Written Public Comments

IACC Full Committee Meeting

May 12, 2008

List of Written Public Comments

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

Sandra Wort

May 12, 2008

I have a son with autism. Through years I have seen how budgets have been given for research in genetics, in psychology, in environmental factors and allergies. I am firmly convinced that if you have not found yet anything is because there is nothing there. Would you consider hearing what we parents have been saying for so much time, that children get better with fevers, antibiotics, antivirals and antifungals? Children also have subnormal temperatures frequently which are a classic sign of infection. Would you consider that autism could possibly be an infection of some sort and that is why it is so prevalent, almost like an epidemy? Would you consider the possibility of getting involved infectology and give some moneys to research on this. Even though it does not meet all the criteria to consider an infection. Many of the biggest discoveries in humanity have been through things that were never expected.

I gave my son a dosis of Tamiflu for a very bad cold he started. His advance in all fields focus, language, thought social interaction and in all areas was almost a miracle. I had never seen him improve the way he did after this treatment. Even though he has had some regression he has kept a lot of the improvement. Please do not try to give other explanations of why it worked. Ijust beg you to please consider doing research on infection.

I agree children need to be vaccinated but could there be an infection transmitted through vaccines? Some particle or virus or fungus or unknown bacteria or parasite responsible for such a pervasive disorder?

I would like to say that I am a Registered Nurse and a trained observer of medical conditions. I am telling you what I have observed professionally with my son. Some people would say this is anecdotal information. I would like to point out that one of the greatest medical breakthroughs in medical history was the anecdotal observation that milk maids did not get small pox. Milk maids got exposed to cowpox and received protection against small pox. Pasteur followed up on this and thus we have the small pox vaccine. Just because something is anecdotal does not mean that it doesn't have an element of truth.

Thank you,

Sandra Worrt BSN RN
School Nurse
[PII redacted]

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Eileen Nicole Simon

May 12, 2008

- What is the size of the budget for the strategic plan
- Do the FY2007 dollar amounts reflect spending in that year only, or total amounts granted including the entire multiyear grant?
- Do the institutes just report total in the grant, or do any of the institutes pro-rate funds, to count just the portion that is autism-related when a grant relates to multiple disorders?
- Do the dollars presented include intramural work
- Do the numbers reflect only 2007 expenditure
- What are you doing to reduce heavy metals children that cannot excrete heavy metals that children that are worse are chewers and we now know of toys having lead paint
- How do you define treatment? ABA or medicine
- Mercurous chloride, also known as sweet sublimate, was once the most commonly prescribed form of mercurial medicine, but by 1863, the U.S. Surgeon General William A. Hammond had removed it from the Union army's pharmacopoeia.(8)
- If it were found that Mercury is responsible who would be responsible?
- The previous strategic plan was conceptualized better because it had short term, medium term and long term goals. While your listing of areas for research was comprehensive, it did not give your participants a level playing field of knowledge of what projects were a prerequisite to others. Furthermore, some of your participants really had populous views like saying that they want more money for environmental factors, when it is likely that they are arguing that it is the vaccines.
- Why is this evidence not discussed and made a focus of research on environmental factors that might lead to autism? Please respond to [PII redacted].

Thanks,

Eileen Nicole Simon (conradsimon.org)

Eileen Nicole Simon

May 12, 2008

Attached is a suggestion I have for research on perinatal factors and auditory system vulnerability. I hope the seven points I have listed can be considered. References with some illustrations are also included.

Eileen Nicole Simon's attachment can be viewed here:
Attachment (PDF – 273 KB)

Richard Creamer

May 12, 2008

Recently, I was reminded of two other factors that are of concern to me which perhaps you can forward to the group that was going to evaluate parent/family input.

Here are two potential environmental sources of mercury:

1. Standard 4' fluorescent lights such as in kitchens contain mercury vapor. I'm sure they leak, are easily damaged during installation causing more leakage, and sometimes fall on the floor and break releasing their entire contents.

2. Also, I've heard that the government's "green" and/or global warming movement is considering banning tungsten light bulbs in favor of the new energy-efficient compact fluorescent light bulbs. Since these also probably contain mercury, I am adding them to my list.

Recent research seems to suggest a link between mercury and autism. As a result, I feel all wide-spread sources of mercury such as the above should be on the suspect and research study list. I don't know when fluorescent light bulbs became prevalent in single-family homes, but suspect it might coincide with the 80s.

I think that, just as the fire triangle (heat + fuel + air) describes how fires can occur, a similar triangle for ASD (genetic susceptibility + mercury + TBD environmental trigger) may explain the occurrence of ASD in children.

Thank you for your time and I apologize that I was not aware of the above at the time of the RFI. Please forward this input to the RFI group.

Best Regards,

Richard Creamer

PS: I also did not think of satellite TV broadcasts and government satellite radar (Doppler + synthetic aperture terrain mapping + LIDAR) at the time of the RFI. This type of effect might be correlatable to the TBD environmental trigger above, or, it may not.

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Tracy Hutchins

May 12, 2008

As a pharmacist and parent, I never fail to be amazed at the misconceptions surrounding the puzzle of autism. In fact, I'm very concerned that these misconceptions will lead to the re-emergence of deadly childhood diseases. I have 3 children, a son, almost 8 years old and autistic, a daughter, age 6 and oh so typical, then there's another son, 22 months and autistic. This is a trend that I've found among my research and in meeting families throughout my son's therapy. It was no surprise to me that my youngest was diagnosed with autism at the age of 14 months. In fact, the first words out of my mouth at my 20 week ultrasound were, "I wonder if he'll have autism like my eldest."

I am in a very unique position and so very fortunate. In the past 14 years, I've been taught invaluable skills in providing drug and medical information as well as how to interpret and evaluate studies. The first thing I researched was the causes of autism. In school we were always taught that there was no link between vaccines and autism, but this wasn't enough for me. I had to be sure of it, so I began my research. I evaluated study after study. I then began attending continuing education seminars and came up with some very interesting trends. I couldn't find any link between autism and vaccines, but the genetic links and boy factor were overwhelming. I also did a lot of research trying to find the best treatment for my children. All of the experts, including our specialist recommend 25 to 40 hours per week of one on one intervention using an ABA method. Yes, this seems like a bit much, but if you do this for a couple of years, miracles can happen and your child has a bright future. When my son began his program which included speech and occupational therapy, he was turning 4 years old and struggled with simple commands like "Give" and "put in". One day, he got it and then it was like this whole new world opened up for him. Before long he had taught himself to read. His progress has been amazing. His therapists had never seen a child make this kind of progress, but he was also the first one they had seen receive the intense therapy. He is now finishing up 2nd grade. He has been mainstreamed all the way and does wonderful academically. We just updated his MFE and he received his first good speech evaluation. In fact, his vocabulary skills are near the 95%. This was the boy who was always near the 15% in anything speech related. What an inspiration. Needless to say, I'm not concerned about my youngest; he's already made huge strides. We've found the method that works and it's nothing more than hard work and dedication.

Throughout my journey I have come across some things that are very concerning. So many parents still believe the vaccine theory, regardless of the lack of evidence. The latest case on TV drove me into action. The national media interviewed a family who had supposedly been compensated on the basis that vaccines caused their daughter's autism. This really bothered me, so I contacted the CDC. The response I received from one of their medical doctors was nothing less than shocking. I will quote word for word his response to my email. "I will add that all the media attention to the Poling case is to date based on documents LEAKED illegally from the Department of Justice, and sheer speculation and spin by vaccine and autism activists. CDC has still not received the actual facts of the case, and the basis on which the Vaccine Injury Compensation Program decided this particular case was compensable, because this information remains confidential." This is a copy and paste of my email from the medical doctor at the CDC. I responded to him saying that I felt the public needed to hear this side of the story as well. He agreed and referred me to a grass roots group called Voices for Vaccines. This group is aimed at educating parents about the lives vaccines have saved over the years. My generation doesn't understand the devastation of diseases like polio as it has been practically eliminated. They also promote evidence based therapy rather than some unfounded program that profits by selling vitamins and glutein free food. This program has been enriching and has served as a wake up call. If children stop getting vaccinated, then deadly diseases will resurface and children may die. Another myth is that if you're vaccinated, you are protected. Unfortunately not everyone develops immunity from vaccinations, so this is why it's so important to continue vaccinating all children. I can speak to this first hand. I received my mumps measles and rubella (MMR) booster prior to my clinical rotation in college, yet still did not have a positive titer.

I have one last area of concern and it involves the therapies desperate parents turn to. I've read about parents "detoxing" their kids through chelation, dietary restrictions and supplements. I'm concerned because children have ended up in the hospital with Vitamin A toxicity due to some of these treatments and there's no evidence that it works. My sons have made miraculous progress without any more than hard work and applied behavioral analysis (ABA) therapy. There's a reason why autism mostly affects boy and runs in families; genetics. It is believed that [PII redacted], [PII redacted] and many others had autism and that it ran in their families and that was before vaccines. We've been very fortunate and I count myself blessed to have 2 little boys with phenomenal minds as well as my sweet daughter. Autism really isn't so bad, but deadly childhood diseases are. Please consider the evidence based facts and protect your children and others.

Tracy Hutchins, BSPH, Rph

Eileen Nicole Simon

May 12, 2008

Subject: Suggested Focus for Research in the IACC Plan

Suggested focus for research in the IACC Plan

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Kristina Chew

May 12, 2008

On May 15, my son [PII redacted] turns 11. He is smack in the middle of the autism spectrum: He has minimal language, a history of serious behavior problems, and is severely delayed in his academic skills and cognitive ability. He is starting middle school in the fall and one word is now regularly applied to [PII redacted]'s pre-reading program, speech therapy, occupational therapy, and all aspects of his educational programming: "Functional." All aspects of [PII redacted]'s education are now based on teaching him the skills that he will need for the rest of his life. [PII redacted] is already learning some pre-vocational skills and, sometime during his high school years, will start vocational training at different jobs in our community.

A little more about [PII redacted]: [PII redacted] was diagnosed with autism when he was just turning two years old. We immediately started him on the gluten-free casein-free diet and he received intensive ABA therapy (40 hours/week) from the time that he was two years and four months old. We also gave [PII redacted] a number of supplements and tried some other treatments mentioned in the DAN! (Defeat Autism Now!) Protocol and took him to a DAN! practitioner. [PII redacted] also received speech therapy and occupational therapy. He has been in special education classrooms since the time he was four years old. At the age of seven, he went through a severe regression, during which his self-injurious behaviors became so severe that we feared he would have to be institutionalized. We began to look for a school program that would best provide [PII redacted] with the education he needs and were fortunate to find such a program: It is based on the principles of Applied Behavior Analysis (ABA) and highly structured, and the staff are highly trained and carefully supervised. By the time [PII redacted] was 8, we had discontinued all supplements; some of these made his behaviors (head-banging and aggression) worse.

Today, [PII redacted] is a happy school boy who is learning to play piano and cello, loves to swim and ride his bike on several-mile rides through our town with his dad, and looks forward over the weekend to the bus showing up at our door on Monday.

How can we---can society---ensure that [PII redacted] is not only a happy school boy, but that he has a happy and a good life? These are the questions that I think need to be kept in mind as a Strategic Plan for autism research is developed. I hope that, alongside funding research into causes and treatments, we can also think about how to support autistic individuals at all parts of the spectrum throughout their lives. More specifically:

1) How can we ensure that group homes and other supported living facilities for autistic adults are adequately funded throughout the lifetime of autistic adults? The current cost of caring for an autistic person over the course of his or her lifespan has been estimated to be $3.2 million, according to an April 2007 study in the Archives of Pediatrics & Adolescent Medicine. Further, the cost of autism to society is more than $35 billion in direct and indirect expenses each year. These are huge figures, and we need to think of what measures can be taken and what initiatives created so that we can provide for those autistic persons who, like my son, will need care and support throughout their lives.
2) How can we plan to ensure that staff will be adequately trained and supported? There have been too many cases of autistic and developmentally disabled adults being abused by staff and even dying in

group homes. We need to begin to think about how staff can be trained and supported to ensure that these kinds of incidents do not happen, and that the use of physical restraints is minimized on autistic persons. There is research available about alternate, non-aversive methods to assist an autistic person, and we need to draw on this to find out how to train staff in group homes and supported living environments as well as in schools.

3) How can we create a comprehensive employment system for autistic adults? How can we motivate companies (such as Walgreens with its South Carolina distribution center, which has an 800 person workforce that is one-third disabled) to create jobs for autistic adults and to support them? How can we create programs not only to train autistic adults in getting jobs, but in keeping them? How can pre-training for jobs be integrated into a school curriculum?

Many parents of autistic children have noted that, what is the use of giving a child an excellent education, only to prepare them for nothing when that child turns 21---for no job that is meaningful, no place to live, no community to be part of. We have come a long way in creating schools and educational programs for autistic children. Our children who are autistic today will be adults for most of their lives and it is our task to find the means to provide them with not only a good life but the best we can.

Kristina Chew, Ph.D.
Assistant Professor of Classics
Co-director, Honors Program
Advisor, Special Scholarships and Graduate Studies
Department of Modern and Classical Languages
Saint Peter's College

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Christofer Foss

May 12, 2008

I am here to express my strong support for the positions advocated by the Autistic Self-Advocacy Network: (1) Funding for Improved Service Delivery, Educational Methodology, and AAC Research; (2) Funding for Community-Based Participatory Research; (3) No Funding for Research with Eugenic Applications; (4) Placing Additional Autistic Representatives on the IACC and the Workgroups; and (5) Taking a proactive stance in eliminating stigmatizing language. I am here as both a professional and a parent to urge you to work earnestly in concert with groups like ASAN to realize these goals as fully and as promptly as possible.

Professionally, I am an Associate Professor of English at the University of Mary Washington in Fredericksburg, VA. During the past two years I have increasingly focused on disability studies in my research and this past semester I taught the first iteration of a new First-Year Seminar on Representations of Autism in Contemporary Literature and Film. Among the many highlights, my students and I started with [PII redacted], returned from Spring Break to an on-campus visit from Ari Ne'eman of ASAN, and spent the last day of class watching YouTube videos by [PII redacted]. Any one of these three remarkable human beings should be evidence enough of the brilliance and creativity that we all may continue to benefit from as long as America (and the world) dedicates itself to a non-pathological understanding of individuals with disabilities in general and of autistics in particular—an understanding which emphasizes accommodation over cure, diversity over defectiveness, and inclusiveness over discrimination.

On April 2 (World Autism Day), I gave a talk on campus entitled "Emerging from Emergence." My thesis was that, during past dozen years or so, one may observe a marked shift in how most writers of book-length accounts of living with autism spectrum disorders position themselves relative to what traditionally had been the typical pattern for such life writing. In the earlier trajectory, the narrative inevitably moved toward the autistic individual's recovery, or at least emergence, from his/her disability.

Recently, however, most writers (from both first- and third-person points of view) have been rethinking the merits of such a teleology, often opting instead to insist upon their autism spectrum diagnoses as a fundamental aspect of their self-concept rather than as a hindrance to a more normal life and full self-realization. Writers as diverse as [PII redacted], [PII redacted], [PII redacted] (and [PII redacted]), [PII redacted], and John Elder Robison—including, significantly, some who relied upon the older trajectory in their earlier work, such as [PII redacted] and [PII redacted]—all ultimately insist upon an understanding of disability as (in the words of [PII redacted]) "human variation and difference" rather than "inherent defectiveness."

Near the end of my talk, I expressed concern that this welcome new trend may be overshadowed, even eventually countered, by media blitzes (such as those generated by Jenny McCarthy's *Louder than Words*, or by some of the initiatives from Autism Speaks) which appeal to the outdated paradigm of disability left over from telethon culture—a paradigm in which, according to [PII redacted], "the ideology of cure and the mandate for normalcy intertwine, crowding out any possible narrative of accommodating rather than eliminating disability."

I concluded my lecture, however, on a personal note, as a parent of a child with an autism spectrum diagnosis. When my son was diagnosed, I confessed, I felt robbed of all my pleasure in his quirkiness and left only with how difficult a child he was to raise. It has been a very slow process for me to stop pathologizing every single aspect of his behavior, especially the negative traits. I know first-hand it is too easy always to be looking ahead to some future version of a "real boy" that he might become through his occupational therapy, his speech therapy, his social skills groups, his sensory integration work, his therapeutic horseback riding, or maybe through some magical fairy godmother—too easy to miss living each moment for that moment's sake, too easy to miss the real boy, right here, right now.

I am increasingly convinced (contra McCarthy) that it is I who has been locked inside the label of autism, not my son. It is I who needs to emerge from the sort of thinking that too often sees a label instead of a boy—my boy, the same "beauty boy" I've been singing to since the day he was born.

Autistics are not, like Pygmalion, stone statues who need to be magically transformed into living, breathing human beings; nor are they Eliza Doolittles, who need to learn good manners and proper English before they may pass as fully human. Autistics are not empty-headed wooden puppets—they are real boys and girls, real men and women. My point here is not that one mustn't pursue a whole spectrum of research programs and support services to try to better enable both society and autistics themselves to accommodate for their all-too-real deficits. Rather, it is never to lose sight of the full personhood in front of us at every stage of the process, from the nonverbal 18-month-old [PII redacted] to [PII redacted].

Sharrill Hemry

May 12, 2008

I was stirred by an idea discussed at the 21 April IACC Strategic Planning Workgroup Telephone/Web Conference in which some of the Workgroup members conceptualized a special IACC-focused grant panel. Armed with its own pot of funding, the panel could be charged to seek out and fund ground-breaking ideas targeting the IACC's key priorities. The panel would be comprised of both NIH and community advocates for widest perspective.

Since the 21 April Workgroup, I have found myself frequently drawn back to ponder the potential of a special NIH grant panel, mostly because I believe that this could be the best means to get funding for desperately underfunded autism treatment options, such as biomedical interventions.

To ensure that the grant applications received by this panel would include the freshest ideas and that first-time NIH grant applicants would be motivated to apply, the panel would need to provide the public with clear, specific target areas of interest and would have to repeatedly publicize this information over multiple venues to give it broadest dissemination and generate interest.

But then, as I continued to study the IACC Workgroup's tentative priority rankings and thought about how a grants panel could employ some of these priorities to identify target areas of interest, I began to realize that some of IACC priority listings are so generic, their applicability will be limited.

As an example, I was initially pleased to see "Interventions for Adults and Older Children with ASD" as the Workgroup's top vote getter in the Treatment category, but then I realized that "intervention" is not defined. This priority, for Adults and Older Children, would have been better as two separate priorities: biomedical interventions and therapeutic/ behavioral interventions.

I was impressed with the progress that the IACC Strategic Planning Workgroup was able to make in only six hours and was moderately pleased with the merit of their final recommendations.

However, I did have a concern regarding the prioritization process, in that the Workgroup didn't vote directly on the 41 priorities, but instead voted for them under six categories, with anywhere from 4 to 9 priorities listed under each category. This system appears to have created quotas for the voting, as there were only so many votes to go around in each category. At least one Workgroup member seemed to imply that, due to limited voting points in each category and a desire to spread the votes around, there was one priority that was ranked high under one category, while a quite similar priority was ranked low under another category. I'm sure there are other instances of this because the items weren't prioritized 1 to 41.

The Workgroup was presented PowerPoint slides at the end of the meeting, showing that their voting priorities matched up with the number of times the public commented on the same issues in the Jan 2008 RFI's, but the format for the Jan 2008 RFI's also used categories (Treatment, Diagnosis, Biology, and Risk Factors), so there was an automatic data bias inherent in the RFI inputs, as well.

I was one of those who provided a Jan 2008 RFI input and I made comments in all four categories. Had I known that my comments were going to be tallied, with equal weight given to each category, I would have made comments only under Treatment and then left the other three categories blank.

In future, may I recommend that the public be given a means by which they can weight each RFI category? For example, had I been allotted 100 points to weight across the four RFI categories, I would have given 90 of 100 points to the Treatment category. My comments in that category could then have been weighted accordingly.

During the 21 April Workgroup, IACC member Lyn Redwood stated that the list she had of the different autism trials included only one biological intervention, similar to what I found on the NIH website. A PowerPoint slide provided during the Workgroup showed that only 13 percent or so of NIH autism funding went to biological intervention. These figures are disheartening for those of us with evidence that a medical condition underlies our loved ones’ autistic behaviors, because there continue to be few treatments available to mitigate their issues.

I very much hope that the IACC finds a way to give a high priority to biomedical interventions. Maybe that will help to get grant funds focused on interventional follow-up to Johns Hopkins' 2005 findings associating neuroimmune/ neuroinflammation issues with Autism Spectrum Disorder.

One last: Since the public has to submit our comments in writing in advance and, thus, cannot comment on events that occur during the meeting, I would request that we be allowed to speak in the morning in future, so that our words have the opportunity to impact upon your discussion and recommendations.

My thanks for your time.

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Terri Jackson

May 12, 2008

My name is Terri Jackson, I am here today to share with you about my all too common experiences during the last 5 years trying to navigate my way through local agencies and institutions here in the nation's capital to obtain a diagnosis and treatment and an appropriate education for my son who was finally correctly diagnosed at the age of 3 years and 8 months with classic autism.

My husband and I while initially terrified of the thought of Autism, when we initially began to suspect problems with our son at approximately 1 year of age. The process of identifying and providing necessary Developmental Disorders, and in particular Autism spectrum Disorders is made more difficult by an firstly pediatricians who are not aware of the red flags of autism or persist on basing referrals on outdated criteria or fail to refer children to the Early Intervention System as soon as the parent voices concerns. Continuing to spout the age old lines of "every child develops at their own pace" or "that he/she is still at the low end of the normal range and to give it time ". Secondly, here in the District of Columbia (and as statistically shown in many other urban areas) the Early Intervention System lacks the understanding of the urgency of the very services they are supposed to aid the family in accessing. Further there is an unwillingness to inform and educate parents in a practical and culturally competent manner; present the huge number of intervention methodologies in a way that is meaningful and accessible or help families obtain the visual and behavioral materials used in center based care in order to standardize the child's communication and other needs. I am here to advocate for more funding for organizations such as Family Voices which as a parent run organization, is uniquely able to understand and support parents at their level. Thirdly, while I am grateful for the services available through Medicaid MCO's such as the district, even if I have run afoul of problems getting the specialty services that are part of the intent of their mission statement we are blessed. I might have had to avail myself of the assistance of an attorney on occasion, I find myself feeling torn and frustrated because of a lack of an Autism Waiver in the city. I have friends who are solidly middle class, with a child with Asperger's Syndrome I feel for this brilliant little blond haired boy who receives no speech therapy because while he has serious pragmatic and expressive language skills, his flat speech is reflective of his high IQ. He was recently discharged from the 45- 60 minutes a week of Occupational Therapy even though he has clear symptoms of Sensory Processing Disorder which interfere with his ability to focus, attend and participate in activities with peers. All his parents are able to do is supplement his therapy with one visit a month with a developmental specialist. They are dipping into their retirement fund just afford that while trying to raise him and his little brother. This is just criminal to me. Finally the District of Columbia Public School system have no comprehensive system of individualized educational placements or properly educated and certified teachers to meet the wide spectrum of needs whose very diagnosis calls for not the cookie cutter model that is used but a well thought out system of classrooms with all of the accommodations needed to help the student meet his/she high level of proficiently. What I believe DC and cities like it need to do is have these same type of interagency town hall meetings on a local level; the ideal outcomes for the 0-22 population would focus on across the board initiation of a dialogue between a well-informed medical home, early intervention and education institutions and most importantly their willingness to partner with organizations such as Family Voices of DC, Inc and others to provide Parent to Parent Education Initiatives and opportunities.

When I finally demanded that my son's pediatrician take my concerns about his development seriously he was a year old. She suggested that if she called Child Protective Services it would expedite the process. Of course I was horrified, but I persisted. She promised to contact the DC Early Intervention program and gave me the number. The first thing I encountered was interagency stinginess. Literally for months they would not OK a developmental screen because the Medicaid MCO refused to pay. Later after he was deemed qualified for the program, the same issue of who has to spend their agencies money arose, this took up an additional 7 months. He received a total of 14 sessions of Special Instruction, 1 hour weekly before he aged out of the program. In those 14 sessions our son made progress and we wanted to continue. The company providing those services, Out Came the Sun, Inc and its director [PII redacted] did a lot more than provide special instruction, [PII redacted] and the talented educator she sent us, [PII redacted] were patient and sympathetic, most of all supportive of parents who were able to read up on Autism and had questions. They helped us bring our son's abilities to the surface and use them to raise his deficits. Soon after in a search for answers and help we had a disastrous meeting with a developmental neurologist who made me and my child feel like lab rats, told me it's POD-nos, get him in a highly structured program and go to autism.org on the internet. Along with a 2 page written report mailed to me I was handed a bunch of papers explaining Autism and what to expect. After reading a section that said that less than 5% of individuals with the disorder were able to live independent live, I felt downright suicidal- My son at 3 years old was deemed uneducable, untreatable, most of all highly unlikely to have any real quality of life.

Out Came the Sun to the rescue, again. [PII redacted] see him. See him we did, somehow (since the Medicaid mco would not pay for it) we scrapped together the money for a consultation. [PII redacted] would see him in his global evaluation clinic. Before we would get this evaluation we had one more hurdle to jump. The Medicaid issue I had been told that my child was eligible for a Medicaid MCO for children with special needs. The only problem was getting signed up. One would suppose that the Early Intervention would be of some assistance in this capacity, but no, that was not the case. I finally was told by someone in some office of the Medicaid system to call a parent! Did she work for the MCO (HSCSN)? No, actually she is the mother of a child with special needs who is homeschooling her son. She just knows how to get people to listen and get families the help they need. This person I called hesitantly, after all, I had called all over the city and no one could do anything to help. [PII redacted] was just not just some mother in similar circumstances; she was a parent advocate supermom. We talked while she showed me multitasking as an art form. I told her my problem, what I suspected and the problem at hand. She rattled off a name and number immediately told me to call and tell them what was going on. In 20 minutes she worked out our Medicaid problems, gave me some ideas about home programming and just restored the hope I had for my son. She's my hero and mentor. The first thing I think of when I am talking to a client who has hit an emotional hard spot is, "What would [PII redacted] say?" It may sound overly sentimental, but only if you have never been in a similar circumstance. The fact is after she finished with me, she called the individual, told them my problem and they called me. My son was signed up for the program by the end of the week.

We finally did get this comprehensive interdisciplinary evaluation; which generated a 20 page, in-depth written report with numerous resources and recommendations is only available at Georgetown University Hospital by the Autism and Communication Disorders Clinic headed by neurologist [PII redacted]. We met with the team for over 2 hours and they were compassionate, helpful and culturally competent. In November of 2007 it was upgraded to high functioning classic autism. Over the years both as a parent and in the last 6 months working as a parent navigator I have met dozens of parents whose children have received perfunctory evaluations by one or two specialists, who misdiagnose them and leave their caregivers to figure it out or not. In my brief time as a parent navigator I have been horrified by one 12 year old girl's neglect at the hands of the system. Before they moved to DC this girl had emergent speech. Today, she sits in a class, unable to communicate by any means to her mother, caregivers or peers. It is just assumed that she is at least moderately cognitively impaired, simply because she has no functional communication. Her mother had been left in the dark as to how to help her and had given up hope for her child and herself. As a Parent Navigator it has been my responsibility to connect this family with a myriad of medical and educational based services, including a medical home capable of communicating between and with therapists and medical specialties as needed.

The infrastructure of the District of Columbia has failed countless children horribly. From the pediatrician who lacked the knowledge to see the symptoms and the cultural competency to take parental concerns seriously. To the Early Intervention Program in the District of Columbia that to this day is unable to perform the basic tasks of getting children evaluated, developing an Individualized Family Service Plan and get the services in place before a large segment of their population ages out of their program. In my limited experiences it is the norm for an identified child to age out before an IFSP is developed. If like my family you are able to receive a month or two of services before the child ages out of the program, the second the child turns 3 he is unceremoniously discharged, tossed a pile of educational "options" for your child and told to get the child registered or you the parent will be charged with educational neglect. Educational neglect, yes; even though the child has not been receiving services, may be nonverbal unable to function in a typical early educational environment without the proper individualized supports. Initially my son's case the appropriate placement was to have been in a self-contained full time placement with all children with cognitive impairments because of his lack of speech. Those who attempted to label him to be of low cognitive functioning never evaluated him, never saw him; they just assumed Autism is equal to Mental Retardation which is equal to being less than, not acceptable, not wanted.

I pulled my son out of the self-contained preschool class. I obtained the services of attorney [PII redacted], we went to due process and won. On his birthday, August 28, 2006 my son entered a special DIR/Floortime Method pre- school class at the Katherine Thomas School, a part of the Treatment and Learning Center in Rockville, MD. Katherine Thomas is a fulltime special education school for children with learning disabilities or high functioning autism who have average to above average intelligence. He still has autism; he still has problems with self-regulation, attention and auditory processing. He has also made all of this progress without medication.

Which brings me to the PSA's by Autism Speaks, I don't like them because they emphasis the increased rate of the disorder but not the more important message that Autism is not the end of the world for that family or that child. When I see them, I cringe, thinking of others who may have a sense of something being wrong with a child in their lives and that Autism is this big sucking wound that can't be helped, so don't dare say it. I am glad that they did not exist when we started our Autism journey, they would have paralyzed me with a sense of hopelessness, would I have worked so hard to find assistance? I honestly don't think so, I am certain I would have been too afraid and overwhelmed. I would never have called [PII redacted], gotten up the nerve to email parents from internet listservs, I never ever would have had the courage to speak to other parents I met in doctor's offices and school open house event and such.

In conclusion I would like to reiterate my plea for a system of early intervention and education for professionals and parents, the need for an Autism waiver here in DC, better educational initiatives and programming and the inclusion of organizations such as Family Voices in the communities to provide the type of parent to parent support and education as only those who have lived it every day can provide.