



Member Feedback on the IACC Strategic Plan

Full Responses

April 13-14, 2022

Table of Contents

Administration for Children and Families (ACF)	4
Agency for Healthcare Research and Quality (AHRQ)	7
Centers for Disease Control and Prevention (CDC)	10
Centers for Medicare & Medicaid Services.....	14
Department of Defense (DoD)	18
Department of Education (ED).....	21
Health Resources and Services Administration (HRSA)	24
Department of Housing and Urban Development (HUD)	27
Indian Health Service (IHS).....	30
Department of Justice (DOJ)	33
Department of Labor (DOL)	37
Environmental Protection Agency (EPA)	43
<i>Eunice Kennedy Shriver</i> National Institute of Child Health and Human Development (NICHD).....	47
National Institute on Deafness and Other Communication Disorders (NIDCD)	54
National Institute of Environmental Health Sciences (NIEHS)	57
National Institute of Mental Health (NIMH)	62
National Institute of Neurological Disorders and Stroke (NINDS)	76
Social Security Administration (SSA).....	79
Substance Abuse and Mental Health Services Administration (SAMHSA)	82
Alice Carter.....	88
Samantha Crane.....	91
Aisha Dickerson.....	97
Dena Gassner	101
Alycia Halladay	105
Yetta Myrick	113
Lindsey Nebeker.....	116
Jenny Mai Phan	119
Joseph Piven.....	123
JaLynn R Prince	128
Susan Rivera	131
Matthew Siegel	134
Ivanova Smith.....	139

Hari Srinivasan	143
Julie Taylor	146
Paul Wang	149
Helen Tager-Flusberg	152
Stephen Whitlow	155

Name/Agency	Administration for Children and Families (ACF)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	I would say: How Can I Recognize the Signs of ASD, and Why is Early Detection "and early intervention" So Important?
Emerging Opportunities	There are opportunities for training and professional development of teachers and child care providers, more tools and trainings for them to be able to identify early signs and understand the referral process. More information in multiple languages and culturally sensitive.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	

Remaining Gaps	More work around family support and family engagement when it comes to the diagnosis, early intervention and supports for young children. More resources and supports for families, including mental health support.
Emerging Opportunities	Mental health support of families aligned with diagnosis and treatment.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	Culturally and linguistically relevant treatments, supports, and interventions.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	

Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	Consider the importance of mental health supports and assistance for individuals with ASD and their families.
Needs of underserved populations	Consider the development of linguistically and culturally relevant resources for families to understand the importance of early identification and the processes through referral and evaluation. Resources in languages most spoken in communities, links between families to support each other, resources where families would feel identified (multicultural photos, videos, etc).
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Agency for Healthcare Research and Quality (AHRQ)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	simplify - goal ... say "... supports in a timely manner to maximize potential for positive outcomes.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Centers for Disease Control and Prevention (CDC)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	No suggested edits.
Recent advances to include	Just published in March 2022: Zubler et al. Evidence-informed milestones for developmental surveillance tools. <i>Pediatrics</i> . 2022;149(3):e2021052138. The goals of the group that developed this work were to identify evidence-informed milestones to include in CDC checklists, clarify when most children can be expected to reach a milestone (to discourage a wait-and-see approach), and support clinical judgment regarding screening between recommended ages. Improvements in early detection noted in Shaw KA, Maenner MJ, Bakian AV, et al. Early identification of autism spectrum disorder among children aged 4 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018. <i>MMWR Surveill Summ</i> . 2021;70(No. SS-10):1–14. doi: https://www.cdc.gov/mmwr/volumes/70/ss/ss7010a1.htm . Shaw KA, McArthur D, Hughes MM, et al. Progress and disparities in early identification of autism spectrum disorder: Autism and Developmental Disabilities Monitoring Network, 2002-2016. <i>J Am Acad Child Adolesc Psychiatry</i> . 2021 Nov 24:S0890-8567(21)02000-1. doi: 10.1016/j.jaac.2021.11.019. CDC's Learn the Signs. Act Early. program for improving developmental monitoring and referral for developmental screening has shown promise with integration into Early Head Start. This is described here: Abercrombie J, Pann J, Shin F, et al. Evaluation of the feasibility and perceived value of integrating Learn the Signs. Act Early. developmental monitoring resources in Early Head Start. <i>Early Childhood Educ J</i> . Published online August 16, 2021.
Remaining Gaps	Are there health equity issues in the disparities to screening and access to diagnostic services? In other words, it's not sufficient just to identify disparities, but a scientific approach to evaluate causes of the disparities is needed.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	No suggested edits.
Recent advances to include	

Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	No suggested edits.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	No suggested edits.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	No suggested edits.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	

Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	No suggested edits.
Recent advances to include	<p>ADDM Network surveillance has expanded to include 16-year-old children. A manuscript on the results thus far is in preparation. The following will likely be the main findings, but because they have not yet been published, I include them only as informational: In this population-based surveillance cohort, by age 16 years, the majority of children with ASD had co-occurring neuropsychological conditions, and intellectual disability status was generally stable within individuals over time. An educational transition plan was completed for 94% of children with ASD but disparities were observed. What this could mean is that many adolescents with ASD have complex educational and health needs and will likely benefit from transition to adulthood planning and access to services and supports for people with ASD across their lifespans.</p>
Remaining Gaps	<p>The following publication indicates that few adolescents receive the recommended transition guidance and suggest that adolescents identified with autism in early childhood are more likely than adolescents in the general population to have unmet health care service needs. Improved provider training on the health care needs of adolescents with autism and coordination of comprehensive programs to meet their needs can improve delivery of services and adherence to recommended guidance for transitioning from pediatric to adult health care. Powell PS, Pazol K, Wiggins L, et al. Health status and health care use among adolescents identified with and without autism in early childhood – four U.S. Sites, 2018-2020. MMWR Morb Mortal Wkly Rep. 2021;70:605-611.</p>
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	No suggested edits.
Recent advances to include	<p>Speed of surveillance by the Autism and Developmental Disabilities Monitoring (ADDM) Network has been improved through new approaches described in the following: Maenner MJ, Graves SJ, Peacock G, et al. Comparison of 2 case definitions for ascertaining the prevalence of autism spectrum disorder among 8-year-old children. Am J Epidemiol. 2021;190(10):2198-2207. Maenner MJ,</p>

	Shaw KA, Bakian AV, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018. MMWR Surveill Summ. 2021;70(No. SS-11):1–16. doi: http://dx.doi.org/10.15585/mmwr.ss7011a1 .
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	CDC’s Study to Explore Early Development (SEED) is a multi-year, multi-site study to help increase our understanding of autism spectrum disorder (ASD) and other developmental disabilities. CDC, as part of SEED, Phase 3, is collecting information on the impact of COVID-19 on services, behaviors, and health during 2020 to help inform public health strategies for young children (aged 3–9 years) and their families, especially during public health emergencies. Learning more about the outcomes of interest for the study (listed below) could be considered with regard to the impact of COVID-19 on children and their families: Among children: --Education and use of remote learning --Changes in use of services and telemedicine --Experiences with testing and mitigation strategies --Changes in routines, health, and well-being Among families: --Changes in household structure --Health and well-being --Finances, employment, and health insurance --Changes in routines and support --Experiences with COVID-19 infection Behavior problems and everyday life skills before and after COVID-19
Needs of underserved populations	
Aware of any duplicative efforts?	Not at this time.
Final comments	No additional comments.

Name/Agency	Centers for Medicare & Medicaid Services
Preferred title for Strategic Plan	Other (please specify)
Comments on title	I prefer IACC Strategic Plan for Autism Research, Services, and Policy, but if this is largely about what areas we recommend research be developed (and not as much about how services and policies are developed, we should just use "Research".
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	No suggested changes/additions; pleased to see a focus on disparities mentioned in the document.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	No changes to suggest at this time.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	No changes to suggest at this time.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	

Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	Both remain relevant and thorough. No additional edits suggested at this time.
Recent advances to include	While not a “recent advance” the Autism Services page on Medicaid.gov, providing information about Autism and related services/supports covered under Medicaid, as well as the July 2014 Informational Bulletin on Medicaid coverage of services to treat ASD in children, could be included.
Remaining Gaps	Research on the areas currently included will be helpful in improving outcomes and maximizing quality of life across the lifespan. Consider enhancing the focus on various interventions including technologies, services, and other supports to improve outcomes and quality of life as well.
Emerging Opportunities	Nothing more to add at this time.
Outdated concepts	Nothing to add at this time.
Language to include or avoid	None.
Comments on Objectives	No. They continue to be relevant and thorough.
Other comments	None at this time.
Q5: Services and Supports	
Edits to Question or Aspirational Goal	CMS will continue to remain apprised of research in this area and determine how services and supports can be authorized under our programs.
Recent advances to include	As noted above, while not a “recent advance” the Autism Services page on Medicaid.gov providing information about Autism and related services/supports covered under Medicaid, as well as the July 2014 Informational Bulletin on Medicaid coverage of services to treat ASD in children, could be included.
Remaining Gaps	None at this time.
Emerging Opportunities	None at this time.
Outdated concepts	None at this time.
Language to include or avoid	None at this time.
Comments on Objectives	Again, we are glad to see a focus on addressing access and disparities as part of the Objectives for this question area. We believe Question 5 is an important area of focus for research and related funding.
Other comments	No additional comments.
Q6: Lifespan	

Edits to Question or Aspirational Goal	No changes to suggest at this time.
Recent advances to include	<p>o As previously noted, while not a “recent advance” the Autism Services page on Medicaid.gov providing information about Autism and related services/supports covered under Medicaid, as well as the July 2014 Informational Bulletin on Medicaid coverage of services to treat ASD in children, could be referenced if appropriate.</p> <p>o While not specific to individuals with Autism, CMS continues to work on ways to promote and enhance community integration for Medicaid beneficiaries including opportunities to work and live in the community. ☐ CMS continues to work with states and stakeholders to implement the 2014 Home and Community-Based Settings Regulation which set forth new requirements for several Medicaid authorities under which states may provide home and community-based long-term services and supports. The regulations enhance the quality of HCBS and provide additional protections to individuals that receive services under these Medicaid authorities, including by ensuring that they are supported to engage in community living as they desire.</p> <p>☐ In January 2021, CMS released guidance to state health officials designed to drive the adoption of strategies that address the social determinants of health (SDOH) in Medicaid and the Children’s Health Insurance Program (CHIP) so states can further improve beneficiary health outcomes, reduce health disparities, and lower overall costs in Medicaid and CHIP. SDOH describe the range of social, environmental, and economic factors that can influence health status—conditions that can often have a greater impact on health outcomes than the actual delivery of health services. The new guidance describes how states can leverage existing flexibilities under federal law to tackle adverse health outcomes that can be impacted by SDOH and supports states with designing programs, benefits, and services that can more effectively improve population health and reduce the cost of caring for our nation’s most vulnerable and high-risk populations. ☐ CMS is also partnering with the Administration for Community Living and the U.S. Department of Housing and Urban Development on a Housing and Services Resource Center launched in December 2021. The Center was created for people who work in the organizations and systems that provide housing resources and homelessness services, behavioral and mental health services, independent living services and other supportive services, and others who are working to help people live successfully and stably in the community.</p>
Remaining Gaps	None at this time.
Emerging Opportunities	Nothing additional to add at this time.
Outdated concepts	Nothing additional to add at this time.
Language to include or avoid	Nothing additional to add at this time.
Comments on Objectives	CMS agrees with the importance to fund research into the services and supports needed to support individuals with ASD across the lifespan.
Other comments	None
Q7: Infrastructure and Surveillance	

Edits to Question or Aspirational Goal	No changes to suggest at this time.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	Over the course of the Public Health Emergency (PHE), CMS has continued to make available to states tools and flexibilities in the provision of services in order to minimize disruption in the delivery and receipt of needed services. Moving forward, CMS would be interested in the results of any additional research with regard to how the COVID-19 PHE has impacted the autism community.
Needs of underserved populations	CMS was pleased to see the multiple references to understanding disparities in the strategic planning document; continuing to understand those inequities/disparities and how to address them are high priorities in the Biden Administration.
Aware of any duplicative efforts?	No
Final comments	No additional comments at this time.

Name/Agency	Department of Defense (DoD)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	Provide the earliest possible diagnosis for people on the autism spectrum so they can utilize appropriate interventions, services, and supports in a timely a manner to maximize positive outcomes.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	Question-Science instead of Biology? Aspirational Goal: Discover how alterations in brain development and the function of physiological systems lead to ASD to allow for the development of effective, targeted interventions and societal accommodations (not sure what is meant by this?) that improve quality of life for people on the autism spectrum.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	Question: What Causes ASD and Can Disabling (is disabling too strong of a word?) Aspects of ASD be Prevented or Preempted? Aspirational Goal: Causes of ASD will be discovered that inform diagnosis, prognosis, and interventions that will lessen the challenges and disabilities associated with ASD.
Recent advances to include	

Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	Develop a range of targeted treatments and interventions that optimize function and abilities across the lifespan to achieve meaningful outcomes and maximize quality of life for people on the autism spectrum. --should we include "individualized/individual" somewhere here? maybe ..that optimize individual function and abilities.... ---just thing we should emphasize it won't be a one size fits all and that we want many tools that people could choose from that best suits their goals/wants.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	Do we need to include something about affects of covid school shut downs, interruptions in services/therapies here? How to better provide continued services if there are major disruptions to everyday life in the future?
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	I think the question and goal are spot on. It would be very important to get the advocates feelings on this.

Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	noted this in Q5
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Department of Education (ED)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	Provide the earliest possible diagnosis for people on the autism spectrum AND THEIR FAMILIES, so they can be linked to appropriate interventions, services, and supports in as timely a manner as possible to maximize positive outcomes. disparities in childhood diagnosis and provision of services
Recent advances to include	
Remaining Gaps	Additional focus on family needs
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	

Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	Which Treatments and Interventions ARE MOST EFFECTIVE
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	Learning loss communication loss
Needs of underserved populations	
Aware of any duplicative efforts?	As Tom Insell said to a congressional committee--From a research perspective--we don't need less duplication--we need MORE duplication!!!
Final comments	

Name/Agency	Health Resources and Services Administration (HRSA)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	No
Recent advances to include	Impact of the pandemic in driving advances in diagnosis and providing services via telehealth. (This may fit better in another question).
Remaining Gaps	
Emerging Opportunities	Per above, impact of the pandemic in driving advances in diagnosis and providing services via telehealth. (This may fit better in another question).
Outdated concepts	Consideration could be given to updating the workforce section with new resources and increased focus on interdisciplinary care.
Language to include or avoid	The group could consider strengthening language around equity throughout (beyond reducing disparities).
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	No
Recent advances to include	No additions to suggest
Remaining Gaps	No additions to suggest
Emerging Opportunities	No additions to suggest
Outdated concepts	No additions to suggest
Language to include or avoid	No additions to suggest
Comments on Objectives	No edits
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	No
Recent advances to include	No suggestions to add
Remaining Gaps	No suggestions to add
Emerging Opportunities	No suggestions to add
Outdated concepts	No suggestions to add

Language to include or avoid	No suggestions to add
Comments on Objectives	No suggestions to add
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	No suggestions to add
Recent advances to include	No suggestions to add
Remaining Gaps	No suggestions to add
Emerging Opportunities	Increased understanding of new treatments and interventions delivered through telehealth or distant care during the pandemic.
Outdated concepts	No suggestions to add
Language to include or avoid	No suggestions to add
Comments on Objectives	No suggestions to add
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	No
Recent advances to include	Previous comment fits better under this goal related to advances related to providing services through telehealth or distant care
Remaining Gaps	
Emerging Opportunities	Potential opportunities to explore understanding of the workforce to include community health workers and others
Outdated concepts	Replace cultural competence with cultural humility
Language to include or avoid	Cultural competence
Comments on Objectives	No other comments
Other comments	Greater opportunity to focus on equity throughout this goal.
Q6: Lifespan	
Edits to Question or Aspirational Goal	No
Recent advances to include	No suggestions to add
Remaining Gaps	No suggestions to add
Emerging Opportunities	No suggestions to add
Outdated concepts	No suggestions to add

Language to include or avoid	No suggestions to add
Comments on Objectives	The content in this goal is still relevant and seems to be on target.
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	No
Recent advances to include	No suggestions to add
Remaining Gaps	No suggestions to add
Emerging Opportunities	No suggestions to add
Outdated concepts	National Survey on Children's Health released new data in 2021.
Language to include or avoid	No suggestions to add
Comments on Objectives	No suggestions to add
Other comments	
Impact of the COVID-19 pandemic	Understanding the impact of the pandemic on equity and access to care; potential innovations in workforce and delivery of service; issues related to isolation, increased mental health concerns
Needs of underserved populations	Access (including adequate coverage for) to diagnosis, intervention and other supports; interventions and other tools tested with or adapted to meet the needs of various racial and ethnic groups; workforce trained to provide services to a diverse population, including a developing a workforce reflective of the U.S. demographics.
Aware of any duplicative efforts?	No
Final comments	No

Name/Agency	Department of Housing and Urban Development (HUD)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	No
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Indian Health Service (IHS)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Department of Justice (DOJ)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	Topics to possibly add: module/training on recognizing the functional signs of ASD, for early childhood development certification programs, hands on training for head start and other early childhood care programs.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	The only comment I have on the cross cutting objective is to possible understand the differences between boys and men and women and girls, not just the unique challenges of women and girls? It seems that both genders have different sets of challenges because of their unique gender roles or societal expectations?
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	Topics that may be missing in addition to sensory and motor function are: adaptive functioning and the ability to respond to therapeutic strategies (I agree with learning about Biology, then, I would turn to functioning within a biological context)
Recent advances to include	
Remaining Gaps	The goal speaks about interventions, however, I don't see them in the topical area: therapeutic strategies to address biological needs Example: metabolic-dietary needs and physical exercise co-occurring mental health conditions-supported employment or activities that improve self esteem
Emerging Opportunities	Perhaps this section would reference questions 4,5, and 6 to point to biology and intervention together?
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	

Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	What steps can be taken -outside of genetics, that people can impact to prevent ASD? How is the science (what has been learned) underlying causes-informing prevention information for expectant mothers?
Emerging Opportunities	Prevention -how can people affect change?
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	This chapter is really important to assist people with ASD and their caregivers. It should be easily tie back to some of the major biological or mental health challenges that are observable by others. Those biological or behavioral challenges that may prevent a person from being integrated into the community.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	Thinking about how chapters 4,5, and 6 can be easily read, perhaps even printable and, usable for people with ASD and their caregivers.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	I like the goal
Recent advances to include	
Remaining Gaps	Under topics perhaps education should be changed to access and inclusion to education and educational planning.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	Specifically regarding disparities: Reduce disparities in access and in outcomes for underserved populations. Make services equally distributed: e.g. Policy,

	Teachers with training and skillset, equally distributed services across counties and school districts(wealthier neighborhoods v. economically disadvantaged neighborhoods) Shore up disparities in access to services within counties and states.
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	I like the goal
Recent advances to include	
Remaining Gaps	Health and Safety are both quality of life markers. I think one thing that may be missing is access to justice systems. Helping people with ASD have access to diversion programs just like people without disabilities, provides low level offenders the opportunity to stay out of the justice system. As victims, people with ASD need accommodations to have access to justice to be able to hold perpetrators accountable and receive compensation/treatment. Many prosecutors are still in need of understanding people with disabilities. BJA has developed some tools, but much more is needed.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	Infrastructure Surveillance may be a better place for my comment on disparity of services within counties and school districts
Recent advances to include	
Remaining Gaps	strengthening public-private partnerships, health, safety and justice partnerships
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	As a mom with a daughter on the spectrum, we received a letter her last year of High School (2020) that stated: Services are terminated. Although our daughter is high functioning and received services for many years (in a really good place), receiving such a letter was terrible. If I were a mom that relied on services, I was just told, sorry, we can no longer help you and good luck. We

	were looking forward to anything Vocational Rehab could provide, but, they no longer picked up the phone. I'm not sure what the take away is, other than the impact is big and we need a better plan for those in need.
Needs of underserved populations	One underserved community are those with limited English proficiency who may not be able to advocate for their loved one. Another underserved community are children who have incarcerated parents or children leaving foster care at the age of 18.
Aware of any duplicative efforts?	
Final comments	I really like what has been accomplished. My only comment would be to think about translating very helpful information into actionable take-aways (information and helpful guidance)for people with ASD or their care-givers.

Name/Agency	Department of Labor (DOL)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	The community-based question should change to reflect inclusive language. I suggest revising it to state: How Can We Recognize the Traits of Autism and Why Is Early Identification Crucial? Likewise, the aspirational goal would also benefit from a major revision. I suggest revising it to read: Foster practices that promote access to early diagnosis for people on the autism spectrum and their families to increase access to supports, services, and resources and bolster quality of life
Recent advances to include	
Remaining Gaps	Major gaps involve intersectionality. Namely, research and practice needs to examine gaps in diagnosis that can involve race, ethnic background, gender, gender identity, sexual orientation, economic status, etc. Research and practice also needs to focus on gaps in diagnosis that can result from masking or traits of autism, including through adaptation. Some children and youth receive much later diagnoses because of this phenomenon
Emerging Opportunities	Research and practice should seek to address these major gaps that relate to intersectionality. Namely, research needs to examine gaps in diagnosis concerning race, ethnic background, gender, gender identity, and sexual orientation. This focus should include how the diagnostic criteria in DSM may reflect historical cultural and linguistic biases, as well as presumptions.
Outdated concepts	None of the concepts or ideas in this chapter seem to be outdated or need to be retired.
Language to include or avoid	The concepts discussed all seem to be relevant. It would be preferable not to use the word “signs” of autism and instead refer to more neutral language, such as traits and characteristics.
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	The current text of the question focuses only on biology while not describing neurology. I suggest revising it to state: What Core Neurology and Physiological Differences Shape Autism and the Lived Experience of People on the Autism Spectrum? I would likewise suggest changing the aspirational goal to reflect inclusive and neutral language. I suggest revising it to read: Discover how differences in development of the brain and nervous system and human biology shape autism to propel focused supports and services to increase the quality of life of people on the autism spectrum.

Recent advances to include	
Remaining Gaps	This chapter focuses more extensively on certain physiological systems at the expense of under-focusing on other areas. For instance, some recent research has indicated that people on the autism spectrum have major differences in the structure and functioning of the eyes; this affects visual processing. Likewise, people on the autism spectrum have major differences in the nervous system that can extend to peripheral nerves. Yet, research underfocuses on this context.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	This chapter should strive to make use of phrasing that is neutral in tone when possible. This means avoiding use of words, such as intervention and treatment, in favor of inclusive phrases, such as enhanced services to address needs and difficulties.
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	The question and aspirational goal would both benefit from revisions. A suggested phrasing of the question is: Which Key Factors Shape and Underlie Core Characteristics of Autism and How Can Impairments Be Addressed to Promote Quality of Life? The aspiration goal should read: Factors that shape the development and lived experience of autism will be examined to help drive improved diagnosis, outcomes, and supports and services to increase quality of life.
Recent advances to include	
Remaining Gaps	This question area should make sure to consider differences that relate to intersectionality. Notably, most historical knowledge on neurological and physiology has historically come from studying population groups that do not reflect full life diversity.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	The question and goal would both benefit from adjustment. The question should read: Which Focused Health and Educational Services Can Improve Outcomes and Increase Quality of Life? The goal should read as: Development a range of focused health and educational services to that can help improve

	outcomes across the life course and maximize quality of life for people on the autism spectrum.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	The word treatment is non-neutral in tone. One should instead refer to phrases, such as focused healthcare and education services to help address difficulties
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	The phrasing for the question sounds fine. The phrasing for the aspiration goal should be revised to read as: Communities will help advance and foster high-quality promising and best practices to provide supports and services that support people on the autism and their families; this will help maximize the quality of life and wellbeing of people on the autism spectrum and their families across the life course.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	This focus area should make sure to emphasize supports and services that consider people on the autism spectrum who come from diverse backgrounds who may have diverse support needs. It should also promote efforts to scale up high-quality supports and services and drive training for professionals. This chapter and chapter 6 should also make sure to consider supports for understudied and underfocused areas. These areas include supporting access to transportation (for work, school, community life, etc.), career readiness, and resilience and other facets of positive psychology.
Outdated concepts	The concepts and ideas in this chapter appear relevant.
Language to include or avoid	It would be highly preferable not to use ASD given its association with disorder and instead refer to autism and people on the autism spectrum.
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	Both the question and aspirational goal would greatly benefit from revision. The adjusted question should read as: How Can We Best Meet the Needs of People on the Autism Spectrum as They Progress Through and Into Adult Life? The adjusted goal should read as: All people on the autism spectrum can attain key opportunities to lead self-determined lives in the communities of their choice;

	they can fully access work, school, supports and services, community life, and social connections.
Recent advances to include	The plan should make sure to include recent research studies that examine key advances in fostering gainful employment and community life.
Remaining Gaps	Unmet needs involve several key areas. First, limited research and practice examines how to help empower people on the autism spectrum who face major communication challenges and use AAC devices and systems. Second, research and practice has not fully examined these life course focuses in regard to intersectional focuses, including life diversity (e.g., race, ethnic background, gender, etc.). Third, we have much more limited research spending in all of these areas of the life course and quality of life in comparison to research spending on genetics, biology, etc. Fourth, the literature often lacks high quality research on promising and best practices and approaches and scaling.
Emerging Opportunities	The plan should make sure that it notes relevant federal policies that can boost access to gainful competitive, integrated employment for people on the autism spectrum. These policies include the Workforce Innovation and Opportunity Act and the National Apprenticeship Act. The latter law has a 7% utilization goal to recruit, hire, retain, and advance people with disabilities in certain sponsors of apprenticeship programs. This goal parallels the 7% utilization goal for federal contractors to hire, recruit, retain, and advance people with disabilities. (This goal itself also parallels the requirement by the federal government to recruit, hire, retain, and advance people with disabilities. This goal has a 12% requirement for all people with disabilities and a 2% goal for people who have significant disabilities, such as people on the autism spectrum.) This chapter and chapter 5 should also make sure to consider supports for understudied and underfocused areas for the life course. These areas include supporting access to transportation (for work, school, community life, etc.), career readiness, and resilience and other facets of positive psychology.
Outdated concepts	The concepts and ideas in this chapter seem aligned and relevant.
Language to include or avoid	It would be preferable not to use ASD but instead refer to autism given that ASD carries the non-neutral connotation of disorder.
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	The question should include revisions to reflect its context at a more concrete level since infrastructure system sounds rather abstract. I suggest revising it to state: How Can We Foster Key Resources to Meet the Needs of People on the Autism Spectrum and Their Families? The aspirational goal would also benefit from changes to make it sound more concrete. I suggest revising it to state: Improve resources and ways to monitor people on the autism spectrum and advance high quality research, supports, and services.
Recent advances to include	
Remaining Gaps	Unmet needs concern making sure that all infrastructure includes consideration of the life course. At present, much of the discussion on monitoring, resources,

	and infrastructure focuses extensively on young children at the expense of leaving out adolescents and adults. The overall system of resources and infrastructure should match the modern worldview of the lived experience of autism across the life course. This means, for instance, tracking outcomes for adolescents and adults and examining unmet needs and outcomes in similar ways as for children.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	If feasible, it would be preferable not to use the word “surveillance” given that word’s broader connotations in society. It is true that this word has a historical meaning for healthcare tracking. However, it has a non-neutral connotation for much of society. Namely, the word has become associated with problems, wrongdoing, and law enforcement.
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	The COVID-19 pandemic has led to profound hardships for many people and their families. People with developmental disabilities, including people on the autism spectrum, have often faced greater challenges. They have experienced strife concerning employment, access to community-based services, health and wellness, and quality of life. Many folks have faced difficulties concerning mental and physical health and wellness, including from experiences that relate to loss of family members and friends and trauma. They have also faced loss of jobs and lower economic wellbeing. Further, many people have contracted COVID-19 and then developed long COVID at high rates. The IACC should both recognize this context and address it in research and practice. It should also strive to examine how to make resources accessible to help prepare and support people on the autism spectrum for future global health emergencies.
Needs of underserved populations	The IACC should aim to recognize and discuss the widespread barriers to access supports and services. The research body identifies some of these barriers. However, it contains major limitations, particularly with regard to disparities faced by autistic adults who come from underserved population groups. Indeed, the research literature itself reflects major biases about autism and disparities among participants. Research studies are much less likely to include autistic girls and women and autistic people who come from racial minority groups. Likewise, research studies often tend not to gather demographic information on geography gender identity and sexual orientation. Research findings on socio-economic status and income of autistic adults overall and from diverse backgrounds also remain limited. The IACC should thus prioritize efforts to address these gaps in the research literature and among access to supports and services. Furthermore, the IACC should recognize the limitations of the diagnostic criteria for autism in the DSM-5. Issued in 2013, these criteria reflect findings from research studies published a decade or more ago. These studies as a body showed even greater bias for race and ethnicity, gender, socio-economic status, etc. than current studies. The vast majority of autistic people who participated in these studies were likely white, male, and from relatively high socio-economic status. Similarly, the diagnostic criteria in DSM-5 also reflected

	<p>a body of research literature (published in 2012 or earlier) with vastly fewer studies on adults and the life course.</p>
<p>Aware of any duplicative efforts?</p>	<p>I am not aware of duplicative efforts in autism research. If anything, some agencies have a key role in funding research projects that federal departments may lack resources to find. For instance, NIH and NIDILRR have funded research studies and projects on employment and community living. Findings and lessons learned from these studies and projects bear major relevance for other federal departments. Some of these departments may have limited resources to conduct original research studies.</p>
<p>Final comments</p>	<p>With help from OARC staff, IACC members should jointly create a guide for how to use inclusive and strengths-based language in IACC documents. It should consider best practices for this context. For instance, it can include suggestions from the 2020 Autism in Adulthood Article on Avoiding Ableist Language. (The URL for that article is here: https://www.liebertpub.com/doi/10.1089/aut.2020.0014.) As for research focuses, the IACC should also focus on addressing research gaps for certain aspects of the lived experience of autistic people that can hinder efforts to improve quality of life. Notably, the research literature on autism tends to under-focus on the executive functioning, sensory, and motor (gross and fine motor) domains. Most research focuses instead only on communication and social interaction. This imbalance has meant that society and diagnostic criteria in DSM-5 do not sufficiently place priorities on supports and services for these areas. (The criteria in DSM-5, for instance, barely mention sensory focuses and do not mention executive functioning and motor focuses at all.) Receiving key supports, services, and tools to assist with executive functioning, sensory processing, and motor coordination can make a major difference for autistic youth and adults. It can play a large role in increasing access to employment, community living, and health and wellness. Thus, the IACC should acknowledge this situation and consider it for the Strategic Plan.</p>

Name/Agency	Environmental Protection Agency (EPA)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	none
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	<p>I am not certain how to cover this issue or under which objective. EPA has included a cross-Agency strategy, "Consider the Health of Children at All Life Stages and Other Vulnerable Populations" in the final draft of the FY 2022-2026 EPA Strategic Plan. "Children's environmental health refers to the effect of the environment on an individual's growth, wellness, development, and risk of disease at all life stages. EPA actions will be informed by two important considerations: (1) the scientific understanding of childhood as a sequence of life stages, from conception through infancy and adolescence to early adulthood (age 21); and (2) the recognition that protecting children's health at all life stages is necessary to achieve the Agency's mission. Children may be at greater risk to environmental contaminants than adults if exposure occurs during windows of enhanced toxicological susceptibility. Children may also experience greater exposure than adults as they eat more, drink more, and breathe more in proportion to their body size and due to their unique behaviors, such as breast feeding, crawling, and hand-to-mouth activity. Children can be exposed to environmental contaminants that their caregivers may inadvertently bring home from their workplace, while adolescent workers may be directly exposed to harmful chemicals in the workplace. Finally, the effects of early life exposures may become apparent during childhood and/or may not arise until adulthood or in later generations. " The action called for under this cross-cutting strategy is to "Use Science and Policy to Strengthen Protections for Children at All Life Stages and Vulnerable Populations." It seems important to specifically call out the ASD and/or neurodiverse community as potentially vulnerable to impacts of environmental exposures. And to expect that environmental health information and data for ASD individuals at all life stages be evaluated and considered in actions that concern human health (similar language is goal for children in the draft EPA strategic plan).</p>
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	

Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	Again, not certain where this could be addressed. From a research and policy standpoint, it may be worth including as a goal that the neurodiverse community is specifically called out as a potentially vulnerable group, and that the needs of neurodiverse individuals are specifically addressed, in implementation of EO 14035. In addition to ensuring the perspectives and needs of this community are addressed in the research funded and conducted, Agencies can have goals to provide training and employment opportunities that take advantage of the full range of skills and capabilities that members this community can provide. This would be similar to so much of what federal agencies have done under affirmative action policies.
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	Maybe my comment under Question 5 is more appropriate here?
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	Or here?
Impact of the COVID-19 pandemic	As for children and other vulnerable groups, ASD community has be highly impacted by public health policies implemented during this pandemic. Research and policy to address collateral damage to these vulnerable groups should be prioritized urgently. Our federal public health plans and policies need to be based on sound science and updated continuously in real time to evaluate risks and implement actions that maximize welfare of all vulnerable groups - those most vulnerable to impacts of viruses as well as those vulnerable to impacts of policies to minimize transmission.
Needs of underserved populations	Consider that very few within the autism community are fully served.
Aware of any duplicative efforts?	
Final comments	Understanding that this is a research strategy, emphasizing actions and solutions is important. Focusing on updating gaps analyses, funding application and translation of advancements in knowledge generated under the previous strategies should be a priority. Facilitating coordination across Agencies continues to be important.

Name/Agency	Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Spectrum Disorder
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	<p>Carpenter KLH, Hahemi J, Campbell K, Lippmann SJ, Baker JP, Egger HL, Espinosa S, Vermeer S, Sapiro G, Dawson G. Digital Behavioral Phenotyping Detects Atypical Pattern of Facial Expression in Toddlers with Autism. <i>Autism Res.</i> 2021 Mar;14(3):488-499. [PMID: 32924332] Major S, Campbell K, Espinosa S, Baker JP, Carpenter KL, Sapiro G, Vermeer S, Dawson G. Impact of a digital Modified Checklist for Autism in Toddlers-Revised on likelihood and age of autism diagnosis and referral for developmental evaluation. <i>Autism.</i> 2020 Oct;24(7):1629-1638. [PMID: 32466674] Constantino JN, Abbacchi AM, Saulnier C, Klaiman C, Mandell DS, Zhang Y, Hawks Z, Bates J, Klin A, Shattuck P, Molholm S, Fitzgerald R, Roux A, Lowe JK, Geschwind DH. Timing of the Diagnosis of Autism in African American Children. <i>Pediatrics.</i> 2020 Sep;146(3). [PMID: 32839243 Shaw KA, Maenner MJ, Baio J; EdS1, Washington A, Christensen DL, Wiggins LD, Pettygrove S, Andrews JG, White T, Rosenberg CR, Constantino JN, Fitzgerald RT, Zahorodny W, Shenouda J, Daniels JL, Salinas A, Durkin MS, Dietz PM. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016. <i>MMWR Surveill Summ.</i> 2020 Mar 27;69(3):1-11. [PMID: 32214075] Chang Z, Di Martino JM, Aiello R, Baker J, Carpenter K, Compton S, Davis N, Eichner B, Espinosa S, Flowers J, Franz L, Harris A, Howard J, Perochon S, Perrin EM, Krishnappa Babu PR, Spanos M, Sullivan C, Walter BK, Kollins SH, Dawson G, Sapiro G. Computational Methods to Measure Patterns of Gaze in Toddlers With Autism Spectrum Disorder. <i>JAMA Pediatr.</i> 2021 Aug 1;175(8):827-836. doi: 10.1001/jamapediatrics.2021.0530. PMID: 33900383; PMCID: PMC8077044. The research team at Duke University (Chang et al., 2021) developed a prototype app for mobile devices that can screen children at risk for autism spectrum disorder (ASD). In the study, the app could distinguish toddlers diagnosed with ASD from typically developing toddlers by tracking their eye movements while watching videos. With more research, the app could one day screen infants and toddlers and refer them for early intervention, when chances for treatment success is greatest. Wetherby AM, Guthrie W, Hooker JL, Delehanty A, Day TN, Woods J, Pierce K, Manwaring SS, Thurm A, Ozonoff S, Petkova E, Lord C. The Early Screening for Autism and Communication Disorders: Field-testing an autism-specific screening tool for children 12 to 36 months of age. <i>Autism.</i> 2021 Oct;25(7):2112-2123. doi: 10.1177/13623613211012526. Epub 2021 May 7. PMID: 33962531; PMCID: PMC8418999. There is a critical need for accurate screening tools for autism spectrum disorder in very young children so families can access tailored</p>

	<p>intervention services as early as possible. However, there are few screeners designed for children 18–24 months. Developing screeners that pick up on the signs of autism spectrum disorder in very young children has proved even more challenging. Wetherby and colleagues (Wetherby et al., 2021) examined a new autism-specific parent-report screening tool, the Early Screening for Autism and Communication Disorders for children between 12 and 36 months of age. Meera SS, Donovan K, Wolff JJ, Zwaigenbaum L, Elison JT, Kinh T, Shen MD, Estes AM, Hazlett HC, Watson LR, Baranek GT, Swanson MR, St John T, Burrows CA, Schultz RT, Dager SR, Botteron KN, Pandey J, Piven J; IBIS Network. Towards a Data-Driven Approach to Screen for Autism Risk at 12 Months of Age. <i>J Am Acad Child Adolesc Psychiatry</i>. 2021 Aug;60(8):968-977. doi: 10.1016/j.jaac.2020.10.015. Epub 2020 Nov 5. PMID: 33161063; PMCID: PMC8127075. Miller LE, Dai YG, Fein DA, Robins DL. Characteristics of toddlers with early versus later diagnosis of autism spectrum disorder. <i>Autism</i>. 2021 Feb;25(2):416-428. doi: 10.1177/1362361320959507. Epub 2020 Sep 26. PMID: 32981352; PMCID: PMC7870497. This study aims to better understand the emergence of symptoms, particularly potential differences in symptom presentation and developmental functioning, based on timing of diagnosis.</p>
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	<p>Intellectual and developmental disabilities and ADHD should be mentioned as co-occurring conditions as well... We suggest the potential value of blood-based biomarkers based on proteomic, metabolomic, other signatures as an area of potential exploration to objective 1. If one is going to collect large cohorts, it makes sense to store a sample from them for later analysis, not just genomic (objective 3).</p>
Emerging Opportunities	<p>o Comment: Under the section “Circuit Activity in ASD” (Question 2, p. 17 of the Strategic Plan), we would suggest summarizing the findings of Smith et al. <i>J Psych Res</i> 138 (2021) 89–95, https://doi.org/10.1016/j.jpsychires.2021.03.057. This NICHD-supported publication shows differences in neural circuit activity patterns (as measured by EEG) between individuals with fragile X syndrome (FXS) and typically-developing controls, as well as differences between males and females with FXS. Males and females with FXS showed higher activity in the theta band than typically-developing controls. Males with FXS also showed higher gamma power and lower alpha than typically-developing controls. These</p>

	findings are interesting in light of other well-established research showing that theta and gamma frequencies are related to learning and memory (Shirvalkar et al., PNAS 2010, as one example), and that alpha frequencies are related to attentional ability.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	<ul style="list-style-type: none"> o Comment: One of the objectives for Question 2 relates to fever leading to behavioral improvement. Does that remain valid? o Comment: For the Objectives under Question 2, one could add a bullet such as, "Develop biomarkers that are reliably translatable between animals and humans, and which can assess information processing in the brain for specific cognitive tasks, such as neural algorithms for memory encoding vs. recall."
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	<p>Satterstrom FK, Kosmicki JA, Wang J, Breen MS, De Rubeis S, An JY, Peng M, Collins R, Grove J, Klei L, Stevens C, Reichert J, Mulhern MS, Artomov M, Gerges S, Sheppard B, Xu X, Bhaduri A, Norman U, Brand H, Schwartz G, Nguyen R, Guerrero EE, Dias C; Autism Sequencing Consortium; iPSYCH-Broad Consortium, Betancur C, Cook EH, Gallagher L, Gill M, Sutcliffe JS, Thurm A, Zwick ME, Børghlum AD, State MW, Cicek AE, Talkowski ME, Cutler DJ, Devlin B, Sanders SJ, Roeder K, Daly MJ, Buxbaum JD. Large-Scale Exome Sequencing Study Implicates Both Developmental and Functional Changes in the Neurobiology of Autism. Cell. 2020 Feb 6;180(3):568-584.e23. doi: 10.1016/j.cell.2019.12.036. Epub 2020 Jan 23. PMID: 31981491; PMCID: PMC7250485. Bai D, Marrus N, Yip BHK, Reichenberg A, Constantino JN, Sandin S. Inherited Risk for Autism Through Maternal and Paternal Lineage. Biol Psychiatry. 2020 Sep 15;88(6):480-487. doi: 10.1016/j.biopsych.2020.03.013. Epub 2020 Apr 2. PMID: 32430199; PMCID: PMC7483301.</p>
Remaining Gaps	Consider to add other omics for integration to Objective 3: metabolomic, proteomic, microbiome
Emerging Opportunities	
Outdated concepts	<ul style="list-style-type: none"> o Comment: In the section on "Sex Differences" in Question 3, it mentions the extreme male brain hypothesis of ASD. This might benefit from being updated, as the findings are murky (eg, Worsham et al., Front. Psychiatry, 01 July 2021 https://doi.org/10.3389/fpsyt.2021.655438). As noted in that article, prenatal steroid exposure interacts in complex ways with genomic, inflammatory, environmental, and obstetrical risk factors for ASD. o Comment: In the Introduction to Question 3, it says "progress on the causes of these co-occurring symptoms is ahead of that for the core symptoms of autism." Is that really the case? o Comment: Under "Genetic Testing and Communication of Risk" in Question 3, it says, "we expect that WES will gradually supplant CMA." Has this happened?

Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	<ul style="list-style-type: none"> ○ Myers RK, Carey ME, Bonsu JM, Yerys BE, Mollen CJ, Curry AE. Behind the Wheel: Specialized Driving Instructors' Experiences and Strategies for Teaching Autistic Adolescents to Drive. <i>Am J Occup Ther.</i> 2021 May 1;75(3):7503180110p1–7503180110p11. doi: 10.5014/ajot.2021.043406. PMID: 34781345; PMCID: PMC8095704. ○ Curry AE, Metzger KB, Carey ME, Sartin EB, Huang P, Yerys BE. Comparison of Motor Vehicle Crashes, Traffic Violations, and License Suspensions Between Autistic and Non-Autistic Adolescent and Young Adult Drivers. <i>J Am Acad Child Adolesc Psychiatry.</i> 2021 Jul;60(7):913-923. doi: 10.1016/j.jaac.2021.01.001. Epub 2021 Jan 13. PMID: 33453361. ○ The ability to safely drive a vehicle has great potential to increase independence for adolescents with autism spectrum disorders (ASD). Curry and her team used a unique data source to examine adverse driving outcomes such as crashes and traffic violations. In contrast with prior studies with small sample sizes, this study found that newly licensed adolescent drivers with ASD have similar to lower rates of adverse driving outcomes compared with the control group without ASD. They also identified characteristics of real-world crashes that were different between the two groups, providing insights for additional training to augment safe driving for adolescents with ASD. ○ Whitehouse AJO, Varcin KJ, Pillar S, Billingham W, Alvares GA, Barbaro J, Bent CA, Blenkley D, Boutrus M, Chee A, Chetcuti L, Clark A, Davidson E, Dimov S, Dissanayake C, Doyle J, Grant M, Green CC, Harrap M, Iacono T, Matys L, Maybery M, Pope DF, Renton M, Rowbottom C, Sadka N, Segal L, Slonims V, Smith J, Taylor C, Wakeling S, Wan MW, Wray J, Cooper MN, Green J, Hudry K. Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis. <i>JAMA Pediatr.</i> 2021 Nov 1;175(11):e213298. doi: 10.1001/jamapediatrics.2021.3298. Epub 2021 Nov 1. PMID: 34542577; PMCID: PMC8453361 Currently, most children are not targeted for intervention until they receive a formal diagnosis. Whitehouse and colleagues (2021) examined the efficacy of a parent-mediated intervention for ASD beginning at 9 months of age, before symptoms of ASD manifest. The study found that the intervention was effective at both reducing the severity of later ASD symptoms across early childhood and reducing the chances of an ASD diagnosis at 3 years of age. ○ Bodfish JW, Lecavalier L, Harrop C, Dallman A, Kalburgi SN, Hollway J, Faldowski R, Boyd BA. Measuring the Functional Impact of Behavioral

	Inflexibility in Children with Autism Using the Behavioral Inflexibility Scale: Clinical Interview (BIS-CI). J Autism Dev Disord. 2021 Apr 2. doi: 10.1007/s10803-021-04984-z. Epub ahead of print. PMID: 33811282.
Remaining Gaps	Under Objective 1, the number of genetic syndromes related to ASD needs to acknowledge an increasingly large number of monogenic disorders and CNV conditions with ASD symptoms as a frequent feature.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	We've experienced a global pandemic since the last ASD SP, and this surely cannot be ignored. The impact on caregivers and educators, not to mention those impacted by ASD, is immense. Constantino et al paper in Am J Psychiatry in 2020: (https://pubmed.ncbi.nlm.nih.gov/32854530/)
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	o Comment: In the section on "Caregiver Supports" in Question 5, it might be helpful to temper the endorsement of parent training. The preceding paragraph just enumerated the stress and burden that parents/caregivers face (also see Greenberg et al., J Fam Psychol 2021 Apr;35(3):417-422.) The Greenberg et al. article reports significant impacts of caregiving a child with special needs, even beyond the parent's own genetic risk for anxiety or depression. Adding additional responsibilities such as parent-mediated interventions should be undertaken very carefully, if at all.
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	Service coordination, housing, and support needs for adults with ASD continued to be a huge challenge and is inadequately supported (Objective 1). Consider to add transgender or gender-fluid issues for those with ASD in Objective 2 or 3.
Emerging Opportunities	

Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	Services workforce issues seem more relevant in Question 6 than here.
Remaining Gaps	Objective 4 is too limiting in its list of co-occurring conditions. Consider to include GI, ADHD, maybe immune. Issues.
Emerging Opportunities	Expand Objective 1 to urge biological sample collection on ALL cohorts, whenever feasible.
Outdated concepts	Use NDA to replace NDAR.
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	<p>Constantino JN, Sahin M, Piven J, Rodgers R, Tschida J. The Impact of COVID-19 on Individuals With Intellectual and Developmental Disabilities: Clinical and Scientific Priorities. <i>Am J Psychiatry</i>. 2020 Nov 1;177(11):1091-1093. doi: 10.1176/appi.ajp.2020.20060780. Epub 2020 Aug 28. PMID: 32854530; PMCID: PMC8040931. Sherby MR, Walsh TJ, Lai AM, Neidich JA, Balls-Berry JE, Morris SM, Head R, Prener CG, Newland JG, Gurnett CA; COMPASS-T Study Group. SARS-CoV-2 screening testing in schools for children with intellectual and developmental disabilities. <i>J Neurodev Disord</i>. 2021 Sep 1;13(1):31. doi: 10.1186/s11689-021-09376-z. PMID: 34465306; PMCID: PMC8407928. In July, NICHD announced funding for new projects to identify ways of safely returning students and staff to in-person schools in areas with vulnerable and underserved populations. The projects aim to address the needs of children with unequal access to COVID-19 testing, as well as those who face barriers to attending school remotely, such as lack of computer or internet access. Without in-person schooling, many children miss out on school-based meals, speech or occupational therapy, and after-school programs. Loss of such services disproportionately affects minorities, socially and economically disadvantaged children, children with disabilities, and those with medical complexities. NICHD-supported scientists in St. Louis also investigated ways to optimize safety of in-person schooling for children with intellectual and developmental disabilities (IDDs) including ASD. A virtual learning environment can be difficult for children with IDD and their families, but people with IDD may also be more vulnerable to severe disease and complications if they are infected with the coronavirus. The study found that weekly saliva testing and other safety</p>

	measures in schools—such as mask wearing and reduced class sizes—were effective in protecting staff, children, and their families.
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	National Institute on Deafness and Other Communication Disorders (NIDCD)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	no
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	no
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	no
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	No
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	Re: topics, add "communication options for minimally verbal adults"
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	no
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	no
Final comments	no

Name/Agency	National Institute of Environmental Health Sciences (NIEHS)
Preferred title for Strategic Plan	Other (please specify)
Comments on title	Need to clarify whether the strategic plan should include research on services and policy or more generally on services and supports, if the latter is true than that would be a tremendous expansion of areas covered by the strategic plan. Would recommend restricting the strategic plan to research, including research on services and supports.
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	We encourage continuing to emphasize the importance of studies on universal screening to demonstrate its importance and utility in improving outcomes.
Recent advances to include	The strategic plan should emphasize the development of novel tools for diagnosis and screening, including those supported by the recent Early Screening for Autism Spectrum Disorder funding announcements (RFA-MH-19-120, and RFA-MH-19-121). A critical component of this research is the validation of these tools in diverse and underserved populations.
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	One comment we have on the cross-cutting objective is the need to address both sex and gender as biological and social constructs, such that this objective is inclusive of trans and non-binary individuals.
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	We would suggest considering adding a microbiome focus to Question 2, it is currently in Question 3. The microbiome is both modified by and modifies the effects of environmental factors (e.g altering metabolism of toxicants). The broader importance of microbiome research in autism lies in improving our understanding of how differences in the microbiome that arise through any avenue impact brain development and behaviors related to autism. A greater emphasis that could be incorporated into this question is the role of mechanisms underlying genetic regulation, such as epigenetics, as they affect neurodevelopmental processes.
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	Recognition of the multi-factorial biology related to both genetic and non-genetic (e.g., environmental) factors may be a cross-cutting theme or objective that should be reflected in multiple questions rather than solely in Question 2 and 3. This multi-factorial biology not only impacts risk and the identification of vulnerable populations, but also biological mechanisms, treatment and intervention, and services.
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	See our comment on language about the use of causes vs. Contributors; the current language of causation may make it seem like questions related to understanding the etiology of autism refers to simple or single causes rather than the complex multi-factorial contributions that is more common. However, we recognize the need for lay-friendly language in the Question and Aspirational goal.
Recent advances to include	Early research is beginning to explore mitigation of the harmful impacts of environmental factors by other nongenetic exposures (e.g., diet and nutrition). There have been advances in early research on broader autism phenotypes and social impairments beyond traditional autism diagnosis and what can be learned about autism by studying these related traits in the general population.
Remaining Gaps	We would encourage a greater emphasis on modifiable factors for resilience to disabling aspects, such as maternal diet and nutrition and its interaction with other environmental exposures. There have been significant advances in understanding global risk for core symptoms (using diagnosis or diagnostic instruments) and some advances in studies on risk of autism related phenotypes; however, there are currently limits in how existing studies can address questions about associations with specific phenotypes (power, correlation vs. causation, confounders). This research is needed to understand and develop strategies to mitigate disabling aspects of autism. Understanding the shared risk between autism and other mental illnesses is important to better inform interventions to improve quality of life for those with autism as well as other mental illnesses. Additional research in this area is needed. There remains a need for methods to better study gene-environment interactions in large cohort studies, as many genetic studies do not regularly include potentially relevant measurements of environmental exposures.
Emerging Opportunities	The opportunity to expand Precision Medicine, which tailors treatments and services to individuals, to include environment through what is being called Precision Environmental Health. For a more complete description of the concept and promise of Precision Environmental Health, please see: A recent comment: McCarthy, M., & Birney, E. (2021). Personalized profiles for disease risk must capture all facets of health. https://www.nature.com/articles/d41586-021-02401-0 Dr. Rick Woychik's interview with Dr. Cheryl Walker in the Environmental Factor (eFactor) outlining the concept of Precision Environmental Health: Precision environmental health brings nuance to disease prevention https://factor.niehs.nih.gov/2021/2/feature/4-feature-woychik/index.htm Expanding research beyond genome wide association studies (GWAS) and polygenic risk scores (PRS) to incorporate complementary

	epigenome wide association studies (EWAS) or environmental risk scores (ERS). With the growing number of observations in human studies identifying associations between non-genetic and environmental factors and risk of autism diagnosis, there are new opportunities and increasing need to explore the mechanisms that drive those associations (e.g., air pollution and increased risk).
Outdated concepts	
Language to include or avoid	We encourage the continued focus on prevention of disabling aspects in this chapter. To better reflect the multi-factorial and complex etiology of autism, we would encourage placing greater emphasis on factors that contribute to rather than simple causes of autism. "Cause" is a strong word and for many non-genetic/environmental factors they may not be direct causes but may modify gene expression in genetically susceptible individuals.
Comments on Objectives	
Other comments	A more general comment: there is significant cross-talk between Question 2 and 3, as genetic and non-genetic contributors act through biological mechanisms and underlying biology impacts how individuals respond to risk factors. We would suggest considering how they can possibly be combined or re-organized to better reflect this complementarity.
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	Incorporating insights from Precision Environmental Health studies, that combine genomic and environmental exposure data to develop individualized treatment and interventions to prevent disabling aspects and co-occurring conditions and improve quality of life (please see references in Question 3 for more information).
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	

Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	We encourage an increased emphasis on longitudinal studies that follow individuals from early ages through adulthood. It is hard to address early life risk factors that result in later life outcomes through cross-sectional study designs.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	We would encourage adding additional language on increased privacy regulations that restrict sharing of data and specimens from NIH-funded international studies, and how this may complicate and impact research. We would consider adding mention of the need for greater access to resources for exposure assessment, such as Human Health Exposure Assessment Resource (HHEAR), so that a broader research community can incorporate environmental exposure measurements into their studies.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	In addition to the many impacts the pandemic has had on the autism community, we would recommend that any section addressing this topic also consider the impact of the pandemic on the research community, particularly with regards to trainees and early career investigators. A survey on these impacts was published in March of this year: Harrop, C., Bal, V., Carpenter, K., &

	Halladay, A. (2021). A lost generation? The impact of the COVID-19 pandemic on early career ASD researchers. Autism Research. https://onlinelibrary.wiley.com/doi/10.1002/aur.2503
Needs of underserved populations	Not only are disadvantaged populations the ones who are most likely to be exposed to higher levels of environmental chemicals, and there are additional barriers to engaging these communities in research (e.g., health literacy, language barriers, historical distrust, time and resources to participate). Additional attention to engaging these communities in bi-directional research that addresses scientific questions of concern to those communities is critical for advancing research.
Aware of any duplicative efforts?	No, in fact there is not enough research that is performed to replicate findings from prior research. Replication is a critical step in the research process to validate and provide strong evidence for advancing research and making policy decisions.
Final comments	In light of pending large-scale federal efforts to address climate change, including funding for research on the impacts of climate change on health, the IACC should address challenges and opportunities in this area for autism research.

Name/Agency	National Institute of Mental Health (NIMH)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	<p>Section: Implementation of ASD Screening and Diagnostic Tools</p> <ul style="list-style-type: none"> • NIMH suggests including the following new text: “There is a critical need to identify ASD at the earliest age possible, to enable early intervention and better long-term outcomes. Studies have demonstrated that differences in brain development and function (e.g., eye gaze patterns, brain growth, and how different parts of the brain develop connections), as well as some subtle behavioral differences, emerge in the first months of life, before ASD symptoms begin to appear. Many of these early signs were found in infants at high risk for ASD (e.g., having at least one sibling with ASD). There is a need to determine whether these early signs are also evident for infants who are not categorized as at high risk for ASD. Thus, further studies to develop and validate new ASD screening methods that can be used in infancy will be important. NIH is supporting research toward translating early screening methods for infants into practical, efficient, and inexpensive tools that could be implemented in the general population and within community settings. New large-scale studies are examining methods to identify risk for ASD in the first year of life, to test strategies for universal screening, expedited diagnosis, and engagement with treatment (PMID: 28592562, PMID: 28202961, PMID: 24196715, PMID: 28392081).” • NIMH also suggests including science advances from the following areas: <ul style="list-style-type: none"> ○ Early detection: The NIMH-funded ASD Pediatric, Early Detection, Engagement, and Services (ASD PEDS) Network is composed of five research projects testing new strategies to improve early access to screening, diagnosis, and treatment of autism among toddlers (ages 12-24 months). Preliminary findings suggest that routine universal early screening reduces the age of detection, increases early access to services, and is most beneficial for families from historically marginalized populations (PMID: 31034004, PMID: 34982099). In addition, researchers in the NIMH Intramural Research Programs (IRP) collaborated on field testing an autism-specific early screening tool for children 12 to 36 months of age (PMID: 33962531). ○ Referral to services: Several NIMH-funded research studies tested new approaches to improve referrals and linkages to autism services, including a family navigator model to coordinate service delivery and efforts to improve health care provider training and parental engagement for early intervention (PMID: 33427861, PMID: 32144605, PMID: 29633852).

	<ul style="list-style-type: none"> ○ Telehealth assessment tools: NIMH is funding sequentially staged studies focused on the development and validation of tele-assessment tools to detect autism in young children. Researchers tested and validated a tele-assessment tool named “TAP” for virtual use in clinics with young toddlers (ages 18-36 months). The results of these tele-assessments aligned with the diagnostic results obtained from gold standard comprehensive evaluation methods. Researchers expanded the scope of the previous study by testing TAP activity delivery by parents in-home with toddlers and remote guidance by clinicians. Researchers now aim to develop and validate a modified TAP tool for in-home use focused on an older cohort of pre-school children (ages 36-72 months). Ultimately these studies may provide the foundation for future psychometrically sound tele-assessment tools for early autism detection that can be delivered by clinicians in the clinic or at home (PMID: 33417138, PMID: 32488583, PMID: 33125622).
Remaining Gaps	Gap areas include disparities in autism detection as well as referral and access to services. Related research gaps include addressing physician reluctance to refer to autism services (taking a ‘wait and see’ stance), increasing caregiver engagement (parents/caregivers are referred, yet often do not follow through), testing implementation strategies to train early intervention providers to increase competencies, and the use of technology and data mining to detect, refer, and treat youth with autism.
Emerging Opportunities	NIMH notes that additional research is needed to address the United States Preventive Services Task Force (USPSTF) ‘I’ grade on universal autism screening. Research is needed to inform such evidence-based practice recommendations. A more favorable grade may lead to increasing the proportion of primary care physicians and pediatricians who routinely screen toddlers for autism during visits and is likely to play a role in the provision of health care coverage for autism screening and referral to services.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	For Objective 3, consider the following edit (see underlined text): “ <u>OBJECTIVE 3</u> - Improve/validate existing, or develop new tools, methods, and service delivery models for detecting ASD and engaging caregivers in order to facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.”
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	<p>Section: Structure and Function of Brain Circuits in ASD</p> <ul style="list-style-type: none"> ● Sub-section on Structure and Function <ul style="list-style-type: none"> ○ NIMH suggests adding high-density diffuse optical tomography to the potential measures listed in the first paragraph of this section with the following two references (PMID: 31366956, PMID: 25595183).

- NIMH suggests adding the following references to the existing sentence: “These studies have shown differences in activation patterns in individuals with ASD in response to sensory processing of visual, tactile, auditory, and verbal stimuli.”
 - Visual perception and eye movements ([PMID: 31996763](#), [PMID: 34008916](#)).
 - Taste reactivity ([PMID: 3003500](#)).
 - Verbal stimuli (social communication) ([PMID: 30365251](#), [PMID: 27878739](#)).
- NIMH suggests adding the following references to the existing sentence: “Earlier findings from fMRI [functional magnetic resonance imaging], DTI [diffusion tensor imaging], and pathological studies highlighted a pattern of reduced long-distance connectivity and increased local connectivity. While these principles still largely hold, more recent research has revealed greater nuance and specificity.”
 - Neural dynamics and causality ([PMID: 30414457](#)).
 - Magnetoencephalography imaging of brain oscillations ([PMID: 29528295](#)).
- NIMH suggests adding the following references to the existing sentence: “Additionally, there is a need for a better understanding of brain function and connectivity during tasks that better capture the complexity of real-world interactions for individuals with ASD.”
 - Neural dynamics during natural, spontaneous conversation ([PMID: 30698656](#)).
- NIMH suggests removing the following quoted section of the paragraph. It is too specific to reflect the broad range of work being undertaken in this domain. “... including findings of reduced modulation of connectivity between the thalamus (a brain structure responsible for relaying sensory and motor signals to the cerebral cortex as well as regulating consciousness, sleep, and alertness) and cortical regions in response to sound or touch. The extent of this reduced connectivity was related to parent reports of sensory over-reactivity.³⁰ In the domain of touch, reduced response was seen in ASD children in social-emotional brain regions to a soft caress compared to typically developing children, while increased activation was seen in response to non-caress-like touch in the brain’s primary sensory cortex. This over-activation may be related to the hyper-sensitivity to touch seen in some ASD individuals.”
- In addition to deleting the above quoted section, NIMH suggests adding the following references to the end of the remaining sentence: “Ongoing work is linking these functional and structural differences to core features of ASD including studies on social communication, language, and restricted and

repetitive behaviors. Recent work has identified neurobiological correlates of sensory processing in autism.”

- Sensory processing ([PMID: 30350375](#), [PMID: 30740199](#), [PMID: 31230465](#), [PMID: 32860348](#), [PMID: 32869933](#), [PMID: 33587311](#), [PMID: 33956254](#), [PMID: 34003699](#), [PMID: 34145789](#), [PMID: 34499275](#), [PMID: 34556059](#)).
- Sub-section on Circuit Activity in ASD
 - NIMH suggests adding text excerpted and modified from the [October 2019 NIMH Director’s Message](#) to the end of this quoted section: “Variability due to methodological differences among labs may diminish the value of the research findings. Incorporation of a more standardized and systematized approach to studying the altered circuits in ASD models could be valuable to the field.”
 - “Researchers should create models to test hypotheses, rather than to “validate” that animal model by running a series of assays to document similarities between the animal and humans with the disorder. Such studies are problematic for many reasons, not the least of which is low statistical rigor, given that positive publication bias coupled with multiple tests can often lead investigators astray. A strong focus on a mechanistic hypothesis, with the animal model designed to test that hypothesis, coupled with a rigorously planned and sufficiently powered experimental design, could increase the reproducibility of the results.”

Section: Development, Natural History, and Variability in ASD

- Sub-section on Brain Development, Developmental Trajectories, and Natural History of ASD
 - NIMH suggests adding the following references to the quoted section: “Historically, research on early markers has focused on infant siblings of children with ASD, not only because they are at heightened risk for ASD and other developmental delays (prevalence estimates of ASD up to 20%), but also because they are identified prenatally and can be followed from birth.^{[59](#),[60](#),[61](#),[62](#),[63](#),[64](#)} This body of research has led to the identification of atypical behaviors – particularly in the social domain – within the first years of life,^{[65](#)} with some evidence of motor delays^{[66](#)} and altered patterns of social attention^{[67](#)} within the first year.”
 - Research relevant to the first year of life ([PMID: 32632024](#), [PMID: 31519897](#), [PMID: 28923933](#), [PMID: 31034004](#), [PMID:30350375](#)).
 - NIMH suggests adding an emerging focus on infants born prematurely as an additional subgroup at high risk for ASD who can be followed from birth.
- Sub-section on Biomarkers and Prediction of ASD

- NIMH suggests adding the following references to the existing sentence: “Brain response to social stimuli (biological motion) accurately predicts whether boys have autism, but not girls – again highlighting the need for a greater understanding of the neurobiology of females with ASD.”
 - Sex differences in autistic traits and adaptive skills ([PMID: 29204929](#)).
 - Sex differences in the resting-state functional connectivity of the cerebellum in ASD ([PMID: 31024276](#)).
 - Sex differences in parent-reported executive functioning and adaptive behavior in children and young adults with ASD ([PMID: 28568910](#)).

Section: Co-Occurring Conditions in ASD

- Sub-section on Gastrointestinal Conditions
 - NIMH suggests including more recent papers if this topic is included.
- Sub-section on Psychiatric Disorders
 - Clinicians can identify co-occurring psychiatric conditions across the age range, beginning in early childhood (e.g., anxiety, emotional dysregulation). NIMH suggests adding the following reference to the existing sentence: “It has been estimated that 69% of patients with ASD suffer from co-occurring psychiatric disorders and symptoms.¹⁰¹ As with the general population, age appears to be a relevant factor for psychopathology in patients with ASD.”
 - Research and gaps on co-occurring psychiatric conditions in ASD ([PMID: 29683351](#)).
 - NIMH suggests altering the following quoted statement, as Asperger’s Syndrome is no longer included in the Diagnostic and Statistical Manual of Mental Disorders: “One study of adults with Asperger’s Syndrome showed that the most frequent co-occurring conditions were depression and anxiety disorder, and that obsessive-compulsive disorder and alcohol abuse/dependence were also observed.¹⁰²” NIMH suggests using the following language: “One study of adults initially diagnosed with Asperger’s Syndrome showed that the most frequent co-occurring conditions were depression and anxiety disorder, and that obsessive-compulsive disorder and alcohol abuse/dependence were also observed.¹⁰²”
 - NIMH suggests including the following reference for the existing statement: “Research has revealed that consistently high levels of psychological symptoms and distress occur across the adult lifespan in ASD, where individuals with more severe depression and anxiety disorders demonstrated more severe ASD symptoms.^{103,104} At the molecular level, one study suggests that a variation in the serotonin 2A receptor gene may modulate the severity of depression symptoms in children with ASD.¹⁰⁵”

	<ul style="list-style-type: none"> ▪ Research and gaps on co-occurring psychiatric conditions in ASD (PMID: 29683351). ○ NIMH suggests adding a new sentence (see underlined text) to the end of the existing statement: “Research has revealed that consistently high levels of psychological symptoms and distress occur across the adult lifespan in ASD, where individuals with more severe depression and anxiety disorders demonstrated more severe ASD symptoms.^{103,104} At the molecular level, one study suggests that a variation in the serotonin 2A receptor gene may modulate the severity of depression symptoms in children with ASD.¹⁰⁵ <u>There is a critical need for reliable, validated measures for depression, mood lability, and risk for suicide that can be used in ASD populations, including in individuals with ASD and intellectual disability.</u>”
Remaining Gaps	There are gaps in understanding of the role of genomics in ASD and other neurodevelopmental disorders. For example, there are shared neurobiological and cognitive features of ASD and other neurodevelopmental disorders, and differences in developmental milestone profiles between individuals with genetic conditions compared to idiopathic ASD (PMID: 34382689).
Emerging Opportunities	
Outdated concepts	NIMH suggests updating the language for this existing statement: “Additionally, alterations in the composition of the gut microbiome have been implicated as playing a causal role in ASD pathophysiology.” It is inaccurate to imply the microbiome plays a causal role in ASD pathophysiology, as is currently included in the existing sentence. Researchers have found limited associations between the microbiome and ASD, but there is likely a strong association between microbiome changes and a restrictive diet (PMID: 34767757). NIMH suggests changing the language to “Additionally, researchers have found that alterations in the composition of the gut microbiome have limited association with ASD, but there is likely a strong association between microbiome changes and a restrictive diet (PMID: 34767757). The causal relationship between these microbiome changes and autism is therefore unclear. ”
Language to include or avoid	
Comments on Objectives	
Other comments	NIMH suggests changing all references to the NDAR to NIMH Data Archive (NDA).
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	There are no changes suggested related to question and aspirational goals, but for topics, we suggest changing “epigenetics” to “transcriptome and transcriptional regulation”.
Recent advances to include	<ul style="list-style-type: none"> • The development of a framework for the investigation of rare genetic disorders in neuropsychiatry, as discussed in the following Request For Applications (RFA-MH-19-200) and associated publication (PMID: 31648702), represents an area for inclusion that is moving forward at a fast

pace and may continue to be a growing area for neurodevelopmental disorders generally.

- More rare variants have been identified as being associated with ASD:
 - The NIH-funded Autism Sequencing Consortium (ASC) developed a [gene browser](#) that [displays variant and gene-level data from the most recent ASC analysis](#).
 - In 2020, ASC researchers identified 102 genes that were associated with ASD ([PMID: 31981491](#)).
 - NIH-funded researchers found that rare gene-disrupting transmitted variants are enriched in children with autism and contribute to at least 4.5% of autism risk, accounting for similar risk compared to mutations that are not inherited ([PMID: 34312540](#)).
 - Protein disrupting variants occur in 27% of individuals with ASD and are associated with comorbidities, intellectual disability, scholastic skills disorders, and epilepsy ([PMID: 34615535](#)).
- Groups working with the Psychiatric Genomics Consortium, funded in part by NIH, identified common variant risk loci and developed polygenic risk scores (PRS):
 - Researchers have identified five individual genetic variants that are associated with ASD. They also found quantitative and qualitative polygenic heterogeneity across ASD subtypes. ([PMID: 30804558](#)).
- NIH and the autism research community are working to increase genetic diversity in research participants:
 - For example, one NIMH-funded [Autism Center of Excellence \(ACE\) Network](#) has focused on recruiting African American families, a population that has not previously been well represented in ASD genetics studies. Researchers have documented opportunities to expedite diagnosis and ultimately facilitate increased access to care for individuals in this population ([PMID: 32839243](#)).
- Groups working with the Psychiatric Genomics Consortium, funded in part by NIH, identified genetic overlap with psychiatric and neurodevelopmental disorders:
 - Researchers found significant genetic correlations between ASD and several other traits and disorders including schizophrenia, major depression, and measures of cognitive ability such as educational attainment. There was additional confirmed correlation with social communication difficulties at age eight in a non-ASD population sample ([PMID: 30804558](#)).
 - NIH-funded researchers found that genes that are mutated in neurodevelopmental disorders (NDD) significantly overlap with those mutated in ASD. Of the 102 ASD genes identified by the Autism Sequencing Consortium, 53 were identified as ASD-predominant, 49 as ASD-NDD, and 53 as predominant in ASD only. The group with mutations in ASD-NDD genes had greater delays in walking and lower intelligence quotient scores, though these impacts were also seen in the ASD-predominant genes ([PMID: 31981491](#)). These designations are not meant to indicate that any genes listed are “ASD-specific” but rather that some genes may

	<p>have more impact on core ASD features and some on more general NDD features, though all the genes likely impact both (PMID: 32359473, PMID: 33157004, PMID: 33157005).</p> <ul style="list-style-type: none"> ○ NIMH-funded researchers analyzed data from the PsychENCODE Consortium to characterize the organization of the transcriptome in brain samples from individuals with ASD (PMID: 30545856). ○ NIH-funded researchers examining somatic variation in blood and brain samples report that mosaic variation, which is non-heritable, may account for as much as 5% risk for ASD (PMID: 33432195).
Remaining Gaps	<ul style="list-style-type: none"> ● Comprehensive phenotyping for ASD and NDD phenotypes in research participants with rare, large effect variants at scale to understand how mutations in various genes impact quantitative measurement of continuously distributed traits. ● Enhancing the quality of PRS by expanding total case number and ancestral diversity of cases. ● Enhancing understanding of missense, noncoding, inherited, and sex-linked genetic variation, including understanding the genetic factors underlying the observed sex-bias.
Emerging Opportunities	<ul style="list-style-type: none"> ● Single-cell sequencing may improve understanding of impacts on specific cell-types in the brain. ● Functional annotation of the discovered genes may aid in understanding common pathways.
Outdated concepts	<p>Researchers report limited microbiome associations with ASD, but there is likely a strong association between microbiome changes and a restrictive diet (PMID: 34767757). As with the suggestion to modify a statement related to the causality of the microbiome in Chapter 2, NIMH suggests using this evidence base for statements related to causality of the microbiome in Chapter 3 and in other Chapters of the Strategic Plan.</p>
Language to include or avoid	<p>For the terms “epigenetic,” “epigenomics,” and “methylation,” NIMH suggests describing examination of changes in transcriptional regulation with all the caveats described in an article on the topic of the word “epigenetics” (PMID: 29339796). There are many noted pitfalls to “epigenomic” studies which make them difficult to replicate and interpret, not the least of which being the current vague definition of “epigenomics.” In addition, researchers specify “methylation” as a mark for exposure, but there is no reason to privilege the regulatory mark of methylation over other mechanisms of transcriptional regulation. Similarly, the statement, “research to understand how exposure-induced epigenomic changes may transmit autism risk across generations is warranted” would not be consistent with current evidence.</p>
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	

Recent advances to include

- The Lancet Commission is a major effort to move the ASD field forward, especially with respect to global efforts and putting forth the stepped care and personalized health interventions model ([PMID: 34883054](#)).
- The World Health Organization (WHO) launched the Rehabilitation 2030 Call for Action initiative to draw attention to and strengthen rehabilitation in health systems worldwide. ASD and intellectual disability (ID) are among the 20 conditions chosen for the development of a package of rehabilitation interventions. Several NIH IRP staff (NIMH and other ICs) contributed to publications highlighting these efforts and identifying clinical practice guidelines for ASD and ID ([PMID: 34589690](#), [PMID: 31207218](#)).

Section: Intervention and Treatment Types

- Sub-section on Behavioral Interventions:
 - NIMH suggests adding the following reference to the existing sentence: “The National Standards Project and the National Professional Development Center on ASD (NPDC) have conducted critical and rigorous reviews of the intervention research literature and identified sets of focused intervention practices that have evidence of efficacy.¹⁰”
 - Evidence review follow-up for the National Standards Project ([PMID: 33449225](#)).
- Sub-section on Parent-Mediated Interventions:
 - NIMH suggests adding the following references to the existing sentence: “As diagnostic advances have made it possible to identify children with ASD at earlier ages, researchers have tested a number of parent-mediated interventions in order to meet the need for interventions that can be implemented as early as possible.”
 - Parent-mediated interventions ([PMID: 30768394](#), [PMID: 34309743](#), [PMID: 33480474](#)).
- Sub-section on Medical Interventions:
 - NIMH suggests including the following references to the existing sentence: “One promising target is oxytocin, a neuropeptide involved in social cognition that has been investigated in a number of ASD studies.^{46,47,48}”
 - Oxytocin effects ([PMID: 34301983](#), [PMID: 32535618](#)).
 - NIMH suggests adding the following reference to the existing sentence: “Other randomized, placebo-controlled treatment trials have targeted additional mechanisms proposed to contribute to the pathophysiology of ASD, with varying successes.^{50,51,52,53,54}”
 - Meta-analysis of pharmacologic treatment of restricted and repetitive behaviors in ASD ([PMID: 32387445](#)).
- Sub-section on Stem Cells:
 - NIMH suggests including a reference to the existing sentence: “As with brain stimulation, this research is only just beginning, and there are many hurdles to overcome and unanswered questions to address before the field will know whether stem cell techniques can provide safe and useful treatments for ASD.”

- Review of cell therapy approaches to ASD ([PMID: 32448347](#)).

- NIMH suggests including a cautionary statement regarding ethical considerations and the incidents of ethical violations that have occurred with some trials.

Section: Outcome Measures and Biomarkers

- NIMH suggests including the following references to the existing sentence in the introduction of this section: “Several reviews and consensus statements have been published that have evaluated the appropriateness of existing parent report and observational measures for clinical trials, including measures of social communication, anxiety, and repetitive behaviors.^{99,100,101,102}”

- Developments in treatment outcome measures ([PMID: 32446440](#), [PMID: 35034602](#), [PMID: 33274842](#), [PMID: 34914016](#))

- Sub-section on Biomarker Discovery:

- NIMH suggests including the following new language after the existing section: “Early efficacy markers can be used to identify which individuals are most likely to benefit from a given treatment and/or in adaptive study designs to indicate early in the trial whether modifications in the treatment (e.g., dose) should be made.”

- “Given the high risk of failure for central nervous system intervention studies, there is a need to design early-stage trials to incorporate objective measures that adequately test the proposed mechanism of action of the intervention and determine if the intervention target has been modulated. There is a need for studies that demonstrate the effect of the intervention on the proposed mechanism of target engagement or site of action (e.g., the molecular, circuit, neural or system-based target) prior to an examination of clinical efficacy (an association with behavioral or clinical benefit). Clinical studies for these intervention targets should be designed so that even negative results will provide meaningful information.”

- Sub-section on Eye Tracking (ET):

- NIMH suggests adding the following reference to the existing sentence: “While applications of ET to clinical trials and interventions are still relatively new, results have been encouraging and suggest that ET can be used as a method for measuring response across a wide range of treatments.”

- Using ET as a biomarker of treatment outcome ([PMID: 30891960](#)).

- Sub-section on Electrophysiological Measures:

- NIMH suggests adding the following reference to the existing sentence: “Recent studies suggest that electroencephalography, a non-invasive measure that can record patterns of brain activity throughout the lifespan, offers promise as a metric of treatment response related to neural circuitry.¹⁰⁷”

	<ul style="list-style-type: none"> ▪ Face-sensitive event-related potential N170 as a biomarker for ASD (PMID: 30092916, PMID: 34267691). ○ Sub-section on Magnetic Resonance Imaging (MRI): <ul style="list-style-type: none"> ▪ NIMH suggests adding the following reference to the existing section: “Despite the potential for brain imaging techniques to elucidate mechanisms underlying behavioral treatment response, few studies have directly used it for treatment monitoring or prediction of treatment efficacy. However, this appears to be rapidly changing, with several studies expanding on earlier work.” <ul style="list-style-type: none"> ▪ Direct modulation of aberrant brain network connectivity through real-time neurofeedback to improve treatment monitoring and prediction of treatment efficacy (PMID: 28917059). ○ Sub-section on Advances in Developing Measures of Treatment Response: <ul style="list-style-type: none"> ▪ NIMH suggests adding the following reference to the existing sentence: “One example is ABC-CT (Autism Biomarkers Consortium for Clinical Trials), a National Institutes of Health (NIH)-, Foundation for the NIH-, and Simons Foundation-funded consortium of sites that aims to develop, validate, and disseminate objective measures of social function and communication for ASD with the ultimate goal of advancing these measures as markers and predictors of treatment response.” <ul style="list-style-type: none"> ▪ Scientific context, study design, and progress toward biomarker qualification for ABC-CT (PMID: 32346363).
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	<ul style="list-style-type: none"> • The World Health Organization (WHO) launched the Rehabilitation 2030 Call for Action initiative to draw attention to and strengthen rehabilitation in health systems worldwide. ASD and intellectual disability (ID) are among the 20 conditions and disorders chosen for the development of a package of rehabilitation interventions. Several NIH IRP staff (NIMH and other ICs) contributed to publications highlighting these efforts and identifying clinical practice guidelines for ASD and ID (PMID: 34589690, PMID: 31207218). • NIMH has funded several studies that address the following areas: • Scale-up and implementation: Researchers examined the factors influencing implementation of two evidence-based interventions for children with comorbid mental disorders and autism when delivered in

	<p>mental health and education service contexts. Implementation leadership, provider attitudes, and motivation emerged as key influences on successful implementation across both contexts. These results may provide insight and guidance for evidence-based interventions that are being developed for or translated to usual care settings outside of mental health or education service contexts. (PMID: 30905009).</p> <ul style="list-style-type: none"> • Telehealth approaches to deliver evidence-based treatment: Researchers tested parent-implemented functional communication training (FCT) – an intervention delivered via telehealth – and found that it significantly reduced problem behavior and improved social communication in youth with ASD and moderate to severe behavior problems (PMID: 32300910). • Research on benefits of health system integration to improve behavioral and functional outcomes: NIMH supported several projects that advanced research on health system integration of tools, models, Medicaid coverage, and state insurance mandates to improve health care for autistic individuals (PMID: 32859135; PMID: 31311287; PMID: 34251042; PMID: 32900876).
Remaining Gaps	Early and ongoing autism detection throughout the lifespan; disparities and inequities in screening, access, and referral to treatment; delivery of high-quality and personalized health care and supported services; and integration of digital tools in primary and behavioral health care.
Emerging Opportunities	In addition to research focused on the gap areas noted above, there are opportunities to add research on state-level policies for autism services and strategies to address workforce constraints.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	<ul style="list-style-type: none"> • NIMH continues to support research focused on autism across the lifespan: <ul style="list-style-type: none"> ○ Improving transition outcomes for individuals with autism: Researchers tested an evidence-based practice, titled Collaborative Model for Competence and Success (COMPASS), and found that this empirically supported transition planning intervention resulted in improved educational and functional outcomes among adolescent youth with autism (PMID: 29858713). Authors of a related study suggested that diverse stakeholder perspectives highlight the need for implementation efforts to target the provider, organizational, and policy levels to improve transition outcomes for individuals with ASD (PMID: 31957461). Adolescents' successful transition into adult functioning requires them to have the capacity to manage their healthcare. Researchers focused on Medicaid coverage and enrollment, which impacted healthcare access and services (PMID: 34632834).

	<ul style="list-style-type: none"> ○ Employment: Adults with autism experience substantial challenges to attaining competitive employment opportunities and frequently experience unemployment and underemployment. Researchers explored supported employment and virtual reality job interview training to enhance vocational outcomes for participants in community-based treatment settings (PMID: 29034696; PMID: 31631470). ○ Inclusion of individuals with autism as co-researchers: Researchers explored the inclusion of autistic individuals as active research partners which resulted in improvements in service utilization and scale-up (PMID: 30939892; PMID: 31674198). ● NIMH suggests adding the following reference to the existing section: “Co-occurring psychiatric conditions (i.e., two or more mental health diagnoses co-occurring in an individual), known to be high among children and adolescents with ASD, remain challenging in adulthood. Most children with ASD who have other psychiatric disorders continue to have at least one co-occurring diagnosis in adolescence and early adulthood.” <ul style="list-style-type: none"> ○ The gap between adaptive behavior and intelligence in autism and its persistence into young adulthood and linkages to psychiatric comorbidities (PMID: 28710532).
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	<ul style="list-style-type: none"> ● An online survey of caregivers identified changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions (PMID: 32939917).

	<ul style="list-style-type: none"> An Autism Speaks survey indicated widespread challenges for the autism community in regards to COVID-19 and wider disparities for minority communities.
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	National Institute of Neurological Disorders and Stroke (NINDS)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Social Security Administration (SSA)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	No
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	No changes suggested.
Q2: Biology	
Edits to Question or Aspirational Goal	No
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	No changes suggested.
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	No
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	No changes suggested.
Q4: Interventions	
Edits to Question or Aspirational Goal	No
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	No changes suggested.
Q5: Services and Supports	
Edits to Question or Aspirational Goal	Maybe not that adult safety issues are discussed under section 6?
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	No
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	None

Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	No
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	None
Impact of the COVID-19 pandemic	Education interruption, loss of employment, higher risk of hospitalization/death for those on the spectrum from COVID-19, isolation, disruption of medical services
Needs of underserved populations	Note: Recent analyses by JK Law, AR Marvin, et al. using SPARK data (submitted to the Pediatric Academic Societies Annual Meeting for 2022) suggest that those in economically disadvantaged communities are less likely to receive the COVID-19 vaccine.
Aware of any duplicative efforts?	No
Final comments	You are doing a great job! Thank you.

Name/Agency	Substance Abuse and Mental Health Services Administration (SAMHSA)
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	Use of ACOR (autism comorbid risk score (ACoR)) in screening-Onishchenko et al., Sci. Adv. 2021; 7 : eabf0354-Reduced false positives in autism screening via digital biomarkers inferred from deep comorbidity patterns
Remaining Gaps	
Emerging Opportunities	Can update information on state insurance coverage requirements- https://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx Can update info on biomarkers- see e.g., RE Frye et. al., Emerging biomarkers in autism spectrum disorder: a systematic review, Ann Transl Med 2019;7(23):792 http://dx.doi.org/10.21037/atm.2019.11.53
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	Could discuss more overlap of ADHD and autism (briefly mentioned in reference 99 and in chapter 1)- https://www.spectrumnews.org/features/deep-dive/decoding-overlap-autism-adhd/ ; Lau-Zhu A, Fritz A, McLoughlin G. Overlaps and distinctions between attention deficit/hyperactivity disorder and autism spectrum disorder in young adulthood: Systematic review and guiding framework for EEG-imaging research. Neurosci Biobehav Rev. 2019;96:93-115. doi:10.1016/j.neubiorev.2018.10.009
Emerging Opportunities	Neurosubtyping-Seok-Jun Hong, Joshua T. Vogelstein, Alessandro Gozzi, Boris C. Bernhardt, B.T. Thomas Yeo, Michael P. Milham, Adriana Di Martino, Toward Neurosubtypes in Autism, Biological Psychiatry, Volume 88, Issue 1, 2020, Pages 111-128, ISSN 0006-3223, https://doi.org/10.1016/j.biopsych.2020.03.022 . Can discuss substance use as a comorbidity- see e.g., B. Isenberg et. al., Psychiatric comorbidity associated with co-occurring autism spectrum disorder and substance use disorder, Research in Autism Spectrum Disorders 82 (2021) 101728; M. Bowri et al., Demographic and psychological predictors of alcohol use and misuse in autistic

	<p>adults, Autism 2021, Vol. 25(5) 1469– 1480; JS Huang et. al., Risk of Substance Use Disorder and Its Associations With Comorbidities and Psychotropic Agents in Patients With Autism, JAMA Pediatrics, 2021;175(2):e205371. doi:10.1001/jamapediatrics.2020.5371 E. Kunreuther, Autism Spectrum Disorder and Substance Use Disorder A Dual Diagnosis Hiding in Plain Sight, Psychiatr Clin N Am 44 (2021) 35–49 https://doi.org/10.1016/j.psc.2020.11.004; E. Weir et. al., Understanding the substance use of autistic adolescents and adults: a mixed-methods approach, Lancet Psychiatry, August 2021, 8: 673–85 https://doi.org/10.1016/S2215-0366(21)00160-7</p>
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	<p>May want to at least briefly discuss that autism/autism spectrum may pose an increased risk for persons with autism and eventually may like influenza have some potential causal link (Lima MES, Barros LCM, Aragão GF. Could autism spectrum disorders be a risk factor for COVID-19?. Med Hypotheses. 2020;144:109899. doi:10.1016/j.mehy.2020.109899; W. Schott et. al., COVID-19 risk: Adult Medicaid beneficiaries with autism,intellectual disability, and mental health conditions, Autism, COVID-19 risk: Adult Medicaid beneficiaries with autism, intellectual disability, and mental health conditions; Autism p. 1-13, https://doi.org/10.1177/13623613211039662). Steinman G. COVID-19 and autism. Med Hypotheses. 2020;142:109797. doi:10.1016/j.mehy.2020.109797. Still very much an emerging area. Can cite updated info on chemical exposures and autism e.g., Pelch KE, Bolden AL, Kwiatkowski CF. Environmental Chemicals and Autism: A Scoping Review of the Human and Animal Research. Environ Health Perspect. 2019;127(4):46001. doi:10.1289/EHP4386. Could discuss research on exposure to tobacco/smoking, pesticides, parental obesity and nutrition issues to greater extent. Fujiwara Takeo, Morisaki Naho, Honda Yukiko, Sampei Makiko, Tani Yukako, Chemicals, Nutrition, and Autism Spectrum Disorder: A Mini-Review, Frontiers in Neuroscience 10, 2016, https://www.frontiersin.org/article/10.3389/fnins.2016.00174 DOI=10.3389/fnins.2016.00174; Joshua D Alampi, Bruce P Lanphear, Joseph M Braun, Aimen Chen, Tim K Takaro, Gina Muckle, Tye E Arbuckle, Lawrence C McCandless. Gestational Exposure to Toxicants and Autistic Behaviors using Bayesian Quantile Regression. American Journal of Epidemiology, 2021; DOI: 10.1093/aje/kwab065; Jung Y, Lee AM, McKee SA, Picciotto MR. Maternal smoking and autism spectrum disorder: meta-analysis with population smoking</p>

	metrics as moderators. Sci Rep. 2017;7(1):4315. Published 2017 Jun 28. doi:10.1038/s41598-017-04413-1
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	Need for evidence-based interventions- https://autismpdc.fpg.unc.edu/evidence-based-practices See National Clearinghouse on Autism Evidence and Practice https://ncaep.fpg.unc.edu/
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	cite resources for evidence-based practices e.g., https://ncaep.fpg.unc.edu/ could discuss pros and cons of homeschooling (https://www.carautismroadmap.org/homeschooling/) and charter schools emerging for special needs students (https://www.autismparentingmagazine.com/option-for-kids-with-autism/) Update info on autism and Medicaid, https://drexel.edu/now/archive/2021/August/Autism-Institute-States-Use-of-Medicaid/ ; Autism and Medicare, https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/OMH_Dwnld-DataSnapshot-Autism.pdf
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	

Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	<p>Can discuss in more detail autism and foster care https://www.spectrumnews.org/opinion/viewpoint/many-children-autism-end-foster-care/; Foster Care Involvement Among Medicaid-Enrolled Children with Autism Zuleyha Cidav, Ming Xie & David S. Mandell Journal of Autism and Developmental Disorders volume 48, pages176–183 (2018) Update info on diagnosis of autism in adults and aging with autism- https://www.adultandgeriatricautism.com/One issue is that the chapter is understandably focused on pediatric populations (e.g., references to pediatricians). Some adults may have missed being diagnosed or have other diseases and conditions that make diagnosis harder. See e.g., L. Fusar-Poli et. al., Missed diagnoses and misdiagnoses of adults with autism spectrum disorder, European Archives of Psychiatry and Clinical Neuroscience https://doi.org/10.1007/s00406-020-01189-w; https://www.additudemag.com/autism-spectrum-symptoms-adults/; Gesi C, Migliarese G, Torriero S, Capellazzi M, Omboni AC, Cerveri G, Mencacci C. Gender Differences in Misdiagnosis and Delayed Diagnosis among Adults with Autism Spectrum Disorder with No Language or Intellectual Disability. Brain Sci. 2021 Jul 9;11(7):912. doi: 10.3390/brainsci11070912. PMID: 34356146; PMCID: PMC8306851; https://www.spectrumnews.org/features/deep-dive/the-missing-generation/; https://www.adultandgeriatricautism.com/; S. Sagg and H. Belcher, Living with autism without knowing: receiving a diagnosis in later life, HEALTH PSYCHOLOGY AND BEHAVIORAL MEDICINE2019, VOL. 7, NO. 1, 348-361 https://doi.org/10.1080/21642850.2019.1684920</p>
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	<p>Would rephrase to How Do We Continue to Build, Expand, and Enhance the Research and Surveillance System to Meet the Needs of the ASD Community? This is more about research than infrastructure as far as services and support</p>
Recent advances to include	
Remaining Gaps	<p>Would discuss privacy not only from a data sharing perspective but also due to concerns about stigma and bias. See e.g., Mazumder R, Thompson-Hodgetts S. Stigmatization of children and adolescents with autism spectrum disorders and their families: a scoping study. Rev J Autism Dev Disord 2019; 6: 96–107.</p>

Emerging Opportunities	Can cite groups like International Society for Autism Research (https://www.autism-insar.org/page/INSAR); International Collaboration for Diagnostic Evaluation of Autism (https://psychiatry.weill.cornell.edu/idea) under international collaboration discussion See also https://www.autismspeaks.org/international-autism-organizations
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	Stated this earlier in response but 1. need to consider autism as risk factor for COVID W. Schott et al., COVID-19 risk: Adult Medicaid beneficiaries with autism, intellectual disability, and mental health conditions, <i>Autism</i> , 1– 13 The Author(s) 2021 DOI: 10.1177/13623613211039662 2. COVID as a potential risk factor for autism (like influenza?) G. Steinman COVID-19 and autism, <i>MedicalHypotheses</i> 142(2020)109797 3. Uptake of vaccine and access to vaccinations (and other treatments such as monoclonal antibodies and medications as available and approved), https://www.autism-society.org/releases/autism-society-of-america-encourages-autism-community-to-vaccinate-eligible-adolescents-as-the-pfizer-covid-19-vaccine-receives-eua/ 4. Impact of disruption of services and routines such as job loss, school closings and gradual reopening and shift to telehealth K. Ellison et al., Telehealth and Autism Prior to and in the Age of COVID-19: A Systematic and Critical Review of the Last Decade, <i>Clinical Child and Family Psychology Review</i> (2021) 24:599– 630, https://doi.org/10.1007/s10567-021-00358-0 ; Bellomo, Tiffany R. et al. ‘The Impact of the COVID-19 Pandemic on Children with Autism Spectrum Disorders’. 1 Jan. 2020 : 349 – 354.
Needs of underserved populations	Rural-access to services, effectiveness of telehealth, Antezana L, Scarpa A, Valdespino A, Albright J, Richey JA. Rural Trends in Diagnosis and Services for Autism Spectrum Disorder. <i>Front Psychol.</i> 2017;8:590. Published 2017 Apr 20. doi:10.3389/fpsyg.2017.00590 Minority populations- dovetails with earlier question on COVID, which disproportionately impacts minority populations- https://www.autismspeaks.org/science-news/covid-19-survey-reveals-widespread-challenges-autism-community-and-wider-disparities Need to consider issues in tribal areas which face barriers due to minority status and often being in rural and underserved areas- https://www.voanews.com/a/usa_helping-native-american-children-autism-poses-challenges-schools/6184254.html ; https://publications.aap.org/pediatrics/article-abstract/147/3_MeetingAbstract/970/4828/Increasing-Diagnostic-Services-for-Autism-Spectrum LGBT and autism- https://www.autismspeaks.org/lgbtq-information-and-resources Need to consider incarcerated and reentering populations- https://www.spectrumnews.org/features/deep-dive/autism-behind-bars/ . Minorities face higher risks of incarceration.
Aware of any duplicative efforts?	GAO asserted in 2013 that there was duplication of services and lack of coordination. While coordination can always be improved, I do not perceive

	<p>that services are being duplicated at the federal level. See https://iacc.hhs.gov/publications/general/2013/federal-autism-activities.shtml; https://www.gao.gov/assets/gao-16-446.pdf This can get complicated at a state level too with various agencies being involved see e.g, https://www.autismnj.org/information-services/government-agencies/</p>
Final comments	<p>Look forward to participating Along with discussing COVID, would use this as opportunity to stress importance of emergency preparedness for autistic individuals, their families and communities not just for COVID but other types of emergency and disaster situations (https://www.autismspeaks.org/autism-speaks-natural-disaster-resources;</p>

Name/Agency	Alice Carter
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Samantha Crane
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	I would be cautious about talking about "earliest possible diagnosis" because there's not a great evidence base for the marginal effects of an autism diagnosis at extremely young age - such as at 18 months. While it's important to pay attention when child
Recent advances to include	Will answer this through our process for selecting summary of advances.
Remaining Gaps	More research is necessary on the actual long-term outcome differences between early autism diagnosis (particularly diagnosis before age 2-3) and diagnosis later in the preschool years, particularly research that accounts for whether or not a child gets non-autism-specific intervention services pre-diagnosis. This could particularly influence how we structure early childhood intervention programs and whether those programs work best when they target autism specifically versus identified delays. We also need more research on diagnostic disparities and how those later or missed diagnoses affect girls and children of color in the long term.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	Again, would make a careful distinction between identification of delays/provision of general interventions and identification of autism specifically and provision of autism-specific interventions. Would also be careful to tie the timeliness of the interv
Comments on Objectives	While sex differences in diagnosis may in part have a biological basis, the objective should not be phrased in a way that assumes that biological differences exist and are the primary cause of differences in diagnosis. Would rephrase "Strengthen the evidence base" to "further explore the evidence base" - the goal of autism research should not be to prove a specific conclusion but rather to investigate whether or not it is actually true.
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	Would alter the aspirational goal to say "improve health and quality of life," and "that lead to and/or accompany ASD". Some "biological" features of ASD, such as sleep problems, high stress hormone levels, and digestive issues may actually be secondary effects.
Recent advances to include	Will address in summary of advances vote
Remaining Gaps	Motor and sensory concerns, sleep concerns, mental health, and co-occurring rare conditions (such as ehlers-danlos) are dramatically unexplored compared to how important they are to autistic people. Similarly, development of

	medications to address quality of life (such as identifying the best medications to address anxiety or depression, identifying differences in response to anti-seizure medications, etc.) is inadequately explored.
Emerging Opportunities	Community-based participatory research models can help researchers identify areas within this question that most affect autistic people's quality of life.
Outdated concepts	There is undue focus on identifying biological processes that give rise to core autistic traits, such as social communication or repetitive behavior. These traits are not the traits that most impact our quality of life and developing medical interventions to change them is not a high priority to most autistic people.
Language to include or avoid	Language should focus on physiological differences rather than deficiencies, except where the difference directly results in a significant negative health impact. Discussions should not assume that every autism-related biological difference necessarily effects quality of life or should be medically treated.
Comments on Objectives	Would prioritize goals 2 and 3 over 1.
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	Personally do not think that this question is important to the autistic community at all, to the extent that it is separable from elements of Questions 2 and 4. Given that it should probably be kept for the purpose of continuity in tracking autism research, I would rephrase it as: Question: What causes ASD, and how can we prevent outcomes that impair quality of life? Aspirational goal: Causes of ASD will be discovered that inform diagnosis and interventions that improve quality of life; causes of negative outcomes among people with ASD will be discovered that can help prevent those outcomes. Topics include: Genetic and environmental contributions, social determinants of health, epigenetics, microbiome
Recent advances to include	will address in summary of advances.
Remaining Gaps	Inadequate exploration of intervening factors that contribute to negative outcomes - such as the effects of burnout, stress, or co-occurring medical conditions in creating and perpetuating traits that are perceived as "disabling autistic traits" in and of themselves (such as challenging behavior).
Emerging Opportunities	As noted in Question 2, understanding of genetic markers could help us better understand why and how autistic people may respond differently to certain kinds of medication intended to treat anxiety, sleep disorder, seizures, etc.
Outdated concepts	The autistic community is not interested in prevention of autism itself. Merely rephrasing it to prevention of "disabling aspects of ASD" is insufficient because autism is in itself a disability. An aspect of ASD "disabling" in a specific social context does not mean that it necessarily impairs quality of life or is something that an autistic person would like to have prevented; moreover, the association with investigation of genetic causes and "prevention" gives rise to community concerns about eugenic prevention efforts such as sterilization, genetic pre-screening of prospective parents or embryos, etc. Prevention of ASD or "disabling aspects of ASD" should either be taken out of the question or replaced with prevention of negative outcomes.

Language to include or avoid	"Risk factors for autism" should be replaced with "causal factors" or "commonly associated traits/conditions" (depending on whether there is genuine evidence of causality). "Risk factors" is pejorative and reinforces the perception that autism itself should be prevented.
Comments on Objectives	#1: "reducing disability" should be replaced with "reducing negative outcomes" and "risk and resilience factors" should be replaced with "genes associated with either the presence or absence ASD" #2 should be rephrased as "Understand the effects of individual and multiple exposures in early development with diagnosis and expression of ASD, enabling development of strategies for addressing associated needs and co-occurring medical conditions" #3 should be rephrased as "Expand knowledge about how multiple environmental and genetic factors interact through specific biological mechanisms to manifest in different expressions of ASD."
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	Aspirational goal should not necessarily assume a causal link between optimizing function and abilities, with achieving meaningful outcomes and maximizing quality of life. Would simply rephrase as "Develop a range of targeted treatments and interventions that achieve meaningful outcomes and maximize quality of life for people on the autism spectrum across the lifespan" Topics should include educational interventions and environmental changes
Recent advances to include	Address through summary of advances.
Remaining Gaps	There is a real need for more research on providing a full range of communication through AAC, including providing unlimited vocabulary and the ability to form complex phrases at the very outset before someone has "proven" their need for that level of range. In particular we have limited research on communication interventions for older children and adults who have not previously been offered truly effective communication. There is a large gap in our understanding of how mental health interventions can be adapted for autistic people, including autistic AAC users and autistic people with ID. There is almost no long-term follow-up of some interventions, particularly behavioral interventions, and exploration of those interventions often focuses on limited outcome measures such as academic achievement rather than on long-term quality of life and mental health outcomes.
Emerging Opportunities	Community-based participatory research is a good opportunity to focus research on the areas that impact us the most - including prioritizing interventions that directly impact quality of life rather than interventions aimed at making people no longer fit the criteria for ASD.
Outdated concepts	The idea that reducing "core symptoms" has any impact on "function" or quality of life should be retired.
Language to include or avoid	The term "function and abilities" should be replaced with discussion of skills and outcomes; often focusing on developing an ability has a directly negative impact on our quality of life by forcing us to expend effort to overcome disability rather than seeking an accommodation or focusing on strengths.
Comments on Objectives	Discussion of "core symptoms" in these objectives should be eliminated. Instead pharmacological and medical interventions should focus on co-occurring

	conditions. Other interventions (Objective 2) should focus on "improving quality of life outcomes" and addressing co-occurring conditions. The third objective in my opinion artificially elevates technology-based interventions over other interventions listed in Question 2; I would instead simply merge objectives 2 and 3 together.
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	I would consider "implementation of interventions in community settings" to be properly within the realm of Question 4; instead would rephrase as "delivery of services in community settings" or "improving access to community settings."
Recent advances to include	
Remaining Gaps	There is a significant unmet need for scalable, community-based service delivery models for people with significant support needs. This question is historically dramatically underfunded as compared to other questions.
Emerging Opportunities	See previous answers regarding community-based participatory research
Outdated concepts	
Language to include or avoid	
Comments on Objectives	These objectives are reasonable.
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	No edits.
Recent advances to include	
Remaining Gaps	This area is almost all gaps at this point because it has been so dramatically underfunded. In particular, we need more focus on supporting people with high support needs, addressing the needs of aging people with ASD, addressing the needs of parents with ASD, supporting communication among adults who have not previously had access to robust AAC, and exploring how service delivery models and needs may vary across the lifespan.
Emerging Opportunities	See previous answers re: community based participatory research.
Outdated concepts	No edits
Language to include or avoid	No edits
Comments on Objectives	The objectives are reasonable
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	Development of the autism research workforce should specifically address the need for development of the research workforce in areas that have previously been underfunded and unaddressed, as well as development of autistic

	researchers. Development of autistic researchers is NOT merely an employment issue that is adequately addressed by Question 6 - the point is that autistic researchers have a unique perspective that is vital to the health of autism research as a field.
Recent advances to include	
Remaining Gaps	There is a very significant unmet need for information about autism research and services that is accessible to laypeople, especially people with cognitive and intellectual disabilities. Information should be disseminated in plain language, easy read, and other formats as a priority and not an afterthought. Information should be disseminated in a variety of languages used in the US. This issue is not adequately addressed in other questions.
Emerging Opportunities	Many organizations have developed significant expertise in translating complex information into easy read and plain language formats. These organizations should be brought in as experts in improving information dissemination.
Outdated concepts	
Language to include or avoid	while "surveillance systems" is understandable to most public health professionals, laypeople may believe that these are systems that surveil actual autistic people and create privacy concerns. I would replace with "oversight systems" or something similar to clarify.
Comments on Objectives	These objectives are all focused on meeting the needs of researchers, not community members. Moreover, the goal of promoting biorepository infrastructure lacks acknowledgment of the need to balance research needs with community members' valid concerns about privacy of their health information. Objective 4 will be viewed by many members of the public as being about conducting surveillance of individual autistic people and should be rephrased. A separate objective about information dissemination, including dissemination of accessible information, should be created and prioritized.
Other comments	
Impact of the COVID-19 pandemic	The pandemic has dramatically impaired our community's access to services, interventions, health care, and early identification. In addition, we don't yet know how COVID-19, including COVID-19 during pregnancy and isolation from previously normal childhood activities such as group play and childcare, will affect the expression of autism in young children.
Needs of underserved populations	These populations are understudied and under-consulted in development of research projects. They need to be brought in at all points in the process of research development, execution, and analysis. In addition, information about autism research is often not disseminated in a way that is accessible and relevant to underserved communities.
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Aisha Dickerson
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	<p>Patti MA, Newschaffer C, Eliot M, Hamra GB, Chen A, Croen LA, Fallin MD, Hertz-Picciotto I, Kalloo G, Khoury JC, Lanphear BP, Lyall K, Yolton K, Braun JM. Gestational Exposure to Phthalates and Social Responsiveness Scores in Children Using Quantile Regression: The EARLI and HOME Studies. <i>Int J Environ Res Public Health</i>. 2021 Jan 30;18(3):1254. doi: 10.3390/ijerph18031254. PMID: 33573264; PMCID: PMC7908417.</p> <p>Patti MA, Li N, Eliot M, Newschaffer C, Yolton K, Khoury J, Chen A, Lanphear BP, Lyall K, Hertz-Picciotto I, Fallin MD, Croen LA, Braun JM. Association between self-reported caffeine intake during pregnancy and social responsiveness scores in childhood: The EARLI and HOME studies. <i>PLoS One</i>. 2021 Jan 15;16(1):e0245079. doi: 10.1371/journal.pone.0245079. PMID: 33449933; PMCID: PMC7810310.</p> <p>Lee BK, Eyles DW, Magnusson C, Newschaffer CJ, McGrath JJ, Kvaskoff D, Ko P, Dalman C, Karlsson H, Gardner RM. Developmental vitamin D and autism spectrum disorders: findings from the Stockholm Youth Cohort. <i>Mol Psychiatry</i>. 2021 May;26(5):1578-1588. doi: 10.1038/s41380-019-0578-y. Epub 2019 Nov 6. PMID: 31695167; PMCID: PMC7200274.</p> <p>Oh J, Bennett DH, Calafat AM, Tancredi D, Roa DL, Schmidt RJ, Hertz-Picciotto I, Shin HM. Prenatal exposure to per- and polyfluoroalkyl substances in association with autism spectrum disorder in the MARBLES study. <i>Environ Int</i>. 2021 Feb;147:106328. doi: 10.1016/j.envint.2020.106328. Epub 2020 Dec 30. PMID: 33387879; PMCID: PMC7856021.</p> <p>Shin HM, Bennett DH, Calafat AM, Tancredi D, Hertz-Picciotto I. Modeled prenatal exposure to per- and polyfluoroalkyl substances in association with child autism spectrum disorder: A case-control study. <i>Environ Res</i>. 2020 Jul;186:109514. doi: 10.1016/j.envres.2020.109514. Epub 2020 Apr 14. PMID: 32353786; PMCID: PMC7363534.</p>
Remaining Gaps	
Emerging Opportunities	With the funding provided by NIH for the Environmental Influences of Child Health Outcomes (ECHO) collection of cohort studies, the opportunities to research environmental risk factors for ASD, in combination with potential genetic risk and psychosocial stressors, has been greatly expanded and could be an important resource for people looking for data sources for this type of research.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	

Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	I do not see a discussion in the sex-difference section on the potential impact of endocrine disrupting chemicals and subsequent hormone levels on sex specific brain development.
Emerging Opportunities	There are several ongoing analyses using the collection of cohort study data compiled as part of the Environmental influences of Child Health Outcomes (ECHO) consortium funded by the NIH Office of the Director. Many of the analysis concepts in process intend to address several of the priorities stated in the plan, and this data source could be used to address many others, and I am excited to see it mentioned here.
Outdated concepts	The page still refers to "NDAR" though I do not believe this is what this system is called anymore. Is it not now named the National Institute of Mental Health Data Archive (NDA)?
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	

Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	Honestly, everything I wanted to make sure you included in this section has been covered.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	1. The impacts of changes/reductions in access to services and routines during the pandemic. 2. How caregiver stress during the pandemic has impacted family dynamics 3. Mental health outcomes of both children and adults with ASD.
Needs of underserved populations	1. Interactions with law enforcement, including training for officers and other first-responders, provision of social workers, training of 911 operators, and education for people with ASD and their caregivers. 2. Resources to ensure affordable and timely services for early ascertainment and intervention, and easy access to readable and understandable resources with this information. 3. Infrastructure for internet access to provide telemedicine when appropriate.
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Dena Gassner
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	A. Stop using "Disorder" as well as "ASD" in these discussions. It has been determined that the medical model language is harmful and stigmatizing for autistics and this has been well researched at this point. "How can I recognize the signs of autism and
Recent advances to include	Kapp, S. (2019). How social deficit models exacerbate the medical model: Autism as case in point. <i>Autism Policy & Practice</i> , 2(1), 3-28. Padilla-Petry, P., & Saladrigas-Tuà, M. (2021). Autism in Spain: parents between the medical model and social misunderstanding. <i>Disability & Society</i> , 1-22. Anderson-Chavarria, M. (2021). The autism predicament: models of autism and their impact on autistic identity. <i>Disability & Society</i> , 1-21. Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. <i>British Journal of Developmental Psychology</i> , 39(1), 1-18. Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. <i>Autism in Adulthood</i> , 3(1), 18-29.
Remaining Gaps	There is nothing here challenging the age of all of this EI research. We need an entirely new lit review that includes trauma informed insights from autistic research examining how autistic persons retrospectively report their experiences of EI. Also, there is no research about persons who did NOT use ABA and still experienced success through a child driven focus. There is nothing about naturalistic therapies, sensory work, or interoception. There is too little focus on training PARENTs to embrace and support autistic children.
Emerging Opportunities	We need to focus on policy and services involving systems navigation. Many parents experience limited choices due to poor policy navigation.
Outdated concepts	Nearly all of the research that is over 10 years old.
Language to include or avoid	Disorder. Disability. People first language.
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	Language. Eliminate all research more than 10 years old. Discuss the ethics of neurobio science. How do we tease out the brilliant autistic "cells" from the disabling ones? This discussion is incomplete without these aspects. Who decides what is "non-invasive" testing? This is very invasive unless the participant is deceased.
Recent advances to include	
Remaining Gaps	

Emerging Opportunities	
Outdated concepts	Anything more than 10 years old. Also the illusion that there is a 4:1 ratio M/F as we are seeing this is inaccurate and continues to bias research on girls/women.
Language to include or avoid	Disorder. Disabled. Normal.
Comments on Objectives	
Other comments	This area terrifies me. I fear our world will be negatively impacted if we don't address the risks and ethics of these kinds of studies before we have the power to eliminate certain neurotypes.
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	The disabilities discussed as "co-occurring" are all significant genetic conditions- there is no discussion, in any way regarding more commonly experienced co-occurring issues such as learning disabilities, intellectual disability, anxiety, depression, ADHD, or trauma as co-occurring items to be addressed. These are much more common are experienced as barriers to autonomy. You do not mention ableism and it's role in 'disabling' autistic persons.
Recent advances to include	Too many for me to search for. A new literature review will be required.
Remaining Gaps	Gender diversity, social barriers, biases and ableism. Less genetics. More social implications.
Emerging Opportunities	See above
Outdated concepts	Anything over 10 years old. Seriously? 24. Folstein S, Rutter M. Infantile autism: a genetic study of 21 twin pairs. J Child Psychol Psychiatry. 1977 Sep;18(4):297-321. [PMID: 562353] 39. Baron-Cohen S. The extreme male brain theory of autism. Trends Cogn Sci. 2002 Jun 1;6(6):248-254. [PMID: 12039606]
Language to include or avoid	Do not compare autism to cancer-it's not a disease. Autism is fine-no ASD or Disability.
Comments on Objectives	
Other comments	Needs a rehaul.
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Alycia Halladay
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Spectrum Disorder
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	Early diagnosis provides autistic individuals a better understanding of their abilities, strengths, weaknesses and needs for supports as they age. Those who have not received an early diagnosis not only miss out on interventions, but they struggle with a basic understanding of who they are and how they fit into society.
Recent advances to include	An important one is www.autismnavigator.com , which provides a video guide of supports for families that they can implement in their home, and regular webinars to support both caregivers and clinicians. The Baby Siblings Research Consortium (www.babysiblingsresearchconsortium.org) includes finding and a video library of experts answering questions from parents, and continues to be the largest group of infant siblings researchers representing 5 countries and over 30 research sites. The BSRC has now launched a study to look at the children of undiagnosed siblings to determine their risk of an autism diagnosis and the unique signs and symptoms of that "next generation" of siblings to understand early signs across generations.
Remaining Gaps	The link from early autism diagnosis to access to intervention to intervention outcomes. The USPSTF has dinged these studies for not making this direct link. Despite even more research in this area, there are gaps in the diagnosis of black and hispanic kids. There are studies after studies, year after year, that show this, but the disparities still exist. What are we not doing that we should be doing and HOW do we do it? It's not enough anymore to say we should just do better.
Emerging Opportunities	Telehealth and methods involved video libraries such as the Autism Navigator. The pandemic has changed the way that families receive services and families have become more versed and reliant on online technologies. These new skills and abilities should be harnessed for good.
Outdated concepts	Honestly, these concepts are still relevant after 4 years. However, we need to add something about preemptive interventions, or interventions prior to a formal diagnosis when there are concerns. I'm not sure if this goes under diagnosis (since it's pre-diagnostic) or interventions but I'll put it in both places.
Language to include or avoid	We need to continue to use the words treatment and interventions, and not shy away from them. We need to continue to use the word impairments and deficits as well as strengths and abilities.
Comments on Objectives	With regards to the cross cutting objective, I think we have enough research to show we don't need a new assessment instrument, but we do need to consider how to modify existing instruments to fit the needs of females. We also need to focus on earlier diagnosis of females, there is a current lag in diagnosis and many women are not being diagnosed until adulthood. A better understanding of factors impeding an earlier diagnosis n females is desperately needed, which includes biological differences.

Other comments	The issues relating to racial and ethnic disparities probably needs attention to the way research is conducted and the hypotheses and the interactions with the community as much as the research question itself.
Q2: Biology	
Edits to Question or Aspirational Goal	No, I think it's fine
Recent advances to include	There is now considerable evidence of the female protective effect in ASD. Now there needs to be further investigation of what that protective effect is. ASF and Simons are both leading efforts in understanding sex differences in ASD from a biological perspective. This includes 7 new grants supported by the Simons Foundation and the Sisters Project from ASF.
Remaining Gaps	There still need to be some sort of standards for what is considered a preclinical model of ASD. Does it rely on face validity or construct validity? What is unique about these models and which ones show the most promise? There is just a list of model systems and we are still at a point of considering each equal. It's time to not just prioritize the genes, but prioritize the model systems themselves. Also, germ cell mutations have been examined but need further study, there is preliminary evidence of mutations in sperm (eggs are hard to obtain, I get that) and issues around pre conceptional mechanisms are important and missing.
Emerging Opportunities	While the brain is still the most important organ in neurodevelopmental disorders there is not enough resources of autism postmortem brain tissue to truly understand the subtle nuances across the different features of autism. This needs to be continually reinforced and built up in a way that focuses on public awareness not just collecting brains. There needs to be ongoing work to better determine the uniqueness of each donor. Also, the brain is not the only organ affected. Many individuals experience profound gastrointestinal problems that are debilitating and made worse in those who cannot communicate.
Outdated concepts	There is an emphasis on the immune system, and I'm not sure why. Gene expression affection microglia have been shown to possibly account for some of the sex differences, but the idea that the immune system is somehow innately involved has been debated.
Language to include or avoid	Individuals with autism have unique strengths, but that does not mean they show impairments and disabilities, and both should be used. I think we should also accept the use of the term both "person with autism" and "autistic adult" depending on the audience we are speaking of.
Comments on Objectives	The role of rare genetic forms of ASD/NDD's, those rare variants, are not necessarily always studied in a way that provides information across disorders. Each rare disease is unique, and it is critical that they work collaboratively to identify and address issues that are cross cutting. This includes a potential larger registry across different diseases where researchers can access multiple information. They are usually not required to join NDAR.
Other comments	Longitudinal studies are included under biology, but they also should be included in diagnosis, and risk factors and interventions. The ABC CT study is close to being finished can we hear more about it?
Q3: Genetic and Environmental Factors	

Edits to Question or Aspirational Goal	The word "heritability" is used incorrectly. Heritability can refer to both genetic and environmental factors that are passed on from generation to generation. That section needs to be rewritten. Also, we need to acknowledge that statistical models to look at gene vs. environment do not include the interaction of genes + environment. Finally, we can stop talking about common vs. rare variants, because in many papers, they have been shown to work together.
Recent advances to include	NIEHS and AS has formed a network called the Environmental Epidemiology of Autism Research and Neurodevelopment (EEARN) that has been important in not just identifying research opportunities but
Remaining Gaps	Rare genetic disorders not overlap with ASD, they overlap with NDD's, one of which are ASD's. More information about their uniqueness and commonness with idiopathic autism is desperately needed. Also, gene + environment is given just talk in the strategic plan, but the policy analysis does not really show much progress in this area. There need to be some tangible questions asked based on the science of how environmental factors work and also what the genes control. The work so far has been half hazard. Also, this goes back to animal model research in Q2.
Emerging Opportunities	Collaboration, collaboration, collaboration. The sample sizes needed to detect common variant effects as well as g x e are way more than have been previously possible. This means that studies need to 1. harmonize data collection methods and times, 2. share bio banking and analysis methodologies and 3. align themselves methodologically or figure out ways to do this post-hoc
Outdated concepts	We need a serious reexamination of NDAR, which is listed as a data repository. There is a lot of work put into NDAR. But I think we need to consider how often it is used or accessed. Also, there should be a central repository of research studies that includes information about all research projects so that individuals seeking research options has an easy to find directory that is searchable.
Language to include or avoid	We should keep pre-emptive interventions and prevention of disabling features of ASD. Preventing ASD is a far fetched goal, but prevention of disability is something that can be thoughtfully considered.
Comments on Objectives	There has been sadly, little movement in the gene x environmental arena. I fear that many of the studies that are accounted for in the portfolio analysis as g x e are really less relevant for g x e than they are for genetics alone. Twin studies show heritability, not necessarily the dissection of genetic and environmental factors. New statistical models need to be built and incorporated. And we need to work with exposure scientists to better understand novel methods of quantitative exposure (like baby teeth, etc.) We also need training opportunities BIG TIME for g x e studies. This should be a funding focus.
Other comments	A cross cutting issue is the importance of longitudinal studies which is mentioned in Question 2 but relevant for intervention and supports. There is a critical need to continue to support new longitudinal studies and also extensions of existing studies (great new support for SEED for example) to examine lifespan issues and how to help prepare for adulthood.
Q4: Interventions	

Edits to Question or Aspirational Goal	I think we should change it to "which interventions or treatments will help each individual person on the spectrum"? We can't continue to use a one size fits all approach.
Recent advances to include	Whitehouse, A.J.O., et al., Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis. JAMA Pediatr, 2021. 175(11): p. e213298.
Remaining Gaps	The use of parents and Telehealth - Telehealth is often new thanks to COVID, but now it's time to really start understanding the use and how it helps and may not help, who it can uniquely reach and who it is not helping. We need to talk more about pre-emptive interventions, before a diagnosis is made. Also, behavioral interventions are given a bad reputation by self-advocates, but there is not a non-biased, well designed study out there that shows the harms. Only anecdotal evidence by the same group of people that are willing to bully others over twitter. this may need to be a priority. We also need to continue to support behavioral interventions, that, while not perfect, have historically shown to help families with ASD. Perhaps we need a study to assess the feasibility and acceptability of some of these interventions done by an independent agency that will not bias the results (as I have witnessed). I want to urge that marijuana be moved from a Schedule 1 controlled substance to a Schedule 2 because that will allow more research to be conducted on both CBD and THC in the treatment of autism.
Emerging Opportunities	For those who cannot speak, we need to figure out ways for them to communicate that does not involve the use of a 2nd person, a facilitator, a helper or anyone that can be interpreted to speak for them. There are new technologies as well as advanced ABA devices that can help those communicate more independently. We cannot rely on facilitated communication to be an effective and valid method of helping those who cannot communicate verbally to express themselves. Other methods need to be explored. I think we need a section on facilitated communication as well as other interventions (like stem cell treatments) that have no evidence base. The issue of FC is incredibly divisive, with supporters showing complete disdain and even threats towards those who exhibit any sort of doubt or questioning of the methodology at all. This is a red flag.
Outdated concepts	we need to remove the stigma of ABA. ABA is immediately dismissed as being abusive and there is no known evidence of that. Only some anecdotal reports, which I do take seriously, but also some very badly designed studies which I think poison others against the possibilities of ABA. I'm not sure there is enough other than TMS to talk about "direct brain stimulation" in autism.
Language to include or avoid	WE HAVE TO CONTINUE TO USE THE WORD TREATMENT AND INTERVENTION, as well as supports.
Comments on Objectives	Biological markers should help guide intervention decisions. As we get better at biomarkers, they can tell which person should be receiving what intervention. This has been aspirational. It is 4 year later. We have better clues.
Other comments	We need to ensure we consider family factors. For example, we need more information on sibling perspectives, needs, and family dynamics. research has shown they can be incredibly important, while not a direct "intervention" it is

	important. 7. Rosen, N.E., J.B. McCauley, and C. Lord, Influence of siblings on adaptive behavior trajectories in autism spectrum disorder. Autism, 2021: p. 13623613211024096.
Q5: Services and Supports	
Edits to Question or Aspirational Goal	No. looks fine
Recent advances to include	There was a very well done systematic review led by Sandbank in 2020 that highlighted the gaps that need to be addressed in behavioral intervention, how moderators need to be incorporated and how to better determine their evidence base. That should be highlighted in the strategic plan.
Remaining Gaps	see below, but there needs to be something about evidence based interventions, meaning interventions that have been studied and SHOWN not to be effective, or misleading, or expensive and not approved by the FDA. the strategic plan should highlight or even decide how those should be handled by advocacy organizations, or even the NIH, or whoever. This is becoming a bigger and bigger problem and it is not being fully addressed by regulatory agencies who keep tossing the ball back and forth to eachother. We should have an actual process within the IACC to bring checks and balances for these "unproven" or "dangerous" treatments. PS I'm happy to help work on that.
Emerging Opportunities	there continues to be an enormous influx of potentially dangerous interventions that sometimes do or don't get approved by the FDA and sometimes do or don't get communicated accurately to the public. One that comes to mind is stem cell infusions for treatment of autism. While this may be a very big pool of potentially dangerous interventions, we need to reinforce in this strategic plan the importance of studying them rigorously and then reporting the findings accurately to the press, and being very very critical of those that seek to make money. There needs to be a section in the report about criteria for accepting a treatment that is new, not approved by the FDA (rather than given an IND), and charges extraordinary amounts of money and do not even show to be effective in early studies. The term "evidence based" can be loaded given that we all know that not even study is perfect, but some studies are lacking and can be dangerous.
Outdated concepts	There needs to be a stronger emphasis on CHOICE. Choice of employment, choice of living situation, choice of supports.....
Language to include or avoid	The three objectives are really spot on, but we need to continue to enforce the implementation and testing of ways to reduce racial and ethnic disparities. And report back on it. And learn from it.
Comments on Objectives	There is another issue that needs to be addressed = many families are turning to hospital emergency rooms for behavioral outbursts, aggression and other behaviors that are not able to be managed. These ER's are not equipped to handle these behaviors and there is a backlog of facilities that are sufficiently trained to manage these issues in a crisis situation. We need to seriously look at how critical care facilities like hospitals or urgent care places. In the words of Bethany Frankle "thisisamentalhealthcrisis" There is another issue that needs to be addressed = many families are turning to hospital emergency rooms for behavioral outbursts, aggression and other behaviors that are not able to be managed. These ER's are not equipped to handle these behaviors and there is a

	backlog of facilities that are sufficiently trained to manage these issues in a crisis situation. We need to seriously look at how critical care facilities like hospitals or urgent care places. In the words of Bethany Frankle "thisisamentalhealthcrisis"
Other comments	In "outcome measures" on thing that is needed is an autism specific QOL measure. Many have been piloted, but none are really "loved". I think that is priority for Question 5. We need to continue to support evidence based interventions, get constructive and useful feedback from the community on these interventions, and warn the public about those that could be possibly dangerous, expensive, and produce no improvements.
Q6: Lifespan	
Edits to Question or Aspirational Goal	NO - other than we are now learning or need to learn more about becoming seniors. Does "lifespan"work better? Adulthood implies to age 60. We need to be more expansive to even geriatric and end of life issues.
Recent advances to include	Giacomo Vivanti at Drexel showed an increased risk for dementia. This is now a documented problem.
Remaining Gaps	We need to better understand what quality of life is for people along the spectrum. For some, it's competitive employment. For others, it's having one friend. I think the definition of "the needs of people across the lifespan" has been uniform, that every single person with autism is expected to have the same outcome or the same expectation for happiness and fulfillment of their lives.
Emerging Opportunities	There is a increase in the awareness of why certain people, particularly females, receive a later diagnosis than males, many of which are not diagnosed until after their OWN child receives a diagnosis. These individuals significantly suffer because of a lack of diagnosis early on. This goes to question #1, but we need to explore the impacts of later diagnosis on those who do not have access.
Outdated concepts	I'm not sure this is accurate anymore "Research focused on adult issues has lagged far behind other types of ASD-related research, comprising only 2% of all autism research spending in 2015" I think if you look carefully at the research being conducted, it is way more than 2%
Language to include or avoid	We need to not only better train care workers, we need to pay them better. that's missing. Sex education is also a critical part of adolescent/adult training Sex- relevant vocational opportunities are needed.
Comments on Objectives	Objective one talks about "coordination of integrated services" but there is no listing underneath for the coordination of these integrated services such as family navigators. There also needs to be a single resource, not multiple books, on preparation to transition to adulthood. It should include legal issues.
Other comments	Lifespan issues differ based on severity, IDD, verbal ability, ability to live independently, and of course cultural and familial issues. There needs to be acknowledgement of this and an objective to better measure these effects across the lifespan using longitudinal studies to examine what is a good outcome for someone. Expecting each person to live independently and pay their own bills is not realistic.
Q7: Infrastructure and Surveillance	

Edits to Question or Aspirational Goal	No
Recent advances to include	The ADDM methodology has been expanded to 4 year olds and a methodology was validated that will help with counting. We might want to think about doing a mini- South Korea project. I know one was funded by Autism speaks but what was the result of that? It's mentioned (SUCCESS) but still no data? Nothing published? I can't find it and I think that needs to be pushed.
Remaining Gaps	I'd like a report on how often NDAR is actually used and a survey on how friendly the system is to upload data. Maybe it needs to be focused on only certain types of research to start out with and not be a 'catch all' with data fields all over the place. There needs to be an external analysis of how NDAR is being used, what the problems are, what the successes are, and how it can be expanded or compartmentalized to make it more user friendly.
Emerging Opportunities	There are data sharing efforts in genetics, but phenotypic information attached is very limited. There should be more financial incentives to create and allow these collaborative databases, including those for rare genetic disease research to share their information on a suitable platform. As I said before, collaboration collaboration collaboration. Rare genetic diseases organizations with similar issues are collaborating to share best practices and avoid duplication. Collaborative efforts need to be expanded in a strategic way, but not necessarily to a point which it becomes unmanageable. Early career investigators should receive priority on publications and expanded funding options.
Outdated concepts	A lot of the objectives should be reworded. Objective 3 should focus on early career researchers. Objective 2 should be more specific: what repositories? Those with JUST genetic information or JUST phenotypic information? How can the two be integrated? It's important that as much information as possible be put into data linkages. And unfortunately because this is an international autism community, NDAR needs to adapt to make that happen. And there needs to be incentives to put data into NDAR.
Language to include or avoid	There needs to be more focus on early career investigators. There needs to be a move from CMA technology to microarray as a standard of assessment.
Comments on Objectives	It seems like nothing has been really achieved other than the GUID which is specific to the US only. We also need specific training on the access of databases. Under infrastructure we need to acknowledge and promote the role of early career investigators and carve out some opportunities for them either in IACC discussions, at IACC meetings, or other opportunities. It's up to the funding agencies to make funding decisions, but the IACC could certainly make this a cross cutting issue.
Other comments	Outreach to donate should be among the top if not the top examples of a priority. "Build it and they will come" is NOT the way things are working. Certain programs are not relying on outreach to the autism community and in fact shying away from meaningful interaction with those with ASD. We also need a reexamination of the questions in these registries. They are overwhelming. There should be some common measures developed with the community and then used across studies for better harmonization. It's not enough for NDAR to just use what is given, they need some common measures.

Impact of the COVID-19 pandemic	Thank you for making this a supplemental question because I wasn't sure where to put these answers. Not only do we need to understand the differential effects of social distancing, we need to better understand the advantages and disadvantages of Telehealth practices. What is it good for? What is it not good for? Where are there advantages (like convenience for families) and what does it miss, specifically for families with neurodevelopmental disorders.
Needs of underserved populations	The IACC needs to do more than just identify issues but do something about them. This is where implementation science comes in. There needs to be additional representation on the IACC from black and hispanic communities, and economically disadvantaged communities. The IACC needs to advocate for internet access for ALL regardless of SES or where someone lives.
Aware of any duplicative efforts?	I will say that ASF makes a deliberate choice to try and fill in gaps, not create new resources. MSSNG and SPARK are incredibly duplicative and while Simons funds SPARK,, MSSNG partially comes from federal money and the two need to be independently funded. There should be more focused efforts towards gathering information from underserved communities: rare genetic disorders, females, black and hispanic people. There is a circular problem that needs to be addressed: fewer diagnosed individuals means less participation in research and that leads to less understanding of that population.
Final comments	We need to embrace the term "neurodivergent" and profound, and recognize that there is a significant proportion of people in between. They may be verbal and have an IQ in say, the 80's range, but they cannot speak for themselves and need continuous support. The neurodiversity community has created this rift within the community and need to take account for their role instead of acting like this is "happening to them without their ok"

Name/Agency	Yetta Myrick
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	Question: How Can I Recognize the Signs of "Autism", and Why is Early Detection So Important?
Recent advances to include	
Remaining Gaps	Training researchers on how to engage culturally diverse populations.
Emerging Opportunities	ECHO Autism, a telementoring model moves knowledge not patients. Learn more here: https://echoautism.org/
Outdated concepts	Developmental monitoring using the CDC's "Learn the Signs. Act Early" materials need to be highlighted. Developmental monitoring complements screening and can increase access for many families.
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	I'm not sure. This is not my area...what I can say is that my original thought about the question is that it does not get to the heart of what this section is about, but I do not know how to reword it...
Recent advances to include	
Remaining Gaps	

Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	How these services can be accessible to the community, especially those that are under-resourced and across different cultural backgrounds.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	Under coordination of services, there is a need for peer to peer supports, parent navigators, etc. to support families in navigating services. Providers do not have the bandwidth to help families on an individual basis.
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	

Outdated concepts	
Language to include or avoid	
Comments on Objectives	Under objective 3 we need to add: "Train skilled workers on how to support adults with ASD." There are still too many people on the ground that do not understand what autism is and how to support individuals.
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	I would like to see the ADDM network funded in every U.S. State and Territory so we have a clearer picture the autism numbers across the country.
Impact of the COVID-19 pandemic	How the COVID-19 pandemic has disproportionately affected racial and ethnic minorities, economically disadvantaged communities, and rural populations making it more difficult for them to access resources and services.
Needs of underserved populations	The IACC needs to consider how to engage these communities on the ground and include them in the conversation to find out what the needs are and how best to support them.
Aware of any duplicative efforts?	No
Final comments	It think it would be helpful to have an overview of some of the more complete topic ie: biomarkers, etc. explained to lay member who are not trained researchers. I did not feel comfortable commenting, because I do not understand of all it. Thank you for the opportunity.

Name/Agency	Lindsey Nebeker
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	Suggestion: Replace "Prevented" with a synonym (example: Alleviated, Addressed)
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	Substance Use Disorder - Risk of Substance Use Disorder and Its Associations With Comorbidities and Psychotropic Agents in Patients With Autism https://jamanetwork.com/journals/jamapediatrics/article-abstract/2774700 - Demographic and psychological predictors of alcohol use and misuse in autistic adults https://pubmed.ncbi.nlm.nih.gov/34232103/
Remaining Gaps	- Add "substance use disorders" (i.e. alcohol, recreational drugs) to the list of topics.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	Military: Autism-related traits and suicide risk among active duty U.S. military service members. https://doi.apa.org/doiLanding?doi=10.1037%2Fser0000418
Remaining Gaps	- While there is a paragraph in the publication that acknowledges the mental health needs of autistic people, it should be integrated into the Aspirational Goals and/or Topics Areas. This is an area that needs crucial attention for implementing services and supports. - There are only 3 mentions of "racial disparities" in the publication. I suggest we expand upon this more to address how we can create a more solid expansion of services and supports to non-white families and autistic individuals (children and adults). - Add "gender disparities" to the objectives. - Add "military" to the objectives and/or topics. (refer to 2021 study) - Add "eating and feeding disorders" to the topics. There is not a single reference to it in the publication, which I am surprised about, because this topic had been brought up to the committee since over a decade ago.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	- Definitely keep the topic of wandering, but replace the phrase "wandering behavior" in the text as it implies the wandering issues are intentional. Also, add water safety to this topic since that is related. - Replace references of "severe" with "significant" and/or "intense", depending on context.

Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	add "mental healthcare"
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	The impact of COVID-19, mental health and isolation within the autism community.
Needs of underserved populations	- Access to diagnostic services - Access to information and resources about autism (free or low cost) - Access to education for autistic kids and youth - Access to housing and support options
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Jenny Mai Phan
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	I have no suggestions for edits to the Question and Aspirational Goal of this chapter.
Recent advances to include	I have no suggestions here.
Remaining Gaps	<p>1. Under Disparities in ASD Screening, please insert a sentence on which populations are more likely to receive school-based diagnosis than clinical diagnosis of ASD, which highlights the disparity in clinical evaluations for a diagnosis of ASD in certain racial/ethnic groups. I am referencing this paper: Barnard-Brak, L. (2019). Educational versus clinical diagnoses of autism spectrum disorder: Updated and expanded findings. <i>School Psychology Review</i>, 48(2), 185-189.</p> <p>2. Under Validity of Screening Instruments in Diverse Groups, please insert a sentence or two about the practice of using ASD screening tools in different languages and cultural settings. For instance, there is a lack of shared resources across clinicians and practitioners in better-resourced locations to low-resourced locations. Policies can be directed toward a funding stream that would allow better-resourced locations to engage in efforts to provide screenings and evaluations for non-English speaking families. A shared effort would be experienced Spanish-speaking professionals, Mandarin-speaking professionals, etc. from better-resourced locations to guide and assist in screening and evaluations in low-resourced locations. In sum, research on the application of screening tools in different languages and cultural settings among professionals is needed; in other words, perspectives from families and professionals of non-English speaking backgrounds on screenings and evaluations is needed.</p>
Emerging Opportunities	I have no suggestions here.
Outdated concepts	I have no suggestions here.
Language to include or avoid	In Objective 2, first bullet point: I would replace "healthy" developmental milestones with "typical" and replace "warning signs" of concern with "signs of ASD."
Comments on Objectives	In Objective 2, second bullet point: Please add in validity "and reliability" of different screening and diagnostic tools. For CC1: Please add a bullet point about assessing identity development (age-appropriate questions about who they identify as) as a part of screening and diagnostic tools.
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	

Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	

Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Joseph Piven
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	If the overall goal of the Strategic Plan is to promote research I think we should broaden his item beyond 'early detection', which implies the existence of a diagnosis, to include the concept of 'presymptomatic' detection. In most cases ASD unfolds over
Recent advances to include	As above, MRI prediction in infancy of later diagnosis -- papers by Hazlett et al 2017 and Emerson et al 2017 are included already but a recent white paper on future research on this topic by Grzadzinski et al 2021 should be added. Rebecca Grzadzinski , Dima Amso , Rebecca Landa , Linda Watson , Michael Guralnick , Lonnie Zwaigenbaum , Gedeon Deák, Annette Estes, Jessica Brian , Kevin Bath , Jed Elison , Leonard Abbeduto , Jason Wolff , Joseph Piven. Pre-symptomatic intervention for autism spectrum disorder (ASD): defining a research agenda. J Neurodev Disord . 2021 Oct 15;13(1):49.
Remaining Gaps	There is an emerging literature on presymptomatic interventions in animal models of autism that would be extremely informative to include. This could go in the section on 'intervention' or on 'biology' but I think it also warrants consideration here as it demonstrates the importance of detection and intervention prior to the downstream development of brain changes and their associated symptoms. Cas9 gene therapy for Angelman syndrome traps Ube3a-ATS long non-coding RNA. Wolter JM, Mao H, Fragola G, Simon JM, Krantz JL, Bazick HO, Oztemiz B, Stein JL, Zylka MJ. Nature. 2020 Nov;587(7833):281-284. doi: 10.1038/s41586-020-2835-2. Epub 2020 Oct 21. PMID: 33087932 Presymptomatic training mitigates functional deficits in a mouse model of Rett syndrome. Achilly NP, Wang W, Zoghbi HY. Nature. 2021 Apr;592(7855):596-600. doi: 10.1038/s41586-021-03369-7. Epub 2021 Mar 24. PMID: 33762729
Emerging Opportunities	We should consider including other papers relevant to the idea of presymptomatic detection including: research on ethical issues and financial impact that expand on the complexity of presymptomatic or preemptive intervention. The Ethics of Predicting Autism Spectrum Disorder in Infancy. MacDuffie KE, Estes AM, Peay HL, Pruett JR Jr, Wilfond BS. J Am Acad Child Adolesc Psychiatry. 2021 Aug;60(8):942-945. doi: 10.1016/j.jaac.2021.01.006. Epub 2021 Jan 19. PMID: 33482291 Presymptomatic Detection and Intervention for Autism Spectrum Disorder. MacDuffie KE, Estes AM, Harrington LT, Peay HL, Piven J, Pruett JR Jr, Wolff JJ, Wilfond BS. Pediatrics. 2021 May;147(5):e2020032250. doi: 10.1542/peds.2020-032250. Epub 2021 Apr 14. PMID: 33853890 Cost-Effectiveness of MRI-Based Identification of Presymptomatic Autism in a High-Risk Population. Williamson IO, Elison JT, Wolff JJ, Runge CF. Front Psychiatry. 2020 Feb 19;11:60. doi: 10.3389/fpsy.2020.00060. eCollection 2020. PMID: 32140115
Outdated concepts	

Language to include or avoid	the term 'risk' has become unpopular in some circles. We might consider using the term 'likelihood' although that is not without consequences e.g., moving the autism literature further away from mainstream medical genetics and other risk marker terminology
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	I would broaden objective #3 to specify specifically mention understanding the biology 'older age' in ASD adulthood, as the general understanding of the former is often about transition to adulthood and early adulthood and not specifically the problems of older age. The problems of older age in ASD have not been well studied but there are early signs that there may be degenerative changes that differ in this group, with aging (i.e., different biological mechanisms/issues than seen earlier in ASD).
Recent advances to include	Consistent with the above point: The health status of adults on the autism spectrum. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, Kripke C. Autism. 2015 Oct;19(7):814-23. doi: 10.1177/1362361315577517. Epub 2015 Apr 24. PMID: 25911091 Giacomo Vivanti 1 , Sha Tao 1 , Kristen Lyall 1 , Diana L Robins 1 , Lindsay L Shea The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder. Autism Res. 2021 Oct;14(10):2189-2199. doi: 10.1002/aur.2590. Epub 2021 Aug 11.
Remaining Gaps	Consistent with the above comments on older age, I think we are still missing comprehensive longitudinal studies of autism from early childhood through older age -- that include biological measures (e.g., brain imaging, molecular markers, EEG). These studies are very costly and require a longer term commitment than the typical 5 year RO1 funding. They are more akin to the ABCD (Adolescent Brain Cognitive Development) study. References to the ABCD Study should be added to the text. The Adolescent Brain Cognitive Development Study. Jernigan TL, Brown SA, Dowling GJ. J Res Adolesc. 2018 Mar;28(1):154-156. doi: 10.1111/jora.12374. PMID: 29460352
Emerging Opportunities	New research on brain organoids should be added to this section. iPSC toolbox for understanding and repairing disrupted brain circuits in autism. Chiola S, Edgar NU, Shcheglovitov A. Mol Psychiatry. 2021 Sep 8. doi: 10.1038/s41380-021-01288-7. Online ahead of print. PMID: 34497379 Cortical overgrowth in a preclinical forebrain organoid model of CNTNAP2-associated autism spectrum disorder. de Jong JO, Llapashtica C, Genestine M, Strauss K, Provenzano F, Sun Y, Zhu H, Cortese GP, Brundu F, Brigatti KW, Corneo B, Migliori B, Tomer R, Kushner SA, Kellendonk C, Javitch JA, Xu B, Markx S. Nat Commun. 2021 Sep 1;12(1):4087. doi: 10.1038/s41467-021-24358-4. PMID: 34471112
Outdated concepts	
Language to include or avoid	
Comments on Objectives	

Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	Most risk factor research is looking for group differences. I included comments in chapter 1 that had to do with individual level risk factors that have a high specificity for detecting later onset of ASD in individuals. I think it might be time to make this distinction given that it has significant, direct clinical relevance as a screening test for ASD that would emphasize the importance of individual level risk from prospective studies.
Recent advances to include	Challenging the validity of the rigid boundaries inherent in the current nosology that define psychiatric disorders, recent molecular genetic studies have revealed overlapping sets of common, pleiotropic, genetic variants in ASD, ADHD and affective disorders. These conditions are also known to aggregate in non-ASD family members identified through an ASD proband ; and to co-occur with ASD at rates higher than in the general population Consortium, P. G. Genomic Relationships, Novel Loci, and Pleiotropic Mechanisms across Eight Psychiatric Disorders. <i>Cell</i> 179, 1469-1482.e11 (2019). Lee, P. H., Feng, Y.-C. A. & Smoller, J. W. Pleiotropy and Cross-Disorder Genetics Among Psychiatric Disorders. <i>Biol. Psychiatry</i> 89, 20–31 (2021). Hyman, S. E. Wringing Biological Insight From Polygenic Signals. <i>Biol. Psychiatry</i> 89, 8–10 (2021). Gandal, M. J. & Geschwind, D. H. Polygenicity in Psychiatry—Like It or Not, We Have to Understand It. <i>Biol. Psychiatry</i> 89, 2–4 (2021). As past NIMH Director Steven Hyman recently articulated in a commentary entitled “Psychiatric Disorders: Grounded in Human Biology but not Natural Kinds”, the true nature of ASD cannot be understood as a discrete category defined by historically observed symptom clusters. I think this point needs more emphasis in studies aimed at elucidating biological risk markers rather than identifying risk markers of relevant categories. Hyman, S. E. Psychiatric Disorders: Grounded in Human Biology but Not Natural Kinds. <i>Perspect. Biol. Med.</i> 64, 6–28 (2021).
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	As noted in Question 1 on early detection, I think we are missing the developmental component that suggests that intervention prior to diagnosis i.e., presymptomatic intervention in infancy or before, would have the potential to have even greater impact on outcome. This concept is missing from this

	section. It is the emphasis of all intervention research on degenerative brain diseases e.g., Parkinson's and Alzheimers. In medicine we routinely treat hypertension to prevent later cardiovascular sequelae. This idea needs to be included in the intervention section. Relevant references to this issue are included in prior sections of this survey.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	The knowledge base on services and training the work force relevant to providing services for older age autistics is minimal and is in need of expansion. We do not know the specific issues involved with caring for this population. This deserves to be a separate paragraph and subheading, given that it is almost entirely absent from the research literature and the general conversation on services and policy relevant to autism.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	while it is tangentially mentioned within the section on adulthood, again, older age needs to be specifically identified as an important area. Geriatric medicine and psychiatry are fields unto themselves with specific training fellowships and textbooks and academic divisions. Older age or 'geriatric issues in autism' is missed when lumped together with 'adulthood' and issues like transition. I think this section needs specific mention and significant development given its almost complete absence from the conversation.
Emerging Opportunities	
Outdated concepts	

Language to include or avoid	
Comments on Objectives	I think a specific objective regarding issues in older age is warranted.
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	1. Specific impact on autistic individuals - health outcomes, services (educational, medical, behavioral treatment). 2. Impact on risk e.g., prenatal covid infections 3. Impact on family function 4. Impact on service systems (care providers, schools)
Needs of underserved populations	1. How to expand inclusion to services eliminating disparities and group specific outcome differences where appropriate and understanding underlying mechanisms where differences may be a consequence of biological differences (e.g., genetic variation) to enable development of targeted, group-specific interventions. 2. Expanding the work force in academia and research to include proportionate representation.
Aware of any duplicative efforts?	
Final comments	

Name/Agency	JaLynn R Prince
Preferred title for Strategic Plan	Other (please specify)
Comments on title	IACC Strategic Autism Research Plan for Children and Adults, Services, Policy and Perceptions
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	Yes - TBD
Recent advances to include	
Remaining Gaps	Diagnoses of adults
Emerging Opportunities	Educating and training more capable people to diagnose adult autism, more research into implications of aging with autism - TBD
Outdated concepts	TBD
Language to include or avoid	"them" "those" "high functioning" "low functioning" - TBD Like "high support needs" "Low support needs"
Comments on Objectives	TBD
Other comments	TBD
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	

Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Susan Rivera
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	no.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	no
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	I think that the title of the question "what is the biology underlying ASD?" does not sufficiently capture the scope of what is in this chapter.
Recent advances to include	More recent advances have been made on the "neurobiological correlates of sensory processing in autism" particularly with respect to identifying sub-groups with distinct sensory phenotypes. For example: Dwyer, P., Saron, C. D., & Rivera, S. M. (2020). Identification of longitudinal sensory subtypes in typical and autism spectrum development using growth mixture modelling. <i>Research in Autism Spectrum Disorders</i> , 78: 101645. https://doi.org/10.1016/j.rasd.2020.101645 Dwyer, P., Wang, X., De Meo-Monteil, R., Hsieh, F., Saron, C. D., & Rivera, S. M. (2020). Defining clusters of young autistic and typically developing children based on loudness-dependent auditory electrophysiological responses. <i>Molecular Autism</i> , 11: 48. https://doi.org/10.1186/s13229-020-00352-3
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	

Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	

Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Matthew Siegel
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Spectrum Disorder
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	change to: "Provide the earliest possible diagnosis for people on the autism spectrum and deliver appropriate interventions, services, and supports in as timely a manner as possible to maximize positive outcomes."
Recent advances to include	a few articles on new forms of diagnostic methods using remote assessment/telehealth
Remaining Gaps	Establishing scalable distance diagnostic approaches that overcome the significant barriers required by current in-person gold standard observational measures, while assessing the relative difference in sensitivity/specificity of those approaches. While never a strong, scalable approach, the pandemic has revealed how fragile our reliance on in-person diagnostic measures are and has resulted in a significant roadblock to children being identified and accessing services.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	The cross-cutting objective of sex differences should be retired at this point as a cross-cutting objective. This has been clearly established as an area of focus in multiple research portfolios and there are other cross cutting areas that would benefit from attention.
Other comments	Propose a new cross-cutting objective: Communication Challenges. Communication is the key domain that drives almost all aspects of quality of life, the development of mental health conditions and challenging behaviors, and ability to more readily access education, family and community life, the workplace and non-biologic interventions. Communication, however, has received relatively little research, service or policy focus over the past 2 decades across the spectrum of individuals with communication impairments, from those who are non-verbal to those with subtle social communication challenges. Large, systematic RCT's on interventions for language acquisition, use of AAC, and provision of functional communication interventions, are almost entirely lacking, despite the critical nature of communication, and equally lacking is a focus on the neurobiology and genetics that underlie communication impairments and rigorous assessment of the relationships between communication impairments and other key impairments, such as behavior challenges, ID, anxiety, depression, non-employment and others.
Q2: Biology	
Edits to Question or Aspirational Goal	

Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	"What Causes ASD, and Can Aspects of ASD That Cause Impairment be Prevented or Preempted?"
Recent advances to include	Recent articles by Jill Fodstad and others preemptive treatment of emerging self injurious behavior and other challenging behaviors in very young children with ASD. An area of prevention that has received little attention, but once these behaviors develop they can lead to lifelong disability and exclusion from needed services and settings.
Remaining Gaps	Prevention of the development of challenging behaviors.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	Add an objective: Research to address effective means for preventing the emergence or routinization of challenging behaviors in young children with ASD.
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	Intensive inpatient treatment of challenging behaviors and mental health conditions: Pedersen K, et al, JADD, 2017. Decreasing inclusion of individuals severely affected by autism in treatment studies over the past 3 decades: Stedman A, JADD, 2018
Remaining Gaps	- We are lacking large RCT's of ABA assessment and treatment for challenging behavior. This is almost entirely a single subject design literature, which has inhibited the development of manualized approaches that can be widely disseminated and moved into clinical practice, and accepted and reimbursed by health care insurance. - We are lacking almost any controlled evidence for one of the most common and expensive interventions utilized: residential treatment. Thousands of people with ASD are in various forms of residential treatment (group home, PRTF, ICF-ID, other), with no systematic study of the efficacy or effectiveness of this intervention, and hundreds of millions of dollars spent. - Longitudinal assessment of development, maintenance,

	<p>recurrence/resolution of challenging behaviors in ASD. We have little information on risk factors, key developmental periods, and natural history of challenging behaviors across the lifespan. - Comprehensive assessment and treatment packages for challenging behaviors and mental health conditions. We have very few studies that assess a systematic multi-disciplinary approach, though this is what is widely used in clinical practice and recommended by most experts in this area. - Developing evidence for approaches that treat emotion regulation deficits. in the last 5 years a burgeoning literature has described the prevalence of emotion regulation deficits in people with ASD across the spectrum, and now we need to study interventions to address this core deficit area. - referred to in my proposal for a cross-cutting objective: Rigorous study of communication intervention, particularly for the minimally verbal. - Study of intervention models for crisis behavior presentations, such as a mobile crisis team and other approaches. - Pharmacologic studies for the treatment of the most prevalent psychiatric co-morbidity in ASD, anxiety disorders, using measures validated for anxiety in people across the ASD spectrum. There have been no trials that meet this criteria.</p>
Emerging Opportunities	- study of multi-component treatment packages for challenging behaviors and mental health conditions, utilizing a treatment algorithm and just-in-time adaptive intervention.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	- Study of the utility and meaningfulness of distinguishing profound autism, as proposed in the recent lancet commission article, from the rest of autism. Would this reduce heterogeneity in study samples and create more meaningful results and policy opportunities?
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	

Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	- Surveillance and reporting nationally on the use of residential treatment settings (group homes, prtf, etc.) for individuals with ASD. - Surveillance on adults with ASD. - Linkage and greater promotion of existing biorepositories/databases: SSC, SPARK, AIC, AGRE, ASC, NDAR.
Emerging Opportunities	NDAR has had very little impact or functionality, despite its potential. Can NDAR receive an expert review and recommendations to increase its usability and impact, and can it be brought into a larger coordination of the many existing databases: SSC, SPARK, AIC, AGRE, ASC?
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	Assess the loss of services for young children in early intervention, school age children and adults, and the impact on developmental progress of children and psychiatric hospitalization, morbidity and mortality for adults.
Needs of underserved populations	The underserved and underresearched population to focus on, who are the most vulnerable and suffering the greatest morbidity, are the severely affected/profound autism group. Those who are minimally verbal, have intellectual disability and/or serious challenging behaviors (aggression/self injury). This group needs more research attention on their specific needs and risks, effective assessment and treatment of communication impairment, challenging behaviors and mental health.
Aware of any duplicative efforts?	no
Final comments	We need to retain the use of the words: treatment, prevention, impairment, etcetera. While there are some individuals who are able to function in a way that their autism is an aspect of who they are, and something that they find enhancing or not in need of treatment, there are many individuals who cannot

	speak for themselves on the IACC, have severe and disabling impairments, whose families and caregivers desperately seek treatment and desire prevention.
--	--

Name/Agency	Ivanova Smith
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	Just say autism instead of ASD.
Language to include or avoid	
Comments on Objectives	No I don't see any problems. S
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	I think be good to do more reseach in how horomones and how they effect Autistics expecially teen autistic more reseach in how purbty effects Autistics people differently how to make it more comfortable autistic
Emerging Opportunities	Going down path how make life more smooth for autistic people how make bodies respond to environmental that don't cause pain.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	There isn't a cure for autism it is life long disability and should be reorganized as permanent disability.
Recent advances to include	How inclusive acceptance practices have helped autistic people.
Remaining Gaps	How society views about autism impact how autistics get services and how some autistics get left behind.

Emerging Opportunities	Research in Alternatives forms of communication show people can communicate their needs in ways family can understand
Outdated concepts	The idea that autism can be cured are it good try change the autistic person or make them look less autistic that don't help autistic just makes use stress out instead allow autistics be and help with independent skill instead of popularity skills.
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	There has been more research in plant based medicine used for autistics and helped some autistics
Remaining Gaps	What are side effects for every treatment
Emerging Opportunities	Research in more herbal options for treatment and treatments lead by autistic people
Outdated concepts	
Language to include or avoid	Cure should be removed
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	There needs be person centered planning and person centered services the supports should respect the dialy routine of the person needing services not be other ways around.
Emerging Opportunities	That services allow for communication and allowing autistic to lead in what treatments they want.
Outdated concepts	Safety should not be used to restrict a person access to community. Example autistic people being deny access to community because Covid 19 protrocals
Language to include or avoid	
Comments on Objectives	It be good define more what eevidence based means and how that dwfined
Other comments	
Q6: Lifespan	

Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	It be good show harms or mental age theory on autistic people and how that been used to restrict the lives of autistic adults.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	Communication supports for autistics and consent to surveince making sure it informed consent to get and use tracking devices.
Emerging Opportunities	Education on communication and supporting autistics and giving consent and how support autistics in learning what consent is for such devices.
Outdated concepts	I don't like word surveillance I thinking remote support be better term then surveillance.
Language to include or avoid	Same as above
Comments on Objectives	Supporting autistics in safety shouldn't be about spying on them agienst there will. It should be about helping a person explore their environment with suppprts they need and not feel controlled to have support
Other comments	
Impact of the COVID-19 pandemic	<p>policy should not justify discrimination and many of the policy at the CDC has made life inaccessible for many autistics and this has caused lots of trauma. many autistic including myself can't wear masks it like burning on our face. Many autistics more impacted it been same issue because of this many of daily Activieks been taking away. Many been forced into isolation and segregation and any progresss that made in our health regress because lack of activity and aneigty been left out. I can speak I speak on I am feel alone many autistics that are low impact not had this problem some autistics seem like masks but many can't and we been left out. Many autistics that are in supportive housing have their daily lives disrupted and even after getting vaccinated still don't have their right to community restored. This has caused many health issues in autistics. Many non speaking autistics can't tell you that mask is burning them they respond with their behavior and they being ignored for sake of policy and I don't think that right. This not only effect me but many autistics with intellectual disabilities who being retruamating! The CDC need to make it clear</p>

	<p>that policy should not be used discriminate against autistics who still want be in their community. not everyone can do same thing and autistics with sensory should be forced into isolation. Vaccinated autistics should not have go through more barriers to get to their freedoms then non disabled vaccinated people. It seem that is policy I like that changed supporting living faculty shouldn't get keep people trapped because of Covid 19. If it continues to be this way then I fear the mental health autistic people will decline even more.</p>
Needs of underserved populations	<p>We need to make information about autism more accessible and in more language and it needs to use language that is empowering and not language that is negative about autism</p>
Aware of any duplicative efforts?	<p>I don't know what that is. I am not aware</p>
Final comments	

Name/Agency	Hari Srinivasan
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Spectrum Disorder
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Julie Taylor
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	Perhaps the question could be rephrased as "How can I recognize the signs of autism, and why is early detection so important?"
Recent advances to include	The US Preventative Services Task Force recommendation (or lack of recommendation) for universal autism screening made a lot of waves. I'm not sure if there have been updates on research related to the recommendations, but that would be important to include.
Remaining Gaps	The use of telehealth to improve access to diagnostic services
Emerging Opportunities	I wonder if adult diagnosis might be considered here? If not here, it probably needs fuller treatment in Question 6.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	It might be helpful to provide additional text about the benefits to autistic individuals of understanding underlying biology.
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	Maybe change "ASD" to "autism" to reflect current preferences of the autism community.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	

Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	greater leveraging of technology to support intervention delivery
Remaining Gaps	There is a section about difficulties identifying effective outcome measures, but it would be nice to also add a section about challenges identifying what the outcome should be, and who decides. A section on advances in implementation science (interventions actually implemented in the community) would be a good addition.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	I think service disparities within the autism population should be a greater focus.
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	I think most important things are covered in this section.
Q6: Lifespan	
Edits to Question or Aspirational Goal	change "people with ASD" to "people with autism" or "autistic people"
Recent advances to include	there has been a lot of additional research since this report on all areas of adulthood - particularly mental health, employment, suicidality, and adult diagnosis. Most studies remain descriptive.

Remaining Gaps	There likely should be a greater focus on sex differences in adulthood (outcomes of women vs. men) as well as those who are gender non-binary. Limitations of the research base in terms of race/ethnicity should be highlighted more strongly, and good studies that examine racial/ethnic differences should be highlighted.
Emerging Opportunities	autistic researchers who are interested in issues in adulthood can inform the research in important ways (with an example being the study of autistic burnout).
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	In addition to the impact of the pandemic itself, the impact of moving out of the pandemic should also be considered. For some individuals and families, the pandemic was very hard, with loss of access to structure, services, and supports. For some autistic adults, the pandemic relieved some external/social pressures, and moving back out into the world may be more challenging. There may also be lessons from the pandemic (e.g., flexible rules around working from home) that could be helpful to autistic individuals and their families.
Needs of underserved populations	I think research with under-represented groups or underserved populations (and the need for this research) should be a strong theme throughout this entire strategic plan.
Aware of any duplicative efforts?	
Final comments	

Name/Agency	Paul Wang
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Spectrum Disorder
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	Services should be made available whenever there are needs/delays/impairments, regardless of formal diagnosis. Therefore suggest rewording the aspirational goal to "Provide the earliest recognition/identification of autism-related needs, so that appropriate interventions, services..."
Recent advances to include	
Remaining Gaps	Very large gap between screening and full evaluation - many fall through the cracks here. Another gap between evaluation and connection to services.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	Not sure if "early detection" or "early identification" is better
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	Since the Question uses the word "underlying," suggest matching language in the Aspirational Goal: "...underlie ASD.." instead of "...lead to ASD..."
Recent advances to include	
Remaining Gaps	We still lack a broad neuro-cognitive theory of autism. Must account for social and sensory and RRB symptoms. Thus, theory of mind and joint attention are too narrow. Central Coherence and Intense World theories are too vague and inadequately proven. Other theories also lacking in many ways. Prediction Deficit is underspecified. Etc.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	

Edits to Question or Aspirational Goal	The word "prevention" is inherently triggering, even though it applies to "prevention of the challenges & disabilities." Suggest "amelioration." Could say "...of ASD and its co-morbidities."
Recent advances to include	
Remaining Gaps	Could specifically call-out Gene x Environment Interaction (in addition to its mention in the Objectives for this Question).
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	The word "prevention" is inherently triggering, even though it applies to "prevention of the challenges & disabilities."
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	Could delete "treatments."
Recent advances to include	
Remaining Gaps	There is a severe lack of research comparing the efficacy of different approaches. There remains little research on "dose-response" for ABA or other interventions. Critically, there remains severe under-resourcing for intervention in lower-income and rural communities.
Emerging Opportunities	Combined therapies (e.g., behavioral plus pharmacologic) are understudied but thought to hold important potential. Studying such combinations could be a 4th objective.
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	Does gestational COVID-19 increase the likelihood of autism in the offspring?
Needs of underserved populations	These communities and populations are far less resourced for interventions and supports than urban, suburban and more affluent communities.
Aware of any duplicative efforts?	
Final comments	NIH, DoD, CDC and other relevant agencies should regularly examine each other's portfolios of biological research to ensure no duplication.

Name/Agency	Helen Tager-Flusberg
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Spectrum Disorder
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	I would add to this question, identification of earliest culture-free risk signs or biomarkers, prior to the onset of behavioral signs of autism.
Recent advances to include	Numerous studies on early brain development in the first year of life that predict, at high levels of probability later diagnoses of autism. There are also promising studies on early attention, though these measures have lower positive predictive values.
Remaining Gaps	Validation and replication of early brain and attention markers; studies on integrating early predictive measures into pediatric practices; policy changes that would enable research findings in this area to be translated into practice.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	I would hate to see the IACC become the new language police. It is important to use terms that are widely recognized in the clinical community.
Comments on Objectives	This question is one of the cornerstones of the Strategic Plan.
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	I recommend emphasizing that the term biology encompasses cognition and behavior.
Recent advances to include	Advances in this area are incremental and the extent to which published studies impact our understanding depends on the quality of the science. Human neuroimaging studies using MRI and associated technologies have recently made headway by including much larger sample sizes; but they highlight the overlap between autistic and non-autistic brains.
Remaining Gaps	More attention should be given in human studies to individuals who have not been included in prior research (e.g., young children, profound autism, minimally verbal). Understanding the developmental dynamics across the childhood to early adulthood is critical. There is a significant disconnect between biological studies using animal models and those focused on humans - this should be addressed with more direct translational studies.
Emerging Opportunities	See above for gaps in research.
Outdated concepts	
Language to include or avoid	Same comment as in Question 1.
Comments on Objectives	
Other comments	

Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	A focus on risk rather than cause will more accurately reflect the state of the science.
Recent advances to include	The dominant role of genetics - both inherited and non-inherited.
Remaining Gaps	Less is known about the common risk alleles associated with autism.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	See comment on language in response to Q1
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	The text should emphasize the need for evidence-based treatments and interventions. There is a growing acceptance and encouragement of interventions that have little to no evidence to support their use.
Recent advances to include	The importance of evidence-based Naturalistic Developmental Behavioral Interventions NDBIs has grown in recent years.
Remaining Gaps	Objective research is sorely lacking in this area. Novel objective outcome measures, novel research designs and studies on treatment combinations are critically needed to advance this area.
Emerging Opportunities	Broaden the scope of behavioral treatments that are covered by insurance etc to include NDBIs.
Outdated concepts	
Language to include or avoid	see earlier comments
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	topics should be expanded to explicitly include adults.
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	

Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	Medical infrastructure needs at all levels, but most especially for young children (to meet diagnostic/intervention needs) and adults, particularly aging people.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	At last count there are 238 publications listed on pubmed on this topic including reviews and meta-analyses. It isn't clear what else needs to be considered...
Needs of underserved populations	Diagnostic and intervention services that reach the underserved using innovative, community-based approaches, supported in some cases by new technology.
Aware of any duplicative efforts?	No
Final comments	In my view the current structure and core questions are still highly relevant and have driven progress over the past decade. New specific topics have emerged but these can be folded into what has been developed.

Name/Agency	Stephen Whitlow
Preferred title for Strategic Plan	IACC Strategic Plan for Autism Research, Services, and Policy
Comments on title	
Q1: Screening and Diagnosis	
Edits to Question or Aspirational Goal	I would comment on the availability of early screening. We experience long waiting times for evaluations. Perhaps: Provide the earliest possible diagnosis, in a timely manner, for people...
Recent advances to include	
Remaining Gaps	See above regarding availability of timely evaluations.
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q2: Biology	
Edits to Question or Aspirational Goal	No.
Recent advances to include	
Remaining Gaps	I would like to see an emphasis on the interrelatedness of physiological systems and the impact of coordinated and comprehensive care on individuals on the
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q3: Genetic and Environmental Factors	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	

Language to include or avoid	
Comments on Objectives	
Other comments	
Q4: Interventions	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q5: Services and Supports	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Q6: Lifespan	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	

Comments on Objectives	
Other comments	
Q7: Infrastructure and Surveillance	
Edits to Question or Aspirational Goal	
Recent advances to include	
Remaining Gaps	
Emerging Opportunities	
Outdated concepts	
Language to include or avoid	
Comments on Objectives	
Other comments	
Impact of the COVID-19 pandemic	
Needs of underserved populations	
Aware of any duplicative efforts?	
Final comments	