

2016 IACC Strategic Plan Request for Public Comment

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IACC Full Committee Meeting

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2016 IACC Strategic Plan Request for Public Comment

- On behalf of the IACC, OARC issued a Federal Register Notice soliciting public comment on the research, service, and policy priorities for the topics addressed by the current strategic plan:
 - Q1 Diagnosis and Screening
 - Q2 Underlying Biology
 - Q3 Risk Factors
 - Q4 Treatments & Interventions
 - Q5 Services
 - Q6 Lifespan
 - Q7 Research Infrastructure and Surveillance
- Comments were provided to Strategic Plan Working Groups and all comments are now publicly available on the IACC website
- Within each question comments are grouped by themes addressed
- **Over 1,100 comments were received**

Respondent Categories

- **Parents and family members**
- **Service providers**
- **Researchers**
- **Advocates/Professional Societies**
- **Educators**
- **Medical/Therapy Practitioners**
- **Family Assistance/Navigation**
- **Self advocates**
- **Research trainees**
- **Government employees**
- **International**

Question 1: Diagnosis & Screening

- Need better recognition and diagnosis of subgroups
- Need better understanding of early signs and symptoms
- Families need emotional support following diagnosis and assistance in navigating access to services
- Improve accuracy and awareness of diagnosis in females/address sex and gender disparities in diagnosis
- Improvements in the accuracy and usability of screening and diagnosis tools
- Need more and increased access to genetic screening
- Need greater research and identification of biomarkers, and use of these biomarkers in screening and diagnosis
- Need improvements in access and accuracy of adult and adolescent diagnosis
- Need to address the multifaceted disparities in diagnosis across racial, cultural, socioeconomic, and regional lines
- Need to increase/decrease early screening and diagnosis of ASD in children
- Need to reduce the time to diagnosis by improving service access and diagnostic tools/process
- Need to strengthen link between initial diagnosis and access to services and interventions
- Parents and caregivers need greater education so that they can recognize signs and symptoms
- Practitioners need to listen to and consider parent concerns about early signs and symptoms
- Universal screening for ASD is needed
- Workforce development, including access to qualified practitioners and improvements in the training of the existing workforce
- Current priorities are appropriate (diagnosis and screening tools, early signs, symptoms and biomarkers, identification of subgroups, disparities in diagnosis)

Question 2: Underlying Biology

- Need further research on the genetics of autism, and genetic tests should be more accessible
- Need more developmental biology research
- Need more research and a better understanding of genetic syndromes related to ASD
- Need more research and better understanding of the biomarkers and symptoms of ASD, and the heterogeneity of symptoms
- Need more research into the contribution of immune and metabolic pathways to autism
- Need more research on cognitive and behavioral biology
- Need more research on the basic neuroscience of ASD
- Need more research on the biology and relationship of co-occurring conditions in ASD
- Need more research on the molecular biology of ASD
- Need more research on sex and gender differences, inclusive of both biological sex and self-identified gender
- Need research to better understand, differentiate, and treat subgroups of people with autism
- Need more research to better understand sensory processing and motor function in ASD
- Need more translational and interdisciplinary research to improve the lives of people with ASD
- Need to prioritize gut-brain interaction research
- 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)
- Understanding the biology of ASD is not a priority, relative to other areas (i.e. treatment and services)

Question 3: Risk Factors

- Need better methods for testing contributions of risk factors from multiple domains to better understand risk of autism
- Need more research into better understanding of environmental risk factors, defined broadly to including both chemical and social environments
- Need more research on epigenetic risk factors
- Need more research on genetic risk factors
- Need more research on immune and metabolic risk factors
- Need more research on maternal and prenatal factors
- Need more research on the interaction of genetic and environmental factors
- Need more research on the risk factors for co-occurring conditions in autism
- Need more research on the role of the microbiome and gastrointestinal risk factors
- Need more research to better understand heritability and risk of autism in families
- Need more research to understand the role of vaccines in causing autism
- Need less/no additional research on the role of vaccines in autism
- Current priorities are appropriate (genetic and environmental risk factors, gene-environment interactions, and the potential role of epigenetics and the microbiome)
- 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 & Interventions (385 responses rec'd as of 6/29)

- 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
- Need to prioritize early intervention
- Need to educate parents about available treatments and interventions, and to help provide these interventions
- Endorsement of specialized or ASD specific treatments and interventions
- Improve availability and efficacy of treatments and interventions specifically for adult and adolescents with ASD
- Improve efficacy and availability of behavioral treatments and interventions
- Improve efficacy and availability of interventions in educational settings
- Improve the evidence base for treatments and interventions, and make that information more readily available and widely used
- Personalized combinations and types of treatments and interventions will be the most efficacious
- Positive and negative comments about searching for a “cure” rather than treatments or interventions
- Research and availability of technology based or assistive technology treatments and interventions
- Research and availability of treatments and interventions for co-occurring conditions
- Need research on biomedical and pharmacological treatments and interventions to improve efficacy and reduce side effects
- Need research on the efficacy and availability of complementary, alternative or integrative treatments and interventions
- Need research on long term outcomes of treatments and intervention, as well as the translation and implementation of research based treatments and interventions
- Improve coordination of treatments and interventions between services and practitioners
- Current priorities are appropriate (behavioral, medical/pharmacologic, educational, technology-based, and complementary/integrative interventions)

These slides do not reflect decisions of the IACC and are for discussion purposes only.

Question 5: Services

(467

responses rec'd as of 6/29)

- Access to early intervention services is a priority
- Disparities in access to services should be addressed
- Families need access to services to reduce the mental and emotional burden of caring for those with ASD
- Improve the efficacy and cost effectiveness of services and service delivery
- Improve the quality and availability of services within the educational systems
- Improve the service systems and service models
- Increase the accessibility and utilization of 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
- Need for an adequately trained and compensated workforce to improve available services and service delivery
- Need for better services to foster community inclusion of those with ASD
- Need to be more and better access to specialized services for ASD
- Parents/caregivers need assistance navigating complicated service systems.
- Prioritize services to improve the health and safety, including addressing interactions with law enforcement and wandering
- The broader community needs to be better educated about ASD, to lead to better understanding and inclusion
- The cost of services is prohibitive, and research and policies are needed to reduce these barriers to access
- 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 the treatment or cause of autism rather than the delivery of services

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Question 6: Lifespan

- Improve access to and quality of adult services, including additional research to improve evidence based services for adults
- Improve access to diagnosis for adolescents and adults
- Improve community integration/inclusion, including social isolation and community education about ASD
- Improve the quality, accessibility of housing options
- Improve transition services, and provide better assistance for young adults and their families during transitions
- Long term and financial planning are a priority for research, services, and policy
- Need assistance for adults with autism and their families in navigating available adult services
- Need for a larger, better trained and compensated workforce for adults with ASD
- Research and services to improve health, medical care, safety and quality of life across the lifespan
- Research, services and policies are needed to improve vocational/employment and post-secondary education opportunities
- Services and research should take into account the perspective and choices of adults and their families/caregivers
- 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 should be on early intervention or developing effective treatments; adults/lifespan are not a research priority
- Improve caregiver support

Question 7: Research Infrastructure and Surveillance

- Improve services infrastructure
- Increase collaboration and coordination among services providers
- Increase collaboration and coordination of research including interdisciplinary research
- Increase the dissemination of research, and the translation of research into practice
- Need greater development of the research workforce
- Need more and improved surveillance of ASD prevalence, including by race/ethnicity, gender and age
- Need research infrastructure, i.e. databases, research and clinical trial policies
- Research should include the voices and participation of individuals with autism and their families
- Current priorities are appropriate/important (research infrastructure needs, ASD surveillance research, research workforce development, dissemination of research information, and strengthening collaboration)
- Prioritize services and interventions rather than research

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- Prioritize services and interventions rather than research