

# Why Does Autism Spending Need to Follow the IACC Strategic Plan?

July 29, 2014

## Better Outcomes, More Accountability and Real Help for Our Children

The APRC, Canary Party and other autism groups representing over 100,000 families with children with autism are frustrated by the lack of progress towards treatment for our loved ones and prevention of new autism cases. We believe that some of this lack of progress is directly related to lack of leadership, lack of accountability, ignoring what planning has been done for autism and very poor follow-up at the federal level. We are not asking that any new money be allocated to autism; **we are asking that the CARES bill require that federal spending accurately and proportionally reflect the IACC Strategic Plan.**

### Background

The IACC Strategic Plan has been developed under the authorization of the CAA and its most recent update is available here: [http://iacc.hhs.gov/strategic-plan/2013/IACC\\_2013\\_Strategic\\_Plan.pdf](http://iacc.hhs.gov/strategic-plan/2013/IACC_2013_Strategic_Plan.pdf)

Please note that the Strategic Plan report includes both federal and private funding of research but that federal spending is 82% of the total per the 2010 report here: <http://iacc.hhs.gov/portfolio-analysis/2010/index.shtml#figure2> The 2011/2012 report has not been released yet (8 months into 2014), which reflects the lack of oversight we are concerned about: <http://iacc.hhs.gov/portfolio-analysis/2011-2012/index.shtml> The Strategic Plan is not a perfect document, but its implementation as written would be a step in the right direction.

The IACC includes the heads of many federal agencies involved in autism activities along with public members as appointed by the Secretary of HHS. All members and external advisors to the plan are listed on pages 128-133 at the first link, if you would like to see their credentials. The plan has been developed and revised over the past 5 years and is divided into 7 “questions” with recommendations for goals and funding allocations for those goals. Unfortunately, the funding allocation recommendations have been largely ignored for many goals. The problems fall into five major areas with some examples below:

### 1) Overfunding of genetic research:

On page 21 - Goal 2.S.D. - funding for known syndrome research - \$9 million recommended - \$53 million spent

On page 22 - Goal 2.S.G - genotype/phenotype connections - \$22.6 million recommended - spent \$41.8 million

On page 43 - Goal 3.L.B – identifying genetic risk factors in 50% of individuals with autism - \$33.9 million recommended over 6 years - spent **\$169 million** over 5 years. Also note that they have only identified potential genes so far for 20-30% of the autism population and most of those occur in just a small percentage of the kids.

### 2) Underfunding of environmental research:

On page 22 - Goal 2.S.F - regression risk factors - \$4.5 million recommended - only \$993,000 spent

On page 38 - Goal 3.S.B - biomarkers of environmental exposures - \$3.5 million recommended over 3 years - only spent \$813,000 over 5 years

On page 39 - Goal 3.S.E. - environmentally susceptible subpopulations - \$8 million recommended over 2 years - only spent \$3.6 million over 4 years

On page 39 - Goal 3.S.F. - 10 environmental factors - \$56 million recommended over 2 years - only spent \$10.7 million over 5 years

On page 41 – Goal 3.S.I. – microbiome - \$1 million recommended over 2 years – only spent \$749,263 over 3 years

On page 43 – Goal 3.L.D. – environmental factors and subtypes of autism – \$25.1 million recommended over 7 years – have only spent \$5.3 million over 5 years

Comment – Goal 3.L.A. is the only environmental goal that was overfunded, but there are concerns about continued funding for the EARLI study, now that it is underway.

### **3) Underfunding of studies to prove efficacy of current practices:**

On page 7 - Goal 1.S.D – studies to understand the impact of early diagnosis on choice of intervention and outcomes – \$6 million recommended – spent \$0.

Comment – To put this in perspective, \$57 million was spent on identifying markers for early diagnosis – without knowing if early diagnosis actually impacts outcomes...

On page 60 – Goal 4.S.C. – safety and efficacy of current interventions – \$27.8 million recommended – only \$8.9 million spent

On page 77 – Goal 5.L.B. – efficacy and cost-effectiveness of community supports - \$16.7 million recommended – only \$603,000 spent

### **4) Significant spending not “specific to any objective” in the plan:**

At the end of each section you can see that large dollar amounts are being spent on research that is not directed to any goals in the strategic plan – much of this is going to “basic science”. While a small amount of discretionary funding should be allowed to follow-up interesting leads, the total for the five years reported for all seven questions is \$384,167,382. If roughly 80% is federal spending, then \$307,333,905 was spent on things not related to strategic plan goals. This begs the question of who is actually coordinating all of this spending and ties into the problems of potential duplication in autism research as reported by the GAO.

### **5) Underfunding of special populations, support and treatment (minorities, adults, females, non-verbal individuals, etc.):**

On page 20 - Goal 1.S.B – females/sex differences in autism - \$8.9 million recommended - only \$5.8 million spent

On page 23 – Goal 2.L.A – trajectories of females, youths and adults over time – \$126 million recommended over 12 years – only \$20 million spent over the 5 years so far

On page 39 – Goal 3.S.D. – enrolling racial and ethnic diversity – \$3.3 million recommended – only \$188,455 spent

On page 62 – Goal 4.S.G. – interventions for non-verbal individuals - \$3 million recommended over 2 years – \$9.6 million spent over 3 years

Comment – This goal was overfunded, but we would argue that both amounts are far too low considering that the average lifetime costs for a single individual with severe autism run over \$2.3 million dollars – so even the amount spent would only equal about 4 individuals.

On page 63 – Goal 4.L.A. – medication trials for core symptoms - \$22.2 million recommended – only spent \$9.7 million

On page 63 – Goal 4.L.B – reducing risk of recurrence in siblings - \$6.7 million recommended – only spent \$831,000

On page 76 – Goal 5.S.C. – models for community-based service - \$25 million recommended over 5 years – only spent \$5.4 million over 4 years

On page 76 – Goal 5.S.D – health, safety and mortality - \$4.5 million recommended over 4 years – only spent \$164,000

**On pages 90-92 – The entire section on question 6 – What does the Future Hold, Particularly for Adults? – has been underfunded. The recommendation for the 8 goals in this section was \$54 million – only \$17.6 million has been spent**

## Summary

The bulk of current federal spending on autism is focused on genetics, basic science and creating research networks. While this may pay off 20 years from now, it is not helping individuals affected today. Several hundred thousand families are facing the “cliff” of adult services that don’t exist and have not even been studied. There has not been a single new treatment developed despite all the federal spending and even the treatments that existed before the IACC have not been proven effective. The under spending on environmental factors means that we cannot reduce risk for women getting pregnant today, nor prevent a single case of autism – which has huge implications for future federal costs. Autism is currently estimated to cost \$137 billion dollars annually in the United States. It is critically important that the federal dollars authorized through the CARES Act be spent effectively and that they help those affected now. Even the IACC admits that their goals have not been met; here is a quote from page 115 of their report:

*While the past 5 years have seen rapid growth and substantial scientific progress, the Committee recognizes the large gap that still remains between advances made in research settings and practical benefits that are ready to be delivered to individuals and families living with ASD today. We remain far from the overall intention of the IACC Strategic Plan to foster research that will yield tangible improvements in quality of life for people with ASD across all settings and communities.*

**Please help the autism community by amending the language of the CARES act to require that the Strategic Plan be followed proportional to any spending appropriations. Continuing the current imbalances will not help those individuals affected by autism today, nor prevent any new children from being affected, and the leadership of our agencies must be held accountable for results.**