



441 G St. N.W.
Washington, DC 20548

April 3, 2014

Ms. Alison Singer
President
Autism Science Foundation
28 West 39th Street, Suite 502
New York, NY 10018

Delivered via e-mail

Dear Ms. Singer,

Thank you for the March 6, 2014 letter you sent on behalf of yourself and some non-federal/public members of the Interagency Autism Coordinating Committee (IACC). I appreciate your interest in our work as well as your concerns. GAO recognizes that autism is a serious public health matter. We understand that the IACC performs a valuable role in monitoring federal autism activities and coordinating those sponsored by the Department of Health and Human Services. We also appreciate that it has issued several reports and offers a forum for discussion. Your letter has raised a variety of concerns about our report's findings and conclusions and I would like to take this opportunity to respond to the key points raised. However, let me begin by first noting that we recognize—and regret—that there has clearly been some significant mischaracterization of our findings by the press and others who have not read our report carefully. As a result, our objectives and findings have been misreported, leaving some with the erroneous impression that we have determined the bulk of autism research has been outright wasteful. To be clear, the objectives of our work and our methodology were specifically designed to address the extent to which federal agencies fund *potentially* duplicative autism research and other autism-related activities, and to also assess the extent to which the IACC and agencies coordinate and monitor federal autism activities. We identified instances of *potential* duplication and the need for enhanced coordination and monitoring of federal autism activities. It should be noted that we consistently use the term “potential” in describing our findings—in the report's title, the Highlights page, and throughout the report (see p. 16, for example). We stand by these findings and hope that our more specific comments below will help clarify your understanding of our work.

First, you note that we did not interview “many” of the 14 currently serving non-federal/public members of the IACC. At the time we did our work, 9 of these members were relatively new to the IACC. Because these newer members would be less able to address questions regarding the IACC's operations and effectiveness, we selected members to be interviewed based, in part, on their tenure on the IACC. In total we interviewed 6 non-federal/public members—including 3 individuals who signed this letter.

Second, the letter indicates disagreement with our finding that the majority of federally-funded autism research projects have the potential to be duplicative. It also takes issue with our definition of what constitutes potential duplication. The letter notes that it was never the IACC's view that each objective could be accomplished by one project. We understand this and at no point do we suggest that there should only be one study funded per objective. However, the multiplicity of studies associated with a single objective leads to the *possibility* of potential

duplication, which is something we believe that the IACC should be aware of and that funding agencies should actively consider. The example on the Highlights page of our report indicating that 5 agencies awarded approximately \$15.2 million for 20 autism research projects related to a single objective is illustrative of the situation we are describing. We are not saying that simply because there are 20 projects related to one objective there is duplication. But given that all 20 projects shared a single purpose, it is possible that one or more projects *were* duplicative or partially duplicative of one another. We therefore consider this to be an instance of *potential* duplication. During the course of our review, we found no evidence that funding agencies had reviewed the autism research projects they funded to ensure they were indeed not duplicative. Our point is that the prospect of potential duplication suggests more coordination is essential so the risk of actual duplication can be reduced. We explicitly discuss the methods we used to examine potential duplication on pages 3-4 and 41-44 of the report, where we state that: “Determining that projects were categorized to the same strategic plan objective or research area suggests potential, but not actual duplication. Funding similar research on the same topic is sometimes appropriate and necessary; for example, for purposes of replicating or corroborating prior research results.”

Third, the letter suggests that the underlying premise of our report is that duplication is wasteful. It also notes that we do not recognize that in some cases there can be coordinated efforts by multiple agencies to fund different types of projects within the same objective, which reflects cooperation, and not duplication. We addressed this topic on pages 3, 32, and 35-36 of our report. Let us emphasize—as we do in the report—having multiple agencies involved in autism research and other autism-related activities can be advantageous. We recognize that replicating or corroborating prior research results can also be critically important. While we agree that it may be beneficial to have multiple projects and agencies associated with the same strategic plan objective, we believe that it is also important to carefully review the data to ensure that projects are indeed essential to achieve research goals and not unnecessarily duplicative. Further, careful review could help identify research needs—such as research that is needed to complement or follow-up prior research or research that requires further corroboration—and move autism research forward in a coordinated manner.

Fourth, your letter expresses disagreement with our finding that the IACC’s coordination and monitoring efforts are limited. Your letter states that we did not provide examples of these potential missed opportunities or indicate how the IACC might improve its coordinating activities. We disagree and believe that the IACC may have missed opportunities to coordinate federal autism activities and reduce the potential for duplication of effort and resources. For example, the report:

- discusses that IACC members provided mixed views on the usefulness of the IACC’s meetings, highlighting that information shared during IACC meetings is typically at a high level and the structure of the meetings provides little opportunity to discuss detailed information.
- points out that the IACC does not focus on the prevention of duplication among individual projects in agency portfolios as it is not specifically assigned this role in the Combating Autism Act. OARC officials explained that it is up to individual federal agencies to use the information contained in the IACC’s strategic plan and portfolio analysis and the related web tool to prevent duplication. Yet we found that IACC members were not necessarily well versed on the contents of these documents. For example, during our review, Education officials stated that the type of autism-related research the agency funds does not fit within the IACC’s strategic plan objectives.

However, we found that the strategic plan did include a research area focused on interventions, as well as one related to lifespan issues—two areas that could encompass the type of autism-related research funded by Education.

- notes that OARC officials do not review the data that they collect on behalf of the IACC for duplication or for coordination opportunities. Instead, they said that they fulfill their role in assisting the IACC in its cross-agency coordination activities in other ways, such as by facilitating interagency communication and gathering information.
- states that OARC officials acknowledged that the IACC could choose to use the portfolio analysis to make recommendations for increased interagency coordination, but to date this has not occurred.

Fifth, your letter suggests that we did not adequately support our finding that shortcomings in data collection resulted in the IACC's inability to identify coordination opportunities or indicate how the IACC might improve its coordinating activities. Again, we must disagree. We pointed out that the data the IACC uses is:

- Outdated. The most recent portfolio analysis and web tool contained data from 2010, which was not useful in identifying gaps in current research as they relate to the strategic plan objectives. Agencies could not use these data to determine whether a prospective autism-related research project was potentially duplicative of a new project funded since 2010.
- Not tracked over time. Information on the research projects relating to autism was reported for one year only and not for multiple years combined. Information on the progress of the objectives over time was also not presented.
- Inconsistent. The guidance and methodology for determining what projects constitute research changed over the years.
- Incomplete. We identified 16 autism research projects that were not included in the IACC data, such as a DOD Air Force study on autism gene sequencing and other topics and autism research projects funded by Education and HRSA.

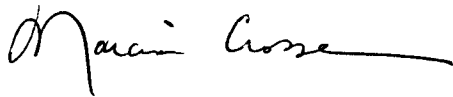
We continue to believe that these weaknesses limited the IACC's ability to monitor its progress on its coordination and monitoring efforts. In addition, these weaknesses limited agencies' ability to use these data to identify coordination opportunities and avoid the potential for unnecessary duplication. In our report, we also recognized the efforts of the IACC to improve its data, which occurred toward the end of our review.

Sixth and finally, your letter states that we did not acknowledge IACC's positive contributions to national autism policy nor recognize where the IACC has facilitated improvements in research and services. For example, your letter states that we ignored instances of interagency collaboration and specifically cites the efforts of several agencies to support a research project to examine reports of a higher than expected diagnosis rate of autism in the Somali community in Minnesota. We specifically acknowledged this successful collaboration in our report on page 22. We also included other positive examples about agencies using the IACC meetings as a springboard to develop contacts at other agencies and share information, such as when DOD reached out to HRSA after learning about HRSA's autism activities during an IACC meeting. It is also important to note that GAO's mission is to focus on improving the performance of the

federal government and finding ways to help it become more efficient and effective. Our reports are designed to be fact-based, nonpartisan, and non-ideological. To that end, we believe we fairly captured the IACC's performance by describing the frequency of its meetings, its issuance of several reports including the strategic plan and portfolio analysis, and its development of a companion database to its portfolio analysis.

The federal government plays a key role in funding autism research and non-research activities. We have identified concerns and offered recommendations in the hope of stimulating improvements that will maximize the effective use of federal funds in this very important area. Our report is meant to be constructive. I regret that it disappointed you, but hope you find this response to be helpful. We notice that your letter to me was posted on the IACC's website. I would appreciate you doing GAO the courtesy of placing my response to that letter on the website as well.

Sincerely yours,

A handwritten signature in black ink, appearing to read "Marcia Crosse", with a long horizontal flourish extending to the right.

Marcia Crosse, Ph.D.
Director, Health Care

cc: Idil Abdull
Co-Founder
Somali American Autism Foundation

James Ball, Ed.D.
President and CEO
JB Autism Consulting and
Board Member, Autism Society

Anshu Batra, M.D.
Developmental Pediatrician
Our Special Kids

Sally Burton-Hoyle, Ed.D.
Associate Professor of Special Education
Eastern Michigan University

Matthew Carey, Ph.D.
Contributor, Left Brain, Right Brain Blog

Jose Cordero, M.D., M.P.H.
Dean, Graduate School of Public Health
University of Puerto Rico

Geraldine Dawson, Ph.D.
Director, Duke University Center on Autism Diagnosis
and Treatment
Duke University, School of Medicine

David Mandell, Sc.D.
Associate Professor, Department of Psychiatry and Pediatrics
University of Pennsylvania, School of Medicine

John Robison
Self Advocate and Author

Susan Daniels, Ph. D.
Director, Office of Autism Research Coordination
National Institute of Mental Health/National Institutes of Health