



8/20/2026

On behalf of the Consortium for Constituents with Disabilities (CCD) Developmental Disabilities, Autism and Family Supports Task Force (Task Force) and the undersigned organizations, we submit the following comments to the Interagency Autism Coordinating Committee (IACC) regarding the 2026–2028 working draft Strategic Plan.

We appreciate the Committee's efforts to develop a comprehensive Strategic Plan and recognize the importance of completing this work in a timely manner. We also value the Committee's commitment to incorporating stakeholder and public input throughout the process. However, we have concerns regarding the draft's approach to funding recommendations and appropriations, as well as several procedural issues that affect transparency, continuity, and public accountability.

Retain the Seven-Question Framework for the Strategic Plan and Portfolio Update

Since the initial formation of the IACC, each Strategic Plan and Portfolio Analysis has adopted a seven-Question framework to classify autism research: Identification, Biology, Causation, Treatments and Intervention, Services and Supports, Lifespan, and Infrastructure. Consistent use of this framework over the past thirteen years has enabled stakeholders to track resource allocation and research progress consistently over time and identify questions that are consistently under-funded, such as understanding the needs of autistic people across their lifespan and improving services and supports. Abandonment of this framework would reduce the public's ability to understand trends in resource allocation and compare to previous years. We urge the IACC to reimplement this framework in the final Strategic Plan.

We also urge the IACC to ensure **each Question and sub-Question includes a clear funding target or identified funding need**. The current draft Strategic Plan appears to include detailed funding recommendations only for specific topics, such as selected therapeutic and life course domains; several research recommendations contain no specific funding recommendation at all. We urge the IACC to ensure that each Question and sub-Question is associated with a clear, specific funding target.

This is particularly important in light of the Autism CARES Act, which requires federal agencies to coordinate autism research, services, surveillance, and related activities and provides the primary statutory framework for federal autism research coordination. The Strategic Plan should clearly identify the resources necessary to carry out the activities contemplated under Autism CARES and should not establish priorities that are disconnected from the appropriations necessary to implement them. A recommendation should not be considered achievable simply



because an agency has general authority to pursue it if sufficient appropriated funding, staffing, infrastructure, or administrative capacity does not exist. If agencies outlined in the strategic plan do not receive additional appropriations beyond what is authorized in the Autism CARES Act, the IACC should seek stakeholder input on how to modify the strategic plan to account for that potential reality. For initiatives that involve agencies receiving Autism CARES Act funding, IACC federal and public members should work with those agencies to identify whether existing authorized funds can support the proposed activities and pursue any additional resources through the appropriate appropriations process.

Since the passage of the Autism CARES Act of 2024 in December 2024, the Director of the National Institutes of Health, in coordination with other relevant agencies, as appropriate, has been responsible for preparing an annual budget estimate for carrying out the strategic plan. As far as we are aware, this has not occurred. This estimate and justification should have been prepared for fiscal years 2025 and 2026. We urge the IACC, which has the opportunity to comment on this estimate, to urge that the so-called professional judgment budget be produced and shared with the public for future fiscal years.

Additionally, we urge the IACC to produce a full Portfolio Analysis that is the product of human review by someone familiar with autism research. Past Portfolio Analyses were comprehensive overviews that analyzed autism research and funding by question and sub-question, and included information both on the number of studies funded and amount of total funding; analyses of spending on each question by each federal agency and large private funder; and a full dataset that enabled the public to easily review individual grants along with their funding agency, question, subquestion, and grant size. This individual, grant-level information, combined with the fact that an expert had confirmed each grant's assignment to a question and sub-question, provided greater assurance to the public that the analysis accurately reflected the amount of funding allocated toward each topic. The last full Portfolio Analysis covered Fiscal Years 2019 and 2020. While we think it is important to eventually address the current backlog, it is vital that future portfolio analyses, including ones for Fiscal Years 2025 and 2026, should be released promptly so that we may assess the state of autism research and research funding, as well as how grants are associated with the strategic plan at the individual and sum level.

Procedural Transparency and Continuity

The IACC's process for developing and adopting the Strategic Plan should be transparent, consistent with the Committee's statutory responsibilities, and structured to allow meaningful public participation. Historically, when developing a new strategic plan, a request for information (RFI) was issued as it was in October 2021 for the 2021-2023 IACC Strategic Plan and in January 2024 for the unpublished 2024 IACC Strategic Plan. Federal and Public members of the IACC worked with ONAC to address submitted comments and produce an analysis of the



RFIs in both instances. Several additional comment opportunities were offered before the IACC voted to finalize either plan. Given the lack of a formal RFI and the importance of the Strategic Plan in guiding federal autism research and policy, stakeholders should have sufficient opportunity to review proposed changes, understand how public comments are considered, and assess the basis for final recommendations.

The Committee should build upon the continuity of prior Strategic Plans and Portfolio Analyses while making the improvements laid out in the GAO Report to ensure adherence to the plan is measurable. Changes to the framework, methodology, or presentation of funding data should be clearly explained and should not make it more difficult to compare current priorities and investments with previous years.

We also urge the IACC to provide greater transparency regarding how recommendations are developed, prioritized, revised, and ultimately adopted, including how stakeholder input is incorporated into the final plan. We ask that as the IACC considers future changes, whether it be to the strategic plan or other initiatives related to autism research and policy, the IACC issues an RFI and later provides an analysis of the responses. Some of the elements an analysis should include are an understanding of how public comments are considered, recurring themes in comments, and an assessment of the basis for final recommendations. Public participation is most meaningful when stakeholders can see how their input affected the Committee's recommendations.

Further, the final Strategic Plan should be accompanied by a clear implementation and accountability framework identifying responsible agencies, available and necessary resources, measurable outcomes, and mechanisms for reporting progress. Without this information, the Strategic Plan risks becoming a broad statement of priorities rather than a meaningful roadmap for implementing the federal commitments established through the Autism CARES Act.

A meaningful roadmap is also grounded in current federal realities. The Strategic Plan should acknowledge how changes to federal agency capacity, Medicaid, the Department of Education, civil rights enforcement, and the grantmaking process may affect the feasibility of its recommendations. In particular, recent departures from standard federal grantmaking practices raise concerns about transparency, continuity, and implementation. The final plan should clearly identify the authorities, appropriations, staffing, grantmaking mechanisms, and infrastructure needed to carry out its recommendations.

In addition, previous IACCs have not consistently provided meaningful opportunities for the full autism community to engage, particularly autistic people who benefit from plain language, including children and teens, older adults, and people with intellectual or cognitive disabilities. Strategic Plan materials have often been difficult for the public to access and understand; the



final Strategic Plan should therefore include a stand-alone, public-facing version written at approximately a sixth-grade reading level, along with a two- to four-page summary clearly identifying the IACC's major recommendations and proposed actions.

We appreciate the IACC's consideration of these comments and urge the Committee to strengthen the final Strategic Plan by ensuring that its priorities are supported by transparent funding analysis, realistic appropriations assumptions, and a clear, accountable process for implementation and public oversight.

Sincerely,

Access Ready Inc

American Association on Health and Disability

American Music Therapy Association

Association of University Centers on Disabilities

Autism Society of America

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

CommunicationFIRST

Family Voices National

Institute for Exceptional Care

Lakeshore Foundation

National Disability Rights Network (NDRN)

Society for Developmental and Behavioral Pediatrics

The Arc of the United States

The Partnership for Inclusive Disaster Strategies