PUBLIC COMMENT ON THE INTERAGENCY AUTISM COORDINATING COMMITTEE (IACC) 2026–2028 STRATEGIC PLAN WORKING DRAFT

Submitted by: The Arc of Massachusetts and Advocates for Autism of Massachusetts

Introduction & Massachusetts Landscape

The Arc of Massachusetts and Advocates for Autism of Massachusetts appreciate the opportunity to provide comments on the Interagency Autism Coordinating Committee's (IACC) 2026–2028 Strategic Plan Working Draft. The Arc of Massachusetts advocates for the rights, inclusion, and well-being of individuals with autism and people with intellectual and developmental disabilities (IDD) across Massachusetts. Through our statewide network, we represent more than 250,000 individuals with autism and IDD and their families. We are also informed by our seventeen local chapters, who provide direct services to individuals across the state. AFAM is a division of The Arc of Massachusetts made up of 16 member organizations dedicated to autism advocacy, programming and services.

Below are public comments submitted by Maura Sullivan, Chief Executive Officer of The Arc of Massachusetts and a parent of two young adults with autism, pairing our key strategic priorities with crucial policy recommendations and community insights from the Profound Autism Alliance, Catherine Boyle (Autism Housing Pathways and parent), and Jillian Eisloeffel (Founder, *Bobby's World Profound Autism Advocacy*).

From the perspective of The Arc of Massachusetts, we are witnessing a significant surge in need across our commonwealth. We are seeing greater numbers of individuals entering adult services alongside a significantly higher acuity of need—particularly within the autism population, where more individuals present with profound autism, complex medical profiles, and challenging behaviors. Furthermore, for autistic individuals without a co-occurring intellectual disability, funding remains severely limited despite a sharp rise in acuity surrounding mental health supports, housing, and urgent long-term planning when aging parents are no longer able to provide care.

Although we have a robust medical school and health professional education programming in our state (The Arc's Operation House Call), we continue to face long dental waitlists and significant systemic and attitudinal barriers to care. These healthcare challenges are compounded by a massive workforce shortage—impacting access to day, residential, transportation and home-based services and programs—driven by inadequate pay rates, limited training and career pathways, and federal immigration restrictions that have severely disrupted adult service delivery. Compounding these systemic crises, states are

already facing severe Medicaid cuts. Massachusetts is feeling these cuts directly in Home and Community-Based Services (HCBS) such as Personal Care Attendant (PCA) and Adult Family Care (AFC) programs. These are vital lifelines for autistic individuals and their families. Federal leadership must halt these devastating cuts to Medicaid programs by turning around the massive federal reductions enacted under OB3.

We commend the Committee for developing a Strategic Plan that reflects a broader understanding of autism as a lifelong condition. We particularly appreciate the increased emphasis on adult services, transition supports, housing, caregiver supports, workforce development, and the needs of individuals with profound autism, co-occurring conditions, and complex support needs. This plan also represents an important shift towards greater federal accountability by proposing measurable goals and public reporting mechanisms. We also appreciate the Committee's decision to expand the public comment period from four days to thirty days. Meaningful stakeholder engagement is essential to developing a Strategic Plan that reflects the experiences of autistic individuals, families, providers, researchers, and advocates.

Just as importantly, we encourage the Committee to recognize that these goals cannot be achieved through planning alone. The success of this Strategic Plan will depend on sustained federal investment in Medicaid, home and community-based services, the Direct Services Professional workforce, and other programs that enable individuals with autism to live, work, and thrive in their communities.

While we commend these strengths, we strongly urge the IACC to elevate the following concerns as paramount federal priorities across the draft.

<u>Structural & Process Recommendations for the Draft Plan</u>

(Reflecting the Profound Autism Alliance's Core Recommendations)

Standing Public Drafting Process & Pre-Finalization Workshop: Modeled on the national Alzheimer's plan, we urge the IACC to utilize a standing, public drafting process with subcommittees reporting in the open, alongside a public interactive workshop before finalization.

Plain-Language Standards: We call on the plan to meet federal plain-language standards and provide an open public comment period prior to committee voting.

Funding for CMS & Model HCBS Waiver: CMS must be fully resourced to execute its initiative list. To address 7- to 18-year waitlists for home and community-based services,

we recommend that the federal government issue a model HCBS waiver template designed specifically for profound autism.

Dedicated Budget Line and Section for Profound Autism: Although referenced 45 times in the draft, profound autism currently lacks a dedicated section or funding line. The CDC estimates that 26.7% of 8-year-old autistic children have profound autism, yet a 2019 study showed only 6% of clinical research included participants with profound autism. We believe the plan must establish a dedicated section and explicit budget allocation.

Adopt Delphi Consensus Definition: We recommend that the plan adopt the peer-reviewed Delphi expert consensus definition (*Molecular Autism*, June 2026), which includes intellectual disability as a qualifying pathway.

Direct Support Professional (DSP) Workforce & Continuity of Access

Life Course Domain V (p. 220) & Life Course Domain VI (pp. 224–230)

DSP Career Pathways & Hour Tracking: We emphasize that strengthening the direct-support workforce requires paid training, portable credentials, competitive compensation, and pipelines through vocational and healthcare programs. Additionally, we urge federal oversight to measure *authorized service hours* against *hours actually delivered* to reveal where staffing shortages prevent authorized care from reaching families.

Ending Redundant Redeterminations: Under Initiative 5 (p. 227), we urge the IACC to work with CMS to eliminate repetitive administrative eligibility reviews for individuals with documented lifelong disabilities, preventing unnecessary disruptions in Medicaid, home-based services, and healthcare access.

Lifespan Communication Supports & Adult Provider AAC Training: Individual communication supports provided during school-age years often dissolve during the transition to adult services. We recommend federal guidelines requiring adult service providers and Direct Support Professionals (DSPs) to receive specialized, speech-language pathologist (SLP)-designed training on supporting individual communication styles, ensuring continuous access to preferred communication tools across the entire adult lifespan.

Closing the Support Gap for Autistic Individuals Without Intellectual Disability: Autistic individuals without a co-occurring intellectual disability (ID) face a dangerous "support cliff." Excluded from traditional developmental disability eligibility frameworks, this population encounters severe gaps in housing, case management, and mental health care—factors that drastically increase risk for psychiatric hospitalization and suicidality.

Federal HCBS guidance must encourage states to establish service eligibility based on functional need and mental health acuity rather than IQ or ID diagnosis alone. We urge the IACC to recommend targeted federal research and emergency crisis response models that explicitly address suicide prevention, sensory-safe crisis stabilization, and trauma-informed mental healthcare tailored to autistic communication styles.

Healthcare Equity, Diagnostic Protocols, and Workforce Training

Life Course Domain I (pp. 183–192) & Domain IV (p. 210)

Addressing diagnostic overshadowing—where acute medical issues or pain are mistakenly presumed to be "just autism"—requires both systemic clinical pathways and mandatory workforce preparation.

Health equity must also be addressed across racial, ethnic, and socioeconomic lines. Racially and ethnically marginalized children and adults and those in low-income families can face compounded barriers to timely developmental surveillance, screening, and accurate diagnosis. The IACC should explicitly recognize these disparities and support strategies that improve equitable access to culturally responsive support systems.

Standardized Healthcare Training via Operation House Call (OHC): Diagnostic protocols alone cannot succeed if clinicians lack foundational training. We recommend that federal guidelines advocate for integrating standardized healthcare curricula—modeled on **The Arc of Massachusetts' Operation House Call (OHC)**—across medical, nursing, dental, and allied health education. By engaging families and self-advocates as paid educators, OHC builds provider confidence, addresses attitudinal barriers, reduces implicit bias, and embeds two foundational clinical concepts:

- **Combating Diagnostic Overshadowing:** Explicitly training future providers to look beyond an autism diagnosis when an individual experiences acute functional decline, sleep disturbance, or behavioral shifts, ensuring underlying medical, gastrointestinal, or neurological issues are thoroughly investigated.
- **Understanding Behavior as Communication:** Teaching clinicians that distressed behaviors, self-injury, or agitation are often the primary means of communicating unmet physical needs, pain, or severe sensory overload—especially for nonspeaking individuals.

Procedural Access and Safe Sedation: As highlighted by community advocates, diagnostic pathways must account for individuals with profound autism who cannot safely

tolerate testing. We urge that clinical guidelines explicitly address accessible protocols for sedation or anesthesia during MRIs, EEGs, blood draws, and dental procedures.

Sensory-Adapted Emergency & Crisis Protocols: Autistic individuals in distress face prolonged emergency department boarding in environments (high noise, bright lights, lack of routine) that exacerbate crisis states. We call for federal recommendations to mandate sensory-adapted emergency room pathways and require clinicians to screen for physical pain, catatonia, or seizure activity before classifying an acute presentation solely as a psychiatric crisis.

Housing Supply and Sustainable Models

Life Course Domain V — Housing Supply, Supported Living, and Caregiver Succession (pp. 217–223)

While the draft correctly identifies the severe housing shortage, we emphasize that its primary focus on Section 811 omits critical federal tools and community-led solutions.

Expanding Portable Vouchers: Section 811 Project Rental Assistance (PRA) is tied to multi-family units and capped at 25% occupancy for individuals with disabilities. To create real mobility and group-living options, we recommend that the IACC call for new federal funding for portable Mainstream vouchers and Non-Elderly Disabled (NED) vouchers.

Replicating Family-Built Housing Models: As emphasized by Catherine Boyle and advocates across the country, families are creating innovative housing models out of necessity. Under Initiative 5 (p. 220), we recommend that federal demonstration programs study, document, and scale these family-built models—evaluating financing structures, operating costs, and Medicaid frameworks while strictly preserving individual choice across all support levels.

Detailed Feedback on the Working Draft

Part I: A New Federal Framework for Autism

We strongly support the plan's efforts to rebalance federal priorities by directing greater attention to services and supports across the lifespan, particularly for transition-age youth and adults. The recognition that federal investments must better reflect the realities of housing shortages, workforce instability, caregiver needs, and the growing population of autistic adults is an important shift. We also appreciate the recognition of the severe shortage of Direct Support Professionals (DSPs) and its commitment to improving accountability through measurable performance indicators and public reporting.

However, the Strategic Plan also acknowledges an important limitation: the IACC remains an advisory body without the authority to require federal agencies to implement recommendations. Without stronger mechanisms for accountability, many of the plan's recommendations may not be implemented. We encourage the Committee to identify additional strategies to promote implementation across federal agencies, including strong coordination, clearer agency commitments, and recommendations for changes where appropriate.

We also encourage the Committee to strengthen transparency throughout future Strategic Plan development. Given the important role that this document plays in informing federal priorities, future plans should be developed through a more open public process that includes more opportunities for engagement throughout drafting. Public workshops and opportunities for ongoing input would improve transparency and help ensure that the final plan reflects the diverse perspectives of the autism community. In addition, the final Strategic Plan should be revised in a way that is more accessible for autistic individuals, family caregivers, and community members to read.

Parts II-IV: Research, Precision Infrastructure, and Therapeutic Priorities

We appreciate the IACC's recognition that the growing prevalence of autism has significant implications for service systems, and that this reality should be matched by increased federal investment in needed supports and services. We also strongly support the expanded focus on co-occurring medical conditions including gastrointestinal disorders, epilepsy, sleep disorders, mental health conditions, and other issues that significantly impact quality of life for many individuals with autism, which have been overlooked for far too long.

The emphasis on improving medication safety, reducing unnecessary polypharmacy, and ensuring that research measures functional outcomes, including communication, participation, and quality of life is particularly important.

Research priorities should also address disparities across the lifespan. Autistic adults of color, women, nonspeaking individuals, and people with co-occurring intellectual disabilities may experience delayed or missed diagnosis and consequently reduced access to lifelong services and home and community-based supports. The IACC should prioritize research that examines how race, gender, socioeconomic states, and co-occurring health conditions intersect over the lifespan.

The IACC should also promote equitable representation in research by addressing the overrepresentation of white and higher-income participants in autism studies. Research on culturally adapted diagnostic tools, mobile health screening, and telehealth should be

designed to reduce barriers for medically underserved urban and rural communities and should evaluate whether these approaches improve access and quality of care across diverse populations.

At the same time, we encourage the IACC to maintain an appropriate balance between biomedical research and investments in proven community-based supports. While continued scientific discovery is important, it must not come at the expense of urgently needed investments in housing, home and community-based services (HCBS), employment supports, caregiver assistance, and the Direct Support Professional (DSP) workforce.

Likewise, the proposed National Autism Precision Therapeutics Initiative (NAPTI) should explicitly include evidence-based interventions, environmental supports, communication supports, and other community-based approaches alongside biomedical research. Many of the greatest improvements in quality of life result not only from medical advances but also from accessible services and effective community supports.

Part V: Life Course Supports

The Life Course section is a very strong part of the Strategic Plan. We support the Committee in recognizing that individuals with autism require coordinated supports throughout childhood, adulthood, and later life, and for addressing many of the barriers families encounter every day.

We strongly support the proposed Autism.gov as a centralized navigation resource for families and individuals. If implemented well, it has the potential to significantly reduce the complexity of navigating federal and state systems. We encourage the Committee to ensure that the portal is fully accessible, incorporates plain language, supports diverse communication methods, and is available in multiple languages.

We also strongly support efforts to improve timely diagnosis, expand communication access for nonspeaking individuals, improve crisis response systems, address housing shortages, strengthen caregiver supports, expand employment opportunities, and improve services for older autistic adults.

Caregiver supports must similarly reflect the realities of family caregivers, particularly those who are older. The IACC should recognize the growing number of autistic adults who remain at home with aging parents and the need for person-centered transition planning before a caregiver can no longer provide support. The plan should support pathways for paid family caregiving and other supports to help families maintain stability while expanding access to sustainable community-based options.

We also appreciate that the plan recognizes the importance of ensuring that new housing models comply with the federal Home and Community-Based Services (HCBS) Settings Rule, including the heightened scrutiny process for settings with institutional characteristics. Recognizing heightened scrutiny is an important step toward protecting community integration while supporting innovative growth and access to high quality, sustainable housing opportunities.

Several sections, however, would benefit from revisions:

Workforce Quality: While the Strategic Plan appropriately recognizes the Direct Support Professional workforce crisis, we encourage the Committee to place greater emphasis on workforce quality in addition to capacity. Expanding the workforce must also include improving training, competency, retention, and service quality. Individuals with autism and complex support needs deserve a well-trained workforce capable of providing high-quality, person-centered supports across the lifespan.

Special Education & IDEA Protections: We are deeply concerned by the inclusion of parent-directed school choice as a recommended policy option within the Special Education domain. Voucher and privatized school choice programs frequently fail to provide the procedural safeguards guaranteed under the Individuals with Disabilities Education Act (IDEA), including individualized education programs (IEPs), civil rights protections, and accountability requirements. These programs also risk diverting limited public resources away from the public education system that serves most students with disabilities. We respectfully urge the Committee to remove this recommendation from the final Strategic Plan.

Protecting Individual Communication Rights: Although the plan appropriately recognizes communication as a fundamental civil right, we encourage funding support for communication across the lifespan. Children and adults need access to these supports and service providers need training on these critical communication support systems, such as AAC.

Key Recommendations

1. **Ensure a robust, well-trained, and supported workforce**: The stability of the DSP workforce is crucial to every other priority mentioned here. Specifically helping to address the “service cliff” when individuals turn 22 years old. Competitive compensation, training, and bolstering the pipeline of qualified and passionate staff is key to reducing waitlists and increasing access to and quality of programs.

2. **Mandate Healthcare Equity Curricula:** Recommend national implementation of family-led clinical training programs, structured like *Operation House Call*, across medical, dental, and nursing school curricula to directly target diagnostic overshadowing, teach behavior as communication, and eliminate health disparities.
3. **Expand HUD Housing Vouchers:** Explicitly advocate for renewed federal awards for portable Mainstream and Non-Elderly Disabled (NED) vouchers alongside Section 811 reforms.
4. **Curtail Medicaid cuts to disability programs and expand access to Applied Behavior Analysis** for adults over 21 years old.
5. **Streamline Lifelong Disability Redeterminations:** Direct CMS to establish simplified renewal processes for individuals with permanent, established disability profiles to ensure continuous access to care.
6. **Establish Dedicated Funding & Standards for Profound Autism:** Formally adopt the Delphi consensus definition, allocate a dedicated budget line/section for profound autism, link claims to sources, and publish a model HCBS waiver template.
7. **Formalize Procedural, Emergency, and Suicide Prevention Protocols:** Expand diagnostic guidelines to include standardized sedation/anesthesia access for routine medical procedures, sensory-adapted emergency room protocols, and specialized suicide prevention pathways for individuals in acute mental health distress.
8. **Prioritize Functional Exercise for Longevity and Health:** Recognize functional exercise and motor maintenance not merely as recreational activities, but as a medically necessary component of health and physical/mental wellness to maintain mobility and prevent functional decline as individuals age.
9. **Study Innovative Housing, Day, and Vocational Supports:** Study existing innovative housing models that provide community integration, safety, workforce supports and sustainability for people with autism and their families.
10. **Expand Specialized Oral Health and Hospital OR Access:** Address critical oral health disparities by incentivizing hospitals and ambulatory centers to dedicate Operating Room (OR) time and specialized anesthesia teams to eliminate multi-year waitlists for specialized dental procedures.
11. **Ensure Lifespan Communication Supports & Adult Provider Training:** Mandate access to individualized communication supports across the lifespan and require SLP-designed provider training to ensure communication continuity into adulthood.
12. **Expand Services for Autistic Individuals Without Intellectual Disability:** Direct CMS and federal agencies to update eligibility frameworks so that individuals with autism but no co-occurring ID can access HCBS waivers, mental health supports, housing, and suicide prevention services based on functional need.

13. **Recognize the Growing Number of Autistic Adults who Remain at Home with Aging Parents,** including those with complex challenging behaviors and co-morbid conditions, who require additional supports. Also recognize the need for person-centered transition planning before a caregiver can no longer provide support. The plan should support pathways for paid family caregiving and other supports to help families maintain stability while expanding access to sustainable community-based options.
14. **Eliminate Systemic Disparities Across the Lifespan**: Direct federal agencies to address compounded racial, ethnic, and socioeconomic disparities across the entire autism continuum—from delayed screening and diagnosis, to unequal access to lifelong community services and healthcare, to the historical overrepresentation of white, high-income participants in clinical research.
15. **Mandate Robust Training for Police, Fire, EMT, and mobile crisis providers. Roll out "Blue Envelopes**" for autistic drivers and passengers nationally.

Conclusion

The Arc of Massachusetts and Advocates for Autism of Massachusetts appreciate the IACC developing a Strategic Plan that meaningfully expands the federal conversation beyond diagnosis and research to include services and supports across the lifespan. The increased focus on accountability, adult services, communication access, caregiver supports, housing, employment, and individuals with significant support needs represent substantial progress.

As the Committee finalizes the Strategic Plan, we encourage continued stakeholder engagement through an accessible and transparent process. A revised, more accessible version of the Strategic Plan would help ensure that individuals with autism, caregivers, and community organizations can meaningfully engage with the federal policies that affect their lives.

Thank you for the opportunity to provide comments.

Sincerely,

Maura Sullivan
Chief Executive Officer, The Arc of Massachusetts
On behalf of The Arc of Massachusetts & Advocates for Autism of Massachusetts