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The Autistic Self Advocacy Network appreciates the opportunity to submit comments for the January 24, 2024, IACC meeting. In our last comments to the IACC, ASAN used the opportunity to share our response to the National Institute on Deafness and Other Communication Disorders (NIDCD) Request for Information on research directions to support communication in minimally verbal/non-speaking people. ASAN appreciates the IACC for producing the Report to Congress, the Research Summary, and the updated Strategic Plan for 2021-2023. Our current comment will focus on the three end-of-year documents provided by the IACC: the Report to Congress, the Summary of Research, and the 2023 Strategic Plan.

Report to Congress

The 2022 Report to Congress on Supportive Services for Individuals with Autism is a very comprehensive document. ASAN appreciates that the IACC acknowledged that “Adding to the complexity of supportive service needs is the fact that an autistic individual’s service needs are likely to vary and evolve at different points across the lifespan.” IACC research funding and priorities should recognize this complexity of support service needs with increased funding for services and supports research in order to ensure that supports meet individuals needs across the lifespan. The report also notes that the 2016-2017 Interagency IACC Strategic Plan for Autism Spectrum Disorder (2017 Strategic Plan) includes services and supports as a top priority: “Develop and implement high-quality, evidence-based, and widely accessible services and supports that maximize quality of life and health across the lifespan for all people on the autism spectrum and their families.” However, the 2014-2015 and 2017 IACC Autism Spectrum Disorder Research Portfolio Analysis Reports show that Biology, Risk Factors, and Treatment and Services continue to be prioritized over Services when it comes to research funding and practitioner training continues to receive a plurality of the funding for Services research. ASAN urges the IACC to ensure that the allocation of research funding reflects its stated priorities.

The Report to Congress also mentions that “Applied behavior analysis (ABA) and other behavioral interventions can be helpful in addressing emotional and behavioral issues in autism. ABA and therapies based on its principles are the most commonly researched and practiced behavioral intervention for autism...A meta-analysis of ABA studies showed that ABA resulted in significant improvements in socialization, communication, and expressive language.” ASAN disputes this framing of ABA as “helpful” and notes the lack of context given for how and by whose standards the reported “improvements” for autistic people are defined. The IACC should continue to work with autistic self-advocates to provide a more complete understanding of the impacts of ABA and other behavioral interventions.



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Summary of Research

This year, in addition to providing a Summary of Research, the IACC also produced an “Easy Read Version” of the document. Unfortunately, the Easy Read version does not meet the standards of Easy Read, or even Plain Language. There is a difference between Easy Read and Plain Language and the two should not be conflated. Easy Read “shows information in two ways - with pictures and words - and repeats the main ideas of the document to make sure the most important information gets understood” while Plain Language “does not have pictures and is usually written between a 6th and 8th grade reading level.” Federal agencies can find the official guidelines outlined in The Plain Writing Act of 2010 at plainlanguage.gov. ASAN recognizes the effort by the IACC to provide more accessible documents for the public, however additional investment is needed in order to ensure that documents labeled as “Easy Read” or “Plain Language” are actually accessible to members of our community. Where possible, the IACC should work with impacted community members who would benefit from the use of Plain Language and Easy-Read materials to ensure that these resources provide meaningful access to IACC’s work.

The Summary of Research highlighted four articles on Screening and Diagnosis, five articles on Biology, one article on Genetic and Environmental factors, one article on Interventions, two articles on Services and Supports, six articles on Lifespan, and one article on Infrastructure and Prevalence. ASAN supports the emphasis on Lifespan and encourages the research community to give more focus to Services and Supports and less focus on Biology.

2021-2023 Strategic Plan

Similar to the Summary of Research, the IACC produced the 2021-2023 Interagency Autism Coordinating Committee Strategic Plan for Autism Research, Services, and Policy (2023 Strategic Plan) and an accompanying 2021-2023 Interagency Autism Coordinating Committee Strategic Plan for Autism Research, Services, and Policy, “Easy-Read” Version . Again, the Easy Read version of the Strategic Plan does not meet the standards of Easy Read, or even Plain Language. As stated above, ASAN recognizes the attempt by the IACC to provide more accessible documents for the public. However, the IACC must take further measures and enlist outside expertise if necessary to ensure that documents labeled as “Easy Read” or “Plain Language” are actually in those accessible formats.

The 2023 Strategic Plan differs in several ways from the 2017 Strategic Plan and the Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder 2018-2019 Update (2019 Update). One of the first noticeable differences is the thoroughness and thoughtfulness of the 2023 Strategic plan. There is a marked difference in the language used in reference to autistic people and the autistic community throughout the entirety of the document. While this is mostly a symbolic change, ASAN appreciates that the IACC is continuing to incorporate the feedback it



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gets from autistic self-advocates and the rest of the autistic community when it comes to the language used around autism. ASAN acknowledges the work the IACC has done and also notes that there are still improvements that can be made in terms of updating language and recognizing the complete experience of autistic people.

The 2023 Strategic Plan shows that there have been steep funding increases for Biology from 2014-2019 and a steep increase of funding for Risk Factors (changed to Genetic and Environmental Factors) from 2014-2016 before a noticeable decrease in funding. ASAN urges the IACC to prioritize funding for Services and Lifespan Issues. Lifespan continues to have the lowest of funding allocations, while Services and Supports has historically received the second lowest amount of funding. While Services and Supports have risen slightly above Screening and Diagnosis recently, this priority remains a relatively low funding priority.

Finally, the 2023 Strategic Plan has two new sections that are not in the 2016-2017 Strategic Plan or the 2019 Update: Cross-Cutting Recommendations and Covid-19 and the Autism Community. ASAN welcomes these important additions by the IACC to the strategic plan.

2023 Strategic Plan Section by Section Review

Question 1: How can we improve identification of autism

The Screening and Diagnosis section includes the Aspirational Goal of Provid[ing] a timely diagnosis for people on the autism spectrum, so they can be linked to appropriate interventions, services, and supports to maximize positive outcomes. The section also acknowledges the disparities in screening and access to diagnostic services and discusses underserved populations. ASAN supports the inclusion of Recommendation 2 which aims to “Reduce disparities in early detection and access to services” because of the long-term impacts diagnostic disparities have on access to services and service disparities across the lifespan.

Question 2: What is the biology underlying autism

The Biology section includes the Aspirational Goal of Discover[ing] the roles of brain development, cognition, and physiological function in autism and its co-occurring conditions to enable the development of effective, targeted interventions and societal accommodations that promote positive outcomes across the lifespan. ASAN supports the inclusion of Recommendation 2 (Support research to understand the underlying biology of co-occurring conditions in autism and to understand the relationship of these conditions to autism.) and Recommendation 3 (Support large-scale longitudinal studies to answer questions about the development and natural history of autism across the lifespan, from pregnancy through childhood, adolescence, adulthood, and older adulthood.) in this section.



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Question 3: What are the genetic and environmental factors that contribute to autism and its co-occurring conditions

The Genetic and Environmental Factors section includes the Aspirational Goal of Discover[ing] and understand[ing] genetic and environmental factors that influence the development of autism and its co-occurring conditions in order to better inform diagnosis and interventions to improve outcomes for people on the autism spectrum. ASAN is encouraged by the strong focus on co-occurring conditions in this section. ASAN supports the inclusion of Recommendation 1 (Strengthen understanding of genetic factors that influence autism and its co-occurring conditions across the full diversity of individuals on the autism spectrum.) and Recommendation 2 (Understand the influence of environmental factors on the development and progression of autism and its co-occurring conditions, enabling the development of strategies to maximize positive outcomes.) in this section.

Question 4: Which interventions will improve health and well-being

The Interventions section includes the Aspirational Goal of Develop[ing] a range of interventions that optimize outcomes across the lifespan to maximize the health and well-being of people on the autism spectrum. Pages 57-58 of this section discuss Applied Behavioral Analysis with greater nuance than the Report to Congress, however, ASAN reiterates our concerns about the implicit promotion of ABA as helpful compared to other interventions and services because of the lack of context around the standards of behavioral improvement.

ASAN applauds the inclusion of the perspectives of those in the autistic community who disagree with the use and effectiveness of ABA, i.e., “Some members of the autism community argue that behavioral differences are part of what makes people on the autism spectrum unique, and that the responsibility should be placed on society to understand and accommodate autistic people as they are and celebrate differences. They also object to ABA’s focus on eliminating certain behaviors, particularly self-soothing behavior such as hand flapping, without acknowledging the emotional purpose those behaviors serve.” ASAN also commends the IACC for acknowledging the importance that any intervention must center an autistic individual's own desires and goals, instead of compliance to non-autistic societal norms. ASAN urges the IACC to promote research into interventions that are effective at meeting the stated needs and goals of autistic individuals.

Question 5: What services and supports are needed to maximize health and well-being

The Services and Supports section includes the Aspirational Goal Develop[ing] and implement[ing] high-quality, evidence-based, and widely accessible services and supports that maximize health and well-being across the lifespan for all people on the autism spectrum and their families. This section highlights the importance of person-centered planning and self-direction on pages 82-83 and discusses Home and



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Community-Based Services throughout. ASAN is encouraged by the inclusion of the emphasis on addressing ongoing areas of need like HCBS, Self-determination, services cliff, and more on pages 85-88.

Question 6: How can we address the needs of people on the autism spectrum throughout the lifespan

The Lifespan section includes the Aspirational Goal of Promot[ing] inclusion, support, and acceptance of all people on the autism spectrum so that they can participate in the communities of their choice through school, work, and meaningful relationships. This section represents a significant improvement from the corresponding section in the previous plan. ASAN supports all of the Recommendations in this section.

Question 7: How do we expand and enhance research infrastructure systems to meet the needs of the autistic community

The Infrastructure and Prevalence section includes the Aspirational Goal of Develop[ing], enhanc[ing], and support[ing] research infrastructure and statistical data gathering systems that advance the speed, efficacy, and dissemination of autism research and services. ASAN applauds the recognition of the priority to “increase recruitment and training of autistic researchers, as they are intimately aware of important issues and thus well suited to address the needs of the autistic community” on page 117 and the acknowledgment that “the participation of autistic individuals in research studies is crucial in order to build knowledge about the autistic experience across the lifespan, to build the evidence base for interventions, and to identify the most effective and efficient services and supports on pages 117-118.

Cross-Cutting Recommendations

The Cross-Cutting Recommendations section is a new addition to the 2023 Strategic. ASAN is encouraged by the inclusion of the recommendations to support research to understand sex and gender differences in autism and support diversity, equity, inclusion, and accessibility efforts in research, services, and policy that reduce disparities and increase equity for underrepresented, underserved, and intersectional populations within the autism community and enhance opportunities for autistic people. We urge the IACC to specifically pursue more research into supports for reproductive and prenatal health needs of autistic individuals; autistic individuals are frequently underserved on issues of reproductive health and pregnancy care, and these disparities make reproductive health a critical cross-cutting priority area that implicates both lifespan health implications and sex and gender differences within the autistic community.

Covid-19 and the Autism Community: Impact and Lessons Learned

ASAN reiterates the importance of including the Covid-19 and the Autism Community section and hopes for the continued inclusion of the section in future IACC strategic plans.



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Budget Recommendation

ASAN supports the recommendation to increase annual autism research funding to \$685 Million by 2025. We urge the IACC to prioritize “Lifespan issues” and “Research on disparities and development of culturally responsive tools and services as areas in need of research growth” while focusing more on the supports and services than interventions when increasing resources for “Evidence-based interventions and services.”

We again thank the IACC for inviting interested stakeholders to comment and help the IACC direct the future of autism research. For more information on ASAN and the autistic community’s research priorities, please visit our website at www.autisticadvocacy.org.