

Oral Public Comments

**IACC Full Committee
Meeting**

January 14, 2014

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Marian Dar

January 14, 2014

Good afternoon,

I am the parent of an adult son with autism. In recent years I have been approached by people to talk about our family's medical experience and what I've observed about others'.

IACC may be the group that might understand these issues and events best and, better, be able to do something about them.

My comments are in the form of a short video ("Inside Autism") and I will bring a DVD. Thank you,

Marian Dar

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

Linda Varsou

January 14, 2014

At the January 14, 2014 Full Committee meeting of the Interagency Autism Coordinating Committee, IACC, which will discuss and finalize the 2013 IACC Strategic Plan Update, we cannot overlook the financial crisis which mostly affects families having children (or adults) with autism. Therefore, every dollar spent or invested by the Government, the States, the different Organizations, Agencies and Associations for the autism research, diagnosis, treatments, interventions, education and services, must lead to the highest positive outcome within the cost-benefit analysis, which unfortunately, according to the parents' view, is not always the case. As a result, we could revise our ways of thinking and proceeding in finalizing the IACC Plan, within the concept of a "*sybiotic relationship*", to enforce cooperation, education of people providing services related to autism and to increase social awareness. Here below are only a few issues which can be addressed immediately and researched fast and at low cost:

1-Chronic Denial: This is the 3rd time that I am bringing to the IACC meetings the devastating issue of parental chronic denial (*non-acceptance or non-resolution*) of their child autism, causing family dramas, the child (or adult) with autism being the final and definite victim. Since we have a serious study from Israel assessing parental denial as high as 53% (*J Autism Dev Disord (2010) 40:89–99*), we cannot ignore the prevalence of chronic denial in the US families having children with autism. As I explained at length, in my written statement for the 11/15/2013 IACC meeting, with a **low-cost, fast** research protocols and a meta-analysis, we could investigate the issue of chronic denial, its extent and consequences, as well as the measures taken to face the problem and prevent family dramas, detrimental to the child (or adult) with autism. These results will be very useful and can be used for social awareness and for every service, agency, State and Government.

2-The Judiciary System: Unfortunately, family cases involving a child with autism ending up to Courts are on the increase, the legislation is poor, and the judiciary system -from the Lower Courts to the Supreme Court-, has limited knowledge or ignorance of the insights of autism (*....after graduation from school autism is not a serious problem anymore...!*, from a trial); as a result, the family dramas continue and the vulnerable child with autism becomes the ultimate victim. Methods and research on how to incorporate education on autism in Law Schools, is mandatory and an emergency. A new legislation related to autism must be implemented and in effect. Based only on solid scientific data, IACC and Autism Organizations could propose the much needed mandatory changes in the judiciary system, considering also "chronic parental denial" and the act of abandoning a child with autism, as serious as "child abuse".

3-Law Enforcement Department: As victims from police officers ignoring the insights of autism are on the increase, methods and research on how to incorporate their mandatory training on autism, is an emergency. Research on the treatment of diagnosed or non- diagnosed people with ASD in jails, could bring amazing and terrifying results, leading to the mandatory and urgent changes.

4-Services: Although providers and persons working in different services have credentials and the best intentions most of the time, their striking ignorance of what autism is all about, makes them ineffective if not harmful to the person with autism they supposed to serve. The money paid by the families, the States or the Government is wasted. Therefore, research must be conducted to evaluate families' satisfaction (*if they are not in "denial" themselves!*), by collecting data from past

research done at State level, and to enforce mandatory training and education for any person dealing with a case involving a child or adult with autism.

5-An Autism Friendly Society will benefit us all: The “Autism Friendly Society” where a person with autism can thrive and even excel, is in a few words the “best society for all of us”, as it is closer to human physiological needs. Within this society all risk factors, epigenetics, social, educational, sensorial, etc. will be addressed and every one will benefit from them (pure water and air, healthy food, regular exercise, preventive medical care, low cost holistic medical system, educational methods according to the strengths and not only the weaknesses, etc. This “society” could be the subject of a thesis, and it is worthwhile to be done.

I am willing and available to help anyone from the IACC Committee in many different ways due to my scientific background in epidemiology and autism, because relevant scientific literature is sadly wanting right now. My extensive personal data from the literature, the blogs, and autism groups, etc., are available to anyone upon request.

In conclusion, I would like to see IACC within its Strategic Updated Plan addressing at least some of the issues mentioned here above, and particularly the devastating question of “denial”, so as to show its support and commitment to every family and person struggling with autism in the US.

By Dr. Linda (Angeliki) Papadimitriou-Varsou, PhD, MPH, DABCC, Asst. Professor, interested person representing herself.

Mother of a 28-year-old college student son with autism, advocate for the Rights and Strengths of People with Autism, and a fervent supporter of the concept: **“An Autism Friendly Society will benefit us all”**. Contact: [PII redacted], Baltimore, MD 21218-2378, [PII redacted]

Linda Varsou’s attachments can be viewed here:

[Attachment 1](#) (PDF – 519 KB) | [Attachment 2](#) (PDF – 629 KB)