Written Public Comments

IACC Full Committee Meeting

January 14, 2009

List of Written Public Comments

Eileen Nicole Simon

January 3, 2009

Subject: Obstetric procedures: Suggested addendum for the IACC strategic plan

Obstetric procedures: Suggested addendum for the IACC strategic plan

Robert DiMona

January 5, 2009

Subject: Autism Funding

There is an obvious need for objective, unbiased, research into the cause and treatment of Autism in the United States. Millions of children and their families are at risk; with the associated costs of this situation being enormous.

Regarding causation, the people of this country will not be satisfied with any plan unless the research takes a sober and earnest look into the potential causal factors without regard to politics and lobbyists. This means that vaccines need to be fully investigated. This is not to say that vaccines are the only area of concern. However, the government's refusal to adequately address this question is reprehensible. Instead of truly addressing the present crisis of losing so many children to autism and its related disorders, the government cowtows to the pharmaceutical lobbyists; citing flawed clinical research sponsored by pharma as evidence that there is no association between vaccines and autism.

However, the people of this country aren't all [derogatory language redacted]. They have seen time and again in our history how political expedience has taken precedence over the welfare of our people. Personally, this [derogatory language redacted] me.

You have a choice. Maintain the current stance and perpetuate the [derogatory language redacted] on the American people, [offensive language redacted] our children in the name of the pharmaceutical industry or, take an open, honest look into the causes of autism, including vaccines, using objective scientific methods.

Sincerely,

Robert DiMona

Eileen Nicole Simon

January 7, 2009

Subject: Neonatal resuscitation procedures: Suggested addendum for the IACC strategic plan

Neonatal resuscitation procedures: Suggested addendum for the IACC strategic plan

Also, I have seen comments online that a draft of the strategic research plan from the November meeting will include research on vaccines. Is research on obstetric and neonatal protocols included as additional environmental stressors?

Eileen Nicole Simon

January 8, 2009

Obstetric and neonatal care protocols must be looked at as possible environmental factors in the increased prevalence of autism. If they can provide solid evidence that cutting the umbilical cord right at birth and resuscitating via ventilation are safe, then ok. But most of the research literature is providing evidence to the contrary, that clamping of the cord should be delayed, and that aids to lung function like surfactant and prenatal steroids, are not helpful and may also be dangerous.

Eileen Nicole Simon

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

Lisa Sigismondi

January 8, 2009

Subject: Autism research budget agenda

I strongly support the following objectives:

- The budget must, as a minimum, reflect spending objectives defined in the Combating Autism Act;
- Adoption of language for the Strategic Plan's Introduction that embodies a sense of urgency and the critical need for the government to apply the resources to address a crisis situation and the adoption of oversight as submitted by IACC member Lyn Redwood;
- Ensure accountability with the adoption of a review and evaluation mechanisms, such as an Autism Advisory Board and a Department of Defense grant review model;
- The convening workgroup in January 2009 to focus on additional enhancements to the Strategic Plan that ensures the integral participation of the diverse community representing families and individuals with autism.

Sincerely,

Lisa Sigismondi
Aylett, VA
[PII redacted]

Filomena Laforgia

January 9, 2009

Concerns that remain as the next meeting approaches are the adoption of proposed introduction language that adequately expresses urgency and prevention in addressing the autism crisis, expansion of the budget to better reflect monetary outlays necessary to accomplish mission goals and interpretation of funding identified in the CAA as a floor, not a ceiling, in the budgetary process. SafeMinds has been diligently spearheading organizational consensus statements on the community expectations for the research agenda. Much gratitude is owed to these organizations for their participation in these efforts. The consensus created by these efforts was on proud display during the December meeting, putting Federal agencies on notice that we plan on boldly going where science has not gone before to get answers to autism's riddle.

- The budget must, as a minimum, reflect spending objectives defined in the Combating Autism Act;
- Adoption of language for the Strategic Plan's Introduction that embodies a sense of urgency and the critical need for the government to apply the resources to address a crisis situation and the adoption of oversight as submitted by IACC member Lyn Redwood;
- Ensure accountability with the adoption of a review and evaluation mechanisms, such as an Autism Advisory Board and a Department of Defense grant review model;
- The convening workgroup in January 2009 to focus on additional enhancements to the Strategic Plan that ensures the integral participation of the diverse community representing families and individuals with autism.

Sincerely,

Filomena Laforgia
Parent and advocate for children with Autism.

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

Noreen Albright

January 11, 2009

Subject: $16.000 Is Not Enough!

There are literally millions of parents that find their Autistic child had a reaction to a shot or a few shots and suddenly came down with Autism.

Most of these children also have allergies! Why don't they spend more money on the vaccine / Autism link? Personally, I believe it's the live viruses and also the bacteria in the vaccines from improper storage or handling. There are also cases of "recalled" vaccines????? How do you pull a vaccine from an infant?

How many children have to die or SUFFER their entire life before millions of dollars spent here?

As a community, the large majority of these children cannot protect our country, cannot be firefighters, policemen and the like. Three quarters of these kids are boys, and their as so many of them (NJ is #1 in mandatory shots / #1 in Autism).

Can we not see as a community, as a WHOLE, how Autism is effecting us? How it will affect our future and those of our children?

In 20 years, when it's too late, I feel the community as a whole will pay dearly for ignoring these kids, parents and their serious concerns with vaccinations, reactions and long life suffering.

This should be a TOP priority and I could raise this much money in a month.

Let's get Serious people. Our community as a whole is going to GREATLY suffer because of this.

If there were no way to prevent this, that would be one thing, but parents will testify that there are ways, let's do it NOW!

STOP Shotting up children (HEP B VACCINATIONS) they day they are born, especially when children have jaundice!!! Jaundice means they are sick! Start educating parents and giving free choice.

Noreen Albright [PII redacted]

"Live & LET live - PROLIFE -Natural law + Divine Intervention ;o)
A miracle is born everyday!

Marian Dar

January 13, 2009

I inquire:

(1) As part of the proposed longitudinal study, are they considering cluster of disease, disease patterns among immediate and extended family members (as in Iceland, etc.)?

(2) In today's New York Times, and often in the media, we hear about "gluten-free" and other diets. What about neuro-immunology and the possible gut-brain connection? As mentioned, I am the parent of an autistic child. I am also a celiac (gluten-intolerant). How might this potential relationship and source of insight be explored?

Thank you,

Marian Dar

Eileen Nicole Simon

January 13, 2009

Subject: What factors are associated with de novo MECP2 mutations?

What factors are associated with de novo MECP2 mutations? For the “What caused this to happen?” section of the IACC strategic plan.

Lyn Redwood

January 13, 2009

Attached is a recent epidemiology article funded by NIH regarding autism prevalence in California. Below are a few quotes from a recent media report and interview with the lead author.

“A study by researchers at the UC Davis M.I.N.D. Institute has found that the seven to eight fold increase in the number children born in California with autism since 1990 cannot be explained by either changes in how the condition is diagnosed or counted and the trend shows no sign of abating.”

“Published in the January 2009 issue of the journal Epidemiology, results from the study also suggest that research should shift from genetics to the host of chemicals and infectious microbes in the environment that are likely at the root of changes in the neurodevelopment of California's children.”

"It's time to start looking for the environmental culprits responsible for the remarkable increase in the rate of autism in California,” said UC Davis M.I.N.D. Institute researcher Irva Hertz-Picciotto, a professor of environmental and occupational health and epidemiology and an internationally respected autism researcher. "The methodology eliminated migration as a potential cause of the increase in the number of autism cases. It also revealed that no more than 56 percent of the estimated 600-to-700 percent increase, that is, less than one-tenth of the increased number of reported autism cases, could be attributed to the inclusion of milder cases of autism. Only 24 percent of the increase could be attributed to earlier age at diagnosis." . . .

Lauren Agoratus

January 14, 2009

On page 18 of the strategic plan under What do We Need, the second paragraph states "Special attention is needed on co-occurring medical issues". I would urge you to mention mental health issues. Despite comorbidity, there is little research and treatment for children who have both a developmental disability and mental illness. I commented on our state's dual diagnosis task force-please see attached. Of note is the fact that in our state the prevalence of mental illness in the DD population is 30-40% and that the hospitalization stay is three times longer. Thank you for your time and consideration.

Lauren Agoratus, M.A.
NJ Coordinator-Family Voices
parent

SPAN
35 Halsey Street 4th Floor
Newark, NJ 07102
(973) 642-8100
(973) 642-8080 – Fax
E-Mail address: span@spannj.org
Website: www.spannj.org

Statewide Parent Advocacy Network, Inc.
Empowered Families: Educated, Engaged, Effective!

SPAN and Family Voices Comments on the Dual Diagnosis Task Force

Submitted 10/8/08

Thank you for the opportunity to comment on the draft proposal of the NJ Department of Human Services' Dual Diagnosis Task Force recommendations. Family Voices is a national network that advocates on behalf of children with special healthcare needs and our NJ Chapter is housed at the Statewide Parent Advocacy Network (SPAN), New Jersey's federally funded Parent Training and Information Center and Family-to-Family Health Information Center and a chapter of the Federation of Families for Children's Mental Health. The Family Voices Coordinator also serves as the NJ Caregiver Community Action Network representative for National Family Caregivers Association in a volunteer capacity. Family Voices receives up to 2000 requests for assistance per month and there has been a tremendous increase in recent years in calls regarding children's mental health. From the calls that we receive, as well as my own experience as a parent of a child with both developmental and mental health/behavioral challenges, it is clear that individuals, particularly children, with a dual diagnosis of developmental disability and mental illness have extreme difficulty accessing services. This is also supported by the information that the prevalence of mental illness in the DD population is 30-40% and that the hospitalization stay is three times longer.

Under **I. B. Background 1) The Urgent Need for Reform,** we were pleased to see the myths exposed regarding mental health treatment including:

- "impairments in cognitive abilities…make psychotherapy ineffective." We have heard too often directly from professionals and from parents who have been told by various professionals from the Child Behavioral Health Services system that children with DD "are not capable of benefiting from mental health services".

- Another myth is that "maladaptive behaviors are a function of the developmental disability." Individuals with developmental disabilities can have co-occurring mental health disorders just like anyone else.

- We were also pleased to see the recognition of misperception that "the only treatment…is medication." National research indicates that therapy and intervention is most effective depending on the condition. Further for certain mental health conditions, only therapy is needed. In addition, too often medication is merely used as a chemical restraint.

- It is also a myth that "either one system of the other must take full responsibility". The problem is the DDD community doesn't have the mental health expertise; but the mental health

> community doesn't know how to deal with challenging behaviors or modifying their approach for someone with a developmental disability. The expertise in both the areas of developmental disabilities and mental health is essential for cost effectiveness and, more importantly, better patient outcomes. (This supports our recommendation that all children's services – including services for children with developmental disabilities – should be housed at the NJ Department of Children and Families. Why should children with the dual diagnosis of DD and MH have to access two separate systems and state agencies to get the services they need?)

Under the **2) What is Dual Diagnosis a) Definition** of dual diagnosis, we concur that "there is nothing about in intellectual…or developmental disorder…which explains aggression, property destruction, elopement or other unsafe behaviors." Regarding **2) b) Experiences of Individuals and their Families,** we agree that there is "fragmentation of responsibility". Even with NJ's System of Care, services are fragmented and triaged rather than preventative. We also see that children are isolated regarding schooling and sent to out-of-district placements or the homebound program, which was initially developed for medically fragile children, yet being inappropriately utilized for children with challenging behaviors who are stuck at home getting only academic instruction and now the support services they need such as counseling, positive behavior supports, and other related services.

In **3) Overview of the Available Services and Supports a) Services and Supports for Children,** we strongly support a System of Care that is "individualized, community-based, child-centered, family-driven, culturally competent, comprehensive, integrated…" We also support "increasing access…to non-clinical support…in-home supports and respite care." Under **Status in NJ** we agree that there is an over-reliance on institutional care". In view of the recent Olmstead decision and the fact that NJ is first nationally in overuse of segregated institutional care, and has the highest rate of out-of-district placements for children with disabilities (3 times the national average), expansion and enhancement of community based services is essential. If services are not easily available, they will not be recommended on IEPs, etc.

We hope that "DCBHS and DDD understand the complexity of need and are committed to appropriately serving dually diagnosed children, youth and young adults" but have not found this to be the case. Currently when families call Value Options, the CSA (Contract System Administrator), they are asked if their child is DDD eligible and if so to contact DDD. Then the only thing that's offered is behaviorists. And by the way, there is a one year wait list for behaviorists. A child who is saying "I'm going to kill you" or "I'm going to kill myself", is in crisis and does not need behavior modification, they need mental health help. Under **The Need for Comprehensive Clinical Evaluations,** we strongly support the use of the CECs (Child Evaluation Centers). We agree that DCBHS, DHSS, and DDD need to be linked and welcome more involvement with Special Child Health Services.

Further, national research has shown that the top priority for caregivers across the lifespan is respite. In fact, more people enter institutional care due to caregiver burnout rather than deterioration of their health condition. Any services and supports system must include a system of accessible and quality respite services for caregivers.

Under **3) b) Services and Supports for Adults,** we agree that while Trinitas has an excellent reputation, there are only 10 available beds for those with a DD/MI dual diagnosis. We agree that there need to be "more residential services and day programs". But this needs to be in the area of housing, not institutional care, and day programs should be community-based. We also strongly support the SCCAT (Statewide Clinical Consultation and Training) hotline for DD/MH and were disappointed that it didn't also cover dually diagnosed children. We agree with the concept of "regional training sessions targeting mental health and developmental disabilities service providers, care coordinators, case managers…agencies."

In **Table 1 under II. First Steps,** we agree an essential question is how to "educate both systems about each other." However, this is harder than it sounds. There is significant turn-over in both systems and thus there must be an ongoing system of education and re-education as well as opportunities for both systems to get together face-to-face to develop relationships. Further, parents of children with this dual diagnosis and parent advocates must be an inherent part of the training as trainers and as participants. We also concur in the need to look at both the strengths and challenges of the current system. One of the areas of strength was the development of the mobile response system. One of the challenges, however, is that it's basically triage and there is no consistency across counties.   For example, in a case of joint custody crossing county lines, Mercer Co. refused to send mobile response but Middlesex did, for the same child with no change in diagnosis or situation.

Under **III Recommendations A. Underlying System Philosophy 1: Components a) Vision, Values, and Principles,** in the section on **Vision** we were pleased to see the vision of a "lifespan responsibility" with recognition that children have these issues, too. In the section on **Values and Principles,** we were pleased to see the emphasis on "wellness and recovery" in line with national research and evidence-based practices, particularly for children.

Under **III, B. System Infrastructure 1) Components a) Learning & Workforce Development,** we were very pleased to see involvement of "superintendents, principals, child study teams, student assistance counselors…school…liaison" in the model program This is in keeping with the research and recommendations shared in national conference calls of both Georgetown University's National Technical Assistance Center for Children's Mental Health and NAMIs (National Alliance for the Mentally Ill) Child and Adolescent Action Center on the importance of school involvement with children's mental health.

Regarding **III, B., b) local planning teams,** while we support the concept of the CIACC (County Interagency Coordinating Council) on children's mental health, more outreach and awareness must be raised for opportunities for public/parent participation and supports must be offered to facilitate parent participation.

Under **III, B., c)** we agree that there must be a "seamless transition to adult services". We would like to recommend involvement of the CILS (Centers for Independent Living) which focus on transition, including mental health, and also collaborate with the Department of Education in schools. In addition, SPAN's Transition to Adult Life projects provide invaluable resources for parents, professionals and youth themselves. Youth with this dual diagnosis must also be involved and learn to participate and lead as much as possible in their IEP and transition process.

In part **III, C. Recommended Service Continuum for Children and Adults, 1. Recommended Service Continuum for Children,** we agree that children "should have access to the full spectrum of services…regardless of point of entry." We would suggest revising the uniform application used by Title V to include mental health so that all entities utilize the application for SCHS, early intervention/special education, DDD, and mental health. We also agree on the need to "increase availability of respite", the number one concern of caregivers across the lifespan. We strongly agree with the use of the ELP (Essential Life Planning) model but note that it is much easier to develop a plan using the ELP tools than it is to actually implement those plans with fidelity to the themes of consumer/family direction and flexibility of services. We concur that services would be improved by "reducing DDD case loads" and suggest looking at the caseload ratio in SCHS as well. The "Family Access Line" for families to get information on DDD is an excellent idea and we participate in the DDD family listserv and are on the DDD newsletter email listing as well. We strongly support "linkage to advocacy organizations… (SPAN, FSOs, ARC)" and would suggest adding the National Alliance for the Mentally Ill. NAMI NJ is one of six states launching the national Basics class which is free to parents of children with challenging behaviors. NAMI also has NAMI Cares support groups, speaker meetings, NAMI Kids outings for children and community service, and Educating the Educators (ETE) where a doctor, teacher, and parent panel presents to schools opportunities for collaboration on children's mental health.

We agree on the need to "increase the availability of PBS (Positive Behavioral Supports) and ABA (Applied Behavioral Analysis)" and "shared consents for releases of information" but there needs to be a reference added to HIPAA. We also caution that behavior modification may not be the best intervention for mental health. In treatment of developmental disabilities, we suggest "Educating Children with Autism" (www.nap.edu) which was a national study researching interventions proven clinically effective, in addition to ABA.

We also note that, while there is some limited research supporting ABA, the way in which it is implemented in many public and private programs in NJ is inconsistent with the research and makes inappropriate use of aversives and restraints. Disturbingly, no mention is made in the document of the need to eliminate use of aversive interventions and greatly reduce the use of restraints. We are aware that currently the NJ Dept. of Human Services allows for this in state regulations. We urge the department to consider the national trend towards elimination of use of these techniques that currently result in 150 unnecessary deaths each year (source: Child Welfare League) and which international research indicates is harmful psychologically. The following national actions regarding the use of aversives and restraints support this recommendation:

- American Academy of Pediatrics guidance http://aappolicy.aappublications.org/cgi/content/full/pediatrics;119/5/1018
- Exceptional Parent Magazine national policy statement www.eparent.com/home_ep_news/EP_Position_Statement_on_the_Use_of_Restraints.asp (IACC Note: URL is not valid.)
- MCH Child Death Review-data tracking (forthcoming) www.childdeathreview.org/cdrprocess.htm
- SAMHSA guidelines http://www.samhsa.gov/news/newsreleases/060601_seclusion.htm (IACC Note: URL is not valid.)
- All of the above are incorporated in the MCH Knowledge Path on children's mental health http://www.mchlibrary.info/KnowledgePaths/kp_Mental_Conditions.html

Lastly, under **Assessment** in this section, we agree services must "radiate around the person and family/caregiver." Family Support is essential for best outcomes, rather than just treating the individual.

Under **III, C., 1. , B. Crisis Response,** we again urge consistency in services across counties in light of the previously mentioned variation in mobile response and other services in Mercer and Middlesex as well as other counties. We also support the appropriate use of "telepsychiatry" and note that national Family Voices supports the concept of telemedicine in reaching isolated families. However, we add a note of caution as telemedicine is appropriate in some situations and not in others and we must not allow cost-saving considerations to outweigh what is best for the child and family. For example, children with dual diagnosis of DD/MH can be very challenging to their parents who may need face-to-face interaction with professionals to address their needs.

Regarding **III, C., 1. D. Dual Diagnosis Acute Care/Partial Care/Partial Hospital Day Program,** we agree that "caregivers to be intimately involved" but again a reference needs to be made to HIPAA. We note that NJ is one of the last 8 states that doesn't have assisted outpatient treatment legislation which makes intervention more difficult. In addition, minor consent for mental health treatment in NJ is ages 14-16 in which children can decline hospitalization and medications can be prescribed without parental input even though families are still legally responsible until age 18. We would like to see NJ have legislation similar to that in PA regarding minor consent, in which there are procedural safeguards in place when parents and children disagree on treatment options.

Under **III, C., 1., H DDD Case Management/Liaison Services**, we agree that service should be available statewide "to all DDD consumers 24/7/365". We also strongly support case managers to provide linkages both in DDD and the "'outside' social services." However, there needs to be consistency statewide in all DDD services such as respite, which currently greatly vary by county and by knowledge base and advocacy skills of families. White middle and upper middle class families appear to have greater access to respite services than lower income families, families of color, and immigrant families or families speaking languages other than English. If funds are limited to provide these services, then we would support some form of family cost share for upper income families rather than continuing to see families in greatest need going without services.

Regarding section **III, C. 1., K. Family, Staff, Professional, and Paraprofessional Education,** we agree that DDD should look at "expanding educational opportunities for medical professionals". We would suggest tapping into the previously mentioned NAMI ETE workshop, the Council on Children with Disabilities of the NJ AAP, and SPAN's UMDNJ project with medical students. Again, families must be involved in all professional and paraprofessional education as trainers to share their personal perspective as well as broader family perspectives, and families must have expanded opportunities to participate in culturally competent, accessible, and easy to understand parent development opportunities which must be developed and presented in collaboration with families and family advocates.

For section **IV. Implementation and Sustainability, D. Strategic Opportunities with Current of Anticipated,** we do know that recently there were two RFP reviews in Trenton for children with a dual diagnosis which we helped review. But the criteria specified the developmental disability must also include a cognitive disability based on IQ. The group requested a third RFP (forthcoming) as this would account for the majority of children with autism who do not have associated cognitive disabilities, but could still fall under the category of dual diagnosis, as co-morbidity is common. As nationally the number of children with autism has risen to 1 in 150 but in NJ it's 1 in 94 (1 in 60 boys), we expect there will be even more need for services for these dually diagnosed children.

Lastly for section **V. Task Force Future Agenda, A. Comprehensively Examine the Transition Process for Young Adults with Co-Occurring Disorders,** we agree that there are "challenges…facing youth with behavioral health needs…as they approach…adulthood." Indeed, children with mental illness have the highest dropout rates. We would again suggest tapping into the local CILS as well as continued collaboration with SPAN's Alice Hunnicutt who specializes in both transition and children's mental health issues.

Thank you for the opportunity to comment on the Dual Diagnosis Task Force.

Sincerely,

Lauren Agoratus, M.A.-parent
NJ Coordinator- Family Voices at the Statewide Parent Advocacy Network
NJ Caregiver Community Action Network-Nat'l Family Caregivers (volunteer)
35 Halsey St., 4th Fl.
Newark, N.J. 07102
(800) 654-SPAN ext. 110
Email familyvoices@spannj.org
Website www.spannj.org

Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.