Public Comment from the Independent Autism Coordinating Committee (I-ACC) in response to the federal IACC Draft Strategic Plan

Learn more about the I-ACC at www.I-ACCAutism.org. The names of I-ACC members are listed at the end of this document.

The 2026 draft IACC Strategic Plan contains many important and constructive recommendations, particularly its attention to autism across the lifespan; people with high support needs; co-occurring medical and psychiatric conditions; special education; mental health; caregiver support; housing; employment; transportation; and aging. It also appropriately recognizes that autism is heterogeneous and that research, treatment, and services must better reflect that heterogeneity.

At the same time, the draft would benefit from substantial revision before it is finalized. Our principal concerns are that the plan does not adequately build on previous IACC work or the existing scientific literature; lacks a clear process for prioritizing an extraordinarily large number of proposed initiatives; devotes disproportionate attention to biological and therapeutic hypotheses with very different levels of evidentiary support; departs from its own evidentiary standards in its treatment of partner-assisted communication; and proposes an ambitious research and services agenda the lacks sufficient infrastructure without adequately addressing the federal capacity and financing necessary to implement it. The document's extraordinary length and complexity also make it difficult for the autism community and the broader public to understand what IACC is actually proposing.

Restore Continuity:

The new plan represents a radical shift in organization and format from previous IACC Strategic Plans. That makes it difficult to determine what has been learned, what progress has been made, and which previously identified priorities remain unresolved. Most notably, the draft does not adequately incorporate the 2024 Strategic Plan Update or explain what happened to the substantially completed work of the previous IACC cohort, mentioning only that they did not have access to it. This is puzzling because there is considerable overlap between the previous plan and the new draft, including the focus on heterogeneity and co-occurring conditions. Science is cumulative, and federal research planning should be as well. In order to communicate to the public what has been accomplished and the connections with past research and planning documents, the final plan should explicitly describe how it builds on previous IACC plans, portfolio analyses, public comments, and research findings. Where the new committee has chosen a different direction, it should explain why, with clear supporting literature, including citations, and comparison of pros and cons between previous and new directions.

The absence of a formal handoff between IACC cohorts also suggests the need for a permanent process for preserving institutional memory. In the past, ONAC and the National Autism Coordinator served these functions. Future committees should routinely receive and review the work products of predecessor committees, including unfinished or unreleased work, so that each new committee does not effectively begin again. The final plan should also address the extended transition between IACC cohorts, including why the current committee did not hold its first meeting until 2026, and explain how the process leading to the new Strategic Plan fulfills the responsibilities established under the Autism CARES Act of 2024.

Establish Clear Priorities:

The draft proposes an extraordinary number of new initiatives spanning basic and clinical research, treatments, health care, education, Medicaid, mental health, housing, employment, transportation, caregiver supports, aging, and federal navigation. It also proposes new federal structures, including NAPTI, autism.gov, and a National Developmental Regression Initiative. It is unclear how these new entities would interact with existing federal structures, particularly ONAC and the National Autism Coordinator, or what resources would be required to establish and administer them. Not everything proposed in the plan can be accomplished during its three-year timeframe. The final plan therefore needs a transparent process for setting priorities and, as stated in the Autism CARES Act, budgetary requirements.

Each major recommendation should specify who is responsible for carrying it out, what resources and statutory authority are required, what funding source would support it, what can realistically be accomplished during the life of the plan, and how progress will be measured. While some metrics are included in the plan, in many sections these remain underspecified or not specified at all. The plan also assumes an extraordinary level of coordination across federal agencies—including HHS, NIH, CDC, CMS, ACL, HRSA, SAMHSA, ED, OCR/OSEP, DOL, SSA, HUD, DOJ, DOT/FTA, OPM, EEOC, and others. Many initiatives assign responsibilities to multiple agencies and expect coordinated guidance, demonstrations, data collection, reporting, funding, and implementation. This raises a fundamental question of whether the federal government currently has the infrastructure, staffing, authority, data systems, funding, and interagency mechanisms needed to execute the plan. Several sections identify ambitious five-year timelines without demonstrating that the systems necessary to achieve the proposed outcomes exist. The plan frequently relies on “coordination” as a solution to problems that are actually structural capacity problems. For example, better coordination cannot by itself address shortages of housing, DSPs, health-care providers, mental-health providers, transportation, or Medicaid waiver capacity. And even coordination within the NIH may be hampered when none of the relevant institutes have permanent leaders in place and, in contrast to previous committees, the IACC does not include institutional leadership.

In addition, many of the suggestions are not practical or feasible in the context of current scientific and clinical practice in real-world settings. Autism research is supported by independent labs across many institutions; access to clinical services is extremely limited, with long waitlists and in-depth clinical phenotyping is significantly constrained by insurance coverage. While some of the plan's ideas could improve clinical and research practices, the level of detail for medical characterization or standardization across unrelated institutions minimizes the reality of how academic research and healthcare operate in the United States. Autism clinicians and scientists must work alongside these federal representatives and community partners to craft these priorities.

Epidemiology and Public Health:

The report takes the strong position that the available data suggest an actual increase in the prevalence of autism, and that the cause of this increase needs to be investigated. In this section the report recommends an extensive series of efforts to address this supposed increase. The report makes reference to many specific claims of fact, several of which are demonstrably false, and others of which are mischaracterized or overly definitive. For example, the report states, "Contemporary data indicate that 25–30% of individuals with autism are minimally verbal, and a substantial proportion have diagnosed intellectual disability." This is in direct contradiction to published peer reviewed studies that demonstrate that the rate of intellectual disability in autism plummeted from 56% in 2001 to 6.7% in 2020 — a drop of nearly 8-fold (Salkic et al., 2026, Psychiatry Research, 363:117426 https://doi.org/10.1016/j.psychres.2026.117246). Similarly, Furnier and colleagues found, in the ADDM network data, that the prevalence of autism with mild, borderline, or no significant adaptive challenges increased between 2000 and 2016, from 5.1 per 1000 to 17.6, while the prevalence of autism with moderate to profound challenges decreased slightly, from 1.5 to 1.2 per 1000 (doi: 10.1002/aur.70167). These findings suggest that the entirety of the rise in the rate of autism diagnosis can be accounted for by the group without intellectual disability, consistent with the conclusion by the majority of the autism epidemiology community that the main drivers of the increase are changing diagnostic criteria and greater awareness. However, the Hughes et al. analysis, which used the Lancet definition of profound autism (IQ <50 and/or minimally/nonverbal) to measure prevalence in the CDC's ADDM sample, reported that that absolute prevalence of profound autism increased, from 2.68 per 1,000 in 2000 to 4.59 per 1,000 in 2016, but the increase was much smaller than for non-profound autism, which rose from 3.94 to 14.26 per 1,000 (https://pubmed.ncbi.nlm.nih.gov/37074176/). The IACC report should more accurately reflect the scientific consensus, and more fairly represent the scientific literature.

Services:

The services portion of the plan contains a substantial and, in many respects, constructive agenda. Its strongest recommendations concern increasing workforce capacity, making special

education accountable for outcomes, increasing access to mental health care, and expanding Medicaid home- and community-based services, respite, housing, supported employment, transportation, and aging services. However, this laudable services agenda is weakened substantially in four ways:

1. It devotes disproportionate attention and resources to treatments based on weak evidence.
2. It exempts partner-assisted, letter-based communication methods from the evidence standards to which it holds other interventions.
3. Its service recommendations often depend on federal agencies, enforcement authorities, Medicaid financing, and community-integration protections that the executive branch is currently weakening.
4. It is too long, technical, and complex for a public strategic plan intended to be understood by autistic people, families, and other nontechnical stakeholders.

Special Education

The plan recommends fully funding IDEA; fiscal and service-delivery dashboards; measuring missed IEP services; increased preparation and retention of special educators and related-service professionals; restored Office for Civil Rights staffing; complaint-resolution benchmarks; and additional functional and transition outcomes for students with significant disabilities. These are strong recommendations. The draft identifies underfunding, workforce shortages, delayed evaluations, missed services, and weak enforcement as central problems. It also directly calls for OCR staffing to be restored.

The plan is less evidence-based in its endorsement of education savings accounts, vouchers, micro-schools, and autism-specific school-choice arrangements. Families using private-choice mechanisms do not necessarily retain the same procedural protections, accountability, inclusion opportunities, or entitlement to services they receive under IDEA. The plan should not present school choice as an answer to public system failure without addressing selection, exclusion of students with the greatest support needs, segregation, provider qualifications, fiscal accountability, and waiver or loss of IDEA protections.

Mental health and crisis services

The plan recommends autism-adapted screening, psychotherapy and medication management, competent 988 and mobile-crisis systems, reduced restraint and seclusion, continuity after hospitalization, network-adequacy standards, and alignment across Medicaid, schools, CCBHCs, HCBS, and community mental-health systems. These are potentially very valuable recommendations, although there is little discussion of the research or other efforts needed to identify what the “federal standards” should be. The drafters should also consider:

- immediate calls to increase accessibility and nondiscrimination;
- requiring evidence- and outcomes-based interventions for special education;

- a longer term vision for service-system models that require additional federal funding and state participation.

Medicaid, caregiver support, and workforce

The draft makes an excellent set of recommendations regarding Medicaid and workforce development, including, higher reimbursement tied to level of need, increasing direct service providers' wages, benefits, credentials, and career ladders, funding respite care and emergency respite care, caregiver mental-health and sibling support, transition planning and reserved residential capacity when aging caregivers can no longer provide care. These recommendations will require sustained Medicaid financing, which goes counter to current federal policy. The draft should explicitly call out the changes the current administration would have to make to the Medicaid system for these recommendations to be implemented.

Long-term care

The plan proposes linking multiple federal initiatives to address the long-term care needs of autistic adults. These include, expanding housing and residential capacity, using Medicaid HCBS to finance daily supports, but not housing, creating acuity-based reimbursement for people who require intensive staffing, developing crisis or reserved residential capacity for caregiver incapacity, beginning caregiver succession planning in adolescence, expanding the direct support workforce, testing residential models, including supported apartments, small specialized homes, clustered housing, intentional communities, farmsteads, and campus-like settings, and connecting older autistic adults to aging networks, Medicare preventive care, Medicaid LTSS, supported decision-making, and palliative care. These are laudable recommendations. The report does not identify what the funding stream is for these supports, especially for families where a tax benefit is not enough. There also is no plan to regulate housing quality. The US has a history of lacking clinical oversight in some residential settings, as well as instances of abuse including restraints and seclusion. Plans to improve housing must address these concerns. The report also ignores the existing infrastructure for skilled nursing and congregate care, other than to see these placements as failures. It's not clear, however, how some of the housing options described in the report would differ from these settings.

We also recommend that the report state explicitly, in its adult and aging-related sections, that support needs are lifelong for many autistic people and are not contingent on continued developmental progress, so that lifelong support is treated as a baseline expectation rather than a fallback for cases where intervention did not produce gains.

Conflicts with current federal policy

The most striking weakness in the services section of the draft report is the disconnect between the plan's proposed service infrastructure and current federal actions. Below are some examples:

Department of Education and special education: The plan assumes that there will be a Department of Education, OSEP, OSERS, and OCR. It calls for restored OCR staffing, stronger IDEA monitoring, dashboards, workforce grants, technical assistance, and civil-rights enforcement. Yet the federal government initiated a reduction in force affecting nearly half its workforce in March 2025, and the administration has explicitly described its objective to break up the federal education bureaucracy and return functions to states. In June 2026, the administration announced interagency arrangements under which HHS would partner on special education and rehabilitation functions and DOJ would partner on civil-rights enforcement. The draft notices that responsibilities are "in transition," and even includes a contingency provision concerning further reductions or closures, but it does not forcefully call out that reducing the agencies responsible for monitoring IDEA, providing technical assistance, collecting national data, and investigating disability discrimination directly undermines the plan's own recommendations. We also find that the plan's proposal to redirect hypothetical administrative savings into IDEA is not an adequate response. Loss of federal expertise, institutional memory, investigation capacity, and national monitoring cannot simply be replaced with formula funding.

Civil-rights enforcement and the ADA integration mandate: The housing, crisis, aging, and transportation chapters repeatedly rely on the roles of DOJ, HHS OCR, Olmstead, and the ADA integration mandate. The plan calls for preventing unnecessary institutionalization and describes DOJ as responsible for Olmstead and disability-rights protection. That is in direct tension with the July 2026 Office of Legal Counsel opinion stating that neither Section 504 nor Title II of the ADA imposed an integration mandate on states and that executive agencies lack authority to impose one. The strategic plan should explicitly oppose policy changes that weaken community-integration protections, while still supporting the expansion of housing options. Instead, it treats DOJ enforcement as an available implementation tool while avoiding direct confrontation with the administration's newly stated legal position.

Medicaid: The plan depends on Medicaid for many services from early childhood through adulthood, including many services for which Medicaid does not currently reimburse. However, current federal Medicaid policy is moving in the opposite direction. The recently enacted changes include community-engagement or work requirements for portions of the population, more frequent eligibility verifications, and financing restrictions. CMS began implementing the community-engagement framework in June 2026. The new rules include exemptions for some caregivers and medically frail people, but the administrative burden and coverage-loss risks extend beyond those directly subject to the requirement. CMS has also implemented restrictions

affecting provider taxes and other state Medicaid financing mechanisms. Even if autistic adults are exempt, reductions in state financing capacity can affect almost all the services the draft report calls for. The plan cannot credibly recommend higher wages, expanded HCBS, more residential capacity, better network adequacy, and new demonstrations without confronting the federal financing policies that make those objectives less attainable.

On the whole, we find that the lack of critique of these federal policies stands in sharp contrast to the plan's critique of the federal autism research infrastructure, NIH portfolio allocation, duplication, evidentiary practices, and lack of accountability.

Treatment

The plan devotes considerable space to folate, immune, microbiome, mitochondrial, and related hypotheses, although frequently acknowledging that these approaches are not ready for routine use. It devotes little or no space to pharmacological, neurotechnology, cognitive or behavioral interventions that show equal or more promise. In short, there is little space in the draft for broad science on treatments. Instead, implicit (and sometimes explicit) in the draft is that autism is a result of immune dysregulation, despite the lack of evidence for this particular hypothesis for the vast majority of autistic people. Treating immune biology, folate metabolism, microbiome interventions, mitochondrial/redox biology, autonomic dysfunction, regression, motor planning, and network excitability as parallel national therapeutic domains creates the impression that each represents a comparably promising treatment pathway. They do not. Some contain worthwhile questions and some address co-occurring medical conditions, but the evidence supporting each differs enormously. The draft should more clearly separate:

- evidence-based care that should be implemented now, such as identification and treatment of epilepsy, gastrointestinal disease, sleep disorders, mental-health conditions, pain, medication adverse effects, and established metabolic disorders;
- promising but unconfirmed treatments requiring conventional safety and efficacy trials;
- exploratory biological hypotheses, for which biomarker validity, causal relevance, and therapeutic implications remain uncertain.

The draft strongly challenges the existing NIH autism research portfolio, but it does not demonstrate that expanding investment in the domains outlined above will improve autistic people's lives more than expanding comparative-effectiveness, implementation, health-services, educational, workforce, and long-term-support research. The plan acknowledges that adult services, caregiver support, implementation, and outcomes for people with high support needs have been underdeveloped, yet the document's length and detail remain heavily weighted toward speculative therapeutic biology.

Partner-Assisted Communication

The section on communication begins with a set of important points. Nonspeaking autistic people are drastically underserved; communication is essential for health and safety; access to independently used augmented communication devices should be improved. The plan then moves to discuss only one of these: partner-assisted, letter-based methods, even though every rigorous study has found that these methods convey the thoughts and words of the partner, not the autistic person. The draft states that letter-based methods used with a trained communication partner should not be considered invalid even though evidence is absent. It recommends preserving access while research proceeds and directs Medicaid and civil-rights agencies to make this particular set of methods available.

This framing conflates two very different issues: whether a person should have training and access to communication assistance and independently operated AAC; and whether messages produced in the presence of a partner, using a held letterboard, physical support, and/or systematic cueing can reliably be attributed to that person. The draft's position is especially problematic because the communications it emphasizes include pain reports, consent and refusal, abuse allegations, medical decisions, and safety concerns. Those are precisely the situations in which unverified authorship creates the greatest risk of harm.

Profound Autism

At many points the plan refers to "profound autism", thus addressing one of the important areas in the 2024 CARES Act. However, it is of great concern that the plan uses a different definition of "profound autism" than one that has been adopted by the broad autism research community through a consensus Delphi process, and recently published in Molecular Autism, a leading journal in the field. It is another example of the plan failing to recognize and build on advances published in the current scientific literature. Failure of the IACC to adopt the consensus definition will harm future progress, as the vast majority of scientists will use the established definition of profound autism in their research.

National Developmental Regression Initiative

We welcome the plan's attention to the phenomenon of regression, which has a significant adverse impact on autistic individuals and their families. The clinical literature documents that regression takes place at different time points in the development of autistic children, during early childhood, middle childhood, and adolescence. This latter time period is sometimes associated with catatonia. The plan devotes considerable attention to regression during early childhood. In describing the proposed cohort study, while the expectation is to follow a large cohort of children longitudinally, there is no discussion of the age at which children would be enrolled. Over the last 20 years, many research groups in the United States and around the world

have carried out longitudinal cohort studies that are prospective in design, as this is recognized as the optimal approach, beginning with infants soon after birth (see https://www.babysiblingsresearchconsortium.org for a complete listing of studies and summaries of major research findings). In this way, researchers can capture the changes that are taking place in behavior and development in those infants who may later be diagnosed with autism. As the committee revises the plan, we hope it will provide more detail on cohort studies to address this important topic, and will develop methods for capturing regression prospectively beyond the toddler years.

Make the Strategic Plan Understandable to the Public

A federal autism Strategic Plan should be accessible to autistic people, families, clinicians, researchers, service providers, and policymakers. The current draft is extraordinarily long, technically dense, and filled with jargon and complex sentences. The Flesch–Kincaid tool reported a grade level of 19 for the document, meaning graduate school level of education. The final version should include a stand-alone public version written at approximately an eighth-grade reading level and a two- to four-page summary identifying the major proposals IACC is recommending.

It would also benefit from a simple framework showing what interventions are supported by evidence and can be implemented now, which need to be tested with more research, and which have insufficient evidence and should not yet be implemented. For each major recommendation, the reader should be able to determine who would benefit, what would change, which agency would implement it, how it would be funded, and how success would be measured. Major scientific disagreements and evidentiary controversies should be stated explicitly rather than buried within hundreds of pages.

A shorter, more focused, evidence-driven plan with clearly defined priorities, responsibilities, costs, timelines, and measures of success would provide a much stronger roadmap for federal autism research and policy, and would make it possible for the autism community to hold the federal government accountable for achieving its stated goals.

The draft plan also makes many unsubstantiated claims, with rather limited references to the purported empirical support. The provided references are also not formatted in a standard manner that allows easy cross-reference of the information. Citations to relevant work should be provided throughout the document and should either be numbered in the text with the same numbers in the bibliography or by using author names. Studies should also be compared to show the real strengths and weaknesses of the evidence for the various highlighted domains. Many of the biological or therapeutic mechanisms are presented in more simplistic/positive terms than the literature actually supports.

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