Public Comment on the IACC Working Draft Strategic Plan 2026–2028 August 20, 2026

The Profound Autism Alliance is committed to the recognition of the unique challenges that people with profound autism and intellectual disability experience. Our mission is to improve their health and connection through inclusive research and focused advocacy that will result in meaningful services and supports.

The Working Draft reflects a great deal of hard work by the Committee, and we're glad to see urgency and action prioritized throughout. We offer the suggestions below in that same spirit, hopeful they can help this Plan reach its full potential.

1. A Critical Window

The American Psychiatric Association's committee on the future of the DSM has already formed active subcommittees and published a formal roadmap in January 2026.[1] Whatever that process ultimately produces will depend on the evidence base available to it. A coordinated body of research on profound autism needs to exist now, while that process is still underway, not after it has already moved forward without one.

This Plan has the chance to help build the body of research this population has waited for. Profound autism is named throughout the Plan, across nearly every domain. It even anchors the Plan's own central funding-justification argument in Part I, built around a stated $2.4 million lifetime cost per individual.[2] But it never becomes its own line item in any budget or initiative table, and has no integrating domain or accountability owner anywhere in the Plan. A research definition only becomes a usable clinical diagnosis through coordinated work, consistent assessment tools, and a shared evidence base.

Additionally, the Committee's April 2026 vote adopted a functional-only definition, with no intellectual disability criterion. But a committee vote isn't scientific consensus. Our organization, with the Autism Science Foundation, co-funded a formal Delphi consensus study on this exact question, published in Molecular Autism in 2026, which reached 76 percent consensus among 137 researchers, clinicians, caregivers, and autistic individuals. IQ below 50 is included as a qualifying pathway alongside minimal verbal communication, not as a replacement for it.[3]

Recommendation: Give profound autism its own dedicated domain, with a named budget line and accountability owner, and adopt the Delphi consensus definition already available to the Committee.

2. Transparency and Inclusion

This Working Draft was developed without any open, publicly noticed working group or subcommittee meeting, a departure from the transparency the Federal Advisory Committee Act requires of IACC meetings.[4]

At 336 pages, this draft runs three to four times longer than comparable federal plans, like the National Plan to Address Alzheimer's Disease (93-109 pages) and the National HIV/AIDS Strategy (about 90 pages), and in far denser, more technical language than either.[5] Appendix C lists 727 sources, but none are linked to any specific claim anywhere in the text, so there's no way to trace what's actually behind any given recommendation, or verify who connected it to its source.[6]

Additionally, a plan this consequential, for a population that includes many people with intellectual and learning disabilities themselves, must be written so the people it's about can read it, and so the public can see how it was made.

Recommendation:

Before this Plan goes to a vote, the Committee must:

- Link citations to the specific claims they support.
- Provide a plain language version, as required by the Plain Writing Act of 2010.[7]

For future cycles, we also ask that drafting sessions happen in the open.

Without these, this Plan excludes the very people it is meant to serve.

3. Budget

The dollar figures in this Plan are labeled "order-of-magnitude planning ranges."

The breakdown, from page 256:[8]

- National Neurodevelopmental Regression Initiative: $57 million
- NAPTI and all 11 Priority Therapeutic Domains combined: $270 million
- CDC surveillance: $20 million
- HRSA diagnostics workforce: $10 million

We are concerned that, of the Plan's nine Life Course Domains, only Diagnosis has a dollar figure. The other eight, including every domain where profound autism is named as a priority population, show zero.

Housing is a particular concern. It has no dollar figure anywhere, even though it says some of its own tools "require congressional action or appropriations," despite the Plan's rationale for giving Part V no new dollars, which states that these domains "can be carried out without new appropriations."[9] This is especially concerning given the 2025 federal reconciliation law's estimated $911 billion cut to Medicaid, the very authority this section leans on.[10] It's also worth noting that farmstead communities were settled as not an isolated setting by CMS years ago, under its HCBS Settings Rule.[14]

Recommendation: Bring the budget for the Life Course Domains in line with the budget already given to the research domains.

4. Swift Action

More than 600,000 people nationally are already on Medicaid HCBS waiting or interest lists, according to KFF, with waitlists in 41 states.[11] Many of these are people with profound autism.

In 1981, the Reagan administration acted quickly and decisively to help one specific population in crisis. It granted Katie Beckett an individual Medicaid waiver so she could receive care at home instead of in a hospital, a case Congress later built into permanent law.[12]

Recommendation: Act with the same speed and focus for people with profound autism, through a funded Medicaid Home and Community-Based Services waiver that gets them off waitlists and into the services that work best for them.

Finally, we want to acknowledge meaningful progress in the Plan, and thank the Committee for it:

- Profound autism's acknowledgement throughout the document is meaningful, and we're glad to finally see it addressed directly.
- The Housing domain's Initiative 2 recommends a national heightened-scrutiny definition, consistent with civil rights protections, that would prevent institutionalization while still allowing individually appropriate living situations chosen through person-centered planning.[13]

We'd welcome the chance to work with the Committee on any of these points.

Thank you for considering this comment, and for all you do on behalf of this community.

Sincerely,

Judith Ursitti

Cofounder and President, Profound Autism Alliance

Sources

[1] American Psychiatric Association, Future DSM Strategic Committee, roadmap and subcommittee structure announced January 2026.

[2] IACC Working Draft Strategic Plan 2026–2028, Part I.

[3] Siegel M, Lord C, Tager-Flusberg H, et al. "Delphi consensus definition of profound autism." Molecular Autism. 2026; IACC, Attachment C, April 2026 meeting materials.

[4] Federal Advisory Committee Act, Public Law 92-463.

[5] National Plan to Address Alzheimer's Disease, recent annual updates; National HIV/AIDS Strategy, 2022-2025.

[6] IACC Working Draft Strategic Plan 2026–2028, Appendix C.

[7] Plain Writing Act of 2010, Public Law 111-274.

[8] IACC Working Draft Strategic Plan 2026–2028, pp. 256-257.

[9] IACC Working Draft Strategic Plan 2026–2028, Housing domain (Life Course Domain V), p. 217, Initiative 5.

[10] Congressional budget reconciliation law (H.R. 1, 2025); KFF and McKnight's Home Care, analysis of Medicaid home care impacts, 2026.

[11] KFF, Medicaid home and community-based services waiting list data, 2025.

[12] Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), codifying the Katie Beckett Medicaid eligibility option.

[13] IACC Working Draft Strategic Plan 2026–2028, Housing domain, Initiative 2.

[14] 42 C.F.R. § 441.301; Centers for Medicare and Medicaid Services, "Guidance on Settings that have the Effect of Isolating Individuals Receiving HCBS from the Broader Community," 2014.