with specialty care and school/community resources. However, many PCPs remain untrained in the care of and resources for ASD patients. We propose a "Systematic Network of Autism Primary care Services" (SYNAPSE) model as a framework of practice to improve health outcomes for individuals with ASD. Each network would consist of ASD-trained PCP "function teams" in dispersed community practices, in primary care offices affiliated with tertiary care facilities, or in ASD centers that incorporate in-house PCPs.

Under the SYNAPSE model, patients and families should benefit from more streamlined referral pathways in collaboration with pre-determined networks of medical and psychiatric specialists with expertise in ASD. Specialists may be able to reduce wait times if patient flow is predictable and referrals attend to all necessary pre-work. A system ensuring that referrals occur only if and when needed also maximizes limited resources. The PCP team and specialists can also develop workflow to promote bidirectional collaboration with services in the community (e.g. Individual Transition Plans in school) and the medical system. Finally, the SYNAPSE team can extend beyond patient care. The PCP team can support and cultivate peer networks of ASD families, organize ASD family rounds, multidisciplinary grand rounds, professional case discussions and partake in training and research collaboration within the SYNAPSE network across specialties.