CommunicationFIRST
Because communication is a human right.

Comments of CommunicationFIRST to the Interagency Autism Coordinating Committee in Advance of its November 20, 2026 Meeting

Submitted November 16, 2026
via IACCPublicInquiries@mail.nih.gov

CommunicationFIRST appreciates the opportunity to submit the following comments to the Interagency Autism Coordinating Committee ("IACC" or the "Committee") in advance of the Committee's meeting to discuss the Summary of Advances.

CommunicationFIRST is the only organization led by and for and dedicated to the rights and interests of the estimated 5 million people in the United States who must rely on communication tools and supports to be heard and understood due to speech disabilities and conditions. CommunicationFIRST is a cross-disability organization, seeking to represent children and adults who are born with, acquire, or experience intermittent speech-related disabilities. Autistic people with expressive communication disabilities comprise a large segment of our constituency, along with people who experience aphasia, rare genetic syndromes, ALS, Down syndrome, traumatic brain injuries, and other conditions. We advance our mission by educating and engaging the public, advocating for policy and practice change, and working within the legal system to protect rights and advance systemic change. More information about CommunicationFIRST's work is available at www.communicationfirst.org.

I. Summary of Advances

We are unable to provide any meaningful feedback on the items to be considered for the Summary of Advances because meeting materials, including a list of such items, have not been posted to the website in advance of the comment deadline.

In general, we urge the Committee to prioritize high-quality, credible, peer-reviewed research that can immediately be translated into improved supports for the autistic community, particularly those with speech-related disabilities.

II. Requests Regarding Strategic Plan Implementation

We write to urge the Committee to meaningfully address our previous comments, submitted in April and August, 2026, during the course of its implementation of the Strategic Plan. A copy of those comments is attached.

A. Direct meaningful research funding towards communication and other service needs

In particular, we urge the Committee to clarify to grantmaking agencies that its budgetary recommendations concerning the Priority Therapeutic Domains and National Autism Precision Therapeutics Initiative were not intended to replace spending on other critical research topics, including but not limited to communication and mental health. The recently-approved Strategic Plan classifies these topics as "Life Course Domains" that are "principally about deploying and scaling existing authorities, services, and infrastructure rather than maturing new biology."[1] It is critical that all of these domains *also* be included in funding for new research.

While we appreciate that the Committee chose to amend the Strategic Plan to set a $12 million target for research on communication, this should be the floor, not the ceiling. Research to understand and address the communication needs of autistic people should be a top research priority, not an afterthought.

We also urge the Committee to clarify that agencies that receive CARES funding, such as the National Institutes of Health (NIH), may also fund critical research priorities that the original Strategic Plan assigned to entities without CARES funding. Many activities concerning Life Course Domains, including the domain focused on communication, are assigned to such agencies, including the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and Administration on Community Living (ACL).

B. Clarify objectives related to communication-related research

Our comments on the Strategic Plan also requested clarification on communication-related research objectives, which we hope that the Committee can still provide. For example, while

[1] Interagency Autism Coordinating Comm., 2026 IACC Strategic Plan for Autism 177 (Draft July 17, 2026), https://iacc.hhs.gov/meetings/iacc-meetings/2026/full-committee-meeting/july/IACC%20Strategic%20Plan%20Working%20Draft%20July%2017.pdf.



we support research to explore which communication-related interventions are most likely to work for people with different needs—including which are most likely to work for people with significant motor impairments—we believe it is critical that this research is not used to gatekeep or otherwise exclude supports from entire categories of people. We urge that the needs of people with speech-related disabilities be meaningfully addressed across all domains—including mental health, employment, housing, and life course/aging.

C. Focus on specific disability-related needs rather than on stigmatizing "catch-all" categories, such as "profound autism"

Finally, we reiterate our strong concerns about the use of "profound autism" as a label for autistic people with speech-related disabilities. Such labels are often used to stigmatize and underestimate the capabilities and potential of people with speech-related disabilities. A recent study, available now as a pre-print, found "no evidence supporting 'profound autism' as a biologically distinct phenotypic group," but *did* identify biomarkers "distinguishing nonspeaking and speaking autistic children."[2] This emerging evidence further supports our position that a "profound autism" category lumping people with speech-related disabilities together with others who are in need of intensive supports does not further the goals of precision research.

As we noted in our earlier comments, **we believe that accountability and transparency are better served through use of *several* overlapping categories to describe under-recognized areas of need**, such as autistic people with significant 1) expressive communication disabilities, 2) sensorimotor disabilities, 3) and cognitive disabilities, 4) co-occurring medical conditions, and 5) safety-related needs. This will help ensure transparency regarding the resources devoted to people in need of significant supports, while avoiding stereotypes and recognizing the diversity of the autistic population.

If the Committee still wishes to create a single category to describe people in need of the most supports, it should use terminology such as "people requiring intensive or lifelong support." The Committee should also make it clear that it includes all people with *at least one* characteristic resulting in a need for intensive or lifelong support. Moreover, it should frame this category as a means of prioritizing research towards the populations with the highest support needs, rather than as a distinct "subtype" of autism.

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[2] Tara Eicher, Ari Ne'eman & John Quackenbush, *Genomic, Transcriptomic, and Regulomic Analyses Do Not Support Profound Autism as a Distinct Biological Category* (bioRxiv, Working Paper No. 2026.06.01.729392v2, 2026), https://www.biorxiv.org/content/10.64898/2026.06.01.729392v2.



III. Improvements In Public-Facing Communications

We also reiterate our concern about continuing gaps in public-facing communication and opportunities for public feedback. Once again, on the deadline to submit comments, materials for the coming meeting and an agenda have yet to be posted. Without access to the materials under consideration, we have no opportunity to provide feedback on items to be considered for the Summary of Advances. Without an agenda, we have no opportunity to provide feedback on any other topics that may be discussed in the upcoming meeting.

IV. Portfolio Analysis

We reiterate our call to publish a meaningful Portfolio Analysis that can be easily compared with previous Portfolio Analyses. Such analyses are required by statute and help us track federal support for research on topics important to our community. The brief, AI-assisted analysis appended to the Draft Strategic Plan falls far short of the detailed information provided by previous Portfolio Analyses, does not allow us to track trends over time, and does not allow us to track different agencies' contributions to research on each topic. Without review by human experts, AI-assisted analyses may also include misclassification errors.

Thank you for the opportunity to provide comment. Any questions may be directed to info@communicationfirst.org.

ATTACHMENT

CommunicationFIRST
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Comments of CommunicationFIRST to the Interagency Autism Coordinating Committee in Advance of its August 27, 2026 Meeting

Submitted August 20, 2026
via IACCPublicInquiries@mail.nih.gov

CommunicationFIRST appreciates the opportunity to submit the following comments to the Interagency Autism Coordinating Committee ("IACC" or "the Committee") on the Committee's Draft 2026-2029 Strategic Plan and on other concerns related to the Committee's business.

CommunicationFIRST is the only organization led by and for and dedicated to the rights and interests of the estimated 5 million people in the United States who must rely on communication tools and supports to be heard and understood due to speech disabilities and conditions. CommunicationFIRST is a cross-disability organization, seeking to represent children and adults who are born with, acquire, or experience intermittent speech-related disabilities. Autistic people with expressive communication disabilities comprise a large segment of our constituency, along with people who experience aphasia, rare genetic syndromes, ALS, Down syndrome, traumatic brain injuries, and other conditions. We advance our mission by educating and engaging the public, advocating for policy and practice change, and working within the legal system to protect rights and advance systemic change. More information about CommunicationFIRST's work is available at www.communicationfirst.org.

We write in support of several aspects of the Committee's Draft Strategic Plan and agenda, while requesting changes to others. We appreciate the Committee's strong commitment to increased access to communication supports and better recognition of the needs of autistic people with speech-related disabilities. On the other hand, other proposals may negatively affect our community or may inadequately address our needs. We also suggest that the plan be restructured to provide greater transparency into the drafting process, realistic targets relative to program funding, and greater visibility into funding practices over time.



For the purposes of these comments, all references to a page number, unless otherwise specified, is a reference to the page of the Draft Strategic Plan released by the IACC in July 2026. All references to specified sections are references to sections of these comments.

I. Recommendations Regarding the Strategic Plan

We appreciate that the Draft Strategic Plan includes numerous specific recommendations regarding access to communication, including "Life Course Domain III: Improving Communication and Access for Nonspeaking and Minimally Speaking Autistic Individuals." Nevertheless, we urge several revisions to better serve the needs of autistic people with speech-related disabilities.

A. Create specific targets for research funding related to communication outside of the Priority Therapeutic Domains.

Changes requested:

1. Provide comprehensive funding targets for all topics of research funded through CARES, including communication
2. Restructure the Strategic Plan such that communication is framed as a research topic in itself, rather than simply as a life course domain
3. Ensure that high-priority research relevant to communication is assigned to agencies receiving CARES funding

Rationale

Our greatest overarching concern is ensuring robust funding for research related to the needs of people with speech-related disabilities. Although speech-related disabilities are addressed at various points throughout the Draft Strategic Plan, the only concrete, immediately-actionable funding recommendations appear to relate to the twelve Priority Therapeutic Domains, all of which appear to be biomedical in focus and none of which fully addresses the needs of people with speech-related disabilities. Although some of these Domains—particularly Domain 10, regarding motor planning—have real relevance to many people with speech-related disabilities, they do not account for the full range of communication research priorities.



We are particularly alarmed by the suggestion on page 68 of the Draft Strategic Plan that the funding targets attached to these Priority Therapeutic Domains is meant to account for the large majority of the NIH's funding for autism research, at a total of $270 million out of the existing $306 million in funding that it receives through the Autism CARES Act (p. 256) - approximately 88% of existing appropriations.

Although we recognize that the Committee is recommending that funding to NIH be increased to over $600 million, the IACC provides no clear contingency plan for how existing funds should be allocated if Congress fails to increase its appropriation. In the absence of clear direction, there is a meaningful possibility that this Draft Strategic Plan will be read as suggesting that nearly 90% of NIH funding be allocated towards the Priority Therapeutic Domains, to the exclusion of other research that is relevant to people with speech-related disabilities. This includes exploratory research on issues that the Committee itself identified as not adequately researched, such as "how partner training, coaching, motor support, regulation, proximity, pacing, environmental structure, and fading of support affect communication outcomes over time" (p. 202), and evaluating "emerging technological approaches . . . for use in functional communication and as diagnostic tools, outcome measures, tracking tools, and as potential strategies for interventions" (p. 205).

Moreover, although some of the Priority Therapeutic Domains include goals relevant to communication, we remain concerned that the Priority Therapeutic Domains are overly narrow and that communication itself has been relegated to the section on "Life Course Domains," which are described as "deploying and scaling existing authorities, services, and infrastructure rather than maturing new biology." It is simply not the case that communication-related disabilities among autistic people are sufficiently well understood that these needs can be addressed simply by deploying and scaling existing infrastructure. The core research agenda itself should fully address all research priorities relevant to autistic people, including building a comprehensive understanding of both the causes of communication challenges and effective interventions.

Nonspeaking autistic people deserve research, *funded through Autism CARES*, to help identify new supports, develop and evaluate best practices, and track outcomes. While we support access to effective communication regardless of specific modality, it still matters which interventions are most likely to result in improvements in access to the full range of communication, literacy, quality of life, and self-determination.



Research can also help understand the range of underlying concerns that can affect access to communication, as well as why different communication supports work well for some nonspeaking autistic people but not others. This lack of high-quality research can present a major barrier to meaningful communication access, as without this understanding nonspeaking people are frequently offered augmentative and alternative communication (AAC) supports that do not work for them and written off when they fail to benefit from those supports.

For example, we note that the Committee outlines in Life Course Domain III (Communication) several areas where additional research is needed - such as achieving a better understanding of the role of the presence of familiar people in helping people self-regulate and access communication supports. This should be a priority for research; however, research on this topic does not appear to fit clearly within any of the existing proposed Priority Therapeutic Domains. Similarly, NIH is listed as the lead for Initiative 5 (Precision Research) and Initiative 7 (Leveraging Emerging Technology) within this Life Course Domain, but these initiatives do not map clearly onto any of the Priority Therapeutic Domains and therefore have no funding earmarked towards them through the Draft Strategic Plan.

Additionally, many activities concerning the Life Course Domains, including the Domain focused on communication, are assigned to agencies such as the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and Administration on Community Living (ACL), which receive no Autism CARES funding at all. We urge that all important research priorities and related programs be assigned to agencies receiving CARES funding, or, alternatively, not assigned to any specific agency in order to maximize flexibility in locating funding.

B. Improve research on motor planning and apraxia

Proposed Changes:

Amend Priority Therapeutic Domain #10 (Motor Planning) by:

1. Clarifying the recommendation regarding motor phenotyping to ensure that these phenotypes are not used as a basis to gatekeep access to specific supports or



interventions.

2. Reassigning key research responsibilities, such as longitudinal tracking of real-world outcomes for people with motor-driven speech-related disabilities, be reassigned to agencies with CARES funding or to agencies with CARES funding in collaboration with other agencies (see Section I.A).
3. Tracking additional functional access outcomes, such as social connection, self-reported well-being, employment, and retention of legal decisionmaking capacity.
4. Adding language recognizing that misinterpretations of motor concerns can be traumatizing, which additionally highlights the importance of developing improved pathways to recognition of motor planning support needs.
5. Adding language recognizing that whole-body apraxia, including apraxia affecting speech, may affect people across a wide range of support needs.

Rationale:

As the Committee notes in its discussion of Priority Therapeutic Domain 10, motor planning concerns are often a major driving factor of speech-related disability in autistic people. We appreciate the Committee's interest in additional research into this nexus.

Although better understanding of the diversity of motor phenotypes may be helpful, there is a real risk that providers or other professionals may insist that AAC interventions establish a separate evidence base for each sub-population, and/or determine that only some sub-populations are likely to benefit from AAC in general. Clinical decisions should be individualized, rather than based on someone's categorization into a specific profile.

As we discuss in Section I.A, it is critically important that key priorities be assigned to agencies receiving CARES funding; unfunded recommendations are less likely to be acted upon.

Elements We Support

We would like to express our appreciation and support for the Draft Strategic Plan's recognition that:

1. Motor difficulty is often misinterpreted as behavioral, psychiatric, wilfully



noncompliant, or related to comprehension, leading to an underestimation of a person's "competence and needs," including need for AAC supports. (p. 156, 161-162).

2. "Access to action," rather than "impairment-level improvement," is the key goal (p. 162).
3. Research on motor planning concerns suffers from failure to include people with higher support needs (p. 157).
4. Motor ability (alongside sensorimotor processing) "can determine whether an autistic person can use the services and supports already offered to them" - that is, that they may not be able to communicate effectively with support until they also have the other supports they need. (p. 160).
5. Motor access assessment must be integrated into "communication access and device-selection pathways" - such that communication supports are actually usable. (p. 157)
6. "Speech-motor impairment is likely a major and under-recognized contributor to limited speech," that speech production and language comprehension are different functions entirely, and that "the dominant clinical and research risk in this population is not overdiagnosis of speech-motor impairment; it is systematic failure to recognize, assess, and treat it." (p. 158)
7. People with motor access needs are often excluded from research that requires motor skills, such as writing, imitating, sitting, device use, or pointing.
8. People with motor access needs are often incorrectly evaluated by existing assessments, particularly IQ testing and testing to evaluate language comprehension
9. People face pervasive barriers to accessing communication supports, underscoring the importance of clarifying guidance from agencies such as CMS and improved training for DSPs

C. ***Additional comments on the proposed Life Course Domains***

Recommended Overarching Change:

1. Include research related to life course and effective supports in the research agenda, rather than the implementation agenda

Rationale



While we appreciate the attention to autism research and services over the full course of autistic people's lives, we are concerned that the structure of the Strategic Plan relegates important research topics to the Life Course Domains, which are characterized primarily as implementation-focused rather than as targets of research funding (see Section I.A.). As a result, entire categories of research funding from previous Strategic Plans—such as access to services and supports and the needs of autistic adults—now have *no* concrete research funding targets attached to them. We are concerned that the failure to assign targets for funding of research in these Domains will result in de-prioritization of such research.

Moreover, as noted in further detail in Section I.F., we are concerned that the overall restructuring of the Strategic Plan, including the new categorization of Life Course Domains, will make it difficult to compare research targets to those included in previous Strategic Plans.

Additionally, we provide the following feedback on specific initiatives within these domains:

Domain II (Education)

Recommended Changes:

1. Recognize the role of supports provided through IDEA Part C (Early Education)
2. Address the effects of school choice policies on access to services, especially for people with higher support needs
3. Recognize the role of the IDEA in funding a full range of educational supports in addition to school placements

Rationale

The public education system, including early education programs authorized under IDEA Part C, is a key point of access to communication supports for children with speech-related disabilities. We are therefore highly concerned that this section under-recognizes the role of IDEA in providing access to communication-related supports and the impact of some of policy proposals—such as school choice vouchers—on access to



services through the IDEA.

For example, the Draft Strategic Plan suggests "parent-directed school choice" may "reduce dependence on conflict-based remedies." However, charter and private schools frequently refuse to admit students with higher support needs and students in these placements often do not have the full plethora of rights that they would enjoy under the IDEA. While we appreciate the Committee's interest in weighing in on education funding policy, it is impossible to support "transparent" parent-directed school choice without flagging and addressing these concerns.

The Draft Strategic Plan also notes that families may rely on educational savings accounts when "a family may need a customized combination of tuition, therapies, behavioral supports, assistive technology, transportation, and curriculum rather than a single school placement." Although we recognize the utility of educational savings accounts in many circumstances, we are unsure why these services are listed without an acknowledgment that the IDEA requires schools to provide therapies, behavioral supports, assistive technology, transportation, and an appropriate curriculum to all students with disabilities for free—not just a school placement.

We believe this section should also more thoroughly address the impact of IDEA Part C, which again forms a critical point of access to early communication-related evaluations and supports.

Elements We Support

1. We commend the Committee for its recommendation that the Department of Education restore staffing to the Office of Civil Rights and increase its capacity to enforce the civil rights of students with disabilities—which must include the right to access effective communication in schools.
2. We also support the Committee's proposal to expand the special education workforce needed to provide necessary services to students.

Domain III (Communication)

While we maintain our position that communication should be recognized as a research topic and not merely a matter of "deploying and scaling existing authorities" (See Section



I.A.), we appreciate the Committee's recognition of communication as an important access need throughout the course of autistic people's lives and strongly support many of the recommendations in this section. Please see the following proposed changes and areas of agreement.

Proposed Changes

1. Revise language discussing people with communication disabilities and higher support needs as discussed in further detail in Section I.D.
2. Include additional outcomes to be tracked, including improvements in mental health, social relationships, educational attainment, and ability to exercise legal capacity.
3. Revise language contrasting "standard-of-care AAC" with "text-based approaches" to reflect that these are not mutually exclusive and avoid prioritizing one modality over another
4. Clarify that precision research should be used only to guide exploration, not to gatekeep or screen out autistic subpopulations from some or all or some AAC supports

Rationale

While we agree that programs to promote access to communication should be evaluated according to a range of outcomes that include ability to communicate in health care settings and increased community participation, we believe that additional outcomes should also be tracked—particularly improvements in mental health, education, social relationships, and ability to exercise legal capacity. Communication affects almost every aspect of life; improved communication supports should be expected to result in improvements across a wide variety of domains.

While it is true that "standard-of-care AAC" does not currently meet the needs of every autistic person and that "text-based" approaches work for many people, speech-generating devices are often themselves "text-based." We urge IACC to recognize that "text-based approaches" and "speech-generating devices" are not mutually exclusive and that text-based approaches also may not be effective for everyone at every moment of life (*id.* at 200). IACC should broadly focus on promoting a range of AAC options that facilitate robust communication and that can be used flexibly in response to different



communication environments.

We believe that precision research can help people decide which approaches to try first and reduce time spent on interventions and AAC modalities that are unlikely to be effective for them. Nevertheless, the Draft Strategic Plan should clarify that its Precision Research initiative should not result in gatekeeping access to a full range of interventions based on individual needs and priorities. Ultimately, the individual receiving support is the best expert on which approaches are and are not working for them specifically.

Elements We Support

We would like to express our appreciation and support for the Draft Strategic Plan's recognition that:

1. Communication is an important civil right and that agencies should act to protect this right for participants in federal programs, including protecting individuals' right to use their preferred form of communication.
2. The goal of ensuring that people with expressive communication disabilities can "obtain [an] individualized communication evaluation and appropriate supports without delay." (p. 199)
3. Communication supports should promote a full range of communication rather than simply facilitating "requesting behavior."
4. Nonspeakers should be included in the implementation process.
5. Deliverables should span the entire life course. This is particularly important for adults and older children who have previously not been provided with effective communication supports.

Domain IV: Mental health

Proposed Changes:

1. Address accessibility and availability of mental health services for people with communication-related disabilities
2. Promote best practices in mental health supports for people who use AAC, particularly those who benefit from a communication support person.



Rationale

We support inclusion of mental health as a priority domain and appreciate the Committee's concern to include autistic people with speech-related disabilities.

It is critical that, when addressing the needs of nonspeaking autistic people, accessibility and availability of services are also addressed. Simply having a model to support mental health for AAC users doesn't mean that it's actually available. Therapists may still turn away AAC users as clients even when info on how to support them is available. We should also be meaningfully engaging with challenges associated with supported communication in mental health contexts, such as by developing and promoting best practices for communication supports, privacy, and confidentiality. People with speech-related disabilities should lead these efforts.

Domain V: Housing

Proposed Changes:

1. Promote housing models that facilitate choice of provider—including models that enable people with high support needs to receive supports in any home
2. Eliminate language suggesting that people with higher support needs are best supported in congregate settings
3. Recognize the importance of provider choice and self-direction to people with speech-related disabilities
4. Recognize the impact of existing funding structures on access to affordable housing that is *not* tied to a particular provider
5. Ensure that access to the community is measured according to whether residents meaningfully participate in and build connections with the broader community—not by availability of scheduled day trips, "reverse integration," or interactions with nondisabled staff or volunteers
6. Eliminate transportation savings as a desirable goal for housing models
7. Track additional outcomes, such as employment outcomes, mental well-being, and breadth and quality of social connections with community members
8. Distinguish stability of housing from length of tenancy; voluntary changes of location in response to differing priorities and life stage may be positive, while relocations due to loss of housing, inappropriate supports, or other adverse



experiences are negative.

Rationale

We urge the Committee to revise its discussion of housing needs to better reflect the existing regulatory environment and the importance of maintaining safeguards protecting access to the community. Although we share the Committee's belief that the focus should be on residents' actual experiences of community, we believe that that focus is already reflected in the existing regulatory environment. In particular, the 2014 Home and Community-Based Services (HCBS) Settings Rule contains *no* provisions that automatically exclude settings based on location, with the exception of locations that are already licensed as intermediate care facilities (ICFs) or other institutions. Although the rule subjects some settings to additional scrutiny based on location, this additional scrutiny reflects the reality that larger settings, provider-owned settings, and settings involving co-location of housing and services have historically engaged in practices that reduce residents' mobility and access to choice. Regulatory oversight of these settings does not pose a barrier to meaningful community integration—it ensures that federal dollars earmarked for community-based settings are actually spent on settings that facilitate community access.

Existing heightened scrutiny oversight has not prevented the establishment of intentional communities or villages, including many with hundreds of residents. When CMS has required changes prior to approval, the reasons have been extremely clear: for example, in Idaho, CMS found that a setting had not met heightened scrutiny requirements when the provider actively prohibited residents from going to the community outside of regularly-scheduled trips, micromanaged residents' schedules and daily activities, and actively discouraged intimate relationships.[1] We are concerned that any easing of critical safeguards may increase the risk that additional settings will similarly curtail residents' rights—resulting in housing placements that are institutional in nature if not in name.

This risk is particularly pronounced in provider-owned and operated settings, particularly those with a large number of residents. Providers tasked with offering services at a large scale in a single location are frequently tempted to impose policies in the interest of their

[1] https://www.medicaid.gov/medicaid/home-community-based-services/downloads/id-heightened-scrutiny-site-visit.pdf.



own convenience rather than maximizing residents' self-determination and integration into the community. Without the ability to choose a different provider without moving, residents have few built-in safeguards.

The risks of such settings are higher for people with significant support needs, including need for 24-hour supports. Indeed, they are of particularly of concern to people with speech-related disabilities, who may be severely harmed by settings that result in isolation and deprive residents of opportunities to make choices—including choice of communication and service providers. When housing is tied to a specific service provider, the housing stability of people with speech-related disabilities becomes contingent on a specific service provider's willingness to provide and/or accommodate their communication supports. As a result, many people with speech-related disabilities prefer self-directed supports, which enable them to select and train their own direct support professionals (DSPs), including by hiring people with whom they have existing relationships—such as family members. These supports are typically available *only* in non-congregate settings, such as an individual apartment or family home; self-direction within clustered housing models is more challenging.

Funding structure is a significant reason why clustered housing models are less likely to facilitate provider choice. Medicaid HCBS funding does not, and cannot, directly cover housing costs. These costs must be covered out of residents' limited Supplemental Security Income (SSI) allowances and other sources of state or federal funding. As a result, group homes and other clustered housing models often operate at a loss with respect to cost of location and maintenance. These costs are often cross-subsidized by revenue earned through provision of HCBS services.

At the same time, there are *no* such cross-subsidization opportunities for non-congregate settings: someone who wishes to live in their own apartment, receiving supports from a provider of their choice, may find it difficult to find any affordable housing options outside of living with family members. Autistic people will continue to lack meaningful choices about housing unless this fundamental concern is meaningfully addressed. Creation of additional housing models will not improve access to one of the most frequently desired options: living in one's own apartment, in the neighborhood of one's choice.

Finally, while we agree that community integration must be assessed to some extent by outcomes such as is assessed by outcomes such as access to the community and not solely



by location, we urge the Committee to clarify how these experiences will be measured. Meaningful access to the community cannot be provided simply by occasional opportunities to leave a campus; events that pull community members into the setting rather than facilitate residents' ability to move to locations of their choice throughout the community; or placement of nondisabled staff members or volunteers in nearby housing units. Nor is it clear how the Committee intends CMS to evaluate whether residents have real opportunities to build relationships with nondisabled people, control their schedules and services, change providers, leave the setting, or choose housing elsewhere, aside from the standards it is already imposing pursuant to the HCBS Settings Rule.

We are particularly concerned that the Committee suggests that clustered settings may result in "transportation savings," which could be read to suggest that these settings may purposefully be designed to minimize residents' incentives to leave the site or diverting residents into shared outings rather than individually selected activities. As noted in further detail below, research suggests that free, varied movement through the community has positive effects on mental well-being.

We support efforts to track not only housing availability but also quality-of-life outcomes that may be impacted by housing. This should additionally include employment outcomes, mental well-being, and breadth and quality of social connections with community members.

While we understand the importance of tracking housing stability, we urge the Committee to ensure that stability is well-operationalized so as not to discourage natural, voluntary changes in housing. Length of residence alone is not an indicator of housing quality or well-being: when someone moves to a different housing option that could indicate that they have simply found one that better fits their needs, or because their needs have changed. People who initially wish to live with a roommate may later wish to live with someone else, alone, or with a specific partner or family member. The goal should be quality of life, self-determination, and avoidance of involuntary housing disruption - not expecting people to stay in the same setting forever.

Access to the correct level of support should also be tracked as a performance indicator. Housing options should enable people to add or reduce services as their needs change, without requiring them to move to a new location.



Domain VI: Caregiver Stabilization

Recommended Changes:

1. Add discussion of communication needs for continuity planning
2. Recognize the potential benefits of paid family caregiving

Rationale

We urge the IACC to specifically recognize access to communication as an essential part of continuity planning for autistic people with speech-related disabilities, regardless of Medicaid status. Often, known caregivers are essential advocates for communication access and sources of communication supports. Without continuity planning that specifically addresses the need for communication supports, nonspeaking autistic people who lose a caregiver often face not only loss of services and supports, a housing crisis, and more, but also loss of a communication lifeline that may never be replaced. We believe that this concern overlaps with our previously expressed comment on the importance of research on the impact of familiar communication partners. For people who communicate best with familiar partners, continuity planning must include efforts to cultivate and train additional partners as well as efforts to increase independent communication. Improved research could significantly facilitate more effective planning.

The IACC should additionally address the impact of paid family caregiving as a possible component of caregiver stabilization. In states that allow family members to serve as paid Disability Support Professionals (DSPs), advocates have reported improved quality of care and increased caregiver stability. These programs can reduce caregiver burnout by relieving caregivers of the need to choose between supporting their loved ones and managing their own needs. Yet these programs are at significant risk, with some suggesting that caregivers should be expected to provide direct supports for upwards of 16 hours per day while working another job for the remaining eight hours—leaving no time for rest, personal care, or providing care to other children. The IACC should recommend additional studies on the effects of paid family caregiving programs on caregiver stabilization.

Domain VII: Employment

Recommended Changes:



1. The IACC should revise the initiatives in this Domain to reflect that people with high support needs and those who need or use AAC may benefit from *all* of these Initiatives—including initiatives to promote competitive integrated employment. The same person may benefit *both* from pathways such as vocational rehabilitation and supported employment, and from improved accommodations and management practices in competitive work environments. Competitive integrated employment should be a goal for *all* autistic people who seek employment, including people with high support needs.
2. We further request changes to the framing section to ensure that people with higher support needs—including people with speech-related disabilities—are not implicitly contrasted with people who have "average or high cognitive ability." Support needs should not be conflated with cognitive abilities or job-related skills.

Domain VIII: Aging

Recommended Changes:

1. Recognize the importance of long-term supports, decision-making supports, and overall health concerns to non-aging adults
2. Address additional concerns, such as burnout, catatonia, and other common health issues

Rationale

Although the concerns of aging and older adults should absolutely be addressed in the Draft Strategic Plan, it is concerning that the day-to-day support, health, and decision-making needs of *all* autistic adults appear to have been assigned to this Domain. The Draft Strategic Plan should recognize that these concerns must be addressed throughout autistic people's entire lifespan. The IACC may address this problem by revising this Domain to include supports across the lifespan. Preferably, it should separate it into two Domains: one concerning access to high-quality supports and services, and one specifically concerning the needs of the aging population.

Autistic adults' experiences are different from those of the general population. While nondisabled adults may expect not to need daily supports, chronic health condition management, and decision-making supports until later in life, this is simply not the case for autistic people, especially autistic people with speech-related disabilities. In particular:



- Autistic people may need legal decision-making supports, such as supported decision-making, the moment they reach the age of majority;
- Autistic people often experience progressive health conditions that result in increased disability well before what we would ordinarily consider "midlife" or "advanced age"
- Autistic people may need a very high level of day-to-day support throughout their life, beginning in childhood and continuing through their entire adult life
- Other autistic adults may experience skill loss unrelated to advanced age, resulting in progressively higher support needs.

Additionally, we recommend that any discussion of health and supports over the life course be updated to include:

- Additional common progressive health concerns, including dysautonomia, hypermobility, and catatonia
- "Autistic burnout" and other potential causes of progressive skill loss, including loss of communication skills
- Ensuring that communication supports are adequately factored into every aspect of this Domain, including supported decision-making, access to high-quality health care, and access to HCBS

Domain IX: Transportation

Suggested Changes:

1. Remove or revise recommendation to reduce "compulsory travel"

Rationale

We are concerned that the IACC's goal of reducing "compulsory travel" through HCBS guidance will have the effect of encouraging unnecessary co-location of services that will reduce overall access to the community. While we would support increased availability of in-home services for those who prefer to receive in-home services, we also believe that any program focused on improved transportation should *facilitate* routine travel outside the home—not discourage it.



Routine trips to the community to purchase groceries, go to a workplace, attend social events or attend appointments are how many nondisabled people grow real relationships in the community. Mere "access" to the community is insufficient unless people actually meaningfully interact with it on a daily basis. Studies additionally show that well-being is closely connected to the amount of time people spend outside of their homes *and* the variety of locations visited outside the home.[2] As a result, although some people may face specific challenges making travel inadvisable or may simply prefer to stay near the home, the default policy should *not* be to reduce reliance on transportation. It should be to increase ease of access.

D. Avoid stigmatizing terminology for people with communication-related disabilities and higher support needs.

Although we are very supportive of greater federal attention to nonspeaking autistic people and those with higher support needs, we oppose the IACC's recommendation to adopt the term "profound autism" in federal research programs. Such labels have been used to underestimate the potential of autistic individuals, especially nonspeaking people, and deny them agency. It is particularly troubling that the majority of the IACC voted to adopt a definition of this term that includes all autistic individuals who cannot rely on speech alone, while disregarding the clear concerns expressed by the actual nonspeaking members of the Committee regarding the impact of the label.

It is even more troubling that, in its discussion, members of the IACC referred to the number of comments it received mentioning this proposed term, without regard to whether those commenters were in favor or opposed to its use. We wish to make clear that our use of this term, at any point in these comments, is merely in reaction to proposals that make use of it—not an endorsement of its use.

Additionally, the proposed definition itself has limited operational utility for tracking research. The definition groups nonspeaking people with those who have "limited ability to engage in flexible, reciprocal, or generative communication — meaning spontaneous, non-prompted, and contextually varied communication exchange," and groups both of these groups with people in who need "continuous or near-continuous supervision to ensure safety and substantial assistance with activities of daily living to meet basic needs." While there are many people who have all of these characteristics, there are many others

[2] https://link.springer.com/article/10.1186/s12888-021-03147-9.



who have only one of the three—and the proposed definition is unclear as to whether it includes those with communication-related disabilities who may need significant support with daily living, but do not need continuous "supervision." If it does require that both these prongs be satisfied, the definition may be wholly unworkable for some groups of people—such as children under age three, who *all* need continuous supervision to ensure safety.

By conflating people with these different characteristics and support needs into a single category, the committee undermines the goal of improving federal reporting and research consistency for specific sub-populations. Under the Committee's proposed definition, for example, a study on early use of AAC that does not screen participants to determine their need for "continuous supervision" may not be tracked as relating to people with the highest support needs, whereas other studies that are unrelated to communication supports—such as studies on wandering—may be. This will make it more difficult—not less—to track federal support for communication.

We believe that accountability and transparency are better served through use of *several* overlapping categories to describe under-recognized areas of need, such as autistic people with significant 1) expressive communication disabilities, 2) sensorimotor disabilities, 3) and cognitive disabilities, 4) co-occurring medical conditions, and 5) safety-related needs. This will help ensure transparency regarding the resources devoted to people in need of significant supports, while avoiding stereotypes and recognizing the diversity of the autistic population.

If the Committee still wishes to create a single category to describe people in need of the most supports, it should use terminology such as "people requiring intensive or lifelong support." The Committee should also make it clear that it includes all people with *at least one* characteristic resulting in a need for intensive or lifelong support.

E. Provide greater clarity on operationalization of performance indicators

The Committee should undertake a systematic, detailed review of its proposed executive performance indicators to ensure that they can be actually operationalized and systematically tracked.

Several of the proposed indicators appear to be difficult to actually operationalize or



measure. For example, on page 244 one indicator listed is "reduction in missed treatable contributors and preventable health or residential destabilization." It is unclear how such an indicator could ever be operationalized or systematically tracked, considering that:

- Treatable contributors that are never identified, cannot be identified as having been missed;
- Treatable contributors that are initially missed and later identified, can be detected only after identification practices have been improved - not when they are initially missed; therefore, reports of "missed treatable contributors" are likely to increase when practices improve, and decrease when practices worsen;
- Clinicians who identify a previously-missed treatable contributor do not systematically report such events.

This is simply one example of a larger pattern of indicators that have been proposed without clear pathways to systematic measurement and data collection.

F. The new Strategic Plan should retain the structure of previous Strategic Plans

Since the initial founding of the IACC, each Strategic Plan has followed the same basic structure: A list of seven overarching questions for research. These subquestions were divided into recommendations. As an example, the most recent Strategic Plan divided Question Six, concerning the needs of adults across the lifespan, into three broad recommendations: transition to adulthood, improving physical and mental health outcomes, and improving access to the community. The Portfolio Analysis also tracked research funding by question, enabling stakeholders to easily understand funding patterns by topic over time. This enabled advocates to identify areas that were dramatically under-funded—particularly research on effective services and supports and on the needs of adults.

Moreover, this structure placed research on services and supports and on the needs of autistic people across the lifespan on par with research on biology and interventions. In contrast, the Draft Strategic Plan assigns these concerns to Life Course Domains, without concrete research funding recommendations.

We believe that the current Draft Strategic Plan should, at a minimum, provide a crosswalk between its recommendations and the original seven-question framework. It should also, as noted in Section II.A., ensure that the research agenda itself includes



recommendations for research on issues related to lifespan and services and supports.

Additionally, we have broad concerns regarding the list of Priority Therapeutic Domains itself. These domains do not address many challenges that are particularly relevant to the lived experiences of autistic people, including executive dysfunction; mental health; and other co-occurring medical concerns such as hypermobility spectrum disorders.

Finally, we request that the Draft Strategic Plan be revised to connect claims to citations. Previous Strategic Plans included footnotes and/or endnotes enabling readers to clearly connect claims to supporting authority. The current Draft Strategic Plan simply includes a list of relevant authorities grouped by relevant section, placing significant burden on readers who are interested in understanding how each individual claim is supported.

G. The Autism.gov initiative should come with realistic goals and funding allocation.

While we believe that a one-stop resource hub would provide value to the community, we are concerned that this project will not be successful unless it comes with meaningful resource allocation. The Draft Strategic Plan should include recommendations for funding and address which aspects of this project should be prioritized in the event that this project is not fully funded.

The resource navigation function of the proposed website, in particular, will not be effective in the absence of a significant resource outlay. Information scraped from state or local government websites is often itself outdated or incomplete. State and local governments may, for example, update information on their web site landing page while leaving the outdated information on a page that is still accessible to web scrapers. Users of websites built on such data often find themselves directed to telephone numbers that are out of service. They may be directed to programs that have been closed, are highly waitlisted, or that have adopted eligibility criteria that the users do not meet.

Therefore, a truly useful tool must be developed, at least in part, by staff members tasked with periodically interfacing with program administrators to ensure that the website information is truly up to date.

Accessibility cannot end with plain-language resources and accessible navigation. Where the website provides contact information for relevant programs and services, that contact



information must include—to the greatest extent possible—information on how to communicate with the program via email or other text-based communication, and not just a telephone number.

The Draft Strategic Plan should be realistic about the impact of a web tool on program fragmentation. A one-stop source of information on programs and services does not mean that stakeholders will actually be able to navigate these programs effectively, if these programs are not actually coordinating or working together. For example, an autistic person seeking employment may learn that they can receive employment-related services both through a Home and Community-Based Services (HCBS) waiver and through the Vocational Rehabilitation (VR) program, but find themselves unable to access those services because neither program will take responsibility for providing the services, each instead insisting that the other should do so.

With respect to the proposal that Autism.gov also track outcomes related to the goals of the Draft Strategic Plan, we believe that the common measurement frameworks should be revised to increase focus on lived experiences rather than timeliness of services or process fidelity. For example, while it is certainly relevant to track whether people actually access services to which they are referred, it is far *more* relevant to track whether these services actually improve outcomes such as health, employment, or quality of life.

H. Fragmentation of the Autistic Population.

The Draft Plan promises to organize all clinical and implementation systems around "biologically and clinically meaningful subgroups," among other factors. P. 42. While we recognize that different autistic people have different needs and that research on biomarkers may be promising, over-focus on biological underpinnings can obscure commonalities among autistic people with shared support needs. Additionally, although the Priority Therapeutic Domains appear to be meant to reflect these "subgroups," many autistic people will be affected by multiple of these domains at once (e.g., motor, autonomic, and sleep), and each of these domains may affect people in broadly differing ways.

At the end of the day, nonspeaking autistic people with different biomarkers or patterns of support need, nevertheless share an interest in access to early, high-quality, robust communication supports. The Draft Strategic Plan should be revised to ensure that



systems are organized around specific phenomena and areas of need, rather than entirely around "subgroups."

III. Concerns about matters other than the Strategic Plan

A. We support raising awareness of diagnostic overshadowing.

We support the principle that clinicians must thoroughly investigate health conditions rather than dismissing physical symptoms as "behaviors" or inherent manifestations of autism. This is a critical issue for individuals with significant communication barriers.

We view the IACC's role as not to directly establish clinical practice, but to identify the research needed to improve it and coordinate activities across agencies. We are concerned that, without such support for research and active coordination, its recommendations regarding clinical guidelines are unlikely to achieve meaningful results.

We share the Chair's interest in a swift release of the 2024 Strategic Plan Update on co-occurring conditions, which was finalized nearly two years ago but has not been released. This update was consistent with the current Committee's stated goals. Moreover, further advances in research on co-occurring medical conditions will help improve clinicians' understanding of the importance of thorough medical evaluations and of avoiding diagnostic overshadowing and lumping.

The Committee should also promote research on improving communication access in health care settings, including augmentative and alternative communication (AAC), communication accommodations, and clinician training, and on identifying signs of co-occurring medical conditions in people who cannot reliably communicate through speech. It should also educate researchers on the importance of ensuring that autistic people with significant communication disabilities are meaningfully included in health research through accessible study designs and communication supports.

Finally, the Committee should ensure that federal agencies responsible for establishing internal clinical guidelines, such as CMS and HRSA, are actively represented in any working groups on co-occurring medical conditions. Feedback from these agencies is critical.



B. The IACC should publish a meaningful Portfolio Analysis that can be easily compared with previous Portfolio Analyses

The IACC is required by statute to regularly monitor autism research across federal agencies and issue yearly summaries of advances in autism research. These key functions help the public understand how taxpayer funds are allocated and educate the public and professionals on studies that can improve the lives of autistic people. For example, the Portfolio Analyses published by the IACC provide critical information on the level of federal support for research on issues critical to our community—including technology-based interventions to support communication. Where the Strategic Plan outlines a comprehensive research agenda, the Portfolio Analysis provides visibility as to whether agencies are actually adhering to the priorities outlined in the Strategic Plan.

The most recently published Portfolio Analysis is now **three years out of date**. Although the recently released Draft Strategic Plan includes a brief, AI-assisted analysis of research funding from 2025, this analysis lacks the full range of information included in previous Portfolio Analyses, including breakdowns of topics within each category of research, agency-level analyses, breakdowns of funding by project as well as by dollar amount, analyses of both privately- and publicly-funded research, analyses of historical trends, and public release of project-level data.
Moreover, without thorough human oversight, AI-based classification of studies may miscategorize studies leading to inaccurate information. Year-to-year consistency in the format of the Portfolio Analysis is highly important to members of the public who are interested in tracking trends and understanding whether funding decisions are consistent with publicly stated priorities.

We therefore urge the IACC to continue producing a full Portfolio Analysis through a transparent process rather than replacing it with analyses generated primarily through large language models or other automated tools. The Portfolio Analysis should also be organized in a manner that corresponds directly to the structure and research priorities of the Strategic Plan. This alignment is essential to allow the public to assess whether federal research spending reflects the priorities established by the Committee and to compare funding patterns across years. We support the use of automated tools being subject to meaningful human review, rather than a substitute for detailed analysis, categorization, and public transparency provided by prior Portfolio Analyses.



C. *The IACC Should Operate with Transparency and Adequate Opportunities for Public Input.*

CommunicationFIRST finally expresses deep concern over the lack of opportunities the IACC has so far provided the public to provide meaningful feedback that corresponds to items under consideration by the Committee. In particular, we would like to express our strong objection to the IACC's choice in April to hold a vote on five separate recommendations that were not released to the public and even some committee members until after the public comment period had closed, and just two business days before the April 28, 2026 meeting itself.

We are also concerned that the Committee released a full Draft Strategic Plan without first engaging in public deliberation over the contents of that draft or a public request for comments on the updated plan.

We hope that in the future, the IACC provides the public with sufficient notice of topics on which it seeks comment to obviate the need for last-minute extensions. We understand that ONAC occasionally takes one or two business days to post materials sent by the Chair; we expect that this predictable delay will be factored in when transmitting materials to be posted. We further hope that the Chair provide the public with greater insight into the identity of the drafting committee and the process by which that committee created the draft.

Our interest in a more transparent process does not stem from opposition to the underlying proposals. As we have already noted, CommunicationFIRST shares many of the goals expressed in several of the recommendations in question, including large portions of the Draft Strategic Plan. Nevertheless, the entire community deserves the opportunity to offer its expertise and feedback on all items of business—both at the broad, conceptual level and on the details of specific proposals or initiatives.

When proposals are drafted by unknown members of the Committee without adequate notice to the public and pushed forward to a vote with minimal discussion, this violates both the intent of the Autism CARES Act and the requirements of Federal Advisory Committee Act (FACA). The April materials and the Draft Strategic Plan were the clear result of extensive activity outside of the public eye.



In April, for example, the public had no notice of even the broad topics to be discussed at the meeting before the comment deadline passed and the Committee was given no opportunity to meaningfully deliberate on the full 62-page set of proposals. Instead, discussion was largely limited to the importance of the subject matter rather than the actual substance of the recommendations, and the 25 minutes of allotted "discussion" time was clearly insufficient to constitute meaningful public deliberation. In addition, the IACC **failed even to make visible to the public how each member voted on each proposal**. We have yet to receive this information even two months after requesting it.

The Draft Strategic Plan also was prepared without any public Committee deliberation on the topics to be addressed or initial public request for comment—in stark contrast to previous practices. While the Committee states that it developed its list of Priority Therapeutic Domains in part through reviewing responses to a 2024 Public Request for Information (RFI) on priorities for the 2024 Strategic Plan Update, that RFI specifically solicited feedback from the public on *co-occurring conditions*, to be used in developing an issue-specific update to the existing Strategic Plan. It was not a broad call for comment on priorities for the overall Strategic Plan.

Lack of adequate transparency and timely opportunities for comment undermines public trust in the IACC and its recommendations and shuts out the broader community from the opportunity to provide meaningful feedback. It also deprives the IACC of opportunities for input from member agencies, which the IACC is statutorily mandated to seek out.

It is noteworthy that as of today—the deadline for public comment—the Committee has once again failed to release *any* agenda for the upcoming meeting, and thus has provided the public with no opportunity to weigh in on any anticipated items of business, even in broad terms.

Additionally, the public-facing website for the upcoming meeting continues to reflect the old comment deadline of July 24, 2026, rather than the current deadline of August 20, 2026—meaning that many members of the public may not even be aware that they can still comment at all.

We call on the IACC to proceed with increased transparency by:

1) Disclosing **all** proposed items for discussion or vote to the public in advance of the



closing of the comment window, including release of any proposed documents put forward to the Committee for voting

2) Disclosing to the public the process through which each document for discussion was drafted
3) Holding all votes through a format in which each Committee member's is viewable to the public
4) Reopen all recommendations which were previously subject to a vote for public input
5) Ensuring that the proceedings of working groups are viewable to the public

The IACC serves an important role in shaping the nation's autism research agenda. That role carries with it a responsibility to operate transparently, fulfill the duties assigned by Congress, and ensure that federal research reflects the priorities and experiences of all autistic people, including autistic people with communication-related disabilities.

We urge the Committee to ensure that future recommendations are developed through a transparent process that provides meaningful opportunities for public participation. We look forward to a refocusing of the committee's efforts toward its statutory mandates and a more inclusive dialogue with all stakeholders.

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Thank you for the opportunity to provide comment. Any questions may be directed to info@communicationfirst.org.