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Dr. Marcia Crosse
Director, Health Care
U.S. Government Accountability Office
441 G Street, NW
Washington DC 20548

Dear Dr. Crosse:

We are writing, as a group of non-federal/public members of the Interagency Autism Coordinating Committee (IACC), to provide the U.S. Government Accountability Office (GAO) with comments regarding the recent GAO report "Federal Autism Activities: Better Data and More Coordination Needed To Help Avoid the Potential for Unnecessary Duplication" (GAO-14-16). We appreciate the work that went into this study and the opportunity to provide comment. The public members who were interviewed for this report were part of the IACC authorized under the Combating Autism Act of 2006. The Combating Autism Act was reauthorized in 2011 and new IACC public members were appointed. Thus, although "select non-federal IACC members" were interviewed for this report, this letter represents the first opportunity for many of the currently serving 14 non-federal/public members to share their views with the GAO. The aforementioned group of IACC non-federal/public members, while open to constructive suggestions to make the work of the IACC more effective, does not agree with the GAO report's primary conclusions or with its methodology.

We do not concur with the conclusion that the majority of federally-funded autism research projects have the potential to be duplicative and do not find the metric used to measure duplication to be sensible. In its report, the GAO asserts that "84 percent of the autism research projects funded by federal agencies had the potential to be duplicative... because the projects were categorized to the same objectives in the IACC's strategic plan." It was never the IACC's view that each objective could be accomplished by one project. The IACC's strategic plan offers wide-ranging objectives that are designed to address gaps in research funding. The intention of the IACC was that each broad-based objective would need to be addressed by multiple projects from multiple agencies in a coordinated fashion. For example, the objective to "test methods to improve dissemination, implementation and sustainability of evidence-based interventions, services, and supports in diverse community settings" was intended to be an objective that would engage the efforts of multiple agencies and projects, as it could not possibly be accomplished by one agency funding one project. GAO's conclusion that two projects could be duplicative because they both address community-based interventions is akin to saying two projects could be duplicative if they both aimed to reduce cancer mortality.

Moreover, the underlying premise that duplication is, by definition, undesirable or wasteful is inappropriate in this context. While the report identifies "corroboration" and "replication" as necessary, it fails to recognize that in the case of scientific research, coordinated efforts by multiple agencies to fund different types of projects within the same objective represent cooperation, and not duplication. For example, testing cognitive behavioral interventions for children with autism in school settings requires coordinated efforts from the U.S.

Department of Education (ED) and the National Institutes of Health (NIH). This “coordination function” is exactly the type of work the IACC is charged with doing under the statute, and yet the GAO report considers this coordination to be duplication.

We do not agree with GAO’s overall characterization of the IACC’s efforts to coordinate and monitor federal autism activities as “limited.” Despite being underfunded, the IACC has emerged as a model for other disease groups seeking to coordinate public and private efforts. The GAO report indicates that better coordination efforts are needed, and as non-federal members and advocates, we are always eager to improve coordination and agree that many improvements could result from additional funding to support the committee’s efforts. The report states that shortcomings in data collection resulted in the IACC’s inability to identify coordination opportunities. However, the GAO did not provide examples of these potential missed opportunities or indicate how the IACC might improve its coordinating activities, given its limited resources. The report also did not acknowledge many areas in which the IACC has managed to make positive and meaningful contributions to national autism policy with the resources it has. Over the past few years, the IACC has published several strategic plans and reports that have served to guide public-private efforts and inform the public of the latest developments in autism research and services policy, and the committee has provided an important forum for community input on federal autism issues. Many federal agencies and disease advocates have looked to the IACC as a model for coordination of research and services in the public and private sectors. Despite limited resources, the Office of Autism Research Coordination staff developed a publicly available database of research projects funded by both public and private sources, which is specifically designed to enhance coordination and reduce unnecessary duplication. Such a database does not exist for any other disease or disorder. Several IACC members have been asked to provide consulting and guidance to other disease/disorder advocacy groups, including Alzheimer’s disease and Schizophrenia groups that are eager to create IACC-type committees to coordinate activities for their own diseases, given the success they have seen from the IACC in coordinating autism activities.

The report also fails to recognize the many instances where interagency coordination via the IACC led to improvements in research and services for individuals with autism. For example, multiple agencies (including SAMHSA which is not represented on the IACC) worked together through the IACC to develop policy recommendations and guidelines to reduce instances of restraint and seclusion. The IACC also coordinated efforts resulting in actual research progress, including fostering collaboration among the Centers for Disease Control (CDC), National Institute of Environmental Health Sciences (NIEHS)/NIH, National Institute of Child Health and Human Development (NICHD)/NIH, and non-federal member organizations to support a research project to examine reports of a higher than expected diagnosis rate of autism in the Somali community in Minnesota, and engaging with a private organization to gather data on autistic wandering that could be used to support strategies to reduce instances of wandering and associated safety risks.

In summary, while recognizing that the GAO’s intention in preparing this report was to point out areas of the federal autism effort that could be improved, this group of non-federal/public members of the IACC do not believe that the GAO report accurately or fairly represents the significant progress made by the IACC over the past several years in coordinating the federal efforts to improve the lives of persons with autism through scientific advances. We encourage those who are interested in the goals, methods, and achievements of the

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IACC to interview the current non-federal/public members of the IACC to obtain a more up-to-date perspective on the IACC's efforts to ensure that research funds are used efficiently, strategically, and effectively. We are eager to work with you to make improvements that will ensure your concerns and the public's concerns are addressed.

We thank you for the opportunity to comment on this report.

Sincerely,

Idil Abdull

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