

The Autism CARES Act requires the IACC in its Strategic Plan to provide “Recommendations to ensure that autism spectrum disorder research, services and support activities, to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies, are not unnecessarily duplicative.”

The 2016-2017 IACC Strategic Plan for ASD offers wide-ranging objectives that are designed to address gaps in ASD research, services and support activities. The IACC’s intention is that each broad-based objective will be accomplished through multiple projects addressing various aspects of these complex issues, which will be funded by multiple agencies in a coordinated fashion. The IACC is charged with ensuring that coordination, which is achieved by fostering dialogue among federal agencies and private organizations and engaging their input in the development of plan objectives. The IACC believes that in the case of scientific research, coordinated efforts by multiple public and private agencies to fund different types of projects within the same objective represents cooperation and collaboration, not duplication. In addition, the scientific process requires that studies be independently replicated in order to ensure reproducibility and validate findings. Replication of an experiment or approaching a single problem using different methods can corroborate findings and help researchers distinguish between false leads and important discoveries. Replication also contributes to efficiency in research funding by ensuring the creation of a solid base of validated findings that establish the rationale for later stage, larger, and potentially more costly research efforts. For these important reasons, replication of research is valuable and should not be considered duplication of effort.

In 2013, the GAO released a report entitled “Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication” (GAO-14-16). The GAO report suggested that the IACC should more fully take advantage of research project data collected to identify opportunities to enhance coordination and prevent duplication. The Autism CARES Act provided more specificity in requiring the IACC to make recommendations about ways in which duplication could be avoided in its Strategic Plan. In the process of preparing this Strategic Plan, the IACC reviewed funded research projects to monitor the extent to which strategic objectives are being accomplished, including changes in funding over time. The IACC explicitly asked each of the seven working groups assisting with preparation of content for the Strategic Plan to identify issues related to duplication and to propose suggestions for avoiding unnecessary duplication.

The IACC did not find any specific instances of duplication among projects in the 2013 portfolio of funded autism research projects, but it noted that there are several instances of the opposite of duplication within the portfolio – gaps in research where too few projects are being supported to answer key questions in the field. Examples include the lifespan area in Question 6, which has received relatively little funding over the years that the Strategic Plan has been in place, resulting in gaps in knowledge about the needs of youth and adults on the autism spectrum and research to develop innovative services and supports.

The committee also identified a broader issue that provides an opportunity to reduce duplication - the need for closer coordination of large genomic sequencing efforts. Several different research organizations are building genetic databases and there is concern that different databases may be sequencing the same individuals, which could result in poor stewardship of funds as well as the time and effort of research participants. To reduce duplication of effort in sequencing, the IACC encourages

organizations building databases to publicly share their “manifests” which include information on whose DNA is in each database, to use global unique identifiers (GUIDs) to tag data in order to help researchers know when they are working with an individual who already has been sequenced, and to share data by federating with or contributing to the National Database for Autism Research. As technology advances, there may be instances where resequencing the same individual is necessary to expand coverage or gather additional data that were not gathered previously. Ideally, in an environment where data sharing is maximized, researchers will be able to be more efficient with genomics research funding and participation of subjects in research so as to reduce duplication of effort.