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The Autistic Self Advocacy Network appreciates the opportunity to submit comments for the April 17, 2024, IACC meeting. In our last comments to the IACC, ASAN provided feedback on the Report to Congress, the Summary of Research, and the 2023 Strategic Plan and laid out a vision for future research priorities for the IACC to consider. Our comment will focus on the recently-published 2019-2020 IACC Autism Research Portfolio Analysis Report and the GAO Report titled Autism Research and Support Services: Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened. ASAN urges the IACC to consider increasing the number of projects and total funding for our stated areas of interest in future years to guarantee the IACC adheres to its outlined priorities. ASAN requests NIH and IACC ensure stakeholders are engaged and included in the implementation and results of the GAO's recommendations.

### **Areas of Interest in the Portfolio Analysis Report**

#### Disparities in Diagnosis and the Application of Telehealth

Strategic Plan Objective 2 of Question 1 is to reduce disparities in early detection and access to services. ASAN has emphasized the importance of this objective due to the long-term impacts diagnostic disparities can have on access to services and supports. It is essential to fund research projects with this specific aim in mind to uphold health equity and improve outcomes for underserved populations. ASAN believes both the [Expanding Pathways to Early Screening and Intervention for Underserved Toddlers with ASD \(ASD-PATH\)](#) and [Race and Ethnic Discrepancies in Developmental Surveillance and EI](#) projects are good examples of this in practice. The first project notes three obstacles to early screening, diagnosis, and interventions and how these obstacles are magnified for families from Hispanic and low income backgrounds and seeks to build community capacity through coordination with federal programs and primary care providers. The second project assesses that minority children are less likely to be identified as autistic than white children. It seeks to determine the existence of racial and ethnic disparities in developmental screening and monitoring and explores whether differences in developmental surveillance can predict racial and ethnic disparities among autistic children under the age of 3. We would like to see additional studies on these topics and additional studies dedicated to improving access to screening and diagnostic tools for all ages. Because of these disparities in screening and identification, there are many autistic adolescents and adults who have been overlooked for diagnosis. Even as we work to close these disparities with improvements in screening, we must remember that these gaps will persist for older age cohorts, and recognize the impacts of later diagnosis and the unmet service needs that frequently accompany them.



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ASAN also has a keen interest in how telehealth can be used to close the gap in diagnostic disparities. We were particularly interested in the projects [Can novel telemedicine tools reduce disparities related to early identification of autism](#) and [Assessing Usability of mHealth Autism Screeners in the Medically Underserved](#). Both projects identify delays in diagnosis among children from underserved communities and use telehealth tools such as TELE-STAT, TELE-ASD-PEDS, and mHealth Autism Screeners to address the issue. ASAN would like to see more projects that investigate telehealth as a way to improve access to screening and diagnosis in underserved communities.

### Biology of Co-Occurring Conditions

One of the subcategories for Strategic Plan Question 2 is Co-Occurring Conditions. We support research on co-occurring conditions, but there are two key imbalances that we would like to highlight. First, of the 590 projects and \$190 million dollars dedicated to Question 2 in 2020, only 37 projects and \$8.96 million are dedicated to the biology of co-occurring conditions. ASAN would like to see more projects, and funding, dedicated to the biology of co-occurring conditions. Second, all of the 37 projects in 2020 focused on co-occurring conditions could be classified as pertaining to gastrointestinal, neurological, psychological, and/or chromosomal conditions. There were no projects dedicated to the biology of fine or gross motor skills, connective tissue disorders, dysautonomia, and other co-occurring conditions that have significant impacts on the lives of autistic people. ASAN would like to see studies cover the full-range of co-occurring conditions in line with comments provided in response to the RFI on Co-Occurring Conditions in Autism and the recommendations within Strategic Plan 2021-2023. We would also like to see more investment in translational research that builds on the findings from projects focused on the biology of co-occurring conditions and leads to the development of potential treatments and interventions, especially for physical co-occurring conditions.

### Biology across the Lifespan

The biology of autism across the lifespan is understudied. This makes it difficult to understand and address issues affecting autistic adults, including how our health needs may change as we age. ASAN would like to see more projects that investigate the biology of autism and co-occurring conditions across the entire lifespan such as Principal Investigator Ralph-Axel Mueller's project, [The Autistic Brain Over 45: The Anatomic, Functional, and Cognitive Phenotype](#), to better understand and fill the research gaps around the biology and effects of autism in adults.



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### Interventions for Co-Occurring Conditions

Co-Occurring Conditions is not a subcategory for Question 4 of the Strategic Plan. However, we noticed underinvestment in projects dedicated to co-occurring condition interventions, especially non-psychological and non-cognitive co-occurring conditions. For example, of the thirteen projects in the Occupational, Physical, and Sensory-Based subcategory, only one project, Principal Investigator Nathaniel Shanok's [Pilot Tennis Program](#), focused substantially, but not exclusively, on motor skill development. We implore the IACC to push for more projects dedicated to interventions such as habilitative services for motor skills issues and connective tissue disorders like Ehlers Danlos Syndrome in this subcategory. Other subcategories had more interventions related to co-occurring conditions, but the overwhelming majority of projects focus on psychological and cognitive co-occurring conditions. We support much of this research, but we call for a more equitable focus on the full range of co-occurring conditions in the coming years.

ASAN acknowledges and appreciates the number of projects dedicated to interventions for communication disorders and efforts to improve speech and language abilities. We especially commend projects focused on augmentative and alternative communication (AAC) tools and supports and hope to see a continued and growing investment in similar projects in the future.

### Behavioral Interventions

The behavioral subcategory for Question 4 covers a wide range of behavioral interventions for core autism symptoms and co-occurring conditions. Upon review of these projects we found that while there were several Cognitive Behavioral Therapy based interventions for anxiety and depression as co-occurring conditions, the majority of behavioral interventions for autism were based in Applied Behavioral Analysis or derived from it. ASAN calls upon the IACC to include a greater number of behavioral projects focused on evaluating how autistic people experience existing behavioral interventions and how those interventions affect their subjects' quality of life, including evaluating possible iatrogenic harms from interventions. We implore the IACC to support projects on behavioral interventions that do not rely on the conditioning of autistic people.

### Service Utilization and Access

ASAN has long sought more funding for services and supports research throughout our previous IACC comments, especially for the subcategory of Service Utilization and Access. There are a number of projects we see as exemplifying research we support in this area.



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These include [Disparities in Health Care Access and Utilization of Children during Autism Insurance Reform](#), [Mind the Gap](#), [Understanding the impact of disparity in special education services for underrepresented groups with ASD](#), [Building Better Bridges](#), [Understanding Barriers to Reproductive Health Care among Women with Autism Spectrum](#), [Barriers to Obstetric/Gynecological Health Care among Women with Autism Spectrum Disorder \(ASD\)](#), and [Rehabilitation Research and Training Center \(RRTC\) on Community Living and Participation](#). All of these projects illuminate disparities and barriers to service utilization and access. The first two cover general health care access and utilization. The next two address special education services. The following pair are dedicated to reproductive health care, and the last project consists of seven studies on community living interventions, policy, and outcomes. These are crucial areas of service utilization for the autistic community. We hope to see more projects like these in the next Portfolio Analysis Report.

### Community Inclusion

Another subcategory for Question 5 is Community Inclusion. There were only three Community Inclusion projects in 2020, all funded by the Institute of Museum Services. Autistic people need greater investment in research on community inclusion that seeks to improve the acceptance of autism and empower autistic individuals to participate in our communities. ASAN supports additional projects like Amelia Gibson's [Deconstructing Information Poverty: Identifying, Supporting, and Leveraging Local Expertise in Marginalized Communities](#) that equip autistic people and our loved ones with the skills to become self-advocates. We would like to see people like those trained to be self-advocates in the project involved in programming and planning in all areas of their community, not just at their local library.

### Practitioner Training

Services and Supports is the largest and fastest growing Question within the Strategic Plan. This is largely due to the Practitioner Training subcategory. Practitioner Training is the largest subcategory in Question 5, with over half of the funds and nearly half of the projects associated with the question committed to this subcategory. While practitioner training is an essential part of delivering high-quality services and supports, autistic people would also benefit from greater investment in Services Utilization and Access and Community Inclusion to reduce disparities in access, improve outcomes, and promote independence and community living. We believe this realignment in favor of services and supports research would lead to better outcomes for autistic people.



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### Community Integration

Promoting community living is among ASAN's highest priorities.. There were several great projects in this subcategory for Question 6. Principal investigator Wei Song's project, [Getting Out There: Identifying Individual, Environmental, and Service Use Factors Associated with Community Participation among Adults with ASD](#), correctly identifies community participation as a social determinant of health. It seeks to answer the questions of what types of community participation autistic adults prefer, what environmental challenges are there to optimal participation, and which services are needed to support participation among individuals with complex clinical needs. We would like to see more projects like this one because their results can inform higher quality service provision for autistic adults and our loved ones.

The projects funded by the Administration for Community Living piqued our interest as well. [Understanding Sexuality and Community Participation in Adults on the Autism Spectrum](#), addresses a gap in the research that few other projects in the entire portfolio analysis report engage with. [Getting Out: Development of a Web-Based Application to Leverage Social Capital and Enable Self-Directed Community Participation for Individuals with Significant Cognitive Disability](#) developed an app to help improve community participation rates for people with cognitive disabilities. [Increasing Community Participation in Young Adults with Autism Living in Rural Communities](#) addresses the needs of an underserved population. [Enhancing Community Participation for Adults with Autism Spectrum Disorders Through Peer-Mediated Transportation Interventions](#) explores barriers to community participation. We hope to see similar projects as part of this subcategory in the next Portfolio Analysis Reports.

### Health & Behavior Outcomes

Health & Behavior Outcomes is a subcategory for Question 6. This subcategory had nineteen projects and nearly \$2.8 million in funding in 2020. ASAN appreciates the dedication to the mental health needs of transition-age and adult autistic people and encourages continued investment in this area, but thirteen of the nineteen projects in the Health & Behavioral Outcomes subcategory in 2020 being dedicated to transition-aged youths or younger is a disproportionate representation of lifespan issues. As a longtime advocate for funding lifespan projects, ASAN does not propose cutting the projects or funding. Instead, we encourage further investment in projects that focus on health and behavior outcomes for the entire lifespan, especially for underrepresented age groups



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such as older adults and under-studied outcomes such as those relating to pregnancy and parenthood.

ASAN would like to highlight the projects [Sex-Specific Brain and Behavioral Predictors of Cognitive Aging in Middle-Aged Adults with Autism Spectrum Disorder](#), [The Influence of Social, Educational, and Work Experiences on Psychological Health for Transition-Aged Youth with Autism Spectrum Disorders](#), and [Measuring sexual and reproductive health service use and outcomes for transition-age youth with ASD](#) as examples of projects we would like to see more of in the future, as they either cover populations that are often overlooked, challenges that require more attention, or both.

#### Health Care Systems/Health Care Transition

The last subcategory in Question 6 we would like to focus on is Health Care Systems/Health Care Transition. In 2020, this subcategory had 8 projects funded at \$793,660. All eight projects exclusively focus on transition-age youth. While this is a crucial stage of life, health care systems inform service access across the entire lifespan. ASAN would like to see a deeper investment into this subcategory not only within the existing focus areas as outlined in projects [Alternative Approaches to Supporting ASD Services for Young Adults](#) and [Assessing and Improving Health Care Transition Services for Youth with Autism Spectrum Disorder](#), but also into projects that seek to resolve the eligibility and utilization rate gap, improve health care accessibility, and educate autistic people on self-advocacy in health care. We would also like to see projects that look at autistic people's eligibility and utilization rates for non-Medicaid services such as Medicare disability and Marketplace plans. Research on how to reduce any eligibility and utilization gaps would be particularly helpful.

#### Transition To Adulthood & Postsecondary Outcomes

We would also like to acknowledge that the Transition To Adulthood & Postsecondary Outcomes Subcategory accounts for 41 of 95 projects within Question 6 in 2020 and accounted for over half the funding at \$9.3 million. Similar to our comments for the Health & Behaviour Outcomes subcategory, ASAN supports projects that focus on transition to adulthood and postsecondary outcomes, but we would like to see a more equitable investment of resources in the next Portfolio Analysis Reports to adequately cover the entire lifespan, including living and working in the community.



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### Housing and Employment

In the vein of living and working in the community, we would like to see more projects focused on the barriers to housing and employment faced by autistic people throughout their lifespan across varying support needs, income, and levels of education. We appreciate the projects that have focused on preparing autistic people for competitive integrated employment and the handful of efficacy studies that examine these programs. Specific employment research can and should include studies on employment outcomes for autistic people and strategies for autistic people to get and keep jobs. Specific housing research can and should include efficacy studies on independent and community living arrangements and the effect of these arrangements on the health outcomes of autistic people.

### Cross-Cutting Objective and Theme

The 2016-2017 Strategic Plan contained the Cross-Cutting Objective of Autism in Girls and Women and the Cross-Cutting Theme of Disparities in Autism. Both seek to address underserved populations. ASAN supports the spirit of the objective and theme. Unfortunately, there were no projects in 2020 addressed screening and diagnosis, interventions, or services targeted specifically for autistic girls and women. In future years, we hope to see more funding and a greater number of projects dedicated to the needs of autistic people who are girls, women, or part of gender minorities as outlined in the Cross-Cutting Topic of Sex and Gender in Strategic Plan 2021-2023. Many of the projects we highlighted in this Portfolio Analysis Report belonged to the Cross-Cutting Theme of Disparities in Autism. In future years, we hope to see more projects that would be historically associated with this theme aligned with the priorities and recommendations laid out in the Cross-Cutting Topic of Promoting Equity and Reducing Disparities within Strategic Plan 2021-2023.

### **GAO Report**

The GAO Report released on February 28, 2024, titled [Autism Research and Support Services: Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened](#), provides a glimpse of how the NIH manages the IACC and operates the Office of National Autism Coordination (ONAC). The report looked at how the NIH helps the IACC and the National Autism Coordinator ensure that all coordinating agencies know about all the autism activities being worked on and how the NIH checks that agencies do not conduct duplicative autism activities without good reason.



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The report produced findings for both questions. For question 1, the GAO evaluated the NIH's coordination efforts on the eight leading interagency collaboration practices. The GAO found that while the NIH took steps to ensure all agencies were properly informed and regularly produced three reports for stakeholders, the NIH has no documented process for progress tracking. For question 2, the NIH claims to check for duplication of activities through regular discussions and reports, saying it has not found any duplication of activities. However, the NIH did not provide the GAO with written guidance indicating there was someone responsible for checking that agencies were not working on the same activities, the reasoning the NIH uses to determine if activities were duplicative, or how the results of these checks were documented.

Based on its findings, the GAO produced the following recommendations. It called for the development of a process to clearly track and report progress toward IACC goals and for the NIH to document the procedures ONAC uses to ensure federal autism activities are not duplicative. HHS agreed to both of GAO's recommendations.

While we concur with the GAO's recommendations, they have raised some comments and questions for us as an organization that regularly engages with the IACC. The NIH reported it has fulfilled the leading interagency collaboration practice of Including Relevant Participants by including six agencies and five people outside the federal government. Whether or not an agency or individual works for the federal government should not and hopefully is not the only metric that is used to decide what constitutes a relevant participant. ASAN would like a full list of the metrics NIH uses to ensure diversity of thought and self-advocate representation involved in the coordination process. Regarding the leading interagency collaboration practices of Defining Common Outcomes and Ensuring Accountability, ASAN asks that stakeholders engaged with the IACC receive the NIH's regular progress tracking updates that will be implemented at the GAO's request. We suggest that this take the form of a quarterly report offered in plain language and easy read versions posted online and distributed at every convening of the IACC. We would like more information on opportunities for self-advocates to weigh in on what activities are duplicative and for those opportunities to be created if they do not exist. We are concerned that the programs self-advocates value may be vulnerable to cuts unless the autistic community has the chance to express its priorities.





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### **Concluding Remarks**

ASAN thanks 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](http://www.autisticadvocacy.org).