Oral Public Comments

IACC Full Committee Meeting

March 14, 2008

List of Oral Public Comments

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Paula Durbin-Westby

March 14, 2008

My name is Paula Durbin-Westby. As an autistic citizen and taxpayer, I have an interest in how funds from Pub. Law No. 109-416 are allocated.

I am concerned that research priorities not be driven by emotionally charged language used by fundraising organizations, or a disproportionate allocation of funding to research that may have limited application for autistic people and their families.

What is needed is accurate and well-informed research into the real lives of people on the autism spectrum. A large part of the focus needs to be on treatments and interventions that will be beneficial to autistic people now. Studies are needed into effective service delivery across the lifespan.

Community-based participatory research is a promising avenue for exploration. With community-based research, persons affected by the condition are full participants in every stage of the research process.

As outlined in a recent Funding Opportunity Announcement (FOA) for community-based participatory research (CBPR) into medically underserved communities, “community” refers to populations that may be defined by a number of parameters, including disability or health condition; or to groups that have a common interest or cause. The autistic community, while not a monolithic voice, fits the description in the federal funding announcement.

Treatment research also must include people on the autism spectrum: Treatment studies that focus only on trying to make us seem or be neurologically typical can have detrimental effects. Many anecdotal stories exist of people becoming quite stressed in their 20s, 30s, and 40s, due to a lifetime of pressure brought on by trying to adopt behaviors that are not natural for us. In this area, it is crucial to consult with people on the autism spectrum to determine the best methods for interventions and treatment. Adults who can communicate about our experiences with autism are one of the best resources for determining which treatments and interventions will help without causing unintended damage. Any studies undertaken without the participation of people on the autism spectrum can be marred by incomplete knowledge of the population being researched. Members of the autistic community should be collaborators in the research above and beyond being research subjects.

I am glad to see Stephen Shore as a member of the IACC. I do not know if anyone else on the autism spectrum has a position of authority within the IACC, other federal agencies, or working groups represented by the committee. People from the autistic community need to be involved at every level of research and policymaking.

According to the website for one large fundraising organization, “Today, 1 in 150 individuals is diagnosed with autism, making it more common than pediatric cancer, diabetes, and AIDS combined.” Unlike the diseases mentioned above, however, autism is not a terminal disease. Alarmist language used by fundraising groups has no real place in determining research and policy priorities. Once again, having autistic members on task forces that interface with the public about autism can help determine the best language to use to avoid stigmatizing rhetoric. The current FOA for Reducing Mental Illness Stigma and

Discrimination should include members of the autistic community, since language needs to be developed that will counteract the negative messages often found in the media.

Do not federally fund research that has eugenic implications. Members of the autistic community are quite concerned that tests will be developed that will be used to eliminate us from the broader spectrum of humanity. Currently there is at least one prenatal test for autism, offered by Children's Hospital Boston- the chromosome 16 deletion/duplication test. The current level of misinformation, partial information, and use of emotionally charged language about autism might conceivably lead to the same results that have been seen with Down Syndrome where 80-90% of fetuses are aborted. Who would not seriously consider not carrying a fetus to term whose condition is equated with cancer, diabetes and AIDS, if that's the best information they have? This comment from [PII redacted], saying: "We're now playing catch-up as we try to stem the tide and ultimately eradicate autism for the sake of future generations" really makes little sense unless you can convince entire biological families to stop having future generations of children.

Federal research funding should not be equated with research that could be interpreted as a program of eugenics for any subpopulation of United States citizens. This type of research does not help us or our families, which often have several generations of family members on the autism spectrum.

Thank you for your time and consideration.

Michael Frandsen

March 14, 2008

NIH is certainly doing some great work in autism research, but there has been some discussion that NIH and other federal organizations should do more research on *services* for people with autism. I believe that they should.

An example of how this disconnect between research and real world services can be bridged – rather than having completely separate silos for each area – is greater federal employment for people with disabilities, specifically autism.

As the steward of medical and behavioral research for the U.S., the National Institutes of Health (NIH) aims to "reduce the burdens of illness and disability" and "exemplify and promote the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science." A stated goal of the National Institute if Mental Health (NIMH) is to rapidly disseminate science to “mental health care and service efforts.”

There is a program that the government created to help people with disabilities – the Schedule A program for hiring people with disabilities, including autism. However, the government can certainly do more to implement this program and others like it.

I believe that NIH and other federal agencies should not only develop policy on making the hiring process as inclusive as possible, but should also be accountable to those claims by ensuring that the policies are effectively implemented in a way that will mutually benefit the agencies, the public whom they represent and work for, and the employees who conduct work for these agencies.

Thank you.

Mike Frandsen

Dena Gassner

March 14, 2008

Thank you to all for including public statements at today's event.

My name is Dena Gassner and I am here today, wearing many hats. I serve on the Autism Society of Middle Tennessee's Board of Directors; on an advisory panel for Autism Society of America (ASA) and for Global and Regional Aspereger Syndrome Partnershsip (GRASP).

I am the parent of an 18 year old living with an autism difference, I am a provider of family and individual services to individuals living with autism differences and I was diagnosed at 38 with Asperger's.

My reason for asking for this opportunity is to express to you that soon, there will be two adults from our family living lives with unnecessary challenges and under employment in society. For me to reach my minimum potential, I will require the assistance of a very unique kind of job coach. Many people call them "administrative assistants" but my 'assistant' will have to tell me what to do, where to do it, how long it will take and then manage all the income/output of the financials including dealing with social security reporting and the IRS. This is not going to happen for $13.00 per hour, which was the proposed amount Vocational Rehabilitation has allocated. In addition, for me to reach my maximum income producing status, I will need a housekeeper and in-house support for my son. After 7 years of negotiation with social security, two vocational rehabilitation agencies and two university small business centers, I stand ready to work.

However, without all the aforementioned supports, this will not be possible, despite my master's degree and extensive training.

My son has only endured one vocational rehabilitation experience. They did not review his entire psychological evaluation, but instead, stopped on page one with the IQ score (testing designed to evaluate the normal IQ of individuals with no special needs) and gave him a non-verbal vocational assessment which highlighted menial labor tasks. He was quite understandably insulted and they began to chastise him, asking him if he did not want a job. Insulted, we left. His verbal IQ is 109, he has passed on of three required gateway exams and manages his school hockey team.

Each state should be mandated to provide not only academic diplomas but life skills as well. We are happy in the present district where we reside; however, it was an all or nothing scenario: life skills or a diploma. These individuals need both. While we are all concerned for the needs of younger children, what about individuals for who time has run out? What about "adult find" where you actively and effortfully attempt to seek out maltreated and under identified adults on the spectrum?

When are you going to press for realistic, informed supports for employment? When are you going to push for appropriate post-secondary programs for students with autism differences that are not thousands?

Please help us to obtain meaningful employment. Mandate appropriate training to Voc Rehab centers and social security employees. And please, help our students obtain the well-rounded education they require.

Respectfully submitted,
Dena L. Gassner, MSW
Autism Society of Middle Tennessee’s
Board of Directors
Advisory Panel for ASA

Sharrill Hemry

March 14, 2008

I urge the Interagency Autism Coordinating Committee to place a high priority on interventional trials of immunomodulatory and anti-inflammatory drugs to safely target neuroimmune and neuroinflammatory issues as they relate to Autism Spectrum Disorder (ASD).

There is increasing awareness that the neuroimmune system and neuroinflammation may prove to be the key components in the etiology and treatment of ASD.

In 2005, the John Hopkins University School of Medicine published in the Annals of Neurology and the International Review of Psychiatry the first proof of neuralgia and innate neuroimmune system activation in the brain tissue and cerebrospinal fluid of ASD patients. As a result of their findings, the authors recommended more study of neuroinflammation in the pathogenesis of autism.

On 24 Oct 2007, neurosurgeon Dr. Kevin Tracey of The Feinstein Institute for Medical Research spoke at NIH on the "Physiology and Immunology of the Cholinergic Anti-inflammatory Pathway," during which he highlighted the discoveries made in his laboratory and the clinical trials underway to test the theory that stimulation of the vagus nerve, which engages directly with the immune system through acetylcholine, could block a rogue inflammatory response and treat a number of diseases.

In the 7 November 2007 Science Daily, Dr. Esther Sternberg of NIMH's Neuroendocrine Immunology and Behavior Section offered that, "The discovery that immune molecules play a crucial role in shaping neuronal connections and are even expressed on nerve cells important in learning and memory is opening up a whole range of potential new treatment targets for diseases in which these connections have gone awry, such as…autism… Understanding these neural immune connections at a molecular and cellular level will shed light on the reasons these diseases develop and will help provide new ways to prevent or treat them."

Despite increasing acknowledgement of and interest in the likely connection between neuroimmune issues and ASD, only three NIH-funded autism trials appear to address neuroimmune/neuroinflammatory issues: treatment with Donepezil HCl to increase cortical acetylcholine and control brain inflammation; a test of Omega 3 Fatty Acids as an anti-inflammatory (a supplement already used by ASD parents for years with mixed results); and an immunological investigation of autism subtypes (the latter study is limited to children under seven and is likely to primarily benefit children born 5-10 years from now).

So, many of the current national priorities for ASD are focused on preventing and mitigating autism in the youngest population. Early detection, early intervention and research to find the genetic-based susceptibilities for ASD will hopefully reduce future populations of autistic children.

But there is an invisible cohort of older children whose illness had a high probability of going undetected in infancy and, when detected later, interventional treatments were often limited due to availability of practitioners or personal/public budget constraints. This cohort are now teenagers and young adults, many of whom will require partial or full public assistance starting at age 22 to subsidize their housing, food, medicine and work so that their parents may finally begin saving for retirement.

I believe we owe it to this almost forgotten cohort of older children and young adults to emphasize the need for safe interventional global immunomodulatory/anti-inflammatory treatments having the highest likelihood of easing their illness. Each year that passes, more and more of this older cohort are being locked into a rigid future of low expectations and buried intellectual capacity by school system, community and state budget limitations and ever changing Board of Education rules. The IACC can make a critical difference in the lives of these children through your actions.

More than a decade ago, two medical doctors, each at premiere local hospitals and each with a background in behavioral medicine, separately conducted multiple psychological and behavioral tests on a three year-old male patient and diagnosed him as autistic.

The patient was essentially non-verbal, completely socially internalized, was unable to sleep through the night and presented with multiple self-stimulating behaviors, including clapping, pica, and nearly incessant hand-wringing and moaning.

A year later, a medical doctor with a background in pediatrics and immunology conducted extensive blood tests on the patient and diagnosed him as having an affective central nervous system neuroimmune dysregulation.

Among several immune markers identified, the blood tests revealed that the patient had an Interferon Alpha serum level more than 100 times the top end of the normal range and an antistreptolysin O titer more than 12 times the maximum recommended threshold.

Untreated, the patient had apparently been coping with a lot of physical pain, manifested through his behaviors. With treatment, the patient began to engage the world to varying degrees, slept through the night, and stopped both his hand-wringing and moaning self-stims.

The male patient I speak of is the middle of my three children, who are currently ages 10 to 14. All three have been diagnosed with varying degrees of autism and yet all three children demonstrate blood markers indicating a CNS neuro-immune dysregulation. As a point of information, my spouse and I were diagnosed with auto-immune and chronic gastrointestinal illness, respectively, a few years before the children’s autism diagnoses. So this is definitely a familial condition.

I use the history of my son’s diagnosis to stress once more the need for fresh perspectives regarding the future direction and priorities of autism research as the IACC works to quantify the effectiveness and outcomes of innovative and newly developed intervention strategies by December 2010 in accordance with 42 U.S.C. 280i-3.

My thanks for your time.

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Katie Miller

March 14, 2008

Thank you for allowing me the opportunity to speak this afternoon. My name is Katie Miller and I am here representing myself as an autistic member of society. I am pleased that so many resources are being directed towards autism spectrum. However, there are a number of issues that I believe are important to express my views on.

Firstly, there is a strong need to improve and make available diagnostic services to a wider population. The number of mental health professional sufficiently knowledgeable about autism spectrum disorders to properly diagnose and treat individuals on the spectrum is small. Children have many more opportunities for diagnosis than adults do. While knowledge of autism spectrum disorders is increasing, much of the information health professional have is false.

Others have wide gaps in their knowledge due to receiving medical training in an area when there was little knowledge of ASD. As I'm sure many of you know, many practicing psychologist, psychiatrists, and neurologists received their medical training before Aspergers syndrome was added to the Diagnotistic and Statistical Manual (DSM) in 1994. Because scientific knowledge about autism is rapidly increasing, I propose research on how to give professional the best possible information.

Secondly, please use funding to improve the quality of life for people on the autistic spectrum, not to research a way that prevents more of us from existing. I am very concerned with the amount of funding supplied to research with eugenic applications. If a prenatal test for autism is implemented, the autistic community fears that many parents would choose to abort fetuses that test positive. While I take no stand on abortion in general, this is of great concern to me because there can be no reliable way of knowing how happy a child may be in life simply by identifying certain genes. I don't think it is necessary for me to list the many contributions to mankind made by living autistic individuals, nor to list numerous prominent historic figures suspected of having autism. However, I would like to quote Temple Grandin: "After all, the really social people did not invent the first stone spear. It was probably invented by an Aspie who chipped away at rocks while the other people socialized around the campfire. Without autism traits we might still be living in caves." (Thinking in Pictures p. 122)

There are many ways to improve the quality of life for people on the autistic spectrum. One is better education and training of teachers and doctors so that proper treatment and services can be provided to all individuals on the autism spectrum, whether they are greatly or mildly affected by autism. Better assistive communication devices, social skills training, specialized schools, vocational training, specialized career and relationship counseling, and sensory integration therapy are other examples of services the autistic population needs.

Thirdly, additional representatives who are on the autism spectrum should be placed on the IACC and in workgroups and other areas of research. Nothing about us, without us. We are experts on our own autistic thoughts, ideas, experiences, and needs. No one else has that insight.

Fourth, I as well as others both on and off the autism spectrum are concerned about the continued presence of Alison Tepper Singer on the IACC. Her attitude towards autistic individuals and autism, as evidenced in her comments in the film “Autism Everyday” indicates that perhaps the best interest of people with ASDs are not being served by her membership on the IACC. Like many in the autistic and autism communities, I was horrified and outranged while listening to her talk about almost killing her autistic daughter, [PII redacted], in the Autism Speaks fundraising video, Autism Everyday. Ms. Singer states on camera that she did not drive off the George Washington Bridge with [PII redacted] in the car only because of the fact that she has another child. While the statement itself is derogatory, the most troubling aspect of the incident is that [PII redacted] is playing in the background.

I would like to conclude with the belief that many of the problems autistic people face are not due to autism, but due to society’s lack of understanding and tolerance for neurodiversity. Even the most severely affected, so-called “low functioning” individuals think intelligently, feel like all other humans, and many even make contributions to society. I would like to see more attention spent on promoting an inclusive, tolerant society, and less on trying to cure or eliminate those seen as defective.

Ari Ne’eman

March 14, 2008

Thank you for this opportunity to give comment on the IACC’s important work. My name is Ari Ne’eman and I am here today in my capacity as the President of the Autistic Self Advocacy Network (ASAN), a volunteer non-profit organization run by and for adults and youth on the autism spectrum. ASAN works to promote the autistic culture movement and other opportunities for individuals on the autism spectrum to interact with each other as well as work to improve the representation of the autistic community in public policy deliberations about autism and disability affairs.

I would like to take this time to reiterate and elaborate upon the comments I made at the last IACC meeting, encouraging this committee to re-orient its research agenda in a fashion that will comply with the perspectives and goals of the community of individuals on the autism spectrum. The first step towards this is to follow up on the appointment of Stephen Shore and add additional autistic representatives to the IACC and its workgroups. The concept of “Nothing About Us, Without Us” is a long time pillar of the disability rights movement and it should be respected in autism policymaking, just as it would be with the drafting of policy aimed at any other minority group.

In addition, we encourage this committee to focus its research towards measures that will improve the opportunities for communication and quality of life for autistic individuals, by funding research into Augmentative and Assistive Communication (AAC) technology, early education and service-delivery methods in areas of employment, independent living, housing and other important spheres for autistic individuals everywhere. I’m concerned by the fact that the autistic people, family members and others who make up ASAN’s international membership continue to face skepticism about the very existence of autistic adults. The media portrays the autism spectrum as something new only existing amongst children. Yet, the adult population continues to lack needed support and awareness. State vocational rehabilitation agencies and other aspects of the developmental disability service-delivery infrastructure are ill-informed about the needs of adults on the spectrum. Furthermore, there is a pressing need for more research on how to best serve both adults and youth on the autism spectrum in fields like educational methodologies, restraint reduction, positive behavioral supports and other areas that take practical steps to improve access, inclusion and respect for our community.

I was diagnosed on the autism spectrum at age 12, and I have been fortunate enough to benefit from a family that has been accepting of my differences and supportive of the educational services that have helped me develop. Unfortunately, not all children on the spectrum are receiving that acceptance and support. The current culture of despair and intolerance promoted by groups like Autism Speaks and Generation Rescue does not contribute to positive outcomes for autistic individuals. Statements that devalue autistic life, like those made unapologetically in the fundraising video *Autism Every Day* by IACC member and Autism Speaks Executive Vice President Alison Tepper Singer, do not benefit people on the spectrum and contribute to an environment of stigma and fear. Ms. Singer’s comments, where she states she considered driving her daughter off the George Washington Bridge, refraining "only because of…the fact that I have another child," are of great concern, particularly given the murder of an autistic child by her mother a mere four days after her statement. The inaccurate and incomplete picture of the autism spectrum that Autism Speaks has chosen to promote for fundraising purposes contributes to the environment that makes these atrocities possible. That is why the autistic community continues to be concerned by Ms. Singer’s presence on this Committee and the message her selection sends to people on the spectrum, our families and our supporters. You cannot help us by demonizing our neurology and stigmatizing our very existence.

Genetic research promoting a prenatal test for the autism spectrum is also of grave concern. It should be noted that Dr. Joseph Buxbaum, an Autism Speaks-funded researcher, believes that a prenatal test for the autism spectrum could exist as early as 2015 – in fact, genetic testing for some types of the autism spectrum is already available. There is significant evidence that such tests will and are leading to the use of selective abortion to engage in eugenics against the developmentally disabled. It should be noted that approximately 90% of fetuses that test positive for Down Syndrome are aborted. While a prenatal test for the autism spectrum is significantly more complex to develop, once it is in existence the current climate of fear makes a similar result likely. While we do not hold an opinion on the abortion debate in general, we are deeply concerned by any effort to eliminate a particular kind of individual from the gene pool solely on the basis of neurology. Taxpayer funds should not be going to eugenics.

I consider it a grave human rights concern that many autistic individuals continue to be unable to communicate because the assistive communication technology and educational methodology research that could help many more adults and children convey their needs is being ignored in favor of eugenically oriented genetic research aimed at finding a “cure” for a natural and legitimate part of human genetic diversity. The autism spectrum is not a recent epidemic but a neurological condition that has always existed, but is only now being diagnosed at incidence rates that approach accuracy.

The autism spectrum often comes with significant disabilities that require substantial support. However, rather than trying to eliminate us, we can and should be taking steps to mitigate those disabilities while empowering the strengths that we possess and respecting our legitimate place in the spectrum of human diversity. We encourage this Committee to take the first steps towards shifting the main buzzword about autism from “cure” to “communication” and ultimately, to moving the dialogue about the autism spectrum to one of acceptance, inclusion and, above all, respect.

Thank you for your time. As always, “Nothing About Us, Without Us.”

The Autistic Self Advocacy Network (ASAN)

Alexander Plank

March 14, 2008

My name is Alex Plank and I was diagnosed with Autism at age 9. I'm here representing Wrong Planet (http://WrongPlanet.net), a website for people with Autism which I started when I was in High School. There are over 17,000 registered members of this online community who have cumulatively posted more than one million messages about their experiences living with autism. My site has received critical acclaim from the Washington Post and has been mentioned by Good Morning America, Dr. Phil, Fox News, and The View.

It is troubling to continually hear members of my site's autistic community telling stories about difficulties they face on a day to day basis. Most of these problems are caused by a lack of public understanding of Autism, the absence of any formalized support services in this country, and an egregiously low awareness of autism among medical professionals. Professionals are not equipped with the tools they need to help those of us who are autistic and most importantly, there is a lack of a real understanding of the intellectual processes of autistic individuals.

Consequently, the focus of continuing research should be placed on that which affords autistic citizens a better quality of life. Autism organizations such as Cure Autism Now and Autism Speaks do not see this type of research as a priority. It is unfortunate that such a large percentage of funding is going towards research that provides little to no benefit for the millions of Americans already living with Autism. I am referring to research done with the goal of prenatal screening, a practice that would certainly discourage the many autistics who have been living fulfilling, albeit challenging lives.

I would like to express that there is absolutely no reason to deem an autistic life as any less valuable than another, especially when our intellectual capacity is in no way diminished; many of us have performed in the top percentile of IQ tests and a good number of us have provided valuable services to society. For instance, Nobel laureate Vernon Smith is responsible for creating an entirely new field of economics. He was diagnosed with Autism but is married and leads a fulfilling life as a professor at George Mason University.

By mentioning these individuals, I am in no way attempting to undermine the struggles faced by parents of individuals who are nonverbal. I hear about these struggles from parents on my website every day. However, many of the parents who post about their nonverbal children acknowledge that their child's autism does not take away their son or daughter but only takes away the ability to communicate with their children.

I am going to refrain from criticizing committee member Allison Singer because the problem we face is much bigger than the comments made by one parent; the forces that lead parents to dehumanize their autistic children are systemic.

What kind of message does it send to the general public when the most financially significant Autism organizations are running public service advertisements that continually employ emotionally loaded terms such as disease and epidemic in reference to autistic individuals such as myself? Keep in mind that people like me make up an extremely large percentage of the 1 in 150 and there is hope for all of us living with Autism.

Marketing guru Seth Godin explains that people (and potential customers) take action in response to three emotions: Fear, Hope, and Love. He states that the easiest way to build a brand is to sell fear. While fear may be an easy way to bring awareness, scientific studies resulting from this fear are inherently biased against the goal of increasing the quality of life of autistics that are already living in this world.

In contrast, scientific research done out of hope has the potential to bring about a better quality of life for all of humanity. I personally have the hope that the needs and perspectives of autistic individuals will be better represented by this committee in the future.