

2021 IACC Strategic Plan RFI Themes

Question 1: Diagnosis and Screening

- **Acceptance:** Autism screening and diagnosis should be used to improve access to needed services and supports; prenatal testing, if developed in the future, should not be used to prevent autism.
- **Accessibility:** Ensure that screening and diagnostic services are available, accessible, and affordable to all autistic people and their families, regardless of race, gender, socioeconomic status, sexuality, and geographic location.
- **Co-occurring Conditions:** Develop tools to better diagnosis autism when presenting with other co-occurring conditions such as Down syndrome and ADHD.
- **Diagnostic Criteria:** Update diagnostic criteria to better identify autism across a wider range of people, including girls and women and people of underserved communities, and include non-behavioral signs such as differences in brain structure and functioning and sensory difficulties.
- **Disparities:** Reduce disparities and improve diagnosis, especially for girls and women, ethnic and racial minorities, underserved communities, and adults.
- **Early Screening:** Implement universal screening and develop tools to diagnose children at an earlier age.
- **Education and Stigma:** Educate the public on what autism is and reduce stigma around the diagnosis of autism.
- **Subgroups:** Improve the DSM definition of autism to better reflect the wide spectrum of abilities and challenges across the autism spectrum and include or remove subgroups in diagnosis and research.
- **Training:** Provide additional training for parents and caregivers, healthcare providers, teachers, and other public servants to better identify signs of autism.
- **Current Priorities Still Relevant:** The Objectives as they are stated in the *Strategic Plan* reflect important current topics and issues in the field.
- **Question Area Not a Priority:** This Question topic should not be a priority in the update of the *Strategic Plan*.
- **Miscellaneous:** Response addresses other topics not listed above.

Question 2: Biology

- **Acceptance:** Research on the biology of autism should be conducted with the goal of reducing disabling and negative effects of co-occurring conditions and improving the lives of autistic people, not to prevent or cure autism.
- **Cognitive and Behavioral Biology:** More research is needed on the developmental biology and cognitive and behavioral aspects of autism.
- **Co-occurring Conditions:** More research is needed on common co-occurring physical and mental health conditions.
- **Gender:** More research is needed on the biology of sex differences and girls and women on the autism spectrum.
- **Genetics:** More research is needed to understand genetic contributions to autism.

- **Immune System and Metabolism:** More research is needed on immune and metabolic aspects of autism.
- **Inclusion:** Biological research on autism should be conducted in a culturally competent and sensitive manner and include autistic input and diverse racial, ethnic, and socioeconomic groups.
- **Molecular Biology and Neurobiology:** More research is needed to better understand the molecular biology and neuroscience of autism and the biological basis of neurodiversity.
- **Sensory:** More research is needed on the biology of sensory and motor issues associated with autism.
- **Current Priorities Still Relevant:** The Objectives as they are stated in the *Strategic Plan* reflect important current topics and issues in the field.
- **Question Area Not a Priority:** This Question topic should not be a priority in the update of the *Strategic Plan*.
- **Miscellaneous:** Response addresses other topics not listed above.

Question 3: Risk Factors

- **Acceptance:** Research on genetic and environmental factors that may contribute to autism should be conducted with the goal of improving the lives of autistic people, not to prevent or cure autism.
- **Environment:** More research is needed on environmental factors that may contribute to autism.
- **Gene-Environment:** More research is needed on gene-environment interactions that may contribute to autism.
- **Genetics:** More research is needed on genetic factors that may contribute to autism.
- **GI and Microbiome:** More research is needed on how the microbiome and gastrointestinal issues may contribute to autism.
- **Pregnancy and Birth:** More research is needed on how maternal health and activities, including medical procedures during pregnancy and after birth, may contribute to autism.
- **Society:** Research is needed on how the social environment, social determinants of health, and society as a whole shapes the autistic experience and may cause undue hardships and difficulties.
- **Current Priorities Still Relevant:** The Objectives as they are stated in the *Strategic Plan* reflect important current topics and issues in the field.
- **Question Area Not a Priority:** This Question topic should not be a priority in the update of the *Strategic Plan*.
- **Miscellaneous:** Response addresses other topics not listed above.

Question 4: Treatments and Interventions

- **Acceptance:** The goals of treatments and interventions should be to improve autistic lives, such as treatment of co-occurring conditions, and not to hide or mask autistic traits.
- **Accessibility:** Ensure that treatments and interventions are available, accessible, and affordable.
- **Behavioral Approaches:** More research is needed on behavioral interventions and treatments for autism.

- **Communication:** Improved interventions, treatments, and technologies to assist with communication, such as alternative and augmentative communication (AAC) devices, are needed.
- **Complementary Approaches:** More research is needed on complementary and integrative interventions for autism.
- **Education:** Interventions and treatments are needed in educational settings, and more support should be provided for schools to meet the needs of autistic students.
- **Reduce Negative Effects:** Interventions are not one-size-fits-all, and some interventions may result in negative experiences for autistic individuals, particularly if they focus on deficits and suppress or mask autistic adaptive behaviors. More research is needed on the potential negative effects of certain treatments and interventions.
- **Inclusion:** Include autistic input when researching new treatments and interventions or improving existing treatments and interventions and ensure that treatments and interventions are available for all autistic people, including autistic people with high support needs.
- **Lifespan:** Treatments and interventions are needed for autistic adolescents and adults to improve quality of life across the lifespan.
- **Medical:** Develop more medical and pharmacological treatments and interventions for autism and co-occurring conditions and study possible side effects of existing medications in autistic people.
- **Current Priorities Still Relevant:** The Objectives as they are stated in the *Strategic Plan* reflect important current topics and issues in the field.
- **Question Area Not a Priority:** This Question topic should not be a priority in the update of the *Strategic Plan*.
- **Miscellaneous:** Response addresses other topics not listed above.

Question 5: Services

- **Acceptance:** There needs to be greater acceptance and understanding of autistic individuals and autism by the public, including first responders, teachers, and healthcare workers.
- **Accessibility:** Services need to be more available, accessible, and affordable, especially for those living in lower-resource settings.
- **Adults:** Services for adolescents and adults are needed to improve quality of life.
- **Caregivers:** Services are needed to support parents and caregivers and to ensure the quality of care for children and adults on the autism spectrum in home and community-based settings.
- **Community:** Additional services and supports are needed for community integration, including community-based services and supports, transportation services and supports, and accessibility of infrastructure and the physical environment, to promote independent living of autistic individuals.
- **Education:** Services in educational settings are needed for autistic students to access and obtain high quality education and learning opportunities.
- **High Support Needs:** Additional services specifically tailored for people with high support needs are needed.
- **Housing and Employment:** More services are needed to provide better housing services and encourage employment of autistic individuals so they can lead independent, fulfilling lives.

- **Inclusion:** More services should be developed, delivered, and informed by autistic people with lived experiences, and services accessibility need to be improved for autistic girls and women, adults, ethnic and racial minorities, and other underserved groups.
- **Mental Health:** More services and supports are needed to improve the mental health of autistic people.
- **Current Priorities Still Relevant:** The Objectives as they are stated in the *Strategic Plan* reflect important current topics and issues in the field.
- **Miscellaneous:** Response addresses other topics not listed above.

Question 6: Lifespan Issues

- **Acceptance:** Ensure that autistic people are welcome in and accepted by their communities.
- **Accessibility:** Ensure that services and supports are available, accessible, and affordable.
- **Community:** Implement programs and supports to ensure that autistic adolescents and adults have the skills and support they need to lead independent and fulfilling lives and be integrated within their community.
- **Coordination:** Coordinate services to improve quality of life across the lifespan.
- **Education:** Provide high quality continuing education into adulthood and ensure that the school system prepares autistic students for adulthood.
- **Employment:** Implement training programs to support autistic individuals seeking employment and allow needed accommodations for autistic workers and job seekers.
- **Health:** Ensure that autistic adolescents and adults can access needed physical and mental health care.
- **High Support Needs:** Ensure that adolescents and adults with high support needs on the autism spectrum have the support to meet their needs.
- **Housing:** Support housing programs and options so that autistic people can choose where to live and receive needed services and supports in their homes.
- **Inclusion:** Services and supports should be available to all autistic people and include autistic input.
- **Lifespan:** Ensure that services continue throughout the lifespan for autistic adolescents and adults and additional research is conducted to better understand how autism may change with age.
- **Current Priorities Still Relevant:** The Objectives as they are stated in the *Strategic Plan* reflect important current topics and issues in the field.
- **Question Area Not a Priority:** This Question topic should not be a priority in the update of the *Strategic Plan*.
- **Miscellaneous:** Response addresses other topics not listed above.

Question 7: Infrastructure and Surveillance

- **Acceptance:** There is a need for increased acceptance and understanding of autism in the research community and in society.
- **Collaboration:** Increase collaboration and coordination between agencies and organizations.
- **Funding:** Increase funding and resources for autism research and services.

- **Inclusion:** Include input from the autism community in autism research and services and ensure that research and services are inclusive of genders, racial and ethnic minority groups, and other underserved communities. Include more autistic researchers and use community-based participatory research models more often.
- **Research:** Improve research design to achieve higher statistical power and increase transparency surrounding data use, study recruitment, and dissemination of findings.
- **Standardization:** Ensure that standards of care and services are consistent across state lines.
- **Workforce:** Increase efforts to develop a strong workforce to provide needed research and services for the autism community. Increase research on accommodations to increase workforce participation for autistic people.
- **Current Priorities Still Relevant:** The Objectives as they are stated in the *Strategic Plan* reflect important current topics and issues in the field.
- **Question Area Not a priority:** This Question topic should not be a priority in the update of the *Strategic Plan*.
- **Miscellaneous:** Response addresses other topics not listed above.

Supplemental Question 1: Effects of the COVID-19 Pandemic

- **Accommodations:** Accommodations for COVID-19 restrictions are needed for autistic people.
- **Benefits:** The COVID-19 pandemic has shown that remote options and other accommodations are feasible, and these options should continue to be available in the future.
- **COVID-19:** More research is needed to understand how the COVID-19 disease affects autistic people.
- **Disparities:** The autistic community, along with underserved communities, have experienced additional hardships during the pandemic, such as access to vaccines, healthcare, and other services.
- **Mental Health:** The COVID-19 pandemic increased feelings of isolation and loneliness and negatively impacted mental health in the autism community.
- **Misinformation:** More efforts are needed to combat misinformation surrounding vaccines and COVID-19 and help the autistic community understand the importance of COVID-19 mitigation efforts.
- **Loss of Progress:** There has been a loss of skills and progress during the COVID-19 pandemic.
- **Routine:** Routines are comforting for some autistic people, and the disruptions in routine associated with the COVID-19 pandemic, including re-entry afterwards, can have detrimental effects on mental health.
- **Services Disruption:** The COVID-19 pandemic led to disruptions in access to needed services and supports for the autism community, such as the replacement of in-person schooling and healthcare with remote classrooms and telehealth visits.
- **Question Area Not a Priority:** The effects of the COVID-19 pandemic should not be a priority focus in the update of the *Strategic Plan*.
- **Miscellaneous:** Response addresses other topics not listed above.

Supplemental Question 2: Underserved Communities

- **Accessibility:** Increase access to needed services and supports and make services more affordable.
- **Cultural Competency:** Ensure that services are provided in a culturally competent manner.
- **Disparities:** Conduct more research to better understand and combat racial and ethnic, gender, socioeconomic, and other disparities in service access and health outcomes.
- **Gender and Sexuality:** Recognize gender and sexuality as factors which may contribute to inequities and implement policies to combat disparities in service access and health outcomes.
- **High Support Needs:** Autistic people with high support needs should be recognized as an underserved group and receive more services and support.
- **Inclusion:** Include voices from the autism community in implementing and designing service programs and include people from diverse genders, racial and ethnic minority groups, and other underserved communities in research.
- **Internet:** Internet access should be possible for all families, and increased online options for services, supports, and treatments may be helpful for people without easy access to in-person services.
- **Outreach:** Increase public understanding and acceptance of autism to reduce stigma and increase outreach to encourage autistic people in underserved communities to seek out and receive the services they need.
- **Rural Communities:** Autistic people in rural settings often cannot access needed services.
- **Training:** Ensure that parents and caregivers in underserved communities are informed of available service options and train healthcare workers, teachers, law enforcement officers, and other service providers to provide culturally competent services.
- **Miscellaneous:** Response addresses other topics not listed above.