

Oral Public Comments

**IACC Full Committee
Meeting**

April 26, 2017

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Good Afternoon. I would like to thank this committee for the time and effort spent towards improving the lives of people affected by Autism Spectrum Disorder (ASD). I appreciate the opportunity to share my thoughts regarding how we can help people affected by ASD. My 17 year old daughter was diagnosed with Asperger's Syndrome at the age of ten. Prior to her diagnosis, my daughter visited many doctors including pediatricians, gastroenterologists, pediatric neurologists, a behavioral psychologist, a child psychologist, and speech therapists. All the while my daughter struggled in school, struggled to keep friends, struggled with social convention, struggled with changes in routine, etc. The final straw was the onset of sensory processing issues. When it was finally determined that my daughter had ASD, it was really her mother who made the diagnosis.

In the seven years since my daughter was diagnosed, she has matured into an impressive young lady. She has several friends, is doing well in school, has established her own business, and has been accepted by Meredith College in Raleigh, North Carolina. While I am grateful that my daughter is doing well, I can't get past the fact that it took ten years to get a diagnosis and to identify and implement the needed interventions. Every day I wonder if the diagnosis and interventions would have come sooner had my daughter been screened for ASD. The fact that my daughter was never screened for ASD is especially bothersome to me because I know that still today, there are children with ASD who are not being screened for it.

In January of 2013, then Director of the National Institute of Mental Health (NIMH), Dr. Thomas Insel, gave a TED talk titled, "Toward a New Understanding of Mental Illness" (Insel, 2013). During his talk Dr. Insel made the very simple point that early detection and early intervention will provide the best outcomes for mental illness. To quote Dr. Insel, "The good-news stories in medicine are early detection, early intervention. If we waited until the heart attack, we would be sacrificing 1.1 million lives every year in this country to heart disease." I believe that by not screening every child for ASD early in life and often during their development, quality of life is being sacrificed for individuals and their families. Early detection is possible for many cases of ASD, but early detection will not happen by chance.

Today, I am urging, even begging this committee to make it a top priority to ensure that every child is screened for ASD per the recommendations of the American Academy of Pediatrics (AAP). The current model of recommending that pediatricians provide screening isn't doing the job, but this can be fixed with some imagination and effort. An actionable and measureable plan to ensure that all children are screened for ASD is desperately needed. I am aware that some obstacles stand in the path to achieving screening for every child and I understand that there is much more that needs to be accomplished past screening for ASD. Improved knowledge, better diagnostic tools and effective interventions are sure to come in the future, but those affected by ASD will not fully benefit from current interventions and future advances unless they are identified in a timely manner. Screening is the fundamental first step that will lay a solid foundation for managing ASD in the future, by providing families with knowledge that will allow them to begin solving the puzzle.

Thank You

References

Insel, T. (2013). Towards a New Understanding of Mental Illness. Retrieved from https://www.ted.com/talks/thomas_insel_toward_a_new_understanding_of_mental_illness

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

Albert Enayati

April 26, 2017

This story has made headlines around the world

A man who falsified about his serious mental illnesses when donated his sperm has been suit for \$15 million in damages by each family claiming their children were exposed to a much higher risk of serious neurological disorders ¹. Meanwhile Food and Drug administration, Center for Biologics Evaluation and Research (CBER) have approved use of aborted cell lines (MRC-5) which was derived from lung tissue taken from a fetus aborted for a psychiatric reason from a 27 year old physically healthy woman². There are nine vaccines manufactured from MRC-5 ³, which are given during routine childhood vaccination. The Human DNA in these vaccines has the potential to become incorporated in the host's genes by a process called illegitimate or homologous recombination with the result of triggering auto-immune responses ⁴ and subsequent somatic mutations. Is this practice is safe? Didn't we learn from mad cow disease that we cannot inject protein from same species to another same species?

The package insert for DtaP⁵ vaccine suggests that we need further study. Here's a quote from 2005: "Adverse events reported during post-approval use of Tripedia vaccine include idiopathic thrombocytopenic purpura, SIDS, anaphylactic reaction, cellulitis, **autism**, convulsion/grand mal convulsion, encephalopathy, hypotonia, neuropathy, somnolence and apnea"

In Federal Register / Vol. 49, No. 107 / Friday, June 1, 1984 .1 Rules and Regulations⁷ indicts the followings:

"Any possible doubts, whether or not well founded, about the safety of the vaccine cannot be allowed to exist in view of the need to assure that the vaccine will continue to be used to the maximum extent consistent with the nation's public health objectives".

What pharmaceutical product is known that are given to healthy children and among others adverse effects, causes death and neurological damage. Here is the list of adverse effect on number of childhood vaccine from Vaccine Adverse Events Reporting System (VAERS). According to CDC It is estimated that only 1–10% of all doctors report a severe health problem which occurs after a drug or vaccine is given to a patient.⁸

If the voices of those concerned parents aren't enough, consider this, the US government conceded vaccines had aggravated a young girl's mitochondrial disorder to the point where she developed autism. As a result, the National Vaccine Injury Compensation Program awarded her family an upfront payment of \$1.5 million, and an additional ongoing payment of \$500,000 per year to cover her care as well as the family's lost earnings, pain and suffering⁹. Thus far 85 families have been awarded for autism and more to come.

A recent study among parents by the Simons Foundation found that 42% of parents felt vaccines contributed to their child's autism¹⁰. Webster's dictionary defines a holocaust as follows: "great or total destruction of life". There is a vaccine-triggered holocaust in our country, Childhood immunization program has force my son beautiful healthy son [PII redacted] and approximately one million children to the death camp of autism because simply they may had low immune system or mitochondrial disorder. Dr. Gordon it is your obligation to the parents to initiate the following task

- Initiate of workshop on role of vaccine and regressive autism. Inviting parent's organizations who believe vaccine causes autism and officials FDA (CBER), CDC, National Vaccine Advisory committee.
 - Remove three illegal public member of IACC who are from Autism Science Foundation which have conflict of interest with vaccine and Initiate an investigation to why three members from one organization, are currently are member of IACC, while applications of hundreds of applicant from other autism organizations were discarded.
1. <https://www.thestar.com/news/canada/2016/08/30/sperm-donor-admits-he-falsified-information-say-georgia-police.html>
 2. https://catalog.coriell.org/0/Sections/Search/Sample_Detail.aspx?Ref=AG05965-D
 3. <http://www.vaccine-tlc.org/human>
 4. <http://www.ncbi.nlm.nih.gov/pubmed/26103708>
 5. <http://www.fda.gov/downloads/biologicsbloodvaccines/vaccines/approvedproducts/ucm101580.pdf>
 6. Federal Register / Vol. 49, No. 107 / Friday, June 1, 1984 .1 Rules and Regulations
 7. <http://wonder.cdc.gov/wonder/help/vaers/reportable.htm>
 8. <http://www.renewamerica.com/columns/janak/080330>
 9. <http://www.theage.com.au/lifestyle/life/vaccinations-vexed-link-to-autism-20110914-1k8nm.html>
 10. Goin-Kochel RP, Mire SS, Dempsey AG.. Emergence of autism spectrum disorder in children from simplex families: relations to parental perceptions of etiology. J Autism Dev Disord. 2015 May;45(5):1451-63. doi: 10.1007/s10803-014-2310-8

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Shari Chase

April 26, 2017

I am Shari Chase a widowed mother of a 20 year old son named [PII redacted] who has Autism form being poisoned with Arsenic by a lawn fertilizer at 2.

[PII redacted] has a life sentence and with all the early intervention he remains short on the ability to fully converse. This emerging young man, who so eagerly wants to learn and please, has outbursts from minimal communication skills preventing him from reaching his intellectual potential. For at the magical age of 21 his educational and Autism Waiver supports will disappear.

We as a nation need interventions and detailed, attainable resources that have and have not worked for others on the spectrum to be publicized, researched and created via an interactive web site sponsored by IACC. . This must include chelation and other methods to detoxify their over burdened systems.

It is those who are already on the spectrum and leaving the public education as well as other adults that need immediate support. What is value of bringing someone to a point and then dropping them off the cliff? Individuals like my son want to contribute to society. They cry out for help via behaviors, I Pads, words and family and there is no time to waste. Rather than allowing them to waste their talents, lets offer post secondary vocational training with modified curriculum and mandatory modified programs for different learners at Community college. IACC should come up with proven learning modules for continued education for those on the spectrum. DORS and DDA fall short in this arena

Secondly, small and independent scientists should have access to easily attainable funding to create devices that will allow those on the spectrum to regain control of their over and under active neurological systems. Our young intuitive scientists leaving the college environment who are developing wearable electronics , grew up with those on the spectrum in integrated learning environments so they saw first hand what is needed to function fully in the day to day life.

I ask with in 2 months creation of a National website with informative and interactive facts of what has worked and has not and details on how to implement these procedures provided by practitioners and families. As well as a short route for funding of device development.

We must each put our selves in the shoes of a person on the spectrum, as [PII redacted] brother says, it could have been me mom. We must do the right thing and pull out all the stops and do what we would have wanted someone to do for each of us if we were on the spectrum. There is a young man trapped inside my sons body yearning and pleading to come out, please help each of these people rise and shine. It will in time save millions of taxpayer dollars when we can see each person on the spectrum rising to their fullest potential as contributory citizens.

Shari Chase
[PII redacted]
State of Maryland Health Leader
Host of "Making A Difference" a Comcast TV show
Cardio Medical Products

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Vashti Johnson and Callen Johnson

April 26, 2017

Vashti Johnson is a problem solver with a special ability to bring people together to identify common issues, conduct needed assessments and develop policies and agendas that focus on solutions.

Mrs. Johnson commands over 20 years' experience in private and public economic development for emerging individuals, communities and businesses. Over a decade at Rutgers School of Business and Small Business Development Centers providing workshops, lenders roundtables, coaching, lecturing and advocating for small business which makes her a leader in understanding the barriers and successes of New Jersey's Small Business Community.

As one of Hudson Counties first minority appointed women officials in 1973 Ms. Johnson became the Administrator to the Hudson County Mental Health Board. Her vision and love of community lead the movement of a comprehensive community mental health system of services, designing the plan that reopened Meadowview Hospital for services after being closed for more than 10 years, she is a powerful negotiator, advocate and facilitator dedicated to public service.

Mrs. Johnson's recent interests in autism spectrum disorders and its global affects and increasing trauma that has swallowed up the world.

She has recently accepted the challenge of designing and leading the Bright Minds Institute for Autism New Jersey Inc. Now advocating for new Centers of Service around her mission to improve the quality of direct services currently available to children with autism.

Join the Conversation about Autism!

Vashti Johnson
Bright Minds Institute for Autism, N.J. Inc.
[PII redacted]
Jersey City New Jersey [PII redacted]

2017 - Jersey City: National Association for the Advancement of Colored People; Unit 2086
Chair women: The NAACP Civil Rights Center for Justice, Facilities Committee
Responsible for the Development and acquisition of Sacred Heart Church & facilities design of the new second hundred years of service in the fight for equal rights and justice under the law.
A new Partnership with the Catholic, Archdiocese of Newark, called the " Advancement Project".

2007 to Present:

Founder & Chief Executive Officer: Bright Minds Institute for Autism, New Jersey, Inc.

A 501C (3) organization, composed of parents, advocates and families who have a child with any autism spectrum disorder.

The mission of the Institute is to provide education, advocacy and community awareness to improve the levels of services available to those in Hudson County & New Jersey. When friends and families were

treated with harshness and disregard several of our families became so confused our neighbors sort advice on what and where to go and do to assist their children.

Urban Issues: (2 hour) Police education & training: Designed to work with Jersey City Police Academy enrollees. Provide workshops and seminars for New Police Officers and members of the New Police Academy Institute in Morristown N.J. on the behaviors and habits of Youth with any of the Five Spectrum Disorders. Participants Total to date 180

Because of my previous background as Administrator to the Hudson County Mental Health Board, I lead the team to reopen the Meadowview Psychiatric Hospital which had been closed to the public for a decade. We successfully completed the task, evidenced by the re-licensing and re-opening of the facilities for service.

Special Consultant to Management Intervention a Princeton based corporation. Listed are Environmental Projects supervised or worked on during 2005 – 2006.

Community Impact Assessment Project Manager for Public Involvement related to engaging stakeholders in identified project areas in support of a preferred alternative in New Jersey's largest and oldest urban center. Responsible for information forums, community roundtables community leaders and government briefings with members of city, county, state and federal agencies.

Project Manager for Impact CDC's Winners Wait. A federally funded entitlement program under the Welfare Reform Act of 1996. Providing abstinence- only to adolescent populations and families within Essex County New Jersey. My primary tasks were to develop community partnerships with schools, social services agencies, and local community leaders regarding teen sex and abstinence in their communities.

Senior Project Consultant (2002) for Outreach thru Management Interventions

Marriot Hotel Complex & EEO Compliance process development for both the \$40 million, Marriot Hotel Complex (phase 1) and the \$50 million Country Inns & Suites project (phase 2) in Elizabeth N.J.

INCLUSIVE DATABASE OF LOCAL MBE/WBE Firms and Utilization Programs local subcontractors, facilitating community briefings. My Goal was to increase numbers of contracting opportunities to the construction communities, vendors and disadvantaged businesses, compiling reports on a monthly bases. Rutgers University, College of Business, 1996 to 2003

- New Jersey City University
- William Paterson University, SBDC

Responsible for Start –up of formation of each center at both colleges. Previously no local outreach existed from local higher education units. Community residence enrolled in large numbers; the programs designed for small business varied to meet the need of clients with case management precision.

Created many lenders roundtables and coordinated interventions with local banks and lending institutions. Supports for new programs designed to educate local working class residence were overwhelming, so many wanted to know about the business side of marketing, growth issues or writing business plans.

During this period, I was assigned the task of coordinating The Annual National SBDC Conventions across America. Set –up many outreach events. Collaborated with the many Congressional and Senatorial elected officials regarding policy formation. While attending the New Jersey Commission on Science and Technology, Food Workshops on the Rutgers New Brunswick campus.

URBAN LEAGUE OF Hudson County -1995

Program Director: Successfully completed the planning process that produced the approved designation for bringing into being the Jersey City Charter School, of the Urban League.

Jersey City Medical Center, Director of Volunteers & Outreach, Gift Shop

- Partnered with David Brogna of F.I.T. Mission: Re-Design/relocate a new gift shop and Sales campaign for increased production and sales to \$200,000 per year in revenue. Participated in national workshops and learning conferences through various Hospital associations in the New York/ New Jersey area. Increased volunteer participation by 400%.
- Professional Affiliations: Outstanding Women of the Year Awarded by the Jersey City Council & Mayor Glenn Cunningham.
- Women in Technology International - Global AIG
- Vice President of Satori Athletic Organization
- Seton Hall Non- Profit Center

Educational Background:

2009 Governor Corzine New Jersey Autism Task Force

Montclair State University, Autism Center

Yale University, Autism Center

NJIT University Non-Profit Management

Rutgers University College of Business; American Society of Construction Estimators

St. Peters University Graduate Class, 1972, B.S. Degree in Business Management

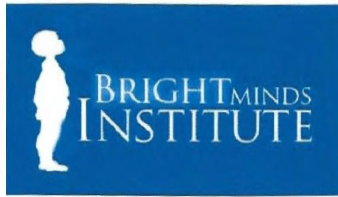
Mother of 3 Children; Grandmother of 3 aspiring young women

Widow



Our Actions Summary 2013





Our Actions Summary 2013



Founded: November 2008

Licensed: April 23, 2009 as a Non for Profit 501-C (3) Organization

Principal: Chair man, Al Garas - 2008 to June 2013

Our Mission:

Bright Minds Institute for Autism, NJ, Inc. Mission is to work to improve the quality of life for all disabled persons over the life span within the underserved urban community of Jersey City. We want to see an increase in residential and employment

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Bright Minds Institute for Autism, New Jersey, Inc.

services for adults with autism and other developmental disabilities in a safe, community based setting.

Our Goal:

To enhance lives – one person at a time – through creating quality of life experiences and community integration that allows each individual to live to his capacity and to be active in civil society.

Accomplishments:

- 2009 - Designed our first vision proposal for youth transitioning into adulthood “The Critical Jobs for Critical Needs” Proposal
- Became a member of New Jersey Governor John Corzine’s ‘ 2009 Adults with Autism’ Task Force
- Applied to NJIT Wachovia Foundation & New Jersey Department of Community Affairs, Housing and Community Development Scholars Program, BMIA was awarded two (2) interns for the summer from the Edward Blaustein School of Planning, Rutgers University New Brunswick Campus.
- The School of Social Work@
- Rutgers University Center for Non-Profit Development. (2) at the School of Social Work, has agreed to support our Strategic Planning, as we move forward. New Brunswick
- Established a Professional Advisory Committee, composed of twenty (20) members who advise, recommend and consult at the request of the Board of Directors.
- The Local Outreach & Autism Awareness at the Jersey City Police Academy “First Responders Workshops” was conducted at the academy. BMIA will present four (4) up and coming workshops reaching over a hundred and fifty (150) Police Trainees.
- Our teams are lead by parents and professionals:
 - Chair, Professional Advisory Committee, Patricia A Simpson, a former Jersey City Board of Education special education teacher; and the parent of a twenty-four (24) year male child with autism.
 - Lead Coordinator / Retired Captain of Newark Police Department, Donna Ramon Hernandez, specializing in prevention methodologies and identifying behaviors.
 - Parent to Parent Outreach and Resources Coordinator, Carolyn Gardon and mother of two (2) school-aged children.

- Crisis Intervention Specialist Technologist, Callen Johnson, who demonstrates different behavioral patterns and techniques necessary to protect and prevent harm of persons or others with any of the five (5) Autism Spectrum Disorders.

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Note: The Community Awareness Workshops continue and are open to all interested groups by request only.

- Our National Outreach: Advancing futures for adults with Autism – November 2009
- Hosted by Former Chicago Mayor, Richard Daly & wife; composed a sixteen (16) City National Town Hall Interactive Communications Events with Autism Organizations across the United States of America with NJ Senator Robert Menendez as key note speaker.
- UMDNJ University N.J. Mission: Designing a National Agenda for Autism to be presented at the congressional Briefings, Washington D.C.
-
- - Al Garas, Bright Minds Institute for Autism, New Jersey, Inc. Chairman of the Board of Directors hosts The First Annual Autism Conference

May 2010 - “The Case for Community Inclusion”

- BMIA hosted the next NJ-AFAA Kick-Off Action Plan meeting at Hudson County Community College, Jersey City in collaboration with Other panelist included:
 - BMIA Founder, Vashti Johnson, CEO
 - Daniel J. Fiddle Foundation Founder, Linda J. Fiddle, Esq.
 - Alpine Learning Group Founder, Dr. Bridget Taylor, Ph.D.
 - Aging with Autism Founder, Cyndy Hayes, Ph.D.
 - Autism New Jersey, Dr. Linda Meyer, Ph.D.

Outcomes:

- Current State of Adult Services in New Jersey
- Agreement on New Jersey Priorities and Strategic Agenda
- Commitment – High Level Action Plans for associated entities



- **The Congressional Briefings held in Washington D.C. July 2009.**
- Senator Robert Menendez presenting the agenda of autism to the many senators and congressmen & elected officials in attendance.
- As a new organization within Hudson County BMIA participated in playing an important role for our community, by joining with other organizations.
- **Our Goal, to get the autism message heard on the national network. Advancing Futures for Adults with Autism (AFAA) saw this as a first step in a long agenda needing to be addressed. BMIA was applauded for our efforts.**



- **Second Annual Conference held May 2011.**
- **“Come Join the Conversation”**
- **“Helping our Children Achieve Supported Independence”.**
- **We mobilize to address major concerns stifling the development of urban programs while extreme numbers of children transition into adulthood with no plan for services to continue.**
- **Mentioned by the New York Times Newspaper, which stated that Autism appears to be the outstanding disease of the 21st Century.**
- **‘The Breakfast Event’ at Hudson County Community College with the support of its President, Dr. Glenn Gaber, Ph. D.**



Key Note Speaker: Michael J. Sluka, Attorney and Founder of Reed Academy, Garfield N.J.

- **Lucy M. Esralew, Ph. D., Director of the DDD NJ SCATT.**
- **10 Bed Emergency Services Program located at Trinita's Hospital, Elizabeth N.J.**
- **Leslie Long, Autism Speaks National Director of the "Adults with Autism Programs" for this major awareness and advocacy organization.**
- **Donna Icovino, Family Advocate & Coordinator of the Dual Diagnosis Task Force**
- **Damanyati Shah, Accountant, India Yoga Instructor, and Specialist in Yoga for autistic children.**



Note: BMIA 's mission is to continue to build the services for our children throughout their life span

As our children age into adulthood we welcome any and all expansion of employment, housing and intellectual opportunities that offer normal humane environments provided in a civil society.

Forward Actions:

Designing the Autism Charter School Applications

October 2011-2013: BMIA organized an educational committee to redesign the Charter High School application for youth with Autism Spectrum Disorders. Members of the PAC and outside professional volunteers gave of their time and expertise to create the vision of what we saw as needed in our urban community. We cannot thank them enough for their willingness to spend countless hours to complete this initiative.

- Beverly Crifasi, Psychologist
- Dolores Conover, Professional
- D. Adrienne Johnson, Professional
- Valerie Mahoney
- Esther Cordero
- Mabel Hawkins

These educators and parents began meeting to prepare The Charter High School's Application with a plan for it to be submitted to the New Jersey State Department of Education for a high school that could offer a unique approach and design for developmentally disabled and autistic adults. We have a proposal for inclusion to model for both children with Individualized Educational Programs (IEP's) and a group of mainstream youth that will assist our youth in the transition into adulthood.

Bright Minds Institute believes, vocational skills, equal employment and opportunity

We do not see liberal arts education as the only path to a good education for our children. We acknowledge the need for diversity in education for children to find their path and passion.

Our first efforts were declined and financial budget estimates were stated as one of the reasons for denial. The committee requested a meeting to get a better understanding of the applications strengths and weaknesses. While incorporating the critique, we re-submitted the application.

- March 31, 2011 upon re-submission, we received no further questions or inquiries except for a request for additional copies of the CD submitted. While waiting, we began collaboration with the Yale University School of Medicine's Center for Child Study School Development at their Autism Center in New Haven Connecticut under Dr. Valkmar, Ph. D. Our mission was to search for a different approach to solutions for our youth in self actualizing them to see a future they could believe in, were possible.
- September 30, 2011 – We received notification from the State Department of Education notifying us that the application was denied a second time. The Newark Star Ledger later reported only four (4) of the sixty (60) applications submitted this cycle had been approved.

Note: Our current conclusion and local data ended with many questions? NJ has approved close to a hundred (100) charter school applications, eighty-five (85) grammar school PK-8th grade and nine (9) high schools state wide.

There are two (2) major concerns that echo across urban America:

1. It has been reported that over 50% of high school aged youths drop out of school at 10th grade. There are no skills, limited ability with no job opportunities apply. Many entities want new enrollments to have a high school education.
2. The prison industrial complex reports that the current prison enrollment in America is over 2.5 million prisoners incarcerated and a rising escalating increase of over a million prisoners in a decade. Many are found with severe mental and emotional dysfunction s not identified earlier while enrolled in public educational institutions. BMIA cannot see building a stronger America with this reality.

OUR MISSION

OUR PRIORITY URBAN ISSUE: PLANNING for A BETTER QUALITY OF LIFE FOR OUR MANY DISABLED RESIDENTS.

"AN EFFORT TO BRING NEW JERSEY INTO COMPLIANCE WITH THE AMERICANS WITH DISABILITIES ACT"

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Bright Minds Institute for Autism, New Jersey, Inc.

To assist and create a new self sustaining approach to opportunities for the many children with disabilities growing into adulthood while needing supported help and opportunities to work and earn a fair wage.

Searching for Collaborative Partnerships

- We have enlisted the support of the New Jersey Small Business Development Centers at the Rutgers University School of Business, with an effort to design self-sustaining entities or units of businesses creating work opportunities for the disabled.
- BMIA continues to look with interests at Work Force Development and the Department of Labor programs to assist us in offering a series of technical, vocational and entrepreneurial opportunities. A series of discussions with the New Jersey Small Business Development Centers
- Director, Brenda B. Hopper continues as we work to explore the urgent need to create employment where so little opportunities exist for those with disabilities.

Supported Housing

BMIA has prepared an application for a Licensed Supported Housing. Beginning with a small residential housing unit for those who can benefit from supported living; a small eight to ten (8-10) bedded Convent building has been offered as its first establishment. We are hopeful that the New Jersey Division of Developmental Disabilities (DDD) will approve the application.

Planning for Emergencies in the event of a Disaster for the Disabled in our community

- September 2012 – **An Emergency Management Open Initiative Sub-Grant** was awarded to BMIA to assist FEMA in developing data that will create shelters for the disabled in the event of any future disasters. This effort was a co-sponsored initiative in partnership with the Noah's Ark Institute. Al Garas, Chairman for the BMIA Board of Directors. The Final report is ready for distribution

BMIA @ College of St Elizabeth in Morristown, New Jersey

August 2013 –FIRST RESPONDERS@ POLICE INSTITUTE CONFERENCE

- **Real world discussions held on CRISIS INTERVENTION; DOMESTIC VIOLENCE & AUTISM.**

Retired Police Captain Donna Roman Hernandez a 2010 Board member invited our team to share in

The Police Studies Institute and the Police Community Relations Association hosted a Conference at the College of St. Elizabeth in Morris town N.J. Our members partnered with these organizations to provide Community Awareness information and Crisis Intervention Training to some 80 local and state police officers on the behaviors of ASD and other disabled persons when confronted in escalating type incidents that could cause serious damage to youth when not understood. Our panel of experts reached out to the many officers and we opened by thanking them for all they do as first responders for the residents of New Jersey, these workshops will be open to all First Responders.



- Other distinguished guest were Dr. Kathleen Selvaggi- Fadden, MD,
- Goryeb Children’s Hospital, Morristown Medical Director at the Child Development Center.
- Lt. Richard Cavanaugh, Montclair, Police Department.
- Our panel included moderator Capt. Donna R. Hernandez, B. Madeleine Goldfarb, Director of Noah’s Ark Institute, Patricia Simpson, Mother of a 24 yr old autistic son, & Special Education Teacher. Ed Gilligan, Crisis Intervention Specialist; Callen R. Johnson, I.T Technology Specialist; Eleese Evans, Paterson Police Force.
- Vashti Johnson, CEO
- As the Institute at BMIA continues its work the Directors will come together again as to plan for the **“Listening Project for April 2014”**.

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Bright Minds Institute for Autism, New Jersey, Inc.

October 2013

- Kessler Institute for Rehabilitation Center, West Orange, N.J. Campus
- Senator Robert Menendez, hosted **The Convention on the Rights of Persons with Disabilities (CRPD)** is an international disability treaty.
- The CRPD is a vital framework for creating protecting the rights and dignity of all people with disabilities. The Convention is based on American constitutional values and the Americans with Disabilities Act (ADA). Values of equality independence, respect, and reasonable accommodations are ECHOED IN THE TREATY.
The deep concerns following the United States Senates Failure to ratify the CRPD.
- Why should the U.S Adopt this Treaty? Ratification gives the U.S legitimacy and access to export American values and Goods. The model of the ADA can be exported to other countries. CRPD creates the forum for international discussion on implementing the treaty. If the U.S. is not there the leadership vacuum will be filled by Europe and Asia, places with different, less effective approaches to accessibility. It means Americans could see accessibility technologies and infrastructure abroad incompatible with U.S. standards. U.S businesses would lose out on important markets.
- The Foreign Policy Magazine states; It does.... Make the United States look pretty dysfunctional. In essence, the United States Senates just rejected a treaty protecting the disabled that would have globalized the status quo in the U.S. law on this issue.

October 29-30, 2013:

After meeting the Director Dr. Gerard Costa, Ph. D, Developmental Psychologist and DIR certified I was invited to attend the 2 day Conference at the University to learn about the various strategies and approaches used.

Montclair State University Annual 2013 International Council on Development and Learning with the Center for Autism and Early Childhood Mental Health

The Center serves as a center for professional development, education, clinical services and research around the issues of autism, infant and child development and early childhood mental health. The work of the center is based on social-emotional/mental health and the core of the developmental and educational progress and incorporates strategies to integrate mental health and relation-based approaches to development and education. The center honors the work of Selma Frailberg, Thea Bry and Dr. Stanley Greenspan.

What an amazing 2 day event. I wish to thank Dr. Costa for the chance to listen to the presentations and share in the learning.

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Note: The face of Autism is rapidly changing with a generation of children who will be entering adulthood over the next five to ten (5-10) years. As a society, we are ill prepared to deal with what will be a boom in demand for housing, employment and other critical services needed to appropriately serve adults living with autism. The AFAA initiative is an effort to create with the input of a wide range of stakeholders, a useful and actionable public policy agenda.

Peter Bell Executive Vice President of programs and services for Autism Speaks

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What Is Autism?

Autism or Autism Spectrum Disorders are defined as a developmental disability that by definition begins before the age of three and most often lasts through out a lifetime. Individuals with autism experience challenges in the areas of social interaction and communication. Many individuals with autism have repetitive behaviors or intensely focused interests. The severity of symptoms vary widely among individuals and run the spectrum; from those who do not develop spoken language, and require extensive support to ensure their well being to individuals who are highly intelligent but socially awkward.

Individuals with autism are unique. Each person has strengths and areas of need. The following are a few common characteristics that can be considered challenges or strengths depending on their severity:

- Difficulty understanding languages and social cues
- Excessive or minimal speech
- Concrete thinker, often has difficulty with abstract concepts
- Difficulty relating to others
- Social awkwardness
- Intense interests or concentration

- Repetitive behaviors such as pacing, rocking or hand flapping
- Sensitivity to light, sound, smell or other sensory issues
- Anxiety or abnormal fears
- Complex and in some cases challenging behaviors
- Difficulty managing transitions or changes in routine
- Strong visual skills
- Excellent memory for facts and statistics
- Adheres to rules and honesty to a fault
- Musical mathematical, technological, artistic ability or interest
- Autism is an umbrella term for a class of disabilities called “pervasive developmental disorders”
- Not otherwise specified, Rhett Syndrome, Childhood Disintegrative Disorder.
- For this document we refer to the entire class of disorders as “autism.”

“If you have met one person with autism, you’ve met one person with autism. The heterogeneity of autism is evident in the broad range of severity, abilities, challenges and extraordinary talents.”

Stephen M. Shore, Ed. D. Associate Professor of Education Adelphi University

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“In the End we will remember not the words of our enemies but the silence of our friends!”

Dr. Martin Luther King Jr.

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

Dr. Linda Varsou

April 26, 2017

Where Autism Research leads when autism prevalence increases together with autistics' daily dramas?

Within one generation (20-25 years), genes alone cannot explain the autism epidemic despite all inherited autistic "traits". In genetic studies less than 38% meet the "trio" as in 50% of biological parents, at least one, usually the father remains in chronic denial of child's autism or estranged declining any participation.

How to prevent autism when ~300 genes are associated with it? *Delete genes? Eugenics? Biomarkers?* Why not avoid these genes' expression by considering and eliminating the deleterious epigenetic factors?

The neuroimaging studies (MRI and fMRI) are extremely invasive techniques especially for a young brain. New knowledge is very important but not when it involves a child already at risk, neurologically compromised.

Research on animals can give misleading results. For example, the immune system of mice significantly differs from the human one. Furthermore, their genome is adapted to different environments and needs. Such studies benefit only researchers by increasing their impact factor.

The exponential increase of autism publications doesn't show positive impact on the challenges people with autism and their families face on a daily basis. According to Stanford University professor Dr. John Ioannidis, M.D., mathematician and epidemiologist, the majority of research studies fail to provide us with true findings and many confounding factors when omitted lead often to conflicting or non-reproducible results.

Regarding the "cost/benefit" analysis, nothing is more beneficial and at low cost for any society than a healthy baby, child or adult. The only solution and way to go is Prevention at all levels, pre- and postnatal.

Prevention has to do with searching and assessing all existing epigenetic factors and eliminating the deleterious ones. Even if autism starts in the womb, by addressing at least the epigenetic factors at the prenatal and early postnatal period, maybe the outcome would be less severe or even not openly expressed. Some epigenetic factors to consider include among others: chemicals, pesticides, vaccines, unhealthy microbiome, etc.

The number of cases related to regression into autism, after vaccination is on the increase. Among others, two recent well documented webinars (www.vaccinesrevealed.com and www.thetruthaboutvaccines.com), demonstrated all the undeniable information related to vaccinations' side effects, especially at an early age when the immune and nervous systems are still immature. Also, avoiding any vaccination during pregnancy and breastfeeding must be a woman's main maternal duty.

As for pesticides and other chemical toxic products, showing correlation with the increase of autism, serious measures must be taken. DDT was banned years ago but still remains in the soil. Glyphosate even worse than DDT, is still everywhere, in the fields, gardens and homes and should be banned. The microbiome while extremely important when living in a symbiotic relationship with it, it becomes unhealthy with deleterious health effects when destroyed by antibiotics or inadequate foodstuff.

For existing cases of autism and when it cannot be prevented, medical students, doctors, hospitals, caregivers, educators, services, attorneys, judges, public servants, authorities etc. should be educated to maximize the strengths and minimize the challenges of people with autism. (see my written comments of 10/18/2016)

In conclusion, by addressing the top US Health Institutions, the NIH and the CDC: Please let's direct research and funding towards prevention to decrease autism and optimize functions of those who have it.

From Dr. Linda (Angelique) Papadimitriou-Varsou, PhD, MPH, DABCC, Immunologist, Hygienist, Clinical Biochemist, Associate Professor in Medicine. Mother and legal guardian of a 31-year-old college student with autism; advocate for the Rights and Strengths of People with Autism, a fervent supporter of the concept: "An Autism Friendly Society will benefit us all". SHORT BIO: Long-standing member of different autism related organizations and scientific societies in the US, Europe and Greece. Long-standing member of "Autism-Europe" and elected member to its Council of Administration. MSc in Biochemistry and postgraduate studies, Paris University; Specialization in Immunology, Paris Institute Pasteur, France; MSc in Public Health with honours; Diplomate of the American Board of Clinical Chemistry; Two PhDs in Diagnostic Laboratory Medicine; Research Associate at the University of Maryland School of Medicine, Faculty member at Johns Hopkins University School of Medicine where I studied neurosciences and initiated the "fever study in autism". Current position: Associate Professor at the University of Athens School of Health Sciences responsible for teaching graduate students in three MSc Programs at the Departments of Biology, Chemistry and Clinical Pharmacy -a position which allows me to spend more than half of the year in the US with my son, while continuing my teaching online. Address: [PII redacted] Baltimore, Maryland [PII redacted]

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

Dena Gassner

April 26, 2017

[PII redacted]

Mineola, NY

April 14, 2017

My name is Dena Gassner and I am a PhD student in Social Welfare at Adelphi University. I am the parent of an independently living, 28-year-old student at Marshall University, previously diagnosed with autism and intellectual disability who is currently on track to graduate with his Bachelor's degree in December, 2017. I am also a wife, mother, grandmother, and an autistic woman. Today I wish to give testimony about research priorities and funding for autistic individuals.

In the last year, it was my honor to serve as a reviewer for a research grant funding body. Due to confidentiality, I cannot stipulate the body, however, after two full days of review, it became painfully clear that not a single study we reviewed could or would have any implication for my autistic son or the thousands like us. Millions of dollars are being assigned to research seeking cause and ultimately, cure with total disregard to the outcries of autistics and parents who want a focus on quality of life. Much of the research is couched under the pretense of "easing symptoms" but if there is success, I fear that this slippery slope will result not result in minimizing the co-occurring issues, but instead, in eugenic outcomes as are currently experienced in the Down's Syndrome community—95% termination.

The vast majority of research funding—millions—has been spent seeking a cure. I've watched this for 29 years. Like my colleague, John Elder Robison, I respect the need to reduce suffering, but I strongly believe this is not by finding a genetic or environmental cause of autism. I believe suffering can be reduced by providing research that identifies and understands the co-occurring conditions. And research that seeks to enhance supports and services for families and individuals throughout the lifespan, like that at Drexel.

I believe and support research to minimize the suffering resultant from co-occurring conditions that affect autistics with a greater intensity such as the use of medical marijuana for seizure disorders and painful hypermobility conditions. I believe in research that seeks to explore how to expand supports and services to minimize anxiety-induced mental health conditions. I believe in the use of research to address policy limitations that continue to result in ongoing poverty and ensuing homelessness.

Finally, I support the need for research to examine and resolve the multiple healthcare disparities faced by autistic individuals such as denial of culturally competent access to reproductive and maternal healthcare supports, denials of general healthcare support, social/organizational supports to secure and maintain healthcare relationships, support for LGBTQAI and autism intersectionality, training for doctors, dentists and other service providers, training for government offices that work with us such as social security, vocational rehabilitation, food stamps, Schedule A hiring and housing offices. I am asking for research that disallows the gender bias that by measuring 8 year olds, continues to deny that autistic girls and women exist. I seek to eliminate homelessness, abuse and employment barriers. And we must seek reductions in early death and dying for autistics by accidents, unidentified illness and at the hands of caregivers and ill-prepared first responders.

I am sad to say, none of the research I examined would address any of this. At one IACC meeting, a researcher looking for “optimal outcomes” asked me what elopement was. This reflects the siloed relationship between what individuals and families need, and what researchers are doing—or not. I see the same pattern largely, with research presented at IMFAR. International research communities are listening and incorporating autistic intellect into research priorities, conceptualization, design, and methodology by utilizing autistics as researchers and consultants. We can do better.

I am asking IACC to advocate for and celebrate research that will change outcomes for the autistics who are a substantial part of the world community rather placing such a disproportionate amount of funding for those yet to be. We must prepare the world for them.

Respectfully submitted,

Dena L. Gassner, MSW
PhD Candidate
Adelphi University School of Social Work
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