

EASY-READ VERSION



2021-2023

INTERAGENCY AUTISM COORDINATING COMMITTEE  
**STRATEGIC PLAN**  
FOR AUTISM RESEARCH, SERVICES,  
AND POLICY



OFFICE OF  
NATIONAL AUTISM  
COORDINATION  
NATIONAL INSTITUTES OF HEALTH

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# INTRODUCTION

The Interagency Autism Coordinating Committee (IACC) is a federal advisory committee that advises the Secretary of Health and Human Services on issues related to autism. It was first established by Congress in 2000, and it was most recently renewed under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019 ([Public Law 116-60](#)).

Current IACC members were appointed in July 2021. It is the largest and most diverse IACC membership to date. Committee members include autistic adults, family members of autistic people, representatives of advocacy and service organizations, researchers, clinicians, and federal government officials.

One of the IACC's responsibilities is to develop a strategic plan for autism. The Autism CARES Act of 2019 requires that the IACC Strategic Plan address the "conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports." This *2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy* was developed with input from many different perspectives and areas of expertise represented on the Committee and gathered through public comments.

This *IACC Strategic Plan* summarizes current understanding of autism-relevant topics. It also addresses gaps and opportunities in autism research, services and supports, and policy. As in previous years, the IACC Strategic Plan is organized around seven general topic areas that are represented in the Plan as community-focused Questions (for example, Question 1, "How Can We Improve Identification of Autism?," covers the topic of screening and diagnosis). Each Question is assigned a chapter in the Strategic Plan that provides:

- An Aspirational Goal, or long-term vision for the Question
- A description of the state of the field
- The needs and opportunities in research, services, and policy
- Three broad Recommendations for research and services activities

The IACC's goal during the development of this Plan is to present a collective voice detailing the current status and future goals of autism research, services, and policy. As the work of the IACC continues, it will be important to understand and address the needs of individuals on the autism spectrum and their families in the context of their communities. It is also important for research findings to guide practices in clinical and community settings.

In this Strategic Plan, the focus of the IACC's Recommendations is to encourage activities that will improve health, well-being, and outcomes for autistic people in all communities. The IACC also aims to increase acceptance and understanding of autism and address the issues that cause challenges for autistic people and their families.

This is an easy-read version that summarizes the content and Recommendations of the *2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy*. The full publication is available here: <https://iacc.hhs.gov/publications/strategic-plan/2023/>

## EDITORIAL NOTE ON REFERENCES TO AUTISM

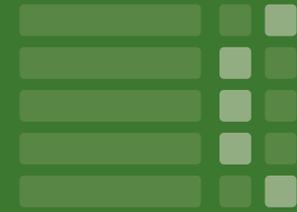
The terms "person with autism," "person with ASD," "autistic person," and "person on the autism spectrum" are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. The Committee respects the different opinions within the community on the use of this language and does not intend to endorse any particular preference. In addition, the term "autism" is generally used in this document, and "autism spectrum disorder (ASD)" is used when referring specifically to the DSM-5-TR defined diagnosis. Overall, enhancing efforts to support the use of accessible language around autism in various publications remains a priority for the IACC.

## QUESTION

# 1

# HOW CAN WE IMPROVE IDENTIFICATION OF AUTISM?

## SCREENING AND DIAGNOSIS



***Aspirational Goal: Provide a timely diagnosis for people on the autism spectrum, so they can be linked to appropriate interventions, services, and supports to maximize positive outcomes.***

## OVERVIEW

For many autistic individuals and their families, use of autism-related services and supports begins with screening and diagnosis. Signs of autistic traits are often visible in the first two years of life. However, the average age of autism diagnosis in children in the U.S. is four years, with disparities in diagnosis related to socioeconomic factors, geographic location, and race/ethnicity.

Researchers believe that starting behavioral interventions for autism within the first three years of life is the most likely way to maximize positive outcomes. However, people diagnosed after age 3 miss the opportunity to receive early intervention and supports. Late diagnosis or misdiagnosis often results in unmet healthcare and service needs in children and adults.

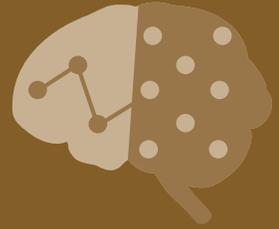
It is important that children and adults are able to access screening and diagnostic services for autism in a timely manner. Research funding in this area is focused on creating better tools that are effective for all autistic people.

### **Topics covered in this chapter include:**

- Screening and Diagnostic Tools
- Early Signs and Biomarkers
- Technological Advances, Including Telehealth Tools
- Universal Screening
- Identification of Subgroups
- Reducing Disparities in Screening and Diagnosis
- Workforce Needs
- Systems Navigation

## IACC RECOMMENDATIONS

1. Support research on how early detection of autism influences outcomes.
2. Reduce disparities in early detection and access to services.
3. Develop and adapt screening and diagnostic tools, including tools that incorporate new technologies to increase efficiency, accuracy, and timeliness of identification.



***Aspirational Goal:* Discover the roles of brain development, cognition, and physiological function in autism and its co-occurring conditions to enable the development of effective, targeted interventions and societal accommodations that promote positive outcomes across the lifespan.**

## OVERVIEW

Current scientific evidence suggests that autism arises during early development and results in differences in brain structure, function, and connectivity. Those brain differences may lead to challenges in areas such as social behavior, learning, communication, sensory perception, motor function, and intellectual ability. Over the course of the last decades, research has revealed that genes and environmental influences in early development are contributing factors.

Much remains to be learned about the specific biological mechanisms that contribute to autistic traits. Research is needed to understand how biological differences lead to observed behaviors and how autistic individuals experience the world. Additionally, studies on the relationship of common co-occurring mental and physical health conditions, intellectual disability, and autism are also needed. Greater insight and understanding of biological differences will allow for personalized, targeted interventions that can promote positive outcomes for all individuals on the autism spectrum across the lifespan.

### Topics covered in this chapter include:

- Molecular Mechanisms
- Structure and Function of Brain Circuits
- Sensory and Motor Differences
- Cognition and Intellectual Disability
- Communication Challenges
- Immune System
- Sex and Gender Differences
- Longitudinal Studies
- Common Co-Occurring Conditions, including:
  - Gastrointestinal Conditions
  - Epilepsy
  - Sleep Disorders
  - Mental Health and Psychiatric Conditions
  - Ehlers-Danlos Syndromes and Dysautonomia
- Research Policy Issues

## IACC RECOMMENDATIONS

1. Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of autism.
2. Support research to understand the underlying biology of co-occurring conditions in autism and to understand the relationship of these conditions to autism.
3. Support large-scale longitudinal studies to answer questions about the development and natural history of autism across the lifespan, from pregnancy through childhood, adolescence, adulthood, and older adulthood.

# WHAT ARE THE GENETIC AND ENVIRONMENTAL FACTORS THAT CONTRIBUTE TO AUTISM AND ITS CO-OCCURRING CONDITIONS?

## GENETIC AND ENVIRONMENTAL FACTORS



***Aspirational Goal:* Discover and understand genetic and environmental factors that influence the development of autism and its co-occurring conditions in order to better inform diagnosis and interventions to improve outcomes for people on the autism spectrum.**

## OVERVIEW

Over the past decade, there have been substantial advances in the understanding of factors that contribute to the development of autism. There has also been an increased appreciation of the incredible complexity and interplay of genetic and environmental factors in the process. Research in the general population on a variety of chronic conditions has highlighted the fact that environmental factors can affect different people in very different ways depending on the individual's genetic background. Therefore, there has been significant interest in better understanding how genes and environmental factors may interact in autism ("gene by environment" interactions).

This chapter emphasizes the desire to understand the genetic and environmental factors that influence the characteristics and trajectory of autism across the full breadth of the spectrum. This includes understanding the factors that contribute to co-occurring physical and mental health conditions, intellectual disability, and communication difficulties that can cause varying levels of challenges. Understanding these factors is necessary to identify interventions that can improve outcomes.

### Topics covered in this chapter include:

- Genetic Factors
- Genetic Overlap with Co-Occurring Conditions and Intellectual Disability
- Environmental Factors
- Exposure Science
- Gene-Environment Interactions
- Epigenetics
- Resource Needs
- Research Policy and Ethical Implications

## IACC RECOMMENDATIONS

1. Strengthen understanding of genetic factors that influence autism and its co-occurring conditions across the full diversity of individuals on the autism spectrum.
2. Understand the influence of environmental factors on the development and progression of autism and its co-occurring conditions, enabling the development of strategies to maximize positive outcomes.
3. Expand knowledge about how multiple environmental and genetic factors interact through specific biological mechanisms to manifest in autism phenotypes.

# WHICH INTERVENTIONS WILL IMPROVE HEALTH AND WELL-BEING?

## INTERVENTIONS



***Aspirational Goal: Develop a range of interventions that optimize outcomes across the lifespan to maximize the health and well-being of people on the autism spectrum.***

## OVERVIEW

Over the past several years, the IACC’s focus has shifted from “preventing disabilities” to encouraging “building adaptive skills”. The IACC now emphasizes lifespan approaches and more meaningful intervention outcomes for individuals on the autism spectrum and their families. This change is driven by the recognition that the goal of autism interventions is not to force autistic individuals to mask their autistic traits, become neurotypical, or lose their identity. Rather, the goal of interventions is to promote positive outcomes for people on the autism spectrum that are meaningful to them.

Recent research has focused on the development and improvement of interventions that can promote health and well-being for people on the autism spectrum by addressing autism, its co-occurring conditions, or other factors that impact quality of life. There have been several promising advances; however, there are still many obstacles to be overcome in advancing research on interventions for autism. The variability of characteristics from one person to another across the autism spectrum creates challenges in planning studies and interpreting results. Interventions may be highly effective for some people and ineffective for others depending on each person’s individual combination of strengths and challenges. Prioritizing understanding of which interventions work and for whom will allow us to develop and personalize new and improved interventions to meet the diverse needs of all individuals across the autism spectrum.

### Topics covered in this chapter include:

- Behavioral and Developmental Interventions
- Technology-Based Interventions and Communication Tools
- Medical and Pharmacological Interventions
- Complementary and Alternative Approaches
- Interventions for Co-Occurring Conditions
- Outcome Measures and Biomarkers
- Research Policy Issues

## IACC RECOMMENDATIONS

1. Develop and improve pharmacological and other medical interventions that will maximize positive outcomes for individuals on the autism spectrum.
2. Create and improve a variety of psychosocial, developmental, occupational, and educational interventions that will maximize positive outcomes for individuals on the autism spectrum.
3. Develop and improve technology-based interventions that will maximize positive outcomes for individuals on the autism spectrum.



***Aspirational Goal: Develop and implement high-quality, evidence-based, and widely accessible services and supports that maximize health and well-being across the lifespan for all people on the autism spectrum and their families.***

## OVERVIEW

Every individual on the autism spectrum has a distinct and unique set of strengths and challenges and may need varying levels of support in different areas. A wide variety of services and supports are available to help maximize health and well-being among children and adults on the autism spectrum.

Some of these services may be covered by insurance or offered at no cost through federal and state programs. Other supportive services may require payment out-of-pocket or otherwise be difficult to access. The result is a “patchwork” system where families and individuals must identify available services and navigate multiple sources and sets of requirements, making it challenging to access and maintain connection to the specific services and supports that they need. Thus, there is a need for continued efforts to strengthen the system of services and supports available to assist individuals with autism and their families.

### Topics covered in this chapter include:

- Education System
- Healthcare System
  - Insurance Coverage
  - Service Delivery Models
  - Mental Health Services and Supports
  - Dental Care
- Law Enforcement and Safety
- Ensuring Individualization, Choice, Person-Centered Planning, and Self-Direction
- Navigation Services
- Caregiver Supports
- Independent Living
- Transportation
- Services for Individuals with Intensive Support Needs
- Workforce Training and Development
- Coordination of Services

## IACC RECOMMENDATIONS

1. Develop service approaches and scale up and implement evidence-based interventions in community settings.
2. Address disparities in service provision and improve access to services for all, including low resource and underserved communities and individuals and families with high support needs.
3. Improve service delivery to ensure quality and consistency of services across many domains with the goal of maximizing positive outcomes and the value that individuals get from services.

# HOW CAN WE ADDRESS THE NEEDS OF PEOPLE ON THE AUTISM SPECTRUM THROUGHOUT THE LIFESPAN?

## LIFESPAN



**Aspirational Goal: Promote inclusion, support, and acceptance of all people on the autism spectrum so that they can participate in the communities of their choice through school, work, and meaningful relationships.**

## OVERVIEW

There is a growing population of youth and adults diagnosed with autism. Once a young adult ages out of school-based services, they and their families are required to navigate the adult services environment, with its many sets of rules and systems. Supportive services needed by adults may include healthcare, disability entitlements, higher education, employment supports, day programs, housing options, and home- and community-based services, among others. There are many barriers and complexities involved in accessing these services.

Across their lifespan, autistic adults report higher than average unmet needs, with receipt of autism-specific services often decreasing with age. Individualized approaches are necessary to effectively prioritize and meet the different support needs of each autistic adult at different life stages across the spectrum. Understanding the factors that contribute to health and well-being across all communities is critical. This increased understanding will aid in the development of improved services and programs that facilitate opportunities for people on the autism spectrum to meet their personal goals, engage in meaningful activities and relationships, and experience health and a sense of well-being.

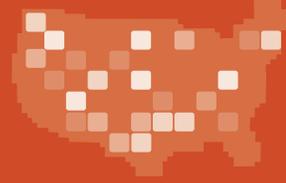
### Topics covered in this chapter include:

- Autism Diagnosis in Adults
- Physical and Mental Health and Healthcare
- Service Delivery
- Community Integration, Support Groups, and Community-Based Services
- Communication Supports and Accommodation
- Housing Services and Transportation
- Continuing Education and Enrichment
- Safety, Victimization, and Interactions with Law Enforcement
- Financial Planning
- Special Considerations for Transition Age Youth
- Special Considerations for Adults with High Support Needs
- Special Considerations for Older Adults
- Policy Issues

## IACC RECOMMENDATIONS

1. Support development and coordination of integrated services to help people on the autism spectrum successfully transition to adulthood and progress through the lifespan with appropriate services and supports.
2. Support research and develop and implement approaches to improve physical and mental health outcomes across the lifespan, with the goal of improving safety, reducing premature mortality, and enhancing health and well-being.
3. Support research, services activities, and outreach efforts that facilitate and incorporate accessibility, as well as acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum.

# HOW DO WE EXPAND AND ENHANCE RESEARCH INFRASTRUCTURE SYSTEMS TO MEET THE NEEDS OF THE AUTISM COMMUNITY?



## INFRASTRUCTURE AND PREVALENCE

***Aspirational Goal: Develop, enhance, and support research infrastructure and statistical data gathering systems that advance the speed, efficacy, and dissemination of autism research and services.***

## OVERVIEW

Appropriate infrastructure is critically important to the success of autism research efforts. This includes repositories for biological materials and data, systems for gathering data on autism prevalence, and enhancing the research workforce.

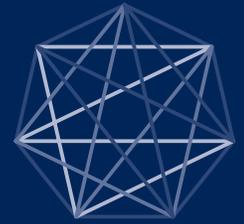
Efforts to increase the participation of individuals with autism and their families in research and contributions to biorepositories are important, as information and samples gathered have the potential to greatly improve our understanding of autism. Inclusion of people on the autism spectrum and their families in the research process, as well as recruiting and training autistic researchers, will help ensure that studies maintain a focus on issues that matter most to autistic people and their families.

### Topics covered in this chapter include:

- Biorepository Infrastructure
- Data Infrastructure
- Data Sharing
- Prevalence Monitoring
- Human Infrastructure
  - Research Training and Workforce Development
  - Participation in Research Studies
  - Dissemination of and Access to Research Findings
  - International Collaboration

## IACC RECOMMENDATIONS

1. Promote growth, linkage, coordination, and security of biorepository and data repository infrastructure systems, equitable access to these systems, and inclusion of diverse samples.
2. Expand and enhance the research workforce, with attention to diversity and inclusion, and accelerate the pipeline from research to practice.
3. Strengthen statistical data gathering systems to advance understanding of the autistic population, while allowing comparisons and linkages across systems as much as possible.



## OVERVIEW

The IACC has identified two topics that span across the seven Questions of the IACC Strategic Plan and warrant special attention: 1) understanding the influence of gender and sex in autism, and 2) reducing disparities and promoting equity.

### SEX AND GENDER

The core features of autism often present differently in girls/women than in boys/men. In the past, many inferences about the development and trajectory of autism and its co-occurring conditions have been made based on research studies where the participants were predominantly male and/or females were disproportionately excluded. More research is needed to understand autism in girls and women, unique aspects of their biology, psychology, and social context, and the potential effects of various types of bias and inequities in the identification process. Girls and women may also need different or customized approaches to intervention to meet their needs.

Studies have suggested that individuals on the autism spectrum are more likely to identify as lesbian, gay, bisexual, transgender, queer, intersex, or asexual (LGBTQIA+) than neurotypical individuals. Thus, it will be critical in the future to understand and better serve the needs of LGBTQIA+ individuals on the autism spectrum.

#### Topics covered in this chapter include:

- Biological Evidence for Sex Differences
- Influence of Sex and Gender on the Presentation of Autism
- Sex- and Gender-Specific Services and Supports

### PROMOTING EQUITY AND REDUCING DISPARITIES

Underrepresented and underserved populations include various groups identified by demographic factors (e.g., sex/gender presentation & orientation, race, ethnicity, age, language preference, socioeconomic status, urban/rural, etc.). The intersection between these underserved populations and autism often enhances disparities in health, social and economic well-being, and opportunities.

Addressing the causes of these disparities will involve examining the effect of discrimination, racism, ableism, cultural differences, and various social determinants of health (e.g., housing, educational and employment opportunities, geographic proximity to providers/specialists, crime and victimization, etc.) on the lifelong outcomes of autistic individuals.

#### Topics covered in this chapter include:

- Cultural Competency and Cultural Humility
- Diversifying the Researcher and Provider Workforce
- Governmental and Non-Governmental Efforts to Increase Diversity, Equity, Inclusion, and Accessibility

## IACC RECOMMENDATIONS

1. Support research to understand sex and gender differences in autism.
2. Support diversity, equity, inclusion, and accessibility efforts in research, services, and policy that reduce disparities and increase equity for underrepresented, underserved, and intersectional populations within the autism community and enhance opportunities for autistic people.

# COVID-19 AND THE AUTISM COMMUNITY: IMPACT AND LESSONS LEARNED



## OVERVIEW

The COVID-19 pandemic has changed the world in profound ways. People around the globe adjusted everyday living to limit the spread of the virus, causing social and economic disruptions, including loss of livelihood and increased symptoms of depression, anxiety, insomnia, and stress.

For the autism community, the pandemic has posed additional concerns and hardships. Individuals on the autism spectrum and people with disabilities in general have been reported to be at increased risk of contracting COVID-19 and experiencing additional mental health and daily living challenges due to sudden changes in routine and loss of needed services. The pandemic exacerbated existing shortages of health care providers, educators, and other direct care workers who interact with autistic individuals and provide services. Stay-at-home orders also increased strain on family caregivers and reduced opportunities for respite.

On a more positive note, the COVID-19 pandemic has provided an opportunity to learn about what kinds of accommodations are feasible for the autism community during public health emergencies. These lessons can be applied not only to future public health crises and natural disasters but also in the immediate future to ensure that the autism community has access to more effective services and supports to improve health and well-being.

### **Topics covered in this chapter include:**

- Impact on Physical and Mental Health
- COVID-19 Mitigation Efforts
- Remote Technology and Accessibility during the Pandemic
- Impact on Autism Research



## OVERVIEW

The IACC calls for the autism research budget to reach \$685 million by 2025. In developing this recommendation, the Committee considered historical autism funding trends and projected budgets. With steady and predictable annual increases, this would require approximately a \$55.2 million annual increase in autism research funding from the 2020 research budget, combined across federal and private funders. The Committee believes that this is a realistic and attainable goal for enhanced research funding to address the critical needs of the autism community.

In addition, future funding will continue to grow with increasing awareness of ways to support people on the spectrum and the involvement of new organizations joining autism research efforts. New private funders will play an important role in the expansion of autism research, as non-federal organizations may have the ability to use creative funding mechanisms and support work in areas that have not been historically covered. If met, this budget recommendation will help to propel autism research forward and ensure that there is meaningful progress on the priorities identified in this Strategic Plan. These funds should be used to support the full range of autism research in order to truly improve the lives of people on the spectrum and their families.

Given the tremendous needs of the autism community as well as the promising opportunities for research and services, the Committee identified three specific high-priority research areas that could greatly benefit from targeted funding increases. While all areas of the autism research portfolio require increases in funding, the areas identified by the IACC that are in particular need of resource growth include:

- **Lifespan issues:** Increased funding is needed in research on issues that are relevant to autistic adults, such as transition to adulthood, higher education, employment, housing, healthcare, lifelong learning, service, and support opportunities, community integration, and healthy aging.
- **Evidence-based interventions and services:** Increasing the evidence base for new and existing interventions and services will provide additional guidance to autistic individuals and their families as they seek solutions to maximize positive outcomes.
- **Research on disparities and development of culturally responsive tools and services:** Continued investment is needed to close the existing gaps in outcome measures due to differences across race/ethnicity/culture, sex/gender, sexual orientation, geographic location, and socioeconomic status.

## IACC RECOMMENDATION

1. Increase annual autism research funding to \$685 Million by 2025.

# CONCLUSION

In the *2021-2023 IACC Strategic Plan*, the Committee has emphasized the need to maximize positive outcomes for individuals across the lifespan and across the autism spectrum. The Plan also stresses the importance of reducing disparities and increasing equity in order to meet the needs of all autistic individuals.

Strategic investments in the autism portfolio have produced promising scientific advances in recent years. Many types of approaches will be needed to continue addressing the existing gaps in autism research and services. The IACC is encouraged by the growth in the field resulting from the entry of additional investigators and new funders to the research landscape.

It is the IACC's hope that this updated Strategic Plan will be used by federal agencies and private organizations to guide their research and services activities. It is important for these agencies and organizations to continue engaging with autistic individuals, their families, and the broader autism community to identify priorities for investment.

The IACC is committed to addressing the range of needs across the autism community, by discussing important topics and identifying gaps and opportunities, providing a forum for public input, and advising the Secretary of Health and Human Services on relevant issues. With this Strategic Plan and future Committee activities, the IACC reaffirms its commitment to improving the lives of people across the autism spectrum and across the lifespan so that they can achieve their full potential.



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