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Public Comments to the Interagency Autism Coordinating Committee (IACC)
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The Autism Society of America appreciates the opportunity to comment on the IACC's working draft Strategic Plan. We commend the Committee for recognizing that the needs of Autistic people and their families extend across the lifespan and beyond research alone, including health care, education, housing, employment, mental health, family supports, and quality of life. We also appreciate the plan's recognition of the diverse experiences and needs of Autistic people, including people with intellectual disability, high support needs, nonspeaking and minimally speaking individuals, people with co-occurring medical conditions, and underserved communities.

At the same time, the breadth of the draft raises significant concerns about prioritization, feasibility, and implementation. The plan encompasses a large number of priorities, initiatives, federal agencies, data systems, demonstrations, and implementation efforts that, taken together, represent an enormous federal undertaking.

Federal resources, staffing, infrastructure, and administrative capacity are limited. Many recommendations also depend on resources and capacity beyond federal coordination, including sufficient funding, housing, health care and mental health providers, direct support professionals, HCBS, respite, and other services. It is also unclear whether the federal government currently has the infrastructure, authority, data systems, funding, and interagency mechanisms necessary to implement the plan at the scale envisioned. The current federal policy environment further complicates these questions of feasibility. Significant changes to Medicaid, threats to the enforcement of the Olmstead decision and other disability rights protections, efforts to close or substantially restructure the Department of Education, and significant disruptions and uncertainty in federal grantmaking and program administration must be considered when assessing

what the federal government can realistically implement. Strategic planning should be grounded not only in the needs of the autism community, but also in the current federal capacity and policy environment.

We therefore recommend that the IACC narrow and prioritize the Strategic Plan around a manageable number of high-impact federal priorities. The final plan should distinguish between areas requiring immediate federal action, areas requiring additional research or infrastructure, and longer-term aspirations. Each priority should identify the responsible agencies, federal authority, resources, and measurable outcomes necessary for successful implementation.

Autism Society's Priority Areas

As the Committee considers how to prioritize the final Strategic Plan, the Autism Society recommends that the federal government focus on the following ten areas, listed in no particular order. These priorities do not represent an exhaustive list of the needs facing the autism community. Instead, they reflect the areas where we believe focused federal investment and coordination are most likely to produce meaningful improvements. We recognize that other areas identified in the draft are important; however, including every important issue as a federal priority would undermine the purpose of prioritization.

- **Behavior Supports, Challenging Behaviors, Self-Injury, Aggression, and Crisis Prevention:** Improve access to effective, person-centered supports that help prevent and respond to challenging behaviors, self-injury, aggression, and crises while promoting safety, dignity, and quality of life.
- **Healthcare Access, Coverage, Affordability, and Provider Capacity:** Ensure Autistic people can access affordable, high-quality healthcare with providers who are trained to understand and meet their needs across the lifespan.
- **Housing, Supported Living, Independent Living, and Community Integration:** Expand affordable housing and research into individualized supports that enable Autistic people to live as they deserve.
- **Mental Health and Co-Occurring Psychiatric Conditions:** Improve access to appropriate mental health services and research addressing psychiatric

conditions that commonly affect Autistic people, including providers equipped to deliver Autism-informed care.

- **Caregiver Supports, Respite, Family Navigation, Parent Training, and Succession Planning:** Strengthen supports that help families and caregivers navigate complex systems, access respite and training, and plan for long-term care and support.
- **Federal Autism Research Coordination, Data, and Surveillance:** Strengthen federal coordination, data systems, and surveillance to better understand the Autistic population, identify unmet needs, track outcomes, and guide effective research and policy.
- **Healthcare Navigation, Care Coordination, and Quality:** Improve coordination across healthcare and service systems so Autistic people and their families can more easily find appropriate providers, understand their options, and receive continuous, high-quality care.
- **Direct Support Professional Workforce:** Address the shortage, turnover, compensation, and training challenges facing direct support professionals who provide essential day-to-day assistance to Autistic people and others with disabilities.
- **Health and Service Disparities, Equity, and Access for Underserved Communities:** Identify and address disparities in diagnosis, healthcare, services, and supports (including communication supports), with particular attention to Autistic people and families who face additional barriers because of where they live, income, race, language, disability, or other factors.
- **Autistic Adults, Adult Services, Aging, and Later-Life Health:** Ensure federal Autism policy addresses the full adult lifespan, including access to health care, housing, employment, community living, long-term services and supports, safety, and aging-related needs, while building systems that support Autistic adults as they age.

These priorities reflect areas where the Autism Society sees particularly significant and persistent gaps across the lifespan and where stronger federal leadership could have meaningful impact for Autistic people and their families. They also reflect the need to balance research, health care, services, workforce capacity,

family support, and the infrastructure necessary to translate federal investments into meaningful improvements in people's lives.

Our priorities are not intended to suggest that other areas identified in the draft are unimportant. Rather, they reflect our view that the final Strategic Plan should make difficult choices about where limited federal resources can have the greatest impact.

Additional Praises and Concerns

Within that broader framework, the Autism Society offers the following additional observations about the draft.

Research and evidence. We support increased federal investment in autism research and a diversified portfolio that maintains important genetic research while exploring emerging areas of biology, co-occurring conditions, and services. The plan appropriately identifies gaps in epidemiology, data, and federal research coordination.

At the same time, the plan should distinguish between areas with established evidence and those where substantial uncertainty remains. Immune biology, folate metabolism, microbiome interventions, mitochondrial and redox biology, autonomic dysfunction, regression, motor planning, and network excitability represent different bodies of evidence and stages of development. We are not advising against biological research, but expansion should be held to rigorous standards of study design, replication, and meaningful inclusion of people with high support needs and diverse communication profiles. The portfolio should also maintain balance across biological, behavioral, cognitive, pharmacological, and implementation research.

Research should prioritize outcomes that matter to Autistic people and their families, including quality of life, participation, communication, independence, safety, caregiver burden, and treatment side effects, rather than focusing primarily on eliminating core characteristics of Autism.

Inclusion and individualized care. We support the plan's attention to populations historically underserved or excluded from research. Inclusion should extend

beyond identifying these populations in the text. People with high support needs, intellectual disability, limited communication, complex medical needs, and their caregivers should be meaningfully involved in developing and evaluating initiatives that affect them.

The plan should also place greater emphasis on individualized medical decision-making. Expanded evaluation should not imply that every Autistic person requires the same assessments. The final plan should address accessible testing and procedures, caregiver input, communication supports, trauma-informed care, and improved access to diagnosis for adults.

Mental health, trauma, and distressing behaviors. The plan should more fully recognize psychiatric, psychological, trauma-related, sensory, communication, and environmental contributors to distressing behaviors, including self-injury and aggression. These behaviors should not be viewed primarily through biological or neurological explanations. Trauma-informed, sensory-friendly, and communication-accessible care should be incorporated throughout the plan, including discussions of crisis prevention and regression.

Workforce and service capacity. Workforce capacity is a major implementation consideration throughout the draft. Many recommendations assume a workforce that does not currently exist at the necessary scale, particularly in health care, mental health, education, direct support, supported employment, and residential services.

The final plan should include a stronger workforce strategy, including a robust focus on the Direct Support Professional workforce. New standards, guidance, and action agendas will have limited impact without enough qualified professionals to implement them. The plan should also define what **"autism-competent"** care means across health care, mental health, education, crisis response, employment, and community services.

Federal navigation and family supports. We support efforts to make federal systems easier for families to understand and navigate. A centralized resource such as Autism.gov could provide valuable, accessible information and common-language roadmaps for major transition points.

However, navigation cannot substitute for increasing the availability and funding of HCBS, respite, housing, and other services. Given significant state variation in Medicaid, HCBS waivers, eligibility, provider networks, and waitlists, the federal government should focus on useful navigation tools and connections to state-specific resources rather than attempting to maintain comprehensive information about every local system. Families need both systems that are easier to navigate, and systems that have sufficient capacity to serve them.

Education and IDEA. We strongly support IDEA implementation, adequate federal special education funding, workforce capacity, and effective civil rights enforcement. We have concerns about creating new accountability structures where existing IDEA mechanisms may already provide an established framework.

We are also concerned that the draft is less evidence-based in its discussion of education savings accounts, vouchers, micro-schools, and autism-specific school-choice arrangements. Families using private-choice mechanisms may not retain the same procedural protections, accountability, inclusion opportunities, or entitlement to services available under IDEA. The final plan should not present school choice as a solution to public-system shortcomings without addressing selection, exclusion, segregation, provider qualifications, fiscal accountability, educational outcomes, and potential loss of IDEA protections.

Housing, employment, aging, and transportation. We support including housing, employment, aging, and transportation in a lifespan strategy because these areas are fundamental to independence, community participation, and quality of life.

These sections also highlight the broader feasibility challenge: federal coordination and demonstrations alone cannot create housing supply, resolve workforce shortages, or establish transportation systems. The final plan should identify where federal action can make a meaningful and achievable difference and what additional resources are needed.

Conclusion

The Autism Society appreciates the IACC's effort to develop a Strategic Plan that recognizes the full range of needs facing Autistic people and their families. We support the plan's direction, its lifespan approach, its attention to underserved populations, and its recognition that federal action must extend beyond research to the systems that determine whether people can access health care, education, housing, employment, community participation, and family supports.

However, a comprehensive plan should not become an unimplementable plan. The federal government cannot adequately fund, staff, coordinate, and execute every initiative included in the current draft. We therefore urge the IACC to make difficult but necessary choices and establish a focused set of priorities that can realistically be supported with available federal resources and authorities.

The Autism Society encourages the IACC to use the final Strategic Plan not simply as a comprehensive inventory of everything that matters to the Autism community, but as a focused roadmap for what the federal government can and should accomplish with the resources available. A more focused plan would provide clearer accountability, make federal investments more strategic, and increase the likelihood that the recommendations ultimately lead to measurable improvements in the lives of Autistic people and their families.