2021-2023

INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN

FOR AUTISM RESEARCH, SERVICES, AND POLICY

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

OFFICE OF
NATIONAL AUTISM
COORDINATION
NATIONAL INSTITUTES OF HEALTH

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ABOUT THE IACC

The Interagency Autism Coordinating Committee (IACC) is a federal advisory committee charged with coordinating federal activities concerning autism spectrum disorder (ASD) and providing advice to the Secretary of Health and Human Services (HHS) on issues related to autism. The Committee was established by Congress under the *Children's Health Act of 2000*, reconstituted under the *Combating Autism Act (CAA) of 2006*, and renewed most recently under the *Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019.*

Membership of the Committee includes a wide array of federal agencies involved in autism research and services, as well as public stakeholders, including autistic adults, family members of those on the autism spectrum, advocates, service providers, and researchers, who represent a variety of perspectives. The IACC membership is composed to ensure that the Committee is equipped to address the broad range of issues and challenges faced by individuals and families in the autism community.

Under the CAA and subsequent authorizations, the IACC is required to (1) develop and annually update a strategic plan for autism research, (2) develop and annually update a summary of advances in autism research, and (3) monitor federal activities related to autism.

Through these and other activities, the IACC provides guidance to HHS and partners with other federal departments, research and advocacy organizations, and the broader autism community to accelerate research and enhance services with the goal of positively impacting the lives of people on the autism spectrum and their families.

For more information about the IACC, see **https://iacc.hhs.gov/**.

EDITORIAL NOTE ON REFERENCES TO AUTISM:

The IACC supports the use of accessible language around autism in its publications. 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.

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 (HHS) 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 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. The current Committee is the largest and most diverse to date. Committee membership includes autistic adults; 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 or multiple perspectives on the Committee, for example both as a professional in a field 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. The Committee includes members from diverse communities across the United States.

Historically, the IACC Strategic Plan has been an influential document that has provided recommendations to the HHS Secretary and federal agencies on priorities for research, services, and policy that reflect the collective input of both public and federal members of the IACC, as well as views represented in the broader autism community. The IACC Strategic Plan, along with input collected by the IACC through public comments and targeted requests for information, has played an instrumental role in highlighting the need for research and services related to adults and transition age youth, co-occurring conditions, and wandering, bringing these issues to national attention at a time when they were not well-represented in federal autism programming. The spotlight provided over the years by the IACC for these and other issues has contributed to the breadth of federal activities that exist today. This new *IACC Strategic Plan* similarly has the potential to foster growth and enhancement of federal activities to address the needs of the autism community.

There have been several important shifts in the autism community over the past several years. The neurodiversity movement has advocated for greater societal acceptance and inclusion of autistic people in addition to increased access and accommodation of autistic individuals' needs. Autistic adults, as well as 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, enabling the expansion of autism research and services efforts. 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 across the full range of the autism spectrum. These are not mutually exclusive goals. To best meet the needs of all autistic people, it will be important to engage them, their families and caregivers, and service providers to identify the most pressing issues and develop solutions that will improve outcomes across the spectrum.

The COVID-19 pandemic has had a profound impact on the autism community. Individuals with disabilities such as autism were disproportionately affected 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 remote service delivery. Workplaces that had not previously considered remote work options were suddenly forced to make these options available, resulting in some benefits for autistic people who found that 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 challenges for individuals on the autism spectrum and their families. 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 and interventions. In particular, it is important to provide mental health supports to autistic individuals and their caregivers. Advocates have long noted the need for access to acute and long-term mental health services to provide appropriate interventions and supports for autistic individuals who also have co-occurring mental health conditions, which can have a dramatic impact on well-being. Research on autism and mental health, as well as additional resources for service provision, are needed to address challenges associated with anxiety, depression, trauma, chronic stress, and other mental health issues that are faced by many individuals on the autism spectrum.

It is also critical to make advances in understanding communication challenges and providing appropriate communication supports to autistic people who need them. Research is needed to develop new approaches and technologies to help those individuals with communication challenges develop their communication skills and access the communication modalities of their choice that are most effective for them. Opportunities to improve language and/or communication skills are essential for individuals to express their wants and needs and participate more fully in all aspects of community life.

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 only serving as research subjects. By receiving input based on the lived experiences of advocates during the initial experimental design and every step afterward, researchers can tailor their work to better address the needs of individuals on the autism spectrum. Community-informed research priorities have the potential to be more easily translated into effective practice.

The IACC is committed to advocating for increased 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 *2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy* summarizes current understanding of autism-relevant topics and addresses current 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 (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 *2021-2023 IACC Strategic Plan* provides, in many cases, a substantial update to the text of the recommendations from the *2016-2017 IACC 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 by the Autism CARES Act of 2019. As in previous years, the IACC recommends a substantial increase in funding, which would allow for enhanced 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, state and local governments, and private organizations will be necessary in order to better meet the needs of the autism community. The 24 total updated Recommendations in this *Strategic 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 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 vital to learn more about the needs of individuals and their families in the context of their communities so that those needs can be properly addressed. Similarly, it is important for research findings to inform practice in clinical and community settings. In this *2021-2023 IACC Strategic Plan*, the focus

of the IACC's Recommendations is to encourage research and services activities that will improve health, well-being, and outcomes for autistic people in all communities, while also increasing acceptance and understanding of autism. The *IACC Strategic Plan* addresses 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, genders and gender expressions, all racial, ethnic, and cultural backgrounds, and diverse communities across the country to thrive in their home and family environments, engage in pursuits that they find meaningful, and find belonging in their communities.

IACC 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.

IACC CORE VALUES

The IACC adopted the following core values and emphasized their significance to the *2021-2023 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 well-being, 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 RECOMMENDATIONS

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 Recommendations 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. An evaluation of these research areas over time (2008-2020) will be provided in the forthcoming *2019-2020 IACC Autism Research Portfolio Analysis Report*.

The size of the U.S. autism research portfolio has grown significantly over the past 13 years. In 2008, the reported autism research funding for federal agencies and private organizations was $222.2 million (Figure 1). In 2020, funding for autism research among both federal and private funders totaled $418.9 million, supporting projects relevant to all seven Questions in the *2016-2017 IACC Strategic Plan for ASD Research*. In addition, all of the Objectives/Recommendations 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.
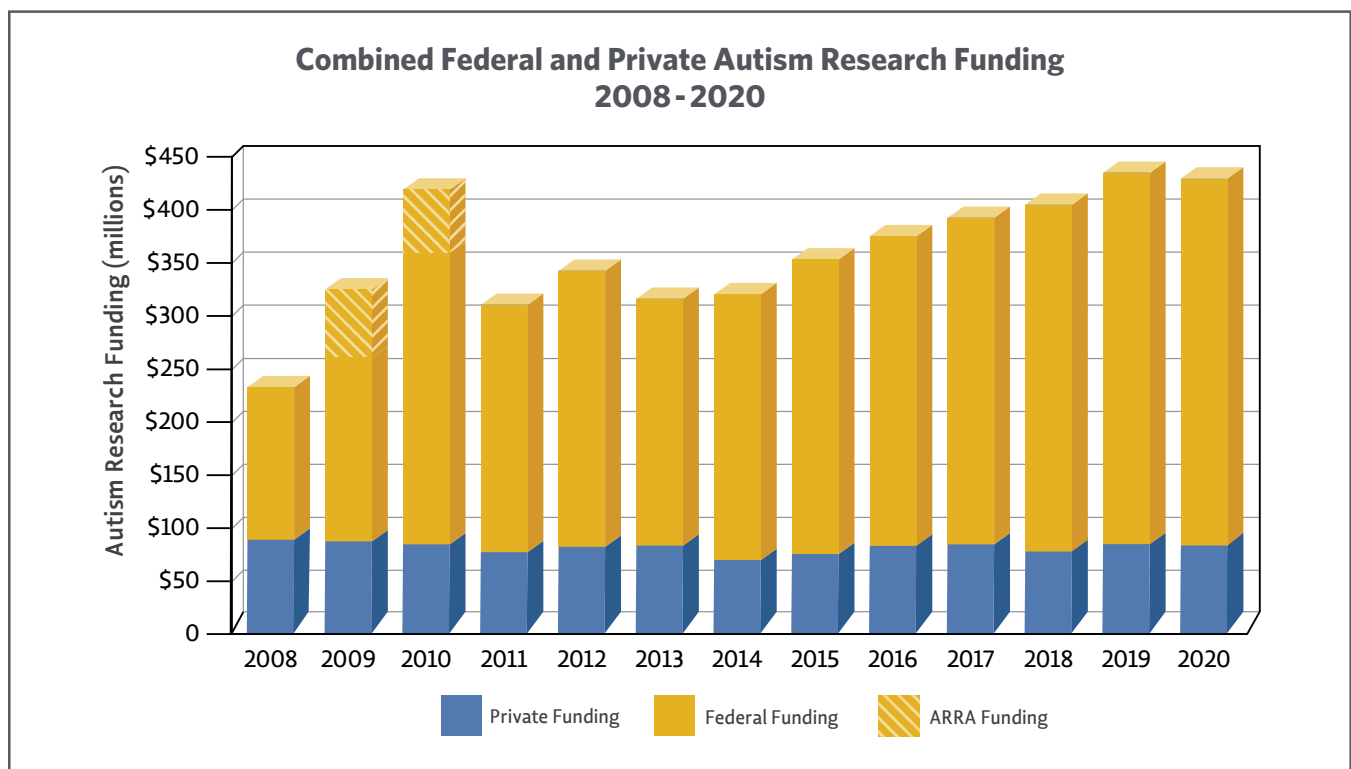

Figure 1. 2008-2020 autism research funding from federal (yellow) and private (blue) sources based on data collected for the IACC Portfolio Analysis Report of those years. Yellow dashed shading indicates supplementary funding provided by the American Recovery and Reinvestment Act (ARRA) in 2009 and 2010.

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 (Genetic and Environmental Factors), research

aimed at identifying factors that may contribute to autism, had the second largest portion of funding (18%). Question 3 research projects addressed topics such as identifying genetic variations 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 Interventions (Question 4) both had a significant proportion of funding at 9%. Projects in Question 7 covered data sharing,
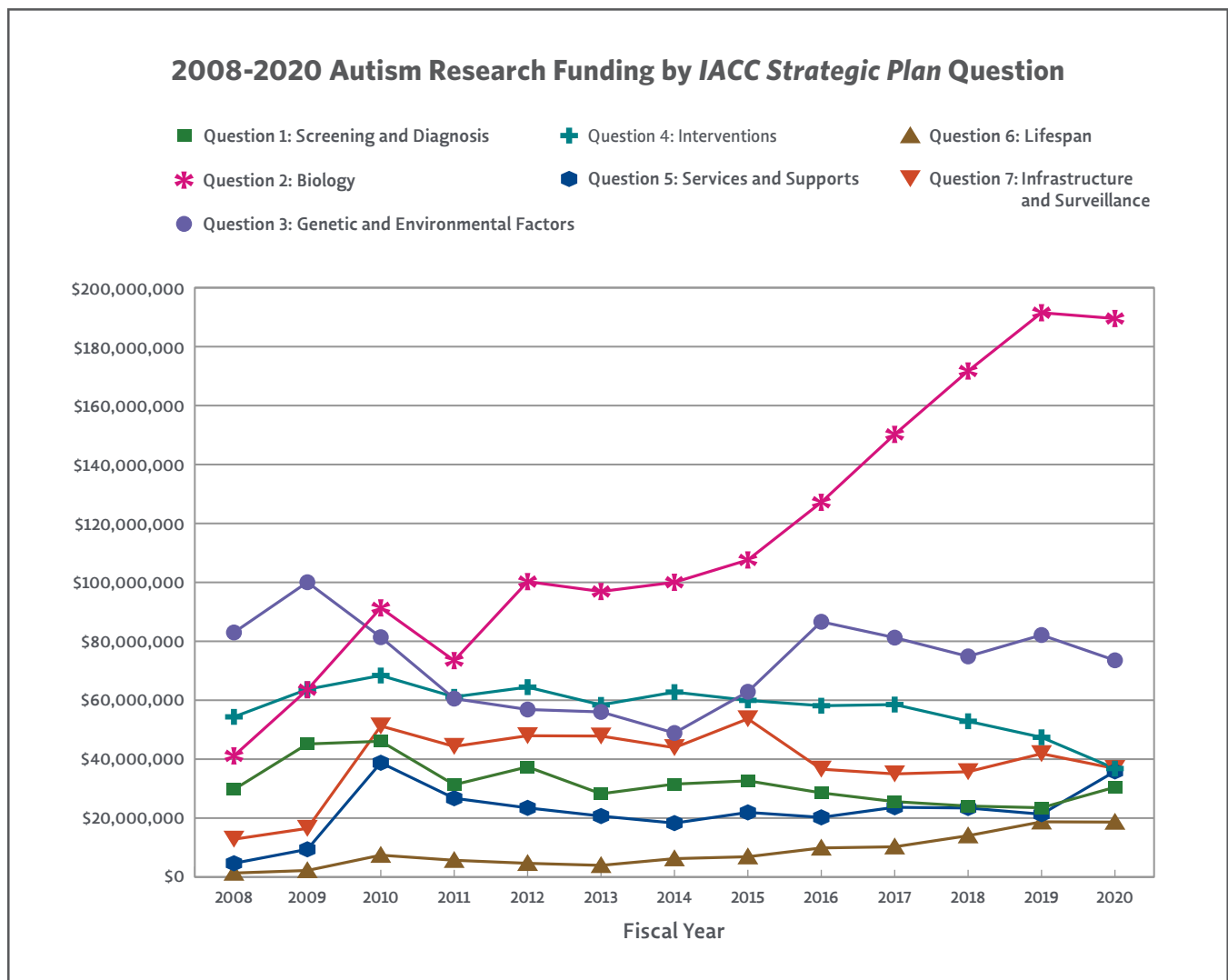

2008-2020 Autism Research Funding by *IACC Strategic Plan* Question

Figure 2. Autism research funding from 2008 to 2020, broken down by *Strategic Plan* Question area.

research workforce development, epidemiological studies on autism prevalence, and communication/dissemination of research findings and evidence-based practices. Question 4 projects 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. Services and Supports (Question 5) followed with 8% of total funding. Question 5 projects addressed issues surrounding access to services; coordination of community-based supports; assessment of health and safety; and improving the efficacy, cost-effectiveness, and implementation of evidence-based practices. Research to improve Screening and Diagnosis (Question 1) of autism was 7% of funding in 2020. Question 1 projects focused on research to develop biomarkers, screening tools, and diagnostic instruments to aid in early identification. Question 6 (Lifespan) research remained the smallest area 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 2 shows the trend in funding for each of the Question areas over time. From 2008-2020, total autism research funding, increased by 89% from $222.2 million in 2008 to $418.9 million in 2020. However, not all Question areas have shown the same pattern of growth. Question 2 (Biology) is the research area that has shown the largest increases in funding, reaching $192.3 million in 2019. From 2015 to 2020, research on Genetic and Environmental Factors (Question 3) has received the second largest amount of research dollars. Question 1 (Screening and Diagnosis) and Question 5 (Services) both showed an increase in funding from 2019 to 2020, and funding for Question 7 (Infrastructure) has been relatively flat from 2016 to 2020. Question 4 (Interventions) funding has also been consistent for many years but has been on a downward trend in recent years. Research focused on Lifespan (Question 6) has historically received the lowest levels of funding but has shown growth over the last four years analyzed.

Looking over the last thirteen years of analysis, 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 would benefit from additional 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 can 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 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 the Autism CARES Act of 2014, Congress added a new component to the federal coordination structure by requiring 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 autism 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 on federal autism activities 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. For example, the National Institutes of Health (NIH), Autism Coordinating Committee coordinates NIH intra-agency efforts on autism research.

Other advisory committees and agencies across the federal government that contribute to federal coordination on issues of relevance to autism and disabilities are listed in Table 1.

Each of these advisory committees focuses on specific topics related to disabilities, which are informative to the efforts of the IACC to coordinate autism activities.

FEDERAL ADVISORY COMMITTEES RELATED TO DISABILITY		
FEDERAL ADVISORY COMMITTEE	MANAGING AGENCY	AREA OF FOCUS
Advisory Committee on Accessible Air Transportation (ACCESS)	U.S. Department of Transportation	Air transportation and disabilities
Coordinating Council on Access and Mobility (CCAM)	Federal Transit Administration	Human services transportation for people with disabilities, older adults, and individuals of low income
Federal Communications Commission (FCC) Disability Advisory Committee (DAC)	Federal Communications Commission	Communication technology for people with disabilities
Federal Partners in Transition (FPT)	U.S. Department of Labor	Youth with disabilities
Interagency Committee for Disability Research (ICDR)	Administration for Community Living	Disability research
Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)	Substance Abuse and Mental Health Services Administration	Mental illnesses, including those that may co-occur with autism
National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)	Administration for Strategic Preparedness and Response	Disaster preparedness and response and disabilities
National Council on Disability (NCD)	Independent federal agency	Disability policy
President's Committee for People with Intellectual Disabilities (PCPID)	Administration for Community Living	Intellectual disabilities
RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregiving Advisory Council (FCAC)	Administration for Community Living	Family caregiver issues

Table 1. Additional federal advisory committees that conduct work on disability-related issues.

2021-2023 IACC STRATEGIC PLAN RECOMMENDATIONS

QUESTION 1 HOW CAN WE IMPROVE IDENTIFICATION OF AUTISM?
SCREENING AND DIAGNOSIS

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.

QUESTION 2 WHAT IS THE BIOLOGY UNDERLYING AUTISM?
BIOLOGY

1 Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, brain circuitry, and cognitive development 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.

QUESTION 3 WHAT ARE THE GENETIC AND ENVIRONMENTAL FACTORS THAT CONTRIBUTE TO AUTISM AND ITS CO-OCCURRING CONDITIONS?
GENETIC AND ENVIRONMENTAL FACTORS

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 onset 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.

QUESTION 4 WHICH INTERVENTIONS WILL IMPROVE HEALTH AND WELL-BEING?

INTERVENTIONS

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.

QUESTION 5 WHAT SERVICES AND SUPPORTS ARE NEEDED TO MAXIMIZE HEALTH AND WELL-BEING?

SERVICES AND SUPPORTS

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.

QUESTION 6 HOW CAN WE ADDRESS THE NEEDS OF PEOPLE ON THE AUTISM SPECTRUM THROUGHOUT THE LIFESPAN?

LIFESPAN

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.

QUESTION 7 HOW DO WE EXPAND AND ENHANCE RESEARCH INFRASTRUCTURE SYSTEMS TO MEET THE NEEDS OF THE AUTISM COMMUNITY?
INFRASTRUCTURE AND PREVALENCE

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.

CROSS-CUTTING 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.

BUDGET RECOMMENDATION

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

Priority areas:
- Lifespan issues
- Evidence-based interventions and services
- Research on disparities and development of culturally responsive tools and services

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.**

INTRODUCTION

For many autistic individuals and their families, engagement with 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, autism prevalence studies from the Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disorders Monitoring (ADDM) Network indicate that most 8-year-old children with ASD are evaluated after 36 months of age, and evaluation practices were found to vary widely in different locations.[1] Many people on the autism spectrum are initially misdiagnosed with other health conditions, and in many cases they may not receive a correct autism diagnosis until adolescence or adulthood. Others may recognize traits of autism in themselves or a loved one but have difficulty accessing diagnostic services. The consequences of these delays are myriad, including missed opportunities to receive services and supports.

Given the immense growth of the brain during the first three years of life, behavioral interventions initiated in autistic toddlers within this time period are most likely to maximize positive outcomes. However, due to the lag in diagnosis, many children miss the opportunity to receive intervention and supports during this critical period of brain development. For older children and adults, lack of a proper diagnosis often results in unmet healthcare and service needs. Thus, it is critical that children and adults are able to access screening and diagnostic services for autism in a timely manner. Much investment is focused on developing and optimizing screening and diagnostic tools, particularly for special populations such as women, adults, non-native English speakers, and racial/ethnic minorities. This chapter reviews the state of knowledge about screening and diagnostic tools, as well as the current state of service delivery and challenges families face when trying to access screening and diagnostic services.

SCREENING AND DIAGNOSTIC TOOLS

Researchers have developed several tools for identifying children with ASD. These include screening tools that identify developmental delays and issues of concern, and diagnostic tools, which are fuller evaluations designed to provide a definitive indication of autism in an individual. The American Academy of Pediatrics (AAP) **recommends** that children should be screened for ASD at ages 18 and 24 months during well-baby visits. The AAP also recommends that children should be screened for general developmental delays at 9, 18, and 30 months of age. By identifying children with potential traits of autism at these ages, they may be connected to diagnostic and early intervention services as soon as possible.

CURRENT SCREENING TOOLS

The most commonly used parent-report screening tools are the *Modified Checklist for Autism in Toddlers* (**M-CHAT**) and its two revised versions, *Modified Checklist for Autism in Toddlers, Revised* (M-CHAT-R) and the *Modified Checklist for Autism in Toddlers, Revised, with Follow-Up* (M-CHAT-R/F). The M-CHAT and other similar screening tools are brief, making them ideal to be administered in primary care settings. In recent years, researchers have leveraged technology to administer screening instruments on digital platforms.[2-4] These studies have shown that a full administration of the M-CHAT-R/F on a computer tablet not only resulted in greater and more accurate documentation of the screening results within electronic medical record systems, but also reduced some of the time constraints involved in screening for ASD during well-baby visits.

While the M-CHAT instrument and its revisions have many strengths, there are some challenges associated with their use. In particular, large-scale studies examining the efficacy of screening demonstrate that the M-CHAT/F is less accurate in community settings than in clinical settings.[5] Many cases of ASD may be missed, especially in children younger than 24 months. This may be due to many factors, including the accuracy of the screening tool, ability of parents to identify early signs of autism, the ease of accessing follow-up diagnostic services, and the heterogeneity in presentation of autistic traits at this young age. Recent studies have developed new screening tools designed for children as young as 12 months.[6, 7] These and other screening instruments may reduce some of these detection issues and be better suited to individuals of particular age groups or subsets of the autism community. In the future, it will be important to further characterize and develop new screening tools to ensure that there are appropriate instruments for use across the full spectrum of autistic individuals and across the lifespan.

CURRENT DIAGNOSTIC TOOLS

Once autism is suspected in an individual, they are typically referred for a diagnostic assessment. There are many diagnostic tools available; the gold standard is to conduct a parent interview (for children) using an instrument such as the Autism Diagnostic Interview-Revised (ADI-R) and a clinician assessment of the individual using the activity-based Autism Diagnostic Observation Schedule-Second Edition (ADOS-2).[8] The combination of these two instruments allows clinicians to gain a comprehensive view of an individual's behaviors. The ADOS-2 includes five different modules that are targeted to different age groups (toddlers through adults) and verbal communication abilities.[9] Similar to screening tools, it is important to identify which existing diagnostic tools work best in individuals across the spectrum and across the lifespan.

TECHNOLOGICAL ADVANCES IN SCREENING AND DIAGNOSIS

Early Signs and Biomarkers

In order to enable early linkages to services and interventions (and subsequently improved long-term outcomes), it is critical to identify ASD at the earliest age possible.[10] Studies have demonstrated that differences in brain development and function (e.g., eye gaze patterns, brain growth, and some brain connectivity patterns)[11-14] as well as some subtle behavioral and motor differences (e.g. social communication and attention, ability to hold up head), emerge in the first months of life, before more overt ASD signs begin to appear, such as non-responsiveness to their name or delayed language development.[15-20] Many of these early signs were found in infants with a higher likelihood of developing ASD (i.e., having at least one sibling with ASD). There is a need to determine whether these early signs are also evident for infants who are not categorized as high likelihood for ASD who later receive a diagnosis. Thus, further studies to develop and validate new ASD screening methods that can be used on infants and toddlers will be important.

Large-scale studies are testing innovative strategies and technologies for diagnosis by age 12 months, universal screening, and expedited diagnosis and engagement with intervention. In addition, ongoing research is aimed at translating early screening methods for infants and toddlers into practical, efficient, and inexpensive tools that can be implemented in the general population and within community settings. For example, a recent study developed a screening tool that uses computer vision analysis to analyze toddler facial expressions or eye gaze patterns while they use a mobile device.[21, 22] Another study used machine learning to identify "digital biomarkers," patterns of previous medical encounters in electronic health records, that are predictive of a later autism diagnosis.[23] In 2021, the FDA approved a digital diagnostic tool that allows caregivers to upload videos of a child and answer a questionnaire that can be evaluated by primary care physicians.[24] These tools may be helpful in reducing long waitlists for a diagnosis and make diagnosis more equitable across different communities.

Researchers and clinicians are considering the potential of pre-symptomatic intervention, which is beginning intervention before traits of autism are fully apparent.[25] The goal in any such intervention would be to target brain development during the period when it is most adaptable to change. The identification and characterization of early biomarkers will be critical for any efforts in this realm. Given the potential ethical, social, and legal implications, the concept of pre-symptomatic interventions may be somewhat controversial. Therefore, it will be crucial to fully engage the autism community, including autistic individuals and their families, researchers, clinicians, and policy experts, during the development of any such interventions.

Telehealth Evaluation Tools

There are significant delays between when an individual first screens positive and when they are able to receive a diagnostic evaluation for ASD. These delays are largely due to a lack of developmental-behavioral pediatricians or other providers trained to perform this assessment; in many cases families must wait months for an appointment and travel long distances from their homes to meet with an available provider. The closure of facilities during the COVID-19 pandemic has exacerbated these issues. Several studies have explored the use of telehealth methods to conduct diagnostic assessments for ASD.[26, 27] One team of researchers has developed the TELE-ASD-PEDS tool, specifically in response to the COVID-19 pandemic, that mediates remote diagnostic evaluation of children with signs of autism.[28]

Surveys of clinicians using tele-assessment tools identified benefits and challenges of conducting assessments for autism remotely.[29, 30] Benefits included increased child

comfort and increased caregiver involvement. Some of the stated challenges include difficulty adapting to the absence of an in-person assessment, technological challenges, suitability of the child's home environment for assessment, and difficulty assessing older children or those with more subtle traits of autism. In some cases, clinicians reported reduced confidence in their

assessments that were made remotely rather than in person. Therefore, it will be necessary to continue to enhance tools for remote assessment so that they can be better adapted to differing home environments and a wider range of individuals, including older children and adults. It will also be important to improve the training of clinicians on the use of these tools.

UNIVERSAL SCREENING FOR ASD

Studies consistently report that screening using validated autism-specific parent-report tools can result in ASD detection as young as 12-18 months,[31] and has been shown to be more reliable than clinical judgment alone.[32] However, many primary care providers do not routinely screen all children at these ages.[33] In 2007, the AAP first **recommended** universal ASD screening using standardized tools as the gold standard for detecting ASD. The AAP currently recognizes screening as a critical service need to improve early access to care. Barriers that prevent widespread use of parent-report and other screening tools within primary care settings include lack of education and understanding of ASD, lack of familiarity with screening tools, uncertainty about where to send a child with a positive screening result, lack of effective and timely means of connecting families to available resources, and the extra time and resources required to utilize standardized screening tools.[34-38]

Although early intervention has been associated with improvements in social behavior, language ability, and overall IQ,[39-42] no study has directly examined if children with ASD detected by early screening have better outcomes than those detected by other means, (e.g., parent or provider concern). This issue is highlighted by the U.S. Preventive Services Task Force (USPSTF) report on universal early screening for ASD.[43] However, such a study would

require large representative samples from across the country to be randomly assigned to either a screening or non-screening condition, and then years of follow-up to determine long-term outcomes and societal costs.[44] As an alternative to this type of study, the NIMH-funded ASD Pediatric, Early Detection, Engagement, and Services (ASD PEDS) Network investigated several new strategies to improve early access to screening, diagnosis, and treatment of autism among toddlers (ages 12-24 months). Findings from these five research projects suggest that routine universal early screening reduces the age of detection, increases early access to services, and is most beneficial for families from historically marginalized populations.[45, 46] In addition, researchers in the NIMH Intramural Research Programs (IRP) collaborated on field testing an autism-specific early screening tool for children 12 to 36 months of age.[6] The collective results of these projects increase the evidence base for the benefits of universal screening; however, additional studies are still needed.

IMPLEMENTATION OF SCREENING AND DIAGNOSTIC TOOLS AND SERVICES

While early detection is an essential step in maximizing positive outcomes for autism, it is just one step on the path to eventual intervention. Families must follow through with subsequent diagnostic evaluation, then identify and

engage with quality interventions. In order for screening to be effective, ample evaluation centers must be available with appropriate ASD diagnostic expertise. Indeed, uncertainty regarding where to send a child for an evaluation is a barrier to screening noted by over 75% of pediatricians.[37] Therefore, an increase in the number and accessibility of evaluation centers is necessary, based on population and expected rates of autism. Likewise, significant enhancement of the screening and diagnostic system is meaningful only if high-quality intervention services are available, accessible, and affordable. There is still a need to investigate more cost-effective modes to deliver screening tools, such as those that are either partially or fully deployed by parents. Additional research is needed to identify key factors that must occur following a screen for ASD to increase the likelihood for successful engagement with interventions and services.

Potential improvements to early screening and diagnostic services will also call for the need to standardize policies regarding eligibility for services under the Individuals with Disabilities Education Act (IDEA) Part C, the federal program that funds intervention services for infants and toddlers (ages 0-3 years) showing developmental delays,

including autism. Generally, children must first qualify for basic Part C services by exhibiting a particular state-mandated level of delay (usually a 25% delay in two or more areas), which often provides for just a few hours of speech or occupational therapy. Although autism is an automatic eligibility category, a child must be identified as either ASD or showing signs of ASD in a separate evaluation visit in order to be eligible to receive ASD-specific treatment. Currently, there are no guidelines mandating that all toddlers receiving Part C services should be examined for possible ASD. Even once a child is referred for an in-depth ASD evaluation, there are no policies regarding specific diagnostic and other evaluation tools that should be used to determine if a child is eligible for ASD-specific services. Unsurprisingly, many toddlers already receiving Part C services for a developmental delay have not been properly evaluated for ASD. Even more concerning, the vast majority of toddlers with ASD (at least 75%) who will go on to qualify for special education at school-age are not identified in time to receive early intervention. Providing clear guidelines regarding ASD detection and subsequent treatment eligibility through Part C will help to eliminate these deficiencies.

DISPARITIES IN ASD SCREENING AND DIAGNOSIS

Research has demonstrated several disparities in the process of ASD screening and diagnosis, based on factors such as race/ethnicity, primary language spoken, maternal education, and private vs. public insurance.[47-53] In addition, economic challenges, geographic distance between families and service providers, reduced professional resources and capacity, and characteristics impacted by cultural knowledge such as stigma, often contribute to diminished service availability and utilization in rural, minority, or other disadvantaged communities.[50, 54-56] Examining and

understanding these differences will be critical in reducing disparities in screening and diagnosis.

DISPARITIES IN ASD SCREENING

ASD screening rates during primary care visits vary greatly, with different levels of use of standardized screening tools. Some of this variability has been shown to be associated with children's sociodemographic characteristics (e.g., race/ethnicity, socioeconomic status, geographic

location, language spoken at home). Research has shown that non-White children are diagnosed on average more than a year later than their White peers.[57, 58] However, it has been demonstrated that universal screening for ASD following a standardized protocol, including immediate referral for screen-positive cases, drastically reduces disparities in age of diagnosis.[46, 52, 59] Therefore, access to screening for all children, regardless of sociodemographic characteristics, is crucial to reduce existing disparities that may impact life-long outcomes. Dedicating more resources to early screening in underserved communities, with a corresponding increase in funding for evidence-based diagnostic evaluations, will avoid lengthening waitlists and link individuals to interventions and services more quickly.

CULTURALLY RESPONSIVE SCREENING INSTRUMENTS

A number of studies have examined ASD screening tools in different languages and cultural settings within the United States and across the world.[50, 60-63] The variability of results from these studies indicates that there is a need for additional research to adapt tools that will be valid (i.e., demonstrate adequate sensitivity and specificity) in diverse populations. Factors including level of educational attainment, language/literacy, rural versus urban locale, race, and ethnicity also impact screening reliability and validity as well as screen-positive rates. Examination of medical or state records for specific mention of ASD screening and diagnosis in individuals representing diverse demographic groups would be helpful in documenting disparities and in tracking improvements based on policy changes or improved access to care.

It will be critical to evaluate the effectiveness of screening instruments and programs in diverse samples of individuals, including long-term outcomes. Implementation studies examining the translation from research settings to community settings with diverse populations are also needed.[64-66]

DISPARITIES IN ACCESS TO DIAGNOSTIC SERVICES AND AGE OF DIAGNOSIS

The most recent prevalence data of 8-year-old children from the Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disorders Monitoring (ADDM) Network found higher ASD prevalence among Black, Hispanic, and Asian/Pacific Islander than among White children in 2020,[1] consistent with 2018 data among 4-year-olds. These patterns were consistent across sites, suggesting higher occurrence of ASD in these populations, similar to other neurodevelopmental disabilities.

While demographic differences in ASD identification have changed over time, there are still barriers that children from minority backgrounds may experience. A primary barrier to early diagnosis is the limited availability of diagnostic clinics with providers trained in ASD diagnosis, leading to long waiting lists and poor reimbursement for comprehensive diagnosis.[67] This limited availability is especially pronounced in underresourced and rural areas, with many children not diagnosed until they have entered the school system. In addition, family-level variables such as insufficient financial resources, lack of insurance coverage, language barriers, geographic isolation, and limited knowledge of or experience with complex healthcare systems, may be barriers to the timely diagnostic evaluation of a child.[68] Overall, there is limited research that documents these systemic- and individual-level barriers that exist at all stages; from early ASD screening, to appropriate diagnosis, to intervention. While recent prevalence data from the CDC ADDM Network has demonstrated that universal screening can reduce differences in prevalence rates by racial/ethnic background,[46] it is still important to demonstrate that universal screening can subsequently reduce disparities in long-term outcomes for individuals with ASD.

Strategies to reduce waitlists include increasing the diagnostic workforce, increasing the efficacy of existing diagnostic tools, and increasing the development and

adoption of new or adjunctive tools, such as technology-based screening and diagnostic tools. Additional practitioner efforts that can help to reduce disparities in diagnosis include training to raise awareness and reduce biases/stigma, promoting continuing education programs, using alternative service delivery models when appropriate (e.g., telehealth, web-based, community health workers) or settings (e.g., schools, child care centers, mobile clinics) for screening and diagnosis, and providing wraparound services that address additional stresses (e.g., chronic illness, unemployment, lack of insurance) often faced by individuals in underserved communities. Finally, it is clear that children are often not well-tracked from the time of ASD screening to receipt of services.[58] While telehealth-mediated methods have the potential to increase access to screening services, these tools are dependent on reliable internet service which is often limited for low-income and geographically isolated families.[69] It is imperative to have a system in place that can ensure children and families receive adequate, timely, and appropriate services as they move through the screening, referral for diagnosis, and intervention process. It is also critical to promote best practices in screening and diagnostic processes.

DIAGNOSIS OF INDIVIDUALS FROM UNDERSERVED POPULATIONS

The ADI-R and ADOS-2 have traditionally been viewed as the best available diagnostic tools for evaluating potential cases of ASD. However, these tools may have limitations in their ability to diagnose ASD in non-native English speakers, females, racial and ethnic minorities, adults, and other populations. The ADI-R has been translated into 17 languages, and a small number of studies have examined the validity of the ADI-R in different countries with varying results.[70-73] With respect to validation studies with diverse populations in the United States, researchers found that the sensitivity and specificity of the ADI-R with a U.S.-based Spanish-speaking population of parents of children with ASD were lower than values previously reported for mostly White, middle-class respondents.[74, 75] The communication domains were found to be especially problematic for parents whose primary language was Spanish when reporting on children who spoke mainly English. Little is known about the validity of the ADI-R among low-income families in the United States. The ADOS-2 has been translated into 19 different languages; however, cross-cultural validation studies of the ADOS-2 have not been identified.

The development of screening and diagnostic tools has largely been accomplished in studies where the subjects were predominantly boys, resulting in tools that may not identify girls/women and people from other underserved groups as accurately, putting them at risk of a missed diagnosis. Based on recent literature, there appears to be a diagnostic gender bias, which means that girls are less likely than boys to meet diagnostic criteria for ASD at comparatively high levels of autistic-like traits.[76, 77] Girls may also exhibit different signs and characteristics from boys, which may make current screening and diagnostic tools more likely to miss ASD in girls.[78-80] It is important that future research addresses the gender differences in ASD, both biological and behavioral, in the development of diagnostic tools.

Individuals with ASD that have other co-occurring developmental conditions are also at risk of being underdiagnosed. About one-third of children with ASD also have an intellectual disability,[1] and many individuals with ASD have a dual diagnosis of attention-deficit/hyperactivity disorder (ADHD). Having multiple conditions often leads to a misdiagnosis or a delayed ASD diagnosis.[81] While research is necessary to develop tools that account for the overlap in traits, health providers must be better equipped to discern multiple diagnoses during evaluation.

In addition, increasing numbers of adults are presenting to clinics for first-time diagnoses of ASD, and recent studies suggest that many adults with ASD may be unidentified and living in the community without appropriate supports.[82, 83]

Many autistic individuals diagnosed as adults report being initially misdiagnosed with other mental health conditions, such as borderline personality disorder, generalized anxiety, or mood disorders such as depression or bipolar disorder.[84, 85] These misdiagnoses may result in being overmedicated or being subjected to unnecessary medical treatments. Others report receiving care for mental health conditions such as eating disorders while displaying traits of autism that were unrecognized or ignored by healthcare providers.[86] Thus, there is a need to improve diagnostic tools that are specific for adults. There is also a need for practitioner training to recognize traits of autism in adults.

WORKFORCE

The increased prevalence of diagnosed ASD cases has led to a need for a larger workforce trained in the identification and diagnosis of these disorders, including psychologists, psychiatrists, developmental pediatricians, neurologists, and speech and language pathologists.[87] Early detection of ASD will require training those professionals who come in regular contact with young children, including primary care providers and childcare providers, to incorporate effective screening and referrals in their daily practice patterns.

Evidence demonstrates that healthcare professionals are less likely to detect ASD using developmental monitoring without the use of screening tools. Even experienced professionals may miss or misjudge symptoms during a brief observation.[88] However, primary care providers face barriers to implementing screening that include the time necessary to identify ASD, the cost of conducting screening and the reimbursement for this work, and appropriately trained personnel in their offices or referral networks.[89] Also, practitioners may lack the technical training to assess and compare the quality of developmental screening tools. Training for this workforce is needed to improve their ability to screen effectively, recognize ASD symptoms, communicate clearly with parents/caregivers, and refer appropriately for evaluation and intervention services.

Parents may not recognize signs of developmental delay, or they may have concerns about their child's development but not know how or when to act on those concerns. There is a need to raise public awareness of the early signs of ASD, to encourage parents to observe and track their child's development, and to encourage them to discuss their concerns with their child's doctor, teachers, and other care providers. The "**Learn the Signs. Act Early**." campaign developed by CDC, the **Autism Navigator** project developed by researchers at Florida State University, and the **Baby Siblings Research Consortium** are examples of resources that can be used to raise awareness and facilitate parent-provider collaborations. However, there is still a critical research gap on understanding how parent concerns can impact parent engagement in acting on referral for diagnosis and early intervention.

Addressing gaps in our understanding of how healthcare professionals can best reach families from underserved communities continues to be a challenge. There is an opportunity to improve identification of ASD through translation of materials to other languages, but even more important are efforts to implement culturally responsive practices and engage a workforce with greater cultural diversity in order to better address the needs of culturally diverse populations. For example, outreach activities held in places of worship and other community gatherings where families feel comfortable may improve parent-provider partnerships and reduce disparities in identification of ASD.

Some important service initiatives to address screening and diagnosis training are ongoing, but there is a need for additional efforts. The AAP supports universal screening for ASD and provides training to pediatric providers through several formats (publications, webinars, and face-to-face conferences). Programs such as the **Leadership Education in Neurodevelopmental and Related Disabilities (LEND)**, the **Developmental-Behavioral Pediatrics (DBP) Training Program**, and the **University**

Centers of Excellence in Developmental Disabilities (UCEDDs) also provide training to practitioners from several healthcare disciplines. Additional efforts are needed to increase availability of professional development and training opportunities that will help address unmet needs for early screening and diagnostic services, including access to care. Furthermore, there is a need for improved policies to facilitate the collaboration of community-based programs and social supports with professional services.

SYSTEMS NAVIGATION

It is critically important that individuals seeking screening, diagnostic, or intervention services are able to efficiently navigate the healthcare system to obtain these services. This task is often made more difficult by differences in insurance coverage for various services, inadequate linkages between systems, and a lack of clear instructions to guide individuals and family members through an exceedingly complex process. Currently, families must navigate different service sectors in terms of information, provision, and funding (e.g., medical providers, local government, education), sometimes within a very short period of time to avoid age eligibility cutoffs.

The different service sectors are not always well-coordinated and may not communicate with each other, particularly across healthcare and social service agencies. Systematic barriers for families include considerable differences in the type and amount of services supported by insurance plans, geographic differences in type and amount of services available, and inequities and disparities existing across counties and states. Eligibility criteria and the lead agency for early intervention vary by state (health agencies in some states, and child welfare or education agencies in other states). Similarly, some states or regions have

more comprehensive insurance coverage and/or more coordinated systems of healthcare than others.

Several studies have highlighted the benefits of systems navigation, which assists individuals and their families with accessing and coordinating diagnostic and intervention services. In one study, core components of the Family Navigation model were identified that were essential to families seeking autism services.[90] Importantly, use of this model was shown to reduce racial and ethnic disparities in the length of time to diagnostic evaluation.[91] Coordination of a care team that includes healthcare, educational, and/or childcare providers is critical to address gaps in screening, begin to break down barriers for families to act on screening results, and support family engagement in age-appropriate intervention services over time. In the future, it will be important to expand the availability of systems navigators, particularly those who specialize in assisting older autistic children, adolescents, and adults. It may be particularly beneficial for autistic individuals who have had success navigating these systems to serve as peer navigators or mentors to others who are earlier in the process. For example, autistic adults may be efficient navigators for autistic adolescents and their families.[92]

There are remaining systemic issues to be addressed in order to improve the screening and diagnosis process for all individuals. For example, some insurance plans do not cover quality interventions or may place limits on essential behavioral, medical, or other healthcare services and supports. One study found that nearly half of children diagnosed with ASD have private insurance; most others have public insurance provided by Medicaid or the state-based **Children's Health Insurance Program (CHIP)**, or dual private and public coverage.[93] However, over one-third of families of children with ASD report that their insurance coverage is inadequate to meet their complex needs and costs. As noted earlier, reimbursement for ASD

screening may improve screening rates and more readily become a standard procedure in practices.

In addition, systems do not take into account families' concerns about stigma, the reluctance of professionals to make a diagnosis or share concerns about traits of ASD in very young children, missed or false positive diagnoses, and the need for earlier evaluations and re-evaluations of very early assessments as traits of autism appear. It is critically important for researchers and service providers to address these issues in order to improve accessibility and equity.

SUMMARY

Significant advances have been made toward early identification of individuals with ASD, so they can be linked to appropriate interventions, services, and supports in as timely a manner as possible. However, gaps still remain. There is a need to validate tools in diverse settings, particularly in community primary care practices in low-resource areas. There is a need to evaluate the effectiveness of universal screening for improving outcomes in autistic individuals. There is a great need to understand the disparities in access and/or utilization of screening and diagnostic tools, and entry into intervention services. In addition, research is needed to develop, adapt, and validate tools that will improve detection of autism in special populations, including children with intellectual disabilities, girls and women, racial/ethnic minorities, and adults. Critically, it is important to engage family members and caregivers so that they are able to identify potential traits of autism, address their concerns with their medical providers, and know how to navigate the screening, diagnostic, and intervention processes.

The challenges and barriers include gaps in the evidence base for the benefits of early detection in diverse populations and settings; an insufficient workforce with expertise in ASD diagnosis and intervention; the need for continued insurance reform; disparate and uncoordinated service sectors; and the lack of a data or administrative infrastructure to track children and families in order to evaluate the efficacy of service systems. There have been important strides in the area of early detection of autism and in demonstrating the impact of early intervention. Yet, there are significant challenges and barriers to implementing screening, diagnostic, and treatment services broadly and reducing disparities in access and utilization that must be addressed in the future.

RECOMMENDATIONS

RECOMMENDATION 1: Support research on how early detection of autism influences outcomes.

Examples:

- Implement innovative designs to evaluate the benefit of universal screening for autism.

- Conduct studies focusing on the differences and needs of underserved populations such as girls and women, racial and ethnic minorities, individuals with intellectual disabilities, and adults.

- Conduct research to better understand and develop strategies to address reasons for lack of compliance with screening recommendations and barriers to universal screening.

RECOMMENDATION 2: Reduce disparities in early detection and access to services.

Examples:

- Improve family engagement and help build an awareness of appropriate developmental milestones.

- Demonstrate the validity of different screening and diagnostic tools for culturally diverse communities.

- Increase services in underserved and low-resourced regions; improve inclusion of these populations in research.

- Address differences in state policy requirements for Medicaid and the requirement of a diagnosis to receive services.

- Develop a culturally competent and more culturally diverse services workforce.

RECOMMENDATION 3: Develop and adapt screening and diagnostic tools, including tools that incorporate new technologies to increase efficiency, accuracy, and timeliness of identification.

Examples:

- Continue research on the potential translation of biomarker findings into valid, reliable, and cost-effective screening or diagnostic tools.

- Increase coordination and personalization of screening, diagnosis, and early intervention services through use of the medical home model, person-centered planning, or other service models.

- Evaluate innovative service delivery methods (e.g., use of telehealth and other technologies) to improve detection methods and increase access.

WHAT IS THE BIOLOGY UNDERLYING AUTISM?

BIOLOGY

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.**

INTRODUCTION

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 few decades, research has revealed that genes and environmental influences in early development are contributing factors. The biological mechanisms by which known gene variations may lead to autism by altering the underlying neural circuitry of the brain are areas of active investigation. These genetic variants are associated with several general functions in neurons (brain cells), including regulating when and how genes are expressed and the function of synapses, which are the points of connection and communication between neurons.

However, much remains to be learned about the specific biological mechanisms that lead to autism and differences in cognition (including facial processing and emotion regulation), language development and communication, motor development, and sensory processing. Research is needed to understand how biological differences lead to observed behaviors and how autistic individuals experience the world. More research is also needed to better understand how sex and gender impact the presentation of autism. Additionally, studies on the relationship of common co-occurring mental and physical health conditions, intellectual disability, and autism are also needed, as are longitudinal studies to better understand the developmental trajectories of autism and co-occurring conditions. Greater insight and understanding of these molecular, neurological, and developmental differences will allow for personalized, targeted interventions that can promote positive outcomes for all individuals on the autism spectrum across the lifespan.

MOLECULAR MECHANISMS AND GENES IMPLICATED IN AUTISM

Genetic studies over the past 20 years have identified over 100 genes that contribute to the development of autism, though many of these genes also are implicated in other mental health and developmental conditions.[1-3] This number is growing rapidly, and it is likely that over 1,000 genes that make smaller contributions to the development of autism will also be identified in the future.[2-14] At present, the known functions of some of these genes converge on biological processes that are important for neurogenesis (the development of neurons) and synapse formation and function. However, much more remains to be learned about the molecular mechanisms that may lead to observable characteristics of autism.

The discovery of genetic variants that cause single-gene disorders that often have autism as one component (such as tuberous sclerosis complex, Rett syndrome, Fragile X syndrome, and Phelan McDermid syndrome) and the large number of rare spontaneous or *de novo* mutations that contribute to autism have enabled scientists to explore the biological effects of specific molecular pathways in cellular and animal model experiments. This has led to rapid growth in research toward understanding how these variants alter the biology of cells and impact neural circuitry and behavior. One of the challenges of cellular and animal model research, however, is that sometimes model systems cannot fully replicate the complexity of cognitive or behavioral characteristics observed in humans.

The ability to take skin or blood cells from people on the autism spectrum, create induced pluripotent stem cells (iPSCs), and differentiate these cells into neurons has enabled advances in the study of neural function at the cellular level in various health conditions, including autism. This technology allows scientists to compare how iPSCs derived from autistic individuals differ from those derived from neurotypical individuals on the cellular and molecular level,[15, 16] as well as to compare differences between cells derived from animal models with introduced autism-related genes (transgenic animal models) and those without any genetic alterations.[17] As CRISPR gene editing technology continues to advance, more high-throughput pooled CRISPR screens[18, 19] will also be possible as a means of identifying and validating the relevance of genetic variants to autism. While patient-derived iPSCs are creating new opportunities in autism genetic research, small sample sizes, and variability and genetic heterogeneity of derived cells remain challenges in this research. To date, it has been easier to interpret results in iPSCs derived from patients with autism related to known genetic causes. Identifying cellular phenotypes among iPSCs derived from individuals whose autism does not have a known cause has been more challenging. Larger sample sizes and better powered analyses may be helpful in overcoming these limitations.

iPSCs also make it possible to grow brain organoids, which are clumps of brain tissue partially organized to have some features of the human brain. These partially matured "mini-brains" can be grown in a laboratory and can be used to enable the study of the early development of brain structures that occurs *in utero*, as well as the cellular and neural circuit abnormalities related to autism-linked variants.[20-24] However, careful attention needs to be given to ensuring that variables related to cell-culture conditions do not affect the reproducibility of results.

Brain organoids and iPSCs cannot replace careful studies of postmortem tissues, which have been used to successfully identify differences in structure and gene expression in brains of autistic individuals compared to neurotypical brains.[25-27] Future advances in single-cell RNA sequencing technology will allow for better characterization of these altered patterns of gene expression in specific brain cell types, offering the opportunity to precisely associate gene expression differences at a cellular level.[28] However, the number of available postmortem samples is limited, with a heterogeneous mix of characteristics, including sex, age, and medical history, making high-powered statistical analyses difficult. Therefore, efforts are still needed to increase the accessibility and diversity of brain tissue for autism research. Collaborations such as the **Autism BrainNet**, the **Hispano-American Brain Bank of Neurodevelopmental Disorders (CENE)**, and the National Institutes of Health (NIH) **NeuroBioBank** facilitates the distribution of high-quality, well-characterized human postmortem brain tissue for the research community. Enhancing efforts to increase public awareness about the value of tissue donation for understanding autism will most effectively advance research on the biological mechanisms of autism. Additionally, performing analyses in addition to sequencing and storing samples

to be used in the future as better technology becomes available can also advance our understanding of autism biology.

Another remaining challenge is to understand how the effects of hundreds of implicated genes converge to create the common features of autism. In addition to examining rare variants that lead to high likelihood of developing autism, studying more common gene variants that contribute to the development of autism to a lesser degree may highlight previously undetected gene networks and molecular pathways. Studies of multiple genes in parallel and more complete data about relationships between genes and gene function can also help identify additional connections. Conversely, the autism genes identified so far often play multiple roles within a cell and organism. This presents a major challenge in translating the discovery of an autism-related gene to viable intervention options, as medications targeting such genes can result in unwanted side effects. A better understanding of human brain development will provide valuable information on where and when to look for autism-related biological changes, which can advance needed research to determine how individual genes and their interactions in early life events explain the biological basis of the heterogeneity of autism features.

STRUCTURE AND FUNCTION OF BRAIN CIRCUITS IN AUTISM

Autism is characterized by atypical patterns in physical brain connections (structure) and communication within and between brain regions (function). Brain structure in individuals with autism can be compared to typically developing children using advanced magnetic resonance imaging (MRI) techniques to measure the size and shape

of brain regions over time, as well as diffusion tensor imaging (DTI) to examine the structures of the major connections between brain regions. Brain circuit function can be investigated using non-invasive technologies, such as functional magnetic resonance imaging (fMRI), magnetoencephalography (MEG), electroencephalography

(EEG), and functional near-infrared spectroscopy (fNIRS) to image the brain or detect changes in brain activity. These techniques have revealed neurological differences in cognition, executive functioning, sensory processing, social communication, and language development in autism.[29-31]

Despite a large body of work, challenges remain in fully understanding the neurobiology of autism. Current brain imaging studies often report conflicting results and suffer from reproducibility issues. The heterogeneous nature of autism and technical limitations of the techniques used means large sample sizes and careful statistical analyses are often necessary to obtain truly representative and accurate results. Large collaborations and consortiums can help to increase sample size and improve rigor and reproducibility.[32-35] In addition, females on the autism spectrum, individuals of racial and ethnic minorities, minimally speaking individuals, and individuals with higher support needs are often underrepresented in brain imaging studies. Increasing the diversity of study participants will improve the data quality of brain imaging studies and produce results that are relevant to a broader cross-section of the autism community.

New technologies can also help to overcome some of the logistical issues associated with many brain imaging techniques. For example, MRI scans require the patient to be completely still in a confined and noisy environment, which may present sensory or other issues for many on the autism spectrum and is not representative of real-world environments. Alternatives such as high-density diffuse optical tomography (HD-DOT) are better tolerated, portable, and allow for high-density measurements in more naturalistic settings.[36, 37] Use of these techniques and developing advances to overcome tolerance and sensory issues can improve data quality in brain imaging studies.

Imaging and electrophysiology studies in model animals such as mice have provided invaluable information on the neurobiological and molecular basis of autism. As discussed in the previous section, however, because autism impacts uniquely human aspects of social-communicative behavior (such as spoken language), developing and measuring analogous phenotypes in animals has proven difficult. In addition, because autism impacts brain regions not developed in some animal species, some neural circuitry is not readily amenable to study in model organisms. Therefore, human neuroimaging studies remain critical to understanding how autism impacts brain function and structure.

Lastly, in addition to characterizing how autistic brains differ from neurotypical brains in terms of structure and function, it is important to also ask which of these differences contribute to autism phenotypes and characteristics and which are simply correlations. For example, a recent review suggested that despite a correlation of between differences in functional connectivity in regions of the brain that support complex social interactions and the severity of social symptoms, more data are needed to determine whether connectivity differences cause the observed social challenges.[38] Teasing out these causal relationships by examining brain dynamics in the context of different tasks and situations can be helpful in developing interventions to reduce the cognitive and social difficulties associated with autism.

SENSORY AND MOTOR DIFFERENCES

Historically, cognitive, social, and behavioral differences have been characterized as the core features of autism. Recent studies have suggested, however, that differences in the sensory and motor nervous systems may play a less recognized but significant role in autism and may represent important opportunities for intervention and improvement of quality of life. The vast majority of individuals on the autism spectrum experience hypo- or hyper-sensory abnormalities, which may have negative impacts on cognitive performance,[39] social interactions and communication,[40, 41] and stress.[42, 43] The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) includes sensory characteristics as a diagnostic criterion for autism, highlighting the frequency with which autistic individuals experience sensory difficulties. These sensory difficulties occur across the core sensory systems, including visual, auditory, gustatory, olfactory, tactile (touch and pain), vestibular, and proprioceptive (sense of self-movement and body position) systems, and the severity and impact of these differences vary from person to person.[44, 45] Extensive research in this area in recent years has led to a better understanding of the neurobiological differences within the central nervous system that lead to hypo- or hyper-sensitivity.[46-51]

However, more work can be done to explore how differences in peripheral nerves and organs such as the eye, nose, mouth, ear, and skin can contribute to sensory differences. Additionally, multiple stimuli can activate different sensory systems simultaneously and may lead to cognitive, social, and behavioral challenges. Research in mice has provided some information on the neurobiological mechanisms that lead to multisensory dysfunction in autism.[52] It will be important for future research to determine whether these findings are translatable to humans and develop interventions to improve the sensory experiences of individuals on the autism spectrum. Additionally, sensory challenges occur in a heterogeneous manner across the autism spectrum and across the lifespan.[53-57] Future research should continue to investigate differences in sensory processing in different subgroups of autistic individuals and how these change across the lifespan; this will enable the development of more customizable interventions that can meet the sensory needs of individuals of all ages across the autism spectrum.

Differences in motor development and function are also common in individuals on the autism spectrum, though not currently recognized among the core features of autism.[58] Motor skills that have been reported to show differences in autism include both fine and gross motor skills such as gait, manual dexterity, postural control, motor learning, and motor imitation. Motor differences in infancy, such as delayed postural motor skills, can often be detected prior to and often correlate with later development of differences in social skills.[59-63] Studies have also identified motor differences in autism in adulthood.[64] Currently, it is not clear what neurobiological mechanisms drive atypical motor development and how that may manifest across the lifespan and contribute to other aspects of autism. Research is needed to gain a better understanding of differences in motor development and expand the overall clinical understanding of autism. This has the potential to serve as the basis for new strategies to identify autism in early infancy or in adulthood, as well as develop interventions to improve motor skills at all ages and thus improve quality of life.

COGNITION, INTELLECTUAL DISABILITY, AND COMMUNICATION CHALLENGES

According to data from the CDC, approximately one-third of autistic children have an intellectual disability, as defined by a score below 70 on a child's most recent IQ test. This population is among those who have the most intensive support needs within the autism community and often need long term services and supports.[65] Autistic individuals with intellectual disability are at increased risk for co-occurring conditions such as aggression and self-injurious behaviors. Many autistic individuals with intellectual disabilities also have a language disability, creating additional challenges. In spite of the significant needs of autistic individuals with intellectual disability, they are underrepresented in autism research due to traditional research exclusions created to prevent confounding variables in studies and the challenges that may be associated with working with subjects with difficulties communicating or complying with research protocols.[66]

More research is needed to develop improved methods to assess intellectual disabilities in individuals with autism, and better understand the causes of intellectual disability within autism, the intersection of symptoms of autism and intellectual disability, and the similarities and differences between intellectual disability in autism and intellectual disability in other populations.[67-69] It will also be critical to explore the potential of and optimal modalities for individuals with autism and intellectual disabilities to learn and acquire new skills across the lifespan,[70] and how to best support the needs of this population. To make strides in this area, efforts to include this population in research studies are needed, as well as studies focused on this population specifically, and efforts to learn from research done in the broader intellectual disability community.

Autism diagnosis is characterized by restricted, repetitive behavior and social and communication challenges. Therefore, cognitive studies of psychological and mental processes, including memory, language production and comprehension, executive function, problem solving, decision making, and social communication, are vitally important for understanding the biology of autism. As discussed in the previous section, research has recently highlighted the role of sensory processing in cognitive function and social communication, with multiple studies exploring how eye gaze and movement impacts facial recognition and social interactions.[71-73] In addition, researchers are now beginning to understand the neuronal activities that occur following verbal stimuli and conversation and during speech processing.[74-76] The role of the cerebellum and other areas of the "social brain" (including the prefrontal cortex, amygdala, hippocampus, and limbic system) in cognition and social function has also been intensely studied.[77, 78] An understanding of how differences in executive functioning affect restricted, repetitive behavior and other cognitive difficulties is beginning to emerge, with an imbalance in neural excitation and inhibition being a leading hypothesis.[79, 80]

Some individuals on the autism spectrum have difficulties producing verbal language; these can occur in the presence or absence of intellectual disability. A recent study has demonstrated that differences in vocalizations can be detected as early as 12 months.[81] While some individuals with delayed language eventually catch up to their neurotypical peers, up to 30% remain non-speaking or minimally speaking.[82] Difficulty with spoken language may hinder ASD diagnostic tests and other evaluations of

abilities,[83] which may in turn hinder qualification for and provision of services. In addition, individuals with limited spoken language often experience more challenges in education, daily living, relationships, and community integration. Thus, advances that can lead toward improvement of either spoken language or alternative forms of communication have a high potential for increasing positive outcomes.

Researchers have identified several differences in the structure and connectivity of language-controlling region in the brains of autistic individuals.[84, 85] Identifying biomarkers that predict language development may be a strategy to direct autistic children to appropriate interventions during critical developmental windows.[86] In particular, quantity and quality of parental language, as well as frequency of parental gestures, are both positively associated with language outcomes in autistic children.[87, 88] In many cases, minimally speaking autistic individuals have motor difficulties that limit speech, rather than cognitive difficulties.[89] Use of alternative and augmentative communication (AAC) methods may be especially beneficial in providing a means for these individuals to communicate effectively with others (discussed further in Chapter 4). It is important to identify biomarkers and develop evaluation tools that can effectively characterize the level of communicative ability in all autistic individuals, including those who are minimally speaking.

Much remains to be explored about the neurobiology underlying differences in cognition and social communication. While some regions of the brain have been definitively shown to be altered and play a role in autism, the heterogeneity of cognitive and social phenotypes make it difficult to pinpoint the neuronal and molecular changes that cause cognitive impairments. More studies, potentially in model systems, are needed to better understand the exact nature of neurobiological differences that occur in autism. This knowledge will allow for the development of biomarkers for cognitive processes such as memory and problem solving to better identify how and what interventions may help individuals on the autism spectrum. Additionally, complex cognitive processes likely require communication between multiple brain regions, and studies of the brain at the systems level can lead to a more holistic understanding of brain networks and connections. Information at the connectome-level (pertaining to the wiring and connectivity of the nervous system) may allow for better predictions of cognitive and social communication outcomes in autistic individuals. It will also be important to study how cognition, social communication, and behaviors may change over time to better support individuals on the autism spectrum throughout the lifespan. In particular, research on cognitive and social adaptations of individuals on the autism spectrum can help lead to interventions that promote resilience and maximize positive outcomes.[90]

IMMUNE SYSTEM AND AUTISM DEVELOPMENT

Current evidence suggests immune differences and neuroinflammation are implicated in the severity and pathogenesis of the autism phenotype.[91] For example, recent meta-analyses found higher concentrations of pro-inflammatory cytokine molecules in individuals on the autism spectrum compared to the control group[92] and a subset of immune-related genes were significantly associated with autistic traits.[93] Despite many studies demonstrating altered levels of immune biomarkers and abnormal immune function in both the peripheral and central nervous system in autism, it is still not clear whether the immune system plays a direct role in autism development via alteration of neurodevelopmental processes.

Several recent studies suggest that maternal immunological factors may play a role in the development of autism during gestation. Maternal infection and fever, autoimmune disease, asthma, and obesity are all associated with autism development in the offspring.[91, 94] However, these results are largely based on data from peripheral blood, which may not be representative of changes that occur in the brain. Therefore, future research will need to answer whether the immunological changes observed cause differences during neurodevelopment or whether differences in neurodevelopment change the function and activity of the immune system.

Microglia are immune cells that reside in the central nervous system and are activated as part of the defensive response to infection or inflammation. Even in their so-called resting state, they are essential for maintaining neuron function the central nervous system.[95] Microglial activation has been linked to altered brain connectivity in children on the autism spectrum, and pro-inflammatory cytokines and microglial phenotypes are also seen in autistic individuals.[91] Further investigation of the role of microglia are warranted based on our emerging understanding of their role in typical neurodevelopment and potential contribution to autism phenotypes. In addition, more studies are needed to identify the roles of molecules secreted by immune cells on brain development and function.

SEX AND GENDER DIFFERENCES

The most recent epidemiological data in the United States suggests that autism is about 4 times as prevalent in boys and men as compared to girls and women.[96, 97] Additionally, autism is more prevalent in gender-diverse individuals compared to cis-gendered individuals.[98, 99] While it has been a topic of recent research studies, relatively little is known about the biological mechanisms that contribute to sex and gender differences. Further work is needed to understand the phenotypic differences between males, females, and gender diverse individuals on the autism spectrum and how these differences should inform the development of screening and diagnostic tools, interventions, and services that meet the needs of all autistic individuals, regardless of sex and gender.

One hypothesis for the male to female autism diagnosis ratio is the existence of the female protective effect (FPE), which posits that females would require a greater

accumulation of autism-related genetic differences to reach the diagnostic threshold. Sequencing and genetic data appear to support this hypothesis, with autistic females carrying higher average numbers of rare *de novo* mutations compared to their male counterparts,[1, 2, 100] and common and rare variants of autism genes are enriched in mothers and unaffected sisters of autistic individuals.[1, 2, 101] However, results from family- and inheritance-based studies are more conflicting. Some studies show that siblings of autistic females were more likely to receive an autism diagnosis compared to siblings of males on the autism spectrum,[102] while other results show that the relative risk of autism between maternal and paternal lineage is similar, indicating that FPE is likely not the primary mechanism for the sex differences found in autism prevalence.[103] Additional studies are needed to determine whether the FPE exists and the extent to which such an effect contributes to the sex differences seen in autism diagnosis.

Finally, more studies are needed to investigate the neurological sex differences that occur downstream of the genetic and molecular variances. Recent functional connectivity studies found sex differences in several brain regions which play key roles in sensorimotor, cognitive, and socio-affective processes.[104, 105] Additionally, brain structure and anatomy also differ between males and females.[106, 107]

A recent neurogenetic analysis found that autistic females had a larger number of genetic variants in autism-implicated genes than autistic males.[108] However, these studies investigating sex- and gender-influenced differences in autism neuroanatomy and genetics of remain rare and are often limited by small sample sizes. More research is needed to better understand how differences in genetics, brain functioning, and brain structure can lead to the sex differences seen in autism presentation and outcomes.

In addition to biological theories of sex differences, ascertainment bias is another theory about why more boys are diagnosed with autism (discussed in more detail in Chapter 1). Girls and women with autism are also often diagnosed later than autistic males and not well-represented in research studies, and research to explore the relationship between gender identity and autism development and outcomes is just beginning. Better understanding of the genetic, molecular, and neurobiological differences between males and females and cis-gendered and gender-diverse individuals on the autism spectrum can lead to the development of more accurate biomarkers and diagnostic tools, as well as more appropriate interventions and services to maximize the quality of life for individuals of all genders and sexes on the autism spectrum.

LONGITUDINAL STUDIES

Autism is a developmental disorder, and life outcomes are extremely heterogeneous. While longitudinal studies conducted so far have shown that autism diagnoses at 14 months of age are stable,[109] the strengths, challenges, and support needs associated with autism change over time.[56, 57, 110-112] Longitudinal studies have shown correlations between motor skills and later development of autism and language,[113, 114] as well as associations between autism

symptoms and sleep problems.[115] Studies have also shed light on how differences and changes in the brain over time correlate with different subgroups and mental and physical health outcomes.[116-119] However, much remains to be learned about differences in developmental trajectory and what biological factors and interventions determine better life outcomes for individuals on the autism spectrum.

The brain connectivity changes that underlie autism are not static; they are dynamic during early brain development and continue to change over the lifespan of the individual. Therefore, understanding the biology of autism requires large longitudinal studies to chart the trajectory of neural circuits over time, including how they adapt to inborn differences in wiring and environmental exposures. Studies are needed that include pregnancy and follow maternal exposures and response, fetal development, and brain response to events that occur during pregnancy and perinatally. More longitudinal studies that gather brain imaging data from the same set of subjects repeated over an extended study period are also needed to enhance our understanding of brain development. Furthermore, advances in human imaging technology and longitudinal study designs may provide an opportunity to better distinguish true causes from consequences of specific

findings by making it possible to image brain tissue in live subjects throughout the lifespan. These kinds of studies will require standardized acquisition parameters to enable comparability across studies, and robust data sharing policies should be in place to enable expert analysis of the data by a variety of scientists. Finally, large, organized longitudinal studies across the lifespan are needed to better understand the biology, developmental trajectories, and natural history of autism, from prenatal development to early childhood and through adulthood to older adulthood. In addition, longitudinal studies of adults that extend into older adulthood will be needed to better understand the health and service needs of older autistic adults. These studies are critical to identify the biological variables that can help autistic individuals maximize their strengths and receive the interventions, services, and supports they need to overcome challenges throughout the lifespan.

CO-OCCURRING CONDITIONS

Autism is associated with a wide range of co-occurring conditions that decrease quality of life for autistic individuals. Progress has been made in recent years to better understand the prevalence and underlying biology of conditions that commonly co-occur with autism, including gastrointestinal (GI) conditions, epilepsy, sleep disorders, and psychiatric disorders. However, more research is needed on the underlying causes of these co-occurring conditions and the biological interactions with autism to facilitate interventions that can improve the health and well-being of individuals on the autism spectrum.

GASTROINTESTINAL CONDITIONS

GI symptoms and an inflammatory mucosal pathology has been demonstrated in several studies of autism. Autistic

children are more likely to experience GI symptoms compared to typically developing children or children with other developmental disabilities.[120] GI symptoms lower quality of life and can cause discomfort, distress, and pain. The presence of GI symptoms has been associated with loss of skills and language and communication ability, self-injurious behavior and aggression, sleep problems, and sensory issues.[120] It is common for individuals on the autism spectrum to eat a restricted diet, and studies have shown that the dietary patterns of autistic children differ from that of typically developing children.[121] It is unclear the extent to which this contributes to the development of GI symptoms or if the GI symptoms themselves lead to a more restricted diet. Additionally, while GI symptoms were not found to vary with age and were stable over time,[120] it is unclear if gender and sex play a role in number and severity of GI symptoms experienced and what roles sex

hormones may play in the process. Most surveys also rely on parents to report symptoms, which may lead to inaccuracies. Improvement and standardization of study tools such as questionnaires and surveys are needed to obtain more accurate results that can be compared across studies.

The role of the gut-brain axis and the microbiome in neurophysiology has been under intense study in recent years. The microbiome within the gut plays important roles not only in gut health and metabolism but also in immune activation and neuromodulation.[122] Given the prevalence of GI co-morbidities in autistic individuals, it is hypothesized that the microbiome may play a role in autism development, and studies of fecal DNA have found certain bacterial types overrepresented in children on the autism spectrum compared to neurotypical children.[122] Additionally, some studies have found interventions designed to normalize the gut microbiome improved both GI and autism symptoms.[123-125] However, a recent metagenomics study did not find any association between autism and the gut microbiome,[126] instead positing that the differences in microbiome may be due to dietary preferences. Other recent work has suggested the possibility that gut issues in autism may be linked to differences in the gut neurons.[127] Therefore, more work is still needed to determine the role of the gut-brain axis in autism development.

EPILEPSY

Researchers estimate that epilepsy occurs in 5-46% of individuals on the autism spectrum, and approximately 30% of children with epilepsy also have autism.[128] Studies have shown that many of the genetic factors for epilepsy and autism overlap,[128, 129] suggesting that autism and epilepsy may share a common etiology. In addition, differences in EEG patterns and perturbations in the neuronal excitatory/inhibitory equilibrium are seen in both epilepsy and autism.[130] Despite these connections, it is unclear what the causal relationship is between autism and epilepsy.

For example, epilepsy could be a causal factor in autism development, or the neurodevelopmental differences that lead to autism could contribute to the occurrence of epileptic seizures. Alternatively, epilepsy and autism may occur on a developmental spectrum in which the specific outcome depends upon other factors. A better understanding of the biological underpinnings of both epilepsy and autism and the relationship between the two will lead to more targeted and effective medical interventions that improve the health and well-being of individuals on the autism spectrum who have co-occurring epilepsy.

SLEEP DISORDERS

Autism is frequently accompanied by a variety of sleep problems that cause worsened challenging and self-injurious behaviors, anxiety, hyperactivity, and inattention during the daytime.[131] Studies indicate the prevalence of sleep problems in autism are as high as 50-80%, with initiating and maintaining sleep being one of the most common co-occurring clinical disorders.[132, 133] Several neurotransmitters, including serotonin, melatonin, and gamma-aminobutyric acid (GABA) play vital roles in the maintenance of sleep-wake cycles, and abnormal levels of these neurotransmitters have been described in autism. Model animals have improved our understanding of how genetic changes that lead to autism may also cause sleep disturbances.[134] In the future, it will be important to explore if genes that regulate sleep may also contribute to autism development. Additionally, more research is needed on how confounding variables such as potential sensory issues and GI symptoms may be contributing to disrupted sleep to better design interventions that improve sleep quality.

SELF-INJURIOUS AND AGGRESSIVE BEHAVIORS

Several studies have estimated that up to half of all individuals on the autism spectrum display self-injurious behavior (SIB) and/or challenging behaviors such as

aggression at some point in their lifetime; these behaviors are more common in individuals with intellectual disability and/or communication challenges.[135-140] These behaviors often cause substantial difficulties for autistic individuals, their families, and other caregivers, including significant physical injury, stress and trauma, and property damage. The triggers for these behaviors in any given individual are not always well-understood or observable to caregivers, and their presentation and duration are often unpredictable.

Aggressive behavior and SIB may be due to emotional dysregulation, responses to sensory hyper- or hypostimulation, frustration with limited communication or other adaptive skills, or other co-occurring conditions such as GI distress or sleep problems.[138, 141, 142] The exact mechanisms for these behaviors in autism are not fully understood, but a recent study has indicated that common brain circuitry involved in emotion, motivation, cognitive processing, and decision making may be involved.[143] Anti-psychotic medications are the most common treatments, but continuing research to better understand the underlying causes so that next generation approaches can be developed is needed.[144, 145] The inherent challenges presented by SIB and other challenging behaviors have traditionally made it difficult to include individuals presenting these behaviors in research studies. However, it is critical to increase understanding of these behaviors so that underlying issues can be appropriately addressed and behaviors that are potentially harmful to autistic people and their families and caregivers can be alleviated.

MENTAL HEALTH AND PSYCHIATRIC CONDITIONS

It has been estimated that approximately 70% of people on the autism spectrum have one or more co-occurring psychiatric disorder.[146] The most common of these conditions are anxiety and mood disorders, obsessive compulsive disorder (OCD), ADHD, and oppositional defiant disorder. In addition, depression, bipolar disorder,

schizophrenia, eating disorders, and suicidal ideation and death by suicide have been reported at higher rates in individuals on the autism spectrum compared to the general population. Recent studies have also noted that autism is associated with an increased vulnerability for substance use disorders.[147-150] Many autistic individuals may simultaneously experience multiple co-occurring conditions.

Current research indicates that these co-occurring conditions may share common genetic, epigenetic, and neurological variations.[151-154] However, additional research is needed to establish clear causal links. In addition, research is needed to better characterize the manifestation of these mental health conditions in the context of autism and vice versa to develop improved diagnostic tools and interventions to treat co-occurring conditions, in particular depression and suicide. Studies on co-occurring mental health conditions should also explore the role of sex and gender, intellectual ability, and age to determine if these factors mediate the severity of symptoms and provide more information on what interventions may be most appropriate for people of all genders and abilities across the lifespan.

Individual, intergenerational, and historical trauma also needs to be considered in mental health research of autistic individuals. Current data indicates that adverse childhood experiences (ACEs) are associated with autism;[155] caregivers of autistic youth also experienced higher rates of ACEs compared to caregivers of non-autistic youth.[156] Brain imaging studies indicate that ACEs may lead to changes in neurological functioning, some of which are already known to be associated with autism.[157-159] ACEs and other traumatic experiences greatly impact mental and emotional well-being, leading to suicidal ideation and emotional distress and impacting development into adulthood.[160] More research is needed with larger studies to understand how different traumas may differently affect diverse individuals and the differences in how acute versus chronic trauma impacts life outcomes for individuals on

the autism spectrum. Research is also needed on resilience factors, which may include places of refuge and identity,[160] that may protect individuals from the effects of adverse experiences to better develop interventions that can improve health and well-being.

EHLERS-DANLOS SYNDROMES AND DYSAUTONOMIA

Ehlers-Danlos syndromes (EDS) are a group of disorders characterized by hypermobility of the joints, skin hyperflexibility, and tissue fragility. EDS patients report chronic pain, fatigue, social withdrawal, and anxiety in their daily life.[161] Co-occurrence of EDS and autism has been described in the literature since the 1980s.[162] More recent studies have shown that children on the autism spectrum have greater joint flexibility compared to age- and gender-matched peers,[163] and generalized joint hypermobility and EDS are associated with both autism and ADHD.[164-166] Many co-occurring conditions are also shared in both autism and EDS.[167] However, it is unclear what the exact connection is between EDS and autism and if they share common genetic factors. More research

is needed on the biological mechanisms and interactions of EDS and autism to facilitate interventions for both conditions that can improve health and well-being.

Dysautonomia is caused by dysfunction of the autonomic nervous system, which regulates nonvoluntary bodily functions such as heart rate, blood pressure, breathing, digestion, and perspiration. Symptoms of dysautonomia are varied and can include nausea and vomiting, balance problems, dizziness, weakness, and visual disturbances. Postural orthostatic tachycardia syndrome or POTS is a form of dysautonomia and is characterized by reduced blood volume upon standing leading to lightheadedness and fainting. Recent research indicates higher prevalence of dysautonomia in autistic and neurodivergent populations and strong associations with EDS.[168, 169] However, like with EDS, it is still unclear what the biological connection is between autism and dysautonomia. Research is needed to understand the mechanisms of dysautonomia and how the disorder may manifest differently in individuals on the autism spectrum to develop interventions that can alleviate symptoms and maximize quality of life.

RESEARCH POLICY ISSUES

A major challenge for the biological sciences is to utilize the most sophisticated technologies that produce ever-enlarging data sets while still ensuring the rigor and quality of research. Moving forward, the field should embrace policies that promote collaborations and enhance the reproducibility of findings and promote transparent reporting of experimental methods, use of common data elements, and sharing of data and analysis. Follow-up validation studies are a necessary part of this process, and data sharing should be integrated into the design of studies from the beginning. The **National Institute of Mental**

Health Data Archive (NDA) platform is a valuable repository for high-quality autism data, tools, and methodologies that researchers should leverage to enable re-analysis of data and facilitate collaboration to accelerate research progress.

Larger sequencing, brain imaging, and longitudinal studies require coordination among research centers and a shift toward team science across multiple disciplines. Large-scale science initiatives and collaborations such as the **Autism Biomarkers Consortium for Clinical Trials (ABC-CT)**, **SPARK**, the **All of Us Research Program**, and **ENIGMA**

can contribute greatly to our understanding of the biology underlying autism. The coordinated collection and analysis of valuable imaging, behavioral, genetic, and phenotypic data can also be enhanced by the recruitment of a research workforce that includes not only neuroscientists, immunologists, and psychiatrists, but also experts in bioinformatics, machine learning, and biomedical engineers. Planning of such initiatives, however, requires thoughtful consideration of the needs of autistic individuals and their families, particularly in terms of ensuring meaningful use of data and benefits for participants, and effort to make materials and protocols fully accessible and minimally burdensome.

Community-based participatory research and the inclusion of people across the autism spectrum and across the lifespan in research development, implementation, and dissemination is crucial to identifying practical applications for promoting positive outcomes for autistic individuals and their families. The inclusion of autistic people in research validates the unique lived experiences of individuals on the autism spectrum and empowers them to contribute to important research on autism. When planning studies with human subjects, researchers must ensure that the privacy of participants are safeguarded, and that the data is stored and shared in a secure manner. In addition, researchers must also make certain that participants know what data is being collected and how that data will be used. In longitudinal studies with participants who start as children, informed consent needs to be established as the participants age into adulthood. The results of the study should also be made available to all participants in an accessible and timely manner. The dignity, rights, and welfare of the participants should be kept in mind throughout the research process. Lastly, the inclusion of individuals of underrepresented minority groups as both researchers and study participants will lead to study findings that are more accurate, applicable, and representative of the entire autism community.

SUMMARY

Significant progress in understanding the biological basis of autism has been made, but considerable challenges remain. Though there is a desire to demonstrate the impact of interventions on brain function, fundamental research that will allow us to fully understand the importance of alterations in brain function and development is still needed. Basic science research on the underlying biology of autism continues to be critical to provide the foundation for translational advances that will lead to effective interventions to maximize positive outcomes for autistic individuals across the spectrum and across the lifespan.

RECOMMENDATIONS

RECOMMENDATION 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.

Examples:

- Identify neurological differences that occur in significant groups of individuals on the autism spectrum.

- Understand the differences in cognitive development and communication in individuals on the autism spectrum.

- Understand the role of the immune system and metabolic processes in autism.

- Understand how atypical sensory and motor functions arise and the role they play in autism.

RECOMMENDATION 2: Support research to understand the underlying biology of co-occurring conditions in autism and to understand the relationship of these conditions to autism.

Examples:

- Determine the molecular basis of epilepsy in autism.

- Determine how GI dysfunction impacts autism-related characteristics.

- Determine how sleep disorders impacts autism-related characteristics.

- Determine the relationship of co-occurring psychiatric conditions to autism and their impact on the health and well-being of people on the autism spectrum.

- Elucidate the underlying causes of self-injurious, aggressive, and other challenging behaviors in autism.

RECOMMENDATION 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.

Examples:

- Support the creation of large and diverse cohorts, characterized both phenotypically and genetically through the collection of autism-relevant exposure data and medical data on the autistic person and family members from the prenatal period through childhood, adolescence, adulthood, and older adulthood.

- Support research on how the neurobiology of autistic individuals change throughout the lifespan and into 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.**

INTRODUCTION

Over the past decade, there have been substantial advances in the understanding of factors that contribute to the development of autism and 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 markedly 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 goes beyond the core characteristics of autism to include co-occurring physical and mental health conditions, intellectual disability, and communication difficulties that can cause varying levels of challenges.

There is a critical need to understand the causes of these co-occurring conditions and identify interventions that can improve outcomes.

The neurodiversity movement has influenced the autism community as a whole in recent years as well as the perceptions around autism genetics and environmental research specifically. Prevention of autism was a focus of scientific research in the 1990s and early 2000s, in line with the prevailing notion at the time that prevention of all disabilities was a goal in medicine. In more recent years, however, this idea has come into question, as appreciation of disabilities as a part of human diversity and a focus on disability rights have become more prominent, and there have been calls for the medical field to eliminate language that might stigmatize or devalue individuals with disabilities. Advocates have similarly voiced concerns about the goals of research to understand the causes of autism, with worries that such research could ultimately lead to eugenics or

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* The IACC has adopted a broad definition of studies on "environment" as encompassing research on all non-heritable influences.

otherwise stigmatize, devalue, or harm autistic people. The neurodiversity movement has fostered a new appreciation of the role and value of autistic and other neurodiverse people as an integral part of humanity and has called for a change from research to prevent autism to research to support the health and well-being of autistic people. Nevertheless, it is still critical to increase understanding of the factors that contribute to autistic traits, including those that significantly impair daily living and/or functional skills. Understanding the factors that may link autism and co-occurring physical and mental health conditions, delays in language development and communication challenges, and intellectual disability is also an important avenue of research.

The *IACC Strategic Plan* has reflected this shift from a focus on prevention to a focus on maximizing positive outcomes across the spectrum, including individuals with high support needs. Positive outcomes might be reached by identifying biomarkers that will improve screening and diagnosis to link individuals to services more efficiently and effectively. Understanding of contributing factors may also be helpful in developing personalized interventions to meet a variety of individual needs. This line of research can also provide more basic information on human development that will improve understanding of autism and other developmental disabilities. Overall, research on factors that contribute to autism and co-occurring conditions continues, while researchers and policymakers are increasingly cognizant of needs across the autism community.

GENETIC FACTORS

Studies of the human genome have significantly advanced the understanding of genetic factors that influence the development of autism. Similar to other common mental health conditions, the genetics of autism are complex, involving both common and rare forms of genetic variation.[1] Modifications in more than 100 genes are now known to increase the probability of an autism diagnosis.[2] However, it is important to note that it is unlikely that these genes are specific to autism; rather, they are believed to contribute to the core features of autism to varying degrees and, in many cases, are implicated in other genetic, psychiatric, or neurodevelopmental conditions.[3-5]

The types of genetic variations that are linked to autism are wide-ranging, including *de novo* (new, spontaneous, non-inherited) and inherited mutations. In 27% of individualson the autism spectrum, gene variants that result in disrupted proteins are contributing factors and are associated with co-occurring conditions, including intellectual disability, learning disabilities, and epilepsy.[6]

While some ASD diagnoses can be linked to a mutation in a single gene (syndromic autism), more often differences in multiple genes in the same individual (polygenic variation) contribute to the development of autism.[7, 8] Advances in sequencing methods have greatly accelerated progress in identifying genetic factors. A critical next step will be to integrate understanding of rare variants with large effects with more common polygenic factors to more accurately identify autism on an individual level.

Autism is highly heritable, with up to 60-90% of autism cases linked to known or unknown genetic factors.[9] Siblings of children with autism are 10-20 times more likely to receive an ASD diagnosis themselves than non-siblings.[10-13] Several studies of autism in twins have sought to estimate the relative influence of genes and the environment in autism.[14] Most of these studies have identified substantial contributions of both genetic and environmental factors, although the proportions of the two factors and interpretations of the results have varied substantially

across studies. A recent study found that while twins often shared an autism diagnosis, the characteristics vary from one twin to another, suggesting a significant influence of non-shared environmental factors.[15]

In some cases, specific genetic mutations have been linked with particular phenotypes, or outward characteristics. Using this knowledge to identify sub-phenotypes can prove helpful for establishing guidelines of care for clinicians. While major advances have been made through the understanding of how genes contribute to autism, there is still much to learn about the regulatory and other noncoding (non-gene) regions of the genome and the likelihood of developing autism. These regions of DNA that do not provide the code for a gene are sometimes areas that regulate how or when nearby genes are active, or they serve as signals for other activities within cells. Noncoding DNA regions may play roles in autism that have yet to be discovered.

GENETIC OVERLAP WITH CO-OCCURRING CONDITIONS AND INTELLECTUAL DISABILITY

Autism often co-occurs with other physical health conditions, including sleep disturbances, gastrointestinal issues, and epilepsy (see Chapter 2 for more details). According to the latest data from the Centers for Disesase Control and Prevention (CDC), co-occurring intellectual disability (ID) is observed in 37.9% of 8-year-olds on the autism spectrum.[16] Emerging research is beginning to identify genetic factors that may contribute to these conditions in autistic individuals. For example, researchers used large genetic databases to identify genetic variants in sleep regulation genes that are more prevalent in autistic individuals.[17] Epilepsy and traits of autism are also common in several neurodevelopmental disorders, such as Fragile X syndrome, Rett syndrome, tuberous sclerosis, and Phelan McDermid syndrome.[18-21] Several mental health conditions also co-occur frequently with autism. Neuropsychiatric disorders, developmental disabilities, and ID share many genetic factors,[22] and different combinations of genetic variants can lead to different conditions. In recent studies, researchers found significant genetic correlations between autism and several other traits and conditions including schizophrenia, major depression, and measures of cognitive ability such as educational attainment.[23] In the future, it will be important to further explore genetic commonalities between autism and co-occurring conditions in order to identify targets for interventions that will improve outcomes.

ENVIRONMENTAL FACTORS

In addition to genetics studies, research on potential environmental factors (i.e., all non-heritable factors) reflect the current understanding that multiple types of factors can influence autism and its co-occurring conditions. This includes studies of environmental exposures such as pesticides,[24] hormone-disrupting and other industrial chemicals,[25] air pollution,[26, 27] heavy metals,[28] as well as other factors, such as parental age,[29-31] maternal medications and diet,[32, 33] prenatal infection,[34] preterm birth or birth complications,[35] and time between pregnancies.[36] Some of these "environmental" factors might themselves be genetically influenced, while others might be mediating the effects of environmental exposures.

While the number of studies investigating the epidemiology of autism is increasing, most potential environmental factors have not been investigated sufficiently to draw firm conclusions.[37] The limitations inherent to observational studies mean that multiple studies in different populations and settings, with high-quality measures of exposure and adequate controls, are needed to reconcile disparate findings and establish robust linkages of an environmental

exposure to autism likelihood. The assumption that many different factors, each with modest effect, will contribute to autism means that epidemiological studies using large sample sizes may be needed to detect associations between autism or characteristics of interest with exposure, especially for those exposures that are in low doses or less common. In addition, more research is needed to understand the factors that may influence the impact of these exposures and to identify specific vulnerable periods during prenatal and/or postnatal development that are linked to autism, co-occurring conditions, and/or differences in characteristics and outcomes.

As linkages are revealed between exposures and specific characteristics of autism or its co-occurring conditions, public health strategies should be adjusted to help people avoid exposures that are linked to poor outcomes and increase modifiable factors that confer resilience or maximize positive outcomes. Additionally, improved understanding of what role environmental factors play in autism phenotypes (including risk for co-occurring conditions) may eventually inform strategies for identifying children in need of specific types of early intervention services.

EXPOSURE SCIENCE

One of the most significant obstacles facing epidemiologic studies of environmental contributors to autism is exposure assessment. In many studies, exposure measures are not readily available for very early developmental periods and rely on indirect methods (e.g., participant recall of prior exposures) or biological measurements using methodologies that are not always practical. Direct exposure assessment, such as through personal monitoring or use of an adequate time-course of exposure biomarkers, is expensive and burdensome for participants. Consequently, deep characterization of exposure during relevant time periods is typically limited to studies with small numbers of participants, yielding low power.

In response to these challenges, researchers are developing methods to examine the exposome, or the cumulative exposures experienced during an individual's lifespan.[38-40] This scientific approach is called "exposomics." In combination with other "omics" approaches, such as metabolomics (measurement of metabolism byproducts), researchers have been able to identify biomarkers associated with autism by analyzing and comparing hair, teeth, or blood serum of individuals with autism and typically developing controls.[28, 41-45] Similar to genomics, exposomic studies are well-suited to help understand interactions among multiple exposures and to uncover novel environmental factors. Advances in this field can also lead to development of personalized interventions. However, it will be important to address challenges in capturing and integrating many measures over time.

GENE-ENVIRONMENT INTERACTIONS

There is general agreement that both environment and genetics contribute to the development and trajectory of autism and its co-occurring conditions. Recent research studies have sought to identify gene-environment interactions[46] in order to understand how these multiple factors may influence each other and in turn influence neurodevelopment.[47] While many studies have made progress in understanding the interactions between one or a few genes and environmental factors, it will be critical in the future to integrate data on larger networks of genes and exposures.

Ideally, researchers could leverage existing datasets in order to undertake these studies. However, many large ASD genetic collections include minimal or no exposure information. On the other hand, studies focused on environmental factors often feature deep exposure assessment and have incorporated some genetic information, but smaller sample sizes limit the power of gene-environment interaction analyses. Therefore, a concerted effort is needed to enrich existing, ongoing autism studies by adding genetic data collection to environmental studies and exposure measures to genetic studies. Availability of low-burden exposure measures that can be incorporated in large-scale genetic studies is a high priority.

Increasing knowledge of genetics has led scientists to investigate gene pathways that affect neural circuits; it is unlikely that single genes act in isolation to contribute to autistic traits. Early studies have demonstrated the convergence of genetic influences and environmental factors in the activity of these different gene pathways, providing evidence that genes and the environment might work synergistically, rather than additively.[9] Studies that move beyond identification of genetic and environmental factors to reveal functional biological consequences associated with these factors are a priority. Epigenomics, metabolomics, transcriptomics, and proteomics can provide useful functional readouts for this purpose. Studies using model systems, such as human induced pluripotent stem cells (hiPSCs) and brain organoids generated from autistic individuals with a known genetic background, are also being used increasingly to study genetic and environmental contributors to autism.[48-50] Approaches that incorporate chemical screening and computational methods in these model systems to identify possible environmental exposures should also be priorities for future research.[51, 52]

EPIGENETICS

Identifying how a person's genes can influence how the body responds to exposures is critical for interpretation of autism-exposure associations. Regulation of gene expression (activity), commonly referred to as epigenetics, is a key component in the response to genetic variation and environmental exposures.[53, 54] Epigenetic mechanisms involve molecules that can alter the activity of genes within a person's DNA, either enhancing activity, silencing the gene, or changing the kind of protein that results from the gene's activity. Those regulatory molecules can be influenced by stimuli from the environment, such as chemicals, hormones, light, and nutrients. Changes in the activity of regulatory molecules in response to the environment provides a way for the environment to influence gene activity.

Multiple lines of evidence implicate epigenetic changes in development of autism, and several known genetic syndromes that often result in autism, such as Fragile X and Angelman syndrome, have established epigenetic alterations. A recent study has characterized how epigenetics influence patterns of variation in autism and other mental health conditions.[55] Results from rare-variant ASD genetic discoveries point to the remodeling of DNA as a shared pathway in autism genetics. Additionally, a significant body of work demonstrates that environmental chemicals can alter epigenetic factors, and these alterations have been linked to changes in gene expression and a range of behavioral phenotypes.[56-58]

Autism research that integrates epigenetic, exposure, and phenotype data in the same population are a priority. Studies that identify exposure-induced impacts on a full range of epigenomic mechanisms and determine their relevance to autism are needed. Finally, research to understand how exposure-induced epigenomic changes may transmit autism across generations is warranted.

OTHER PHYSIOLOGICAL CONTRIBUTORS

Outside of the nervous system, several other physiological systems have been implicated in autism (discussed further in Chapter 2). For example, several recent studies have illuminated the influence of immune differences in autism;[59] researchers are now exploring how a range of environmental exposures may contribute to the immune alterations observed in autism, some of which are detectable at birth.[60] Similarly, the endocrine system is another promising area of inquiry. The established role of hormonal systems in brain development, the male-to-female ratio of ASD diagnoses, and a growing recognition that many environmental chemicals act as human hormone mimics (known endocrine-disrupting chemicals or EDCs) sets the stage for investigations exploring possible links between autism and EDCs.[61] Further work elucidating connections across metabolic, hormonal, and central nervous systems in the context of EDCs is needed.

The microbiome (the combined genetic material of the microorganisms in the body) represents an additional priority area of inquiry. There is increasing evidence for links between the gut microbiome, brain, and behavioral phenotypes relevant to autism.[62-64] The microbiome is also emerging as an important component of the response to environmental exposures. Studies have demonstrated persistent changes in the function of the microbiome after exposure to immune activation and environmental chemicals,[65, 66] particularly during early life when the microbiome is being colonized. A role for the microbiome in the metabolism of environmental chemicals has also been established.[67, 68] This means that variations among individuals in microbiome composition can impact how that individual metabolizes environmental chemicals, potentially contributing to variations in the presentation of autism. Small clinical studies using antibiotics or microbiome transplant (fecal transfer) support a potential role for changes in the gut microbiome in contributing to the autism phenotypes. Continued exploration of microbiome function following environmental exposures should further elucidate their influence on autism.

RESOURCES TO ACCELERATE RESEARCH ON GENETIC AND ENVIRONMENTAL FACTORS

LARGE-SCALE STUDIES OF GENETIC AND ENVIRONMENTAL FACTORS

Studies of the genetic architecture of autism have resulted in the appreciation that much larger groups of subjects are needed to fully understand its complexity. In the last decade, several large-scale projects have been initiated. Large-scale efforts include the **MSSNG** project and database (funded by Autism Speaks), which provides access to genome sequences from over 11,500 individuals on the autism spectrum for research, and the **SPARK study** (funded by the Simons Foundation), which has collected exomes sequenced from over 50,000 autistic individuals and 60,000 family members. These studies are contributing to knowledge of additional autism genetics. The **Autism Sequencing Consortium** (funded mainly by NIH) recently published results from their exome sequencing study of nearly 12,000 autistic individuals; they have also developed a **gene browser** that displays variant and gene-level data from their most recent analysis.[2] Other large genomics

efforts, such as the **Psychiatric Genomics Consortium**, are looking more broadly at several mental health conditions, including autism. Work from this large international collaboration has identified five individual genetic variants that are associated with autism, as well as quantitative and qualitative polygenic heterogeneity across autism subtypes.[23]

There are similar large-scale efforts to understand environmental factors that contribute to autism. The **Study to Explore Early Development (SEED)** is a multi-year, multi-site study, funded by the CDC, that seeks to identify early behaviors and other factors related to the trajectory of autism that can impact health and well-being. Initially focused on preschool-aged children, SEED recently expanded to study adolescents as well. Findings from SEED studies have demonstrated the impact of several environmental factors on the likelihood of ASD diagnosis. The **Environmental Influences on Children's Health Outcomes (ECHO)** initiative of the NIH is combining data from more than 60 cohorts comprising over 100,000 people, including approximately 61,000 children. Although the extent of autism-related measures that are, or will be, included in ECHO has not yet been established, this initiative represents an exceptional opportunity to study autism-related traits in large and diverse populations.

BROAD DATA ACCESS AND RESOURCE SHARING

As the studies focusing on autism environmental factors amass increasing amounts of data, attention to broad data access and sharing is critical for ensuring that

the data collected is used for maximum value. Combining data across observational studies can yield increased power and strengthen generalizability, but this will require improved standardization of exposure measures and methodologies. Consideration of privacy and consent issues in environmental health data is needed to ensure the development and implementation of policies that protect privacy while ensuring the value of shared data. The development of consensus data standards will make it possible for investigators to include genetic data in studies of environmental factors and vice versa. With regards to mechanistic tools, new models of autism, especially those with distinguishing genetic mutations of interest, should be made widely accessible to researchers. Finally, efforts must be put into developing the analytic approaches needed to help researchers mine data from large or aggregated data sources.

INTERDISCIPLINARY TRAINING AND CAREER DEVELOPMENT

The workforce needs related to understanding autism contributing factors align with an increasing recognition that answering complex questions will require team science approaches. Programs and opportunities that train scientists and support research in ways that encourage multi-pronged efforts spanning cellular and molecular neurobiology, toxicology, genetics, epidemiology, and exposure science are needed. Training opportunities should be created around novel statistical and big data approaches geared toward complex data, with the goal of accelerating analyses that address probabilities across multiple variables.

POLICY AND ETHICAL IMPLICATIONS OF ADVANCES IN GENETIC AND ENVIRONMENTAL SCIENCE

INCREASING THE DIVERSITY OF STUDY PARTICIPANTS AND STUDIES OF DIVERSE POPULATIONS

New research techniques and technologies can lead to increases in healthcare disparities, as the newer methods can be expensive initially and only accessible to those with higher income or living in certain communities. Researchers, clinicians, and service providers must be vigilant to avoid this and support policies that enable equitable access for all. Because of differences in population histories, an understanding of genetic probabilities in one population may not be informative in others. Thus, more effort must be made to include diverse populations in studies, including genetic studies. As more genetic information becomes available and demand grows for consumer access to this information, there will be a need for more trained professionals who can accurately interpret genetic test results for patients.

Underrepresented minority communities and low-income communities often face disproportionate exposure to harmful environmental exposures.[69-71] Additional attention is needed to ensure that these populations are well represented in research on environmental contributors to autism. Ultimately, it will be critical for disparities in environmental exposures to be addressed in order to improve equity.

Studies that examine environmental factors within sex-specific subgroups are especially important. However, given the lower ASD diagnosis rate in girls and women, many studies to date have not had a sufficient sample of females to conduct such analyses. Thus, additional efforts are needed to increase representation of girls and women in autism research studies to enable meaningful analyses of sex-specific differences and the role of both genetic and environmental factors in affecting those differences.

COMMUNICATION AND DISSEMINATION OF RESEARCH FINDINGS

The incredible complexity of interactions among multiple genetic and environmental factors presents challenges for communicating findings to affected families and the broader public. Many of the factors identified thus far have a modest effect on the likelihood of autism diagnosis or other co-occurring condition diagnosis, and different combinations of factors likely operate in different autistic individuals. Epidemiologic studies that report associations of specific exposures with autism at the population level can lead to misleading misinterpretation if extrapolated to individual cases, and a focus on individual risks can mask the importance of exposures whose modification could have substantive impact when measured across the population. Moreover, the limitations inherent to observational studies means that results of a single study require additional independent studies for replication and assessment of generalizability. Conflicting findings among studies are common; these may reflect spurious results

or an unappreciated dependency of associations on other factors. Additionally, it is particularly difficult to separate the effects of some exposures from other factors, due to inherent collinearity – for example, distinguishing true medication effects from effects due to the underlying health condition for which medication was required. For these reasons, communicating environmental and genetic findings in autism requires careful attention to context, including providing information about the strength of any newly reported finding on the scale most appropriate for the audience, the difference between causation and correlation/association, the specific potential limitations of any individual study including the possibility of unmeasured confounding, the degree of contribution to autism diagnoses on a population level, and the need for additional studies to confirm the association.

SUMMARY

The overarching goal of research on autism contributing factors is to develop strategies to maximize positive outcomes. As genetic and environmental factors that contribute to autism phenotypes continue to be identified, it will be critical to establish relationships among them. In particular, understanding the downstream biological consequences of individual or multiple factors will help to develop and enhance interventions that will maximize positive outcomes for individuals on the autism spectrum. In many cases, genetic and environmental factors for autism are shared by other physical and mental health conditions, including those that commonly co-occur with autism.

As investigations of genetic and environmental contributing factors continue, it is critical to engage the autism community, including autistic individuals and their families, in discussions about what types of research will be most beneficial for them. Careful consideration of research questions and results is needed in order to ensure that research can be conducted without causing unintentional harms such as stigma toward, discrimination against, or devaluation of autistic people and to establish subsequent public health efforts that will have broad utility for increasing health and well-being for people across the autism spectrum.

RECOMMENDATIONS

RECOMMENDATION 1: Strengthen understanding of genetic factors that influence autism and its co-occurring conditions across the full diversity of individuals on the autism spectrum.

Examples:

- Understand the relationship between genes related to autism and co-occurring conditions, phenotypes, and clinical outcomes.

- Understand genetic factors that may confer resilience or improve outcomes.

- Ensure inclusion of diverse participants in genetic studies.

- Understand the contribution of regulatory and other non-coding genomic regions to the likelihood of autism and co-occurring conditions through whole genome sequencing studies and other methods.

RECOMMENDATION 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.

Examples:

- Characterize the timing of environmental exposures relative to the stages of brain development to identify and understand the molecular basis of their impact on autism and co-occurring conditions.

- Conduct multiple studies in different populations and settings to reconcile disparate findings and establish robust linkages of environmental factors to autism likelihood, including in populations and communities that have been underserved.

- Investigate modifiable factors, such as diet and nutrition, that may confer resilience and/or improve outcomes.

RECOMMENDATION 3: Expand knowledge about how multiple environmental and genetic factors interact through specific biological mechanisms to manifest in autism phenotypes.

Examples:

- Develop low-burden exposure measures that can be incorporated in large-scale genetic studies, perhaps leveraging innovations in exposomics, epigenomics, metabolomics, and proteomics.

- Reveal functional biological consequences associated with genetic and environmental factors.

- Understand the role of epigenetics in autism and co-occurring conditions.

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.**

INTRODUCTION

The evolution of the Aspirational Goal for this chapter reflects the progression of priorities in the autism community. Over the past several years, the IACC's focus has shifted from "preventing disabilities", to "building adaptive skills", and now emphasizes the construction of 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. To achieve this goal, researchers, service providers, and policy makers must seek out and include autistic voices and incorporate the diverse lived experiences of individuals on the autism spectrum and their families in the research and implementation of autism interventions so that all individuals across the autism spectrum can achieve their unique goals.

In recent years, 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. Important progress has been made in behavioral and developmental interventions, with a number of interventions leading to improvements in language and social skills development in randomized clinical trials. With increased understanding of the genetic and molecular basis of autism, there have been many clinical trials testing the therapeutic efficacy of molecules and medications to enhance function and manage co-occurring conditions. Interventions to help adults with autism improve their daily living skills and emotional and mental health are also under development. In addition, technological advances have allowed the development of more communication and social training tools for autistic individuals and improved access to interventions for some underserved communities. These are all examples of promising advances in autism interventions with the potential to improve the health and well-being of people on the autism spectrum.

Though progress is being made in several areas for interventions, there is a continuing need for improvements and evidence-based interventions for areas with little coverage, such as interventions for sensory issues and interventions that are effective for individuals who experience aggressive or self-injurious behaviors. Many more intervention options are needed for adults with autism as well.

There are many obstacles to overcome in advancing research on interventions for autism. The heterogeneity (variability from one person to another) of autism 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 characteristics and challenges. This can lead to relatively small sample sizes and potential bias in the reporting of outcomes. More randomized controlled trials with larger samples are needed to determine the efficacy and effectiveness of many interventions. There may also be differences in how interventions work in males versus females with autism or in different cultural settings. Disparities in access to interventions remain for ethnic and racial minority groups and others from underserved communities. Prioritizing understanding 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 as they progress through the lifespan.

BEHAVIORAL AND DEVELOPMENTAL INTERVENTIONS

Behavioral and developmental interventions play a prominent part in the lives of many young children on the autism spectrum. These interventions typically seek to take advantage of the neural plasticity in early development to help autistic children develop strengths and life skills that will promote successful learning and social participation in school, recreational, and home environments. Indeed, recent data shows that pre-emptive interventions before a formal diagnosis may lead to long-term positive outcomes.[1] Many behavioral and developmental interventions for formally diagnosed children on the autism spectrum have been reported to lead to significant improvements in intelligence quotient (IQ), language, and social functioning domains.[2, 3]

However, given the number of different available interventions, it can be overwhelming for families to choose the most effective intervention for their child. Additionally, some methods call for over 20 hours per week of interventions, which may be time- and cost-prohibitive for some families. A recent randomized controlled trial comparing different intervention types and intensities did not find differences in outcomes for young children on the autism spectrum based on intervention style or intensity, but instead the initial autism characteristics observed seemed to be correlated with outcome.[4] A meta-analysis of studies on autism interventions found that most studies were subject to significant bias of various kinds, including detection bias (when assessors are aware of the group assignment of individual participants), reporting bias (selective reporting of only certain outcomes), and performance bias (when participants and/or study

personnel are knowledgeable of assigned interventions or groups).[3] These findings highlight the need to compare the effectiveness of different intervention approaches to determine what interventions work best and how, using larger, better designed, and more rigorous randomized controlled trials.

In addition, it is important to recognize that interventions may not be equally effective or necessary for all individuals on the autism spectrum. Given the heterogeneous nature of autism, individuals across the autism spectrum experience diverse challenges, have varied strengths, and may respond differently to and need different interventions. Additionally, the strengths, challenges, and needs of autistic individuals may change over time. Therefore, long-term follow-up of interventions to determine quality of life outcomes and development of interventions for adolescents and adults are important areas of future research. Ultimately, a better understanding of what interventions work best, for whom, when, and how will allow all individuals across the autism spectrum to overcome challenges, fully develop desired skillsets and their strengths, and maximize their health and well-being.[5]

APPLIED BEHAVIOR ANALYSIS

Applied behavior analysis (ABA) is the most commonly practiced behavioral intervention for autism. Current ABA practices include the Early Start Denver Model (ESDM), Picture Exchange Communication Systems (PECS), Discrete Trial Training (DTT), and Pivotal Response Treatment (PRT),[6] and the basic premise for all of these methods is positive reinforcement of desired behaviors to develop necessary skills and reduce behaviors that interfere with health and well-being, such as self-injurious and aggressive behaviors. Meta-analysis of studies using ABA showed significant improvements in socialization, communication, and expressive language,[6] though few well-designed randomized controlled trials exist to definitively show the impact of ABA interventions on social and developmental outcomes.[3]

Historically, ABA was developed to teach autistic children to behave in a neurotypical manner. ABA also incorporated rewards for desired behavior and negative reinforcements to discourage undesirable behaviors, such as repetitive or disruptive behaviors. There is now recognition, however, that some of the behaviors that were discouraged are rooted in the needs and sensory experiences of autistic individuals and thus should not be suppressed or stigmatized. In addition, it has been realized that the focus of ABA on encouraging neurotypical behaviors sometimes led to masking of autistic characteristics and led to shame and stress for autistic individuals. This legacy has led to continuing controversy around the use of ABA in the autism community.[7] There are many forms of ABA and the results can vary based on how therapy is delivered as well, resulting in a variety of experiences. Some members of the autism community argue that behavioral differences are part of what makes people on the autism spectrum unique and that the responsibility should be placed on society to understand and accommodate autistic people as they are and celebrate differences. They also object to ABA's focus on eliminating certain behaviors, particularly self-soothing behavior such as hand flapping, without acknowledging the emotional purpose those behaviors serve. Others in the autism community have found ABA to be a very helpful therapy that has enabled autistic people to learn skills that have resulted in more success in social and school settings.

ABA has been greatly expanded upon and has evolved since its inception. In comparison to DTT, which was a rigid, clinician-led intervention, current models such as PRT and ESDM allow the children to take the lead and is much more focused on play, developing necessary skills, and reducing self-injurious and aggressive behaviors. To alleviate concerns in the community, larger randomized controlled trials and longitudinal studies should be conducted to definitively demonstrate the potential immediate and long-term benefits and harms of ABA interventions, and efforts need to be made to prevent any possible negative effects

of ABA. The goals of ABA should also be decided by the person receiving the intervention or, if they are unable to communicate their desires, their caregivers and guardians with the goals of the autistic individual in mind. Researchers and clinicians should also recognize that ABA simply may not be suited for some individuals on the autism spectrum, and, in such cases, they should be pointed to other forms of interventions to meet their goals and maximize positive outcomes.

NATURALISTIC DEVELOPMENTAL BEHAVIORAL INTERVENTIONS

Naturalistic Developmental Behavioral Interventions (NDBIs) are based on ABA principles but use a strengths-based model to teach skills in a developmental sequence and in a naturalistic environment, such as during play or other daily activities, with natural rewards (for example, when the child says "car", being rewarded with a toy car as opposed to a piece of candy).[8] Examples of NDBIs include ESDM, PRT, and Joint Attention Symbolic Play Engagement and Regulation (JASPER). These approaches emphasize the integration of knowledge and skills across developmental domains and are taught in a social context that is emotionally meaningful to the individual. Meta-analysis of autism intervention literature showed that NDBIs are the most well supported by randomized controlled trials, indicating it is effective in supporting development of social communication, language, and play skills.[3, 9]

Despite data supporting the effectiveness of NDBIs, a recent survey of behavior professionals indicated that most had no knowledge of NDBIs and few believed them to be appropriate or effective.[10] Therefore, more training and outreach to service providers are needed to implement NDBIs more widely. In addition, it is unclear what components of NDBIs are necessary for improvements in social communication, language, and play skills development. Additional randomized controlled trials on a larger scale are needed to determine what the key components of

NDBIs are for success. Future research should also address what the long-term gains are following NDBI and how to improve NDBIs to facilitate the development of skills and strengths across the lifespan.

INTERVENTIONS IN THE CLASSROOM

School-aged children spend much of their day in the classroom, and autistic children may struggle with sensory, social, and cognitive issues that make learning difficult. Thus, researchers are increasingly developing and testing interventions in school-based settings, from preschool through high school.[11, 12] Studies indicate that these interventions are effective at increasing classroom engagement,[13] improving socialization,[14] and reducing disruptive behavior.[15] As a whole, these and other findings highlight the effectiveness of teacher-implemented interventions in school settings to improve the educational experience for children on the autism spectrum and pave the way for more and continued school-based intervention research. Future research should explore how to best balance academic programming with special education interventions to develop needed life skills and improve social communication and transition preparedness. Additionally, schools should provide resources so that teachers and other school personnel have the training and support necessary to successfully implement interventions in the classroom. Disparities in funding and resources for autism interventions in schools, particularly in underserved communities, must also be addressed.

FAMILY-MEDIATED INTERVENTIONS

As diagnostic advances have made it possible to identify children on the autism spectrum at earlier ages, researchers have tested a number of parent- and sibling-mediated interventions in order to meet the need for interventions that can be implemented as early as possible in the home setting. Studies show that family-mediated interventions can facilitate social, cognitive, and language development in children on the autism spectrum,[16-19] and the presence

of a sibling greatly increases the development of adaptive skills.[20] Additionally, active hands-on parent coaching is more effective than parent education models where the same information is provided without active coaching.[16] Caregiver-mediated intervention can also be cost-effective and reinforcing of family support.

Continued research is needed on how to best train parents and caregivers to provide effective and efficient interventions for their child, recognizing that parents and caregivers may already be overburdened and may only have limited resources to devote to training and implementation. Family-mediated interventions can serve as an early start to intervention at home and continue as an adjunct to other types of interventions that may be delivered in school settings or with a professional. Ideally, training for parents should evolve over time as the needs, abilities, and strengths of their child changes. Future research should also explore how training involving the whole family, including siblings, may be helpful in further facilitating the development of children on the autism spectrum. Caregiver skills training has been developed for some specific populations, including the **Autism Speaks and Color of Autism's partnership** on the **World Health Organization Caregiver Skills Training Program** that provides caregiver skills training support in international and U.S. communities, with a focus on low-resource settings. However, more work is needed to develop culturally and linguistically appropriate interventions for all caregivers of individuals on the autism spectrum.

PEER-MEDIATED INTERVENTIONS

Peer-mediated interventions can also help maximize positive outcomes for individuals on the autism spectrum and can result in more inclusive environments for individuals on the autism spectrum. These types of interventions typically pair autistic individuals with neurotypical peers to improve social interactions. Studies have shown that these interventions can improve social skills in both children and adults on the autism spectrum.[21-25] Interventions mediated by autistic peers have also been shown to be effective[26] and may be especially valuable as individuals on the autism spectrum can bring their own lived experiences to better personalize the intervention. More research is needed on the long-term impact of peer-mediated programs and to determine who would most benefit from peer-mediated interventions. Additionally, peer-mediated interventions are mostly limited to school settings, though programs such as Pennsylvania's **Community Autism Peer Specialist (CAPS) Training** to train autistic peers in delivering peer support services are becoming available in community settings. Studies are needed on how to best implement peer-mediated interventions in different settings, and the efficacy of these programs, both immediate and in the long term, need to be determined.

TECHNOLOGY-BASED INTERVENTIONS AND COMMUNICATION TOOLS

Digital-based technological interventions for individuals on the autism spectrum have continued to increase in accessibility, breadth, and depth of use. Scientific evidence for the effectiveness of technology-based or technology-enhanced interventions has increased, with a large number of randomized controlled trials highlighting the breadth of technological applications in autism research as well as their increasing rigor. Technology-based interventions have tremendous potential to benefit individuals on the autism spectrum in many ways, including by helping them improve social and communication skills and gain greater independence, all of which can help individuals on the autism spectrum achieve their goals and promote positive outcomes.

Telehealth, which uses technologies such as videoconferencing to allow specialists and care providers to deliver interventions remotely, has become increasingly popular in recent years.[27-29] Within the autism community, telehealth programs typically rely on specialists to provide training and supervision to teachers, clinicians, and caregivers of children on the autism spectrum. This remote training has proven to be effective and led to significant improvements in child outcomes.[27] Telehealth is a promising and cost-effective way of delivering needed interventions to a broader swath of the autism community, particularly those living in rural areas and others for whom specialists may not be within easy reach. However, more large-scale randomized controlled trials are needed to better understand the effectiveness of telehealth interventions. Additionally, most studies on telehealth are focused on children and improving communication skills and

decreasing challenging behavior. Future studies should expand to include autistic individuals of all ages and explore other areas of intervention such as social skills (e.g., joint attention) and for co-occurring conditions.

Extended reality (XR) technology, encompassing both virtual and augmented reality, gives users an immersive and interactive environment. Rapid advancements in XR technology over the past few years have led to its increased use in leisure gaming and education. The use of XR technology has also been explored in providing interventions to individuals on the autism spectrum to improve social communication skills, emotion regulation and control, and daily living skills, with positive results so far.[29-31] Additionally, XR interventions are typically well-tolerated and accepted by both autistic individuals and their caregivers.[29] However, improvements still can be made. The scenarios typically used in XR interventions tend to be limited in both number and scope and very confined, making it difficult to develop skills needed to adapt to changes. Additionally, because the virtual environment is not the real world, it is difficult to generalize behaviors in XR to the real-world settings. More research is needed on how perceived reality impacts the efficacy of XR interventions and how to overcome those challenges. Larger studies with more diverse participants are also needed to determine if the results so far are reproducible and relevant across the autism spectrum and in diverse racial and ethnic groups. The safety of XR technology and extended use of XR technology must also be carefully studied.

Robot-assisted technology and artificial intelligence (AI) have been tested in recent years to assist individuals on the autism spectrum with developing learning and social skills.[32-39] Most studies using robots and artificial intelligence report positive improvements and outcomes following intervention and therapy, showing that this is a promising area of future research. Additional trials are needed to determine the reproducibility and generalizability of these results, and future studies should consider long-term follow-up to determine how long improvements last. Considerations should also be given to intervention areas beyond learning and social skills development and how to tailor robots to the specific needs of each autistic individual.

Given the ubiquity of smart phones and personal tablets, mobile applications (apps) are increasingly popular and accessible and are being used for a variety of autism interventions, including speech therapy, improving communication, and building social skills.[40-44] Studies on the use of apps to facilitate skills building have reported improvements in communication and social interactions, and participants typically report greater interest and motivation to participate in the intervention. App developers should use training materials that reflect real-world situations so that learned skills are translatable, as well as implement programming that is adjustable with improvements in skill development. Future studies should also explore how AI can be used to in apps to monitor body language and performance to objectively track improvements in social, communication, learning, and other skills.

Many individuals on the autism spectrum have difficulties with spoken and verbal communication. Augmentative and alternative communication (AAC) tools are increasingly adapted to allow both speaking and nonspeaking individuals to communicate with others more effectively. Assisted modalities of AAC including PECS and speech generating devices (SGDs) have been particularly useful,[45] especially for functional communication such as making requests.[46] More research is needed on how to use AAC and other interventions to facilitate communication of more complex ideas. Additionally, AAC use has traditionally been prescribed only after other interventions to induce verbal speech has failed. However, evidence suggests that AAC use may in fact facilitate improvements in spoken communication.[47] Therefore, research is needed on when the introduction of AAC can be most impactful in promoting both spoken and unspoken communication. It will be important to study how AAC use may benefit older adolescents and adults on the autism spectrum who may not have had previous access to tools for effective communication. Efforts also need to be made to remove barriers to AAC use, including ensuring that AAC use is normalized[48] and validated in educational and health care settings so all individuals on the autism spectrum can communicate effectively.

Wearable technologies such as smart watches have become more commonplace and are now being tested for a variety of uses for individuals on the autism spectrum. So far, wearable technology has mostly been used to gather information on different physiological processes.[49, 50] This information can be useful in predicting episodes of aggression or increased stress and anxiety.[51-56] Wearable technology has also been used to facilitate effective communication and improve socialization by detecting facial expressions, allowing mentors to provide virtual prompts in social situations, and learning and interpreting gestures made by autistic children.[57-59] In addition, wearable sensors can be used to monitor co-occurring conditions such as epilepsy to facilitate timely care.[60, 61] Research on how wearable technology can be used in interventions for autism and co-occurring conditions is just beginning. The preliminary results so far need to be validated in larger randomized controlled trials, and more research is necessary on the long-term efficacy and safety of using wearable technology.

Technology-based interventions and tools have become increasingly effective, important, and useful. Yet a number of challenges and gaps exist, including those that have been highlighted above. For example, with cloud data storage and transfer becoming more common, data privacy and confidentiality issues will need to be addressed when using and developing technology-based tools. Additionally, many of these technologies, including robot-assisted technology and AAC, require training for caregivers, teachers, and clinicians for effective use. More efforts are needed to ensure that such training is available and accessible and that tools are developed with usability in mind. Importantly, some families may not have access to basic resources such as stable high-speed internet to take advantage of these interventions and tools. Efforts are needed to improve access to technology-based interventions for everyone in the autism community, particularly for those in underserved communities.

MEDICAL AND PHARMACOLOGICAL INTERVENTIONS

PHARMACOLOGICAL INTERVENTIONS

Only two medications, risperidone and aripiprazole, currently have Food and Drug Administration (FDA) indication for use in autism, specifically to address irritability, and both of these drugs are associated with side effects such as weight gain and drowsiness that may not be desirable.[62-64] There are no approved pharmacological interventions that address other core features of autism such as social communication difficulties.

Advances in genetics and neurobiology have led to an increase in the number of clinical trials testing medical interventions for autism.[65, 66] However, no new drugs so far have succeeded in clinical trials in the past 5 years. For example, the neuropeptides oxytocin and vasopressin are known to be involved in social cognition and have been investigated in a number of autism studies.[67] Multiple clinical trials have now been conducted with intranasal oxytocin, but the results do not indicate a significant improvement in social functioning compared to placebo.[68-72] Large clinical trials for balovaptan, a vasopressin V1a receptor antagonist, also did not show significant results compared to placebo controls.[73-76]

Several major challenges exist in the development of medical and pharmacological interventions for autism. Given the range and variability of challenges people on the autism spectrum may face, it is critical to recruit a sufficient number of participants in clinical trials in order to fully understand any nuances in the study results. Advocates have also expressed concern about the effects of extended use of medications and the impact of polypharmacy (using multiple medications simultaneously to treat autism and/ or co-occurring conditions).[77] It will be important for researchers and clinicians to have a deeper understanding of the potential interactions and the long-term impacts of medications prescribed to treat autism and/or co-occurring conditions.

Efforts should also be made to determine how genetic factors may influence the response to different medications, paving the way for precision medicine and personalized pharmacological interventions in autism. In particular, advances in the study and treatment of Rett syndrome, Fragile X syndrome (FXS), and tuberous sclerosis complex (TSC) have laid the groundwork for similar mechanism-based treatment trials in genetic disorders associated with autism. For example, a recently completed phase 2 clinical

trial demonstrated cognitive benefits associated with an inhibitor of PDE4D, a protein important for learning and memory, in individuals with FXS.[78] However, translating success from animal studies has not always been straightforward to date, and intellectual disability commonly found in individuals with these neurogenetic disorders can pose ethical and logistical obstacles in designing studies in this field.

In fact, many of the drug trials in autism exclude individuals with intellectual disability and very young children due to ethical and/or practical challenges. However, a mechanism-based intervention intended to improve social and communication challenges associated with autism may be more effective if administered relatively early in life and may be most effective in those with higher support needs. Thus, it is crucial that such individuals are included in upcoming trials. This will require researchers to carefully consider how interventions can be adapted to accommodate individuals across the entirety of the autism spectrum and of all ages and identify age- and ability-appropriate outcomes and outcome measures.

NONINVASIVE BRAIN STIMULATION

Noninvasive brain stimulation (NIBS) methods, specifically transcranial magnetic stimulation (TMS) and transcranial direct current stimulation (tDCS), are additional experimental methods being tested for their potential to identify neural mechanisms and enhance brain function in autism.[79] TMS can potentially offer a non-invasive tool to study aspects of brain differences in autism and intervene in aspects of autism such as repetitive behaviors and executive function by modulating brain plasticity and network activity. In particular, repetitive TMS (rTMS) can alter brain excitability and network activity beyond the duration of a stimulation session and is being examined as an intervention that could potentially improve social skills, as well as communication, cognitive, and learning skills. tDCS induces neuronal plasticity (changes in brain cells) by altering membrane potential (electrical charge), and its effects can

also last beyond the intervention session, depending on the duration and intensity of the stimulation.

Recent reviews of studies using NIBS indicate improvements in restricted, repetitive behavior and executive functioning, as well as changes in the objective measure of brain wave patterns.[80-82] However, the clinical applications of these methods still cannot be determined as many studies were open-label trials, where participants knew which intervention they were receiving. Additionally, the controlled trials used neurotypical individuals as opposed to faux stimulation as a control. Therefore, better study designs are needed to determine the true effectiveness of TMS and tDCS as an intervention for autism. Additionally, NIBS trials must expand the pool of study participants to include individuals of all ages across the autism spectrum, and longitudinal studies need to determine what the long-term outcomes are following brain stimulation. Data on safety and side effects also need to be carefully assessed and reported. Though preliminary results indicate that NIBS is safe,[83] very few studies include detailed data on experienced side effects. These are important considerations for future studies to improve the tolerability and feasibility of NIBS interventions.

STEM CELL THERAPY

Stem cell technology is advancing our understanding of typical and atypical neurobiological processes, thereby offering potential new opportunities for treating neurodevelopmental disorders and co-occurring conditions, including in autism. Some studies suggest that the pathophysiology of autism may involve immune dysregulation and neuroinflammation.[84] Stem cell therapies are thought to modulate immune system activity and facilitate neural connectivity; they are being tested as interventions for autism, with the goal of improving issues such as social communication.[85, 86] Stem cells used in trials are derived from sources such as bone marrow and cord blood. While some small studies conducted so far have reported positive results,[85-88] there have also been

ethical concerns about this area of research related to financial conflicts of interest among those conducting studies and inadequate ethics review of the study protocols.[89, 90] Though there are companies already marketing stem cell therapies, this research is only just beginning, and there are many hurdles to overcome and unanswered questions to address before the field will know whether stem cell therapy can be a safe and effective intervention for autism.

Future studies will need to use standardized and validated outcome measures with large samples to ensure that results are unambiguous and reproducible. Additionally, more research is needed to determine the proper dosage and cell source to be used in stem cell therapies. This will be an important area of investigation to monitor as researchers work to answer these questions and replicate and expand initial findings.

COMPLEMENTARY AND ALTERNATIVE APPROACHES

Complementary and alternative interventions have also been used by some in the autism community. These include mindfulness, art therapy, animal-assisted interventions, yoga, special diets (e.g., gluten-free, casein-free) and supplements, probiotics, plant-based and herbal medicines, and sensory-based interventions. While many people may be using complementary and alternative approaches, the evidence base for these interventions is not yet established. Further research is needed to establish the efficacy of these approaches and whether they should be included more routinely in wellness strategies for individuals with autism.

Approaches such as mindfulness, art therapy, animal-assisted interventions, and yoga have been used to improve emotional regulation, enhance social relationships, and reduce aggression and irritability.[99-105] Results of studies so far seem to indicate that art and music therapy may be useful in promoting nonverbal expression and improving communication,[100, 105] and dance therapy may improve social functioning and intimate relationships between adults.[101, 106] Some studies indicate that equine-assisted interventions and horseback riding may also improve social

communication and behavioral skills.[99, 107, 108] However, limited effects have been found for other animal-assisted therapies and mindfulness-based approaches.[99, 103, 104] Studies on these alternative interventions tend to be small with a limited number of participants followed for a short window of time. Larger, better powered, more rigorous studies are needed to determine what short- and long-term benefits these alternative approaches may have for individuals on the autism spectrum.

Studies of the effect of special diets and supplements on social skills and restricted, repetitive behavior have had mixed results, and data so far is not strong enough to support the recommendation of such interventions for individuals on the autism spectrum.[91-94] The number of studies on this topic suggests there is great interest in further understanding how nutritional status may relate to autism presentation. Future studies should be more rigorously designed and include more participants with longer follow-up periods to provide conclusive evidence as to the efficacy of special diets and supplements in improving quality of life for people on the autism spectrum.

Results for the effect of probiotics are similarly mixed, with randomized controlled trials showing no effect on autism symptom severity, though studies with prebiotic supplementation seem to produce more consistent results.[95, 96] More rigorous and better designed randomized controlled trials with larger and more diverse samples are needed to provide insight into how probiotics and prebiotics may improve autism symptoms. Additionally, while these interventions are generally considered safe in the short-term, the long-term effects of these interventions are not known, and future studies should be conducted on the safety of these interventions and any potential long-term side effects.

The number and severity of side effects associated with commonly prescribed pharmaceuticals have led to increased interest in plant-based medicines and herbal remedies as interventions for both core traits of autism and co-occurring physical and mental health conditions.

Plant-based compounds such as cannabinoids, resveratrol, curcumin, and those found in green tea extract show potential therapeutic effects for autism in preliminary studies.[97, 98] However, the exact benefits and side effects of these compounds still need to be established using carefully designed large clinical trials.

Lastly, sensory hyperreactivity and hyporeactivity are common in individuals on the autism spectrum and can impact health and well-being.[109-112] However, very few sensory-based interventions have been studied for individuals on the autism spectrum, and the available interventions (such as Sensory Integration Therapy, massage, and the use of weighted blankets) show little evidence to support their effectiveness.[3] Much more research is needed to develop appropriate and effective interventions to improve sensory outcomes for individuals on the autism spectrum.

INTERVENTIONS FOR CO-OCCURRING CONDITIONS

A number of intervention trials target co-occurring mental health conditions in autism. This is a particularly important area of research as the presence of a co-occurring mental health condition is predictive of lower quality of life for autistic individuals.[113] Pharmacological interventions for co-occurring conditions in autistic individuals typically involve prescription of drugs tested and approved for the co-occurring condition alone.[114] For example, children on the autism spectrum with co-occurring epilepsy are treated with anti-epileptic drugs such as valproic acid,[114] and autistic children with ADHD are given stimulants such as methylphenidate.[115] However, these drugs have been associated with significant side effects in individuals on the autism spectrum, who may be more sensitive to adverse

reactions. Therefore, careful analyses need to be conducted to determine whether medications prescribed for co-occurring conditions are safe in autistic individuals, and additional pharmacological alternatives are needed so that individuals on the autism spectrum can treat co-occurring conditions effectively with minimal side effects.

In addition to pharmacological interventions, psycho-social interventions may also be effective for some co-occurring conditions. For example, cognitive behavior therapy (CBT) has been shown to be an effective treatment for anxiety, including for children and adults on the autism spectrum.[116-119] However, anxiety and other mental health conditions may present differently in autistic versus

neurotypical individuals. More research is needed to better identify symptoms of anxiety and depression in individuals on the autism spectrum, and interventions tailored for autistic individuals may be more helpful than just standard treatments. In addition, efforts so far have been mostly focused on speaking autistic children without intellectual disabilities,[120, 121] limiting the applicability and generalizability of findings. Future studies should include study participants from across the entirety of the autism spectrum and of all ages, as well as female participants and people from underrepresented racial and ethnic groups.

Multiple studies have shown the efficacy of behavioral therapies and melatonin in treating sleep problems in children on the autism spectrum,[122, 123] and pediatric-appropriate prolonged-release melatonin has been found to be safe and well tolerated with minimal side effects.[124, 125] Other interventions such as the use of weighted blankets, aromatherapy, exercise, and yoga to improve sleep have more limited evidence. Despite the availability of these intervention options, some autistic children still experience sleep difficulties, and many autistic adults report dissatisfaction with their sleep quality.[126] More research is needed to determine if existing medication for primary insomnia improves sleep for autistic people for whom non-pharmacological interventions are not effective and what the side effects may be. Additionally, studies are needed to determine how best to deliver training to parents in the use of behavioral strategies to improve their child's sleep quality. Studies to develop sleep interventions for adults on the autism spectrum are also greatly needed to improve health and well-being throughout the lifespan.

Weighted blankets, aromatherapy, exercise, mindfulness, massage yoga, dance, and animal/pet therapy are all methods that some families and autistic people seek out to help with stress, anxiety, emotional regulation, and sensory awareness. While these modalities may not be clinically proven to be effective for addressing the aforementioned conditions in the context of autism

specifically, they are complementary approaches that can be used by individuals to meet their personal needs or be used alongside mainstream, evidence-based approaches to enhance well-being.

For co-occurring gastrointestinal (GI) problems, treatment generally involves changes to the gut microbiota.[127] Fecal microbiota transplantation (FMT) is an emerging intervention that some are using to try to address a range of concerns, from behavioral concerns, mental health issues, and dietary issues.[128, 129] However, larger randomized controlled trials with diverse study participants are still needed to demonstrate the efficacy and safety of FMT. In addition, research should focus on developing effective alternative approaches to treat GI problems in individuals on the autism spectrum. In particular, food aversions and limited diets may play a role in exacerbating GI issues, and behavioral approaches may be effective in promoting a healthier and more diverse diet and improving quality of life. Dietary and nutritional interventions are also commonly used by parents of children on the autism spectrum as a way to improve both social difficulties associated with autism and to relieve GI symptoms. However, as previously stated, the efficacy of such interventions is not well established.[130] Future research is needed to conclusively determine whether special diets and supplements are safe and effective for treating co-occurring GI discomfort and improving quality of life.

Behavioral interventions that target challenging behaviors such as aggressive behavior and SIB include ABA techniques (as discussed above) and functional communication training (FCT).[131-134] The FDA-approved medications risperidone and aripiprazole can be used to reduce these behaviors, but these drugs have varying levels of success in autistic individuals. Recent studies have investigated the use of wearable devices, such as smart shirts, that can detect physiological reactions and predict the onset of aggression or SIB.[52, 54, 135] Additional studies are needed to improve and refine these and other pre-emptive behavioral interventions.

OUTCOME MEASURES AND BIOMARKERS

Over the past few decades, significant progress has been made in the development of new behavioral interventions and identification of novel drug targets aimed at reducing disabilities associated with autism and improving quality of life across the lifespan. A major challenge in determining whether new treatment approaches are efficacious has been the measurement of treatment response, which are currently mostly reliant on clinician and caregiver reports. In addition, measurement of treatment response is particularly complex in autism due to the heterogeneity resulting from an individual's symptom profile, sex, cognitive and language abilities, and developmental level. Moreover, many existing assessment measures were developed for screening and diagnosis and are not sensitive toward assessing changes in symptoms over time.

Additional research efforts must be directed to increase study sizes and group individuals with similar traits and challenges together. This will increase help researchers determine if there may be specific subsets of autistic individuals for whom certain interventions may work. In addition, current outcome measures for changes in social functioning that are used to judge whether an intervention worked or not rely on self- or caregiver report. Such self-reported measures may be highly subject to bias and the placebo effect, where trial participants may report feeling better than what is indicated when the intervention effect is measured through an objective method, such as a blood test or laboratory measurement. Biomarkers and more objective and sensitive reporting tools need to be developed to collect more accurate data.

Considerable effort has been directed toward evaluating which existing measures are suitable for clinical trials and for developing quantitative, objective, and sensitive measures of intervention response. Increasingly, the input of key stakeholders, including autistic individuals and caregivers, is solicited to ensure that outcome measures reflect the priorities and needs of persons for which the interventions are being developed. Biomarkers of intervention success are needed, as are "stratification" biomarkers for matching people to the best intervention for them at the best time. Until it becomes possible to biologically measure intervention response, negative results from pharmacological and behavioral interventions will be difficult to interpret, and positive results may not definitively indicate the requisite dose or duration of treatment. Predictive biomarkers that help to match individuals to particular interventions will help to create more precise treatments and allow individuals on the autism spectrum and their families to avoid wasted time and resources.

Initial efforts have focused on developing measures that are linked indirectly or directly to underlying neural circuitry, which can offer insight regarding whether the intervention is influencing certain aspects of neural circuitry, inform researchers of the mechanisms that may underlie the intervention effects, and predict intervention response. These measures include eye tracking,[136] electrophysiological measures,[137, 138] and magnetic resonance imaging,[139] among others. Such measures can also serve as an early efficacy signal that can detect response to treatment before changes in more distal measures such as language and social abilities are evident. Early efficacy markers can be used to identify which individuals are most likely to benefit from a given intervention and/or in adaptive study designs to indicate early in the trial whether modifications in the intervention (e.g., timing and intensity) should be made.

Given the high risk of failure for central nervous system intervention studies, there is a need to design early-stage trials to incorporate objective measures that adequately test the proposed mechanism of action of the intervention and determine if the intervention target has been modulated. There is also a need for studies that demonstrate the effect of the intervention on the proposed mechanism of target engagement or site of action (e.g., the molecular, circuit, neural or system-based target) prior to an examination of clinical efficacy (an association with behavioral or clinical benefit). Clinical studies for these intervention targets should be designed so that even negative results will provide meaningful information.

Recently, a number of substantial investments have been made to support large, collaborative efforts aimed at validating biomarkers and outcome measures for use in autism clinical trials. These consortia involve public-private partnerships among academia, advocacy and other non-profit organizations, government, and industry, with a goal of reducing risk of investments into pharmacological autism trials and optimizing the success of such trials. These projects are examining a wide range of potential biomarkers and their relationships with observational and caregiver-report measures of behavior in large samples of autistic versus neurotypical individuals over time. Furthermore, regular communication, data sharing agreements, and shared measures across the existing consortia will increase the scientific utility of these investments. One example is the **Autism Biomarkers Consortium for Clinical Trials (ABC-CT)**, a National Institutes of Health (NIH)-, Foundation for the NIH-, and Simons Foundation-funded consortium of sites that aims to develop, validate, and disseminate objective measures of social function and communication for autism, with the ultimate goal of advancing these measures as markers and predictors of treatment response.[140]

In sum, multiple laboratories are conducting studies to develop better ways of measuring intervention response. Continued investment in such studies will ensure that, as new behavioral and medical interventions are developed, we will have the capability of testing their efficacy. Such investments will also be essential for developing improved methods for identifying specific populations within the autism community that are responsive to specific interventions and identifying the neural mechanisms underlying intervention response.

RESEARCH POLICY ISSUES

There has been continued progress in the development and evaluation of multiple intervention types in recent years. There are now tremendous opportunities for combining therapeutic modalities in ways that potentially result in synergistic impacts that are greater than the sum of the parts. More studies on combination therapy approaches may be helpful in determining which therapies may work well in combination for which individuals. One example would be the combination of medications and behavioral interventions or using technology to facilitate improvements in interventions in the classroom. Advancement of new or reconceptualization of existing interventions into therapies organized into therapeutic modules that can be combined and reused in flexible arrangements can potentially offer opportunities for personalizing and finetuning interventions to the needs of the individual. Combination therapies may especially be helpful in addressing co-occurring conditions such as anxiety, aggression, and depression. The recent Lancet Commission on the future of care and clinical research

in autism laid out a stepped care approach that can be personalized to meet the needs of autistic individuals and their families as their strengths and needs evolve over time.[5] Implementation of a stepped care approach can help promote efficient and equitable distribution of intervention resources, enabling individuals across the autism spectrum to meet their personalized and diverse goals.

Encouragingly, the diversity of study participants in autism intervention research has improved, as researchers more often strive to include underserved communities as well as populations previously excluded or overlooked. However, while representation has increased, participants from racial and ethnic minority groups are still underrepresented overall in autism intervention research,[2, 141] and disparities remain in access to services and interventions.[142, 143] This represents a critical gap in our understanding of how existing interventions may or may not be culturally and linguistically relevant and feasible for autistic individuals from underserved communities. Efforts should be made to include individuals from racial and ethnic minority groups and other underserved communities in intervention research, and culturally and linguistically relevant interventions need to be developed and be widely available so that all autistic individuals can access effective interventions.

Adolescents and adults are another underserved population in autism intervention research as most intervention studies are still focused on young children. Future research should seek to fill this gap by developing effective interventions for autistic individuals across the lifespan. Given the increased understanding that girls and women on the autism spectrum may have a different presentation of autism and face different health challenges compared to autistic boys and men,[113, 144-146] more also needs to be done to include girls and women on the autism spectrum in intervention research to provide access to effective and sex- and gender-appropriate interventions and outcome measures.

Additionally, there is some evidence to suggest that autistic individuals with higher support needs, including individuals with intellectual disability and those who are minimally speaking or non-speaking, are disproportionately excluded from intervention studies.[5, 147, 148] The challenges of working with this population in research settings may have created barriers, but solutions are needed to ensure that these individuals are represented in research generally and that studies that target their specific set of needs for high-quality interventions and supports are addressed. Accommodations may also need to be made to make it easier for family caregivers to participate. Inclusion of individuals of all levels of ability and support needs across the autism spectrum in research is an important goal to ensure that all autistic people have access to effective interventions, regardless of the level of support needs.

In addition to increasing the diversity of study participants, more research efforts are needed in the area of intervention implementation. A recent systematic review found that clinical guidelines for autism contained recommendations based mostly on expert opinion as opposed to empirical evidence.[149] This highlights the continued need to improve translation of research findings and implementation of evidence-based interventions in autism communities. Importantly, individuals with perceived "low" support needs may still have challenges in daily living, unmet support needs and co-occurring physical or mental health conditions – particularly those conditions and issues that might be "invisible" to others. Issues such as challenges with executive function and mental health concerns such as anxiety, depression, and emotional regulation often can result in significant challenges for autistic individuals even if they live independently or have many other strengths. More research on the connections between unmet needs and social determinants of health on mental health in individuals with autism are needed. Therefore, access to interventions should not be based solely on subjective observations of an individual in clinical situations; rather,

interventions should be available to those who report and demonstrate their need for support, regardless of their perceived cognitive and linguistic abilities.

Future resources should be directed towards increasing the accessibility of evidence-based interventions by improving community access to information about the efficacy and safety of different interventions (including rapid dissemination of novel interventions), improving and strengthening the autism service providers workforce, and providing resources to navigate insurance and Medicaid/Medicare systems. It will also be important to reduce disparities in intervention access, by improving transportation systems and access to community resources, improving broadband internet access to facilitate telehealth and other technology-driven interventions, and examining other social determinants of health that may directly or indirectly affect access to interventions. By focusing on practical barriers to ultimate intervention deployment, including insurance coverage, willingness of providers to adopt them, and marginal expenses, a more robust, efficient, and complete pipeline from idea to effective individual treatment can be realized.

SUMMARY

While there have been multiple, important advances in the field of autism interventions, there is still much progress to be made. Researchers must continue to develop new interventions as well as improve on existing interventions for diverse settings and populations, including males and females, individuals with co-occurring conditions and varying levels of support needs, individuals across the lifespan, and those in settings or communities that are under-resourced or underserved. Efforts must also be made to improve community implementation of evidence-based interventions and improve community access to interventions proven to be effective to maximize positive outcomes for individuals on the autism spectrum. Importantly, the voices of autistic people, their families, and potential providers must be included in intervention research and implementation in a participatory and community-based approach. This will maximize the utility and relevance of the research.[5] Furthermore, autistic individuals and their caregivers must be allowed to choose what interventions work best for their unique needs to meet the diverse goals of individuals across the autism spectrum.

RECOMMENDATIONS

RECOMMENDATION 1: Develop and improve pharmacological and other medical interventions that will maximize positive outcomes for individuals on the autism spectrum.

Examples:

- Advance the study and treatment of genetic syndromes related to autism (including, but not limited to, RTT, FXS, and TSC) and utilize the groundwork provided by investigations of these disorders to develop similar mechanism-based, genetically targeted pharmacology treatment trials for autism.

- Explore innovate intervention modalities and combination therapies.

- Development interventions to address challenges across the autism spectrum and across the lifespan

- Develop improved interventions for self-injurious and other challenging behaviors.

- Investigate intervention response, including how girls and women on the autism spectrum respond differently to intervention approaches.

- Determine the safety and efficacy of pharmacological interventions for common co-occurring conditions such as mental health conditions, ADHD, gastrointestinal disorders, and sleep disorders in autistic populations.

- Develop biomarkers that can help inform decisions about the most appropriate interventions for particular individuals across the autism spectrum and provide objective, early assessments of response to intervention.

RECOMMENDATION 2: Create and improve a variety of psychosocial, developmental, occupational, and educational interventions that will maximize positive outcomes for individuals on the autism spectrum.

Examples:

- Support research to ensure that interventions are developed that can address various subsets of individuals as well as the whole autism spectrum, the whole lifespan, and diverse populations (including girls and women, minimally speaking individuals, intellectually disabled individuals, adults, and individuals in under-resourced and underserved communities) and that interventions are accessible across settings, communities, and income levels.

- Develop interventions that can address the needs of autistic people across the whole lifespan – early childhood, adolescence, early adulthood, middle age, and older adulthood – that offer a path toward continued learning and development of life skills, and that maximize positive outcomes.

- Identify the characteristics and components of, and contributors to, successful therapeutic approaches as a basis for future innovation and tailoring of interventions to particular populations or settings.

- Explore combination therapies.

- Develop outcome measures that include biomarkers of treatment success, measures of improvement across multiple domains, and improvements in health and well-being.

RECOMMENDATION 3: Develop and improve technology-based interventions that will maximize positive outcomes for individuals on the autism spectrum.

Examples:

- Develop technology-based interventions that help people on the autism spectrum improve their social and communication skills, increase their independence, and in many other ways help improve the quality of their lives.

- Develop tools allowing individuals on the autism spectrum to track and direct their own interventions.

- Development interventions for minimally speaking individuals and those with intellectual disabilities, with a focus on the use of technology to augment communication as well as adaptive, individualized intervention approaches for both of these underserved groups.

- Increase access to interventions by developing technology-based interventions that can be deployed outside of primary care or clinical settings.

WHAT SERVICES AND SUPPORTS ARE NEEDED TO MAXIMIZE HEALTH AND WELL-BEING?

SERVICES AND SUPPORTS

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.**

INTRODUCTION

Across their lifespan, autistic people may need a range of supports and services in different areas (e.g., healthcare, education, social services, etc.), with adjustments to meet varying needs at different stages of their lives. Question 5 (Services and Supports) *Strategic Plan* Recommendations include supporting research to scale up and implement evidence-based interventions in community settings, reducing disparities in access and outcomes for underserved populations, and improving service models to ensure consistency of services across many domains. Overall, Question 5 highlights the need for accessible, cost-effective services that optimize the health and well-being of people with autism across the spectrum.

There have been notable advancements in the services research portfolio from 2008 to 2020. In 2020, 8% ($35.3 million) of autism-related research funding from federal agencies and private organizations addressed issues related to services and supports.[1] This reflects significant growth from 2008, when 2% of total funding ($4.2 million) was directed to research on services. There have been advances in recent years regarding the direction and

priorities of autism services research and the incorporation of different perspectives, especially from those with lived experience.[2] This includes research focused on supportive services post-diagnosis and during times of transition; self-directed care; increased access to services and supports; identifying optimal ways to support the acquisition of life skills; research addressing disparities in underrepresented groups; and measuring the health, well-being, safety, and mortality of people with autism.

Although there has been some growth in services research funding over the years, there is still a need for translation of findings to community practice, as the quality and accessibility of services for people on the autism spectrum remains uneven, particularly in lower-resource settings.[3] Members of the autism community have continued to voice the need for more services research that can significantly impact the current service infrastructure and those living with autism today. Adequate and sustained funding allocated towards services research will be needed to achieve the Question 5 Recommendations of the *IACC Strategic Plan*.

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. For example, some individuals on the autism spectrum have accompanying language and/or intellectual disabilities or other co-occurring physical or mental health conditions that may require specialized or more intensive services supports across the lifespan. A wide variety of services and supports are available to help maximize health and well-being among children and adults on the autism spectrum. Although some of these may be covered by insurance or offered at no cost through federal and state programs, families and individuals often require assistance in connecting to additional specialists and resources and may be required to pay for certain supportive services out of pocket. 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.

Recent research has identified ongoing unmet needs for adequate, cost-effective services to alleviate some of the financial strain on autistic individuals and their families.[4] In addition, research has revealed that families with a member on the autism spectrum are more likely to experience poverty and outcomes such as food insecurity due to additional cost of care, disparate access to needed services, and loss of income resulting from parental job loss, and that this was heightened as a result of the COVID-19 pandemic.[5, 6] This highlights the need for continued efforts to strengthen the system of services and supports available to assist individuals with autism and their families.

This chapter describes gains and opportunities in research on several specific service-related areas, including education, healthcare, health and safety, person-centered choice and planning, caregiver supports, housing, and workforce training. For all of the recent successes in autism services research, gaps in services remain for children and adults with autism and their families across a continuum of need.

EDUCATION SYSTEM

Schools are one of the primary settings where children with autism receive intensive supports and services.[7] With the growing number of autistic students entering the education system, there is a need to standardize the methods by which eligibility for services is determined. The *Every Student Succeeds Act* and the *Individuals with Disabilities Education Improvement Act (IDEA)* both state that students with autism must have access to high-quality, research-based interventions that help support them in the least restrictive instructional environment that can meet their learning needs. IDEA classifies autism as a "developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally

evident before age three, that adversely affects a child's educational performance." However, many states, and even school districts within a given state, can differ in their interpretation of the "educational impact" required for an autism classification according to IDEA, given limited guidance to define this concept.[8]

Research has highlighted discrepancies between educational eligibility for autism-related services as compared to clinical diagnoses of autism, where more girls than boys may be lost in educational vs. clinical diagnoses.[9] This inconsistency may result in the absence or lack of services provided to students with autism, or

access to services under different eligibility criteria.[10] In order to match students with effective services and supports, classification systems need to be sensitive to the characteristics that are most valid and distinguish between students with autism-related traits and those without.[11] Determining eligibility criteria for appropriate, tailored educational supports and services remains an area of opportunity for continued research.

Federally funded programs such as the U.S. Department of Education's **National Professional Development Center on ASD** have aimed to improve outcomes when students are the recipients of evidence-based practices (EBPs). More research is needed to further understanding of the EBPs that are most effective for students with autism.[12] Furthermore, research suggests that an educator's individual attitudes about EBPs can influence their use of these practices with children with autism in public schools.[13] Strategies targeted at individual provider (teachers and staff) attitudes toward these practices might improve the rates of utilization of EBPs in classrooms. Additionally, optimal leadership (i.e., principals, administrators, etc.) behaviors are associated with a positive school climate for EBP implementation.[14] Given the number of EBPs that teachers and classroom staff may aim to use simultaneously, future research can work to shed light on strategies to implement numerous EBPs in various settings, with the goal of improving educational outcomes and mitigating failed implementation.[15]

Currently, the public education system is not adequately preparing all students with autism for adulthood. Research suggests that Individualized Education Program (IEPs) for students with autism in their final year of school may not be consistently meeting the standards outlined by law or best practice recommendations necessary for successful transition from high school.[16-18] Less is known about the preparation of autistic students enrolled in charter, private, and home schools.

Before students graduate from high school, curricula could focus on building skills for students to be successful in the workplace, including introducing Project-Based Learning (PBL) and encouraging students to seek out paid apprenticeships. PBL helps prepare students for the workforce by building teamwork and interpersonal skills and allows them to explore their learning and communication styles. Studies show that project-based, team-centered problem-solving can help individuals build skills at their own pace and increase engagement.[19, 20] This could be due to the fact that PBL allows students to use practical thinking as they make decisions and discover solutions about issues that interest them.[21] Other programs, such as **Unstuck and On Target**, can help students build executive functioning skills, which are also essential for maximizing post-secondary outcomes.

Apprenticeships are paid positions that include on-the-job training integrated with classroom instruction and usually conclude with the individual earning a nationally recognized credential.[22] The U.S. Department of Labor Office of Disability Employment Policy (ODEP) funds the **Partnership on Inclusive Apprenticeship (PIA)** which provides technical assistance for inclusive recruiting, teaching, and on-the-job training practices. Mentorship plays a large role in the experience of apprentices, as many of them have limited exposure to the industry.[23] Further research is needed to develop best practices to help youth with autism develop the life and vocational skills necessary to support successful outcomes after exiting the education system.

HEALTHCARE SYSTEM

INSURANCE COVERAGE

Health insurance remains an important component of ensuring access to and utilization of autism services and supports. Across the United States, there is wide variability in the type, amount, and extent of service coverage for certain services and supports for individuals with autism and their families. One important funding stream for reimbursement of health services provided to individuals with autism is the **Medicaid** program. Jointly operated between the states and the federal government, Medicaid provides healthcare coverage for individuals below certain income thresholds. Income and eligibility requirements can vary by **state**. Among a menu of both mandatory and optional services, a variety of services and supports may be covered by Medicaid, such as case management; rehabilitative services; and physical, occupational, and speech therapies. The **Early and Periodic Screening, Diagnostic and Treatment (EPSDT)** benefit mandates the provision of medically necessary services found at section 1905(a) of the Social Security Act, including screening, diagnostic, and treatment services, for Medicaid beneficiaries under the age of 21.

If a family earns too much income to qualify for Medicaid and their child is not covered under a group health plan or other creditable health insurance, publicly funded health insurances may be obtained through the **Children's Health Insurance Program (CHIP)**. The program is funded jointly by states and the federal government. Every **state** administers its own CHIP program with broad federal guidance from the Centers on Medicare & Medicaid Services (CMS). Coverage for applied behavior analysis (ABA) and other autism services under the CHIP program varies by state.

Waiver programs are used to deliver certain kinds of services for people with disabilities. A Home and Community-Based Services (HCBS) waiver program approved by the CMS allows states to offer a broad range of long-term services and supports to individuals in their homes and communities, instead of institutional settings. Nearly all states and D.C. offer HCBS Medicaid waivers. States can offer a variety of autism services under an HCBS waiver program, such as intensive individual support services, respite care, and adult life planning.[24] HCBS waivers can help to meet the service needs of people with autism and decrease their unmet healthcare needs.[25-27]

Many families use private insurance to cover healthcare costs. By 2019, all 50 U.S. states had enacted private autism insurance mandate legislation requiring coverage of autism-related services.[28] Further, 47 of these states clearly specify coverage for ABA in their mandates.[29] Research suggests that mandates for private insurance to cover certain autism services can relieve some of the public sector cost of autism care and increase utilization of autism services, but this often is accompanied by shifts in costs to commercial insurers and families.[29-32] Once the law for an autism mandate is enacted in a given state, research suggests that the number of children receiving services increases with each passing year, and rates of ASD diagnosis and service utilization subsequently increase as well.[30, 33, 34]

Research is also beginning to evaluate whether the type of healthcare coverage has an impact on the services an individual receives. A recent study found that privately insured children with autism are less likely to have health insurance plans that covered a fuller range of needed services compared to children on public insurance.[35] Additional

work has found that children with autism enrolled in Medicaid were more likely to have visits to occupational therapists, physical therapists, and behavioral therapists compared to children on private insurance.[32] Furthermore, research indicates that children with autism-related HCBS waivers are more likely to have outpatient visits and less likely to have inpatient visits and long-term treatment than children without HCBS waivers.[36] A recent review found preliminary evidence that HCBS waivers for people with intellectual and developmental disabilities benefit states economically, reduce unmet healthcare needs, increase parental ability to continue working, and reduce racial disparities in care access.[25] Despite these promising developments, it is estimated that approximately 30% of children with autism still do not receive the services they need.[37] Further research in this area is needed in order to ensure consistency of care and services received by individuals with autism and their families.

SERVICE DELIVERY MODELS

The medical home model of care, developed by the American Academy of Pediatrics, is a family-centered teams approach to providing and coordinating medical care and facilitates communication of condition-specific needs and smooth transitions between providers/offices.[38] Research has shown that the medical home model facilitates access to care for autistic children. Parents of autistic children who participate in a medical home report fewer unmet needs than those who did not.[39] Autistic young adults who participated in a medical home were also three times as likely to receive healthcare transition services as those without a medical home.[40] Research also shows that the presence of a medical home is associated with increased parent reports of shared healthcare decision-making, receipt of preventive pediatric care, and reduced frustration in accessing services.[41] This suggests that a medical team approach to pediatric care can facilitate the provision of person- and family-centered, organized, and coordinated

healthcare supports and services for people with autism and their families.

MENTAL HEALTH SERVICES AND SUPPORTS

Co-occurring mental health conditions are more prevalent in the autistic population than in the general population,[42] including anxiety disorders, depressive disorders, bipolar and mood disorders, schizophrenia, and attention-deficit/hyperactivity disorder.[43] Recent studies have also focused on "masking" or "camouflaging" behaviors in autism, which include strategies individuals may use to hide their autistic characteristics so they can fit in better socially. Masking creates stress for the individual, however, and can lead to mental health issues and burnout. Studies suggest that these behaviors are associated with mental health challenges such as depression, stress, and anxiety.[44-49] Research has also suggested that autistic children experience a greater number of adverse childhood experiences (ACEs) in their family and community environments that may later impact their mental and physical health.[50-52] ACEs include issues such as family illness, divorces, deaths, abuse, neglect, incarceration, substance abuse, discrimination, and poverty.

Autistic students have reported that mental health issues interfere with their success in school and that they have difficulty identifying and accessing needed supports.[53-55] For both children and adults with autism, access to high quality mental and behavioral health supports to address these needs is essential.[56, 57] Studies have also suggested that autistic people are at higher risk of suicide than the general population.[58] Progress is being made in understanding risks for suicide and developing tailored approaches to suicide prevention in autistic individuals.[59-61] Additional research efforts are working to bridge the gap between behavioral and mental health through the validation of new tools and instruments that can facilitate symptom recognition by both autistic people and professionals.[62]

DENTAL CARE

Autistic individuals may struggle with maintaining healthy dental hygiene.[63, 64] This could be due to a combination of sensory issues related to sights, sounds, and smells while in dental provider offices, communication issues, and poor dental habits at home.[65] For some autistic individuals, intravenous (IV) sedation for dental procedures may be necessary, but the cost for anesthesia administration may not be covered by insurance, creating a burden for some families. Further, autistic children may have major risk of developing tooth decay, periodontal lesions, and alterations of the oral microbiome due to the aforementioned sensory issues, as well as oral trauma due to self-injury.[66]

Many of these issues can be reduced through preventative approaches, such as personalized educational models, as well as environmental alterations to dental offices to accommodate sensory issues related to autism. Research is beginning to evaluate the effectiveness of environmental alteration approaches (e.g., dimmed lights, images shown on ceilings, calming music, and tactile pressure using weighted vests).[67] Additional work is needed to determine how to scale these approaches in various community service settings. Trainings for families to use with their children and for autistic adults, as well as trainings for dental health providers, are emerging and may be helpful.[68, 69] The National Institute for Dental and Craniofacial Research (NIDCR) publication *Practical Oral Care Guide for People with Autism* is one example of recent educational efforts to address oral health in individuals on the autism spectrum.[70] In a recent review, researchers discussed how collaboration between dentists and occupational therapists to optimize the dental clinic environment and help autistic patients emotional regulation and familiarization with dental procedures can create an approach that works well for individuals with autism.[65, 70]

For autistic adolescents and young adults, transition to different insurance coverage remains as a potential barrier to continued dental care, with the risk of a drop in coverage for a prolonged period of time or a lack of coverage for a particular procedure.[71] Additional research is needed in the area of improving access to cosmetic dental procedures and the physical and mental health benefits of these procedures.

APPROPRIATE SERVICES TO ADDRESS HEALTH AND SAFETY CONCERNS

Many autistic people have coexisting mental and physical conditions.[72] These higher rates of health complications throughout the life course may result in elevated risk of early mortality. Research shows the causes of death to be diverse, including chronic conditions (such as cancer and seizures), accidents (such as choking on food and accidental poisoning), and health complications due to medication side effects.[73] Additionally, the research suggests that even though autistic individuals are more likely to die by suicide and present with more self-harm than do their non-autistic peers, the association can be explained by co-occurring mental health conditions.[74, 75] To address these significant health disparities, it is necessary to increase implementation of services, evidence-based approaches, and trauma-informed care.[76-78] Additional research around improved access to appropriate preventative mental health services and supports across the lifespan may also ameliorate mortality rates seen in the autistic population.

Victimization remains a concern among autistic populations, particularly with regard to sexual violence, physical and online bullying/harassment, financial exploitation, and maltreatment.[79-81] Professionals and providers must be properly trained to provide optimal support for autistic populations experiencing victimization. In addition, there is a need for more training and supports to help autistic people learn how to recognize exploitative behavior, advocate for themselves, and seek help from others when needed. Individuals with communication challenges, intellectual disabilities, and/or high support needs may be particularly

susceptible to victimization, health complications, and early mortality. Services to address health and safety issues must therefore be appropriately tailored to meet the needs of these subsets of the autism community.

There also is a need for the healthcare system to emphasize increasing access to health services in underserved populations and cultural competency among service providers. Language barriers have already been noted as a factor in the decreasing number of hours of direct services received by non-English speaking families compared to English-speaking families.[82] For example, a substantially lower percentage of Latino children receive school-based occupational therapy (OT) and physical therapy (PT), and a moderately lower percentage receive PT outside of school, compared with non-Latino White children.[83] Additional research is needed to improve access to supports and services for families with limited English proficiency.

Further, there is a need to understand and consider diverse experiences, preferences, and values in the design and provision of autism services for families and their children.[84]

Overall, it is important to continue to support research to test quality services and supports as well as evidence-based interventions that can be scaled up and implemented in any community setting and be accessible through health insurance coverage. Although additional research on the utilization of community-based organizations is needed, studies suggests that with greater adoption, implementation, and sustained utilization of EBPs within community-based care settings, there can be significant improvement of appropriate service delivery to individuals with across the spectrum.[85, 86] Additionally, efforts to improve access to high quality autism-related mental health services would require explicit attention to the organization and financing of these mental health services.[87]

LAW ENFORCEMENT AND SAFETY

Law enforcement plays a key role in responding to incidents involving the safety of individuals with autism and developmental disabilities. Wandering, or elopement, behavior presents safety risks for some autistic individuals and is one type of safety-related issue that often involves law enforcement. Approximately one in four children with autism exhibit wandering behaviors away from supervision each year, with about one in five cases resulting in fatalities.[88] Most of the adverse incidents resulting from wandering episodes include unintentional drowning and motor vehicle accidents. For example, in incidents of unintentional drowning near bodies of water around a child's residence, wandering was the most commonly reported activity that precipitated this outcome.[89] Improvements in swim skills have been observed in

autistic children participating in learn-to-swim programs; however, additional focus must be provided on ensuring all autistic individuals have access to these swimming instruction programs.[90] Because the risk for elopement increases with the severity of autism and with co-occurring intellectual disabilities, many of the individuals at greatest risk have limited language and may not be able to tell first responders their names, addresses, or phone numbers if they get lost.[91]

In 2017, Congress passed **Kevin and Avonte's Law**, honoring the memory of two boys with autism, Kevin Wills and Avonte Oquendo, who drowned while wandering. The U.S. Department of Justice has led the implementation of Kevin and Avonte's Law, supporting numerous grant

awards for wandering prevention and training of law enforcement departments across the United States on how to manage cases of wandering by children with autism and other developmental disabilities to maximize the speedy and safe return home of the children.[92, 93] In addition, the Department of Justice and Vera Institute have collaborated on a program called Serving Safely to train law enforcement on how to have safe interactions with individuals with mental illnesses and developmental disabilities in a variety of law enforcement situations.[93]

Additional resources are needed to adequately support and train caregivers and service providers on the risks of wandering. Such resources could include increased access to tracking technologies, improved IEP changes to address wandering, swim instructor trainings that focus on the needs of autistic students, and additional support from pediatricians on wandering mitigation strategies.[94, 95] Additionally, more research is needed in the utilization of outdoor programs to encourage physical activity outdoors and for the purposes of environmental exploration. Trainings that familiarize autistic individuals with how to safely interact with law enforcement and the use of ID cards and medical bracelets to help alert law enforcement to the needs of autistic people they may encounter have also increased the level of education of autistic people, their families, and

law enforcement to increase the chances for positive and productive interactions.

Some autistic individuals may have contact with law enforcement and the broader criminal justice system; it is important that their needs are recognized and that appropriate services are provided.[96] Current research suggests that young adults with autism were not overrepresented in the juvenile and adult justice systems, received similar charges and charge outcomes, and were as likely to reoffend as their peers.[97] However, by age 21, approximately 20% of youth with autism had been stopped and questioned by police and nearly 5% had been arrested.[98] Effective training models for law enforcement built around understanding and recognizing traits of autism, increasing practical skills around typical autistic behaviors (i.e., stimming, communication differences, etc.), and cultural responsivity with regard to autistic people from Black and Hispanic/Latino populations may improve community perceptions during these interactions and improve outcomes.[99-102] Additional research is needed around best practices for policing procedures around evidence-gathering interviews with autistic individuals in order to avoid instances of coercion or unfair interactions with law enforcement.

ENSURING INDIVIDUALIZATION, CHOICE, PERSON-CENTERED PLANNING, AND SELF-DIRECTION

People on the autism spectrum may have a wide range of support needs that evolve over the course of their lifespan. Due to the wide range of needs within the autism community, corresponding supports and services should

optimally be tailored to the needs of each autistic individual. The concept of quality of life (QOL) serves as a conceptual and assessment framework to develop person-centered planning as a basic principle to guide professional

practice.[103] Validated QOL assessment instruments are used to measure personalized support trajectories to ensure that autistic individuals achieve optimal outcomes in the domains of life that they decide are most important to themselves and their families.[104] However, additional research is needed around the use of QOL measurements, the outcomes associated with person- and family-centered planning, and a shift away from deficits-based models of autism.[105]

Legal guardianship, where a designated person has the legal right to make decisions for a person with disabilities, had been the standard practice for individuals with intellectual disabilities for many decades, but person-centered planning has offered an alternative for some families and individuals that allows for the person with a disability to direct their own support decisions and choices.[106] A legal guardian can be involved in person-centered planning processes if needed or desired. There have been advances in person-centered planning, particularly for transition-to-adulthood planning. Within healthcare transition, patient autonomy is frequently cited as the ideal goal during transition planning, citing positive health outcomes over time.[107] Additionally, shared decision-making models are more frequently being seen as a benchmark measure within a successful healthcare transition protocol for autistic individuals.[108] More research is needed around guardianship and alternatives to maximize self-determination and choice for individuals with disabilities.

The role of networks of support (i.e., family caregivers, providers, healthcare workers, etc.) in ensuring patient-centered care has been an emerging topic. For example, while family caregivers provide 70-90% of care for autistic people living in the community, most healthcare providers do not meaningfully involve family caregivers as integral components to delivering person-centered care to autistic individuals.[109] In addition, the lived experience provided from patient- and family-centered care would be ideal in identifying systemic issues and "on the ground" solutions

for local healthcare providers to optimize the supports and services offered to individuals with disabilities in their facilities.[110]

NAVIGATION SERVICES

Family navigation can serve as an important support system for families of individuals on the autism spectrum. Family navigators are professionals who engage with families to enhance access to early identification and services via shared navigation plans that help meet the family's priorities and goals when navigating systems of support. These navigation services have been found to be effective in improving access and adherence to services over time.[111] Comprehensive evidence-based family navigation services consist of key components including individually tailored, family-centered care coordination.[112] Typically, family navigation is designed to assist under-resourced families in navigating potentially complex systems of care.

Tools designed specifically for the development of shared navigation plans for families following a diagnosis of autism are currently limited.[113] In addition, the effectiveness of family navigation is related to multiple factors, including service timing, family factors, case management, and presumed service needs. As a result, these navigation services may be implemented differently across different healthcare delivery systems, resulting in highly variable initial outcomes and family experiences.[114] However, the evidence of the feasibility, acceptability, and potential efficacy of family navigation services at increasing access and reducing time to autism-related diagnostic services has warranted additional research and focus on this service. Additionally, family navigation may help support autistic parents of young children, some of whom may be autistic as well.[115] There is a noted dearth in research around the service and support needs of autistic parents and the strategies that may help them serve as caregivers, highlighting an area for future research.

CAREGIVER SUPPORTS

Several private and non-profit organizations currently offer support, information, and resources to autistic families and caregivers. Organizations such as Autism Society, Autism Speaks, Autism Science Foundation, and The Arc, among others, offer various levels of support to caregivers. This support may often include providing opportunities and platforms to meet, in-person or virtually, for support groups, regional and local access to information pertinent to the care of individuals on the autism spectrum, and resources from others with lived experience.

One of the most frequently identified unmet needs by parent caregivers in the literature is the need for respite care, which is typically a service that allows primary caregivers to take some time away and leave their child in the care of other formal and informal caregivers.[116] Research indicates that caregivers of children with autism may experience impaired mental health, including anxiety and depression, a poorer quality of life and well-being, and higher levels of stress as compared to caregivers of typically developing children.[117-120] In 2018, Congress passed the **Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act**, paving the way for a national strategy to support caregivers, which was released in 2022.[121] The RAISE Family Caregivers Act National Strategy includes respite care development strategies. The development of respite care options for caregivers must prioritize accessibility and affordability to achieve maximal utility.

Sibling perspectives are often missing from the discourse around caregiver supports. One study found that sibling support groups are the least commonly reported family support service available.[122] Further, although siblings generally report interactions ranging from promoting their sibling's development (e.g., promoting academic skills)

to providing more targeted support for autism-related functional limitations, there is evidence of more extensive caregiving roles and parent-like roles among racially and ethnically diverse siblings.[123] Additionally, there is evidence that broad support for the non-autistic sibling of individuals with autism can potentially provide long-term benefits for both siblings, including decreased stress, improved social skills, and improved self-efficacy.[124] Privately funded programs for support of siblings and sibling caregivers are emerging,[125] but there are more opportunities to develop this area to meet the needs of siblings of autistic individuals who may have a lifelong role in supporting their sibling.

There also is a need to improve access to support resources in rural areas for caregivers of individuals with autism. Caregivers of individuals with autism report high levels of stress, social isolation, and poor mental health.[126] Social and emotional support may buffer negative effects of stress for caregivers of individuals with autism; however, those living in rural areas may be disadvantaged due to social isolation and increased distance from resources.[127] Healthcare professionals, including nurses, can play a fundamental role in supporting, educating, and connecting caregivers to other support services. It is important to identify and implement efficient and cost-effective ways to deliver evidence-based practices for autism to rural communities. Lessons learned during the COVID-19 pandemic highlight the potential benefit of telehealth supports and services for caregivers in rural settings in increasing behavioral parent training and navigation of complex health systems.[128-130]

Accessible services and supports for caregivers from underserved minority groups remains an area in need of additional attention. Addressing individual, family, and

systemic barriers to autism-related service access for members of racial and ethnic minorities requires dedicated resources, implementation of explicit strategies and policies, and incorporation of the principles of cultural and linguistic competence.[131] Discrimination based on race and ethnicity continues to present an obstacle to many caregivers. For example, research shows that Black caregivers continue to face more obstacles such as systemic bias and interpersonal racism when seeking supports and services compared to White caregivers of autistic individuals.[132-134] Additionally, many families may forego family employment due to the long-term care of a child. These lost earnings were estimated to reach about $18,000 per year, with families from underserved groups being disproportionately affected.[135] Affordable, evidence-based services available using culturally responsive methods should be a priority for the benefit of caregivers from racial or ethnically underrepresented groups. Private organizations like **Color of Autism**, **Sankofa**, and **Grupo Salto** have emerged to offer support for parents and caregivers of autistic children and adults from minority communities, but more groups like these are needed.

Caregiver supports for aging parents of autistic adults also need additional research and focus. Parents of adult children with autism often experience declining health, as well as shrinking informal social support systems, while caregiver burden remains constant or increases.[136] The high demands of caregiving are of particular concern for the parents of adults with high support needs, as there are often few community resources (such as day programs) available. In addition, costs associated with caring for an adult (e.g., medical care, respite care, transportation, etc.) can increase over time, while aging parents' income may either remain constant or decrease, particularly as they face health challenges and changes in income due to retirement.[137] As the growing number of people with autism enter late stages of adulthood, supports for older and aging caregivers remains an area of urgent need and additional research. Planning for succession of guardianship from parents to siblings and/or appointed legal guardians is an important need for many older and aging caregivers. Supports for family caregivers on financial planning for the care of individuals who require intensive lifelong supports is another critical need.

ONGOING AREAS OF NEED

ACCESSIBILITY AND WAITLISTS

The availability of services and supports is a key measure of their quality. Long waitlists have resulted in a two-year difference between the earliest signs of autism and the average age of diagnosis,[138] with minoritized populations waiting even longer to be evaluated.[139] Depending on state policies, autistic adults who need services and supports may spend time on long waiting lists as well. These autistic adults and their caregivers report unmet needs around functional skills training, employment or vocational services, and mental and behavioral health services while

waiting for HCBS.[140] Recent legislation has been enacted in some states to decrease waiting times.[141] Further disparities have been noted, as recent research suggests that the socioeconomic status of a neighborhood is a factor in the availability and proximity of services.[142] Because many services for autism are delivered via outpatient models, logistic barriers, such as transportation, childcare, and job accommodations, must be addressed to enhance the ability of families to appropriately access services.[143] While there are indications that telehealth may be one way to deliver diagnostic services more efficiently to cut down on the wait time, further research is needed

to establish the validity of diagnostic assessment through telehealth tools for children and adults and to train and increase the number of service providers across a range of geographical and socioeconomic settings to connect individuals to timely diagnostic services.[144-147]

Families from racial/ethnic minority backgrounds are underrepresented in evidence-based interventions and services in autism.[148-150] Additional research is needed to improve access to supports and services for families from diverse backgrounds and for whom English is not their primary language. Further, there is a need to increase cultural competency among service providers[151] and consider diverse experiences, preferences, and values in the design and provision of autism services for families and their children.[84]

THE "SERVICES CLIFF"

As the need for services and supports persists throughout the lives of people on the autism spectrum, ensuring high-quality services is key to achieving positive outcomes. As autistic youth transition to adulthood, a frequently noted disparity is the steep drop-off in the amount of supports and services available for adults compared to those available to younger children and adolescents with autism, particularly those offered through the school system under IDEA.[150] Unmet needs such as speech/language therapy, one-to-one support, occupational therapy, medication management, and social skills training often increase following an individual's exit from the educational system and entry into the adult service system.[152] This drop-off in service availability and utilization upon reaching adulthood is typically referred to as the "services cliff."[153, 154] Autistic individuals with co-occurring intellectual disability may be especially vulnerable to the effects of falling off the services cliff.[155] Youth with autism and co-occurring intellectual disability may already be more likely to experience unmet mental health care needs and receive poorer quality of care than the broader autistic population.[156]

Most autistic individuals will continue to need some types of services or supports in adulthood, but many do not qualify for adult services.[157] It is estimated that approximately 26% of young adults on the autism spectrum receive no services which could help them become employed, continue their education, or live more independently.[157] Avoiding a lapse in service provision during this critical time of transition into adulthood is an area of ongoing concern for the autism community.[158, 159] More coordination of adult services is needed, as well as availability of adult services system navigators to assist autistic adults and caregivers in coordinating adult service plans.

INDEPENDENT LIVING, HCBS, TRANSPORTATION, AND SELF-DETERMINATION

Autistic individuals often report difficulty achieving positive outcomes associated with independent living and employment.[160] Services and supports aimed at facilitating independent living for adults on the autism spectrum should consider common challenges, including limited independent living skills, financial constraints, lack of community integration and housing options, and other sensitivities and needs that may make independent living difficult.[161] For example, the Centers for Independent Living (CILs), supported by the Administration for Community Living (ACL), provide independent living services for people with disabilities, including autism. Designed and operated by individuals with disabilities, these programs provide tools, resources, and supports for integrating people with disabilities fully into their communities to promote equal opportunities, self-determination, and respect.

There is a wide array of private and state-funded services aimed at supporting individuals with autism in competitive employment.[162] The efficacy and standardization of employment related supports and career readiness services across states has not been adequately examined. The Supplemental Security Income (SSI) program provides

monthly financial assistance to individuals with disabilities who meet federally defined income, asset, and medical eligibility criteria. There has been a steady increase in the number of SSI recipients with autism in recent years, despite overall declines in total SSI awards given to adults with mental disorders.[163] However, variations in SSI awards across states could lead to substantial differences in access to other benefits, including Medicaid and vocational rehabilitation services, which often depend on SSI receipt.[164]

For both those who may live independently and those who may live with a family caregiver, HCBS provide an important source of support for many people with disabilities who need assistance to live in the community (not in institutional or congregate care settings). Medicaid HCBS programs allow those who need care to receive services and supports in their homes or communities.[165] Medicaid 1915(c) waivers in particular are a coverage option that states across the United States frequently use to provide healthcare insurance to specific populations for targeted services, including autistic individuals, although further research is needed to compare access, service use, and outcomes among autistic individuals across different U.S. states.[166]

Services and support needs around transportation and community mobility for autistic individuals can vary, depending on their geographic area and individual goals, among other factors. Autistic individuals may encounter challenges in obtaining a driver's license, driving confidence, and driving performance compared to neurotypical peers.[167] Additionally, access to public transportation is a predictor of improved community participation, as well as a significant predictor of a greater number of support service utilization.[168] Additional research is needed around strategies to facilitate public transportation travel training, although studies have begun examining travel planning mobile applications and related technologies in facilitating safe travel.[169] Transportation needs are an under-recognized

barrier to increasing independence in general, and strategies to increase independence in mobility are needed.[167, 170, 171]

The right to self-determination includes decisions around housing and activities of daily living. This aspect of choice remains important in a person's ability to participate fully in their community of choice through independent living and residential supports. There is evidence that incorporating characteristics of self-determination into residential support programs may offer autistic young adults the skills to live independently.[172] Finding affordable housing options as autistic adults age remains an issue of importance throughout the lifespan in order to avoid homelessness. There is a dearth of research exploring the utilization of housing programs by autistic people, the types of homelessness autistic people experience, and the barriers autistic people face when trying to exit homelessness.[173] Further, autistic traits may be overrepresented among homeless people, and autistic homeless people may show a distinct pattern of characteristics and needs, although further research is needed in this area.[174]

Most state developmental disability agencies fund services in the areas of transportation and residential supports.[175] However, supports and resources for improving community participation regardless of residential status remains an area of need.[176] The **Housing and Services Resource Center** was launched in December of 2021, through a partnership between the U.S. Department of Health and Human Services and the U.S. Department of Housing and Urban Development, with the goal of affordable, accessible housing in community settings. The Center will seek to implement a federally coordinated approach to providing resources, program guidance, training, and technical assistance to public housing authorities and housing providers for various populations, including autistic adults.

SERVICES FOR INDIVIDUALS WITH INTENSIVE SUPPORT NEEDS

Due to the wide array of needs and levels of needs across the autism spectrum, the supports needed by an individual can vary greatly from person to person. Autistic people with co-occurring intellectual disability and/or language disability are among those who often need more intensive supports and services across the lifespan.[177] Additional research is needed to identify how best to support autistic people who may require these kinds of services, which can include full time family or staff care, appropriate employment, day programs, medical services, daily life skills training, occupational therapy, communications supports, and other kinds of services. Their families may need additional supports as well including respite care.

The lived experiences of autistic individuals with higher support needs, their caregivers, and providers may often be missing from studies analyzing broader trends in services and supports. However, individuals with fewer perceived or less intensive support needs may still require services and supports at various points of their lives and throughout various domains in life. For example, an independent autistic adult who may appear to have few support needs may go through periods when they need significant support in the area of mental or physical health or during major life transitions. As a result, all individuals on the autism spectrum need access to appropriate supports and accommodations tailored to their individual needs.

In addition, thoughtful planning of public spaces and activities with attention to the principles of universal design, so that they are sensitive to the needs of individuals with various kinds of disabilities, including physical, intellectual and developmental, social, and sensory disabilities, can be helpful for everyone. For example, access to augmented and AAC modalities and options for written communication in group activities, sensory-friendly environments, and automated or live captioning may be beneficial not only for individuals on the autism spectrum, but for people with other kinds of disabilities or people who do not have disabilities. Disability-friendly environments provide options for more community participation for everyone.

WORKFORCE TRAINING AND DEVELOPMENT

A significant barrier in accessing services is the shortage in the workforce of direct support professionals (DSPs).[178] DSPs support people with disabilities to participate fully in their communities, in areas such as caregiving, support with daily activities of living, mobility assistance, accessing resources, emotional support, and employment support.[179] Because of these shortages, families may have to drive long distances to see providers and may experience delays or gaps in access to therapies and services.[180] Despite rising demand for DSPs, it is estimated that the median wage for direct care is approximately $13.00 per hour, with a significant proportion living below the federal poverty level and almost half relying on some form of public assistance.[181-183] DSPs are faced with a physically and emotionally demanding workload with limited training and inadequate supervision, leading to low job satisfaction and high rates of turnover. In 2018, 14% of DSPs reported not having health insurance and 71% reported having their own medical debt.[184] Addressing these issues within the DSP profession would greatly improve the availability of supportive services for people with autism of all ages.

Additional workforce-related barriers for autistic individuals and their families include difficulties accessing properly trained providers with expertise in working with people with autism.[181, 185-187] Over the past decades, several states

have enacted laws requiring health insurers to provide coverage for autism-related child healthcare services, including physical and behavioral healthcare; speech, occupational, and physical therapy; and ABA.[188] Although these state insurance mandates have been associated with a modest increase in certain aspects of the workforce (i.e., board certified behavior analysts), there are still severe workforce shortages in several professions that are critical in providing services to individuals with autism.[189] Primary care providers have often reported a lack of knowledge around a diagnosis of autism and the services and supports that may be required.

Investments are also needed that will substantially increase the direct care workforce, in order to meet the needs of autistic individuals across the spectrum. ACL recently funded a new National Center to Strengthen the Direct Care Workforce to provide support for direct care workers across the United States. The Center will serve as a hub, providing tools, resources and training to assist state systems and service providers and to support the development and coordination of policies and programs that contribute to a stable, robust direct care workforce. The Center will share training and technical assistance materials, as well as facilitate peer-to-peer mentoring and sharing of promising practices through learning collaboratives.

There have also been several recent initiatives seeking to further enhance the care that primary care providers deliver for children with autism, including initiatives offering tele-mentoring of providers like Project ECHO (Extension for Community Healthcare Outcomes), and guided curricula for providers like the **Autism Case Training (ACT)** curriculum advanced by the CDC. [190] Federal agencies such as the Health Resources and Services Administration (HRSA)'s Maternal and Child Health Bureau have leveraged innovative platforms to provide specialized training for professionals and increase access to health services through research-based screening and diagnostic procedures.[191] Further, the National Council on Disability (NCD)'s Health Equity Framework recommends requiring

comprehensive disability clinical-care curricula in all U.S. medical, nursing, and other healthcare professional schools and requiring disability competency education and training of medical, nursing, and other healthcare professionals.[192] More information is needed, however, about the uptake of these initiatives and their impact on the services being received by autistic individuals. Additionally, these workforce trainings should ideally incorporate meaningful partnerships with autistic individuals to highlight their lived experiences and follow the best practices around empowering and supporting autistic individuals.

Community health workers are liaisons between medical and social services and the community, especially in underserved communities. They advocate for change and cultural competency of services delivered, as well as improving access to quality care. They serve a critical role by providing outreach and education and assisting patients with navigating the health service system, informal counseling, social support, and advocacy. Community health workers have been utilized in various communities to convey knowledge around autism and connect families to resources in their communities. These partnerships have also proven effective at building community trust and partnerships with underrepresented groups for the purposes of culturally sensitive recruitment into academic research.[193] Further research is needed to develop evidence-based provider trainings for community health workers to support them in their work.

The literature on services and training the workforce relevant to providing services for older age autistic adults is minimal and represents a gap in the knowledge base. Caregivers employed by retirement homes and/or other long-term care facilities may not be adequately prepared to accommodate the needs of the autistic population.[194] Further research is needed to increase our understanding of the specific issues related to caring for this older population and to identify best practices for providing effective support.

COORDINATION OF SERVICES

An autistic individual's service needs are likely to vary at different points across the lifespan. Service providers, health professionals, educators, and direct support staff continually change across the lifetimes of people on the autism spectrum.[175] As autism-related services and supports become more specialized, there is a growing need for effective care coordination with providers across systems of care.[195] The interdisciplinary nature of the care required by autistic individuals will often necessitate different types of providers working in tandem to optimize positive outcomes. Supportive services may be obtained through a variety of sources: government-funded health insurance; private health insurance; out-of-pocket; federal, state, and local services programs; or grants and foundations. In some cases, services are offered based on functional needs, rather than clinical diagnosis. Individuals with autism and their caregivers often put a great deal of time and effort into piecing together a "patchwork" of supportive services through many different payors and providers in order to obtain adequate services and supports to address different areas of need.

There is evidence that current measures of care coordination in national and state samples may fail to capture lower income, under-resourced members from underrepresented racial and ethnic groups.[196] Additional systematic barriers faced by many families include differences in the type and number of services supported by insurance plans and inequities and disparities in type and number of services available among geographic location. These complexities in the service system require proactive navigation to access early screening and other timely services.

Individuals with autism may require services provided through different agencies and paid for through different systems. Care delivered across these systems often is inefficiently and ineffectively coordinated. Additionally, the financial strain on families can differ depending on the type and coverage of their individual health insurance plans.[197] With the variability in the amount of co-occurring health conditions that may accompany a diagnosis of autism, care coordinating is needed to navigate appropriate coverage of certain services and supports.[198]

SUMMARY

Across their lifespan, autistic people may need a wide range of services and supports to maximize positive outcomes and promote overall health and well-being. The Committee continues to highlight the need for researchers to focus on developing practical, affordable, and culturally competent services and support approaches that can be used in a variety of settings. Whenever possible, these approaches should prioritize the implementation and efficient delivery of evidence-based practices within the communities of choice of each autistic individual.

Effectively supporting caregivers, increasing the direct care services workforce, and enhancing workforce training are all vital to improving service delivery, especially to meet the needs of diverse populations and individuals across the autism spectrum. The services and supports landscape across the United States remains complex and can seem like a daunting undertaking to successfully navigate through. Ensuring the delivery of high-quality, accessible supports and services throughout the lifespan should remain a priority in the pursuit of health, well-being, and positive outcomes for autistic individuals with all types and levels of disabilities and abilities.

RECOMMENDATIONS

RECOMMENDATION 1. Develop service approaches and scale up and implement evidence-based interventions in community settings.

Examples:

- Develop, test, and implement effective services that increase the supply and quality of care.

- Support research to identify best practices, including systematic evidence-based collaborative approaches and federal policies, that can be applied in a variety of settings, including low-resource settings.

- Develop approaches that scale up the use of evidence-based practices in a variety of community-based settings and address the gaps between research and practice.

RECOMMENDATION 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.

Examples:

- Support research to understand and develop strategies to address health disparities, health inequities, and disparities in services access and utilization for underserved and underrepresented populations, including families with low socioeconomic resources, youth and adults with high support needs, and those who are racial/ethnic minorities.

- Develop culturally competent service provision strategies, improve the quality of care to encourage utilization, and increase person-centered care as well as other best practices to reduce disparities.

- Develop approaches for systems navigation, caregiver supports, and other strategies that reduce stress on the individual and family system and increase accessibility of services.

RECOMMENDATION 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.

Examples:

- Support training of general and specialty medical, dental, and mental healthcare and service providers in how to work successfully with patients with autism, including autistic adults with high support needs.

- Emphasize person- and family-centered planning to achieve individual goals.

- Expand the diversity and cultural competence of the service provider workforce.

- Develop improved metrics and measurement tools for health outcomes of people with autism across the lifespan, including individuals with high support needs.

- Quantify outcomes in order to inform effective service models.

- Continue research into determinants of service quality, including accessibility, continuity, and flexibility of 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.**

INTRODUCTION

Based on population and prevalence estimates, around 120,300 autistic youth turn 18 each year in the United States. According to 2017 data from the Centers for Disease Control and Prevention (CDC), an estimated 1 in 45, or close to 2%, of adults in the United States are autistic.[1] Given the growing size of the population of youth and adults diagnosed with autism, there are significant concerns about how this increase will affect adult disability service systems. Research to understand the unique needs of this growing population is required in order to develop services and programs that facilitate opportunities for people on the autism spectrum to lead healthy and fulfilling lives.

The United States does not have a coordinated services system for adults with disabilities that mirrors the system for children with disabilities that is mandated by the Individuals with Disabilities Education Act (IDEA). 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, including healthcare, disability entitlements,

higher education, employment supports, day programs, housing options, and home and community-based services, among others. State developmental disabilities departments and mental health services departments are two major sources of services for people with disabilities who qualify. Individuals on the autism spectrum sometimes do not meet eligibility requirements for services provided through the states if they do not have an intellectual disability, even though they may have significant needs. Given these barriers and complexities, autistic adults often end up not receiving services that they need.

As autistic youth transition into adulthood, studies have shown that they develop co-occurring physical and mental health conditions at higher rates than their neurotypical peers.[2-4] Unfortunately, they may not be able to find adult medical providers with training in autism or developmental disabilities. They may also have challenges finding affording suitable housing, as well as employment or programs that provide enrichment. What is known about the progression from middle adulthood into older adulthood is even less. We do know that often there are multiple transitions that

occur later in life; from employment to retirement, from independent housing to living with family members or from living with family members to living alone in an institutional environment, or from parent caregivers to siblings or other designated caregivers. Without adequate supports, these transitions have the potential to cause further decline in older adults, including accumulating physical and mental health challenges, or conditions such as poverty or homelessness if appropriate planning is not in place.

Issues related to adulthood were highlighted by the IACC in the first *IACC Strategic Plan* in 2009. Since then, there has been some growth and progress in research and development of services focused on adults with autism. Programs and research on transition age youth and young adulthood related to education, employment, housing, and other key issues have emerged. More work is needed in this area, as well as on middle age and older adulthood. The variability of support needs across the autism spectrum necessitates an individualized approach to effectively prioritize and meet the needs of each aging autistic adult at different life stages.

Across their lifespan, autistic adults report higher than average unmet needs, with receipt of autism-specific services often decreasing with age.[5] The needs of autistic adults who require intensive long term supports is an understudied area that needs more focus. Understanding the factors that contribute to health and well-being across all communities, including those with intellectual disabilities or other high support needs and those are members of communities that have been historically underserved, is critical. Learning more about the needs of adults across the lifespan 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.

DIAGNOSIS AND DEVELOPMENTAL TRAJECTORIES OF AUTISM IN ADULTHOOD

There are currently no published national estimates of the percentage of autistic individuals who received an autism diagnosis in adulthood. Autism may be misdiagnosed or particularly difficult to identify in adults due to a lack of standard diagnostic criteria.[6] The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), Module 4 is the most commonly used instrument for diagnosing autism in adults.[7] While the ADOS-2 has proven to be accurate in identifying adults with autism, the social communication difficulties it measures may not be unique to ASD.[8] As the use of DSM-5 becomes more widespread in the coming years, there is an opportunity for researchers to evaluate the effect of DSM-5 criteria on rates of adult autism diagnosis in real-life settings.[9] Additional research is needed to determine more robust standardized diagnostic criteria for autistic adults.

As discussed in Chapter 1, the development of diagnostic measures for non-English speakers, as well as culturally-grounded provision of diagnostic assessments, is needed in order to better reach minority and underserved adult populations. Another important issue for future research is that psychiatric assessment traditionally relies on self-report, whereas autism formal diagnostic practices rely more on direct observation in structured clinical settings and/or caregiver report. Childhood caregivers may not be available

or may have difficulty recalling specific behaviors that occurred many decades ago. Exclusive reliance on self-report may not be ideal, due to possible limitations in insight, communicative difficulties, or overreporting.

Current understanding of the different manifestations of autism in adulthood is limited. Research has shown that there are continuities and changes over time in the developmental trajectory of each individual with autism.[10-13] Longitudinal studies have found that some adults with autism show "improvement" in autism severity and continued growth in social skills.[14] However, the apparent decreases in autistic characteristics may be due to the fact that diagnostic instruments designed for use with children do not adequately query the types of behaviors or symptomology most relevant to adults. Furthering the field's understanding of the developmental profile of autism at all ages will be critical to achieving accurate diagnostic evaluation of autism in adulthood.

State-funded services and support programs often require documentation of an autism diagnosis prior to a certain age. This makes it difficult for a person diagnosed in adulthood to access state-funded autism-related supports. Obtaining a diagnosis in the absence of appropriate services and supports may be detrimental to well-being for some individuals. Research in this area is needed to educate adults self-referring for diagnosis about the possible benefits and disadvantages of obtaining an autism diagnosis.

For example, there is a lack of research in identifying the prevalence of autism among military veterans or active military personnel, although there is preliminary data suggesting a connection between autism-related traits and suicidal ideation/behaviors in active military personnel.[15]

The developmental trajectory of women on the autism spectrum across the lifespan has also not been sufficiently examined, potentially resulting in an underdiagnosis of autism in women. Studies have identified high rates of co-occurring mental health conditions among autistic women, with age of diagnosis being an important moderator.[16] A delayed or missed diagnosis may leave autistic women more likely to miss early intervention opportunities to address potential mental health issues early on. Additionally, the literature is limited on the experiences of women with co-occurring intellectual disability. However, there is emerging evidence on the differences in cognitive abilities and social awareness in autistic women, potentially leading to "camouflaging" of core autistic traits.[17] Studies involving self-reported camouflaging behavior and mental health symptoms in autistic and non-autistic youth and adults have found associations between higher levels of camouflaging behaviors and higher levels of symptoms such as stress, anxiety, depression, and suicidal ideation.[18-20] However, because these studies have been mostly cross-sectional, causality has not been demonstrated.

PHYSICAL AND MENTAL HEALTH

There is a growing body of literature on health and well-being in autistic adults.[3, 21-24] It is now known that adults on the autism spectrum are disproportionately affected by health issues such as immune conditions, gastrointestinal and sleep disorders, epilepsy, obesity, dyslipidemia, hypertension, and diabetes. Rarer conditions,

such as stroke and Parkinson's disease, were also significantly more common among adults with autism. Mental health conditions are also prevalent, the most common being anxiety, depression, bipolar disorder, obsessive compulsive disorder, and schizophrenia. Suicidal ideation and death by suicide have been reported at rates

higher than the general population.[25-27] Perhaps as a result of these increased physical and mental health issues, the average life expectancy of autistic individuals was only 54 years of age, in comparison to about 70 years for non-autistic individuals.[25] Autistic individuals with intellectual disability died even younger, on average at just under 40 years.

The impact of these issues on overall well-being and mortality were not well known until recent years. This was due in part to the relatively small number of studies of autistic adults and the lack of epidemiological studies detailing medical issues across the lifespan. In addition, there are very few screening and diagnostic instruments adequately validated for detecting and diagnosing physical and mental health conditions in autistic individuals.[28] Furthermore, autistic adults are frequently prescribed medications that are associated with side effects that may affect their physical health such as weight gain, although more research is needed to determine the extent of these issues.[29] Further large-scale research is needed in order to grow our limited

understanding of the co-occurring physical and mental health issues that may be experienced by autistic individuals in adulthood and old age.

In addition, more research is needed to understand what factors may contribute to physical and mental health promotion, wellness, and prevention of chronic and acute health conditions in autistic people. Activities that have benefits for neurotypical people, such as exercise,[30] healthy diet,[31] yoga, mindfulness,[32,33] high quality sleep, social engagement, and other similar practices may be avenues of further study to better understand how they may also increase wellness for individuals on the autism spectrum, particularly if tailored to their unique needs.[34] Further research is needed to understand what activities, health practices, and social and physical environmental factors contribute to optimal health and well-being for people on the autism spectrum, and if translated to health practice could have the potential to increase well-being and reduce premature mortality among autistic individuals.

HEALTHCARE

A lack of accessible healthcare services in autistic adults can contribute to increased emergency department use and reduced self-efficacy.[35] The COVID-19 pandemic may hasten the pace of research in the field of telehealth for the provision of healthcare in autistic adults (detailed further in the chapter on COVID-19). Additional research is needed to determine effectiveness of these telehealth models in providing increased access to specialized healthcare in for autistic adults. Research has found that mental health trajectories are associated with individual (e.g., adaptive functioning) and contextual (e.g., neighborhood-specific) variables, which may inform ecological approaches to care, the identification of risk factors, and treatment planning

for autistic adults.[36] The role of trauma-informed care in recognizing the compounding effects of daily stressors and significant sources of trauma,[37] and identifying creative ways to support meaningful social contact in accepting environments have been explored in autistic youth- and adolescent-focused research. This remains an emerging area for prospective research among autistic adults with co-occurring mental healthcare needs.

There is a need to increase access to sex education or reproductive health care during adolescent and adult healthcare provision in ways that will be meaningful and beneficial for life course outcomes.[38-40] Common

misperceptions about autism include the idea that autistic people are asexual or abstain from sexual behaviors. However, autistic people may often seek intimate partnerships, including sexual relationships, without adequate sexual education in preparation for adulthood or parenthood. Provider misconceptions and poor communication between providers, autistic individuals, and caregivers may also lead to key routine health procedures, such as Pap smears, being overlooked.[41] In particular,

transition-aged autistic youth demonstrated the lowest utilization of obstetrics/gynecology services, compared to similar aged youth in the general population and those with other special healthcare needs,[42] highlighting this gap in service utilization, particularly among female adolescents. Additionally, the population of autistic transition-aged youth that identify as LGBTQIA+ require unique healthcare services and may benefit from specialized healthcare models.[43]

SERVICE DELIVERY

A greater awareness of the co-occurring physical and mental health conditions that may accompany an autism diagnosis has led to a growing appreciation of the need for lifelong care for adults with autism. The lack of funding for adult disability services may hamper efforts meant to facilitate accommodation, inclusion, and independence for people on the autism spectrum. In addition, long wait times for enrollment and limited access to services across each state can have negative effects on lifelong outcomes for autistic adults.[44] Further, states also differ in how they manage waiting lists: some require assessment for Medicaid eligibility prior to adding an individual to the waiting list, while others place individuals on the waiting list without assessing eligibility.[45] Autistic adults who may be more vulnerable to poorer outcomes in adulthood due to socioeconomic status or membership in a racial/ethnic minority group also have the greatest difficulty accessing needed services.[46] To effectively meet the Aspirational Goal of greater inclusion and self-determination for all autistic adults across their lifespan, especially for those who are most vulnerable, a significant investment in quality and accessible adult disability services is needed, particularly with an eye towards an active reduction of the historic barriers to services.

An effective method to increase the quality of services provided to autistic adults across the lifespan is through the training of the provider workforce, across many disciplines, on adult-specific provision of care. As discussed in Question 5 of the *Strategic Plan*, few adult care providers have received formal training on how to support adults with autism, and as a result, report less confidence in their abilities to interact with autistic adults. Many autistic adults may often receive their healthcare in pediatric settings, due to a lack of adult providers who feel competent and comfortable treating them. Further, social communication challenges between adult autistic patients and healthcare providers may serve as a critical barrier to care.[47]

Provider trainings should emphasize improved access to up-to-date information and research and skills training relevant to diagnosis, assessment, and interventions for autistic individuals.[48] Further, among medical and pediatric trainees across all educational levels, awareness for sensory and behavioral issues present among autistic children was low.[49] This knowledge gap is significantly more pronounced in providers that treat autistic adults. As such, there is a need for training grants and initiatives focused on training professionals who will be working with adults to detect, diagnose, and address mental and physical health-related needs in this population.

Given that most adults with autism have complex needs that bring them into contact with multiple public service systems, there is an urgent need for research and initiatives focused on care coordination, interagency collaboration, strategies for integrating extant funding streams, and community-based collective impact strategies. For the transition-age autistic youth age frame, researchers have effectively applied a systems perspective to understand how factors related to service systems, as well as individual and family-level factors, impact the transition to adult healthcare services with disabilities.[50] This systems-based approach was useful in identifying strategic systems changes which could promote better outcomes, and similar approaches could be used to improve autism service systems among older adults with autism.[51] Focusing on a wide range of stakeholder perspectives in the autism community, including service providers, service users, family members, and caregivers, research on adult autism services could provide unique insight into system changes which could improve service delivery outcomes for this population.

COMMUNITY INTEGRATION, SUPPORT GROUPS, AND COMMUNITY-BASED SERVICES

Adolescents and adults with autism experience high rates of loneliness.[52] Further, autistic adults with co-occurring mental health conditions, intellectual disability, lower incomes, and those living in supported living facilities report participating in fewer, personally meaningful community activities.[53] Increased community engagement and integration can be a key way to facilitate social participation and assist in skill-building in a variety of areas, including leisure, recreation, and activities of daily living. Quality of life and overall health and well-being are positively impacted by participation in social skills groups and other types of community support groups.[54,55] Empowerment, education, and advocacy training services offered within the community can offer enriching opportunities for participation, leadership training, and volunteerism. These programs, and the incorporation of culturally grounded approaches, are particularly important and beneficial to families from racial/ethnic minority backgrounds, as they may experience increased barriers in access to care and services.[56,57,58] It is important to note that autistic adults with high support needs and/or co-occurring intellectual disability have not been sufficiently included in the literature on community participation across the lifespan, limiting the generalizability of this research to all autistic adults.

Growing awareness of the benefits of community engagement and community-based services is reflected in forthcoming updates to federal regulations. By 2023, the Centers for Medicare & Medicaid Services (CMS) will require states to be in compliance with new requirements for individuals receiving Medicaid services to spend more time participating in communities, rather than in isolated settings.[59] It will therefore be necessary to expand the availability of day programs and other opportunities for community engagement. As more emphasis is placed on the provision of community-based services, research and policy priorities should similarly emphasize the perspectives and interests of autistic adults across the lifespan and across the spectrum of need. Additionally, emphasis should be placed on supporting multi-generational autistic families (i.e., autistic parents with autistic children) in engaging in the community-based services of their choice.

EMPLOYMENT SERVICES AND VOCATIONAL SKILLS

Research has found that only about a third of autistic adults enter the labor force.[60] Many autistic adults are unemployed or underemployed, even when compared to people with other disabilities and in spite of having needed skills for the workplace.[61,62] Barriers to higher rates of employment for autistic adults include employer attitudes, access to services, and social communication in the workplace.[63,64,65,66] Studies also suggest that sustaining continued employment is a challenge for individuals with ASD.[67,68] This may be particularly true for adults with ASD who have co-occurring ID, who are at even greater risk of unemployment.[69,70] Studies of the unemployment and underemployment in autistic adults have been limited by small sample sizes and other factors. Additional research is needed to fully understand employment status stratified by support and service needs, and by income level/economic status.

Promising approaches of supported and competitive integrated employment (CIE) for autistic adults across the spectrum include matching worker skills to the job setting and description, and adjustment of continued job coaching as the individual progresses.[71-77] Another promising approach is through apprenticeships, which include on-the-job training and mentorship and typically conclude with the individual earning a nationally recognized credential. Internship programs have also been shown to be successful in transitioning people with autism to competitive employment.[78,79] Access to these pathways should be widely accessible to all individuals on the autism spectrum. In order to provide ongoing support for employed autistic adults, job-site training and access to workplace learning should remain best practices to optimize positive outcomes.

Further, studies have not yet adequately measured employment outcomes in middle aged and older adults seeking continued employment. Additional research is needed in emerging practices such as technology and customized employment in order to support autistic adults in building lifelong careers in their field of choice. Capacity-building in employment support for autistic adults is recommended based on a lack of evidence guiding existing vocational services.[73] To that end, evidence-informed resources and curricula for employment-support personnel such as job coaches are needed in building proficiency and standards of practice.

Securing CIE remains an ongoing challenge for many individuals on the autism spectrum, particularly young adults. While there remain very few studies examining comprehensive interventions for autistic individuals seeking employment, there have been some intervention research focused on specific critical components of the employment process, such as: work-specific social skills; the use of assistive technology to teach work skills and organizational skills; pre-employment interview skills; and video modeling to teach specific work skills.[71] However, these studies have been mostly quasi-experimental and have generally involved autistic individuals with above average cognitive abilities and life skill functioning.[80]

Additional research is needed to identify evidence-based interventions are needed for individuals with high support needs, such as co-occurring intellectual disability. The development of effective employment readiness practices and interventions will also require high-quality, rigorous research, ideally with randomized control trial (RCT)

designs.[81] Additionally, the high variation across states around vocational rehabilitation (VR) service use and outcomes for transition-aged autistic youth highlights the impact of state-level VR policies on employment outcomes for autistic job-seekers.[82] These VR services (e.g., job placement, on-the-job support, on-the-job training, maintenance, information referral, etc.) were significantly associated with competitive employment, however disparities remain for those with lower educational levels, those who have received cash benefits, and underrepresented racial and ethnic groups.[83, 84] Additionally, fostering early work experiences (e.g., community-based, school-sponsored, paid, unpaid) during high school remains an area in need of continued focus for disability employment policy at federal and state levels.[85] Research is also needed to better understand job retention among autistic individuals, not just job attainment.

COMMUNICATION SUPPORTS AND ACCOMMODATIONS

Communication challenges associated with a diagnosis of autism may persist into adulthood, significantly impacting the quality of life of autistic adults if no adequate supports are readily accessible. About 13,000 non-speaking youth with autism turn 18 each year in the United States.[86] In some cases, they may rely on alternative and augmentative communication (AAC) methods.[87, 88] AAC provides an effective means of communication for many autistic individuals and can involve low-tech options such as gestures, writing, drawing, pointing to photos/words, etc., or high-tech options such as speech-generating devices. While one approach is not likely applicable to all non-speaking autistic individuals, there might also be different points in the individual's lifespan at which AAC is more or less beneficial to speech production.[89-91] Additional research may help determine what AAC transitions (e.g., moving from low tech to high tech or from AAC to speech) look like for some people, as well as what targeted interventions seem best for functional communication across a person's lifespan.

Additionally, professionals in the field of communication have a better understanding of communication in autism and the potential application of AAC than in previous decades. However, many in the community, particularly caregivers of older autistic adults, may be unaware of the available range of AAC options or see the value in communication services and AAC interventions.[92] Further, additional research is needed around the availability and accessibility of live captioning and other communication supports geared at helping autistic individuals process information. Recent research has also argued for a paradigm shift away from individual support that changes behaviors, toward a system that provides support at an environmental level (e.g., peer mentoring, adapting tasks, using individual strengths).[93]

In addition to communication supports, individuals on the autism spectrum may need accommodations to facilitate participation in various domains of daily living. For example, although universities and institutions for higher learning

are required under federal law to provide accommodations for students with disabilities, many students with autism frequently report the need for further accommodations specific to the unique features of autism, such as: sensory friendly spaces and practices, educational practices designed for multiple learning preferences, support groups, and increased awareness and acceptance of self-stimulatory behaviors.[94] Although these accommodations may not be strictly academic in nature, it remains important for university disability accommodations offices to remain aware of self-reported accommodations preferences among students with lived experience.

Similarly, requesting workplace accommodations may present distinct challenges for individuals with autism compared to others with more visible or physical disabilities. For example, disclosing a diagnosis of autism may be a complex and nuanced task for individuals who may already fear stigma and discrimination.[95, 96] Additional research is needed around exploring the process around efficacious disclosures and accommodations and how these processes may potentially vary according to demographic factors (e.g., race/ethnicity, gender, age, etc.), level of support need, and industry type.

HOUSING SERVICES AND TRANSPORTATION

Residential services and housing supports are discussed in more detail in Chapter 5, but it is important to mention that these services must also be integrated with other adult-specific services as part of a coordinated system of services and care for adults with autism. Members of the autistic community and caregivers have voiced the need for additional research and policies to support aging autistic adults, many of whom continue to live with their family of origin, as their caregivers reach retirement age.[97] There is growing research detailing the increased risk of

homelessness faced by autistic individuals.[98-100] These studies highlighted the need for those providing housing services to properly understand traits of autism and the potential need for specialized housing supports. There is also a need for research on transportation access for autistic adults, including for commuting to work and traveling to school, healthcare services, and community life activities.[101] Yet, evidence to support the development of targeted programs and support is lacking in this area.[102-104]

CONTINUING EDUCATION AND ENRICHMENT ACROSS THE LIFESPAN

Pursuing postsecondary education can be important in fostering independence, self-determination, and employment success.[105] It is estimated that approximately 45% of autistic young adults will enroll in a university, college, or

technical/vocational school in the coming years.[106] However, of the students entering post-secondary education, completion rates for autistic students remains lower than that of their neurotypical peers.[107] Students on the spectrum

often report inadequate disability-related services and supports and poorer physical and mental health outcomes including loneliness and anxiety.[108, 109] Despite previous research indicating autistic students' preferences for academic support services while in post-secondary educational settings, few quality studies have delved into this area.[110] For autistic students with co-occurring intellectual disability, additional supports are needed to improve independent living skills. Additional research on promoting college readiness in the autistic students is needed to maximize positive outcomes.

Across the lifespan, autistic adults may require additional life skills building with a focus towards independence, self-determination, and community participation. However, for middle-aged and older adults with autism, the scale of need for social skills services in these populations vastly outweighs the current evidence-based offerings.[111] Ongoing education and enrichment activities should remain a priority in the support of autistic adults as they navigate complex service systems and pursue optimal life outcomes. The emergence of virtual-based social skills interventions for adults also presents unique opportunities for future research.[112]

SAFETY, VICTIMIZATION, AND INTERACTIONS WITH LAW ENFORCEMENT

Safety issues remain a key concern among the autism community. Much of the existing research has focused on autistic children and adolescents (e.g., wandering/elopement,[113] peer victimization,[114] etc.). However across the lifespan, autistic adults continue to be at heightened risk for safety issues, including negative interactions with law enforcement.[115] Autistic adults are more likely to experience victimization such as property crime, maltreatment, teasing/emotional bullying, and sexual assault by peers.[116] This may hold particularly true for adults with high support needs. Among autistic women, the rates of self-reported sexual violence are between two to three times as high as the rates among women in the general population.[117] Research is needed to further understand the experiences of victimization across the lifespan as well as the other safety risks among racial/ethnic groups (e.g., Black and Latino communities), gender minorities, and autistic individuals with co-occurring ID. Research has suggested that autistic children experience a

greater number of Adverse Childhood Experiences (ACEs) in their family and community environments.[118,119, 120] Longitudinal research is needed to examine the long-term impacts of ACEs and the way in which they may impact the mental and physical health of people with autism in adulthood.[121]

Recent advancements have been made in the tracking and reporting of cases of abuse and neglect. The Administration for Community Living (ACL)'s **National Adult Maltreatment Reporting System (NAMRS)** provides a comprehensive, national reporting system for adult protective services (APS) programs. The goal of NAMRS is to provide consistent, accurate national data on the exploitation and abuse of older adults and adults with disabilities, as reported to APS agencies. In addition, the CMS requires States to implement an incident reporting system to protect the health and welfare of the Medicaid beneficiaries who receive services in community-based settings or nursing facilities. However,

during prior audits, the U.S. Department of Health and Human Services' (HHS) Office of Inspector General (OIG) found that some states did not always comply with federal and state requirements for reporting and monitoring critical incidents such as abuse and neglect. Additional research and reports should illuminate whether improvements have been made in the facilitation of incident reporting for individuals with disabilities, including those with autism.

Autistic individuals may interact with law enforcement officers as victims of crime, witnesses to crime, or suspects of crime. Unfortunately, the majority of law enforcement officers report receiving no formal training for interacting with autistic individuals.[122] Law enforcement officers may use physical force unnecessarily or escalate problem behavior when attempting to gain the compliance of individuals with autism, particularly in individuals from racial/ethnic minority populations.[123] There are currently a limited number of programs to improve safety for individuals on the autism spectrum. In some communities, policy officers, judges, and first responders receive specific training on autism. Despite this, the current research is insufficient to inform evidence-based programs to ensure safety among adults on the autism spectrum in all areas of life. Research is needed to support the development of specialized training programs for law enforcement officers and first responders to develop a better understanding of autism, address implicit biases, and improve awareness of safety issues.[124]

FINANCIAL PLANNING

Addressing service needs often requires out-of-pocket expenditures for services that are not covered by public or private insurance. For autistic individuals and their families, financial planning is a way to ensure that costs for desired services can be covered across the lifespan of the individual. The Achieving a Better Life Experience (ABLE) Act of 2014 allows states to create tax-advantaged savings programs for eligible people with disabilities (designated beneficiaries). Funds from these 529A ABLE accounts can help designated beneficiaries pay for qualified disability expenses and thus facilitate planning for future expenditures.

SPECIAL CONSIDERATIONS FOR TRANSITION AGE YOUTH WITH AUTISM

In the years since the release of the *2016-2017 IACC Strategic Plan*, research on the transition to adulthood for autistic youth has continued to reflect findings of suboptimal outcomes compared to non-autistic peers regarding employment, continuing education, relationships, independent living, and physical and mental health. According to a 2015 report,[52] 26% of young adults on the autism spectrum did not receive any services including those that could have helped them gain employment, continue their education, and live more

independently. Individuals from minority backgrounds have even poorer outcomes in these measures.[125] Along the varying spectrum of needs, challenges in social cognition and executive function can cause difficulties as the expectations around adulthood become increasingly complex and supportive services are less readily available.[2, 126] Interventions and services such as college readiness programs, social skills training, and supported employment interventions are becoming increasingly utilized as part of the pathway to successful transition to adulthood. Additional studies are needed to fully assess outcomes during the transition period for autistic young adults, including population-level approaches.[127, 128]

Although existing interventions often focus on skills for independence, members of the autistic community still mention the need for more person-centered strategies tailored to the individuals' unique goals and challenges.[129] Further, interventions that focus on enhancing cognitive and language skills as well as teaching daily life skills are vital in nurturing independence among autistic adolescents.[130] Ongoing assessment of adaptive behaviors can help identify areas that are in need of improvement and help to identify goals that can be targeted across environments.[131] Further research is needed to explore the use of virtual modalities, remote instruction, and person-centered strategies for the support of daily life skills.

Despite the need for high quality healthcare into adulthood, there is ample evidence that healthcare services for autistic youth are frequently disrupted during this transition period. There is a notable decline in service utilization across office/outpatient and inpatient settings but stable use in emergency and home settings as autistic youth transition from pediatric to adult healthcare.[132] More than 1 in 4 autistic adolescents lost Medicaid coverage during the transition into adult healthcare services and fewer than half subsequently regained it.[133] The transition from pediatric to adult systems of healthcare has been noted as a particularly challenging period for children and adolescents with disabilities.[134, 135] The American Academy of Pediatrics (AAP) notes that this critical intersection between pediatric and adult healthcare systems requires that high-quality, developmentally appropriate healthcare services be available in an uninterrupted manner as the person moves from adolescence to adulthood. This requires the careful coordination of patient, family, and provider responsibilities.[136]

Unfortunately, a coordinated approach to healthcare transition is infrequently implemented for autistic youth.[137-139] Further, successful transition of autistic youth to the adult healthcare system requires the availability of transition services. Yet despite facing complex healthcare needs, such services are often simply unavailable to autistic youth, and many in this age group have difficulty finding adult providers on their own.[140] Communication, social, and physical challenges already experienced by this population may compound these difficulties.[141, 142] It is therefore critical to increase the availability of transition services in order to facilitate a straightforward and coordinated transition to adult healthcare.

SPECIAL CONSIDERATIONS FOR AUTISTIC ADULTS WITH HIGH SUPPORT NEEDS

Given the heterogeneity of autism, there are a wide range of supports and services that a particular individual may need as they age into adulthood and beyond. Research indicates that adults with high support needs face poorer outcomes compared to their neurotypical peers or autistic adults with lower support needs (i.e., higher adaptive skills and cognitive ability).[69, 143-145] There has been growing discussion within the community on potential ways to better meet the needs of individuals with high support needs (e.g., autistic individuals with co-occurring intellectual and/or language disability requiring intensive supports) and the generalizability of currently available adult autism services to this population.[146]

There is currently limited knowledge on the services and supports that would benefit autistic adults with co-occurring intellectual disability across multiple domains of life. Currently available outcome measures can be further refined to accurately capture positive outcomes (e.g., social experiences, daily skills and experiences, autonomy, etc.) that are relevant to autistic populations with high support needs.[147,148] The perspectives of families and caregivers are critical in developing relevant and effective supports and services to optimize quality of life and well-being across the lifespan for autistic individuals with high support needs.

SPECIAL CONSIDERATIONS FOR OLDER ADULTS WITH AUTISM

In recent years, studies have begun to identify a high prevalence of health conditions (e.g., autoimmune conditions, obesity, cardiovascular disease, gastrointestinal disorders, sleep disorders, psychiatric conditions) as autistic individuals age into midlife and beyond.[3,149, 150,151,152] Several studies have pointed to elevated rates of neurodegenerative diseases such as Parkinson's disease and related issues (e.g., stiffness, tremor) in adults with autism.[3, 153, 154] In addition, prevalence of early-onset dementia is 2.6 times higher among autistic adults.[155] Research has begun to elucidate the neural and other biological mechanisms, as well as social environmental factors, that may underlie these elevated rates of co-occurring health conditions. Studies have found specific age-related changes in the brains of autistic adults in terms of both cortical thickness and brain volume.[156-158]

Further work is needed, particularly longitudinal studies of lifespan trajectories, to gain a better understanding of the biology of aging in autism as well as associated medical conditions and co-occurring mental health issues. More research is also warranted to better understand the unique challenges of aging in autism. For example, in one study of the developmental trajectories of individuals with autism

as they aged found that in comparison with people with intellectual disability alone, autistic individuals lost their activities of daily living skills faster and more markedly, suggesting that autism may lead to greater levels of disability.[159] A critical question to tackle is the interplay between nature (biology) and nurture (lifestyle, services access, experience) and how these contribute to the physical and mental health outcomes observed for older autistic adults. Additional research is also needed on screening, diagnosis, and assessment tools for older adults; menopause in older autistic women;[160] as well as the effects of long-term psychotropic drug use.

In providing care for aging autistic adults, most geriatric healthcare providers do not have adequate expertise or knowledge about autism, and there is currently no knowledge base about best medical practices that may be specific to this population. Additional work is needed at the systems level to design interventions that can be implemented by geriatric health practitioners in community settings. In addition, enhanced mechanisms to support clinical and research training are needed to support and expand the expertise of healthcare professionals in working with aging adults with autism.[161]

An additional area in need of enhanced focus is the available service and support networks for aging adults with autism. Many older adults with autism live with their families,[162,163] and their support and social needs may be significantly impacted by the death or incapacitation of their parents or siblings.[161] There is a lack of evidence that existing models of care can meet the needs of older autistics adults, and growing concerns that the current long-term care workforce is not trained to address the unique needs of aging adults with autism.[161] Further research, including population based studies, are needed to identify and understand the unique needs of older adults on the autism spectrum so that services can be tailored to address their needs. Supportive services to provide assistance to families and individuals in planning for older adulthood, succession planning, and establishment of financial, housing, and services-related supports are also critical to ensure that older autistic adults have a viable plan for long-term care. Due to advances in autism research and services, the aging autism population of today is likely to be somewhat different from the aging autism population that we will see in 20 years' time. Thus, ongoing evolution of the system of supports and continually updated provider training will be critical to ensure that the changing (and potentially expanding) needs of the population are met.

POLICY ISSUES

In recent years, autistic academics have called for increased community participation in autism research.[164-166] A shift has occurred toward more inclusive research agendas and intervention programs that engage directly with autistic individuals and their families, including their perspectives in conceptualizing research goals and intervention outcomes.[167, 168] There is growing focus on societal accommodation, rather than removal of the differences, that make individuals with autism unique.[127, 168]

Community-based participatory research hinges on meaningful and trusting relationships with members of the autism community; relationships that may take time to develop but are essential for research that is equitable, respectful, and aligns with community priorities.[169] As effective participatory research often takes more time and is more expensive than traditional research, systemic shifts within the autism research establishment are needed in order to facilitate more frequent and more equitable

engagement with community partners.[166, 170] These include greater education and training of autism research stakeholders, adjustments in the evaluation of grant proposals, and extension of funding cycles and project timelines. Several organizations, such as the **Academic Autistic Spectrum Partnership in Research and Education (AASPIRE)** have formed successful academic-community partnerships composed of autistic and non-autistic academic scientists and community partners to conduct research relevant to the needs of adults on the autism spectrum.[171, 172] As service delivery systems and governmental policies are refined to meet the needs of autistic adults, the meaningful participation of autistic lived experiences will be critical in ensuring that the perspectives of all adults on the autism spectrum are adequately addressed.

SUMMARY

There is a growing evidence base documenting the challenges faced by autistic adults in acquiring needed disability services, accessing healthcare, finding appropriate competitive employment or vocational activities, long term supports, community integration, and achieving other positive outcomes in adulthood. However, critical knowledge gaps remain in our understanding of the full range of need across the entire autism spectrum, across all levels of ability and disability, sex/gender, race/ethnicity/culture, and age. It remains unclear how much of the current knowledge regarding best practices will translate to autistic adults and families who are underrepresented in the literature. Thus, further studies should focus on including more diverse participants, including families with low socioeconomic resources, adults with high support needs and their families, older autistic adults, those who are of racial/ethnic minorities, and women and LGBTQIA+ individuals on the spectrum.

It is unlikely that meaningful progress toward the Aspirational Goal will be made without substantially increasing funding for autism research and services focused on adults across the lifespan. Research focused on adult issues has lagged far behind other types of autism-related research, comprising only 4% of all autism research spending in 2020.[173] Fundamental questions around the developmental trajectories and life outcomes of adults with autism remain unanswered. As adult-specific services and supports are developed and implemented across multiple communities, additional research and programming targeted toward addressing the unique needs of autistic adults is necessary in order to ensure that these interventions and services remain effective and efficient across multiple domains of adult life. A strengthened level of support for this work will be needed in order to meet the current and growing needs of the population.

RECOMMENDATIONS

RECOMMENDATION 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.

Examples:

- Use population-level data to understand unmet needs, disparities in access and outcomes, emerging usage trends, cost issues, and the effectiveness of adult services in achieving their desired outcomes.

- Develop improved adult service models and coordination across agencies and systems (e.g., education, vocational rehabilitation, employment, housing, healthcare, social services, communication supports, law enforcement, older adult services).

- Develop strategies for reducing socioeconomic or racial/ethnic disparities in service access and related outcomes for autistic adults.

RECOMMENDATION 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.

Examples:

- Develop approaches for diagnosing autism in adults.

- Develop services approaches to address autism and co-occurring physical and mental health conditions in adults, as well as approaches to promote wellness throughout the lifespan.

- Conduct large-scale longitudinal studies across adulthood into older age to examine trajectories of physical and mental health conditions, and address the additive and interactive effects of biological, cognitive, behavioral, and environmental factors that lead to co-occurring conditions.

- Engage adults on the autism spectrum and their families in collaborative and participatory research to better understand adult needs, provide input on research plans, and conduct research that addresses community-based health priorities.

- Identify social determinants of health that impact autistic adults, including those in underserved populations, and strategies to improve outcomes.

- Conduct long-term follow-up studies examining the effects of interventions and services delivered in childhood on later adult outcomes.

RECOMMENDATION 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.

Examples:

• Support research and programs on accessibility, acceptance, accommodation, inclusion, and universal design, including barriers, impacts, and best practices.

• Support research on person centered planning, self-direction, independent living, and community integration.

• Support efforts to increase the accessibility of research, services and supports programs by providing plain or easy read program guidance, simplified processes, accessible forms, remote access, accommodations for different communication modalities, and other disability-friendly procedures and processes to increase the ease of access for autistic individuals and their families.

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.**

INTRODUCTION

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. Progress toward the Aspirational Goal above has been rapid in recent years. New databases are being built to leverage recent genetics findings, and initiatives to share biospecimens among multiple research efforts are intensifying. Funders such as the NIH are putting increased focus on data sharing by integrating the sharing

requirements into funding announcements. The increased availability of resources has advanced the efficacy and speed of autism research. Meanwhile, many funders are making efforts to increase the breadth and diversity of the research workforce, ensuring that the field is equipped to address the most pertinent issues of the entire autism community. Additionally, new efforts to enhance prevalence data monitoring systems include streamlining methods and expanding the age groups that are monitored.

BIOREPOSITORY INFRASTRUCTURE

Biological materials repositories collect, process, store, and distribute biospecimens to support scientific investigation. In the autism research community, biorepositories have been developed to support collection and dissemination of brain tissue, fibroblasts, and other tissues. Greater participation in brain and tissue banking is needed from members of the autism community in order to obtain enough samples to meet research requests. Outreach campaigns to encourage families to donate brain and other tissue need to be expanded and enhanced, especially among underrepresented groups.

Post-mortem brain tissue is an important resource for understanding the impact of autism on brain structure, organization, and function. The **NIH NeuroBioBank** was formed in 2013 to address the increasing demand for postmortem human brain tissue for research purposes.[1] This resource provides tissues from donors with wide-ranging neurological and neurodevelopmental disorders, including autism. The NIH NeuroBioBank supports six independent brain and tissue repositories. A more autism-focused brain tissue collection effort was undertaken in 2015 by the **Autism BrainNet**, managed and supported by the Simons Foundation Autism Research Initiative (SFARI). The program supports five collection nodes in the United States, Canada, and the United Kingdom that share standardized protocols for tissue harvesting, storage, and tissue dissemination for research purposes. AutismBrainNet has also recently undertaken an effort

to perform genetic analysis of donated brain tissue. This will provide researchers with additional data to understand the linkages between genetic changes and phenotypic differences in autism. Autism BrainNet also has a robust public awareness campaign to encourage donation, led by the Autism Science Foundation.

The **NIMH Repository and Genomics Resource (NRGR)** is another biorepository that plays a key role in facilitating autism research. The Repository collects and stores several types of biomaterials, including DNA, immortalized cell lines, and reprogrammed stem cell lines; accompanying genotypic and phenotypic data are also available to qualified researchers worldwide.

The availability of biospecimens from these repositories has had a substantial impact on autism research. Numerous studies have been published using tissues from these resources, and many researchers have requested access to the data in order to enrich their own data or otherwise further autism studies. In order to expand the impact of these resources, more potential donors must be identified and educated on the benefits of tissue donation. Crucially, researchers must address all ethical considerations, and ensure that donated tissues are managed responsibly. Repositories must continue to ensure that tissues are procured, stored, and distributed according to applicable state and federal guidelines and regulations involving consent, protection of human subjects, and donor anonymity.

DATA INFRASTRUCTURE

Data infrastructure refers to data collection, storage, sharing, and consumption to support autism research, services, and policy development. Autism is a highly heterogeneous condition requiring large sample sizes to make significant findings. Thus far, tens of thousands of research subjects have consented to make their genomics, imaging, and clinical research data available to scientists in the hope that those data will help lead to important research discoveries. These datasets have become very large and have grown exponentially due to rapid advances in technology, new methods of data acquisition, and the integration of patient-directed reporting applications. Other research communities have established related data repositories and funded data sharing initiatives and made those datasets broadly available for use by the autism research community. Given the size of these data and the complexity of the software, algorithms, and analytic methods used, it is essential that all the data and associated metadata be shared when a result is published or a significant finding is announced. Ensuring that all data is shared will increase the rigor and reproducibility of findings, a core responsibility of publicly funded research.

DATA BANKS

New findings, technologies, and research methods have emerged that can drive autism research forward, capitalizing on advances in participant engagement and the collection of large data sets. Together, these participant-powered and clinical data networks can be further leveraged for rapid research on large numbers of participants throughout the country, offering the potential for a broad and rich view of the health and well-being of autistic individuals and their families.

The **NIMH Data Archive (NDA)** houses, harmonizes, and shares all human-subjects data collected as part of NIMH-funded projects with the goal of accelerating progress in the research of mental health. The NDA uses a de-identified research subject identifier (the Global Unique Identifier, or GUID) and a precise method for associating research data with publications/results.[2] NDA also supports common data definitions, which provide a standardized set of data collection measures that ensure that results across studies can be accurately combined or compared. Additional investment is needed to enhance the NDA to maximize its use and usability, and to extend the infrastructure to support big data analytics better and to integrate it more fully with other biobanks and genomics data repositories.

Another mechanism for data sharing is the **Autism Sequencing Consortium (ASC)**, an international group of scientists who share autism samples and genetic data.[3] Currently, ASC has whole exome sequencing (WES) data for over 35,000 samples.[4] Permission to re-contact research participants from completed studies exists for many of the samples within the ASC, which are managed by the contributing site.

In 2016, the Simons Foundation launched **SPARK (Simons Foundation Powering Autism Research for Knowledge)** to recruit, engage, and retain a large cohort of individuals with ASD. SPARK has enrolled 123,000 individuals with autism and over 175,000 of their family members to participate in autism research. To participate in SPARK, families enroll online, provide saliva samples for genetic analysis, and agree to be re-contacted for future research opportunities. SPARK participants are being sequenced and genotyped to identify new genes associated with autism risk, and individual clinically confirmed genetic causes of

autism are returned by a genetic counselor provided by the study. Clinical, behavioral, and genetic data on the SPARK cohort are available to all qualified investigators. ResearchMatch, a nonprofit program that helps to connect people interested in research studies with researchers, has approved 226 studies to recruit SPARK participants to other autism research studies including 12 treatment/ clinical trials. Over 50,000 participants have participated in at least one ResearchMatch study. SPARK partners with 32 U.S. medical schools and autism research centers to recruit autistic individuals and their family members.

DATA SHARING

When all research projects share their data, the quality of the accumulated data increases. For example, when a new research participant is enrolled in a research study, that person may also have registered previously with one or more data or biorepositories. If the data are linked and widely accessible to researchers (with appropriate privacy protections in place), the potential richness of the information available on that participant is thereby enhanced. Sharing of data will also reduce the burden of participation in research studies on the autistic community. If an individual's data can be used for more than one study in a coordinated manner, then the participant can be assured that the yield of their time and energy committed to research participation is maximized.

NDA provides an infrastructure to make data broadly accessible to the research community through a universal platform and federation with other data sources. To make NDA the most useful resource possible, autism researchers must improve both the consistency and quality of the data that is shared. It is especially important to share the data that supports published results, which will allow the infrastructure to be better utilized and support the dissemination of scientific advances. In addition, improvements to the NDA infrastructure will allow easier access to the data contained within it, so that it can be

leveraged to its full value. NDA and similar data sharing efforts can help maximize the return on federal and private investment in autism research made over the last decade.

In 2022, The White House Office of Science and Technology Policy (OSTP) issued guidance on Desirable Characteristics of Data Repositories for Federally Funded Research.[5] This guidance includes several recommendations, ensuring that data is freely and easily accessible, uses unique identifiers, provides clear instructions for how it is to be used, and is stored securely in a common format. The guidance also includes special considerations for the sharing of human data, including additional security safeguards and standards for participant consent. Most repositories already comply with these guidelines, but it is important to continue harmonizing repository standards in the future in order to increase access, maintain privacy, and ensure interoperability. Responsibly sharing high quality data will increase the return on the collective research investment, protect intellectual contributions, and help accelerate research discovery. Collectively, open data sharing offers the best opportunity to reach the sample sizes that are likely needed to improve understanding of autism and related disorders.

Care should be taken to ensure that all stakeholders across the research enterprise understand the importance of data sharing. To facilitate data sharing in research involving human participants, an identifier or code is used to identify and link each individual to his or her specimens and associated medical information. The use of a de-identified code (i.e., a code that does not reveal the identity of the individual) maintains privacy of the individual's information. Use of these unique identifiers across biorepositories and data repositories will allow linkages across these resources and thereby increase their usefulness and efficiency. However, it will be important for study subjects to be fully informed of the potential uses for their tissues/data and to provide consent for future use as they are comfortable.

HUMAN INFRASTRUCTURE

Human infrastructure refers to the development of human resources necessary to support autism research and services. Human infrastructure for research includes developing a professional workforce to conduct research and provide services, as well as encouraging individuals with autism and their family members to participate in research. In addition, systems must be developed to share research findings with community stakeholders and translate research findings into policy and practice. Human infrastructure for services is discussed in more detail in Chapter 5.

RESEARCH TRAINING AND WORKFORCE DEVELOPMENT EFFORTS

There are several efforts underway to enhance research training and workforce development. Several federal and private funders support research training opportunities including, but not limited to, training and career development grants and travel awards for early career investigators to attend conferences. In many cases, these awards emphasize building relationships with experienced mentors and encourage multidisciplinary avenues of exploration. In recent years, the NIH has also offered funding for mid-career investigators from other fields to transition into autism services research. This program was created in response to the recommendations from the IACC to expand the research workforce that studies autism services. Increased attention should be devoted to supporting early career researchers in order to increase their opportunities for developing stable research programs. Additional support for interdisciplinary and transdisciplinary researchers will bring new approaches to answering existing questions in the field.

Workforce development is an area of immense need as the number of identified individuals with autism continues to grow. While progress has been made in early detection and intervention, and in the support of children on the spectrum, much less effort has been expended on research and services relevant to adults. Further, there is a dearth of trained medical professionals that are knowledgeable in providing care to the autism community, particularly the adult community. Federal funding for workforce development and training is limited. It is important to ensure that workforce development programs and training efforts are evidence-based and that their delivery is standardized across communities. The development of best-practices guidelines will enhance the implementation of such training programs.

It is particularly important to increase recruitment and training of autistic researchers, as they are intimately aware of important issues and thus well suited to address the needs of the autistic community. In 2020, the International Society for Autism Research (INSAR) appointed its first Autistic Researchers Committee, in part to foster scientific career development for autistic researchers and to create opportunities for autistic scientists to offer their insights to colleagues. In the future, it will be essential to expand initiatives such as this in order to better support autistic researchers and integrate their experiences into the research process.

PARTICIPATION IN RESEARCH STUDIES

The participation of autistic individuals in research studies is crucial in order to build knowledge about the autistic experience across the lifespan, to build the evidence base for interventions, and to identify the most effective and

efficient services and supports. Individuals on the autism spectrum and their families participate in research studies at relatively low rates, often due to unawareness of opportunities, not perceiving research as relevant to their needs, apprehension about the methods involved or the goal of the research, ethical concerns about how data will be used, and/or fear of stigma or bias.

Coordinated efforts are needed to educate stakeholders from diverse backgrounds on the personal and community benefits of participating in research, the level of risk associated with the study (if any), and the privacy protections in place to maintain anonymity. Simultaneously, researchers should be open to the designing their studies around the stated needs and wants of autistic individuals and their family members and ensure that studies are inclusive of diverse populations. This can be best achieved using Community-Based Participatory Research (CBPR) methods, engaging stakeholders in the earliest stages of research study design, and ensuring that diverse communities are included in outreach efforts. Particular efforts to include individuals across the full spectrum of autism, especially those with intellectual disabilities or communication challenges who are often excluded from research, are necessary. Research should also be conducted to understand the barriers that discourage participation.

It is vital that individuals across the autism spectrum have opportunities to participate in research if desired. In particular, individuals with high support needs are often excluded from research studies due to the nature of their traits/behaviors and the potential difficulty of accommodating them in certain research methodologies. Researchers must identify ways to overcome these obstacles to participation.

DISSEMINATION OF AND ACCESS TO RESEARCH FINDINGS

Increasing and improving mechanisms for dissemination of research findings after publication should be a priority for the autism community. It is vital that findings and data become more accessible to researchers, practitioners, autistic individuals and their families, and the general public. Training to improve science communication skills should be more readily available to researchers who wish to share their work with lay audiences.

Clear communication about the risk and/or benefit of research methods and findings is particularly important, as the information disseminated to the public is sometimes contradictory, oversimplified, overstated, or sensationalized. This misinformation can have a negative impact on research participation. Whenever possible, it is important that the research information communicated to the public is written in plain or lay-friendly language. Information should also be translated into multiple languages when appropriate, in order to increase the accessibility of information to non-English speaking populations. Mechanisms that allow for the summation of the evidence base into actionable recommendations such as systematic reviews and meta-analyses are encouraged. Much of this work will be more feasible as the data sharing infrastructure further develops and expands.

INTERNATIONAL COLLABORATION

Most autism research is currently published by researchers in the United States, Canada, Europe, Australia, and China, with only a small proportion representing international collaborations and/or studies in low- and middle-income countries (LMICs).[6] Thus, many of the benefits of autism research may not be reaching or be applicable to populations in LMICs. In addition, the research community may be missing opportunities to include and learn from diverse cultures and settings, to diversify their study samples, and

to study populations with different kinds of challenges. Therefore, researchers and funding organizations should seek opportunities to collaborate with researchers from other regions of the world, particularly those with lower research capacity.

International research collaborations not only present opportunities to disseminate and implement evidence-based science and services in diverse settings around the world, but also allow the autism research community to learn about how diverse populations, including those from low-resource settings, have addressed issues such as limited research infrastructure and large service gaps. For these reasons, it is imperative that international research efforts and collaborations continue to be promoted and supported.

PREVALENCE MONITORING

Population-based statistical data gathering, or surveillance, for autism spectrum disorder is essential for monitoring prevalence over time, assessing patterns by demographic factors and necessary level of support, characterizing co-occurring conditions, estimating resource needs, and stimulating research into potential environmental factors. For the data provided to be used effectively, surveillance efforts should be as complete and valid as possible. Population-based studies of the prevalence and characteristics of ASD among children in the United States has been ongoing since the year 2000, and more recent studies have also estimated the prevalence of autism among adults. However, sustained investment is necessary to continue and expand these efforts to fully assess the needs of the autistic population.

There are several different methodologies currently used for estimating the prevalence and characteristics of ASD among children, including: 1) use of administrative records; 2) parent or caregiver surveys; 3) expert review of records from multiple sources; and 4) screening and examination of children. Each of these methodologies has strengths and limitations. Administrative records are readily available and cost-effective to use, but are collected for other purposes and do not always contain adequate and pertinent information. Health surveys are nationally representative, generate data relatively quickly, include extensive questions on service needs and utilization, include a comprehensive age range of children, and are cost-effective. However, the validity of parent/caregiver-reported ASD has not been established, and low response rates have raised concerns about bias. Expert review of records from multiple sources, including healthcare and education records, can ascertain records-based data on a number of factors such as demographics, educational placement, intellectual and adaptive function, and behavioral phenotype. However, this methodology is dependent on the data that is present in children's records, focuses on a few specific ages, and is resource- and time-intensive. Therefore, it cannot currently be done at a national level. Finally, screening and examination of children using a standardized and validated ASD diagnostic tool is a rigorous methodology that attempts to give all children in the selected population an opportunity for ascertainment. However, this methodology is also resource- and time-intensive and cannot currently be done on a national level. In addition, low response rates in previous studies suggest a potential for bias.

Autism prevalence monitoring systems should be complementary, offering unique strengths and contributions that will further the understanding of the population of autistic individuals. Where appropriate, data collection

should be designed to allow comparisons across systems. Further linkage of surveillance data with other state and federal datasets should be encouraged to leverage existing surveillance efforts and expand the scope and utility of the information collected.

While many research studies are focused on understanding and meeting the needs of children on the autism spectrum, much less research has been done on adults. Using state-based data on children with ASD, the CDC recently estimated the prevalence of adults with ASD at 2.21%.[7] There is an urgent need to expand autism surveillance efforts to adults to fully understand prevalence, adolescent/young adult transition needs, employment and housing, co-occurring conditions, premature mortality, and other lifespan issues. In particular, investigating autism prevalence in adults will help researchers understand how the interaction of autism and co-occurring conditions impacts the ability to adults with autism to live and work.

FEDERAL PREVALENCE MONITORING PROGRAMS, SURVEYS, AND ADMINISTRATIVE DATA SOURCES

Autism and Developmental Disabilities Monitoring Network

The **Autism and Developmental Disabilities Monitoring (ADDM) Network** is a population-based surveillance program for ASD and other developmental disabilities. The CDC has been conducting surveillance for ASD among 8-year-old children through the ADDM Network every 2 years since 2000 at sites throughout the United States. The most recent prevalence estimate for 2020 was 27.6 per 1,000 (1 in 36) 8-year-old children.[8, 9] In 2010, the ADDM Network was expanded to include surveillance for ASD among 4-year-old children. The program was further expanded in 2018 to conduct follow-up studies on 16-year-olds who came to attention 8 years earlier in ADDM Network surveillance.

In 2018, the ADDM Network streamlined its methodology; rather than training clinicians to review records for symptoms, ASD cases are determined by presence of either an ASD diagnosis, autism special education classification, or ASD ICD-9 or -10 code for autism in health records.[10] Compared to the more labor-intensive review methods, the streamlined case definition yields similar results but has sped up the reporting timeline by a full year. There are currently 11 sites monitoring 8- and 4-year-old children; 5 of which are also performing follow-up studies on 16-year-olds. The updated methods have allowed linkage to additional important data sources such as Medicaid and early intervention (Part C) programs, and enabled a pilot project to provide statewide county-level ASD prevalence estimates for the first time.[11]

National Survey of Children's Health

The National Survey of Children's Health (NSCH) is currently administered by the Maternal and Child Health Bureau of HRSA. This nationally representative telephone survey of children's health and development is based on parent/caregiver report. It includes questions on whether the child currently has ASD, as well as whether a healthcare provider ever informed the parent or caregiver that the child had an ASD diagnosis. Data are also collected on a variety of topics including the child's health, health as an infant, recent healthcare service, experiences with healthcare providers, health insurance coverage, sociodemographic factors, and the child's learning, home, and family environments. In the most recently published dataset (collected in 2020), ASD prevalence was 2.7% for children aged 3-17 years. Beginning in 2016, this survey was moved to a mail-invitation, online survey based on a U.S. Census Bureau sampling platform. This survey has been combined with the previously fielded National Survey of Children with Special Healthcare Needs. State-level estimates are available for many variables.

National Health Interview Survey

The CDC conducts the National Health Interview Survey (NHIS), a nationally representative survey of parents/caregivers that provides data on the health of children in the United States, including information on whether a healthcare provider ever informed the parent or caregiver that the child had an ASD diagnosis. Data is collected by the U.S. Census Bureau through personal household interviews. The content and structure of the NHIS were updated in 2019 to better meet the needs of data users. Aims of the questionnaire update were to improve the measurement of covered health topics, reduce respondent burden, harmonize overlapping content with other federal health surveys, establish a long-term structure of ongoing and periodic topics, and incorporate advances in survey methodology and measurement. Data are collected on children aged 0-17 years every year on a variety of topics including the child's health status, healthcare access and utilization, and a mental health screener (the Strengths and Difficulties Questionnaire), as well as family factors, including sociodemographic factors. ASD prevalence was 2.76% for children aged 3-17 years in 2016.[12] As with NSCH, linkages to data from other federal agencies should be encouraged to expand the scope and usefulness of the data.

IDEA Section 618 Child Count Data

The Individuals with Disabilities Education Act (IDEA) requires the Department of Education (ED) to classify children with disabilities who receive special education and related services into 13 primary disability categories, including ASD. Under Section 618 of IDEA, states are required to report the number of students (ages 3-21 years) with the primary disability category of ASD who receive special education and related services under IDEA Part B. States must also submit data about the infants and toddlers (birth through age 2) who receive early intervention services under Part C of IDEA. These data can be used to estimate the number of children and young adults with ASD, although it only accounts for those currently receiving services

through IDEA. Therefore, children who have not yet been diagnosed with ASD or those who are receiving services from other sources are not included in this count. Also, children may be assigned an autism classification based on service needs, even if the state does not consider the child to have autism.

Medicaid Administrative Data

Prevalence estimates can also be generated by examining administrative claim data submitted to the Centers for Medicare and Medicaid Services (CMS). All states send Medicaid healthcare administrative claims data to CMS annually. Children with ASD are identified by those who are receiving Medicaid benefits who have at least two outpatient billing codes for ASD or one inpatient billing code for ASD in the specified year. These prevalence estimates are limited to children using Medicaid insurance.

LINKAGES ACROSS NATIONAL SURVEY AND ADMINISTRATIVE DATA

As noted above, several federal departments and agencies collect information about individuals on the autism spectrum. Although each responsible agency may focus on its own research and services priorities when collecting and analyzing the data, synchronization of the national data sources will maximize their utility. Concordance of questions and sampling across surveys and administrative data could greatly add to the comparability of research undertaken across these national platforms. Additionally, infrastructure for linking these surveys to other sources of data is essential. For example, the CDC links the NHIS to administrative records from the Department of Housing and Urban Development (HUD), which allows for the addition of detailed housing information for NHIS participants who use HUD services. The CDC recently launched and updated an **interactive autism data visualization website** which presents the most up-to-date state-based autism prevalence information from four major data sources: CDC ADDM Network, ED administrative data, CMS administrative

claims data, and HRSA's NSCH. Additionally, Federal Statistical Research Data Centers make national data from the Census bureau, CDC, and the Agency for Healthcare Research and Quality (AHRQ) available to researchers in one place. More projects like these, and additional means of capitalizing on existing datasets, are key priorities in order to generate an expansion of the information available on autism to a nationally representative sample.

SUMMARY

Continuing to build the infrastructure necessary for autism research is an important priority. In particular, researchers must continue efforts to standardize data collection and share with others in order to build higher-powered studies across multiple areas of research. Research institutions must continue to support biobanks and databanks, and to work towards integrating common collection and processing methods. 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 make significant contributions to 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 those who are impacted by autism. Continued optimization of prevalence data monitoring efforts, including expansion to gather data on adults, will better inform research and service priorities. Finally, funding agencies should continue to devote resources to ensuring dissemination of research findings and best practices, gaining better understanding of autism prevalence across the lifespan, and training the next generation autism researchers, clinicians, and care providers.

RECOMMENDATIONS

RECOMMENDATION 1: Promote growth, linkage, coordination, and security of biorepository and data repository infrastructure systems, equitable access to these systems, and inclusion of diverse samples.

Examples:

- Promote biological sample donation to ensure that demand for research studies is met.

- Make efforts to standardize data collection, and responsibly share all the data supporting any findings when those findings are announced.

- Develop and expand programs and outreach campaigns to encourage families from diverse backgrounds to participate in autism research, join registries, and donate biological samples.

- Ensure equitable access to federal data sets so that all communities can benefit from these resources.

RECOMMENDATION 2: Expand and enhance the research workforce, with attention to diversity and inclusion, and accelerate the pipeline from research to practice.

Examples:

• Expand and enhance programs that provide funds to train current and future researchers on innovative research techniques.

• Support programs to train autistic researchers and researchers from diverse communities to conduct research related to autism.

• Develop programs to translate and disseminate autism research findings into actionable recommendations and real-world practice.

• Improve recruitment and retention of early-career autism researchers.

RECOMMENDATION 3: Strengthen statistical data gathering systems to advance understanding of the autistic population, while allowing comparisons and linkages across systems as much as possible.

Examples:

• Continue to expand prevalence data monitoring activities to gain a better understanding of needs and concerns over the lifespan.

• Expand data monitoring efforts to collect more descriptive data regarding co-occurring conditions, including intellectual disability, seizure disorders, anxiety, and depression to increase understanding of the prevalence of these conditions in the autistic population.

• Support inclusion of autism and disability research through large surveys, including those conducted by federal agencies such as CDC, HRSA, and ED.

• Promote efforts to ensure that diverse samples are captured in survey data.

CROSS-CUTTING RECOMMENDATIONS

The IACC has identified two topics that span across the seven Questions of the *Strategic Plan* and warrant special attention: understanding the influence of gender and sex in autism, as well as reducing disparities and promoting equity. The goal of these "cross-cutting" Recommendations is to encompass the numerous research and services priorities identified by the Committee throughout the *Strategic Plan* and allow for these areas to be identified as priorities for funders. In future publications tracking progress in funding for these Recommendations, individual projects assigned to these Cross-Cutting Recommendations will be coded to different Questions of the *Strategic Plan* depending on which aspect of autism is being studied. This will ensure the funding associated with those projects will be counted toward the totals of their respective Questions, but also allows the projects to be added together into a single Recommendation.

CROSS-CUTTING RECOMMENDATION: SEX AND GENDER

The topic of sex and gender differences in autism is mentioned in several chapters of the *Strategic Plan*, indicating the Committee's strong interest in this area. 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.[1] Thus, it will be critical in the future to understand and better serve the needs of girls, women, and/or lesbian, gay, bisexual, transgender, queer, intersex, asexual plus (LGBTQIA+) individuals on the autism spectrum.

The most recent prevalence data from the CDC suggests that autism is 3.8 times more prevalent in males vs. females;[2] other estimates have consistently estimated that males are 3-4 times more likely to be diagnosed with autism than females.[3] These estimates may not, however, reflect the true ratio of autism in females versus males, as they are based on diagnoses made using definitions that were based on how autism typically presents in males and using screening and diagnostic instruments that were developed using predominantly male subjects in research. A recent longitudinal study examining infants and toddlers with an autistic sibling suggests ASD-associated behaviors occur equally in males and females.[4] Many girls and women on the autism spectrum are missed early on or misdiagnosed with other mental health conditions before they receive an ASD diagnosis. It is therefore important for clinicians to be trained to recognize the differences in autism presentation among girls and women, as well as understand and recognize potential masking behaviors.[5] Additional research is also needed to understand how the presentation of autistic traits may change over time.

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. With increasing understanding, awareness, and improvement of screening and diagnostic methods, it is likely that more girls will be

identified with autism earlier in life and given the opportunity to be connected with supportive services sooner. Progress in these areas and in tailoring interventions and services to meet the unique needs of girls will be critical steps in closing gender gaps.

BIOLOGICAL EVIDENCE FOR SEX DIFFERENCES IN AUTISM

One hypothesis proposed to explain the difference in prevalence is the "female protective effect" (FPE), which suggests that females are biologically 'protected' from autism such that, on average, a greater number of genetic factors is necessary for a female to display autism traits. There has been some research that supports the FPE concept,[6-8] but there are others in the field who question this hypothesis. In a recent study, researchers analyzing health records from a population-wide registry found that the unaffected sisters of autistic individuals were just as likely to have autistic children as the unaffected brothers of autistic individuals.[9] This study demonstrates that a potential FPE cannot fully account for the sex differences in prevalence.[10] It is therefore critical to continue exploring potential female protective effects and other genetic contributors to autism that are differentially influenced by sex.

Differences in underlying biology may account for some of the differences in autism phenotypes based on sex (discussed further in Chapter 2). For example, autistic girls have been found to activate different parts of the brain in response to social stimuli than their neurotypical girl counterparts or autistic or neurotypical boys.[11] Girls also have been shown to activate neural reward circuits in response to social stimuli, while autistic boys decrease activation in the same part of the brain in response to similar stimuli. Another recent study used deep-learning technology to compare hundreds of brain scans of autistic and neurotypical girls and boys and found that autistic girls displayed unique brain connectivity patterns in areas of the brain involved in motor, language, and visuospatial attention.[12, 13] These biological differences may influence how autism is expressed in girls and women and how they respond to their environments. Understanding the biology of autism in girls and women may help to develop personalized interventions to better serve this population.

THE INFLUENCE OF SEX AND GENDER ON THE PRESENTATION OF AUTISM

The core features of autism often present differently in girls/women than in boys/men.[14] For example, restricted interests in young girls are less likely to be viewed outside of the range of normal than in boys, often because their intense interests, such as animals and fashion, are in line with social expectations for girls.[15, 16] Conversely, social communication is more likely to be affected in young girls diagnosed with ASD versus boys.[17] Adolescent girls and adult women on the autism spectrum are more likely to present with internalizing traits, such as anxiety and depression, while boys/men typically display externalizing traits.[18] Qualitative studies suggest that girls and women are also more likely to mask or camouflage their autistic features.[19-21] As a result of these and other factors, autistic girls/women are diagnosed later than autistic boys/men on average.[22-25] Recent studies have revealed intriguing results around motor regions of the brain in autistic girls. A study using an autism screener and developmental skills assessment found that girls with autism were more likely to present with signs of motor impairment than boys.[26] In a separate study using deep learning to compare brain scans of girls and boys with and without autism analyses showed that girls with autism had significantly different patterns of brain connectivity in motor areas.[13] Together, these findings suggest that more investigation into motor and other brain differences in girls with autism may be warranted.

Studies have suggested that individuals on the autism spectrum are more likely to identify as LGBTQIA+ than neurotypical individuals.[27-30] This intersectionality between disability and gender identity or sexual orientation can result in increased social stress, stigma and discrimination, which can in turn contribute to reduced access to services and increased mental and physical health challenges. In order to address these issues, additional research is needed to better understand the unique needs of these populations.[31, 32] It is also important to properly train medical practitioners and other service personnel on ways to properly interact with autistic individuals who identify as LGBTQIA+.

SEX- AND GENDER-SPECIFIC SERVICES AND SUPPORTS

Research has suggested that women on the autism spectrum have more or different physical and mental health care needs than men on the spectrum as well as neurotypical women.[33-35] Autistic LGBTQIA+ individuals also have unique healthcare needs. However, many autistic women and LGBTQIA+ individuals have difficulty accessing appropriate medical care, including routine reproductive health care and prenatal care.[35-37] Needs for educational or employment supports may also vary. It is important for service providers to be made aware of the potential differences in need and carefully listen and make adjustments to ensure that they are responding to the stated needs of all individuals on the autism spectrum. People of all genders and sexual orientations on the autism spectrum are more likely to report adverse sexual experiences than their neurotypical peers.[30, 38] It is critical that autistic individuals receive age-appropriate sexual education.

SUMMARY

As researchers continue to explore the biological mechanisms that underlie autistic traits and co-occurring conditions, it will be critical to identify sex- and gender-specific influences on life outcomes. It will also be important to develop and refine screening and diagnostic tools, interventions, and services that can accommodate the unique qualities and needs of girls, women, and members of the LGBTQIA+ community.

RECOMMENDATION

CROSS-CUTTING RECOMMENDATION 1: Support research to understand sex and gender differences in autism.

Examples:

- Understand differences in the presentation of autistic traits in girls and women to enhance screening and diagnosis.

- Conduct research exploring the influence of sex and gender on the underlying biology of autism (differences in brain structure, function, physiology) and how this may create differences in phenotype.

- Identify genetic and environmental factors that contribute to differences in phenotype.

- Understand differences in the social context, including the societal expectations and intersectional impacts of ableism and sex/gender/sexual orientation discrimination, that may influence outcomes for girls, women, and LGBTQIA+ individuals on the autism spectrum.

- Develop strategies to better meet the intervention, service, and support needs of girls and women and of LGBTQIA+ individuals with autism.

CROSS-CUTTING RECOMMENDATION: PROMOTING EQUITY AND REDUCING DISPARITIES

The IACC supports the concepts of diversity, equity, inclusion, and accessibility within and for the autism community and the reduction of disparities in access to opportunities, services, and positive outcomes in health and well-being. People with disabilities, including autism, are a vital part of our diverse society, yet they often experience disadvantages, disparities, and discrimination. The work of the IACC has raised the profile of autism and increased autism awareness in an effort to foster inclusion and acceptance of autistic people. The IACC has also supported efforts toward reducing disparities that occur at the intersection of race/ethnicity and autism since the first *IACC Strategic Plan* was issued in 2009. At this time, with increased momentum from sources ranging from federal agencies to private organizations, more opportunity exists than ever before to promote equity and reduce disparities, and the Committee renews its commitment to this effort.

Underrepresented and underserved populations, as defined in the *Strategic Plan*, may 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. The Committee recognizes that reducing disparities in underrepresented and underserved populations is an important aspect of all topics across the *Strategic Plan.*

Disparities among underrepresented and underserved populations with autism are evident across many research and service domains, including access to early assessment, diagnosis, therapeutic interventions, and social services in areas such as education, housing, employment, and justice. Prevalence estimates from the Centers for Disease Control and Prevention (CDC) show higher rates of ASD among Asian/Pacific Islander, Black, and Hispanic children than among White 4- and 8-year-old children in 2020.[1-3] This could suggest improvements in ASD identification among these groups leading to evidence of a higher occurrence of ASD, similar to other neurodevelopmental disorders in these populations. However, missed diagnosis or misdiagnosis is still more common among Black and Hispanic/Latino children.[4, 5] The delays in diagnosis observed in some underrepresented groups may then lead to further delays in access to early intervention services for children on the autism spectrum, particularly during important periods in child development. Subsequently, across the lifespan, these disparities may compound, resulting in disparate negative health outcomes typically seen in underrepresented and underserved populations as they progress into and through adulthood.[6]

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. For example, for populations in rural settings, there are noted disparities in access to transportation, stable and reliable internet access, and access to appropriate healthcare services. These social determinants of health are key to providing a holistic view of how best to reduce disparities. Additionally, further disaggregating racial/ethnic data may assist in identifying critical within-group differences and disparities and allow service and resource delivery to populations most at need.[7, 8] Consideration should also be given to qualitative research and mixed-methods approaches that may highlight disparities not yet captured in quantitative studies.

Despite the heterogeneity of autism presentation and support needs, much of the autism research in previous decades had been conducted in mostly White, male, middle- to upper-class children with higher cognitive and language abilities. Improving the diversity of participants will aid in improving the generalizability and applicability of research findings to broader populations of the autism community. For example, disparities have been noted in the lack of inclusion of research participants from female/gender minorites,[9] racial and ethnic minorites,[10] lower socioeconomic status,[11] rural,[12] and older adults.[13] As a result, their historic lack of inclusion in intervention and services research has resulted in notable gaps in the literature, potentially limiting the ability of autism programs and funding from effectively reaching these underrepresented populations to reduce disparities.

As more intersectional approaches are being developed in the investigation of autism disparities, researchers, educators, and care providers have begun embedding aspects of cultural competency, culturally responsiveness, and cultural humility into their respective practices. Becoming more culturally competent entails increasing provider knowledge, confidence, and self-efficacy in communicating and working with diverse patients, while being culturally responsive calls for listening to patients

to understand their lived experiences and ensuring patients receive their desired care. Cultural humility training encourages providers to reflect on their own beliefs, values and biases—explicit and implicit—through introspection, thus revealing the impact of their own culture on patients.[15,16] Cultural humility trainings are more process-oriented and aim to enhance provider capability to deliver patient-centered care. Given that some autism-related disparities arise from barriers at the familial, cultural (e.g., cultural perceptions of autism), and structural levels,[17] the utilization of culturally competent, culturally responsive, and culturally humble approaches are key in enhancing the ability of the workforce to provide optimal care, ideally leading to positive outcomes in the autism community.

Further, the effect of the COVID-19 pandemic on research communities is discussed in greater detail in Chapter 7 and the COVID-19 section of the *Strategic Plan*. However, the availability of telehealth and remote avenues for service provision and research participation could potentially reduce barriers to access for many underrepresented and underserved populations. Future research and additional evidence are needed to shed light on the potential benefits of the research adaptations enacted as a result of the pandemic.

Another key step in advancing inclusion and equity in research, services, and reducing disparities involves diversifying the researcher and provider workforce, in addition to recruiting diverse research participants. A concerted effort to diversify the workforce will help to reduce the various biases contributing to disparities, such as structural, personally mediated, and internalized racism that affects the health and well-being of autistic stakeholders.[18] For example, although there is a shortage of pediatric specialists overall, a recent workforce survey showed that only 2% of developmental-behavioral or neurodevelopmental pediatricians are Black.[19] The diversity of the research workforce also needs to be more inclusive of other aspects of diversity, including autistic

researchers who are working in the autism field. In 2020, the International Society for Autism Research (INSAR launched its Autistic Researchers Committee to foster scientific career development for autistic autism researchers and add valuable autistic perspectives to research discussed within INSAR. Recruiting and effectively training a workforce that reflects the diverse populations served has been the target of recent mentorship and pipeline programs, although more investment is needed in this area.

On his first day in office, President Biden signed **Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government**, encompassing efforts to improve opportunities and outcomes for communities of color, Tribal communities, rural communities, LGBTQIA+ communities, people with disabilities, women and girls, and communities impacted by persistent poverty. The Executive Order directed the federal government to advance an ambitious government-wide equity agenda that has resulted in equity activities across every federal agency. One example of an initiative that has targeted heath disparities is the Department of Health and Human Service's Office of Minority Health's **National Culturally and Linguistically Appropriate Services (CLAS) Standards**, a set of 15 action steps intended to advance health equity, improve quality, and help eliminate healthcare disparities by providing a blueprint for individuals and healthcare organizations to implement culturally and linguistically appropriate services. Another example is the **Health Equity Framework**, released by the National Council on Disability in 2022, which lays out a set of goals to create health equity for individuals with disabilities.

In addition to federal efforts on equity, many state agencies, private organizations, and academic institutions are also supporting research, services, and policy initiatives to address equity and disparities within the autism community. For example, Drexel University's Policy Analytics Center and Life Course Outcomes Program published a National

Autism Indicators Report in 2022, ***The Intersection of Autism, Health, Poverty, and Racial Inequity***, that describes social determinants that influence health and well-being for individuals on the autism spectrum, and they propose that programs addressing these determinants are needed in order to close the gaps in health for intersectional populations. Overall, the ripple effects of many different federal, state, private, and academic equity-related initiatives, including those that address intersectionality across multiple underserved groups, will provide new opportunities to improve the health and well-being of individuals on the autism spectrum.

In addition to acting as research participants, the diverse perspectives from members of the autism community should serve to guide the research agenda and priorities moving forward, to ensure that the research aligns with the needs and desires of those with lived experience. The development of culturally relevant, feasible, and acceptable interventions and services involves direct feedback on challenges, perspectives, and preferences from community members.[20] Outreach efforts aimed at building trust within communities has been seen as the benchmark for building relationships for the purposes of informing research aims and increasing community knowledge on autism-specific information. For example, in Hispanic/Latino communities, *promotores de salud* (i.e., community health workers; *promotores*) are becoming critical participants in health promotion and delivery of healthcare.[21] These workers are able to effectively complete outreach activities and aid in improving participation from underrepresented populations due to the inherent trust they are afforded as members of their own community. Actively listening to the needs of these communities will serve to directly address the disparities noted for these populations. The use of community liaisons and cultural brokers (i.e., people who build trust between different cultural communities) can help in these efforts to provide services and conduct research within diverse communities.

In summary, increasing diversity, equity, inclusion, and accessibility and addressing disparities remain an objective that informs numerous research projects and programs across the *Strategic Plan* Question areas. This Cross-Cutting Recommendation serves as a method to track the progress made to ensure that underrepresented and underserved populations receive appropriate education, services, and opportunities and benefit from research that encompasses and targets the needs of diverse communities. These efforts are essential to reduce disparities in health outcomes for autistic individuals. While additional information on specific areas of disparities is expanded upon in each Question of the *Strategic Plan*, this section and the Cross-Cutting Recommendation outlined here serve as an indicator of the urgency felt by the Committee to comprehensively address areas of disparities and promote equity in research and services moving forward.

RECOMMENDATION

CROSS-CUTTING RECOMMENDATION 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.

Examples:

- Develop culturally competent, culturally responsive, and culturally humble research and service approaches aimed at building trust with historically underrepresented populations.

- Increase the diversity of the scientific and service research workforce, including autistic researchers and researchers from underrepresented groups.

- Include individuals and family members from underrepresented groups in the planning and conduct of autism research studies.

- Include racially, ethnically, and culturally diverse autistic individuals and family members, and individuals from other underserved communities, in autism service and policy development activities.

- Develop appropriate trainings and supports/services for providers and caregivers in underserved communities.

- Support research on disparities and underserved or intersectional populations within the autism community.

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

COVID-19 (coronavirus disease 2019) is an infectious disease caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). Since its discovery in Wuhan, China, in December 2019, COVID-19 has rapidly spread around the world and was declared by the **World Health Organization (WHO)** as a global pandemic on March 11, 2020. COVID-19 can cause severe flu-like symptoms and has led to significant loss of life. Over one million people have died from the disease in the United States alone, and over 6.5 million have died worldwide. The COVID-19 pandemic has changed the world in profound ways, and people around the globe adjusted everyday living to limit the spread of the virus, causing both 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 as 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 and work 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 and improved services and supports to improve health and well-being.

IMPACT OF COVID-19 ON PHYSICAL AND MENTAL HEALTH

COVID-19 symptoms include fever or chills, cough, shortness of breath or difficulty breathing, and fatigue, among many others. Symptoms can range from mild to severe. The Centers for Disease Control and Prevention (CDC) defines severe outcomes as hospitalization, admission to the intensive care unit (ICU), intubation or mechanical ventilation, or death. While **age** is the strongest predictor for severe disease, other factors such as certain underlying health conditions and living in congregate settings can also increase the risk of COVID-19 infection and severe outcomes. For example, intellectual and developmental disabilities (IDD),[1, 2] attention-deficit/hyperactivity disorder (ADHD),[3] depression,[4] and schizophrenia spectrum disorders[3] have all been shown to lead to higher risk for severe COVID-19 outcomes. Additionally, studies show that adults with IDD living in congregate settings are at greater risk of contracting COVID-19 compared to the general population.[5] A recent **report** by the National Council on Disability examined several of the negative impacts of the COVID-19 pandemic on people with disabilities, including the high death toll among individuals with disabilities living in congregate settings, and called for the strengthening of supports available through Home and Community Based Services (HCBS) waivers and a "Community Living Bias" to protect individuals with disabilities from being disproportionately endangered in future public health emergencies.

Individuals on the autism spectrum may be at increased risk of COVID-19 infection and hospitalization as they often have co-occurring ADHD, IDD, or other physical and mental health conditions and may live in congregate settings.[6-8] Indeed, one study conducted in Israel found higher rates of COVID-19 infection and greater odds for hospitalization for autistic men but not women.[9] A study using data from one of the United States' largest databases of private insurance claim records found that individuals with autism and intellectual disability were nine times more likely to be hospitalized following COVID-19 infection compared to those without autism and intellectual disability.[10] However, more research is needed on whether these results are generalizable to autistic individuals across the United States and what specific factors lead to increased risk for COVID-19, controlling for gender, co-occurring conditions, and differences in housing. As we move towards the next phase of the pandemic, it will be important to assess which individuals on the autism spectrum are at higher risk of contracting COVID-19 and severe disease and how to minimize risk and infection.

Some individuals infected with SARS-CoV-2 also experience long-term health effects known as "long COVID." Commonly reported symptoms of long COVID include fatigue that interferes with daily life and symptoms that worsen with physical or mental exertion. In addition, long COVID is associated with respiratory, cardiovascular, neurological, and digestive symptoms. These symptoms can last anywhere from weeks to years and are more common in individuals with severe COVID-19 illness or underlying health conditions prior to COVID-19. A preliminary study indicates that a history of anxiety disorder is associated with higher risk for long COVID.[11] Given that many autistic individuals have co-occurring anxiety and other conditions, it will be important to conduct epidemiological research to determine whether individuals on the autism spectrum are at increased risk for long COVID. Research to identify biological and molecular markers is also important to accurately diagnose long COVID and provide needed treatments and supports, particularly for individuals on the autism spectrum who may not be able to clearly communicate their symptoms.

In addition to how COVID-19 directly impacts autistic individuals, it is important to consider how COVID-19 infection during pregnancy may contribute to possible autism development in the offspring. Previous studies have shown that maternal immune activation and prenatal infection can increase the odds of developing autism.[12, 13] Viruses such as Zika, Influenza A, and Cytomegalovirus are already known to affect brain development in offspring.[14] Maternal COVID-19 infection increases risk of preterm births and neonatal intensive care unit admissions,[15] though vertical transmission of SARS-CoV-2 from the mother to the fetus is rare.[15, 16] A study of 222 mothers who tested positive for COVID-19 during pregnancy early in the pandemic found that their children were more likely to receive a neurodevelopmental diagnosis in the first year after birth.[17] However, it is unclear if severity of COVID-19 disease is associated with neurodevelopmental outcomes or how vaccines (which were not available at the time of the study) or new SARS-CoV-2 variants may affect these results. Since SARS-CoV-2 is a new virus, it is also unknown how COVID-19 may impact child development beyond the first year. Future longitudinal studies with larger study populations are needed to determine whether and how prenatal infection and maternal infection may impact neurodevelopment and/or development of autism in the offspring.

During the pandemic, the issue of healthcare rationing and discrimination against people with disabilities in prioritization for healthcare came into the spotlight. Devaluation of the lives of people with disabilities has often been used as a rationale to de-prioritize them for intervention when availability is limited.[18] Healthcare resources were scarce at the beginning of the pandemic, and many places implemented Crisis Standards of Care (CSC) in an attempt to allocate resources fairly. A review

of CSC from 29 states in the United States found that half listed equity as a guiding principle, and approximately 66% said that decisions should not factor in disability, race, ethnicity, and other identity-based factors.[19] Internationally, a review of 21 guidelines from other countries found that only one explicitly precluded using disability as an exclusion criterion for care.[20] Additionally, a literature review of public preferences for allocation of scarce medical resources found bias against giving preference to patients with disabilities or frailty and that approaches based on egalitarian principles received the least amount of support.[21]

These attitudes and guidelines highlight some of the discrimination and ableism faced by individuals with disabilities, including individuals on the autism spectrum.

Individuals with disabilities were also unable to access vaccination earlier in the pandemic due to lack of consideration for accommodations to enable disability access. In the case of autism, however, the CDC and many community organizations such as the Eagles Autism Foundation and the Autism Society developed autism/sensory-friendly vaccination clinics to facilitate access for autistic individuals and their families to COVID-19 vaccines. Eventually, sensory-friendly vaccine clinics were launched in many locations across the nation in an example of what can be accomplished through awareness and community partnerships. In the future, policies surrounding allocation of scarce resources and access to care must have equity as a major component so that all individuals can be provided with life-saving care, regardless of ability or disability.

COVID-19 MITIGATION EFFORTS AND THE AUTISM COMMUNITY

COVID-19 mitigation efforts have mainly focused on three methods: vaccination, the wearing of face masks, and physical distancing. While these methods are effective at limiting the spread of COVID-19, guidance on proper mitigation efforts over the course of the pandemic has changed rapidly and can be difficult to follow, particularly for individuals with intellectual and other disabilities. In addition, for some people with disabilities, mask-wearing presented a challenge for sensory reasons, mental health-related reasons, or due to an intellectual disability. For future public health emergencies, public health authorities should ensure that new policies surrounding mitigation efforts and public health plans are developed in partnership with people with disabilities and the welfare of all vulnerable groups are considered during the development process. Accommodations should be developed for those who may, for reasons related to

their disability, be unable to wear a face mask or unable to wear certain types of face masks. Alternative mitigation strategies or accommodations should be put in place during the planning phase. Information surrounding mitigation efforts also must be accessible for everyone, including those with intellectual and other disabilities and in other underserved communities.

Vaccination is currently the primary method to prevent COVID-19 infection and severe disease. A survey of autistic adults found that 78% of respondents reported having received or planning to receive a COVID-19 vaccine, with 55% having received at least one dose.[22] This was higher than the 42% vaccination rate in the total population at the time, indicating that autistic adults were more likely to be receptive to the COVID-19 vaccine as compared to the general population. However, despite these high numbers

and numerous studies showing the safety and efficacy of COVID-19 vaccines,[23] anti-vaccine rhetoric continues to drive vaccine hesitancy.[24] Among those not planning on receiving a COVID-19 vaccine, most were concerned about vaccine safety and about one-third reported they were not worried about contracting COVID-19.[22] In addition, a survey of parents of children on autism spectrum found that only 35% of parents intended to vaccinate their child against COVID-19.[25] These parents reported a higher level of belief in vaccine harm compared to the national average. Additional research is needed on whether these survey results are representative of the autism community across the United States and whether there have been any changes in attitude with time. Given that autistic individuals may be at higher risk of COVID-19 infection and severe disease, it will also be crucial to understand how to combat misinformation surrounding COVID-19 and vaccine safety and efficacy to promote vaccine uptake among those who are hesitant and at risk. Collaborative efforts to make vaccines and available treatments accessible for autistic people who may have sensory or executive functioning difficulties that make it hard to make or get to vaccination appointments will also be critical for COVID-19 mitigation in the autism community.

Since the start of the pandemic, public health authorities around the world have advocated, and at times mandated, the use of face masks to limit the spread of COVID-19. A cloth mask can lower the odds of contracting COVID-19 by 56% in indoor public settings, and an N95 or KN95 respirator can lower the odds by 83%.[26] However, face masks can affect recognition of facial expressions,[27] making social interactions more difficult, especially for autistic individuals. Additionally, face masks may not be well tolerated by those on the autism spectrum, particularly those with sensory difficulties. Children on the autism spectrum may not understand why face masks are necessary and therefore have challenges in wearing face masks. While a handful of studies have explored how to improve tolerance of face coverings for children on the

autism spectrum,[28-31] more research is needed to evaluate how to improve tolerance for face masks among both children and adults. Further research is also needed to develop, improve, and evaluate additional tools to overcome the sensory and social communication limitations of face masks.

In addition to vaccination and face masks, physical distancing and limiting contact with individuals who may be infected by SARS-CoV-2 has played a critical part in containing COVID-19. However, this has arguably had the largest effect on everyday life. Efforts to limit in-person contact led to the closure of schools and many businesses. For many autistic individuals and their families, this has meant the loss of or reduced access to diagnostic and screening services, in-school services, housing and support services, and healthcare services.[32-34] Families reported that children on the autism spectrum experienced a loss in developmental progress and communication and learning skills and an increase in challenging behaviors during this time.[33, 35] In addition, the pandemic led to increased caregiver stress and feelings of isolation and loneliness and other mental health challenges for many autistic individuals and their families.[36-38]

While research has explored the short-term impact of the COVID-19 pandemic on the autism community, it will be important to monitor how the pandemic affects service access and the mental and physical health of people on the autism spectrum and their families in the long term. Future research is needed to assess the long-term impacts of the COVID-19 pandemic on autism traits, including social development, learning, and communication. In addition, studies are needed on how social isolation in early childhood may affect autism traits and quality of life outcomes. As the pandemic has progressed, research is needed to evaluate the long-term effects of the pandemic on mental health, including feelings of isolation and loneliness, depression, and suicidality. Studies are also needed on how to better support mental health and promote resilience

in autistic individuals and their families, including how to alleviate caregiver stress, for the duration of the COVID-19 pandemic and in future public health emergencies. In addition, autistic individuals may have settled into a "pandemic routine" and may be anxious at returning to the physical workplace or school as pandemic restrictions lift. Therefore, research on how to reduce anxiety and ensure a smoother transition is also necessary.

Economic hardship has also been reported as individuals on the autism spectrum and caregivers reported loss of employment and heightened food insecurity.[33, 39] The pandemic also highlighted the disparities faced by those in underserved communities, as people with lower income and members of racial and ethnic minorities have an even more difficult time accessing needed support and healthcare

services.[33] Importantly, research is needed on how to improve equity and access to services, care, and supports for all individuals across the autism spectrum and across the lifespan, particularly for individuals and families from underserved communities. Research is also needed to fully evaluate the impacts of the pandemic and extract lessons learned that can be applied to future national or global disruptions of a similar nature. Efforts by government bodies to plan for future public health emergencies must include consideration of individuals with disabilities. The establishment of the **National Advisory Committee on Individuals with Disabilities and Disasters** within the U.S. Department of Health and Human Services is a step in this direction that will help ensure planning to meet the needs of people with disabilities in future disasters and public health emergencies.

REMOTE TECHNOLOGY AND ACCESSIBILITY DURING THE PANDEMIC

The COVID-19 pandemic allowed the development of a grand global experiment with remote technologies to help maintain continuity of activities and services, especially during earlier days during the pandemic when people in many countries were encouraged or required to stay home to reduce the spread of the virus. For people with disabilities, remote technology enabled the continuation of some services and supports throughout the pandemic. For example, telehealth services allowed for the continued diagnosis and screening of children with autism.[40-42] Additionally, some healthcare providers used telehealth platforms to provide needed services for individuals on the autism spectrum.[33, 34, 43] Schools also took advantage of virtual platforms to allow children to continue receiving educational instruction, and some workplaces also shifted to remote work to allow for physical distancing and prevent the spread of COVID-19.

Some autistic individuals have indicated that remote schooling and work have been a welcome change, as it allows for more control over individual environments and fewer sensory and social challenges.[44] However, remote options did not benefit all individuals on the autism spectrum. Some individuals on the autism spectrum, including some living in care facilities, and their families may not have access to the technology necessary for remote school, work, and telehealth.[33, 44] Others found that the shift to a remote environment increased isolation, disrupted previously established routines, and caused anxiety and stress.[44] Still others indicated that telehealth services and virtual classrooms did not achieve the same level of effectiveness as in-person appointments and education.[33, 35, 41, 44] For others, however, use of remote technologies and options to telework increased opportunity

for inclusion and engagement in work and connection with colleagues and friends.[38] Some people with disabilities reported being more at ease in a remote environment where they could control sensory inputs and felt reduced social stress.[45]

As remote technologies continue to develop and be used, it will be necessary to increase access to stable internet connections and the hardware and software necessary to participate in and take advantage of virtual opportunities and communities. Additionally, research is needed to determine if telehealth services are just as effective as healthcare services and supports delivered in-person and how to best close any gaps in efficacy. Educational research is also needed to ensure that students receiving remote education are not at a disadvantage compared to students in the classroom. Continued innovations are necessary to take advantage of new remote technologies to improve services delivery for the autism community to maximize positive outcomes.

Equally important, in-person services need to be available and safely accessible to individuals for whom remote options were not feasible or did not work well. Some in-home support services personnel and direct support staff personnel left the industry during the pandemic, leading

to workforce shortages. Efforts are needed to attract and train additional staff so that HCBS can resume and provide individuals on the autism spectrum with the services they need. These services are more critical than ever as some autistic individuals have lost caregivers due to COVID-19 and are now left with no support at home. Addressing the workforce shortages and delivering services and supports more efficiently will greatly improve the health and well-being of individuals on the autism spectrum.

With increased vaccine uptake in the general public, mitigation efforts have lessened, and mask mandates have been lifted in most settings. However, community transmission of COVID-19 remains at medium to high rates. This has forced many individuals on the autism spectrum who have autoimmune issues or other co-occurring conditions to remain at home and in physical isolation to protect themselves from severe disease. As we continue to navigate this transition period out of the pandemic, it is important to consider how to make in-person interactions in schools and communities are safe for individuals at high risk for serious illness. Additionally, remote options must continue to be available when possible to accommodate those who may not be able to take advantage of in-person services and supports.

THE IMPACT OF THE COVID-19 PANDEMIC ON AUTISM RESEARCH

In addition to its direct impact on individuals on the autism spectrum and their families, the COVID-19 pandemic also caused significant disruptions in scientific research. Many universities shut down research labs and halted studies and clinical trials with human subjects to comply with physical distancing requirements during at least part of the pandemic. Training modules and classes also shifted to virtual delivery methods. Research that continued largely shifted to focus on COVID-19-related experiments. These changes resulted in a sharp decline in the amount of time scientists spent on research early in the pandemic, and investigators initiated fewer new projects in 2020 compared to previous years, indicating the pandemic may have long-lasting effects on scientific research.[46]

Early career researchers and trainees have borne the brunt of the impact of the pandemic on autism research, citing fewer training opportunities, fewer chances to network and establish meaningful collaborations and mentorships, lack of funding and resources, and a decrease in the number of open positions for those on the job market.[47, 48] Increasing the amount of available funding for autism researchers, allowing funding extensions for current projects, providing institutional support, and adjusting tenure and promotion requirements can alleviate some of the strain felt by early career researchers and trainees. Implementing these changes will be necessary to prevent "a lost generation" of researchers who could greatly improve the health and well-being of people on the autism spectrum.

SUMMARY

The COVID-19 pandemic has impacted every part of life. The autism community may be especially vulnerable to COVID-19 infection and severe health outcomes due to common co-occurring conditions. However, autistic individuals may have difficulties with mitigation efforts such as getting vaccinated and wearing face masks due to sensory and other issues. Physical distancing also comes with its own challenges as it causes disruptions in needed services and leads to feelings of isolation and loneliness. While remote options such as telehealth and virtual schooling are viable and preferred for some members of the autism community, others have trouble adjusting or find that remote services are less effective compared to in-person interactions.

Autism research has also suffered as scientists had to shut down experiments and halt clinical trials to comply with physical distancing requirements earlier in the pandemic, resulting in lowered productivity and fewer new projects, which may have long-lasting consequences. COVID-19 highlighted existing hardships and disparities experienced by the autism community. As the world emerges from the pandemic, policy makers and researchers must consider how to use the lessons learned during the pandemic to improve access to needed services and promote equity to improve health and well-being for all people on the autism spectrum across the lifespan.

BUDGET RECOMMENDATION

In the preceding chapters, the IACC has provided information about recent research progress and services activities as well as strategic Recommendations to guide future efforts to better understand and address the needs of people on the autism spectrum across the lifespan and all levels of ability and disability. Under the Autism CARES Act, the IACC is also required to include "proposed budgetary requirements" in the Strategic Plan. The following information provides the IACC budget recommendation and supporting background information for the 2021-2023 Strategic Plan for Autism Research, Services, and Policy.

THE IACC CALLS FOR $685 MILLION IN ANNUAL AUTISM RESEARCH FUNDING BY 2025

To spur significant growth in autism research, the *2016-2017 IACC Strategic Plan* called for a doubling of the 2015 autism research budget to $685 million by 2020. To accomplish this goal, the IACC recommended a nearly 15% annual increase in autism research funding across combined federal and private funders. The Committee recognized that this was an ambitious goal, but it believed that such an increase could have great impact if achieved. Based on the upcoming *2019-2020 Portfolio Analysis Report*, autism research funding in 2020 was approximately $419 million (see Figure 1). While this did not meet the *2016-2017 IACC Strategic Plan* recommendation, autism research did experience a substantial growth in funding from when the original 2016-2017 budget recommendation was made, increasing by 15% since 2016.

To update the budget recommendation included in the current *Strategic Plan*, the IACC now calls for the autism research budget to reach $685 million by 2025. This new recommendation extends the timeline to reach the target of $685 million. Although there was significant growth in autism research funding from 2008 to 2010, and additional federal funding from the American Recovery and Reinvestment Act (ARRA) provided a boost in 2009 and 2010, autism research funding levels have since become relatively flat. The loss in momentum has been accelerated by the loss of purchasing power over time due to inflation (Figure 3).

The Committee considered historical autism funding trends and projected budgets and decided to extend the target amount of $685 million to 2025. With steady and predictable annual increases, this would require approximately a $53.2 million annual increase in autism research funding 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 in 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 innovative funding mechanisms and support work in areas that have not been historically covered. If met, this budget recommendation will help to accelerate autism research 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 that will require attention and resources in order to truly improve the lives of people on the spectrum and their families.

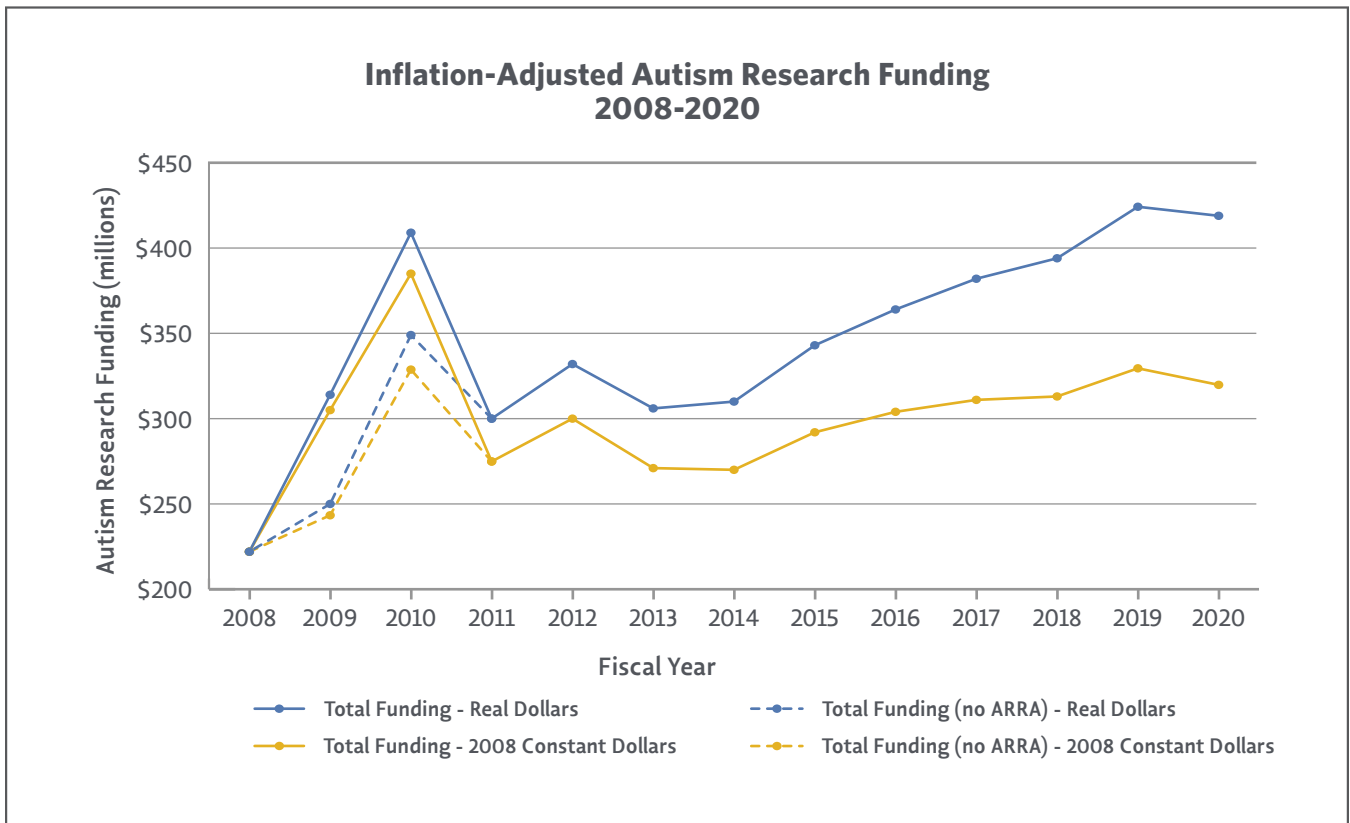**Figure 3.** The history of combined federal and private autism research funding from 2008 to 2020 in actual (blue) dollars and 2008 constant (yellow) dollars. The dotted lines indicate funding levels excluding American Recovery and Reinvestment Act (ARRA) stimulus funds, which provided supplementary funding in 2009 and 2010. Inflation effects were calculated using the Biomedical Research and Development Price Index (BRDPI).[2]

It is important to point out that this budget recommendation applies to only the autism research budget; this does not include funding for autism services, supports, and programs that comprise much of the day-to-day spending of families and autistic individuals. The research funding described will help to provide the evidence needed to identify interventions, services, supports, and community programs that are effective and work for individuals with a variety of needs and co-occurring conditions across the lifespan. It is also important to note that while a significant increase in autism research funding has the potential to rapidly spur advances in autism research, the recommended increase would not be sufficient to accomplish all the research goals identified in this Plan.

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:

1. **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.

2. **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.

3. **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.

The sections above highlight three high-priority research areas that are in particular need of resources and attention. An infusion of resources would be wisely and efficiently leveraged in these areas, as research progress to date demonstrates that researchers in these fields are well-poised to capitalize on additional investment. Moreover, the targeted allocation of resources to these areas would serve not only to incentivize research on these topics but also to expand the diversity of the workforce and encourage additional well-trained scientists to specialize in these research areas of significant need. With expanded resources and a diversified workforce that includes those with lived experience, the full range of autism research will have the potential to make significant advancements in the coming years and positively impact the lives of individuals across the autism spectrum and lifespan.

STATEMENT ON DUPLICATION OF EFFORT

The Autism CARES Act of 2019 requires the IACC in its Strategic Plan to provide "Recommendations to ensure that autism spectrum disorder research, services and support activities, to the extent practicable, of the Department of Health and Human Services and of other federal departments and agencies, are not unnecessarily duplicative."

The IACC believes that in the case of scientific research, coordinated efforts by multiple public and private agencies to fund different types of projects within the same topic area represent cooperation and collaboration, not duplication. In addition, the scientific process requires that studies be independently replicated in order to ensure reproducibility, validate findings, and ultimately build the evidence base. Replication of an experiment or approaching a single problem using different methods can corroborate findings and help researchers distinguish between false leads and important discoveries. Replication also contributes to efficiency in research funding by ensuring the creation of a solid base of validated findings that establish the rationale for later-stage, larger, and potentially more costly research efforts. For these important reasons, replication of research is valuable and should not be considered duplication of effort.

The *2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy* offers a range of broad Recommendations that are designed to address gaps and opportunities in ASD research, services, and support activities. The IACC's intention is that each Recommendation will be accomplished through multiple projects addressing the many varied aspects of these complex issues, which will be funded by multiple agencies focusing on their respective and complementary areas of expertise. The IACC is charged with ensuring coordination across federal agencies, which is achieved by fostering dialogue among federal agencies

and private organizations and engaging their input in the development of Strategic Plan Recommendations.

In addition to the IACC, the National Autism Coordinator (NAC) monitors and assists with internal coordination of federal autism efforts. As specified by the Autism CARES Act of 2014 (**Public Law 113-157**), the NAC is an existing official within the Department of Health and Human Services appointed "to oversee, in consultation with the Secretaries of Defense and Education, national ASD research, services, and support activities." The duties of the NAC include coordination and implementation of federal autism activities, taking into account the IACC Strategic Plan, as well as ensuring that federal autism 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 the following federal departments and agencies:

Department of Health and Human Services (HHS)

- Administration for Children and Families (ACF)
- Administration for Community Living (ACL)
- Agency for Healthcare Research and Quality (AHRQ)
- HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)
- Health Resources and Services Administration (HRSA)
- Indian Health Service (IHS)
- National Institutes of Health (NIH)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

Department of Education (ED)

Department of Defense (DoD)

Department of Justice (DOJ)

Department of Housing and Urban Development (HUD)

Department of Labor (DOL)

Department of Transportation (DOT)

Environmental Protection Agency (EPA)

Social Security Administration (SSA)

Food and Drug Administration (FDA)

Department of Veterans Affairs (VA)

In addition to managing FIWA activities, the NAC also monitors activities of other federal interagency groups whose activities are relevant to autism (see Table 1).

Going forward, the combined activities of the IACC and the NAC will continue to help ensure that autism research, services, and supports activities are not unnecessarily duplicative.

CONCLUSION

Throughout this *2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy*, the IACC has highlighted recent advances in research that contribute to our understanding of autism and its co-occurring conditions, diagnosis and interventions, factors that influence outcomes, and services and supports that are needed by people on the autism spectrum across the lifespan. The plan also identifies remaining gaps and potential opportunities in research, services, and policy for autism-related issues.

Strategic investments in the autism portfolio have produced promising scientific advances over recent years. For example, research findings have highlighted effective approaches for screening and diagnosis, the identification of multiple biological, environmental, and social factors that contribute to autism and outcomes, improvements on existing interventions, and tools for autistic adults that enhance their health and well-being. Continued investments in these and other areas will have a significant impact on the lives on autistic individuals and their families.

In this edition of the *IACC Strategic Plan*, the committee has further emphasized the need to focus on autism across the lifespan, including improved screening and diagnostic tools for adolescents and adults, tailored interventions to address physical and mental health challenges, increased access to communication tools and devices, and expanded services and supports to improve community integration and maximize positive outcomes across the spectrum and the lifespan. The *Plan* also stresses the importance of reducing disparities and increasing equity so that all autistic individuals are able to have their needs met, regardless of their race/ethnicity, gender identity and sexual orientation, geographical location, socioeconomic status, or level of support needs.

Multidisciplinary approaches will be needed to address many of the existing gaps in autism research. The Committee is encouraged by the growth in the field resulting from the entry of additional investigators and new funders to the research landscape, thus enabling novel, varied, and innovative approaches as well as additional sources of investment. The Committee also recognizes the importance of sustained partnerships between government and non-government organizations that work on behalf of people with autism and disabilities, and the need to actively engage with autistic individuals and their families to identify priorities for investment in research, services, and supports.

As with previous editions of the *Strategic Plan*, it is the IACC's hope that this updated Plan will be used by federal agencies and private organizations to guide their research and services activities. With continued interagency coordination, the federal Departments and agencies involved in autism-relevant activities will assess existing programs and plan new activities that seek to close existing gaps. The 24 Recommendations in this *Strategic Plan* describe priorities for autism research, services and supports, and policy that reflect the most important opportunities and needs in the autism community. Included in these Recommendations are emphases on:

- Improving efficiency of and access to screening and diagnostic services

- Advancing knowledge of the biology of autism and co-occurring conditions across the lifespan

- Understanding the individual and combined contributions of genetic and environmental factors to the development of autism

- Developing a wide array of interventions and supports that will address needs across the spectrum and across the lifespan

- Implementing interventions and services in community settings and improving access

- Improving outcomes for adolescents and adults

- Supporting the infrastructure that enables innovative autism research and prevalence monitoring

- Understanding autism in girls, women, and LGBTQIA+ individuals

- Reducing racial and ethnic disparities and promoting equity across all communities.

The Committee also includes a Recommendation to substantially increase federal and private investment for autism research, services, and supports.

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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CHAPTER 2: BIOLOGY

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CHAPTER 4: INTERVENTIONS

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CHAPTER 5: SERVICES AND SUPPORTS

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CHAPTER 6: LIFESPAN

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CHAPTER 7: INFRASTRUCTURE AND PREVALENCE

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

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