Oral Public Comments

IACC Full Committee Meeting

July 16, 2010

Listing of Oral Public Comments

Dr. Joseph Nyre

July 16, 2010

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Chairman Insel and members of the committee, it is a privilege to address a group that has made such a significant impact on the system of care for individuals with ASD. Your work has not been easy. This Committee, in collaboration with researchers and clinicians from across the country, has been charged with building a system to develop and sustain effective, evidence-based services for the future, while hundreds of thousands of individuals and families struggle with limited access on a daily basis. Some, out of frustration, have argued that the IACC and the CAA have ignored service needs. I would argue that a careful review of CAA funding priorities reveals a commitment to the type of research, workforce development and collaborative effort necessary to develop AND sustain quality services at the local, state and national level.

Researchers, clinicians and families in Illinois have seen the solid, progressive benefits of the CAA and are hopeful that the reauthorization will integrate the research, workforce, and system development work funded in the past, to service initiatives funded in future years. The Autism Program of Illinois, Hope Institute for Children and Families supports a network of over 30 university and agency partners committed to research, workforce development and service for individuals with ASD and their families. The Autism Program of Illinois is the largest statewide network of services in the country. Since its inception during FY2003, TAP has provided more than forty-one thousand clinical contacts and trained more than forty-three thousand parents and professionals. TAP partners at the University of Illinois Chicago Institute for Juvenile Research and the Institute for Disability and Human Development have been involved in NIH research, training and system development funded through CAA. The Hope Institute submitted and received one of the first HRSA state implementation grants funded under CAA. Illinois, through state, national and foundation funding, has built an infrastructure with the capacity to advance a major service initiative.

My work as an administrator, clinician, educator and researcher at The Hope Institute for Children and Families, The Harvard Medical School, Baylor University and University of Kansas has given me a unique opportunity to experience the tremendous gains that are possible through integration of research, workforce development and service. Leaders in Illinois are calling for the IACC to build upon the strong foundation created in Illinois and in other states to advance services and to link services to research. Recent legislation, including the ATAA, expresses a clear call for service initiatives. Illinois is an example of the early success of the CAA's foundational work. The Autism Program's state allocation provides a base of support for service programs; however, service funding from the CAA is necessary to effectively link service to research and to scale service to need.

Organization Overview-IACC presentation

The Hope Institute for Children and Families (HICF) is a nonprofit organization which provides residential, educational and health services for individuals with developmental disabilities ages 5 -21. Established in 1957 by Dr. and Mrs. Charles E. Jordan as a place to educate their daughter Judith Ann, Hope has grown to include: The Hope School Learning Center; The Hope Center for Residential Services; The Hope Health and Wellness Center; The Autism Program of Illinois; The Hope Institute Learning Academy; and The Noll Medical Pavilion. HICF programs impact more than 24,000 individuals and families.

The Autism Program of Illinois (TAP), with programmatic and fiscal leadership provided by HICF, is working on the front lines of Autism research and system development through the following:

1) TAP's partner at University of Illinois Chicago one of the original NIH Autism Centers of Excellence;
2) TAP's partner at University of Illinois Chicago Institute for Disability and Human Development UCEDD, and LEND site;
3)TAP-Hope Institute HRSA State Implementation Grant; and
4) Advancing Futures for Adults with Autism National Town Hall Sponsor and Steering Committee member.

Caroline Rodgers

July 16, 2010

Subject: Verbatim text of Rodgers' presentation regarding prenatal ultrasound & autism

Good afternoon,

Everyone is searching for what is causing autism. Geneticists are studying gene arrays, epidemiologists are looking everywhere – even under the kitchen sink – and others are seeking proof that would convince non-believers that vaccines are causing autism.

Meanwhile, emerging facts indicate that pregnant women who get first trimester prenatal care and/or the most ultrasound exposure are at the highest risk of bearing autistic children. This is a surprising discovery that is showing up along ethnic, educational, age and economic divisions – four different categories that all wave red flags.

Along ethnic lines, by combining information from two CDC reports, we find that White women, who had significantly more autistic children than Black or Hispanic women,[i] were much more likely to receive first trimester prenatal care.[ii] That is a red flag.

Another ethnic finding is that Hispanics, who had the lowest autism rate in both the 2002 and 2006 reports,[iii] [iv] were 20% less likely to receive an ultrasound during a prenatal visit than White women.[v] This is another red flag.

Several studies have shown that highly educated mothers are more likely to have children diagnosed with autism than mothers without high school diplomas. A study published earlier this year showed that in the majority of 10 newly identified California autism clusters, the rate was 4 to 1.[vi] A CDC entry into prenatal care report reveals that the percentage of pregnant women without high school diplomas to not have first-trimester prenatal care or to skip prenatal care altogether was between three to four times greater than for women with high school diplomas and some college.[vii] This is another red flag.

Maternal age is also a factor in autistic outcomes. A 2009 study found that for every 10-year increase in a mother's age, her risk of having an autistic child increased 38%.[viii] Since women over age 35 average three or more ultrasounds than younger women,[ix] I think this deserves another red flag.

Economic differences also emerged. The only two states among those monitored in the 2006 autism prevalence report to suffer cutbacks in Medicaid funding for prenatal care had the lowest autism rates[x] – another red flag.

On the other end of the economic spectrum, two studies regarding autism prevalence and socioeconomic status – one out of the Wisconsin School of Medicine and Public Health and the other from the CDC – found significant associations between higher household income or socioeconomic status and autism.[xi] [xii] This is the same group of people that can afford the best prenatal care and buy "keepsake" ultrasound image packages that cost hundreds of dollars. I believe this deserves a red flag.

In a study of prenatal ultrasound trends, differences in ultrasound exposure emerged according to health care payer type, with mothers who had private health insurance averaging three or more scans per pregnancy than economically disadvantaged mothers who relied on Medicaid or who had no health insurance.[xiii] This is another red flag.

Geographical differences in autism and ultrasound exposure may be emerging. The prenatal ultrasound trends report found that by 2005-2006, Southern women were 40% less likely to get an ultrasound scan

during a prenatal visit than Northeastern women,[xiv] but since we don't yet have autism figures for children who were exposed to ultrasound during that time it is too early to flag it – but worth watching.

Studies regarding prenatal ultrasound's effect on neurological health have waved other red flags in the past. More than one Scandinavian study has associated children exposed to ultrasound with dyslexia – that's a red flag.[xv] A 1993 Canadian study found that children with speech delays were twice as likely as controls to have been exposed to prenatal ultrasound [xvi] – another red flag. Studies have also found that boys exposed to prenatal ultrasound have a significantly higher incidence of left-handedness [xvii] [xviii], considered a subtle marker for neurological damage, when not inherited – another red flag. Plus there is Yale neuroscientist Pasko Rakic's 2006 study that showed pregnant mice exposed to ultrasound had offspring with changes in brain formation similar to those found in autopsies of autistic humans[xix] – another red flag.

In view of these facts, it is worth noting that autism prevalence went from 2.4 children per 1,000 in 1994[xx] to 1 in 110 in 2006[xxi] – about the same period during which the odds of a woman receiving an ultrasound during a prenatal visit nearly doubled. I think this deserves another red flag.

Yet despite all of these red flags, prenatal ultrasound is not being investigated as an autism risk factor.

Many people expect that the National Children's Study and the EARLI study – two prospective longitudinal investigations currently underway – will yield answers, but neither one is investigating prenatal ultrasound. Even more distressing, neither is collecting prenatal ultrasound data in a way that could lead to meaningful research down the line.

Is prenatal ultrasound causing autism? Maybe not – but let's do whatever it takes to find out, without further delay.

Thank you.

References

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[i] Prevalence of Autism Spectrum Disorders – Autism and Development Disabilities Monitoring Network, United States, 2006. *MMWR Surveillance Summaries*, Dec. 18, 2009/ 58(SS10);1-20. http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

[ii] Entry into Prenatal Care – United States, 1989-1997. *MMWR Surveillance Summaries*, May 12, 2000/49(18);393-8 http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4918a1.htm

[iii] Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002. *MMWR Surveillance Summaries*. Feb. 9, 2007/ 56(SS01);12-28. http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm

[iv] See Note 1.

[v] Siddique J, Lauderdale DS, et al. Trends in prenatal ultrasound use in the United States, 1995 to 2006. *Med Care*, 2009 Nov: 47(11):1129-35.

[vi] Van Meter KC, Christiansen LE, et al. (2010) Geographic Distribution of Autism in California: A Retrospective Birth Cohort Analysis. *Autism Research*. 2010. 3;1-11.

[vii] See Note 2.

[viii] Grether JK, Anderson MC, et al. Risk of autism and increasing maternal and paternal age in a large north American population. *Am J Epidemiol.* 2009 Nov 1; 170(9):1118-26. Epub 2009 Sep 25.

[ix] See Note 5.

[x] 2002 PRAMS Surveillance Report: Multistate Exhibits Medicaid Coverage for Prenatal Care. http://www.cdc.gov/PRAMS/2002PRAMSSurvReport/MultiStateExhibits/Multistates9.htm

[xi] Maenner MJ, Ameson CL and Durkin MS. Socioeconomic disparity in the prevalence of autism spectrum disorder in Wisconsin. *WMJ*. 2009 Aug; 108(5):253-5.
[xii] Bhasin TK and Schendel D. Sociodemograhic risk factors for autism in a US metropolitan area. *J Autism Dev Disord*. 2007 Apr;37(4):667-77.
[xiii] See Note 5.
[xiv] See Note 5.
[xv] This claim was made in error but remains here because this is a verbatim text of my 7- 16-2010 IACC presentation. Scandinavian studies, the most frequently cited of which is Stark, et al (1984), did not find prenatal ultrasound caused dyslexia. However, Pasko Rakic's 2006 mouse study (see Note 20) found that prenatal ultrasound caused disruptions in neuronal migration that were thought to cause disorders that "range from mental retardation and childhood epilepsy to developmental dyslexia, autism spectrum disorders and schizophrenia." Further, the 2002 article, "The safety of prenatal ultrasound exposure in human studies," in *Epidemiology* by D Marinac-Dabic, CG Krulewitch and RM Moore Jr, refers to reports of ultrasound causing dyslexia and recommends further research.
[xvi] Campbell JD, Elford RW and Brant RF. Case-control study of prenatal ultrasonography exposure in children with delayed speech. *CMAJ*. 1993 149(10):1435-40.
[xvii] Salvesen KA, Vatten L, et al. Routine ultrasonography in utero and subsequent handedness and neurological development. *BMJ*. 1993 Jul 17;307(6897), 159-64.
[xviii] Kieler H, Cnattingius S, et al. Sinistrality – a side-effect of prenatal sonography: a comparative study of young men. *Epidemiology*. 2001 Nov;12(6):618-23.
[xix] Ang, ES Jr, Gluncic V, et al. Prenatal exposure to ultrasound waves impacts neuronal migration in mice. *Proc Natl Acad Sci U S A.* 2006 103(34): 12903–10. Eput 2006 Aug 10.
[xx] Newschaffer CJ, Falb MD and Gurney JG. National Autism Prevalence Trends from United States Special Education Data. *Pediatrics*. 2005 Mar;115(3)e277-82. (The 2.4 in 1,000 prevalence figure is extrapolated from Table 1, where it was stated as 24.1 autism cases per 10,000 6-year-olds.)
[xxi] See Note 1.