

Request for Public Comment on IACC 2016 Strategic Plan for ASD – List of Themes

Question 1: Diagnosis and Screening	
Subgroups	Need better recognition and diagnosis of subgroups
Early Signs/Symptoms	Need better understanding of early signs and symptoms
Family Support (Post Diagnosis)	Families need emotional support following diagnosis and assistance in navigating access to services
Sex/Gender Disparities	Improve accuracy and awareness of diagnosis of females
Screening/Diagnosis Tools (Accuracy/Usability)	Improvements in the accuracy and usability of screening and diagnosis tools
Biomarkers	Need greater research and identification of biomarkers, and use of these biomarkers in screening and diagnosis
Adult/Adolescent Diagnosis	Need improvements in access and accuracy of adult and adolescent diagnosis
Genetic Screening	Need more and increased access to genetic screening
Cultural/Racial/Regional Disparities	Need to address the multifaceted disparities in diagnosis across racial, cultural, socioeconomic, and regional lines
Greater/Lesser Early Screening/Diagnosis	Need to increase/decrease early screening and diagnosis of ASD in children
Faster Diagnosis	Need to reduce the time to diagnosis by improving service access and diagnostic tools/process
Link Diagnosis to Services	Need to strengthen link between initial diagnosis and access to services and interventions
Parent Education	Parents and caregivers need greater education so that they can recognize signs and symptoms
Parent Concerns	Practitioners need to listen to and consider parent concerns about early signs and symptoms
Universal Screening	Universal screening for ASD is needed
Practitioner Training (Diagnosis/Screening)	Workforce development, including access to qualified practitioners and improvements in the training of the existing workforce
Endorse Current Priorities	Current priorities are appropriate (diagnosis and screening tools, early signs, symptoms and biomarkers, identification of subgroups, disparities in diagnosis)

Question 2: Underlying Biology	
Autism Genetics	Need further research on the genetics of autism, and genetic tests should be more accessible
Developmental Biology	Need more developmental biology research
Genetic Syndromes	Need more research and a better understanding of genetic syndromes related to ASD
Biomarkers/Symptomology	Need more research and better understanding of the biomarkers and symptoms of ASD, and the heterogeneity of symptoms

Immune And Metabolic Pathways	Need more research into the contribution of immune and metabolic pathways to autism
Cognitive Behavioral Biology	Need more research on cognitive and behavioral biology
Sex/Gender Differences	Need more research on sex and gender differences, inclusive of both biological sex and self-identified gender
Neuroscience	Need more research on the basic neuroscience of ASD
Co-Occurring Conditions	Need more research on the biology and relationship of co-occurring conditions in ASD
Molecular Biology	Need more research on the molecular biology of ASD
Sensory/Motor Function	Need more research to better understand sensory processing and motor function in ASD
Translational Research	Need more translational and interdisciplinary research to improve the lives of people with ASD
Subgroups	Need research to better understand, differentiate, and treat subgroups of people with autism
Gut/Brain Interaction	Need to prioritize gut-brain interaction research
Endorse Current Priorities	Current priorities are appropriate (molecular biology and neuroscience, developmental biology, cognitive and behavioral biology, genetic syndromes related to ASD, sex differences, immune and metabolic aspects, and co-occurring conditions in ASD)
Prioritize Treatment/Services	Understanding the biology of ASD is not a priority relative to other areas (i.e. treatment and services)

Question 3: Risk Factors	
Multiple Domains/Better Testing	Need better methods for testing contributions of risk factors from multiple domains to better understand risk of autism
Epigenetics	Need more research on epigenetic risk factors
Genetics	Need more research on genetic risk factors
Immune	Need more research on immune and metabolic risk factors
Maternal/Prenatal	Need more research on maternal and prenatal factors
Gene-Environment	Need more research on the interaction of genetic and environmental factors
Risks For Co-Occurring Conditions	Need more research on the risk factors for co-occurring conditions in autism
Microbiome	Need more research on the role of the microbiome and gastrointestinal risk factors
Familial Factors	Need more research to better understand heritability and risk of autism in families
Environmental	Need more research to better understanding environmental risk factors, including both chemical and social environments
Vaccines	Need more research to understand the role of vaccines in causing autism
	Need less/no additional research on the role of vaccines in autism

Endorse Current Priorities	Current priorities are appropriate (genetic and environmental risk factors, gene-environment interactions, and the potential role of epigenetics and the microbiome)
Prevention/Cause Not A Priority	The cause and prevention of autism are not a priority, either because resources can be better used in other areas or because preventing autism should not be a goal

Question 4: Treatments and Interventions	
Specialized Tx/Ix	Endorsement of specialized or ASD specific treatments and interventions
Adult Tx/Ix	Improve availability and efficacy of treatments and interventions specifically for adult and adolescents with ASD
Coordination Of Tx/Ix	Improve coordination of treatments and interventions between services and practitioners
Educational Tx/Ix	Improve efficacy and availability of interventions in educational settings
Behavioral Tx/Ix	Improve efficacy and availability on behavioral treatments and interventions
Evidence-Based Tx/Ix	Improve the evidence base for treatments and interventions, and make that information more readily available and widely used
Practitioner Training (Treatments & Interventions)	Need a qualified workforce trained in providing treatments and interventions ; need both a greater number and improved training of current clinicians, therapists, and school employees
Biomedical/ Psychopharmacological	Need research on biomedical and pharmacological treatments and interventions to improve efficacy and reduce side effects
Long Term Outcomes/ Implementation/Translation	Need research on long term outcomes of treatments and intervention, as well as the translation and implementation of research based treatments and interventions
Alternative/Complementary/ Integrative Tx/Ix	Need research on the efficacy and availability of complementary, alternative or integrative treatments and interventions
Parent Education	Need to educate parents about available treatments and interventions, and to help provide these interventions
Early Intervention	Need to prioritize early intervention
Personalized Tx/Ix	Personalized combinations and types of treatments and interventions will be the most efficacious
Search/ Don't Search For Cure Not Tx/Ix	Positive and negative comments about searching for a "cure" rather than treatments or interventions
Technology Based/Assistive Technology	Research and availability of technology based or assistive technology treatments and interventions
Treatment For Co-Occurring Conditions	Research and availability of treatments and interventions for co-occurring conditions
Endorse Current Priorities	Current priorities are appropriate (behavioral, medical/pharmacologic, educational, technology-based, and complementary/integrative interventions)

Question 5: Services	
Early Intervention Services	Access to early intervention services is a priority
Disparities In Access/Services	Disparities in access to services should be addressed
Family Well Being	Families need access to services to reduce the mental and emotional burden of caring for those with ASD
Efficacious And Cost Effective Services	Improve the efficacy and cost effectiveness of services and service delivery
Educational Services	Improve the quality and availability of services within the educational systems
Service Systems/Delivery	Improve the service systems and service models
Access To Services	Increase the accessibility and utilization of services.
Coordination/Choice/Relevant Services	Need better coordination between service providers, taking into account what is relevant for the individual and the choices of those with ASD and their families/caregivers
Qualified Workforce	Need for an adequately trained and compensated workforce to improve available services and service delivery
Community Inclusion	Need for better services to foster community inclusion of those with ASD
Specific ASD Services	Need to be more and better access to specialized services for ASD
Assistance Navigating Services	Parents/caregivers need assistance navigating complicated service systems.
Health And Safety	Prioritize services to improve the health and safety, including addressing interactions with law enforcement and wandering
Community Education	The broader community needs to be better educated about ASD, to lead to better understanding and inclusion
Cost Of Services	The cost of services is prohibitive, and research and policies are needed to reduce these barriers to access
Endorse Current Priorities	Current priorities are appropriate (service access and utilization, service systems, education, family well-being, efficacious and cost-effective service delivery, health and safety issues affecting children, and community inclusion)
Focus On Treatment/Cause	Focus on the treatment or cause of autism rather than the delivery of services

Question 6: Lifespan	
Access To Quality Adult Services	Improve access to and quality of adult services, including additional research to improve evidence based services for adults
Adult Diagnosis	Improve access to diagnosis for adolescents and adults
Community Inclusion/Integration	Improve community integration/inclusion, including social isolation and community education about ASD
Housing	Improve the quality, accessibility of housing options
Transition	Improve transition services, and provide better assistance for young adults and their families during transitions
Long Term/Financial Planning	Long term and financial planning are a priority for research, services, and policy

Assistance Navigating Services	Need assistance for adults with autism and their families in navigating available adult services
Qualified Workforce	Need for a larger, better trained and compensated workforce for adults with ASD
Quality Of Life/Health And Safety Across The Lifespan	Research and services to improve health, medical care, safety and quality of life across the lifespan
Vocational Training/Employment/Post-Secondary Education	Research, services and policies are needed to improve vocational/employment and post-secondary education opportunities
Choice/Autistic Perspectives	Services and research should take into account the perspective and choices of adults and their families/caregivers
Endorse Current Priorities	Current priorities are all important/relevant (health and quality of life across the lifespan, aging, transition, and adult services, including education, vocational training, employment, housing, financial planning and community integration.)
Focus On Early Intervention/Not Research Priority	Focus should be on early intervention or developing effective treatments; adults/lifespan are not a research priority

Question 7: Research Infrastructure and Surveillance	
Infrastructure (Services)	Improve services infrastructure
Collaboration/Coordination (Services)	Increase collaboration and coordination among services providers
Collaboration/Coordination (Research)	Increase collaboration and coordination of research including interdisciplinary research
Research Dissemination/Translation	Increase the dissemination of research, and the translation of research into practice
Workforce Development (Research)	Need greater development of the research workforce
ASD Surveillance	Need more and improved surveillance of ASD prevalence, including by race/ethnicity, gender and age
Infrastructure (Research)	Need research infrastructure, i.e. databases, research and clinical trial policies
Autistic Voices/Perspectives	Research should include the voices and participation of individuals with autism and their families
Endorse Current Priorities	Current priorities are appropriate/important (research infrastructure needs, ASD surveillance research, research workforce development, dissemination of research information, and strengthening collaboration)
Prioritize Services	Prioritize services and interventions rather than research