

# **Oral Public Comments**

**IACC Full Committee  
Meeting**

**January 19, 2010**

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

**Paula Durbin-Westby**

January 19, 2010



The Autistic Self Advocacy Network

Thank you for this opportunity to comment on updating the Interagency Autism Coordinating Committee Strategic Plan. I am representing the Autistic Self Advocacy Network.

Much good work has been done to update the Strategic Plan for 2010. Among the positive changes to the Plan is the Aspirational Goal for Question 3, with the addition of services and supports as a goal, and the improvement of quality of life rather than the language of “prevention and preemption.”

Because of some of the reversions to language and concepts found in the 2009 Strategic Plan, I need to reiterate several concerns from ASAN’s past commentary.

The aspirational goal that was generated by the recent Scientific Workshop’s Panel 1, for Question 1, “When Should I Be Concerned,” has been replaced with the original language. Although adults are mentioned elsewhere in the text of the plan, this Aspirational Goal should at least reflect some concern with the diagnosis and assessment of adults on the autism spectrum.

The sections in the Plan that address the ethics of communicating genetic risk should be amended to read “genetic and other risk,” in the light of recent developments in maternal autoantibody research.

Under “Research Opportunities” in Question 2, “Research on individuals with ASD who are nonverbal and /or cognitively impaired” should be qualified in some way to indicate that “nonverbal” is a contested concept, depending on how it is used. For example, some people on the autism spectrum communicate other than with spoken language, so it will be necessary to distinguish whether or not the person uses another communication system.

In Questions 5 and 6, there is a stated goal to investigate “... the use of medications to control challenging behaviors in people with ASD, particularly adults.” Do not assume that “we all know what this means.” “Challenging behaviors,” depending on who is getting to do the defining, could mean anything from hand flapping to serious threats to self and others. Any such study should rigorously examine the ethics of using medications to control harmless but socially stigmatizing behaviors.

Another research goal in this section brings up the same concern: “Conduct a study to evaluate current practices leading to the use of psychopharmaceutical medications and their effectiveness in

the treatment of “co-morbid” (which should be changed to “co-occurring”) conditions or specific behavioral issues with adults across the autism spectrum.”

Without careful attention to ethical and legal concerns, this research goal could lead to what is in essence *chemical restraint*, which is one of the prohibited categories in the *Preventing Harmful Restraint and Seclusion in Schools Act* recently introduced by Representatives George Miller (D-CA) and Cathy McMorris-Rodgers (R-WA) and supported by organizations such as the Autistic Self Advocacy Network, the major teachers’ associations, the Association of University Centers on Disabilities, and many others.

The new proposed Question 7 needs to also be addressed carefully. Avoid autism registries that use personally identifying information without the informed consent of the person on the autism spectrum. If a person cannot (or cannot at that time) give informed consent, or is a child who cannot, or cannot yet give informed consent, every precaution should be taken to make sure that personally identifying information is not included. People who have been added to a registry during childhood should have the right to remove themselves from the registry upon attaining legal adulthood, should they choose to do so. All participation in autism registries should be on a voluntary basis.

To the statement “As more professionals become involved in autism research, there is a need for organized input from established scientists to provide guidance and expertise” should be added the need for organized input from adults on the autism spectrum, in order to assist researchers in making sure research is relevant to the needs of people on the autism spectrum as well as family members and the community.

I would like to close by repeating the call for additional members on the Interagency Autism Coordinating Committee, drawn from the community of autistic adults who have a perspective that focuses away from questionable cures and “elimination” of autism. Nothing About Us Without Us.

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## **Caroline Rodgers**

January 19, 2010

First of all, I want to thank Dr. Insel and the rest of you serving on the Interagency Autism Coordinating Committee (IACC) for allowing me this opportunity to share my thoughts about the 2010 Strategic Plan. You have undertaken a huge, multifaceted task that has only become more difficult since you began. I hope that my comments today will help you in your endeavors.

In the spirit of full disclosure, I am the author of the article, —Questions about Prenatal Ultrasound and the Alarming Increase in Autism published in Midwifery Today in 2006 and reprinted in Pathways to Family Wellness last summer. I have no financial, professional or personal interest in either prenatal ultrasound or autism, although like you, I am deeply concerned about the autism crisis. Driven by this concern, I have continued my research, which has given me a unique perspective in interpreting new autism findings.

I know that the IACC has put many long, tedious hours into updating the Strategic Plan and that you hope to approve it today. The line-by-line edits you made in Section III, —What Caused This to Happen and Can This Be Prevented were made on November 10th. Since then, like movies vying for Oscar consideration that open the last month of the year, important and intriguing studies have been published that raise new questions about what is causing autism. There is even the possibility that the relentless increase in autism could be reversed in the time it takes to yank an electrical plug out of its socket. At the end of this talk, I have specific, line-by-line suggestions for making changes in Section III. Due to time constraints, I will be unable to present these proposed changes orally, but they are available to the committee in the document I submitted in advance and will be available to all others as part of the public record.

### **Alabama's intriguing Hispanic anomaly**

On December 18th – a little more than a month after the IACC revised Section III – the Centers for Disease Control (CDC) published shocking figures that showed a 57% increase in autism among children who were eight years old in the four-year period starting in 2002<sup>1</sup>. I'm sure your hearts sank when you saw those numbers – I know mine did. But a closer look at the facts revealed a puzzling anomaly: At the same time the overall autism rate charged ahead 57%, it DECREASED 67% among Alabama Hispanics. Hey – that's the direction we want the whole nation to go!

I wondered what could possibly have changed in Alabama's public health policy that could have caused such a great about-face among the Hispanic population. Was there a special outreach program or an increase in public assistance? Imagine my surprise when I discovered a 2002 CDC report revealed that starting in 1993 – the year when mothers of the first set of eight-year-olds were pregnant – Alabama, along with Florida and West Virginia, cut Medicaid for prenatal care<sup>2</sup>. So the year Alabama Hispanics started a dramatic turnaround in their autism rate coincided with the year the neediest mothers in that state were denied state-funded prenatal care.

*Could prenatal care cause autism? That's [offensive language redacted] talk!*

Maybe not: Alabama and Florida – two of the three states that cut public assistance for prenatal care from 1993 to 2002 – had the lowest autism rates of the 11 states that participated in the CDC's surveillance program. The third state, West Virginia, did not participate in the study.

Did this correlation between lower autism rates and lack of prenatal care hold up throughout the study?

There were significant ethnic differences in the autism rates reported in last month's CDC report. White women had a higher rate of children diagnosed with autism than either black or Hispanic women. Per 10,000 women, the autism rate for children of non-Hispanic white women was 110, versus 76 for black women and only 61 for Hispanic women. The numbers provide substantial and irrefutable ethnic differences in autism rates, but was there a correlation with prenatal care?

The answer is yes – although I had to delve into another CDC multistate surveillance report to find it. The report, regarding the timing and entry into prenatal care from 1989-1997, showed that more than twice the percentage of black and Hispanic mothers lacked first-trimester prenatal care than did non-Hispanic white women. By 1997, although the overall percentage of women who received first-trimester prenatal care increased, the ethnic differences remained<sup>3</sup>.

Taken together, these three CDC reports tell a disturbing story: as more women across all ethnic groups received first-trimester prenatal care, the autism rate among their children increased, with greater increases among the groups that had more first-trimester prenatal care. This seems counter-intuitive: Shouldn't first-trimester prenatal care result in healthier children? While these studies do not prove causation or even a correlation between prenatal ultrasound and autism, they raise the question:

*What aspect of prenatal care may place babies at greater risk of autism?*

### **Poked, prodded, measured – and scanned**

While the autism rate has increased dramatically in the last three decades, very little has changed regarding prenatal care. The pregnant woman is weighed and her vital signs are taken. The height of her expanding belly is measured and her ankles are checked for swelling. She will be asked to give blood and urine samples to check for diabetes and preeclampsia, prescribed prenatal vitamins with folic acid to protect against spina bifida, advised about diet and warned regarding the dangers of smoking, alcohol and recreational drugs.

What HAS changed in prenatal care in the last few decades has been the addition of ultrasound to monitor pregnancies. Like many interventions that were initially used only in high-risk groups, reliance on prenatal ultrasound rapidly became standard practice for all pregnancies. Prenatal ultrasound has also undergone rapid and extensive changes in terms of the technology, different applications, the number of scans per pregnancy, as well as the gestational window of exposure, which has extended to all three trimesters. Therefore, although every aspect of prenatal care should be carefully reconsidered, prenatal ultrasound deserves especially close scrutiny.

## **Say it ain't so: Educated moms are at higher risk of having children diagnosed with autism**

A UC Davis study published this month found 10 autism clusters in California and concluded that highly educated white parents were more likely to have children diagnosed with autism. In six of the clusters, couples in which one parent graduated from college had four times the rate of having an autistic child than parents in the same area who did not finish high school<sup>4</sup>.

This seems counter-intuitive: Don't highly educated white mothers hold all of the cards? They enjoy educational opportunities, have their pick of the best jobs and receive the finest medical care available - why wouldn't their children be the healthiest? Could the best obstetrical care available have a downside? What if the use of prenatal ultrasound, considered essential to monitoring pregnancies, sometimes backfires?

Highly educated white women are more likely to undergo prenatal ultrasound because they are more likely to . . .

1. . . . have health insurance
2. . . . start prenatal care in the first trimester
3. . . . independently research prenatal care and do everything they can to assure healthy pregnancies
4. . . . be able to afford and even demand diagnostic imaging they believe will help ensure a healthy baby
5. . . . defer having children until they are older, due to education or career pursuits, ultimately placing themselves in the —high-risk category of older moms who undergo amniocentesis or chorionic villus sampling — both of which are guided by ultrasound
6. . . . have disposable income that can pay for —extras, such as the keepsake prenatal ultrasound portraits and DVDs that are available at many malls
7. Finally, if they have fertility issues, the —older, white and highly educated parents are more likely to be able to afford and undergo assisted reproduction, which involves additional ultrasound scans

## **Canadian moms have 55% more scans per pregnancy while autism rate rises 50%**

It is difficult to find hard data on prenatal ultrasound use. In the multibillion-dollar ultrasound industry, this information has value and is not freely available, so a Canadian study published this month helps provide an idea of industry trends.

The study showed that for the 10-year period ending in 2006, there was a 55% increase in the number of ultrasound scans per pregnancy among Ontario women, with the biggest increase in additional ultrasound scans in routine pregnancies, rather than in high-risk pregnancies<sup>5</sup>.

Although these figures apply only to Ontario, principal investigator Dr. John You, noting “that a 55% increase is pretty substantial,” told the Canwest News Service: “I wouldn’t be surprised if we saw similar findings across the country.”

Meanwhile, Canada’s autism rate has increased 50%, from 1 in 250 live births to 1 in 165, according to the Autism Society of Canada<sup>6</sup>.

While these two independent statistics regarding ultrasound exposure and an increase in autism do not provide causation or even correlation, they are red flags that deserve further investigation.

### **New facts raise new questions**

The results of the three studies I have discussed today – one showing that ethnic groups with the least access to prenatal care had fewer autistic children, a second showing that women who had educational, economic and medical advantages had children with a much higher autism rate and the third indicating that the number of ultrasound scans per pregnancy has increased dramatically suggest that we start asking new questions.

Do some people have genetic predispositions that make them more susceptible to ultrasound- induced damage? Early studies showed that ultrasound can damage mitochondria – could ultrasound be causing non-inherited mitochondrial disorders that lead to autism? Ultrasound heats tissue – could this damage heat-shock proteins, hampering their ability to protect newly vaccinated children experiencing prolonged, high fevers? Could the thermal effects of ultrasound be causing changes in gene expression that result in autism?

We need to ask whether fetal brains sometimes are being harmed by the very imaging technology intended to help ensure healthy pregnancies. It is a horrifying possibility. The good news is, if prenatal ultrasound is causing autism, strict rules regulating its use could cause a swift turnaround in the autism rate. Picture that!

Specifically, I am asking the IACC to consider making the following changes to Section III of the Strategic Plan.

- On P.1, —What caused this to happen and can this be prevented? I suggest adding the bullet: What aspect of prenatal care may be increasing the risk of ASD?
- On P.5, line 17 after the sentence ending in the word —risk. I recommend adding: —New studies regarding ethnic differences in autism rates, combined with previous studies regarding entry into prenatal care, indicate that some aspect of current prenatal care may contribute to causing autism.
- On P.5, line 21 after the sentence ending in the acronym —(EPA). I recommend adding: —Wherever possible in the previously cited studies, efforts should be made to record data regarding ultrasound exposure including the output power, type and length of examination, as well as information regarding optional, keepsake ultrasound sessions.



- On P.9, Line 18, I recommend a new paragraph, as follows: —Since prenatal ultrasound exposure may prove to be a factor in causing autism, we need to provide all ultrasound operators with a standard format for recording the output power, type and length of examination, along with any other factors recommended by experts who specialize in fetal ultrasound safety. This format must be required, so that accurate data in a standard format are available for future analysis.
- On P.10, remove the word —ultrasound from the seventh bullet listing potential environmental factors. Instead, add the following bullet: —Changes in prenatal care, specifically changes in the application, technology (including but not limited to increases in potential acoustic output, harmonic imaging, Doppler imaging, both spectral and color, 3-dimensional imaging and ultrasound contrast agents) and gestational window of exposure for prenatal ultrasound.

If the IACC agrees to incorporate the above suggestions, then additions will also need to be made in both the short-term and long-term objectives sections.

In closing, I want to extend my deepest gratitude to the IACC for the time and attention you have given to these ideas. Your task is not an easy one and it is far from done. I am sure you appreciate that if prenatal ultrasound is causing autism, then every delay of even one day will cause unnecessary, untold heartache for families across the nation. I hope that you will find the information and insights I shared with you today useful in updating the 2010 Strategic Plan.

**Thank you.**

Caroline Rodgers

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<sup>1</sup> Prevalence of Autism Spectrum Disorders – Autism and Development Disabilities Monitoring Network, United States, 2006. MMWR, Dec. 18, 2009. <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>

<sup>2</sup> 2002 PRAMS Surveillance Report: Multistate Exhibits Medicaid Coverage for Prenatal Care. <http://www.cdc.gov/PRAMS/2002PRAMSSurvReport/MultiStateExhibits/Multistates9.htm> (IACC Note: URL is not valid.)

<sup>3</sup> Entry Into Prenatal Care – United States, 1989-1997. MMWR, May 12, 2000. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4918a1.htm>

<sup>4</sup> Van Meter, KC et al. (2010) Geographic Distribution of Autism in California: A Retrospective Birth Cohort Analysis. *Autism Research*, 3, 1-11.

<sup>5</sup> You JJ et al. (2010) Proliferation of prenatal ultrasonography. *Can Med Assoc J.* Jan. 4 (epub ahead of print). <http://www.cmaj.ca/cgi/rapidpdf/cmaj.090979v1>

<sup>6</sup> [http://www.autismsocietycanada.ca/asd\\_research/research\\_prevalence/index\\_e.html](http://www.autismsocietycanada.ca/asd_research/research_prevalence/index_e.html) (IACC Note: URL is not valid.)