Introduction

Background on the IACC Strategic Plan

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 spectrum disorder (ASD). It was established by the *Children's Health Act of 2000* (Public Law 106-310), reconstituted under the *Combating Autism Act of 2006* (CAA; Public Law 109-416), and was most recently renewed under the *Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019* (Public Law 116-60). One of the statutory responsibilities of the IACC under the CAA and subsequent authorizations is the development of a strategic plan for autism, to be updated annually. 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."

The *IACC Strategic Plan*, first issued in 2009, is developed by the full IACC membership and each edition has been informed by the range of perspectives and expertise represented on the Committee and gathered through public input. The newest slate of IACC members was appointed in July 2021 under the Autism CARES Act of 2019. As a result, the current committee is the largest and most diverse to date. Committee membership includes autistic adults and parents, siblings, and other caregivers of autistic children and adults who represent a wide range of support needs; representatives of advocacy and service organizations; researchers, clinicians; and Federal officials. Several of the members have dual perspectives on the committee, for example both as professionals in fields related to autism and as an autistic adult or family member, or as both an autistic adult and a parent of an autistic child or adult.

There have been several important shifts in the autism community. The neurodiversity movement has advocated for greater societal acceptance and inclusion of autistic people as well as increased access and accommodation of individuals with needs. Autistic adults and family advocates who began their advocacy work as parents of young children and have now seen their children grow to be adults, have expanded the discussion of autism in adulthood to encompass the wide variety of service needs, including those who need intensive lifelong supports. In recent years, autistic individuals and family caregivers have increasingly become involved in autism advocacy and collaborative partnership efforts with national and local organizations and governments to ensure that programs and policy are informed by lived experience perspectives. The number of private organizations engaged in advocacy, research, and services for autism has also grown. Advocates have emphasized the importance of reducing stigma and increasing acceptance and inclusion of autistic people, while also ensuring that there are solutions that will help people with a wide variety of support needs. The IACC believes that it is critical to promote acceptance of autistic people while also identifying and providing appropriately tailored interventions, services, and supports. These are not mutually exclusive goals. To best meet the needs of all autistic people, it will be important to engage them, their caregivers, and service providers to identify the most pressing issues and develop solutions that will improve outcomes.

The COVID-19 pandemic has had a profound impact on the autism community. Individuals with disabilities such as autism were disproportionately impacted by COVID-19 and experienced poorer outcomes and higher mortality. In addition, changes in daily living such as social distancing and stay-at-home orders disrupted routines and disconnected many autistic individuals from necessary services and supports. Educational and other supports ordinarily delivered in school settings were particularly impacted by school closures during the pandemic, resulting in setbacks for students with disabilities. Research progress was also slowed by pandemic-related closures. Meanwhile, there were also some positive changes that came about in response to the pandemic. Many healthcare and service providers were able to effectively pivot to remote service delivery. In some cases, researchers were able to design new or redesign existing protocols for service delivery. Workplaces that had not previously considered remote work options were suddenly forced to try pilot remote work, resulting in some benefits for autistic people who found working from home reduced some of the social, communication, and sensory challenges that they had experienced in traditional work settings. While the long-term impacts of the pandemic on health and well-being for individuals with autism remain to be revealed, these innovations will have impacts beyond the pandemic by helping to reduce existing disparities in access to services.

The autism community has emphasized the importance of addressing the physical and mental health conditions that often co-occur with autism, as these conditions are often the greatest source of challenge for individuals on the autism spectrum. The IACC added objectives addressing co-occurring conditions to its very first Strategic Plan in 2009, and in the time since then, a substantial body of research has been conducted on these conditions and initial clinical guidelines to help address these conditions have been published. There is still much more to be done, however, to understand the mechanisms behind these conditions and develop more effective treatments. Researchers are currently more often examining the mechanisms that underlie autism and its co-occurring conditions together, rather than studying them in isolation. Advocates have voiced the need for more community-based participatory research, in which autistic voices and those of family members are incorporated into every stage of the research process instead of just serving as research subjects. By receiving input from advocates during the initial experimental design and every step afterward, researchers can better tailor their work to better address the needs of individuals on the autism spectrum communicated from a lived experience perspective. There is growing evidence to suggest community-led research priorities are more easily translated into effective practice.

The IACC is committed to increasing inclusion of autistic individuals on multiple levels. Across the field of autism research and service provision, there are many documented disparities based on race/ethnicity, gender and gender identity, sexual orientation, geographical location, level of support needs, and more. These disparities are seen across many measures, including age of diagnosis, access to intervention services, level of unmet healthcare needs, and inclusion in research studies. The consequences of these disparities can have long-lasting impacts on the health and well-being of individuals on the autism spectrum and their family members. This edition of the *IACC Strategic Plan* places a greater emphasis on highlighting existing disparities and identifying potential strategies to reduce them while also promoting equity and inclusion, in line with Federal diversity, equity, inclusion, and accessibility (DEIA) goals.

With each update of its *Strategic Plan*, the IACC re-evaluates the needs of the autism community and the best ways to achieve progress. The *2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy* summarizes current understanding of autism-relevant topics and addresses remaining gaps and opportunities for 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 (e.g., Question 1, "How Can We Improve Identification of Autism?," which 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; and three broad Objectives. In this edition of the *IACC Strategic Plan*, the Objectives from *the 2016-2017 IACC Strategic Plan* have been updated and renamed as “Recommendations.” This change was made in order to clarify to the community that these Objectives serve as recommendations to the Secretary of Health and Human Services, as specified in the Autism CARES Act of 2019. The *2021-2022 IACC Strategic Plan* provides, in many cases, a substantial update to the text of the recommendations from the 2016-2017 Strategic Plan. There are also two cross-cutting recommendations, focusing on sex and gender and promoting equity and reducing disparities in autism research and services. In addition, the Plan contains a budget recommendation as required in the Autism CARES Act of 2019. As in previous years, the IACC recommends a substantial increase in funding, which would allow for continued investment in research and services activities that are critical for improving the health and well-being of autistic individuals in the near- and long-term. The IACC continues to believe that aggressive but strategic investment from the Federal government and private organizations will be necessary in order to better meet the needs of the autism community. The 24 total updated objectives in this *Plan*, including the new equity recommendation and the budget recommendation, address critical gaps and potential opportunities for advancement that were identified by the IACC.

The IACC’s goal during the development of this *Plan* is to present a unified voice detailing the current status and future goals of autism research, services, and policy. As the work of the IACC continues, it will be vital to learn more about the needs of individuals in their communities so that they can be properly addressed. Similarly, it is important for research findings to inform practice in clinical and community settings. In this *2021-2022 IACC Strategic Plan*, the focus of the IACC’s recommendations is to encourage research and service activities that will improve health, well-being, and outcomes for autistic people in all communities, while also increasing acceptance and understanding of autism, and addressing the issues that cause challenges for autistic people and their families, such as intellectual disability, communication disabilities, co-occurring physical and mental health conditions, behavioral challenges, and unmet service needs. The IACC hopes that this new *Strategic Plan* will shine a light on some aspects of autism and community needs that have not been highlighted previously, as well re-emphasize other important topics. The committee aims to foster more collaborative efforts between government agencies and community partners to create opportunities for autistic individuals of all ages, levels of ability, and all racial, ethnic, and cultural backgrounds to thrive in their home and family environments, engage in pursuits that they find meaningful, and find belonging in their communities.

Editorial Note on References to Autism

The terms “autistic person,” “person with autism.” 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-defined diagnosis.

Mission and Vision Statement

The purpose of the *IACC Strategic Plan for Autism Research, Services, and Policy* is to focus, coordinate, and accelerate innovative research and foster development of high-quality services and supports. The *Plan* will emphasize the critical importance of partnerships among government and community partners to address the urgent questions and needs of all autistic people across the spectrum and across the lifespan. Ultimately, the *Plan* will catalyze federal and private activities that will improve health, well-being, acceptance, and inclusion for all people on the autism spectrum and their families.

Core Values

The IACC adopted the following core values and emphasized their significance to the *2021-2022 IACC Strategic Plan* development and implementation:

Impact: We will focus on making a difference in the lives of people in the autism community, including people on the autism spectrum, their families, researchers, medical practitioners, educators, and other service and support providers.

Community Focus: We will emphasize the need for inclusion of community stakeholders with lived experience and partnerships with underserved communities, to enhance research, services, and supports. Increasing the diversity of the research and services workforce will assist in realizing the impact of research, services, and policies on the quality of life, human rights, and dignity of autistic people across the whole spectrum and across the whole lifespan.

Equity and Inclusion: We will prioritize the need to increase equity and reduce disparities across the lifespan, spectrum of ability and disability, sex and gender, racial and cultural boundaries, socioeconomic status, and geographic location.

Excellence: We will pursue innovative scientific research of the highest quality, foster collaborations, and support the development and equitable dissemination of evidence-based services and practices to maximize the health and well-being of people on the autism spectrum.

Responsiveness: We will focus on responding rapidly and efficiently to the needs and challenges of people on the autism spectrum and their families while identifying opportunities to maximize strengths.

Spirit of Collaboration: We will treat others with respect, listen with open minds to the diverse lived experiences of people on the autism spectrum and their families, consider multiple solutions, and foster discussions where participants can comfortably share different opinions.

Overview of Progress on Strategic Plan Objectives

The *IACC Strategic Plan* provides a framework to guide the autism research efforts of federal and private funders. The *Plan* organizes research priorities around seven general topic areas represented as community-focused "Questions." The Questions are divided further into research Recommendations (previously called Objectives) that address key research needs, gaps, and opportunities identified by the Committee. For the current *Plan*, the IACC made several updates and text changes to the Objectives to reflect the voices and current needs of the autism community. The organization of the general topic area Questions remained unchanged, which enables evaluation of research progress in these areas over the last thirteen years. A complete evaluation of these research areas over time is provided in the *2019-2020 IACC Autism Research Portfolio Analysis Report*.

In 2020, autism research funding supported projects relevant to all seven Questions in the *2016-2017 IACC Strategic Plan for ASD Research*. In addition, all of the Objectives of the *2016-2017 IACC Strategic Plan* were supported by funded projects. This indicates that the priority areas identified by the IACC were deemed by federal and private research funders to be worthy of investment. However, some areas received greater proportions of funding than others due to the activities of the funders included in the analysis. As in previous years, Question 2 (Biology) received the largest portion of funding (45%) in 2020. Research in this field focuses on identifying the biological differences and mechanisms in early development and throughout life that contribute to autism, as well as the characterization of the behavioral and cognitive aspects of autism. Projects ranged from basic neuroscience using cellular and animal models to human/clinical studies. Question 3, research which aimed at identifying genetic and environmental factors that may contribute to autism, had the second largest portion of funding (18%). Question 3 research projects addressed topics such as identifying genetic mutations commonly found in individuals on the autism spectrum, developing improved approaches to studying environmental exposures and gene-environment interactions, and exploring the potential roles of the microbiome and epigenetics in autism. Investment in research infrastructure and prevalence (Question 7) and services and supports (Question 5) both had a significant proportion of funding at 9%. Projects in Question 7 covered data sharing, research workforce development, epidemiological studies on autism prevalence, and communication/dissemination of research findings and evidence-based practices. Question 5 projects addressed issues surrounding access to services; coordination of community-based supports; assessment of health and safety; and improving efficacy, cost-effectiveness, and implementation of evidence-based practices. Interventions (Question 4) followed with 8% of total funding, which included research on behavioral therapies, pharmacological/medication-based approaches, and technology-based interventions, including assistive communication technologies and computer and artificial intelligence-based skill training. Research projects in Question 4 encompass the development of new interventions using model systems and small-scale experiments as well as full-scale clinical trials. Research to improve screening and diagnosis (Question 1) of autism was 7% of funding in 2020. Question 1 Objectives focused on research to develop biomarkers, screening tools, and diagnostic instruments to aid in early identification. Research focused on lifespan (Question 6) remained the smallest areas of funding (4%). Research projects within Question 6 attempted to identify and address gaps in transition to adulthood and long-term outcomes in quality of life for people on the autism spectrum, including research on post-secondary education, employment, housing, adult healthcare, and community integration.

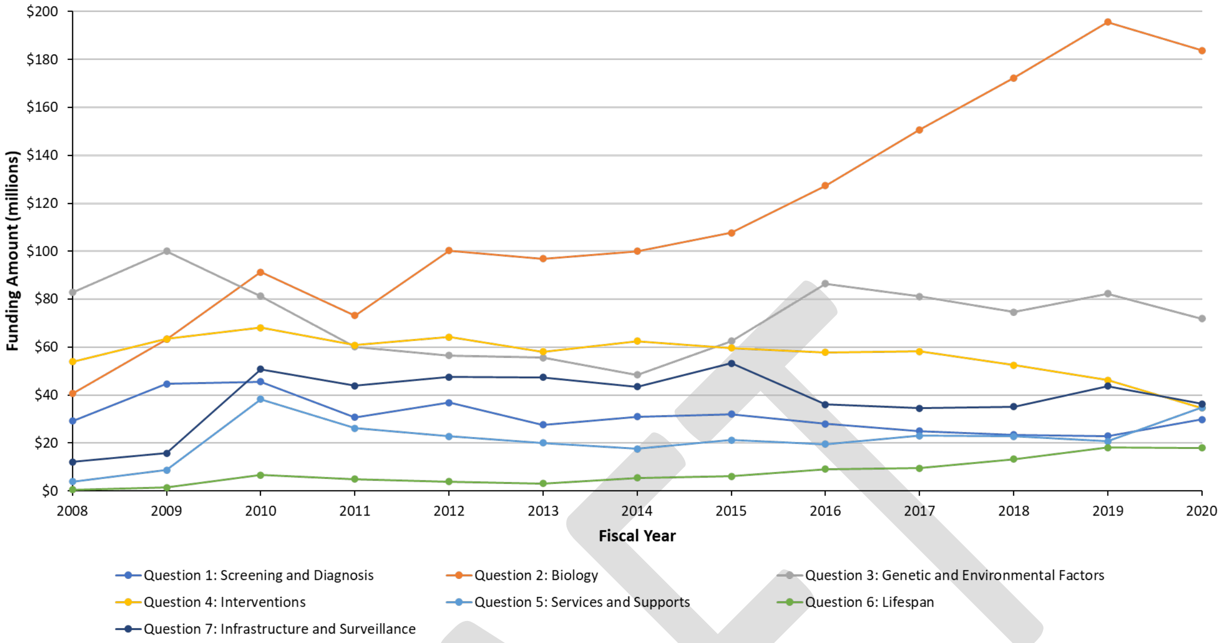

Figure 1. Autism research funding from 2008 to 2020, broken down by *Strategic Plan* Question area.

Figure 1 shows the trend in funding for each of the Question areas over time. In 2008, the reported autism research funding for federal agencies and private organizations was $222.2 million and 745 projects. In 2020, funding for autism research among both federal and private funders totaled $409.2 million and spanned 1,536 research projects. Over the thirteen years, autism research showed a general upward trend in funding, increasing by 84% since 2008. However, not all Question areas have shown the same pattern of growth. Question 2 (Biology) is the research area that has shown by far the most dramatic increases in funding, peaking at $195.6 million in 2019. In 2020, research on genetic and environmental factors (Question 3) received the second largest amount of research dollars. Funding amounts for Question 3 started out relatively high in 2008, then dipped from 2011-2014, but have shown relative increases in recent years. Question 1 (Screening and Diagnosis), Question 5 (Services), and Question 7 (Infrastructure) have received largely consistent investments in research since 2008. Funding for Question 4 (Interventions) has also been fairly stable but has been on a slight downward trend in recent years. Research focused on lifespan (Question 6) has consistently received the lowest levels of funding but has shown encouraging growth over the past four years.

Looking over the last thirteen years, significant advances have been made in autism research in each of the Question areas prioritized by the Committee. Since the development of the last *IACC Strategic Plan*, autism researchers have made several important discoveries and reached many milestones. However, there are still many areas of research that lack sufficient support. An overall increase in funding to support the entire autism portfolio will be critical to move the field forward and capitalize on scientific opportunity. This new edition of the *IACC Strategic Plan* builds on the priorities established in the previous editions of the *Strategic Plan*, identifies gaps in research, and provides recommendations for future research and services endeavors so that we continue to make a difference in the lives of people on the autism spectrum and their families.

Federal Coordination of Autism Activities

Autism- and disability-related programs exist at numerous federal agencies to address a wide variety of issues ranging from health, research, disability services, justice, housing, employment, transportation, military needs, communication, and other diverse issues. Given the large size and distributed nature of federal activities, the U.S. Congress and federal agencies have also put in place several structures to coordinate federal activities around disabilities and, in some cases, autism specifically. These coordination structures foster interdepartmental and interagency communication and collaboration on issues that are essential to autism and disability-related federal activities.

The Interagency Autism Coordinating Committee (IACC) is a foundational part of the federal coordination structure for autism that was created under the *Children's Health Act of 2000* (Public Law 106-310), reconstituted under the *Combating Autism Act of 2006* (CAA; Public Law 109-416), and most recently reauthorized under the *Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019* (Public Law 116-60). It is the only autism-specific interagency federal advisory committee in the federal government. The Autism CARES Act of 2019 outlines requirements for the membership of the IACC, which includes officials representing an array of federal departments and agencies and public members who represent a variety of perspectives within the autism community. Collectively the committee provides advice to the HHS Secretary concerning issues related to autism and coordinates federal autism efforts.

In 2014, Congress added a new component to the federal coordination structure by requiring in the Autism CARES Act of 2014 the designation of a National Autism Coordinator (NAC), "an existing official within the Department of Health and Human Services to oversee, in consultation with the Secretaries of Defense and Education, national ASD research, services, and support activities." The duties of the NAC include coordinating and implementing federal autism research, services, and support activities, taking into account the IACC Strategic Plan, as well as ensuring that federal ASD efforts are not unnecessarily duplicative. The NAC accomplishes cross-agency and cross-departmental coordination in part through the activity of the Federal Interagency Workgroup on Autism (FIWA), an all-federal working group of representatives from multiple federal departments and agencies, most of which are also represented on the IACC. The NAC has led the development of several comprehensive reports to Congress and other projects requiring cross-agency collaboration.

A third layer of interagency and intra-agency coordination is composed of a series of federal advisory committees and coordinating committees that work on specific issues related to autism and disabilities. At the National Institutes of Health (NIH), the NIH Autism Coordinating Committee coordinates NIH intra-agency efforts on autism research. Other advisory committees across the federal government that contribute to federal coordination on issues of relevance to autism include:

- Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act Council (family caregiver issues)
- President's Committee for People with Intellectual Disabilities (intellectual disabilities), the Interagency Committee on Disability Research (disability research)
- Federal Partners in Transition (youth with disabilities)
- National Council on Disability (a federal agency for disability policy)
- Interdepartmental Serious Mental Illness Coordinating Committee (mental illnesses that may co-occur with autism)

- Federal Communications Commission Disability Advisory Committee (communication technology for people with disabilities)
- National Advisory Committee on Individuals with Disabilities and Disasters (disaster preparedness and response)
- Advisory Committee on Accessible Air Transportation - ACCESS Advisory Committee (disabilities and air transportation).

All of these advisory committees focus efforts on specific topics related to disability efforts and contribute to informing activities related to autism.