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

Family Voices-NJ Comments on the IACC Strategic Plan 7/12/10

Thank you for the opportunity to comment on the proposed strategic plan for the Interagency Autism Coordinating Committee (IACC). Family Voices is a national network that advocates on behalf of children with special healthcare needs; our NJ Chapter is housed at the Statewide Parent Advocacy Network (SPAN), New Jersey's federally funded Parent Training and Information Center, Family-to-Family Health Information Center, Statewide Parent to Parent program, and chapter of the Federation of Families for Children's Mental Health.

SPAN's foremost commitment is to children with the greatest need due to disability; poverty; discrimination based on race, sex, or language; geographic location; or other special circumstances. It is from these perspectives, the perspectives of the many families we assist, and our own experiences as parents of children with special needs, that we are sharing these comments. Personally, as the Family Voices Coordinator for New Jersey, I am the parent of a child with multiple disabilities, including autism.

Introduction

Although the Centers for Disease Control (CDC) estimates that autism affects 1 in 110 children, in NJ it is higher with 1 in 94 children (source NJSA 26:2-185). Further the prevalence rate of the autism diagnosis for boys is 1 in 60. In 2009, the NJ Department of Health revised our birth defects registry to include autism using disorders listed by the Diagnostic and Statistical Manual (DSM-IV). We were pleased to see heterogeneity acknowledged in the strategic plan, particularly an increased focus on nonverbal individuals. We agree with the concept of environmental factors examined under prevention but would also include further research into the vaccine controversy, immunological disorders, and gastrointestinal symptoms. As a parent of a child on the spectrum, I was pleased to see the American Academy of Pediatrics' (AAP) recommendation of removal of thimerosal as a precautionary measure. As a parent of a child who is also medically fragile due to end stage renal disease, I must balance this with taking all medical precautions, including additional vaccinations such as annual flu and pneumonia shots. As other parents have chosen not to vaccinate, there is now a cohort which can be studied for comparative purposes without the ethical dilemma of putting children at risk. Finally we strongly support the lifespan approach and recognize that early intervention results in better outcomes, particularly with additional focus on adults and transition of teens to adult life.

We agree that the revisions for the strategic plan should include recent accomplishments, strengths/weaknesses, and we participated in the scientific workshops. We support the framework mentioned with the vision statement to accelerate research for better health outcomes, a mission statement to partner with stakeholders, and the core values which include

a sense of urgency, collaboration, consumer focus, cross-disciplinary partnerships, and accountability. We agree with the framework themes in terms of heterogeneity of symptoms, prevention (autism as a biological disorder with a genetic trigger), earlier detection/intervention (improving average age of diagnosis), a lifespan perspective, and data sharing for pooling resources and validation. We support comparison data collection from typically developing peers, public-private partnerships including advocacy groups, and community engagement.

1. When Should I be Concerned?

We strongly agree that caregivers “are often the first to identify signs”. 80% of parental concerns are correct and accurate (source International Family Centered Care conference 1993). We agree that most children will exhibit signs by age 2 and that at risk (e.g., sibling) children may be detected at 12 months. We are deeply concerned that the most current estimates cite the average age of diagnosis as 5 years old. We strongly support the CDC’s “Learn the Signs, Act Early” campaign as well as the American Academy of Pediatrics recommendations of developmental screening. We agree that there is a need for more research on both current and new screening and diagnostic methods and in particular validation in underserved populations.

We support the *Aspirational Goal: Children at Risk for ASD Will be Identified through Reliable Methods Before ASD Behavioral Characteristics Fully Manifest*. We agree that there should be research on measures that are “easy to administer and sensitive to incremental changes.” We would like to see the “detailed criteria for specific ASD subtypes...underlying pathology” in line with forthcoming DSM-V in 2013 which may redefine pervasive developmental disorders. We would also include biomarkers and genetic testing. We would strongly support research on tools for diverse populations, ethical considerations in screening, and barriers to screening in minority populations. However, we do not feel that more research needs to be done on “valid and reliable ASD screening instruments”, except as they apply to underserved populations or those with a dual diagnosis. In general, we support the use of the tools developed by the AAP in their national medical home webinar 4/20/09 “Developmental Surveillance, Screening, and Diagnosis” at www.medicalhomeinfo.org/training/archivescall3.html.

Under short term objectives, we agree with the development of at least one diagnostic tool that is valid in diverse populations. We also support improvement of the sensitivity and specificity of existing tools. We do not agree with the new objective to allocate \$2 million for 3 studies on identifying the reasons for health disparities because much data already exists and funding could be used in a more efficient manner to help eliminate the health disparities that exist given the information we already have and directly engaging populations that face health disparities in concrete and decision-making roles. We do support the new objective on researching the impact of early diagnosis as it relates to the outcomes based on the type of intervention.

Under long term objectives, we agree with identifying biomarkers, examining measures of behavioral and/or biological heterogeneity. We also support development of “continuous dimensions” for measurement of outcomes using response to intervention.

2. How Can I Understand What is Happening?

We support the continuing investigation of a biological basis, including the new research on maternal antibodies, resulting in the development of autism. We would like to see research on gender differences and particularly prioritizing research for etiology for non-verbal individuals.

We agree with looking at subsets within the disorder such as regression as well as co-occurring disorders.

Under the *Aspirational Goal: Discover how ASD affects Development which will Lead to Targeted and Personalized Interventions*, we agree with research on high risk siblings, brain imaging, metabolic, and immune markers, and research on females. We also support additional research on environmental factors. Again, we support looking at biological causes of regression and co-occurring disorders.

With regard to short term objectives, we support metabolic and/or immune studies and studies on females with ASD. We support all four of the new short term objectives looking about related genetic conditions (e.g., Fragile X), biological targeting of co-occurring disorders, genotypes, and studies on regression.

Under long term objectives, we strongly support longitudinal studies, including emphasis on females, and changes over time compared to typically developing peers. Again, we support the new long term objective of studying phenotypes.

3. What Caused this to Happen and Can this be Prevented?

We agree again that both genetic and environmental factors must be researched. Despite twin studies showing a 70% correlation, all genetic factors taken together only account for 10% (per strategic plan, yet 7/16 IACC noted may be 20-25%) of cases and individual genes only account for 1-2%. Despite the lack of relationship between ASD and vaccines, we strongly support investigation into “susceptible subpopulations that could be more genetically vulnerable.” We agree with continued coordination with the National Vaccine Advisory Committee. At the IACC, it was mentioned that although mercury distribution is the same in children with and without autism, children with autism have genes with a heightened response to mercury. Until this controversy is resolved, fear will cause “herd immunity” to decrease which is a public health risk.

Under *Aspirational Goal: Causes of ASD Will be Discovered that Inform Prognosis and Treatments and Lead to Prevention/Preemption of the Challenges and Disabilities of ASD*, we agree with research into genetic/epigenetic variations, environmental influences, family studies, and monitoring scientific literature on vaccines and other environmental factors (ultrasound, toxins, and pesticides as presented at the IACC).

Regarding short term objectives, we again support genome studies, identifying markers of environmental exposure, and enhancement of studies on diverse populations. We strongly support the two new objectives of investigation of susceptible subpopulations as well as environmental factors.

Under long term objectives, we support the study of at risk siblings and identifying genetic risk factors “in at least 50%” by 2014.

4. Which Treatments and Interventions Help

We were pleased to see the comprehensiveness of interventions such as speech and occupational therapies, and especially recognition of sensory integration. We agree that some adaptive technologies are helpful but also suggest the use of “total communication” using sign language and speech simultaneously prior to using facilitated communication. While we agree that Applied Behavioral Analysis has been researched as proven effective, we are concerned

with the lack of standardization for qualifications of behaviorists, and believe a more eclectic approach (e.g. combined ABA/Floor Time or Miller Method) as most effective. We would suggest the addition of social skills as an intervention to be researched because this will aid in successful transition to adult life. We are deeply concerned that challenging behaviors often result in the inappropriate use of aversive interventions, restraints, and seclusion which are harmful to children with autism. We urge the IACC to address this. Further, positive behavior supports must be utilized as the preventive and intervention method of choice.

Update Risperadol and Abilify

We recognize also that no medication has been FDA approved for autism but again caution against “chemical restraint” and recommend that any prescriptions, if needed, be used in conjunction with other therapy. We support looking into other biological treatments such as omega 3. We agree that gluten-casein free diets only identify allergens, and that secretin is ineffective as is chelation which is actually harmful. We also support investigation into co-occurring disorders such as gastrointestinal or sleep disorders.

Regarding the *Aspirational Goal: Interventions Will be Developed that are Effective for Reducing Both Core and Associated Symptoms, for Building Adaptive Skills, and for Maximizing Quality of Life and Health for People with ASD*, we agree with comparison of interventions and as well as combinations of therapies. We agree with the importance of early intervention, particularly for “at risk” children. Again, we support the use of assistive technology but with caution to ensure the individual is directly communicating his needs. We strongly support treatment of co-existing medical and especially psychiatric conditions, as there remains a “de-linking” of services between the developmental disabilities and mental health communities despite the high occurrence.

For short-term objectives, we support the proposed studies of co-occurring conditions. We also support testing the safety and efficacy of five common therapies such as nutrition, medications, assistive technology, sensory integration, and other medical procedures but with the cautions on dietary, pharmaceutical, and technological interventions previously mentioned above. We also highly recommend expanding on the National Research Council’s “Educating Children with Autism” at www.nap.edu which was clinically researched interventions proven effective in the treatment of autism thus far. Due to the high use of alternative interventions, we would recommend the use of the National Institute of Health’s research of the National Center for Complementary and Alternative Medicine found at <http://nccam.nih.gov> .

Under long-term objectives, again we support investigation of medications with the caution that it be used in conjunction with therapy. We support the new objective on medications for co-occurring disorders with the same caveat.

5. Where Can I Turn for Services?

We are concerned with the mentioned lag between research and practice estimated at 20 years. We agree that behavioral interventions must be researched but again the focus must be on positive behavioral supports and interventions. We agree that children with autism have more difficulty in accessing healthcare, even for something as simple as basic dentistry. We agree that insurers and schools “need assistance creating organizational structures and financial incentives so that high-quality interventions are institutionalized.” Our hope is that both mental health parity and healthcare reform will facilitate this. However, in education, we caution that this must be done in an inclusive manner such as capacity building grants to include students in public schools, not to build additional segregated settings. Another challenge is funding based on geographical location and we agree there needs to be consistency. We strongly support

families as “partners in research” because research indicates that parental involvement results in better academic and health outcomes.

Under the *Aspirational Goal: Communities Will Access and Implement Necessary High Quality, Evidence-Based Services*, we believe practices must be both evidence-based as well as community-based. We strongly support the development of a “coordinated, integrated, and comprehensive community-based service delivery system for people with ASD” similar to the American Academy of Pediatrics concept of the medical home. We reviewed the Autism Speaks 100 Day Kit found in English/Spanish at www.autismspeaks.org/community/family_services/100_day_kit.php and we would recommend a summarized version of this tool.

For short-term objectives, we agree with studying how access to services affects families, not just the child, and particularly underserved families such as immigrant families, families speaking languages other than English, African-American families, and other families of color. We strongly support the new objective of studying self-directed community-based supports. We also strongly support the new objective of studying models that “enhance access to services...self-determination, economic self-sufficiency, and quality of life...” particularly for those of transition age.

Under long-term objectives, we strongly support improvement of evidence-based services in diverse community settings. So we also strongly support the new objective on studying evidence-based services for those living in community settings. Lastly, we strongly support increasing skill levels “in service providers, including direct support workers, parents and legal guardians, education staff, and public service workers,” and urge that families be required co-presenters of training for providers.

6. What Does the Future Hold?

We agree with the costs of autism but focus more on the “human” cost. Even in the education system “where services are mostly obligatory”, families are having difficulty accessing services for their children. As students transition to adult life, they are put on waiting lists for services. We also feel that the “institutional level of care” requirement for home and community based waivers is too restrictive. We agree that there is little information on ASD and the justice system, but there is much data on mental health which may include autism. For example the National Center for Mental Health and Juvenile Justice study found that 70% of the children in the system had mental health disorders. Autism is listed in the DSM IV, the Diagnostic and Statistical Manual of Mental Disorders. There must be recognition that autism and mental illness are both *brain disorders*. We would highly recommend consultation with Dennis Debbaudt who trains emergency personnel nationally on autism issues (see www.autismriskmanagement.com/index.cfm).

For the *Aspirational Goal: All People with ADS will have the Opportunity to Lead Self-determined Lives in the Community of Their Choice through School, Work, Community Participation, Meaningful Relationships, and Access to Necessary and Individualized Services and Supports*, we agree with longitudinal studies to understand what is needed for transition, as well as the scope of the spectrum. We strongly support projects to coordinate state and local service systems.

Under short-term objectives, we strongly support the new objective on studying quality of life for adults on the spectrum. We also strongly support the new objective on investigating existing

programs for transitioning students. As mentioned above, we also strongly support specialized training for families and professionals.

For long-term objectives, we agree with the studies on quality of life or health and would suggest using health outcomes, as overall health determines quality of life; further research shows that people with brain disorders die on average 20 years earlier. We strongly support the new objective on studying how interventions during childhood affect adult life. However, we don't feel that there needs to be a new objective on further study of cost effectiveness to examine community based supports as this data already exists, unless extended to look at quality of life and health outcomes. We would also support the new objective on long term studies on health and quality of life.

7. What Other Infrastructure and Surveillance Needs Must be Met?

We strongly support the development of the Interactive Autism Network. We agree that there are multiple data sources and hope that the ARRA funding on Health Information Technology will facilitate data-sharing. We also support bio-banking for both genetic and environmental research. We agree that new information needs to be disseminated quickly and to the public as well as the need for rapid replication of studies. We agree that there must be increased workforce development and interdisciplinary research.

Under Aspirational Goal: Develop and Support Infrastructure and Surveillance Systems that Advance the Speed, Efficacy and Dissemination of Autism Research, (short and long term objectives combined) we support conducting a needs assessment and then merging or linking existing databases. We believe an annual state assessment could be helpful. As mentioned above we support the concept of bio-banks for research. We agree with the new objective of development of a "web-based toolbox to assist researchers." We also support creating funding mechanisms for study replications. We support the new objective of a "web based tool...of ASD prevalence" as well as the objective regarding investigation changes in prevalence rates. As mentioned above we support workforce development. We strongly support the development of "promising practices".

In summary, we support the majority of the strategic plan with the exceptions noted above. We recommend looking into existing diagnostic tools, clinical practice guidelines/policy statements, and current research rather than "reinventing the wheel" to be more cost effective. We also believe that there are many more areas where the needs of and strategies for other developmental disabilities mirror those for ASD and would welcome a more integrated approach rather than the current focus which seems to be "all autism all the time."

Thank you again for the opportunity to provide input on the IACC strategic plan.

Sincerely,

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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.