2024 IACC Strategic Plan Update
Draft Chapters

September 2024

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Introduction

Co-occurring health conditions are commonly reported by members of the autism community. These include physical, behavioral, and mental health conditions and issues, such as gastrointestinal (GI) issues and disorders, sleep disturbances, epilepsy, sensory and motor challenges, substance use disorder, depression, and anxiety. Many autistic individuals also experience other challenges that impact health outcomes, including learning disabilities, self-injurious and aggressive behaviors, suicidality, expressive communication and/or speech-related disabilities, and co-occurring intellectual disabilities.

Co-occurring conditions are important factors that can reduce health and well-being in autistic individuals when not acknowledged, recognized, and properly addressed. Over the last decade, several studies have been published that highlight the health issues faced by individuals on the autism spectrum. Population studies in Sweden and the U.K. found that the average life expectancy of autistic individuals was lower than non-autistic individuals, and individuals with autism and intellectual disability had an even lower average life expectancy.[1, 2]

In addition, studies examining health record data have found that transition-age youth and adults with autism had significantly higher rates of all major psychiatric disorders, including depression, anxiety, bipolar disorder, obsessive-compulsive disorder, schizophrenia, and suicide ideation and attempts.[3, 4] Nearly all physical health conditions studied were found to be significantly more common in adults with autism, including seizures, immune conditions, and GI and sleep issues, compared to non-autistic individuals. Rarer conditions, such as stroke and parkinsonism, were also significantly more common among adults with autism.

The prevalence of co-occurring conditions across the autistic population is not well understood. Reported prevalence rates of individual co-occurring conditions can vary widely across studies. Additionally, it is common for individuals on the autism spectrum to have multiple co-occurring conditions, with certain conditions occurring together frequently. For example, a population-based study found that 41% of autistic children in a population-based study had two or more mental health conditions, and 24% had three or more.[5] Other common patterns of co-occurrence include both sleep and constipation or both feeding and speech issues.[6]

There is also little known about the onset and progression of co-occurring physical and mental health conditions over the lifespan in autistic individuals; different conditions may be more likely to be diagnosed in childhood, adolescence, or adulthood.[7] Prevalence and impact of various co-occurring conditions may also vary widely in specific subsets of autistic individuals. Additional longitudinal studies are needed to understand how co-occurring conditions develop over time. Data on physical and mental health conditions in autistic adults, and older adults especially, is limited. Prevalence and impacts of co-occurring conditions also vary by sex, gender, race, and ethnicity; in many cases, the intersection between autism and racial ethnic minority status or sex and gender minority status can result in more negative outcomes.[8-11]

Co-occurring conditions contribute to additional negative health and life outcomes, including higher utilization of health care services and higher associated health care costs for autistic individuals, as compared to age-matched peers in the general population.[12, 13] Accessing health care services is often delayed, which can lead to symptoms being overlooked, ignored, or misdiagnosed. Rates of psychotropic medication use are very high among autistic individuals, and polypharmacy (simultaneous use of multiple drugs) is also common.[14-16] Co-occurring conditions also impact other aspects of life for autistic individuals, including educational attainment and employment, financial security, housing needs, and participation in the community.

As outlined in the *2021-2023 Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Research, Services, and Policy*, the autism community has called for more research and improved services to address co-occurring conditions. Since the first *2009 IACC Strategic Plan*, the Committee has been proactive in identifying co-occurring conditions as a priority area and has contributed to the expansion of research in this area. There is a growing body of knowledge on co-occurring physical and mental health conditions that affect people on the autism spectrum, but further research is needed, with the community continuing to call for further progress in this area. Additionally, there is a lack of adequate health care services to address co-occurring health issues. Low availability of trained personnel who can address health needs across the lifespan and access to health care services are issues that continue to present ongoing challenges.

The goal of this *2024 IACC Strategic Plan Update* is to provide an overview of current knowledge and community perspectives of conditions that commonly co-occur with autism, highlight recent federal activities to address these conditions, and identify gaps in research, services, and policy for individuals across the spectrum and across the lifespan. In addition, recent IACC activities related to co-occurring conditions are summarized in Chapter 1. It is the hope of the IACC that this report will help to spur additional research on co-occurring conditions, increase understanding of these conditions among health care practitioners and service providers, and increase investment in services that improve access and health outcomes for autistic individuals and their families.

Chapter 1: IACC Interest in the Impact of Co-Occurring Conditions

Formation and Activities of the IACC Working Group: Improving Health Outcomes for Individuals on the Autism Spectrum

During the Autism CARES Act of 2014 authorization period, the IACC convened a Working Group on Improving Health Outcomes for Individuals on the Autism Spectrum to gather information, discuss issues, and identify gaps in research and services for consideration by the full IACC. The Working Group was composed of IACC members and invited external stakeholders, including autistic individuals, family members, service providers, researchers, and other advocates. The Working Group roster is provided in Appendix III. The Working Group focused their efforts on identifying challenges people on the autism spectrum face pertaining to health and general wellness, as well as co-occurring physical and mental health challenges.

The Working Group planned several activities. Members met by conference call in 2018 and convened public workshops in September 2018 and May 2019. The September 2018 workshop on "Addressing the Health Needs of People on the Autism Spectrum" was focused on several of the most common physical health issues experienced by autistic individuals, as identified by the Working Group. The Working Group aimed to improve access to care for co-occurring physical health conditions; increase community and provider awareness of these conditions and their treatment; and facilitate the development of practice guidelines, policies, training, and service approaches to enable better patient-provider interactions and improved health outcomes across the lifespan. Six main topics were explored at the workshop:

- Health and Healthcare for Adults on the Autism Spectrum
- Overview of Physical and Mental Health in ASD
- Epilepsy
- GI Disorders
- Sleep Disturbances
- Healthcare Experiences of Children and Adults with ASD

In May 2019, the Working Group convened a workshop on "Addressing the Mental Health Needs of People on the Autism Spectrum." The workshop included discussion of community experiences with mental health issues and services, premature mortality related to mental health issues, and caregiver and family mental health, among other concerns raised by participants at the workshop. The six topics discussed at the workshop were:

- Mental Health Needs of People on the Autism Spectrum
- Personal Perspectives on Mental Health Issues in Autism
- Anxiety and OCD
- Depression and Suicide
- SIB and Aggression
- Mental Health Services for People on the Autism Spectrum

Detailed summaries of both workshops can be found in Chapter 2 of the *2018-2019 IACC Strategic Plan Update*. Overall, discussions of the Working Group were spirited and diverse, with topics ranging from biological factors that may link the features of autism to other physical and mental health conditions, to issues related to the transition of autistic individuals from primary care under pediatricians to care under adult physicians. Family members spoke about their challenges in obtaining adequate care for their loved ones across a fragmented health system and how debilitating physical and mental health conditions were often minimized as "part of being autistic" rather than being treated as they would be in a non-autistic individual.

In 2018, members of the Working Group began work on a report to raise awareness of the physical and mental health challenges that affect autistic individuals, guide future efforts and discussions of the IACC, accelerate and inspire needed research, and enhance health care service provision and access for individuals with autism and their families. While the Working Group ended its activities in 2019, this report was not completed before the expiration of the IACC under the Autism CARES Act of 2014. Following the enactment of the Autism CARES Act of 2019, the IACC voted to resume the work of this Working Group and focus on co-occurring physical and mental health conditions and their impacts on health outcomes for the *2024 IACC Strategic Plan Update*, using the draft report initiated by the Working Group as the foundation.

Recent IACC Activities and Interest Related to Co-Occurring Conditions

In addition to activities of the Working Group under the Autism CARES Act of 2014, co-occurring physical and mental health conditions have been a focus of many recent IACC meetings, events, and activities. Brief summaries of these activities are provided below. The full recordings of meetings and events, as well as minutes summarizing IACC meetings and discussions, are available on the IACC website.

The April 2021 IACC/National Institute of Mental Health (NIMH) Autism Awareness Month Special Event, "The Federal Response to COVID-19: Addressing the Needs of the Autism and Disability Communities," included presentations from the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the U.S. Department of Education (ED), and the U.S. Department of Labor (DOL). The event focused on issues related to health, education, and employment for people with disabilities during the pandemic and featured a discussion with leaders from the autism advocacy community. Discussions at the event focused on ways to address food insecurity and accessibility of vaccines and vaccine information for individuals with autism and their families. In addition, Dr. Joshua Gordon, NIMH Director and IACC Chair, spoke about the "Mental Health Impacts of the Pandemic on the Autism/Disability Community" and NIH and NIMH efforts to promote resilience in mental health for vulnerable populations.

The impact of COVID-19 on physical and mental health was also discussed at the July 2021 IACC Full Committee Meeting. It was noted that individuals with autism and individuals with mental health conditions were at greater risk of being hospitalized from COVID-19. The Committee also discussed how restrictions and complications in accessing in-person health check-ups and treatments led to the worsening of co-occurring health conditions for some people with autism during this time.

The July 2021 IACC meeting also included a discussion of racial equity and health disparities in autism. Fundamental, systemic barriers to receiving health services and treatment for people of color with autism was noted by the IACC. Committee members discussed how training and education to improve the cultural competency of health care providers will be critical in addressing inequities moving forward. In order to advance research on health disparities experienced by the autism community, multiple members strongly endorsed the use of community participatory research to ensure that the lived experiences of people with autism and their families are incorporated in the research design and process.

The October 2021 IACC Full Committee Meeting was focused on understanding mental health needs among autistic individuals. This meeting included a presentation on Drexel University's *National Autism Indicators Report: Mental Health*, which found that autistic children experience high rates of mental health conditions, are more likely to see a mental health provider, and are more likely to use psychotropic medication compared to their peers with other special health care needs. The Committee also heard a presentation on the Patient-Centered Outcomes Research Institute (PCORI) Engagement project, Autistic Adults and Other Stakeholders Engage Together (AASET), which sought to meaningfully include and engage autistic stakeholders in research. This project identified mental health interventions and outcomes; access to health care and accommodations; and gender inequalities in diagnosis, treatment, and sexual health as priority areas for mental health research in relation to autism.

The January 2022 IACC Full Committee Meeting featured a presentation on the *Lancet Commission on the Future of Care and Clinical Research in Autism*. The Commission recognized that autism is a lifelong condition, with heterogeneous presentations across the autism spectrum and proposed a stepped care personalized health approach to meet the physical and mental health needs of autistic individuals across the lifespan. In addition, the Commission noted the need to increase understanding of what interventions work for whom, what, when, and how in order to improve health outcomes for individuals on the autism spectrum. The report also addressed inequities in medical and service provision, including the current shortage of available service providers to address the needs of autistic individuals.

The April 2022 IACC Full Committee Meeting included a session on "Addressing Diverse Communication Needs in Autism." The session included presentations on advancing research on minimally speaking autistic individuals, as well as augmentative and alternative communication (AAC) supports for individuals with autism. Lack of such communications research and supports was noted as a potential barrier to appropriate health care supports and services, among other daily living challenges. Following the presentations, two community members discussed lived experience perspectives on research and services needs related to AAC use. They highlighted the need for inclusion of AAC users in shaping research priorities, as well as the need to improve access to high-quality AAC devices and training for educators and service providers.

The October 2022 IACC Full Committee Meeting featured a lived experience panel and research presentations on "Autism in Older Adulthood." Members of the panel described multiple co-occurring health conditions, including chronic fatigue, tremors, arthritis, dental issues, and dementia. Researchers also noted the many medical conditions observed in aging adults with autism, including hypertension, obesity, diabetes, and sleep problems. Studies have identified high rates of parkinsonism in individuals with autism and an elevated risk for dementia, which may be linked to underlying autism-specific changes in brain development that may continue beyond childhood. Further research on autism in older age is needed to advance the field's understanding of these conditions and why they may be more frequently experienced by aging adults with autism.

The January 2023 IACC Full Committee Meeting included a session on "Beneficial Supportive Services for Individuals with Autism." Supportive services such as physical therapy, dietary and nutritional supports, family/systems navigation, sensory integration therapy, therapies for sleep disorders, and complementary interventions, among others, are used widely by the autism community to alleviate co-occurring conditions. The Committee discussed the need for further research on these approaches and increased systems navigation supports to help autistic individuals and their families navigate the complexities of the health care and services systems.

The April 2023 IACC Full Committee Meeting featured a panel on "Increasing Racial Equity and Improving Disparities in Autism Outcomes," which focused on the impact of racism and discrimination in autism research, as well as promising practices towards reducing disparities in health outcomes. One presentation focused on "Racial and Ethnic Disparities in Healthy Weight and Culturally Tailored Interventions to Address Them," which described community engagement, peer-based methods, and translation of materials as key aspects of successful cultural adaptation of interventions to address racial and ethnic disparities in obesity and health outcomes. Community perspectives shed light on multiple topics, including the importance of equitable access to health care services for autism and its co-occurring conditions.

The October 2023 IACC Full Committee Meeting featured presentations on mental health and autism, including progress and needs in research related to emotion dysregulation, self-injurious behavior, aggression, trauma, and mental health across the autism spectrum. The session also included a research presentation and a panel discussion on community perspectives of mental health interventions and areas of need, with improved patient-provider interactions and provider training emerging as a priority area. This was followed by presentations on "Addressing the Mental Health Needs of Autistic People Through the Mental Health Service System," which described activities and recommendations of different national organizations working to improve and link services systems to improve access for mental health services for autistic individuals.

The July 2024 IACC Full Committee Meeting featured presentation and a panel on the experiences of family caregivers who are caring for family members with autism and co-occurring or complex health needs. The activities of the RAISE Family Caregiving Advisory Council, as well as other programs led by the Administration for Community Living (ACL), were described. Other presentations focused on meeting caregiving needs across the lifespan of autistic individuals and addressing needs specific to underserved communities. Discussions during the panel focused on the challenges in accessing services to address autism and co-occurring conditions, as well as the additional issues faced by caregivers of autistic individuals with high support needs.

Finally, the Office of National Autism Coordination (ONAC) solicited input on co-occurring conditions through the release of a Request for Public Comment on behalf of the IACC in early 2024. The Request aimed to gather public input on the impact of co-occurring conditions for autistic individuals and their family members, on behalf of the IACC. Over 1,200 responses were received. A detailed description of the Request for Public Comments and an analysis of the responses is available in Chapter 2 of this document.

These and other discussions of the IACC have highlighted the need for additional research and services to improve physical and mental health for people with autism and their families, as well as the need for improvements in interventions, services, and supports to address co-occurring physical and mental health conditions for autistic people. The perspectives of autistic individuals and family members, researchers, advocates, health care providers, and representatives of federal departments and agencies are reflected in the Recommendations to improve health and well-being outlined in the *2021-2023 IACC Strategic Plan*.

Chapter 2: Community Perceptions of Research and Services Needs

To identify community priorities related to co-occurring conditions and their impact on physical and mental health for autistic individuals, the Office of National Autism Coordination (ONAC), on behalf of the IACC, released a Request for Public Comment. The comment period was open from January 3, 2024, through February 14, 2024, and the announcement was posted on the Federal Register, the IACC website, and cross-posted by federal agencies and advocacy organizations. The Committee sought public comments on the following questions:

1. What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)
2. What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of co-occurring mental health conditions: depression, anxiety, aggressive or self-injurious behavior, suicidality)
3. What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?
4. What additional research is needed to help address co-occurring conditions for autistic people?
5. What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)
6. What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?
7. What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

A total of 1,254 responses were received for this Request for Public Comment. The complete text of all responses is posted on the IACC website. ONAC staff read and reviewed all responses and coded information in the responses according to the following categories:

- Type of co-occurring conditions
- Impact of co-occurring conditions
- Research needs
- Services needs
- Impacts of COVID-19

The following sections include detailed analysis of each of these categories, as well as demographic information about the 1,254 respondents. It is important to note that the respondents to the Request for Public Comments are not a statistically representative sample of autistic individuals, family members, and others. Therefore, responses received may not be generalizable to the full autism community.

Respondent Demographics

Respondents to the Request for Public Comment were asked if they identified as one or more of the following:

- Autistic individual
- Family member of an autistic individual
- Service provider, health provider, or educator
- Researcher
- Representative of advocacy organization
- Other

Of the 1,254 respondents, 676 individuals identified as autistic, and 711 were family members of individuals on the autism spectrum (**Figure 1**). Among these family members, 256 individuals indicated that they were also autistic themselves. Overall, the vast majority of respondents (1,131 respondents, or 90%) identified as individuals with autism and/or family members of autistic people. Among the other categories, 292 individuals indicated they were a health care provider, service provider, or educator; 87 indicated they were autism researchers; and 79 were representatives of advocacy organizations. The "Other" category was selected by 72 respondents. These included individuals with other neurodivergence such as attention-deficit/hyperactivity disorder (ADHD), representatives of service and research organizations, and advocates not part of an organization. Three individuals did not select any category.

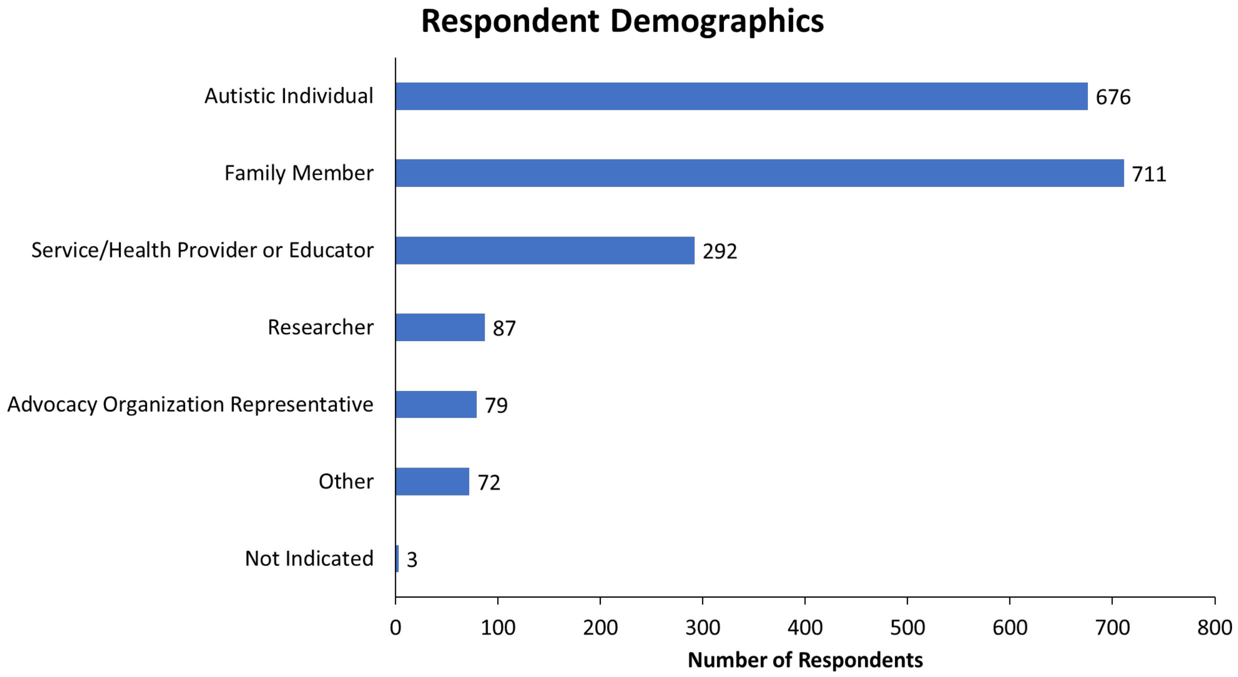

Figure 1. The number of respondents who identified as an autistic individual, family member of an autistic individual, service/health provider or educator, researcher, advocacy organization representative, other, or none selected. Note: Individual responses may be coded to zero, one, or more categories.

Type of Co-Occurring Conditions

In their answers to the seven questions of the Request for Public Comment, respondents highlighted many physical and mental health conditions. These were sorted into 39 categories (see **Table 1** in Appendix II). Many individuals mentioned multiple specific conditions. **Figure 2** shows the top 10 categories described. The most commonly mentioned co-occurring conditions were **sensory and motor**

issues (597 responses), followed by **anxiety** (595 responses). In addition, respondents described the impacts of **sleep disorders** (513 responses), **ADHD** (447 responses), **gastrointestinal (GI) issues** (416 responses), **depression and mood disorders** (413 responses), **communication issues** (379 responses), **self-injurious and aggressive behavior** (317 responses), **learning and memory difficulties** (257 responses), and **suicidal ideation** (210) on the health and well-being of autistic people. Other commonly mentioned conditions included:

- Joint/Connective Tissue, Musculoskeletal, Orthopedic Conditions (207 responses)
- Emotion Dysregulation (157 responses)
- Intellectual Disability (156 responses)
- Pain and Fatigue (154 responses)
- Pathological Demand Avoidance (PDA, 143 responses)
- Feeding and Eating Conditions (141 responses)
- Obsessive Compulsive Disorder (OCD, 106 responses)

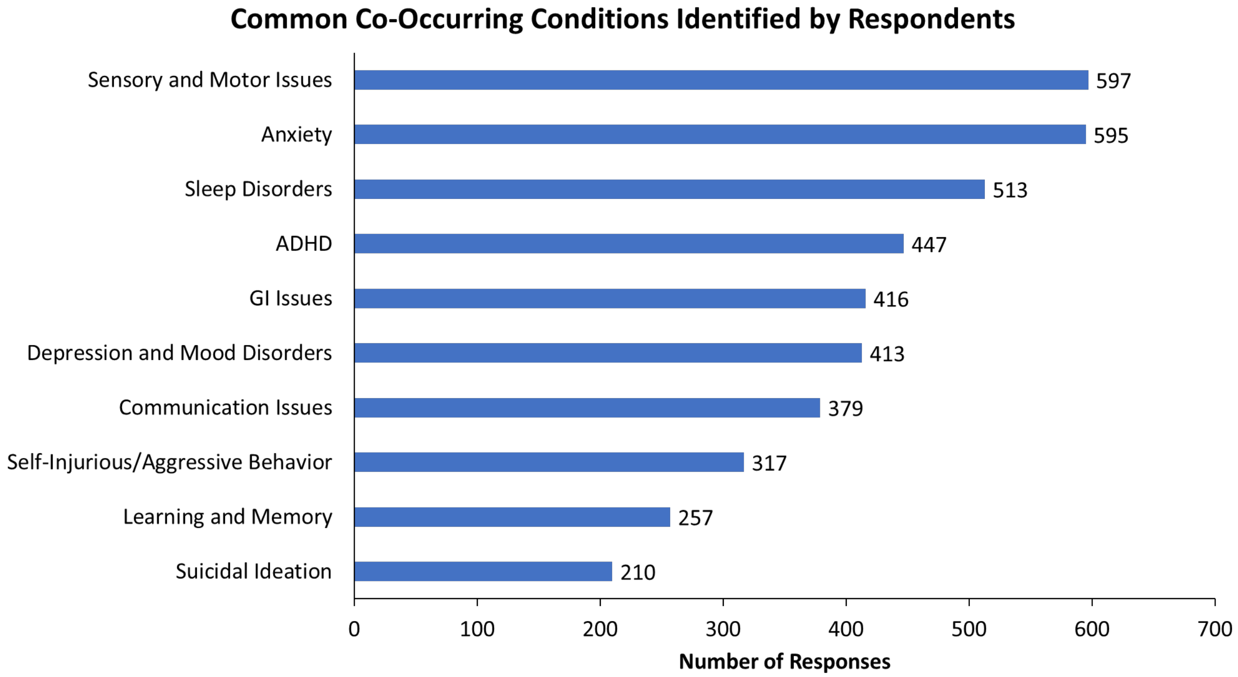

Figure 2. The top 10 most common co-occurring condition categories identified by respondents. See Table 1 in Appendix II for full list of categories. Note: Individual responses may be coded to zero, one, or more categories.

Impact of Co-Occurring Conditions

Co-occurring conditions impacted individuals with autism and their families in many ways. Responses were coded to 20 categories of impact (**Table 2** in Appendix II). Almost a third of RFI respondents (386 respondents) highlighted the **difficulty in finding health care providers** who can effectively work with autistic individuals to address their physical and mental health challenges. In addition, respondents described **communication** (345 respondents) and **social challenges** (335 respondents) that can be exacerbated by co-occurring conditions. Further, co-occurring conditions may contribute to **employment and financial difficulties** (214 respondents). Respondents also described experiences of **bias and stigma** (217 respondents) and **inaccessibility**/lack of accommodations that hindered full participation in community life (204 respondents). Some individuals also experienced **executive function difficulties** (209 respondents), while others described challenges with **daily living skills** (203 respondents). A portion of respondents also described **academic challenges** (202 respondents) in primary school or higher education settings.

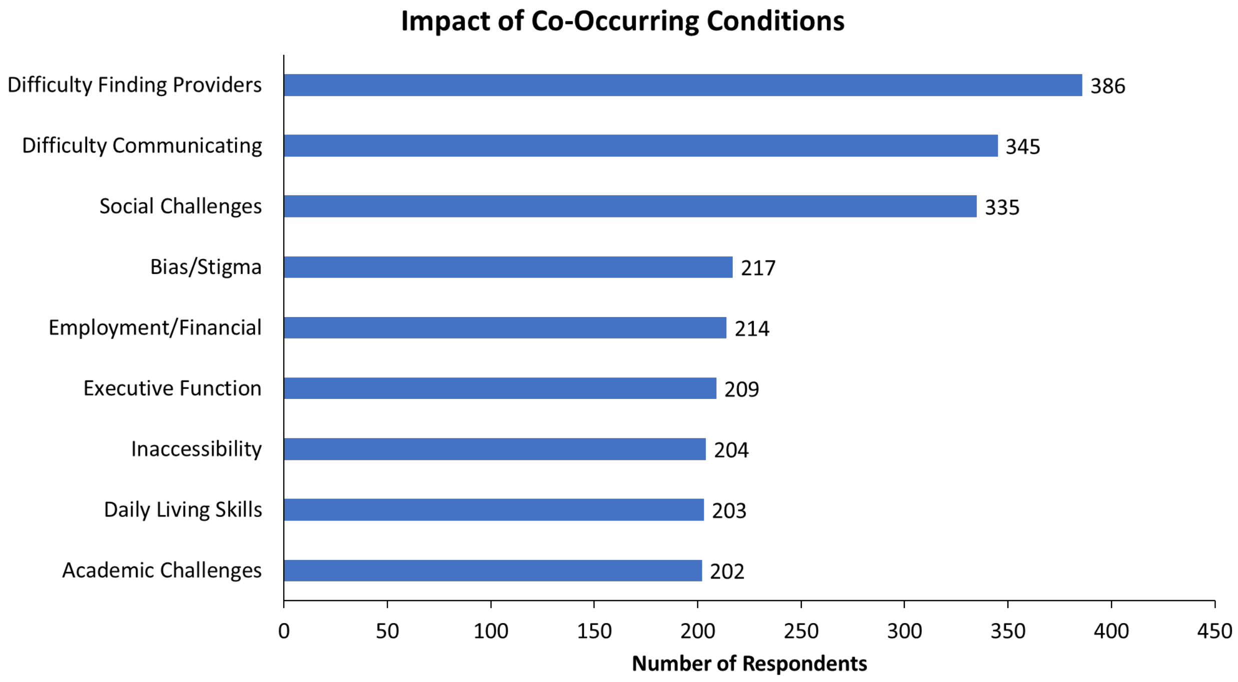

Figure 3. The top 9 impacts of co-occurring conditinos described by respondents. See Table 2 in Appendix II for full list of the coded impact catgeories. Note: Individual responses may be coded to zero, one, or more categories.

Research Needs

Research needs included in the responses were sorted into the seven Questions and the two Cross-Cutting Recommendations of the IACC Strategic Plan. An additional category, inclusion of lived experience in research, was an important theme from the *Strategic Plan* and was therefore included in the analysis. Many respondents mentioned the great need for more research to improve our understanding of the **Biology** (Question 2) of co-occurring conditions and autism (449 respondents). This was the most commonly mentioned research need. Research to improve **Interventions** (Question 4, 310 respondents) and **Services and Supports** (Question 5, 284 respondents) for autistic individuals and their families were also frequently mentioned. Respondents also called for increased research to better understand the impact of **sex and gender** on co-occurring conditions (178 respondents). Research to better under the changes in physical and mental health that occur across the **Lifespan** (Question 6, 169 respondents) of autistic individuals was an additional priority area. Respondents also highlighted the need for research to improve **Screening and Diagnosis** (Question 1) of autism while taking into account any possible co-occurring conditions. Additionally, **inclusion of lived experience in research** was a priority for 123 respondents, and 118 respondents indicated the need for research on **promoting equity and reducing disparities**. Research on the **Genetic and Environmental Factors** (Question 3) that may lead to the development of co-occurring conditions was mentioned by 84 respondents. Lastly, 48 respondents described the need for additional research **Infrastructure and Prevalence** research

(Question 7), largely focused on better understanding the prevalence of co-occurring conditions among autistic individuals.

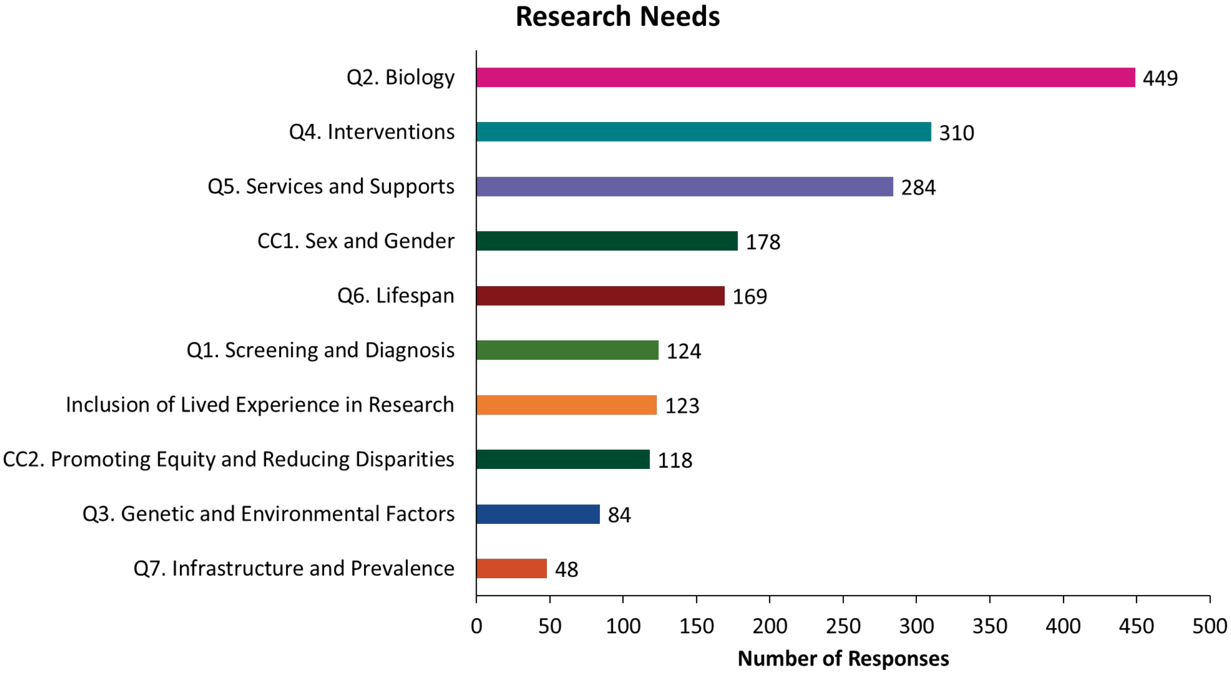

Figure 4. Categories of research needs expressed by respondents. See Table 3 in [Appendix II](#) for more detailed descriptions and examples for each category. Note: Individual responses may be coded to zero, one, or more categories.

Services and Supports Needs

Respondents identified many services and supports needs to improve the health and well-being of autistic individuals. These were coded to eight different categories. As was similarly found in the analysis of the impact of co-occurring conditions, **provider training**, including improving cultural competency and reducing ableism and stigma, was the most commonly mentioned service need (576 respondents). The need for **more benefits and insurance coverage** for interventions and services was noted by 568 respondents. In addition, 535 respondents mentioned the need to improve the **accessibility of services and interventions**, including reducing disparities due to socioeconomic and geographic factors. Respondents also noted the need for **better and more personalized services** that can meet the needs of autistic individuals across the spectrum and across the lifespan (442 respondents). **Systems improvements**, including improved systems navigation, increasing workforce capacity, and addressing systemic barriers for marginalized populations, was mentioned in 387 responses. **Support for caregivers** was mentioned in 113 responses, and **training for autistic individuals**, including support to strengthen daily living skills and employment training, was mentioned in 81 responses. Lastly, **acute care and crisis management** was mentioned as a service need in 47 responses, where individuals described the need for increased awareness of the unique challenges of autistic people in hospital emergency rooms and in interactions with law enforcement.

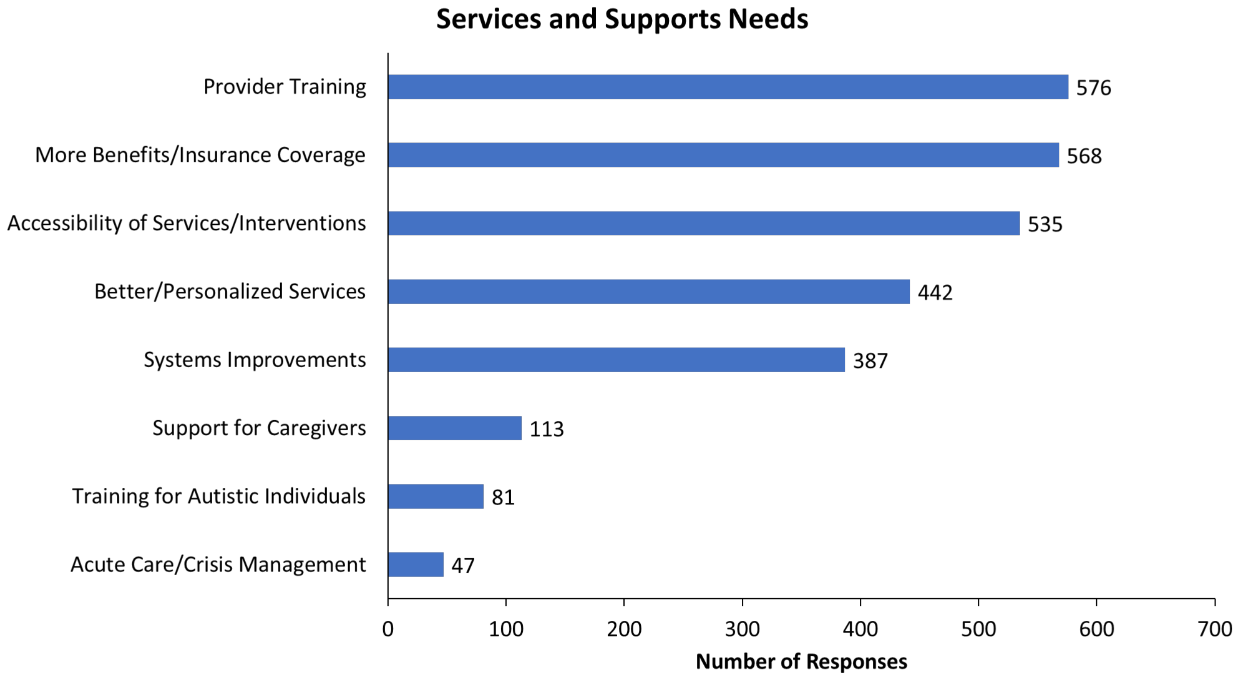

Figure 5. Categories of services needs expressed by RFI respondents. See Table 4 in Appendix II for more detailed descriptions and examples for each category. Note: Individual responses may be coded to zero, one, or more categories.

Impact of COVID-19

Respondents were asked to describe how the COVID-19 pandemic affected them, including impacts of COVID-19 infection and public health measures taken to reduce COVID-19 transmission. These responses were coded to 13 different categories (**Table 5** in Appendix II). Some of the impacts described were negative and some were positive. Many of the respondents (491) noted the **benefits of remote technologies,** including uses for telehealth and remote work. Respondents (313) also noted new physical and mental **health challenges** that arose during the pandemic, as well as exacerbation of existing health challenges. In addition, 310 respondents detailed the **hardships of increased isolation** and reduced social interactions, and 297 respondents described how the pandemic contributed to the **decreased availability of services**. Relatedly, 276 respondents noted pandemic-related **disruption of routines and regression** of social and other skills of autistic individuals. Many responses (248 respondents) also discussed **concerns about public health guidelines and society** that resulted from the pandemic; these included fears and lack of trust in others to adhere to public health guidelines, de-prioritization of people with disabilities, and sensory and social difficulties due to the wearing of face masks. Respondents (203) also discussed the **benefits of reduced social obligations** for autistic individuals, including how the wearing of face masks alleviated social pressures for some individuals with autism. The **lack of in-person services** was noted in 166 responses. Many of these responses discussed how remote technologies are not yet sufficient to meet the needs of all people with autism, and in-person health care services and education are critically important for many autistic individuals.

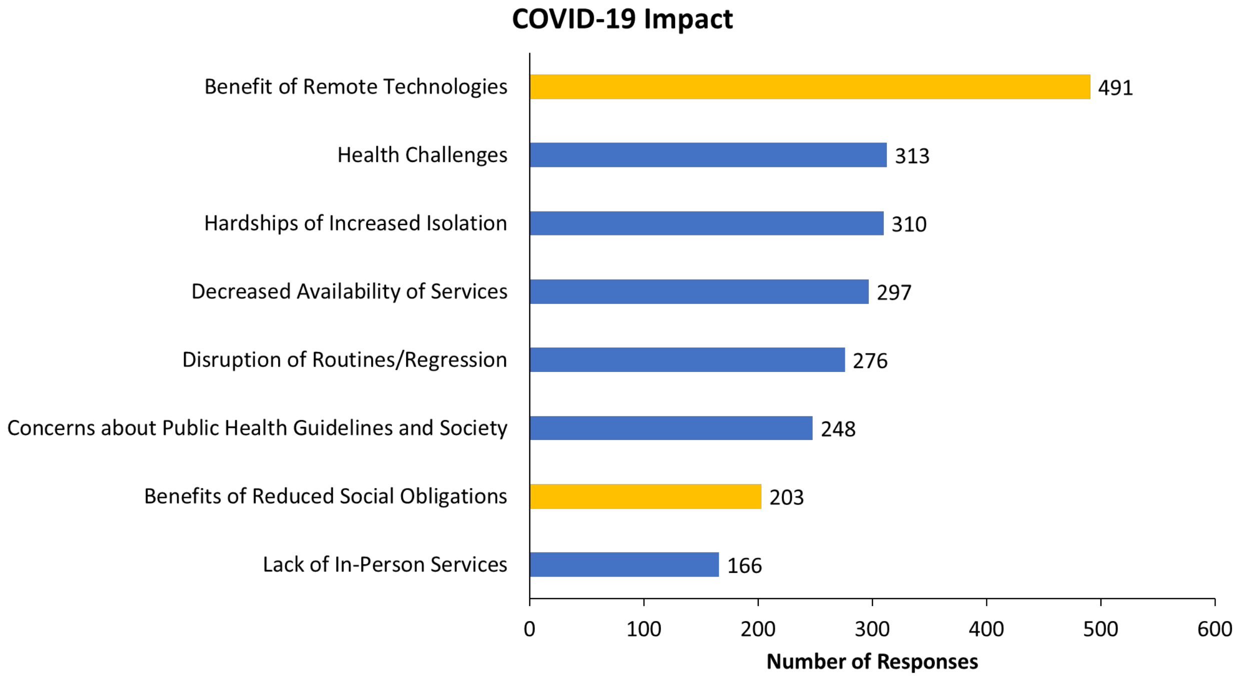

Figure 6. Categories of COVID-19 impact on the health and well-being of autistic individuals with co-occurring conditions expressed by respondents. Yellow bars highlight categories of positive impacts of the changes that came about as a result of the pandemic. Blue bars are categories of negative impacts of the pandemic. See Table 5 in Appendix II for full list of categories.
Note: Individual responses may be coded to zero, one, or more categories.

Summary

The 1,254 responses from autistic individuals, family members, health care and services providers, educators, researchers, and advocates raised many important issues surrounding the physical and mental health conditions that commonly co-occur with autism. From these responses, it is clear that improved interventions, services, and research on co-occurring conditions are priority areas for the autism community. In particular, the responses highlight the need for workforce development and additional training for health care providers to strengthen the treatment of co-occurring conditions often experienced by autistic individuals.

The following chapters detail the current research and gaps in knowledge on common co-occurring physical and mental health conditions in autism. The chapters also describe ways to potentially improve research, interventions, and services to address the needs and priorities of the autism community.

Chapter 3: Co-Occurring Physical Health Conditions

Introduction

Autism is associated with a wide range of co-occurring physical health conditions. These include epilepsy, gastrointestinal (GI) problems and disorders, sleep problems and disorders, sensory and motor challenges, dysautonomia and Ehlers-Danlos syndromes, and health issues that emerge in older age. When not acknowledged, recognized, and properly addressed, these physical health issues can have a significant impact on the well-being for autistic individuals, potentially even contributing to shortened lifespans.[1] Physical health issues impact not only the body but may affect other areas of life as well. For example, disrupted sleep and GI conditions can increase irritability and contribute to anxiety,[2, 3] which in turn can affect a person's interactions at school, work, within their families, and in the community.

In the *2021-2023 IACC Strategic Plan*, the Committee emphasized the importance of further research in these areas to facilitate interventions and treatment approaches that can benefit the health and well-being of individuals on the autism spectrum. The sections below focus on several health conditions that co-occur with autism: epilepsy, GI issues and disorders, sleep issues and disorders, sensory and motor challenges, Ehlers-Danlos syndromes and dysautonomia, and health in midlife and older adulthood, including aging-related conditions. Each section provides an overview of the health condition, followed by discussion of current gaps in the field and barriers to research progress, and concludes with description of promising avenues for future research.

Epilepsy

Overview

The prevalence of epilepsy in autistic individuals is estimated between 2% and 46%.[4-12] These estimated rates differ widely due to the heterogenous nature of autism and differences in study methods and populations.[13] Conversely, the prevalence of autism in epilepsy has been reported between 15% and 74%.[8, 9, 14] People on the autism spectrum develop epilepsy at a rate of up to 25 times that of the general population[15-17] and epilepsy is more prevalent in syndromic forms of autism (related to known genetic syndromes) than in non-syndromic forms of autism.[18, 19] To date, research has not identified any particular type of epilepsy that is more common in autism than others.[13, 20] Epilepsy can have a major impact on an individual's life, with potentially negative effects on behavior, motor function, communication, and cognition.[21-24]

Several factors have been associated with a greater risk of developing epilepsy in autism. Studies have identified an association between epilepsy severity and intellectual disability.[25-32] Rates of epilepsy have been found to be higher in individuals with autism and co-occurring intellectual disability.[9, 33-35] Age is another factor strongly associated with the development of seizures in individuals with autism. Several studies have suggested there are two age peaks of epilepsy in autism; one in early childhood (0-8 years) and a second in adolescence (10-19 years).[36-39] Large cross-sectional studies have found that the risk of epilepsy increases with age, peaking in adolescence but continuing into adulthood.[25, 40-42] Some studies suggest that the co-occurrence of epilepsy in autism is higher for females,[43, 44] however others have not found sex to be a contributing factor.[25]

Many of the genetic factors for epilepsy and autism overlap,[45, 46] suggesting that autism and epilepsy share a common etiology that interferes with synaptic function and neurodevelopment.[20, 33, 47, 48] Epilepsy and traits of autism are also frequent in several neurodevelopmental disorders, such as Fragile X syndrome, Rett syndrome, tuberous sclerosis, Dup15q syndrome, Angelman syndrome, and Phelan McDermid syndrome.[49-55] The biology of autism and epilepsy is shared among several different potential mechanisms, including nerve cell communication, seizure related cell processes, and similar alterations of brain structure and function.[56-58] Differences in EEG patterns[36, 59, 60] and changes in the balance of neuronal activity are seen in both epilepsy and autism.[61-64]

Despite these connections, the directionality of cause and effect is between autism and epilepsy is unclear. Epilepsy could be a causal factor in the development of autism, or it is possible that the neurodevelopmental differences that lead to autism could contribute to the occurrence of epileptic seizures. Because of the myriad of genetic and non-genetic potential causes of epilepsy and autism, a singular pathophysiological mechanism is unlikely.[65, 66] 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.

Knowledge Gaps and Barriers to Research Progress

Gaps continue to exist in the treatment of epilepsy in individuals on the autism spectrum. Currently, there have been no controlled clinical trials which evaluate the effectiveness or efficacy of antiepileptic drugs for the treatment of seizures in autism.[67] The use of anti-seizure medicines such as phenobarbital and clonazepam may result in negative behavioral, communicative, and cognitive side effects in certain individuals.[68, 69] It is not yet clear which medications are less likely to result in these side effects. In recent years, interest has grown in the use of new medicines such as cannabidiol that may control seizures and positively influence autism symptoms.[70, 71] Similarly, the efficacy of anticonvulsant spike suppressing medications, such as valproic acid, is not yet clear.[72] Further research is needed to develop techniques to non-invasively identify the subgroups of autistic individuals who may benefit from these forms of treatment. Lastly, studies are needed to evaluate the therapeutic use of ketogenic "seizure diets," which some individuals use as an approach to control seizure activity.[73, 74] In summary, there is great need to build the evidence base about these various approaches to the treatment of co-occurring epilepsy and autism.

Determining seizure is sometimes challenging because children with autism may exhibit behaviors that are rooted in their core traits, such as staring and seeming inattentive, not responding to their names, or exhibiting stereotyped repetitive movements.[13] Early referral to a neurologist is recommended if there is a suspicion of seizures, as is genetic testing, which can further refine and focus therapeutic options. There are also significant challenges inherent in researchers' attempts to study brain waves in autistic individuals with epilepsy. Existing neuroimaging methods are not accommodating to the needs of many individuals with autism. This makes it difficult to identify those with a higher likelihood of autism diagnosis who experience early onset seizures and those at risk for seizures who have an autism diagnosis. The development of advanced diagnostic and imaging methodologies, along with gene-based therapies, will help to improve neurodevelopmental outcomes for individuals with autism and epilepsy.[13]

There are multiple barriers to progress in this field. There are few clinics and physicians who specialize in treating epilepsy in autistic individuals. Autistic people and their families often struggle to find a provider who can comprehensively address both conditions. Because this area of research involves overlap between autism and epilepsy, neuroscientists and neurologists may experience challenges in securing funding for work that focuses on the intersection of these two conditions. As a result of requiring "controlled" study cohorts, participants with autism are typically excluded from epilepsy studies and participants with epilepsy are typically excluded from autism studies. This has presented a barrier to researchers in fully studying the population of those who have both autism and epilepsy.

Future Directions

There are a variety of potential solutions to address challenges and gaps in the overlap of autism and epilepsy. The lack of available data about individuals who have both autism and epilepsy highlights the need to integrate research efforts in this intersection and enhance the research workforce to address it. Funding mechanisms are needed to encourage studies and recruit investigators to work on epilepsy and autism. There is an acute need for future research to characterize the genetics, clinical risk factors, clinical course, treatments, and outcomes by subgroups of autistic and epileptic individuals. Most importantly, studies should identify critical periods and processes when intervention can prevent and reduce seizures and lessen the impact on cognition, communication, and behavior and improve the health and wellbeing of those with autism and epilepsy.

Treatments for epilepsy in autism are mainly limited to traditional studies of medication-resistant seizures in academic medical centers. The five- to six-fold risk elevation of death in those with autism and epilepsy compared to those with autism alone[7] fuels a sense of urgency. Researchers are working understand the underlying genetics, biology, and range of available treatments to spur the development of personalized seizure prevention and ameliorate the effects of seizures on communication, behavior, and cognition.

Improved supports and accommodations can help individuals with autism and epilepsy become more comfortable with improved clinical assessments, treatments, and research protocols. Emerging technologies, including vagus nerve stimulation, deep brain stimulation, and non-invasive seizure detection technologies including wearable sensors, can help to improve the detection and management of seizures. Because the costs of these technologies and many other treatments, such as seizure diets, are prohibitive, there is a need to advocate for better reimbursement of these interventions and encourage rapid FDA approvals of those with excellent clinical trial evidence. Improved services and supports can also help youth with autism and epilepsy as they are transitioning from child to adult systems, such as inclusive post-secondary education, employment, community, independent/daily living, and healthcare. The Health Resources and Services Administration (HRSA) is currently funding a program to develop and advance national, state, and local/community-level frameworks that support successful transition from child to adult serving systems for youth with autism and/or epilepsy who have complex health and social needs and require a higher level of family support and coordination. An ongoing NIH clinical trial of infants with Tuberous Sclerosis Complex (TSC), a genetic disorder associated with autism (see Chapter 5), is investigating the use of treatment with vigabatrin to lower the risk of seizures.

GI Issues and Disorders

Overview

The occurrence of GI conditions in individuals with autism has been increasingly recognized and progressively evaluated over the past several years. GI disorders are one of the most prevalent medical conditions in autism, along with sleep disorders and seizures/epilepsy.[75-77] Beyond simple co-occurrence of the conditions, interest in the impact of GI conditions on the development or exacerbation of autism has greatly increased in recent years. Autistic children are more likely to experience GI issues compared to typically developing children or children with other developmental disabilities, including constipation, diarrhea, acid reflux, and abdominal pain.[2, 78-80] GI symptoms are experienced by between 9 and 91% of children with autism[81] (prevalence rates vary considerably depending on sample characteristics and methodological approach).[82] GI disorders are also higher among adults with autism in comparison to the general population.[1, 83]

GI symptoms often cause pain, discomfort, functional limitations, and distress, impacting both mental and physical health.[76] This is especially true for individuals who are unable to communicate their pain to their caregiver.[84] GI problems and disorders in autism have been associated with loss of skills and language and communication ability, self-injurious behavior and aggression, sleep problems, anxiety depression, and sensory sensitivities/over-responsiveness.[78, 80, 85-90] GI symptoms in autism also co-occur with food sensitivities and eating issues.[91-93]

The role of the gut-immune-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.[94] Given the prevalence of co-occurring GI issues in autistic individuals, it is hypothesized that the microbiome may play a role in autism development. Studies of fecal DNA have found certain bacterial types overrepresented in children on the autism spectrum compared to neurotypical children.[94] Studies investigating differences in gut microbiota indicate that chronic gut inflammation may play a role in autism.[95, 96] Additionally, some studies have found interventions designed to normalize the gut microbiome that improved GI symptoms of constipation, diarrhea, indigestion, and abdominal pain, in addition to improvements in some behaviors in autistic individuals.[97-99] Other recent work suggests that gut issues in autism may be linked to differences in the neurons found in the gut.[100]

Knowledge Gaps and Barriers to Research Progress

A central difficulty in recognizing and characterizing gastrointestinal dysfunction for individuals with autism is the communication challenges experienced by many individuals, who may find it difficult to recognize and communicate the GI issues that they are experiencing.[80] Because many surveys rely on parent/third party report, GI symptoms can be missed. Questionnaires often used to assess typically developing children do not usually contain a sufficient range of non-verbal behaviors to capture GI symptoms in children with autism, such as facial grimacing, unusual posturing, self-injurious behavior.[76, 80] Further, these measures typically do not capture the restrictive, repetitive, or sensory types of mealtime behaviors common in autism that can affect gastrointestinal health. Improvement and standardization of study tools such as questionnaires and surveys are needed to obtain more accurate results that reflect the true experiences of autistic individuals and can be compared across studies.[101]

An additional challenge is the dietary differences found in many individuals on the autism spectrum, including preference for eating a restricted diet.[79] Feeding and eating disorders, including anorexia nervosa, bulimia, and highly restrictive behaviors known as Avoidant Restrictive Food Intake Disorder (ARFID) or sensory based textural restrictions, can contribute to nutritional deficiencies.[102-108] (See also Chapter 4, which covers [Feeding and Eating Disorders](#) in more detail.) These conditions may require nutritional and behavioral intervention to prevent malnutrition or other adverse outcomes. There are conditions known to be associated with these types of feeding behaviors such as allergic or eosinophilic esophagitis (EoE).[109] Because of these co-occurring feeding issues and conditions, it is unclear the extent to which they may contribute to the development of GI symptoms or if the GI symptoms themselves lead to a more restricted diet.[110] Further research is needed to disentangle these factors, as GI issues continue to be a common co-occurring health issue that affects many individuals on the autism spectrum.

Future Directions

Consideration of GI issues that contribute to the negative symptomology of autism offers a compelling pathway for future investigation. Many of the reports regarding intestinal microbiome disruption and modulation are limited by small patient size at this point but are encouraging enough to proceed with further research. However, it is important to examine the potential impact of confounding factor: A recent metagenomics study did not find any association between autism and the gut microbiome, instead positing that the differences in microbiome may be due to dietary preferences.[110] Current research funded by the NIH is exploring gut-brain dysfunction in the context of maternal stress and how this may contribute to neurodevelopmental conditions such as autism. Another important direction for future research is improving treatment approaches for other co-occurring conditions in autism, such as feeding and eating disorders, anxiety, and sleep issues that may contribute to improvements in GI symptoms. Further research is needed to examine the underlying biological mechanisms and interplay of these conditions.

Sleep Issues and Disorders

Overview

Although sleep problems are not a part of the core autism diagnostic criteria, they are among the most common co-occurring health issues reported by families and medical care providers,[111-114] even before a diagnosis is received.[115, 116] Sleep is critical for synaptic development and brain maturation, and poor sleep can have detrimental effects on children's developmental outcomes.[117] Studies indicate the prevalence of sleep problems in autism are as high as 50-80%.[113, 118-124] The most common sleep problems include struggles initiating and maintaining sleep, frequent and often prolonged night awakenings, early morning waking, and irregular-sleep wake schedules.[118, 125] Sleep problems are associated with severity of core autism features and can cause worsened anxiety, hyperactivity, GI symptoms, and attention problems.[113, 126-132] Poor sleep can also exacerbate aggression, irritability, and hyperactivity.[133]

In a large study of autistic children aged 4-10 years, investigators found that 71% of the children experienced sleep disturbances although only 30% had been diagnosed with a sleep disorder.[134] Sleep problems that develop in early childhood often persist into adolescence, but the type of sleep problem may change with age.[118] A large study found that younger children experienced bedtime resistance, frequent awakenings, parasomnias, and sleep anxiety, whereas the adolescents struggled with sleep onset insomnia, short sleep duration, and daytime sleepiness.[135] Later in life onset of neurologic problems such as seizures may affect sleep patterns, or treatment of these conditions may disrupt sleep.[136, 137] Weight gain from medications or inactivity can contribute to sleep apnea, which in turn can cause night waking and daytime sleepiness.[138] Similar to the general population, the stresses of COVID-19 were associated with high rates of sleep problems for autistic people.[139, 140]

The etiology of sleep issues in autism is multifactorial, involving biological, psychological, genetic, socio-environmental, and family factors.[133] Several neurotransmitters, including serotonin, melatonin, and gamma-aminobutyric acid (GABA) play vital roles in the maintenance of sleep-wake cycles. Atypical levels of these neurotransmitters have been described in autism.[141-147] In comparison to neurotypical individuals, autistic individuals show prolonged sleep latency, reduced total sleep time, lower sleep efficiency, reductions in both rapid eye movement (REM) sleep and non-REM sleep.[148-150] Model animal studies have improved our understanding of how genetic changes that lead to autism may also cause sleep disturbances.[151] Researchers have also used large genetic databases to identify genetic variants in sleep regulation genes that are more prevalent in autistic individuals.[152]

Problems with sleep affect not only the autistic individual, but often their caregivers and family functioning as well.[153] Research has identified a relationship between sleep problems in children with autism and parental sleep, stress, anxiety, and depression.[154-156] High prevalence rates of self-reported sleep disorders and symptoms have been found for caregivers of children with autism.[157, 158] Given this relationship, effective interventions for sleep problems have the potential to improve health outcomes for both autistic individuals and their caregivers and families.

Multiple studies have shown the efficacy of behavioral therapies, caregiver training, and melatonin in treating sleep problems in children on the autism spectrum.[159, 160] Pediatric-appropriate prolonged-release melatonin, which has sleep-promoting and chronobiotic (circadian rhythm-altering) properties, is an approved U.S. Food and Drug Administration nutrition supplement and has been found to be safe and well tolerated with minimal side effects for children with autism.[161, 162] Use of melatonin for treating issues in autism has resulted in improvements in parenting stress.[163] For sleep disorders beyond insomnia, clonazepam and tricyclic antidepressants may be effective treatments for sleep terrors, sleep walking, although their use should be limited to situations where injury is a possibility.[118] REM sleep behavior disorder may also respond to clonazepam. Behavioral sleep interventions have also shown positive caregiver health effects.[164] Contextual sleep hygiene and caregiver education and training have also shown benefits.[165, 166] Other complementary and alternative approaches such as the use of weighted blankets, aromatherapy, physical exercise, cannabidiol (CBD) and yoga to improve sleep are being used by many in the autism community, but they currently do not have substantial evidence of efficacy. [167-171]

Knowledge Gaps and Barriers to Research Progress

One challenge to advancing the field on sleep issues in autism is that sleep problems may present as a co-occurring symptom, a consequence arising from neurobiological differences in autism, or a clinical phenotype.[116, 172] Poor sleep can increase certain autistic features, such as repetitive behaviors, which in turn can make sleeping even more difficult.[173] Sleep and GI problems are overlapping co-occurring health conditions that can create a challenging feedback loop.[91, 174] In addition, newly emerging sleep problems may reflect the onset of a depressive episode or reflect recent experiences of anxiety and/or trauma.

Due to the common areas of overlap described above, medical conditions potentially contributing to sleep disorders in autism should be carefully evaluated when considering interventions for sleep. Despite the availability of interventions to address sleep issues, some autistic children still experience sleep difficulties, and many autistic adults report dissatisfaction with their sleep quality.[175] 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.

Future Directions

In the future, it will be important to explore if genes that regulate sleep may also contribute to autism development. The potential genetic component of sleep problems might be examined on a large scale through collaborations with autism registries collecting genetic samples, such as Simons Powering Autism Research (SPARK) and the Autism Genetic Research Exchange (AGRE), in which patient/caregiver reported outcomes, including effectiveness and side effects of medications and other treatments, can be measured.

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. Neurological issues related to executive function and arousal, and how these contribute to sleep problems in autism, is another area in need of additional research. Currently, the NIH is funding an Autism Center of Excellence that supports preclinical and clinical studies on sleep disturbances in autism.

Cognitive-behavioral therapy for insomnia warrants more study, especially in teens and adults with autism.[164] The Department of Defense Autism Research Program is funding an intervention study utilizing cognitive behavioral treatment for insomnia in children with autism. The study seeks to determine if the intervention will improve the children's sleep and daytime behavior and decrease the levels of arousal. An additional important area for future work is research that compares medications for sleep, including reports from autistic people themselves or parents of children with autism, are critically important. New technology (for example, in-home monitoring of EEG, sleep activity, heart rate, and/or video) can enhance parent and self-report of difficulties with sleep.

Clinical guidelines for healthcare for autistic individuals should include routine screening for sleep difficulties, identification and treatment of any medical, neurological, or behavioral co-occurring conditions, and recommendations for improving poor sleep habits. While clinical guidelines have been disseminated for insomnia and disrupted sleep behavior in children and adolescents[125], there is a need for additional guidance for problems of night waking and early awakening and for older individuals.

Sensory and Motor Challenges

Overview

Historically, cognitive, social, and behavioral differences have been characterized as the core features of autism. However, motor coordination differences and atypical sensory-based responses have frequently been observed in autism, even from infancy.[176-181] People with autism also often have atypical sensitivity to sights, sounds, smells, tastes, or touch. They may experience hypersensitivity and/or hyposensitivity to different stimuli. They may also experience differences in their balance, proprioception (sense of self-movement and body position) or interoception (sense of the body's internal state).[182] A recent systematic review estimates that the prevalence of Developmental Coordination Disorder (DCD), a neurodevelopmental condition characterized by poor motor proficiency that interferes with activities of daily living,[183-185] is present in 87% of individuals with autism.[186]

The growing body of work on this topic indicates that differences in the sensory and motor nervous systems play a significant role in autism. The vast majority of individuals on the autism spectrum experience hypo- or hyper-sensory differences, which may have negative impacts on cognitive performance,[187] social interactions and communication,[188, 189] and stress.[190, 191] 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.[192] These sensory difficulties occur across the core sensory systems, including visual, auditory, gustatory, olfactory, tactile, vestibular, and proprioceptive and interoceptive systems. The degree and impact of these differences vary from person to person.[193, 194]

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.[195] Motor differences can be detected clinically and technologies are emerging to enhance assessment and detect subtle differences.[196] Motor skills that 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 and atypical patterns of crawling can be detected prior to and often correlate with later development of differences in social skills.[197-202] In children, motor differences may include walking asymmetry, sequencing instead of superimposition of one movement on the other for example during gait, unusual positions of arms, poor coordination, muscle tone and reflex abnormalities, impaired finger-thumb opposition; stereotyped movements of the body, limbs, and fingers, and unusual gait patterns.[192, 203, 204] Studies have also identified motor differences in autism in adulthood.[205] Multiple research studies have found that degree of motor impairment correlates with the severity of autism features.[206-208]

Physical therapy (PT) is often used by people with autism who have pervasive gross motor impairments such as poor visuomotor and bilateral motor coordination, as well as postural impairments in static and dynamic balance.[195, 209-211] Research has also shown that PT can help address gross motor delays in young children with autism.[212] Motor, physical activity, and exercise interventions have shown positive outcomes in alleviating social, behavioral, cognitive, and motor impairments in children and adults with autism.[213-216] Sensory integration therapy can help to improve a person’s sensitivities to sensory stimuli that may be overwhelming or cause discomfort. It has demonstrated positive outcomes for improving autistic persons’ individually generated goals of function and participation.[217, 218]

Knowledge Gaps and Barriers to Research Progress

Extensive research has contributed to a better understanding of the neurobiological differences within the central nervous system that lead to hypo- or hyper-sensitivity in autism.[219-224] 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 dysregulation in autism.[225] A gap in our current knowledge is whether these findings can translate to humans.

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. In some cases, the presence of early impairments in the motor development of children with autism can be recognized even before the appearance of “classic” social communication challenges.[197] In terms of facilitating a timely diagnosis and connection to important early intervention services, further diagnostic and clinical guidelines could be developed to detect motor differences early in life.

Future Directions

Sensory and motor differences in autism represent important opportunities for research and intervention. Several studies have begun to explore the connection between sensory integration differences and how these may explain motor challenges in autism.[226-228] Recently, NIH supported found that disruptions to somatosensory neurons (cells that produce touch perception) may contribute to the development of social and other behavioral deficits in autism mouse models.[229] Because sensory challenges occur in a heterogeneous manner across the autism spectrum and across the lifespan,[230-234] future research should continue to investigate differences in sensory processing in different autistic individuals and how these may 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.

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. In recent work, researchers supported by the NIH used sensory integration therapy to improve functional skills in children with ASD and sensory issues. The researchers identified sensory difficulties that are not typically assessed or considered for individuals with ASD, and further research could lead to more personalized treatments.[235] Because motor and communication skills (both verbal and non-verbal) are connected, interventions aimed at improving motor skills could also have positive effects on other aspects of development.[133]

Ehlers-Danlos Syndrome

Overview

Ehlers-Danlos syndromes (EDS) are a group of disorders characterized by hypermobility of the joints, skin hyperflexibility, and tissue fragility, and are related to genetic mutations in genes that provide the blueprint for collagen. Complications of EDS can include arterial and organ rupture, chronic pain, and joint dislocation. Joints can be severely affected, predisposing individuals to injury or mobility disabilities. Hypermobile EDS can also affect the GI tract and cause GI dysfunction.[236, 237] Like autism, EDS are complex spectrum conditions. EDS patients report fatigue, social withdrawal, and anxiety in their daily life.[238] Co-occurrence of EDS and autism has been described in the literature since the 1980s.[239] More recent studies have shown that children on the autism spectrum have greater joint flexibility compared to age- and gender-matched peers,[240] and generalized joint hypermobility and EDS are associated with both autism and ADHD.[241-243] Many co-occurring conditions are also shared in both autism and EDS, including seizure disorders, sleep disorders, and anxiety and mood disorders.[243-248]

Knowledge Gaps and Future Directions

Proprioceptive impairments co-occur with EDS, which alters coordination and posture. In a cascading effect, these impairments may ultimately affect neurodevelopment and the acquisition of verbal communication and motor skills, contributing to features commonly associated with autism.[244, 249, 250] In addition, pain and dysautonomia, frequently experienced by people with EDS, have been associated with cognitive deficits in attention and executive function.[251, 252] Further research is needed to investigate these connections and their underlying mechanisms.

Maternal immune activation may be a shared mechanism for EDS and autism.[253] Preliminary research has found that more than 20% of mothers with EDS report having autistic children, and that rates of autism in children were related to severity of maternal immune disorders.[244] Further work is needed to improve our understanding of the role of the maternal immune system in autism susceptibility and connective tissue disorders.

Given the overlap of EDS and autism, assessments of joint hypermobility could be more regularly integrated in clinical assessments of individuals with autism. For those who show hypermobility, further genetic testing should be performed to rule out other conditions such as hereditary connective tissue disorders. Working with physical and occupational therapists who are familiar with hypermobility-related issues could also be of great benefit to autistic individuals who experience proprioceptive differences and poor overall body awareness.[244, 254, 255]

Dysautonomia

Overview

Dysautonomia is caused by dysfunction of the autonomic nervous system (ANS), 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 (POTS) is a form of dysautonomia and is characterized by reduced blood volume upon standing leading to lightheadedness and fainting. Dysautonomia itself is often experienced by people with EDS and POTS.[256, 257] Recent research indicates higher prevalence of dysautonomia in autistic and neurodivergent populations and strong associations with EDS.[258, 259 260] Automimic dysregulation can present as part of the profile of many genetic syndromes, which may also be associated with autism.[258, 261, 262]

Knowledge Gaps and Future Directions

More research is needed on the psychopathological, neurological, and biological mechanisms of dysautonomia and autism. Recent studies have found that anxiety and stress mediate the relationship between autistic traits and ANS dysfunction, leading researchers to hypothesize that ANS dysfunction may not be a feature of autism itself, but attributable to the high levels of anxiety and stress experienced by autistic adults.[263, 264] Few studies have controlled for anxiety/depression when examining ANS dysfunction in autism, which may be an important factor to consider.[265, 266] An additional challenge in research is consistency in methods, which vary from self-report measures, parent-report questionnaires, and physiological measures such as heart rate.

Some promising interventions have emerged in the treatment of dysautomia in individuals with autism. Propranolol (a beta blocker) has shown modest success, with positive effects on autonomic nervous system symptoms. Randomized clinical trials are needed to further demonstrate efficacy.[267] Use of low-frequency repetitive transcranial magnetic stimulation (rTMS) in experimental settings has also shown promise in improving autonomic nervous system dysfunction in people with autism.[268]

Immune System Dysfunction

Overview

The immune system protects us from disease and is made up of many interconnected organs, molecules, cells, and pathways.[269] There is growing evidence of immune system dysregulation in autism and related immune system issues that can impact daily life.[270-272] Research has found allergies, autoimmune disease, and immune-mediated conditions such as asthma, inflammatory bowel disease, and atopic dermatitis to be more common among children and adults with autism.[11, 273-275] These may be linked to other co-occurring conditions, such as chronic inflammation, GI problems, and autoimmune disease.[276] Studies of family history of autoimmune diseases suggest that this plays a role in the pathogenesis of autism.[277, 278] Current work supported by the NIH is investigating the association between endocrine-disrupting chemicals and maternal and child immune function in the etiology of autism.

Multiple genes associated with the development of autism are also known to be involved in the function of the immune system,[271, 279-283] in particular genes encoding immune-related proteins such as cytokines, which play a role in responses to infection, injury, inflammation and disease.[284] Altered cytokine profiles have been found in children with autism.[285] Post-mortem work has demonstrated increases in cytokines relative to controls.[286] Increased levels of certain cytokines have also been associated with increased behavioral challenges in children with autism.[287]

Knowledge Gaps and Future Directions

Further research is needed to expand our understanding of immune-related co-occurring conditions, environmental factors, and how immune regulation may be affected in autism.[288] Further studies are also needed to investigate treatment of immune-related issues and how these may contribute to behavioral changes.[269] Recent studies exploring the effects of some anti-inflammatory drugs, including resveratrol and palmitoylethanolamide, have yielded some early positive results in reducing inflammation, hyperactivity, and irritability.[289, 290] Development of targeted treatment approaches for the variety of immune system issues experienced by individuals with autism across the lifespan has the potential to greatly benefit health and wellbeing.

Physical Health Conditions in Midlife and Older Adulthood

Overview

Individuals with autism accrue 60% of their lifetime direct medical costs after age 21.[291] 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.[1, 292-295] A longitudinal, population-based study conducted in Sweden found that autistic adults were at increased risk of bodily injuries such as falls, heart failure, cystitis, and self-harm.[296] Several studies have pointed to elevated rates of neurodegenerative diseases such as parkinsonism and related issues (e.g., stiffness, tremor similar to that found in Parkinson's disease) in adults with autism.[1, 297, 298] In addition, recent research has found that the prevalence of early-onset dementia is higher among autistic adults.[299] Impaired motor skills and atypical functional connectivity of the sensorimotor system have also been identified in older adults with autism.[300] Vision and hearing impairments as well as vitamin deficiency have also been found to be more common in adults with autism.[1]

Research has begun to elucidate the neural and other biological mechanisms, as well as social environmental factors, that may underlie the elevated rates of co-occurring health conditions in aging adults with autism. Aging with autism presents unique challenges. Isolation, lack of accessible options for physical activity, and limited diets as a result of sensory sensitivities could contribute to multiple health problems. The social and communication difficulties experienced by many autistic people may decrease access to healthcare, and difficulty reporting symptoms might delay or prevent people from obtaining timely treatment and/or preventative care for co-occurring health conditions.[301] 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.[302] When experiencing menopause, individuals with autism have reported more extreme anxiety and depression.[303] In addition, the long-term use of psychiatric medications, commonly prescribed to people with autism, likely contributes to metabolic conditions.[301]

Recent research also points to racial/ethnic disparities in chronic health conditions that are experienced by autistic individuals as they age. Black, Hispanic, and Asian autistic Medicaid beneficiaries have higher odds of diabetes, hospitalized cardiovascular diseases, and hypertension, in comparison to white autistic beneficiaries.[304] Many of these disparities are also present in the general population, such as higher prevalence of hypertension, cardiovascular disease, obesity, and asthma among Black Americans[305, 306, 307] and higher prevalence of hepatic disease, obesity, headaches, and low vision among Hispanic Americans.[308-311] These disparities are likely driven by environmental, behavioral, and psychosocial differences,[305, 307, 312, 313] and autistic adults who are also members of underserved racial/ethnic groups may face many barriers in accessing appropriate and culturally competent healthcare.

Knowledge Gaps and Barriers to Research Progress

In general, research on middle aged and older autistic adults remains limited, with research on adults at age 50 and older accounting for less than 1% of published autism studies.[314] In addition, research deriving prevalence estimates of co-occurring conditions such as dementia from Medicaid data is an important first step, but is limited by the fact that it does not include autistic people who are on private health insurance plans or Medicare. 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 health issues. Gathering further evidence on aging in autism will give autistic people, their families, and health care providers more certainty in meeting and foreseeing the needs of the autistic people as they age.[296] A critical question to address 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.

A notable knowledge gap is potential neurological differences within the aging autistic population. Some studies have found specific age-related changes in the brains of autistic adults in terms of both cortical thickness and brain volume.[315-317] However, other work has found no difference in gray matter volume, thickness, surface area, or gyrification between adults with autism and controls.[318] Conflicting results such as these may be due to differences in study design, sample size, inclusion of adults with co-occurring intellectual disability and/or psychotropic drug exposure.[301] Further work is needed to address these limitations.

An additional challenge to research progress are issues surrounding the diagnosis of autism in adulthood. Because autism has traditionally been thought of as a childhood disorder, many older adults with autism are likely misdiagnosed or undiagnosed.[301] For example, one study of a Pennsylvania state hospital found that 10% of long-term adult patients who had been diagnosed with schizophrenia actually met criteria for autism.[319] Additional research is needed to develop and improve screening, diagnosis, and assessment tools for older adults. A challenge to receiving a later-in-life diagnosis is that adults may not have reliable informants available to provide information about their developmental history. Furthermore, co-occurring psychiatric disorders with onset in adolescence or adulthood may share similar features to autism, which can make diagnosis challenging.[302]

Future Directions

As described above, untangling the biological and social factors that contribute to health outcomes for autistic adults is an area ripe for future research. Currently, NIH is supporting an Autism Center of Excellence (ACE) to specifically study aging-related differences in autism. Researchers also supported by NIH are studying the shared mechanisms of autism and congenital heart disease, as well as autism and Alzheimer's disease.

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. In addition, the continued development of non-invasive effective screening tools for aging-related conditions, such as blood biomarkers to detect Alzheimer's disease,[320, 321] could be especially beneficial for this population. 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.[322] More work is needed at the systems level to design interventions that can be implemented by healthcare providers, including geriatric medicine specialists, in community settings. In addition, there is evidence that racial and ethnic disparities are strong and persist among the subpopulation of autistic adults. Further public health interventions are needed to address these disparities, such as cultural evidence-based and competency programs and community-based service providers.[323]

Summary

Physical, psychiatric, and neurological co-occurring conditions result in a wide range of issues and challenges for individuals with autism. Common health conditions experienced by autistic adults and children include epilepsy, GI problems and disorders, sleep problems and disorders, sensory and motor challenges, dysautonomia and Ehlers-Danlos syndromes, and health issues that emerge in older age. The field has made advancements in our understanding of the incidence and overlap of these conditions in the autistic population, but many gaps remain in our knowledge of the underlying biological, pathophysiological, neurological, genetic, and socio-environmental mechanisms. Further research is needed on the natural trajectory of these conditions across the lifespan, their impact on other areas of life such as education and employment, as well as their relation to the core traits of autism.

Research funded by private organizations and federal agencies has fueled progress in recent years to better understand the prevalence and underlying biology of physical health conditions experienced by autistic individuals. For example, the Study to Explore Early Development (SEED) by the Centers for Disease Control and Prevention (CDC) now includes data from over 1,800 children with autism, and describes the behavioral phenotypes and co-occurring health conditions such as GI symptoms and sleep problems.[324, 325] The Autism Intervention Research Network on Physical Health (AIR-P) by HRSA is working to develop interventions to improve physical health and well-being across the lifespan, including a focus on medical, dental, visual, nutrition, and speech/hearing issues. HRSA also supports the Healthy Weight Research Network (HWRN) for Children with ASD and Developmental Disabilities, which targets research to prevent and treat overweight and obesity.

Assessment and treatment care for co-occurring health issues can be a complex and costly process for autistic people and their caregivers. Timely identification of health needs is an essential first step to providing intervention. Unfortunately, access to health care providers with experience in autism and co-occurring health conditions is limited. Individuals with autism who are also members of underserved racial/ethnic groups may face additional barriers to timely and comprehensive health care. Enhanced educational support for primary care providers is needed on health and health care disparities experienced by people living with disabilities.[326-328] Cross-specialty education for specialists in pediatrics, neurology, development, behavioral health, and psychiatry could aid in the recognition of these medical issues in the autistic population, as some issues may be linked to mental and behavioral health issues such as depression, anxiety, and self-injurious behavior, but the underlying root cause is a physical health issue, such as a GI or sleep disorder. Training programs need to expand exposure to these topics during medical training. In the next chapter, we turn to discuss co-occurring mental health issues experienced by individuals on the autism spectrum.

This chapter includes discussion of topics, including depression, self-injury, trauma, abuse, and suicide, that may cause significant distress for some individuals. If you are in crisis, call or text the 988 Suicide & Crisis Lifeline at 988, available 24 hours a day, 7 days a week. The Lifeline provides confidential support to anyone in suicidal crisis or emotional distress. Support is also available via live chat. Para ayuda en español, llame al 988.

Chapter 4: Co-Occurring Mental and Behavioral Health Conditions

Introduction

Co-occurring mental and behavioral health conditions are highly prevalent in autistic individuals,[1-3] with many people on the autism spectrum simultaneously experiencing multiple co-occurring conditions.[2] Common co-occurring mental and behavioral health conditions include attention-deficit/hyperactivity disorder (ADHD), anxiety disorders, and obsessive-compulsive disorder (OCD), as well as catatonia, self-injurious behaviors (SIB), aggressive behaviors, and emotion dysregulation. Depression, suicidal ideation, and death by suicide have also been reported at higher rates in individuals on the autism spectrum compared to the general population. Risk for many of these co-occurring conditions may be exacerbated and compounded by trauma and lasting impacts of adverse childhood experiences (ACEs).[2, 4, 5]

These conditions can significantly impact the health and well-being of autistic individuals and lead to challenges with employment, daily living, community participation, and, in some cases, premature mortality. In the *2021-2023 IACC Strategic Plan*, the Committee emphasized the importance of providing 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. Research on autism and mental health, as well as additional resources for service provision, are needed to address challenges associated with anxiety, depression, SIB and aggressive behaviors, suicidality, and other mental health issues that are faced by many individuals on the autism spectrum across the lifespan. This chapter provides an overview of current knowledge, gaps and barriers to progress, and future directions for research and services related to autism and:

- Anxiety disorders
- Attention-deficit/hyperactivity disorder (ADHD)
- Catatonia
- Depression
- Obsessive-compulsive disorder (OCD)
- Self-injurious behavior (SIB), aggressive behavior, and emotion dysregulation
- Suicidality

In addition, this chapter also includes a brief summary of current research on autism and:

- Bipolar disorders
- Feeding and eating disorders
- Gender dysphoria
- Pathological demand avoidance (PDA)
- Schizophrenia
- Substance use disorder (SUD)

- Tourette syndrome (TS) and other tic disorders
- Trauma and post-traumatic stress disorder (PTSD)
- Wandering and elopement behaviors (WAEB)

Anxiety Disorders

Overview of Current Knowledge

Anxiety disorders include generalized anxiety disorder, panic disorder, phobias, and social anxiety disorder and are diagnosed when feelings of anxiety, fear, nervousness, and worry interfere with daily activities and functioning.[6] In the general population, lifetime prevalence of anxiety disorders is estimated to be between 20-30%.[6, 7] In individuals with autism, prevalence estimates for anxiety range widely from 11-84%, with approximately 40% of autistic children meeting diagnostic criteria for at least one anxiety disorder.[8, 9] Girls and women with autism may also be more likely to experience and have higher levels of anxiety compared to autistic boys and men.[10]

Anxiety symptoms can significantly affect the daily lives of autistic children, adolescents, and adults, often preventing full participation in home, community, and academic life and interfering with the development of peer relationships and employment opportunities. Anxiety is also associated with additional co-occurring physical and mental health conditions, including sleep disturbances, gastrointestinal problems, aggression and irritability, and ADHD.[11] Research also suggests that autistic children experience a broader range of fears and worries than neurotypical children; examples include fears of highly specific sounds or sights (e.g., happy birthday song, gloves) and anxiety related to change, intense interests, or confusion interpreting social cues.[12]

These sources of worry have also been reported anecdotally by autistic adults,[13] and social fears and anxiety have been found to be elevated in autistic adults.[14] Social misunderstandings, as well as executive and social inattention challenges, can lead to anxiety around performance, leading autistic individuals to fear that they may not be meeting both social and non-social expectations.[15, 16] In addition, studies suggest that differences in sensory processing may also impact anxiety in autistic adults.[17] Several genetic factors have been linked to both anxiety and autism,[18] suggesting a common biological mechanism may underlie both conditions. Autism may also increase the risk for anxiety due to increased social difficulties and barriers to mental health care.[9]

There has been much interest in studying the assessment and treatment of anxiety symptoms in autistic individuals. Cognitive behavior therapies (CBT) are evidence-based practices for the treatment of anxiety (and other mental health conditions) in neurotypical children, adolescents, and adults.[6, 7] Modified CBT approaches have been developed for the treatment of anxiety in children and adolescents on the autism spectrum, and more than 25 randomized controlled trials have been conducted, primarily focusing on autistic children with anxiety.[19] Overall, these therapies have been shown to be moderately effective.

Core components of CBT for anxiety in autistic youth include strengthening emotional awareness and shifting thought patterns, building coping strategies, and introducing graded exposure (slowly exposing an individual to sources of fear). Although much progress has been made, many challenges remain in improving the delivery of behavioral therapies for autistic youth and developing improved behavioral and other interventions for anxiety disorders, including pharmacological interventions, for both children and adults with autism.

Knowledge Gaps and Barriers to Progress

Due to differences in how anxiety may emerge and be expressed in individuals with autism, and the overlap between many features of autism and anxiety (e.g., social withdrawal), it can be difficult to differentiate between the two conditions and accurately diagnose anxiety in autistic individuals. Additionally, some people on the autism spectrum may be minimally speaking, have intellectual disabilities, or have other challenges recognizing and communicating their internal states and feelings, and anxiety may be expressed in other ways such as avoidance or disruptive behaviors. Sex and gender may also play a role in how anxiety manifests among autistic individuals.[20]

Researchers are actively examining the strengths and challenges of existing diagnostic tools and developing new or modified measures to assess anxiety in autistic children. Continued research is needed to develop better tools to accurately screen and diagnose anxiety in autistic individuals of all ages and abilities. Though awareness of the challenges in assessing anxiety in autistic individuals in research settings has grown, the impact of these challenges on clinical practice is unclear. An understanding of current practices in community-based settings could clarify the extent to which anxiety disorders are likely to be missed or misdiagnosed in autistic individuals and inform future research and provider training efforts.

In addition, it remains important to better understand the neurobiology and development of anxiety in autistic individuals. Current evidence suggest that common biological mechanisms may underlie both autism and anxiety, including changes in brain structures such as the amygdala, hippocampus, ventromedial prefrontal cortex, and insula.[8] However, as most studies are cross-sectional, prospective and longitudinal designs are needed to clarify the typical onset and trajectory of anxiety symptoms in autism, as well as to identify predictors which might clarify mechanisms of risk and resilience and lead to novel intervention approaches. Finally, multi-method investigations are warranted to identify the biological underpinnings of anxiety in autism, which may also inform interventions and potentially offset the limitations of behavioral, as well as self- and observer-reported, measures.

In terms of interventions, the enthusiasm regarding the development and delivery of modified CBT approaches for autism and anxiety is encouraging, and mindfulness,[21] app-based,[22, 23] and virtual reality (VR)[24, 25] approaches are also being explored. However, most of the evidence for efficacy of CBT approaches is in school-aged children with autism who do not have intellectual disabilities, though trials have been conducted and are ongoing for adolescents and adults. There is also evidence to suggest that the majority of children and families in these studies identify as White and come from households with relatively high levels of parental education.[26] Thus, it is essential that future research efforts include participants from diverse racial, ethnic, and socioeconomic backgrounds and are inclusive of autistic individuals across the spectrum, including those with intellectual disabilities and high support needs, and across the lifespan, including young children, adults, and older adults. It may also be important to focus efforts on autistic individuals that display subthreshold anxiety symptoms in efforts to identify risk and resilience factors for anxiety and establish preventative approaches to the development of clinical anxiety symptoms.

In comparison to the emphasis on the modification and/or development of psychosocial interventions specific for the treatment of anxiety in autistic individuals, there has been much less attention paid to the use of medication to treat anxiety in people with autism. Notably, CBT in combination with medications can be useful for individuals who have severe anxiety or are not responsive to either intervention alone;[6] however, treatment trials comparing medications paired with CBT, CBT alone, or medication alone have not yet been systematically studied in autism. In fact, more research is needed to better understand which medications yield positive benefits for autistic individuals who experience interfering anxiety symptoms.

Finally, many of the existing CBT interventions to manage anxiety symptoms in autism have been delivered in clinics and/or universities. Unfortunately, many autistic individuals and their families may have difficulty accessing interventions in these settings. Challenges such as long wait lists, lack of trained providers, insurance and/or other financial difficulties, problems with transportation, and the inability to make time for therapy appointments due to competing work demands represent significant barriers to accessing evidence-based interventions. It is essential that next steps in intervention research focus on the dissemination and implementation of evidence-based practice in "real-world" settings such as schools or community mental health centers. In recent years, studies of telehealth delivery of interventions for anxiety in autism have demonstrated opportunities for increasing access to evidence-based mental health care.[27, 28]

Future Directions

Anxiety is highly prevalent in individuals on the autism spectrum. Federal agencies are funding projects to better understand co-occurring anxiety and autism. In addition, agencies are working to develop interventions to treat anxiety in autistic people, with the Department of Defense (DoD)'s Autism Research Program funding several randomized controlled trials in recent years to test CBT interventions for autistic children and adolescents. However, much more research is needed to ensure that autistic individuals have the evidence-based services and supports needed to successfully manage anxiety symptoms.

In particular, research to develop and validate assessment tools is necessary to accurately diagnose anxiety in diverse autistic individuals. Additionally, more work should be done to better understand how anxiety manifests in people with autism and the biological mechanisms that may underlie both conditions to identify risk and resilience factors that can be used in preventative measures and interventions for anxiety. Equally important is continuing research to modify existing psychosocial interventions to treat anxiety in autistic individuals, as well as conducting trials comparing the effectiveness of pharmacological and combination interventions for anxiety. It will be essential for all of these efforts to be inclusive of autistic people from underserved communities, of all ages, and across the spectrum, particularly those with high support needs, so that all individuals with autism who experience anxiety have access to interventions to improve their mental health.

Attention-Deficit/Hyperactivity Disorder (ADHD)

Overview of Current Knowledge

Attention-deficit/hyperactivity disorder (ADHD) is a developmental disability characterized by inattention, hyperactivity, and impulsivity.[29] In the United States, prevalence of ADHD is approximately 11.4% among children and adolescents.[30] While some studies have suggested that ADHD may be less prevalent in adulthood,[31, 32] other recent studies suggest that ADHD persists into adulthood, though it is unclear what the prevalence is among adults.[33, 34] ADHD is among the most common co-occurring conditions for individuals with autism,[1, 3] with "AuDHD" becoming a popular term used to describe individuals diagnosed with both autism and ADHD.[35, 36] Estimates for ADHD prevalence among autistic individuals range from 30-70%, and approximately 1 in 8 youth diagnosed with ADHD are also diagnosed with ASD.[37-39] Individuals with autism with communication disabilities or who need communication support may be more likely to exhibit hyperactivity and meet the clinical definition of hyperactive-impulsive ADHD.[40]

Co-occurring autism and ADHD is associated with increased risk for delays in autism diagnosis,[41-44] as well as increased risk for developing additional mental health conditions such as anxiety and mood disorders.[37, 39] In comparison to autism alone, those with co-occurring autism and ADHD may have more challenges related to working memory and emotional recognition, suggesting that the these two conditions may be additive. ADHD and autism share common features, in particular inattention, struggles related to executive functioning, differences in sensory and information processing, and difficulties in social interactions.[37, 38, 45-47] Neuroimaging studies have shown similar differences in subcortical volumes and cortical thickness associated with autism and ADHD.[48] In addition, both conditions are highly heritable, and genetic studies have shown strong links between autism and ADHD.[29, 37, 38, 48] These findings have led to the hypothesis that autism and ADHD may be manifestations of changes in the same biological pathway, as opposed to two distinct conditions.[37, 38, 48]

Pharmacologic interventions are available to manage ADHD symptoms in autistic individuals, with the vast majority of individuals with co-occurring ASD and ADHD being prescribed psychotropic medications.[37] However, some of these medications have shown decreased effect size and are associated with more side effects in autistic individuals as compared to the general population. Psychosocial interventions, such as social skills training, are commonly recommended in combination with medication. However, it is unclear whether these types of interventions are effective for individuals with autism and ADHD.[37]

Knowledge Gaps and Barriers to Progress

While there exist gold standard diagnostic tools for both ASD and ADHD alone, and strides have been made in adapting existing measures to diagnose co-occurring autism and ADHD, challenges remain in accurately detecting ADHD symptoms in individuals with autism, and vice versa. As discussed, ADHD and autism share similar features, and apparent features of ADHD such as inattention may be due to autistic traits such as distractions due to special interests or sensory sensitivities.[40] In particular, the presence or absence of ADHD is usually determined based on parent or caregiver reports, which may not be accurate, underscoring the importance of clinician assessments. Therefore, additional research is needed to develop and validate tools that can accurately distinguish between autism and ADHD features.

In addition, while multiple studies have identified common genes and pathways implicated in both ADHD and autism, it is unclear how these biological pathways lead to autism or ADHD. Further, while these two conditions share similar features, there are important distinctions. For example, autistic individuals are more likely to have social communication challenges as compared to individuals with ADHD alone.[40] Therefore, more research is needed to understand how the common changes in gene expression and function lead to two different sets of phenotypes and whether ADHD and autism are indeed along the same spectrum or two distinct conditions. This may also lead to greater insight into how these two conditions interact to identify factors that can be targeted for intervention.

Additional research is also needed to understand what ADHD interventions are effective for individuals on the autism spectrum. While pharmacological therapies exist for ADHD and have proven to be effective in the general population, the effect sizes of these medications have been reported to be lower for individuals with autism.[37] In addition, autistic individuals experience higher rates of medication side effects including social withdrawal, depression, and irritability. Studies are needed to assess the efficacy and safety of existing pharmacological interventions for ADHD in autistic populations, and additional work is needed to identify novel compounds that could be used to manage ADHD in individuals with autism.

Behavioral interventions for both ADHD-alone and autism-alone have been heavily researched and have shown to be helpful for developing and maintaining developmentally appropriate skills and improving academic outcomes.[49, 50] However, some studies have indicated that behavioral interventions such as social skills training may not be effective in individuals with ADHD.[37] In addition, while some studies have shown that behavioral interventions for ADHD can be adapted for autistic children, additional work is needed to determine the efficacy for behavioral interventions for co-occurring ADHD and autism.[51] Additionally, other types of non-pharmacologic interventions, including mindfulness, exercise, and dietary interventions, have the potential to be helpful in improving health outcomes in individuals with ADHD and autism.[37, 52-56] However, more work is needed to establish the evidence base for these interventions.

Several factors may impact ADHD in autistic individuals, including speaking and language ability, gender, age, and intellectual ability. Therefore, it will be important for future research in this area to be inclusive of autistic individuals of all genders, ages, and abilities, particularly those who are minimally speaking. This will allow for the development of interventions that can meet the needs of all individuals on the autism spectrum. Efforts should also be made to ensure that safe and effective interventions are widely disseminated, particularly in school settings where a large percent of autistic children receive mental health services.

Future Directions

ADHD is one of the most common co-occurring conditions in autistic individuals and can lead to greater risk of additional co-occurring mental health conditions including anxiety and depression. However, more research is needed to better understand how ADHD and autism may be linked and how co-occurrence may impact the presentation of either condition.

The National Institutes of Health (NIH) funds several projects to improve diagnosis of co-occurring autism and ADHD and develop medical and behavioral interventions to manage ADHD symptoms. In particular, the NIH Autism Center of Excellence (ACE) at Duke University has conducted multiple studies to understand the overlap between autism and ADHD. The Health Resources & Services Administration (HRSA)-funded Autism Longitudinal Data Project (ALDP) is also leveraging a birth cohort with diverse participants to explore the co-occurrence of a wide range of neurobehavioral conditions, including ADHD.

This and other work will enable the development of improved diagnostic tools to accurately assess ADHD symptoms in autistic individuals as well as pharmacological and other interventions for ADHD that are safe and effective for people on the autism spectrum, including those who are minimally speaking. Finally, improving dissemination of existing interventions in community settings, particularly school settings, can help more individuals on the autism spectrum, especially those in underserved communities, access the mental health care they need to improve well-being.

Catatonia

Overview of Current Knowledge

Catatonia is a collection of behaviors that affect a person's motor, affect, and cognition, in which a person who is awake may appear to be unresponsive for hours or days.[57] Common signs of catatonia include not being able to move or respond to stimuli, little to no verbal communication or response, rigid posture (including holding a posture that is against gravity), repetitive movements, atypical mannerisms, grimacing, and agitation.[58] In some cases, catatonia can be life-threatening and lead to dangerous fluctuations in blood pressure, heart rate over one hundred beats per minute, inability to regulate body temperature, and profuse sweating.[57, 58]

Prevalence of catatonia among inpatients of psychiatric units is estimated to be between 5-18%.[57] Though previously considered a subtype of schizophrenia, catatonia can co-occur with a variety of mental health conditions, including autism, as well as medical conditions such as stroke and head trauma.[57, 58] Among autistic adolescents and adults, prevalence of catatonia is approximately 12-20%.[59-61] Autistic individuals with co-occurring learning or intellectual disabilities may be at greater risk for catatonia.[61] In addition, catatonic symptoms may be even more prevalent among autistic individuals with co-occurring anxiety, OCD, epilepsy, and Tourette syndrome (TS), and self-injurious and aggressive behaviors are often seen in co-occurring autism and catatonia.[60]

Research indicates strong genetic contributions to the presence of catatonia, with clustering of catatonic symptoms occurring in some families and high heritability.[58, 62] In addition, as in autism, γ-aminobutyric acid (GABA) signaling and excitatory-inhibitory (EI) imbalance have also been implicated in catatonia.[58, 61, 62] In addition, some evidence suggests that environmental stressors, including trauma and extreme fear, may also increase the risk of catatonia.[57, 58, 61, 62] The first-line intervention for catatonia is currently benzodiazepine medications, which affect GABA-receptor signaling.[58, 60-62] In cases of severe catatonia that is resistant to benzodiazepine treatment, electroconvulsive therapy (ECT), which is approved by the Food and Drug Administration (FDA) to treat this condition, is used to deliver a mild electrical current to the brain under general anesthesia that can help to normalize irregular brain activity patterns and result in recovery from catatonia.[58, 60-63]

Knowledge Gaps and Barriers to Progress

Previous research indicates that catatonia may be underdiagnosed among individuals with autism.[61] Catatonia can be diagnosed through behavior that is increased, decreased, or generally abnormal, and how patients present with catatonia can vary from day to day.[58] The Bush-Francis Catatonia Scale is often used to assess catatonic symptoms, including for autistic individuals.[58, 61, 62] In addition, the Attenuated Behavior Questionnaire (ABQ) specifically assesses "autistic catatonia."[61, 62] However, the ABQ likely has low specificity, and scores are positively correlated with repetitive/restrictive behaviors.[62] Therefore, additional research is needed to develop more accurate diagnostic tools for catatonia among autistic individuals.

In addition, more research is needed to better understand the etiology of catatonia and autism. This includes both a clearer understanding of the biological mechanisms that underlie catatonia, as well as how environmental factors including psychological stress and trauma may trigger catatonia among individuals with autism. This can lead to the identification of risk and resilience factors that may be helpful in predicting and preventing the onset of catatonia.

While benzodiazepines are the first-line treatment for catatonia, this medication can have harmful side effects and may not be effective for autistic individuals.[60] In addition, while a systemic review found that ECT can improve catatonic symptoms,[60] a drawback of ECT is that some catatonic individuals, particularly those with intellectual disabilities, also may not be able to provide informed consent for ECT, so they would be reliant on a parent or guardian to provide consent on their behalf.[58] Issues related to consent for treatment of individuals with reduced or temporary lack of capacity for self-decision making and needing to rely on surrogates for consent have limited the use of ECT.[64] There are also few quality randomized controlled trials demonstrating the efficacy and effectiveness of ECT to treat catatonia, due to the ethical implications of withholding potentially life-saving treatment for catatonia.[65, 66] Additionally, behavioral interventions for catatonia in individuals with autism and other neurodevelopmental disabilities are understudied.[62] Together, this highlights the acute need for continued research into safe, effective, and evidence-based interventions to manage catatonia in autistic individuals.

Future Directions

Catatonia is relatively common among autistic individuals, and individuals with co-occurring autism and catatonia are at higher risk for physical health complications, including poor nutrition and dehydration.[61] In addition, research indicates that individuals with co-occurring autism and catatonia are at higher risk of premature death, with a large number of these individuals engaging in self-harming behaviors.[60, 61] However, catatonia may be underdiagnosed among individuals with autism.[61] Research is needed to develop better tools to more accurately diagnose catatonic symptoms in autistic individuals. In addition, a clearer understanding of the biological and environmental mechanisms driving catatonia in individuals with autism can help identify factors that can be used to prevent the onset of catatonia. Finally, there is a critical need for more research on effective interventions for catatonia in autistic individuals, with a particular focus on ensuring that interventions are safe for autistic individuals and that treatment of this serious condition is provided using the highest ethical standards.

Depression

Overview of Current Knowledge

Symptoms of major depressive disorder (MDD) consist of sad mood, decreased interest in and pleasure derived from previously enjoyable activities, recurrent suicidal ideation or acts of self-harm or suicide attempts, and other mental and physical symptoms.[67] Global estimates of lifetime prevalence of MDD is approximately 10% in the general population. Meta-analyses indicate that prevalence of depression among autistic individuals is approximately 14%,[1, 3, 68] with estimates in studies ranging widely from 1-76%.[68]

Depression can lead to significant social, emotional, and behavioral challenges for autistic individuals and is associated with risk of serious mental and physical health complications, greater service and medication use, and increased caregiver burden.[69] It is not sufficiently clear if autism-specific presentations of depression exist. People on the autism spectrum tend to have both physical symptoms and cognitive symptoms of depression. Symptom profiles likely differ by age of the depressed individual and may be impacted by the presence of co-occurring intellectual disability. In addition to feelings of sadness or hopelessness, tiredness, and losing pleasure in things ordinarily enjoyed, autistic people may be more likely to experience atypical symptoms of depression such as changes to the quality or intensity of their special interests or increased aggression or self-injury.

Overlap between autism and depression has been noted across studies in several genetic, biological, and psychosocial domains.[69, 70] A large body of literature has documented high levels of depression among family members of individuals with autism, with the vast majority of parents reporting the onset of their own mood disorders beginning before the birth of their autistic child.[71] These findings suggest the possibility that both genetic and non-genetic mechanisms may contribute to higher risk of depression in autistic individuals.

In addition, some characteristics associated with autism might make depression more likely. For example, having difficulty with social interactions or expression of one's problems appears to put people at greater risk for developing depression. Loneliness is a particularly strong predictor of depression in autistic individuals.[72] Because social context is enormously important in regulating mood, individuals with autism may be at increased risk for depression due to experiencing "everyday trauma," such as lack of societal acceptance, bullying, difficulties in obtaining access and supports, feelings of being a burden to others, and lack of fulfilling employment or relationship opportunities.[69] Other contributing mechanisms may be less context specific. For example, cognitive perseveration common to autism is likely a specific vulnerability for developing depression, similar to the way depressive rumination functions in the general population.

In the general population, treatment of depression typically consists of psychotherapy, medication, lifestyle interventions including exercise, and brain stimulation.[67] Preliminary data indicates that psychotherapy may also be effective for managing depression in autistic individuals.

Knowledge Gaps and Barriers to Progress

A diagnosis of depression may be difficult for autistic individuals to obtain. Symptoms of depression overlap with autism in features such as flat affect, social withdrawal, and difficulties with sleep, eating, and attention.[40] Further, depression is known as an "internalizing" disorder, and it tends to be more challenging for some people on the spectrum to identify and communicate internal experiences, particularly if they are emotional in nature. This likely intersects with the high rates of alexithymia (difficulty recognizing or labeling emotions) in autism. It may be particularly challenging to detect signs of depression in autistic individuals who are minimally speaking or have additional challenges with communication. There are mixed findings about the performance validity of common depression screening instruments when used in the autistic population. Recent data suggests that at least one commonly used depression screening instrument (the Beck Depression Inventory, 2nd edition; BDI-II) is a reliable and valid measure of depressive symptoms in adults with autism.[73] Other instruments such as the Hospital Anxiety and Depression Scale (HADS) and the Patient Health Questionnaire-9 (PHQ-9) have been assessed for use in people with autism with some success.[74, 75] However, additional research is needed to validate existing and develop new measurement tools for use in autistic populations.

The field also lacks research on effective prevention and intervention strategies for depression in people on the autism spectrum. Cognitive behavioral therapy (CBT) is a highly effective treatment for depression in the general population when delivered well and has been found to have beneficial effects in autistic populations in small research trials.[67, 69] Behavioral Activation (BA) stems from CBT science and focuses on treating the loss of interest and pleasure that often marks depression by promoting adaptive and reinforcing activities. Although BA has been largely overlooked as a treatment approach in the autistic population, it is a promising lead for further research because it can be applied to minimally speaking individuals. Furthermore, minimally structured lifestyles (for example, with few set obligations or activities) are specifically associated with poorer emotional health outcomes in people with autism. The specific activities promoted and reinforced by BA may help to fulfill this need and promote healthy habits and behaviors. Relatedly, there are a few small trials of mindfulness-based therapies that have reported decreased depression and anxiety in adults with autism.

Treatments that target specific underlying processes, such as emotion regulation, also need to be explored, as do the potential impacts of factors such as nutrition and physical health. Pharmacological interventions, particularly the use of selective serotonin reuptake inhibitors (SSRIs), are very common in autism, but no randomized controlled trials have been conducted to support the efficacy of using them to treat depression specifically in autistic individuals. It is important to note that there is an increased risk of “polypharmacy” (being prescribed or using multiple medications) in individuals diagnosed with ASD and co-occurring medical or psychiatric diagnoses, despite limited evidence supporting the use of multidrug treatments for depression. Again, understanding mood problems in the minimally speaking population is another important gap in knowledge. Finally, as in other areas, there are research gaps related to depression in specific subgroups within the autistic community, such as in older adults and LGBTQIA+ persons, and whether depression presents differently across genders or whether gender/gender identity affects prevalence of depression. In addition, how socioeconomic factors may increase risk for depression in autistic individuals from underserved and underrepresented communities also need to be explored.

There is an acute need for mental health care providers who are sufficiently trained to recognize and treat symptoms of depression in autistic individuals. It can be difficult for clinicians to evaluate depression and autism, in part due to similarities in features described previously. Health care professionals also may not notice the need to screen for depressed mood, attributing symptoms of depression to the individual’s autism diagnosis. This highlights the broader problem that there are few mental health care providers who understand both autism and co-occurring mental health conditions and who are therefore sufficiently confident to treat mental health conditions in people on the autism spectrum.

Future Directions

Depression has been repeatedly identified by the autism community as a high need area and a priority for more services and research. Federal agencies such as NIH and DoD are already conducting to research to better understand the factors that can lead to depression and identify interventions that can improve mental health for autistic individuals. In addition, HRSA is supporting training programs to improve health provider knowledge of the mental health needs of autistic individuals.

This area of research and practice will be accelerated by the development of adapted or novel instruments to detect depression in autism. Research is needed on the validation and adaptation of treatments for depression in the general population for use in autistic individuals, as well as the development of personalized or precision medicine that better targets treatments to individuals. Identifying the overlapping genetic, biological, cognitive, and social mechanisms that underpin depression and other mental health conditions in autism will be important in achieving this goal.

In the short term, education outreach campaigns targeting community providers likely would function to make existing therapy resources more accessible to the autistic community. Finally, there is a need to know more about how to promote mental health and well-being in autistic children and adults through environmental supports and services for individuals and families. In particular, identifying social factors such as environmental stressors, adverse childhood experiences (ACEs), and other trauma that may contribute to depression will be critical to develop preventative approaches that can limit exposure and promote mental health.

Obsessive-Compulsive Disorder (OCD)

Overview of Current Knowledge

Obsessive-compulsive disorder (OCD) is characterized by obsessive thoughts and/or a compulsion to perform some repeated behaviors, with the person affected typically recognizing the irrationality of their actions.[76, 77] In the general population, an estimated 2-3% of individuals have OCD, which is associated with significant disruption to daily life and social interactions, as well as increased risk for early mortality from natural or unnatural causes (such as suicide).[78] Among autistic individuals, prevalence estimates of OCD are significantly higher and range from 9-17%,[1, 3, 8] and individuals with OCD are also more likely to be diagnosed with autism.[79]

Though both OCD and autism are characterized by repetitive behavior, there are important distinctions in how these behaviors manifest with each condition. In particular, while repetitive behaviors associated with OCD lead to distress, repetitive behaviors associated with autism are typically more complex, and may be soothing or comforting.[8] Co-occurring OCD in autistic individuals can lead to increased difficulties in social interactions, increased use of clinical services and medications, and fewer long-term gains in response to interventions.[80] In addition, autistic youth and adults with co-occurring OCD are more likely to exhibit hoarding and ordering behaviors compared to those with OCD alone. Based on studies of family history, there may be common biological pathways that increase the probability of both OCD and autism.[79]

The gold standard for OCD treatment is CBT with an emphasis on exposure and response prevention.[77] However, individuals with co-occurring autism and OCD tend to be more resistant to interventions,[79] and standard CBT programs for OCD are less effective for autistic individuals.[80] Adapted CBT programs for autism and OCD appear to be more effective for treating OCD in people on the autism spectrum. In addition, studies have tested a limited number of pharmacological interventions for OCD in individuals with autism, resulting in conflicting data regarding efficacy and safety of such treatments.[79, 80]

Knowledge Gaps and Barriers to Progress

As noted, though both OCD and autism can be characterized by repeated behavior, these behaviors are often distinct in people who only have OCD versus people who only have autism. However, because previous diagnostic criteria excluded co-occurring OCD and ASD, research on how autism may impact OCD presentation, and vice versa, has been limited.[79] In addition, autistic individuals with co-occurring intellectual disability or who are minimally speaking may have difficulties expressing their thoughts or communicating their feelings around repetitive behaviors. Diagnosis of OCD in these individuals may depend on parent and caregiver interpretation of motivations behind observed actions, which may not be fully accurate. Though some work has been done to validate tools to assess OCD in autistic populations,[79, 80] most currently available diagnostic tools for OCD are not tailored for use in individuals with autism. More research is needed to understand how repetitive behaviors differ in autism versus OCD and to develop and validate OCD diagnostic measures for people on the autism spectrum, particularly those with higher support needs and those who may have difficulties communicating their inner thoughts and motivations.

Recent studies indicate that OCD and autism may share common genetic factors and changes in neurobiological processes, including prenatal development of the cerebral cortex.[81, 82] However, it is unclear how these changes lead to increased probability of autism and OCD and what other biological and environmental mechanisms may be involved. Future research further elucidating the biological link between autism and OCD will be critical to identify risk and resilience factors of OCD in autistic individuals and develop targeted and effective interventions to mediate OCD symptoms. In addition, identification of specific biological pathways can lead to the development of biomarkers to be used in accurately identifying OCD in all autistic individuals, including those who are minimally speaking or have intellectual disabilities.

While CBT is the recommended treatment for OCD, studies have indicated that this may not be as effective for autistic individuals with co-occurring OCD.[79, 80] In recent years, there has been an expansion in the number of studies developing modified CBT strategies for autistic people to treat a number of mental health conditions. Results from these studies show improved efficacy of adapted strategies in treating OCD symptoms for individuals with autism. However, these studies so far have largely focused on verbally fluent autistic individuals without intellectual disabilities,[79, 80] and a Cochrane Review in 2021 found only one randomized controlled trial with 46 participants focused specifically on modified CBT for OCD in people diagnosed with ASD.[83] While there has been a few additional studies in recent years focused on CBT interventions for individuals diagnosed with both ASD and OCD,[19, 84, 85] more research and larger, better powered trials are needed to determine how CBT can be best adapted for individuals with co-occurring autism and OCD.

In addition to psychotherapy, pharmacological interventions are also needed. SSRIs are effective for OCD in the general population.[77] However, results of limited medication trials for OCD treatment in autistic individuals have yielded mixed results.[79, 80] Additionally, there are concerns regarding potential side effects of pharmacological interventions, particularly as individuals with autism may be more sensitive to the behavioral side effects of SSRIs.[8] Therefore, more research is needed to develop effective psychotherapeutic and pharmacological interventions for OCD in autistic individuals across the lifespan, particularly those with high support needs.

Going forward, it will be imperative to ensure that health care providers are aware of available tools to accurately identify and diagnose OCD in individuals with autism. Additionally, evidence-based effective interventions should be disseminated broadly, to ensure that all autistic people, including those in underserved communities, have access to the services and supports they need to improve mental health and well-being.

Future Directions

Prevalence estimates for OCD in autistic individuals are four to five times higher than in the general population, and individuals with co-occurring OCD and ASD can experience additional challenges with social interactions, as well as increased use of clinical services and medications. Federal research funders are supporting projects to better understand the role of genes such as CHD8 in autism and OCD, as well as other mental health conditions.

However, significant challenges remain in improving diagnosis of OCD in autistic populations, and more research is needed to develop accurate diagnostic tools and biomarkers. Additionally, future research should focus on elucidating the link between OCD and autism to identify biological pathways that can be targeted for interventions. Work is also needed to improve existing CBT interventions and test existing and new pharmacological interventions to improve OCD symptoms in autistic individuals. Finally, efforts need to be made to improve inclusion of autistic individuals who are minimally speaking, have co-occurring intellectual disability, and those with intersectional identities in research and ensure that autistic individuals in all communities have access to the interventions and services they may need to treat OCD.

Self-Injurious Behavior (SIB), Aggressive Behavior, and Emotion Dysregulation

Overview of Current Knowledge

Self-injurious behaviors (SIB), such as head banging, skin scratching, and biting, and physically aggressive behavior, either proactive or reactive, toward others are not uncommon in youth and adults with autism. Despite this, these behaviors have been the focus of limited research. Prevalence estimates vary among different research samples. Aggressive behavior has been reported in 5% of a general community sample of youth on the autism spectrum, up to 50% of youth seeking treatment in outpatient settings, and in 80-90% of youth treated in specialized inpatient psychiatry units.[86-89] Self-injury is equally prevalent, with an estimated 25-50% of autistic individuals engaging in SIB at some point in their life.[90-92]

These behaviors can cause self-harm or harm of others and result in significant hardship for some autistic individuals, excluding them from educational, community, and medical settings,[89] which can have the adverse effect of limiting their access to social opportunities and the very interventions and supports they need. In addition, aggressive behavior and self-injury cause distress for families and caregivers, who report that these behaviors are often of greater concern and impact than the social and communication difficulties that define autism.[93, 94] Very little is known about the trajectory of these behaviors over time, but there is some evidence that aggressive behaviors can remain heightened in autism over the course of development for some individuals.[95, 96] In addition, language and communication difficulties may be associated with SIB, aggressive behaviors, and other behaviors of concern.[91]

SIB and aggressive behaviors have been associated with emotion dysregulation, with estimated rates of emotion dysregulation in children with autism ranging from 50-80%.[97, 98] Emotion dysregulation may be more likely in autistic individuals due to core features of autism, including social communication difficulties. One study based on self-reports from autistic individuals found that SIB was used to regulate emotions such as depression, dissociation, anger, and anxiety.[99] Recent studies also suggest that differences in sensory processing may be linked to emotion dysregulation and SIB and aggressive behavior.[100-102] Sensory perception differences may also be a major contributor to SIB, and issues such as hyposensitivity or hypersensitivity to various sensory stimuli, including pain, may be triggering these behaviors.[92, 103-106] Gastrointestinal issues and possible associated gastrointestinal discomfort (discussed in more details in Chapter 3) have also been correlated with SIB.[107-109]

Interventions for emotion dysregulation, SIB, and aggressive behavior consist of behavioral interventions such as applied behavioral analysis (ABA) and CBT, as well as parent training programs to improve emotion regulation. In addition, pharmacological interventions include the antipsychotic medications risperidone and aripiprazole, which have received FDA approval to treat irritability in autism.[97, 110]

Knowledge Gaps and Barriers to Progress

There are numerous unmet research needs in the clinical assessment and treatment of aggressive and self-injurious behaviors in autism. A major challenge in the assessment and intervention of aggressive behavior and SIB in autism is that the behavior is difficult to predict. It is sometimes possible to identify antecedent or triggering factors and to prescribe appropriate environmental responses. However, in some individuals these behaviors often do not have triggers easily observable to a third party and therefore demand that a family or caregiver always be prepared.

Recent research has highlighted several promising approaches to help individuals with autism and their families deal with these challenges. Emerging work is examining the possibility of using objective physiological signals (e.g., heart rate), motor activity, and recent behavioral history to attempt to predict the onset of a problem behavior before it occurs. These approaches include using machine learning and statistical modeling to predict SIB and aggressive behavior using data obtained through wearable biosensor technology and medical histories.[111-114] There is opportunity to combine this work with the strong evidence for behavioral interventions to produce scalable solutions for autistic individuals and their families.

Relatedly, it is important to determine the biological mechanisms that underlie emotion dysregulation, SIB, and aggressive behaviors. For example, some data suggest that pain and sensory sensitivities play a role in contributing to the development and persistence of SIB,[92] and a study in autistic adults found that higher sensory sensitivity was associated with more aggressive behaviors, as well as anger and hostility.[115] Research to better understand sensory perception and processing in these individuals may be helpful in developing ways to regulate environmental stimuli and responses and the overall sensory experience to prevent and reduce SIB and aggressive behaviors.

In addition, more research is needed to understand how emotion dysregulation is related to SIB and aggressive behavior. Future research should also investigate novel biological mechanisms underlying aggressive behaviors and self-injury, such as hyper-arousal. Further, the development of reliable, clinically practical measures is needed to improve the diagnosis of co-occurring psychiatric disorders, which may impact emotion regulation, that can be targeted for intervention.

More longitudinal studies are also needed to determine the natural history and trajectory of these features in autistic individuals across the lifespan, including persistence in adulthood. This will enable the development of tailored and effective interventions for individuals on the autism spectrum of all ages. As well, additional research is needed to better understand the full range of environmental and social factors that may trigger SIB or aggressive behaviors. Modulation and modification of these factors can then lead to effective prevention strategies and improve emotion regulation.

Because autistic individuals often experience challenges with communication, rigorous study of functional communication and other communication interventions can potentially help to reduce externalizing behaviors. Further work can also be done in assessing the predictability of behavioral episodes and preemptive intervention opportunities. Study of real-world, complex intervention packages, such as residential treatment, can aim to identify effective components that may be readily translated to a variety of care settings.

In situations where behavioral and communication interventions are not available, unsuccessful, or the intensity of the behavior is too great, treatment of aggressive and self-injurious behaviors through medication may be utilized. While medications such as risperidone and aripiprazole have proven to be effective in the short term for reducing behaviors of concern in individuals with autism, they are also associated with significant side effects including weight gain and sedation.[110] Other medications, including valproic acid, naltrexone, lurasidone, and SSRIs, do not yet have a strong evidence base in support of their use to treat SIB and aggressive behavior in persons with autism. It is reasonable to utilize some of these medications to target co-occurring conditions that may be contributing to or be the source of these behaviors.

However, few pharmacological trials have specifically reported aggression and SIB as an outcome measure, and adverse side effects were reported inconsistently.[110] Therefore, additional research is needed to identify safe and effective pharmacological interventions that can reduce SIB, aggressive behavior, and emotion dysregulation. Research on how behavioral and pharmacological interventions may be combined are also needed to develop personalized intervention packages that can be used in autistic individuals who may be resistant to single interventions.

Studies are also needed to determine the long-term efficacy of pharmacological and behavioral interventions in individuals with autism. In addition, few pharmacological trials in this area include adults as the target population,[110] further highlighting the need for studies involving autistic individuals across the lifespan. Given the potential link between language ability and SIB and aggressive behavior, it is also critical to include autistic individuals who are minimally speaking or have intellectual disabilities in research to ensure that individuals across the autism spectrum, including those with high support needs, have access to safe and effective interventions.

As in other areas of mental health services for autistic individuals, much more work is needed to improve access to assessment and interventions for SIB, aggressive behavior, and emotion dysregulation. There are few specialized services with limited capacity for these issues, with most individuals seen by their primary care provider or not seen at all. Available services are geographically unevenly distributed, with individuals in rural communities facing additional challenges in gaining access. While residential treatment centers exist in the United States, very few have expertise in managing SIB and aggressive behaviors. Therefore, improving access to existing interventions and services is of critical importance to improve access to needed supports for autistic individuals in all communities.

Future Directions

SIB, aggressive behavior, and emotion dysregulation are common in autistic individuals. Additional work is needed to better understand the physiological mechanisms and environmental and social factors that lead to these behaviors and identify biomarkers and tools that can be used to predict SIB and aggressive behaviors before they start. Federal agencies have already invested in research in these areas, with NIH-funded researchers developing new wearable technology and using machine learning to more accurately predict the onset of aggressive behaviors. In addition, the Health Resources and Services Administration (HRSA) is funding the Telehealth Rapid Intervention for Externalizing Behaviors in ASD (THRIVE-ASD) project to improve access to behavioral interventions for disruptive behaviors through telehealth.

With respect to pharmacological interventions, research is needed to determine predictors of intervention response and drug tolerability. There is also significant need to develop effective drug treatment strategies with improved tolerability and safety compared to commonly used anti-psychotics with associated abnormal movement and metabolic risks. Continued improvement of access to existing supports and services is necessary as well to ensure that autistic individuals in underserved communities can also receive the support and interventions they need to manage SIB and aggressive behaviors. Research in these areas should include autistic adults and individuals with high support needs, including those who are minimally speaking, so that interventions are available for people across the autism spectrum and across the lifespan. Collectively, these future steps will reduce SIB, aggressive behaviors, and emotion dysregulation in individuals with autism and improve the well-being of those in the autism community.

Suicidality

Overview of Current Knowledge

Suicide attempts are defined as acts to end one's life.[116] Suicide behavior refers to death from suicide attempts as well as suicide attempts that may take place during a mental health crisis as a request for help. Suicidal ideation refers to a variety of thoughts, feelings, and preoccupations surrounding suicide and can be fleeting or lasting. According to data from the CDC, suicide is a leading cause of death in the United States, with over 48,000 people dying by suicide in 2021. Suicide was the second leading cause of death for young people ages 10-14 and 20-34 years, and the suicide rate among males was four times higher than among females.

Research consistently shows that autistic people are significantly more likely to contemplate, attempt, and die by suicide compared to the general population.[117-119] In fact, even when adjusted for other risk factors, autism was associated with more than double the risk of suicide compared to the general population.[117] The mental health conditions that commonly co-occur with autism, such as depression and anxiety, increase the likelihood of suicide attempts. In addition, attempts by individuals to camouflage or mask their autistic features is a significant predictor of suicidality, even more so than depression or anxiety. Social communication difficulties and feelings of being a burden were also associated with increased risk for suicide.

Effective suicide prevention, assessment, and interventions for autistic individuals have not been well studied. Research suggests that assessment tools, interventions, and services need to be adapted to the unique needs of those on the autism spectrum.[40, 118, 120, 121] Yet, autistic people report that health care services are not set up for "people like them," which can prevent access to much needed support and result in low satisfaction with health care professionals.[122-125] Previous research indicates that suicidality assessment tools developed for the general population may not be effective for autistic people,[120, 126] and work is ongoing to adapt some of these tools for use in autistic adults without co-occurring intellectual disability.[127, 128] There is very little published evidence regarding the efficacy of suicide prevention and interventions in autistic people.[117, 129] In recent years, researchers have begun developing safety plans and other suicide prevention strategies for autistic adults, and preliminary results show promise for reducing suicidal ideation and suicide attempts.[130, 131] However, the lack of validated assessment tools, prevention approaches, and intervention strategies make it challenging for researchers and clinicians to tackle the urgent issue of high suicide risk in autistic individuals.

Knowledge Gaps and Barriers to Research Progress

Research indicates that assessment tools may not adequately capture suicidality in autistic individuals.[120, 126] While researchers have developed tools that are more appropriate for autistic adults without intellectual disability,[127, 128] work is needed to modify and validate existing measures and potentially develop new tools to accurately assess suicidality for autistic individuals of all ages and across the spectrum. In particular, a recent study found that onset of suicidal thoughts and behaviors in autistic children often can begin before age 8,[132] underscoring the need for assessment and intervention tools across the lifespan. In addition, data suggests that suicidality assessment tools may not accurately predict future suicide attempts, even among the general population, and routine clinical care and patient ratings are better indicators of risk.[133, 134] It is therefore essential to ensure that autistic individuals at risk of suicide have access to critical health care to prevent and intervene during mental health crises.

In addition, researchers and policymakers need access to high-quality, population-wide data. Population findings could be extremely valuable for both informing suicide prevention efforts and evaluating their impact on suicide rates in autistic people over time. For example, there is conflicting data on how gender, age, race, and other socioeconomic factors such as education and employment may impact suicidality in autistic individuals.[117, 135] Population-wide data may be able to resolve some of these ambiguities and determine what populations are most at risk of suicide. However, to enable this, many countries, including the United States, need to improve their capture of community autism diagnoses and linkage to other important sources of data (e.g., education, employment, health care, cause of death, and demographic characteristics).

A body of research has begun to examine risk factors and biological mechanisms for suicidal behavior in autism. Suicide is believed to be related to a complex interrelationship between neurological, biological, and psychological processes, including differences in serotonin signaling.[116] All of these factors may contribute to suicide risk in autism. Recent research also indicates that genetic factors may play a role in contributing to suicide risk in autism.[136] However, additional research is needed to better understand how these factors may increase the probability of suicidality in autistic individuals and what can be targeted to increase resilience or for intervention.

In addition, other co-occurring conditions such as anxiety, depression, and ADHD may contribute to even higher risk of suicide for some autistic individuals.[117, 129, 137] As detailed in other sections of this report, many of these conditions may be misdiagnosed and underrecognized in autistic individuals, including depression.[138] Future efforts to improve diagnosis of multiple mental health conditions in individuals with autism will enhance access to interventions and services that can improve mental health and well-being.

Social and external factors can also contribute to suicide risk for autistic individuals. Interpersonal relationships can significantly impact mental health, with loneliness, feelings of being a burden, not belonging being significantly associated with suicidal behavior.[129] In addition, adverse childhood experiences, bullying, and sexual abuse have been strongly associated with suicidality.[135] Lower socioeconomic status, lack of health care access, and unemployment has also been linked with increased risk for suicidal ideation and attempts.[117, 135] Research is needed to identify intervention methods and resilience factors that can mitigate the impact of these environmental and societal factors to improve mental health for autistic individuals.

There is mixed evidence that sex and gender may impact risk of self-harm and suicide for individuals with autism, with transgender autistic youth at higher risk of suicide compared to non-autistic transgender youth.[117, 135, 139, 140] Autistic individuals experiencing gender dysphoria also experience poorer mental health, with higher risk of anxiety and depression, compared to individuals with autism or with gender dysphoria alone (see later section for more details).[141] More research is needed to better understand how social and biological factors intersect with sex and gender and the impact on autistic mental health, particularly for transgender autistic individuals and those experiencing gender dysphoria.

Overall, there is a profound lack of evidence-based tools and intervention approaches specific to the unique needs of autistic people. Furthermore, the high rates of co-occurring conditions among autistic adults add complexity to understanding and effectively preventing suicide. Communication challenges among autistic people can also affect identification, intervention options, and participation in research. Future research should investigate the effectiveness of existing interventions in reducing suicidal behaviors in autistic individuals. In addition, studies are needed to determine ways to improve access to appropriate services; ensure that services are accessible to all autistic people, including those with co-occurring intellectual disability or alternative communication needs; and develop new and innovative ways of assessing and preventing suicidal thoughts and behaviors.

Future Directions

A recent project conducted by the International Society for Autism Research (INSAR) consulted with over 1,000 autistic people and those who support them to identify and prioritize the top 10 areas for future suicide prevention in autism research. The top priority identified was to understand the barriers to care and support that may put autistic people at high risk of suicide. Other priorities included identifying risk markers, better understanding why autistic people may feel suicidal, developing new ways to identify suicidal thoughts and behaviors, and developing new interventions to prevent suicide in autistic people. These top 10 priorities are crucial for future research and policy initiatives to address.

Federal agencies are funding research to address these priorities, including the NIH ACE at the University of Pittsburgh, which is investigating mental health in autistic adults, with the aim of improving safety and quality of life and reducing premature mortality. The Patient-Centered Outcomes Research Institute (PCORI), an independent non-profit organization authorized by Congress in 2010, is also supporting a national study that will compare two suicide-prevention methods for autistic young adults.

To further enable these critical efforts, researchers and service systems need investments to target suicide prevention in the autism community and to explicitly identify autistic people as a high-risk group in suicide prevention policies and clinical guidelines. Investments in longer term research programs are needed to build a high-quality evidence base which will enable the development of robust assessments, interventions, and supports to reduce the high suicide risk in autistic individuals from diverse communities, of all ages, and across the spectrum of needs.

Bipolar Disorders

Bipolar disorders are characterized by recurring episodes of mania or hypomania alternating with episodes of depression.[142] Lifetime prevalence estimates for bipolar disorders are approximately 2.4% worldwide. Among autistic individuals, prevalence of bipolar disorders is more than double at 5-7%.[1, 3, 143] Autistic females have a higher likelihood of being diagnosed with bipolar disorders as compared to autistic males.[143] Co-occurring bipolar disorders in autistic individuals can lead to increased risked of suicide, psychotic behavior, catatonia, increased anxiety, and emotion dysregulation.[144, 145]

The highly heritable nature of both bipolar disorders and autism suggests shared genetic and biological factors.[71] For example, changes in oxytocin signaling has been linked to both conditions,[146] and SHANK3, a gene important for synaptic functioning, has also been found to be associated with both autism and bipolar disorder.[147] Other studies have also identified comment gene sets that are altered in individuals with autism and bipolar disorder.[148] However, the exact biological mechanisms that contribute to both conditions is unknown, and additional research is also needed to better understand factors that may increase risk of bipolar disorders in autistic individuals.

Overlapping features of aggressive behavior and irritability can make diagnosis of bipolar disorders difficult. Bipolar disorders are more easily diagnosed in autistic individuals without intellectual disability, as they are characterized by alternating cycles of elated and depressed moods.[144] Therefore, more research is needed to develop diagnostic tools that can assess bipolar symptoms in autistic individuals across the spectrum, particularly those with intellectual disabilities.

In terms of interventions, as in the general population, lithium salts is typically the first line treatment for autistic individuals with co-occurring bipolar disorders.[145] The efficacy of other pharmacological interventions such as SSRIs have not been well studied in autistic populations and may be associated with more adverse side effects. Additional trials are needed to develop safe and effective interventions for bipolar disorders in individuals on the autism spectrum.

Feeding and Eating Disorders

Prevalence of feeding and eating disorders is estimated to be between 2-5% of the general population.[149] These include anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant-restrictive food intake disorder (ARFID), pica, and rumination disorder.[150] Feeding and eating disorders can significantly impact both physical and mental health as well as social and emotional well-being, and anorexia nervosa is associated with the highest mortality rate of any psychiatric illness.[149] Approximately 32% of autistic individuals have a co-occurring feeding and eating disorder.[3] Autism prevalence among individuals with eating disorders is also higher compared to the general population, with an estimated 23% of individuals with eating disorders also having co-occurring autism.[151-153]

It is unclear what factors may increase risk of eating and feeding disorders among autistic individuals.[154, 155] However, recent data has suggested that autistic women without intellectual disabilities may be particularly at risk for feeding and eating disorders.[156] While sensory sensitivities have been linked with a range of eating behaviors,[157] there is a need for studies that specifically investigate eating disorder outcomes among autistic individuals and how differences in sensory processing may contribute to the development of feeding and eating disorders.[156, 158] In addition, the preponderance of studies in this area is focused on feeding issues such as selective or picky eating as compared to symptoms of eating disorders such as concerns with weight gain and body image.[154] Some studies also suggest that eating disorders may develop in autistic individuals due to anxiety, ritualistic behaviors, a need for control, and fear of change.[156, 158, 159] Given the serious nature and potential consequences of eating disorders such as anorexia nervosa, it is essential to conduct research to better understand why autistic individuals may be more likely to develop eating disorders and what resilience factors can be targeted for prevention.

Some women who first received an eating disorder diagnosis followed by an autism diagnosis noted that health care providers sometimes thought their autistic traits, such as sensory sensitivities or communication difficulties, were driven by the eating disorder, which caused the women to feel misunderstood and unheard.[160] This underscores the challenges of accurately distinguishing autism versus eating disorders and the need for research to evaluate the efficacy of existing diagnostic tools and interventions for eating disorders in autistic populations. This includes developing new or modifying existing tools as necessary to ensure that individuals on the autism spectrum can be accurately diagnosed and provided with safe and effective interventions to manage feeding and eating disorders.

Gender Dysphoria

Gender dysphoria is diagnosed in individuals who experience significant burdens when gender identity does not match assigned gender at birth.[161] Children with gender dysphoria may or may not go on to identify as transgender in adolescence or adulthood.[162] In the general population, estimated prevalence of gender dysphoria in children and adolescents range from 0.6-2.7%.[161, 162] It is unclear what the exact prevalence of gender dysphoria is among autistic individuals,[40, 163, 164] though data indicates autistic features are more common among gender-diverse individuals.[165]

Research is needed to determine what proportion of autistic individuals may experience gender dysphoria to establish a baseline for services and intervention needs. In addition, research is needed to determine how autism may impact gender development to better understand the biological links between gender dysphoria and autism. Studies on the efficacy of existing tools for diagnosis and interventions, including gender-affirming hormones, for gender dysphoria in autistic individuals are also needed.

In gender diverse people on the autism spectrum, mental health challenges may be compounded due to their intersectional identity, and individuals with co-occurring autism and gender dysphoria are more likely to also be diagnosed with anxiety and depression compared to individuals with just autism or just gender dysphoria.[141, 164] In addition, some studies have shown that transgender autistic females are at greater risk of suicide, and autistic youth experiencing gender dysphoria also have higher prevalence of suicidal ideation compared to other groups.[135]

Interventions tailored to the unique experiences of gender diverse autistic individuals are necessary to improve mental health. Overall, increased investments are necessary to understand how autism may manifest in gender diverse individuals, how autism may impact gender identity, and how the intersection of gender dysphoria and autism may impact the health and well-being of individuals on the autism spectrum.

Pathological Demand Avoidance (PDA)

Pathological demand avoidance (PDA) is a term originally developed by British psychologists to describe observations in a group of children that included challenging behaviors, extreme avoidance of everyday demands, and a need to be in control, with socially inappropriate behaviors sometimes used to achieve avoidance and gain control.[166, 167] PDA is not diagnosis included in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* or the *International Classification of Diseases (ICD)*.[168] Nevertheless, international studies suggest an increase in requests for PDA diagnoses, particularly in the United Kingdom,[167, 169] and several respondents to the IACC's Request for Public Comment highlighted the need to better understand PDA and any relationship to autism (see Chapter 2 for more details).

Studies on PDA have largely been focused on individuals with autism,[167, 169] and assessment tools for PDA largely identify individuals diagnosed with autism.[170, 171] There is controversy as to whether PDA is a separate developmental disorder or a subtype of autism (or other developmental conditions).[167, 169] Some members of the community have criticized the diagnostic criteria for PDA as it does not attempt to understand how the individual concerned may feel about the behaviors described and the role of anxiety and obsessive thinking in the development of avoidant and OCD-like behaviors.[167] Some research studies have found that PDA was similar in autistic children regardless of the levels of autism traits, and other studies have concluded that behaviors characterized as PDA may be common across the autism spectrum and across levels of intellectual ability.

Though most studies connect PDA to autism, PDA has also been linked to ADHD,[172, 173] and some data suggests correlation of PDA and higher levels of anxiety.[167] This indicates a need to better understand PDA and its association to autism and other co-occurring mental health conditions. In addition, PDA studies so far have largely focused on the symptoms of the condition, with a heavy reliance on reports from parents and caregivers, as opposed to the individuals themselves.[167, 169] This highlights the need for future research that explores how the demands that may lead to avoidant behaviors are perceived by individuals exhibiting PDA and identify factors that lead to avoidance. This can then inform intervention strategies to ameliorate potential anxiety associated with demand and improve social and familial interactions and promote health and well-being.

Schizophrenia

Schizophrenia includes symptoms of psychosis, including delusions and hallucinations, as well as lack of volition, reduced speech, catatonia, and cognitive impairment.[174] Schizophrenia is associated with social stigma and isolation, difficulties with employment, as well as reduced life expectancy. Among the general population, estimated lifetime prevalence of schizophrenia is around 1%.[175] Prevalence among autistic individuals may be 4 to 10 times higher than in the general population,[1, 3] with some data showing that older autistic males may be particularly vulnerable.[40]

Despite the increased prevalence of schizophrenia among autistic populations, very few studies have focused on individuals with co-occurring schizophrenia and ASD.[176] In addition, some indicators of schizophrenia may be mistaken for autistic features; for example, disordered speech may be viewed as speech difficulties. Psychosis in individuals with autism also be more frequently atypical,[177] and individuals with communication difficulties may have a harder time describing their experiences.[178] This leads to challenges with accurately diagnosing co-occurring schizophrenia in autistic individuals, and diagnostic and assessment tools that can distinguish between the two conditions are needed to ensure that the correct diagnoses can be obtained.

Genomic and proteomic studies demonstrate substantial overlap between schizophrenia and autism.[179] In addition, research show similar changes in brain anatomy and functional connectivity between brain areas.[176] However, additional studies are needed to better understand how these changes contribute to schizophrenia, what environmental factors may be involved, and how these may be targeted for prevention and intervention. Some data indicates that pharmacological interventions for schizophrenia may be less effective in autistic individuals and can lead to increased risk of seizures.[180, 181] Therefore additional research is needed to develop safe and effective interventions that can mediate symptoms of schizophrenia in autistic patients. In addition, CBT has been shown to be effective for schizophrenia patients in managing delusions and hallucinations, though with small effect size.[174] Trials should be conducted in autistic individuals to determine if CBT and other forms of psychotherapeutic interventions may be helpful in managing schizophrenia symptoms, particularly for older autistic males who are most at risk.

Substance Use Disorder (SUD)

Recent studies have indicated that autism is associated with increased vulnerability for substance use disorder (SUD).[182-187] Research has shown that the presence of depression, anxiety, ADHD, and trauma increase the risk for SUD.[184] Given that these are common co-occurring conditions in autism, it is likely that these factors contribute to SUD in autistic individuals. In addition, feelings of isolation and executive functioning challenges, as well as genetic factors, may also contribute to higher risk of SUD among autistic individuals.[186] Additional studies are needed to better understand risk and resilience factors for SUD in individuals on the autism spectrum. SUD among autistic individuals may be underdiagnosed as screening for SUD in autistic individuals is not common practice.[186] In addition, screening tools are needed to identify individuals who may be more likely to develop SUD.

Research is also needed to develop effective prevention strategies and interventions for SUD in autistic individuals, including for those with co-occurring SUD and other mental health conditions.[188] Currently available interventions include CBT and peer support groups.[189] However, additional research is necessary to build the evidence base for these and other interventions to determine efficacy. In addition, it is necessary to deconstruct narratives and preconceived notions that infantilize autistic individuals and others with disabilities. These narratives may lead health care providers and others to dismiss concerns of SUD and thereby delay access to necessary services and supports. Overall, there is a need for additional research, services, and policy to address the needs of individuals with co-occurring autism and SUD.[190]

Tourette Syndrome (TS) and Other Tic Disorders

Tics are involuntary repetitive movements (motor tics) or sounds (phonic tics) that occur outside of normal context or at inappropriate times.[191] Tics are common during childhood, and the estimated prevalence of persistent tic disorders, characterized by tics that are present for at least one year, is approximately 1% of all children. Tourette syndrome (TS) is the most common persistent tic disorder and is diagnosed by the presence of multiple motor tics and at least one phonic tic. Co-occurring conditions are common with tic disorders, particularly ADHD, OCD, and anxiety, all of which are also common co-occurring conditions in autistic individuals. However, tic disorders have not been well studied in individuals with autism.

Estimated prevalence of co-occurring tic disorders among individuals with autism is 10%,[3] and a recent study of 679 autistic individuals found that over 18% of the study participants had motor and/or phonic tics.[192] In addition, the study found that individuals with autism and tics were more likely to not have intellectual disability but were more likely to have symptoms of OCD and emotional and behavioral challenges. These results highlight the need to better understand what factors may lead to increased occurrence and severity of tics in autistic individuals and to develop appropriate interventions to manage symptoms and improve well-being.

Trauma and Post-Traumatic Stress Disorder (PTSD)

Individual, intergenerational, and historical trauma needs to be considered in mental health research of autistic individuals. Adverse childhood experiences (ACEs), as described in the research literature, are potentially traumatic events that occur in childhood and may include aspects of the environment that can undermine the child's sense of safety, stability, and bonding.[193] Current data indicates that ACEs are associated with autism,[194] and autistic children may be more likely to experience potentially traumatic events.[9] These events include bullying victimization, economic hardships, having parents who are divorced or separated, neighborhood violence, living someone who had a mental health condition or was suicidal, physical abuse, and neglect compared to non-autistic children.[9, 195-198] In addition, caregivers of autistic youth also experience higher rates of ACEs compared to caregivers of non-autistic youth.[199]

Brain imaging studies indicate that ACEs may lead to changes in neurological functioning, some of which are already known to be associated with autism.[200-202] ACEs and other traumatic experiences greatly impact mental and emotional well-being, leading to suicidal ideation and emotional distress and impacting development into adulthood.[4] ACEs are also associated with decreased school attendance, grade progression, and school engagement.[203]

Post-traumatic stress disorder (PTSD) may develop as a response to trauma.[9] Research has shown that autistic individuals may be more likely to develop PTSD compared to non-autistic individuals. Indeed, one paper found that 47% of autistic adults who experienced a prior trauma had probable PTSD, compared to 5% of non-autistic adults with prior exposure to trauma.[204]

However, events that some autistic individuals may view as traumatic may not be typically considered traumatic by the general population, such as changes in routine or sensory sensitivities.[9] In addition, one study found that though autistic children who had experienced abuse exhibited traumatic stress symptoms, few were diagnosed with PTSD.[205] This highlights the need for the development of diagnostic tools tailored to individuals with autism, as well as more research with larger studies to understand how different traumas and ACEs may differently affect diverse individuals and the distinctions in how acute versus chronic trauma impacts life outcomes for individuals on the autism spectrum.

There is also an urgent need to develop efficacious and safe interventions for traumatic stress symptoms in autistic individuals across the lifespan. Few studies have explored the evidence-base for interventions to treat traumatic stress in autistic individuals, with the little research so far predominately focused on adults.[9, 206] While trauma-focused CBT has been shown to be effective for non-autistic individuals, research is needed to modify the intervention for autistic children. Research is also needed to identify resilience factors, which may include places of refuge and identity,[4] that can protect individuals from the effects of adverse and traumatic experiences to better develop interventions that can improve health and well-being. Finally, trauma-informed care is essential to empower and promote healing for autistic individuals.

Wandering and Elopement Behaviors (WAEB)

Wandering and elopement describes when individuals requiring supervision wander from a safe area or away from a caregiver.[207] Approximately one in four autistic children will exhibit wandering and elopement behaviors (WAEB) each year, leading to high risk of injury as well as premature death, especially by drowning.[207, 208] Autistic children who have higher support needs related to social interactions and communications are more likely to wander, and co-occurring intellectual disability and ADHD, as well as co-occurring SIB and aggressive behaviors, also lead to higher risk of WAEB.[207, 208] Negative environmental factors that lead to WAEB include stressful and high-anxiety situations and sensory sensitivities.[207] Notably, caregivers have also reported WAEB while their children were pursuing hobbies and special interests, therefore it is sometimes difficult to predict when WAEB may occur.

Current prevention strategies include physical measures such as locking doors, as well as the use of service animals, off-label use of psychiatric medications, and behavioral interventions.[207, 208] In addition, electronic tracking devices can be used to track the location of a child who has wandered away and is associated with fewer incidences and shorter duration of wandering and elopement.[209] However, these devices may not always be tolerated due to discomfort, and families may not have access to these devices due to the high financial cost associated.[209]

Despite how common WAEB is among autistic children, one study found that only one-third of parents received any counseling concerning WAEB from their health care providers or teachers.[207] Therefore, communication is needed between parents and their service providers, including medical doctors, teachers, and law enforcement officials, to ensure that parents and caregivers have the tools they need to prevent WAEB and a plan in place for when wandering and elopement occurs.

Summary

It has been estimated that approximately 70% of people on the autism spectrum have one or more co-occurring mental or behavioral health condition.[40] The most common of these are anxiety; ADHD; catatonia; depression; OCD; SIB, aggression, and emotion dysregulation; and suicidality. In addition, bipolar disorders, feeding and eating disorders, gender dysphoria, PDA, schizophrenia, SUD, tic disorders, trauma-related disorders, and WAEB can also significantly impact the health and well-being of autistic individuals. An increased number of co-occurring symptoms has been associated with poorer overall health, while fewer symptoms has been associated with higher socioeconomic status.[210]

Current research indicates that these co-occurring conditions may share common genetic, epigenetic, and neurological variations. Federal agencies, as well as private funders, are funding research to better understand the biology of co-occurring mental health conditions and how they are related to autism. Research is also underway to develop and adapt interventions to improve mental health for autistic people. This includes work being done at the NIH ACE at the University of Pittsburgh, which is focused on better understanding factors that lead to poor mental health and utilizing that information to create interventions of autistic adults who may experience suicidal ideation.

However, additional studies are needed to establish the biological and environmental mechanisms that underlie autism and co-occurring mental and behavioral health conditions. This includes the need to understand how co-occurring conditions may be differently impacted by distinct factors to optimize mental and behavioral health outcomes.[211] In addition, research is needed to better characterize the manifestations of these conditions in the context of autism, and vice versa, to develop improved diagnostic and screening tools to better identify mental and behavioral health conditions in people with autism. Effective interventions for and methods to improve the self-efficacy of autistic individuals in managing co-occurring mental health conditions, in particular depression and suicide, are also needed. Studies on co-occurring mental and behavioral health conditions should also explore the role of age, sex and gender, intellectual ability, and language and speaking ability to determine how these factors may 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.

Reports from autistic individuals indicate that their mental health is largely influenced by autism features, including preferences for predictability; difficulties navigating the neurotypical world, including sensory difficulties and lack of supports and accommodations; and stigma, which includes difficulties with social interactions and not feeling a sense of belonging.[212] Autistic individuals also described how a formal diagnosis led to self-understanding and increased self-acceptance and self-compassion.[212] These insights indicate that positive psychology, which provides tools to enhance positive and fulfilling experiences,[213] and strength-based approaches should be also adopted to promote mental health and well-being for autistic people. In addition, given the high prevalence of ACEs and other traumatic events experienced by autistic individuals, trauma-informed approaches are also critical to adequately address the mental health needs of people with autism.

Federal agencies are currently working to improve access to equitable mental and behavioral health services. For example, The Link Center funded by ACL is providing technical assistance and training to state agencies to support policy development, service design, and service coordination to improve mental health for individuals with intellectual, neurological, and developmental disabilities. Other federal agencies, such as the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Centers for Medicare & Medicaid (CMS), are also working on other initiatives to improve services related to mental health, including for people with intellectual and developmental disabilities and their families. However, additional efforts are needed to increase the number of mental health providers, particularly those trained to work with autistic individuals.

Geographical, racial, ethnic, and socioeconomic disparities, as well as intersectional inequities, remain in mental health services needs for autistic individuals.[214-216] Autistic individuals are also more likely to be negatively impacted by social determinants of health, as exemplified by the fact that households with autistic children as more likely to experience food insecurities compared to households of children with other disabilities,[216, 217] which may lead to additional stress and anxiety. In addition, studies have shown that employment and higher job satisfaction is associated with better mental health and well-being. However, autistic individuals experience high rates of unemployment,[218] which may exacerbate mental health conditions. This highlights the need for equitable services that are accessible regardless of race, ethnicity, geography, or other socioeconomic factors to improve the mental health and well-being of all autistic individuals.

Chapter 5: Co-Occurring Intellectual, Communication, Developmental, and Learning Disabilities

Introduction

Intellectual disabilities, learning challenges, communication, and other developmental disabilities often co-occur with autism. Individuals with these challenges may require intensive supports and may be dependent on caregivers to meet their daily needs. Furthermore, they may have significant difficulty communicating their health concerns and other needs to their caregivers and service providers, which can negatively impact health and well-being.[1, 2] Behavioral issues, such as aggressive behavior and self-injury, that affect some individuals in this population, as well as additional co-occurring physical health conditions, such as epilepsy, can have serious impacts on physical health, developmental outcomes, and overall wellbeing. Due to the complexities of these challenges, addressing the needs of this population requires multi-faceted and personalized approaches according to an individual's developmental stage, profile of strengths and needs, and co-occurring conditions.[3-8] The sections below provide an overview, discussion of current gaps in the field, and describe promising avenues for future research for the following topics:

- Intellectual disability
- Community discussion around individuals with high support needs
- Communication disabilities
- Related developmental disabilities
- Learning disabilities

Intellectual Disability

Overview

The CDC estimates that approximately 1/3 of autistic children have an intellectual disability (ID), as defined by a score below 70 on a child's most recent IQ test.[9] (See below for further discussion of IQ tests.) Additional recent studies estimate that 30%-40% of autistic children have ID.[10-15] These estimates are similar to those from other countries.[16-18] This population is among those who have the most intensive support needs within the autism community and often require long term services and supports.[19] It is critical to address the social, adaptive, and communication challenges experienced by individuals with autism and ID.[20] Autistic individuals with ID are more likely to have co-occurring conditions such as aggressive and self-injurious behaviors.[21] The presence of ID with neurobehavioral conditions can complicate diagnosis as well as intervention approaches.[22-25] Autistic individuals with ID may also have speech or communication disabilities and/or executive function difficulties, creating additional challenges.[26]

Identifying ID in a child with autism is critical for developing an Individualized Education Program (IEP) to best support learning needs and independence skills. Additional services and supports such as behavioral interventions, speech-language, psychological, physical, and occupational therapies, academic tutoring and peer-mentoring, as well as assistive technologies, can help meet the needs of individuals with autism and ID and help them fully participate in a range of activities and services.

In adulthood, individuals with autism and co-occurring ID may experience difficulty maintaining sustained employment. It is estimated that about 60% of autistic adults who live with their families and receive developmental disability services have ID.[27] Research has demonstrated that employment outcomes are influenced by individual characteristics, family and community factors, and early childhood school success.[28] Occupational therapy can help to address these challenges, as well as support participation in and performance of activities of daily living, education, work, leisure, and social activities.[29, 30] However for adults with high support needs, these options are limited and families struggle to access appropriate supports and services. Family caregivers of children with autism and co-occurring ID are more likely to report negative impacts on their employment and financial status, compared to caregivers of children with autism only.[31]

Knowledge Gaps and Barriers to Research Progress

Diagnosis of autism in the presence of ID can be challenging and is influenced by contextual factors such as age and severity of ID.[32] Clinical guidelines to help differentiate autism from ID encourage consideration of the age of the child, adaptive functioning, cognitive abilities, motor and sensory impairments, and developmental trajectories, as appropriate.[32] These guidelines also encourage consultation of multidisciplinary teams to provide more than one perspective.

Children with autism and ID may face additional complexities in comparison to children with autism without ID.[25] Children with “complex” autism (children with a significant number of physical anomalies and/or microcephaly) have been found to have higher rates of seizures and pathological EEG and MRI findings.[33] Additional research has found them to be more likely to have behavioral challenges, eating/feeding issues, seizures, GI conditions, cardiac conditions, and vision and hearing anomalies.[34, 35] Recent work by the CDC has highlighted that children with autism and ID are more likely to experience co-occurring neurological disorders.[25] Furthermore, certain genetic syndromes (e.g., Fragile X, Rett, Tuberous Sclerosis, Down, phenylketonuria, and Angelman) are associated with ID and also have a high incidence of autism. Further research is needed to understand this overlap and the high prevalence of co-occurring conditions in individuals with autism and ID.

Despite the significant needs of this population, individuals with ID are underrepresented in autism research. This is largely due to traditional research exclusions to prevent confounding variables in studies and the challenges that may be associated with working with participants who cannot rely on speech alone to be heard and understood.[36] Reexamination of such policies to ensure that studies are inclusive of people with ID where possible would be helpful in addressing this issue. Researchers have identified strategies that can enhance the inclusion of individuals with ID in autism research studies.[37] These include combining play and testing, selecting suitable outcome measures, responding to challenging behaviors, and building relationships with parents and siblings. In addition inclusive healthcare and research settings can better meet the needs of people with autism and ID through the use of adapted tools and protocols, including telehealth to reduce the need for families to travel, plain language materials, and sensory-friendly practices.[2, 38-40]

Future Directions

Research is needed to develop improved methods to assess ID in individuals with autism and to differentiate between autism and ID.[32, 41, 42] This can be achieved by better understanding the causes of

ID within autism, the intersection of traits of autism and ID, and the similarities and differences between ID in autism and ID in other populations.[32, 43-45] Insights can also be gained from research done within the broader ID community.

There is ongoing discussion within the community about the need to develop improved assessments for autistic individuals with ID. Significant discrepancies between different IQ tests and between verbal and nonverbal subtests has been documented in the literature.[46-48] Traditional tests often rely on verbal communication for many test components, and may thus underestimate an individual's abilities.[46, 49, 50] Improved assessments that can provide a fuller picture of an individual's skills and abilities will help to ensure that optimal learning and developmental opportunities are provided across the lifespan. There is also a need for assessments that identify both cognitive disabilities and strengths, such as visuospatial skills for some individuals.[51, 52] Research has shown promising approaches for developing new strengths-based assessments for autistic children who showed poor performance on conventional IQ instruments,[50, 53] although others caution about the interpretation of these findings. Tests that involve a battery of subtests in different areas, such as the NIH Toolbox Cognition Battery, show promise in sensitively measuring cognitive and developmental changes over time.[54] Alternative scoring of standardized tests has also been proposed as a way to better reflect an individual's profile of cognitive strengths and weaknesses.[55]

In addition, efforts to include this population in research studies are needed, as well as studies focused on this population specifically. The NIH-funded *Eunice Kennedy Shriver* Intellectual & Developmental Disabilities Research Centers (IDDRCs) are conducting work to advance the development of therapeutics and interventions for intellectual and developmental disabilities, including autism. Research projects include use of molecular, cellular, and preclinical models to increase understanding of the biological basis of autism; technologies to improve assessment, endpoints, and treatments; and interventions and management of co-occurring conditions, including mental health conditions. Further research is also needed to improve our understanding of the genetics and neurobiology underlying the overlap between autism and lower IQ.[56-59]

Moving forward, it is critical to explore the potential of and optimal modalities for individuals with autism and ID to learn and acquire new skills across the lifespan,[54] and how to best support the needs of this population. To make strides in this area, diagnostic tools and interventions for other co-occurring conditions, such as anxiety and challenges with executive function, may need to be adapted for individuals with autism and ID.[60-62] It is also necessary for service providers to receive regular training on best practices for working with this population. For example, a survey of special educators demonstrated that while they are interested in using evidence-based practices in their classrooms, they do not always receive regular training in the use of these methods.[63]

Community Discussion around Individuals with High Support Needs

In 2021, the Lancet Commission on the Future of Care and Clinical Research on Autism published a paper that described approaches to support individuals on the autism spectrum, including those with high support needs. The authors proposed the label "profound autism" to describe autistic individuals with high support needs, including intellectual disability, with or without communication disability, and the need for 24-hour caregiver support.[64] This population has been historically underserved, and the Lancet

Commission hoped with this term to bring a spotlight to the needs of these individuals. The commission's work spurred community conversations as well as research to further define this population.

The Centers for Disease Control and Prevention (CDC) leveraged its existing Autism and Developmental Disorders Monitoring (ADDM) Network to estimate the number of autistic 8-year-old children in the U.S. that meet the criteria for "profound autism" as described by the Lancet Commission. They found that 27% of the 20,135 children included in the ADDM study met the criteria of profound as described in the Lancet report. Additional analyses conducted by the Lancet Commission of various datasets produced estimates of 18-48% of the autistic population that met the profound autism criteria.[8]

Some advocates have voiced the need for a term to identify autistic individuals with the highest support needs to facilitate the provision of more intensive supports. Others worry that the "profound autism" label may be too imprecise and not be inclusive of high support needs related to other combinations of autism and co-occurring conditions, lead to conflation of autism with its co-occurring conditions,[65] lead to the assumption that because a person does not use speech to communicate reliably, they cannot use language,[66] or cause underestimation of abilities and further exclusion and limitation of opportunities for the individuals this label is intended to help. There is also concern that creating additional functional labels could inadvertently further stigmatize or silo individuals and move health providers away from using a personalized approach that could more precisely address an individual's health care and service needs.[67] The "profound autism" label remains an active topic of conversation within the autism community.[66-74]

Communication Disabilities

Overview

Some individuals on the autism spectrum cannot rely on speech alone to be heard and understood. This can be due to a variety of complex issues, and can occur in the presence or absence of ID. A subset of individuals with autism have speech sound disorders, including apraxia of speech.[75] Difficulties with communication and speech may be linked to auditory processing impairments for some people with autism or differences in the activity or connectivity of brain regions responsible for language.[76-80] Communicative speech challenges may also stem from motor and oral motor issues.[81] Research has identified overlap between autism and selective mutism, an inability to speak in certain situations which may co-occur with social anxiety.[82, 83 84] A recent study demonstrated that differences in vocalizations can be detected as early as 12 months in infants who later are diagnosed with ASD.[85] While some children with speech-and communication-related disabilities eventually match the speaking abilities of their neurotypical peers, up to 30% cannot use speech as their primary means of expression throughout their lives.[86]

Difficulty with speech and/or expressive communication may hinder ASD diagnostic tests and other evaluations of abilities,[87] which may in turn delay qualification for and provision of services. In addition, ID may be misdiagnosed in a person who in fact has communication challenges. Individuals who cannot rely on speech alone to be heard and understood often experience more challenges in education, daily living, relationships, and community integration.[88] Thus, advances that can lead toward improvement of spoken language, alternative forms of communication, and/or address communication access needs have a high potential for increasing positive outcomes.

Speech-language therapy can help people with speech disabilities and their interactions with others.[89] This type of therapy focuses on verbal skills, such as naming people and things, and better explaining feelings and emotions. Speech-language therapy can also teach alternative communication skills, such as using sign language or picture symbols to communicate (Picture Exchange Communication Systems, or PECS). A randomized controlled trial from 2012 found that speech and language therapy in a sample of school-aged children with and without autism had the greatest benefit for learning pragmatic skills, such as conversational ability, classroom learning, and social communication.[90] For older children and adolescents with developmental disorders (which may include those with autism), research indicates that one-on-one intervention with a speech language pathologist can help to improve language skills.[91]

AAC supports serve as communication alternatives to speech. Some AAC supports are in the form of communication software applications that can be run on personal devices such as tablets or laptops that help individuals with autism communicate and maintain communication autonomy. Research studies have demonstrated multiple benefits of using AAC for people with autism, including basic access to communication using nonspeech methods, requesting functions, and increased social communication.[92-96] Use of AAC methods and digital tools can be especially beneficial in providing a means for individuals to communicate and engage effectively with others.

Knowledge Gaps and Barriers to Research Progress

Researchers have identified several differences in the structure and connectivity of language-supporting regions in the brains of autistic individuals.[97, 98] Identifying biomarkers that predict language development is a promising strategy to direct autistic children to appropriate interventions during critical developmental windows.[99] 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.[100, 101] In many cases, autistic individuals who have speech disabilities may have motor difficulties that limit speech, rather than cognitive difficulties.[102] It is also important to identify biomarkers and develop evaluation tools that can effectively characterize communicative ability in all autistic individuals, including those who cannot use speech as their primary means of expression.

Future Directions

Much remains to be explored about the neurobiology underlying differences in language development and communication in autism. While differences in some regions of the brain are known to play a role in autism, the heterogeneity of cognitive and social phenotypes make it difficult to pinpoint the neuronal and molecular changes that contribute to communication differences. 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.

It is critical to make advances in understanding communication challenges and providing appropriate communication supports to autistic people. Research is needed to develop new approaches and technologies to help individuals with communication disabilities develop their communication skills, promote literacy skills,[88] and access the communication modalities of their choice that are most effective for them. Further research on the integration of ACC technology with mobile devices (e.g., mobile phones, tablets) could enhance accessibility, as well as the development of evidence-based instructional strategies.[103-106] Work has been done to elucidate our understanding of predictors of AAC intervention outcomes, but more is needed in this area, as well as work on factors that moderate and mediate response to AAC interventions.[107]

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. Recent NIH-funded research has focused on developing more personalized and effective language intervention approaches[108, 109] and adaptation of a community-based intervention that incorporates peer participation for improving social communication in autistic children.[110] The National AI Institute for Exceptional Education, funded by the National Science Foundation and the U.S. Department of Education, is developing advanced AI technologies to support speech and language pathologists who work with children with speech and language processing challenges. NIH is also encouraging further research to promote language and communication in individuals with autism who cannot use speech as their primary means of expression.

Related Developmental Disabilities

Most of the population with autism does not have profiles with known genetic findings.[8] However, traits of autism are common in many syndromic developmental disorders (those that have been linked to a single gene or a chromosomal change), such as Fragile X syndrome, Rett syndrome, and Down syndrome. To date, research on the genetics of autism has identified more than 100 associated genes that play critical roles in gene expression and neuronal communication in the developing brain.[58, 111] AGENDA, the Alliance for Genetic Etiologies in Neurodevelopmental Disorders and Autism, is a collaboration of over 40 advocacy groups that represent individuals with rare genetic disorders associated with autism and neurodevelopmental disorders. **Table 1** provides an overview of some of the genetic conditions known to be associated with autism.

Genetic syndromes caused by a difference in a single gene or chromosomal region can have an array of effects in the human body and often involve multiple organ systems, as the genes involved may be expressed in multiple tissue types. Many of the genetic syndromes that can involve autism share commonalities in how they impact neurological circuitry and other systems, causing associated co-occurring conditions, such as ID, GI issues, and seizures.[111, 112] Knowledge of the contributing gene(s) in these syndromes has led to the development of biomarkers and outcome measures, insight into affected molecular pathways, and identification of therapeutic targets. The NIH-funded Developmental Synaptopathies Consortium represents ongoing work in this area, where research teams are conducting mechanistic studies of genetic conditions related to autism and ID. Understanding the biology of these conditions can provide insights into molecular pathways that are commonly affected in autism.

[PLACE HOLDER TABLE IS INCLUDED BELOW. SO AS NOT TO FOCUS ON A SELECT FEW GENETIC SYNDROMES, THIS TABLE WILL INCLUDE APPROXIMATELY 20-30 SYNDROMES WITH BRIEF DESCRIPTIONS OF EACH.]

Name	**Description**
Fragile X syndrome	FXS is the most common known inherited form of ID.[113-115] It is the most common known inherited single-gene disorder associated with autism, accounting for 1%-6% of all cases.[116, 117] Common traits of FXS that overlap with autism include social, behavioral, and communication challenges.[118, 119] Many co-occurring conditions also overlap with autism, including attention issues, self-injurious behavior, anxiety, hyperarousal, and seizures.[118, 120-126]
Rett syndrome	Rett syndrome (RTT) is a progressive neurodevelopmental disorder that primarily occurs in females.[127] Individuals with RTT require lifelong personal care, assistance and suitable supportive equipment.[128] Other clinical features include epilepsy, cognitive impairment, scoliosis, feeding difficulties, growth restriction, sleep disturbance, bruxism, and autonomic and motor dysfunction.[129]
Down syndrome	Down syndrome (DS) is characterized by ID and communication challenges. DS is also known as trisomy 21.[130] People with DS can have a variety of other health issues such as congenital heart defects and gastrointestinal problems , autoimmune conditions, respiratory infections, sleep disorders, hearing and vision loss, and early development of Alzheimer's-type dementia.[131-133] Those with DS may also have communication challenges, differences in social awareness and motivation, and restricted and repetitive behaviors. [134-136]
Phelan-McDermid syndrome	Phelan-McDermid syndrome (PMS) is a rare disorder characterized by speech and developmental delays, low muscle tone, motor deficits, ID, autism, epilepsy, and behavioral issues.[137, 138] PMS is one of the most common genetic forms of autism and is present in up to 2% of cases.[139]
Tuberous sclerosis complex	Tuberous sclerosis complex (TSC) is a rare genetic disorder characterized non-cancerous tumor growth in several parts of the body, including the brain, lungs, and kidneys. These tumors lead to symptoms including developmental delays, ID, and seizures. TSC is one of the main syndromes associated with autism. Many individuals with TSC also have autistic traits, although estimates for the prevalence of autism in TSC varies (from 25 – 61%).[140-144] Epilepsy is estimated to occur in about 80% of TSC patients, typically within the first 3 years of life,[145] and is considered to be a risk factor for autism in children with TSC.[146, 147]
ARID1B	Variants in the ARID1B gene are one of the most common causes of ID. The most common condition associated with this gene is Coffin Siris-Syndrome (CSS).[148] People with CSS often have co-occurring developmental and/or cognitive disabilities.[149] People with ARID1B tend to have speech and motor skill delay, feeding difficulties, and ID. Scoliosis, frequent infections, GI problems, and congenital anomalies (e.g. cardiac, cryptorchidism) are also common.[148]
CHARGE syndrome	[Description will be added]

DYRK1A	[Description will be added]
CHD8	[Description will be added]
16p11.2 deletion syndrome	[Description will be added]
Angelman syndrome	[Description will be added]
Neurofibromatosis	[Description will be added]
Prader-Willi syndrome	[Description will be added]
22q deletion syndrome	[Description will be added]
Cornelia de Lange syndrome	[Description will be added]
Duchenne Muscular Dystrophy	[Description will be added]
Smith-Lemli-Opitz syndrome	[Description will be added]
Smith Magenis syndrome	[Description will be added]
Sotos syndrome	[Description will be added]
….etc.	

Table 1. Genetic syndromes, disorders, and conditions associated with autism. Please note that this table is not exhaustive of all genetic conditions that has been found to co-occur with autism, but rather provides an overview of some of these conditions and description of their presentation.

Future Directions

As research progresses, an increasingly large number of genetic conditions and syndromic developmental disorders are associated with autism. Further investigation is needed to better understand the cellular and molecular pathways linked to the affected genes that can co-occur with autism. One promising approach is the use of induced pluripotent stem (iPS) cells from individuals and iPS-derived brain organoids to visualize the developmental processes of the human brain in a dish.[150, 151] Another is the use of large databases and registries, such as the SFARI Gene database and the FORWARD study (Fragile X Online Registry with Accessible Research Database), that can help move beyond the limitations of family surveys and small clinical research studies.[152, 153]

Advancements in these areas will allow for more efficient development of pharmacological treatments and other interventions that can improve health and well-being. It is also necessary to understand the differences in the presentation of autism in the presence of co-occurring genetic disorders, compared to autism alone. This knowledge will help to inform personalized intervention approaches.

Learning Disabilities

Some people with autism have co-occurring learning disabilities which can impact their academic achievement and daily life activities. Autistic individuals vary considerably in their strengths, challenges, and the extent of educational support needed[154] and research has shown that academic achievement varies widely among autistic students.[155] A recent survey of parents found that learning disability was the most commonly reported co-occurring condition.[156] A growing body of work has focused on reading skills in autism.[154, 157-159] As many as 65%[160, 161] of autistic children have been reported to have difficulty with reading comprehension, in comparison to 3-10%[162] estimated among the neurotypical population. Studies have found that autistic children's word decoding and oral language abilities are important predictors contributing to vulnerability of poor reading comprehension outcomes.[163, 164]

Research has also found that a co-occurrence of Specific Learning Disorders, such as dyslexia, dysgraphia, and dyscalculia, among children with autism include challenges in reading, written expression, and mathematical abilities.[165-168] Nonverbal learning disability/disorder and disabilities such as prosopagnosia (difficulty recognizing faces) is also reported to overlap with autism in some cases.[169-172] These learning disabilities may be, in part, related to auditory, visual, and other sensory differences in autism that influence learning abilities.[173-176] Further research is needed to expand our understanding of the reading, learning, and cognitive and sensory-based skills-related challenges experienced by people with autism, and to increase research that covers the full spectrum of abilities, including those individuals who cannot rely on speech alone to be heard and understood.[164, 177] Studies to determine the frequency of co-occurrence of these disabilities would also be informative.

Responses to the Request for Public Comments on Co-Occurring Conditions in Autism released by the IACC in 2024 reflected additional cognitive and learning challenges that are experienced by individuals with autism. Some respondents mentioned that they have dyslexia, a learning difficulty that manifests as reduced accuracy and speed in reading and spelling.[178] Dyslexia also co-occurs with attention deficit-hyperactivity disorder (ADHD) and research has found overlapping genetic correlations between autism, ADHD, and dyslexia.[178] Sensory processing atypicalities have been proposed to contribute to core behavioral features in both autism and developmental dyslexia.[179-181] RFI respondents also described other cognitive and learning disabilities such as dyscalculia (difficulties with numbers and mathematical reasoning), and struggles with executive function.[182] Further research is needed on prevalence, underlying causes, and development of targeted interventions to address the variety of learning disabilities experienced by people with neurodevelopmental disorders, including autism.[183] Interdisciplinary research that bridges neuroscience with education research to understand how brain differences impact learning and contribute to learning disabilities may be particularly helpful, as currently many studies are either focused on education or neuroscience, but few studies connect the findings across both fields. As skills related to reading, mathematical ability, visual learning, spatial perception, facial recognition, and executive function are basic skills needed for daily living, progress in this field will not only help autistic students with learning disabilities have more success at school, but it will also contribute to greater independence and community integration for autistic people with learning disabilities as adults.

Summary

In order to improve outcomes for all autistic individuals, including those with the highest support needs, it will be necessary to better understand the complex mechanisms that contribute to intellectual ability and communication ability. Further research is needed to understand how needs may change across different developmental stages, and which interventions work best at different points in the lifespan.

Interventions that can improve communication, learning, and address challenging behaviors will allow caregivers and service providers to better meet the needs of this population, as well as increase opportunities for communicative autonomy, independence, and full engagement with the community.

Chapter 6: Health Care Service Provision

Introduction

Addressing the health care needs associated with co-occurring conditions across the lifespan remains critical to ensuring optimal health and well-being for people with autism. Given the medical complexity that may be presented by multiple conditions across different life stages, the provision of effective health care may pose a challenge due to the care coordination, specialist training, and service availability needed to facilitate optimal outcomes.[1] The *2021-2023 IACC Strategic Plan* outlined several key areas related to addressing the health care services needs of autistic people across their lifespan, including insurance coverage, service delivery models, mental health services and supports, dental care, and appropriate services to address health and safety concerns. Across these and other domains of health care service provision, the autism community has consistently noted the importance of high-quality and accessible services and supports,[2, 3] accommodations and flexibility in patient-provider interactions,[4, 5] individualized care,[6, 7] and increased health care provider knowledge of autism.[8]

In its *2021-2023 IACC Strategic Plan*, the Committee emphasized the importance of continuing to support research to advance quality services and supports as well as evidence-based interventions that can be scaled up and implemented in community settings and be accessible through health insurance coverage. Although progress has been made around the understanding of diverse experiences, preferences, and values in the design and provision of health care services for autistic individuals and their families, disparities continue to exist in several key areas, especially for underrepresented and underserved populations.

The sections below provide an overview, discussion of current gaps in the field, and describe promising avenues for future research for the following topics:

- Accessibility of Health Care
- Patient-Provider Interactions
- Considerations for Individuals with Complex and High Support Needs
- Promoting Equity and Reducing Disparities
- Impact of COVID-19

Accessibility of Health Care

Overview

A wide variety of services and supports are available to help maximize health and well-being among children and adults on the autism spectrum. Advances in the field of telehealth and service delivery have improved access to various care providers that may need to coordinate across service systems to provide optimal care for co-occurring conditions in autistic patients.[9, 10] However, navigating the health care system can remain difficult due to 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. 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. For example, there are wide differences in Medicare/Medicaid enrollment across states for autistic individuals with and without ID.[11]

Ensuring appropriate insurance enrollment and coverage to address the wide range of needs presented by co-occurring conditions remains paramount for the timely access to health care among autistic individuals. Further, while accessibility to health care has significantly improved through recent program and policy updates, ongoing efforts are essential to address the remaining disparities and challenges in the system. These areas for growth include access to high-quality care, access to trained providers, accommodations, and the use of new and emerging technologies.

Facilitators and Barriers to High-Quality Care

Provider Training

Research on the facilitators and barriers to high-quality health care for co-occurring conditions in autistic individuals has identified access to health care providers with appropriate knowledge and training in serving the autistic population as a key facilitator.[12] [13] Several medical provider training programs have sought to increase provider knowledge, self-efficacy, and attitudes towards working with autistic individuals and people with disabilities overall. However, systematic reviews of the field have suggested a need for studies focusing on providers who care for adult populations, as well as specialized physicians.[14] For example, a review of graduate-level psychology programs suggest limited exposure to autism-specific training among mental health providers, highlighting potential silos in autism training needs.[15]

Strategies to strengthen the health care workforce are needed in order to increase provider training, knowledge, awareness, and skills in addressing autism and co-occurring conditions.[16, 17] For example, navigating healthcare billing and coding can pose challenges for providers of autistic patients, potentially impacting access to and quality of healthcare. Medicare and Medicaid reimbursement rates may limit the number and variety of healthcare providers who will accept public insurance and the types of services offered. Payment rates can also impact the willingness of healthcare providers to pursue training. Some resources have been created, such as Got Transition® and AAP's 2023 Coding and Payment Tip Sheet for Transition from Pediatric to Adult Health Care,[18] which provides guidance on medical billing and coding specifically for transition-related services. Further insurance-related provider guidance may be needed for services needed across the lifespan. Additionally, educational curriculum for all providers across a variety of disciplines should be tested for feasibility and consistency, especially for the fields that are likely to pertain to autistic patients with co-occurring conditions.[19] The lack of qualified providers across specialties may present a barrier for health care access, and additional studies in this field are needed to address this concern. Moreover, clinical care for co-occurring conditions is increasingly hampered by an acute and worsening shortage of pediatric subspecialists, as outlined in a 2023 National Academies of Sciences, Engineering, and Medicine (NASEM) report,[20] highlighting the need for medical and economic changes (e.g., equitable reimbursement rates and earning potential compared to adult-care counterparts) to support these critical roles.

Care Coordination

Referrals from primary care providers to specialty care serve as a crucial component of the care coordination process, and a lack of health care coordination services contribute to increased emergency department use for co-occurring conditions.[21, 22] Wait times and visit length for primary and specialty care continue to be barriers to optimal access to health care.[7] Additionally, care coordination remains a challenge even when caregivers indicate improvements in overall primary care provider accessibility.[23] The medical home model of care, developed by the American Academy of Pediatrics (AAP), is a family-centered teams approach to providing and coordinating medical care. The medical home model promotes communication of condition-specific needs and smooths transitions between providers/offices.[24, 25] Research has shown that the interdisciplinary medical home model facilitates access to care for autistic children, encourages shared decision-making with caregivers, and can serve to improve health outcomes.[26, 27]

Access and Accommodations

There are additional opportunities to increase accessibility of healthcare for autistic individuals. For example, autistic stakeholders have raised the importance of providing sensory-friendly accommodations to improve the accessibility of health care environments.[7, 28] Autistic individuals may experience discomfort in health care settings due to sensory stimuli such as bright lights, proximity to others in crowded waiting rooms, or communication challenges with providers.[5] Soft or low lighting, non-crowded settings or special clinic days for autistic, neurodivergent, and IDD individuals, plain language instructions and forms, streamlined processes and procedures, and ensuring that AAC is available to those who need it can make the visits a better experience.[5, 7, 29]

Novel frameworks have focused on improvements to the physical environment, providing space for processing, sensory needs, and emotional regulation.[4] Additional research is needed to improve clinical environments for specific health subspecialty fields, such as orthopedic settings,[30] dental settings,[31] and pediatric settings.[32] Further, the provision of care for co-occurring conditions may necessitate the use of medical procedures, such as magnetic resonance imaging scans (MRIs), for which sensory challenges become a factor. Some researchers have published protocols and strategies to improve the experience of autistic individuals in such heath procedures.[33-36] Health care providers have noted the need for standardized guidance on practices and protocols, as well as autism-specific trainings for providers carrying out these procedures to ensure uniform quality, facilitate participation, and improve outcomes for autistic individuals.[33, 37]

Collaboration and Patient- and Family-Centered Approaches

Collaboration between autistic patients, their families, and health care staff has served to center the perspectives and lived experiences of the autism community and can serve to further strengthen health care delivery systems.[38] Self- and family-directed services and supports prioritize participant choice, control, and flexibility. Under this type of model, the individual and/or family is involved in all service planning and decision-making activities, which gives the individual and family greater control over their care.[39]

There have been advances in person- and family-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.[40] Additionally, shared decision-making models are more frequently being seen as a benchmark measure within a successful healthcare transition protocol for autistic individuals.[41] Self-directed and person-centered planning is important for adolescents and adults with autism in prioritizing personalized supports and services for transition planning, employment, and community living.[42-44] For families of adults with developmental disabilities, research finds that participation in a participant-directed program is associated with fewer unmet service needs, increased satisfaction with services, and improved community functioning.[45]

Recent progress has been made in enhancing regulations requiring equipment in medical facilities to be accessible to individuals with mobility disabilities. Updates to Section 504 of the Rehabilitation Act, finalized in May 2024 by HHS, have strengthened protections against disability discrimination, including specific requirements for accessible medical equipment such as exam tables, wheelchairs, and mammogram machines.[46, 47] Strengthening of accessibility efforts to include considerations for autistic and neurodivergent people and those with IDD would further center the experiences of autistic patients and their families and ensure that all individuals receive equitable and effective care, directly responsive to their needs.[48-50] By addressing these additional dimensions of accessibility, health care systems can better meet the diverse needs of patients and create a more comprehensive and responsive care environment.

Addressing Knowledge Gaps to Improve Accessibility

Data and Research Gaps

To be effective, healthcare systems need more accurate and timely data to be able to plan for future patient needs. Although recent studies have sought to procure prevalence estimates for co-occurring conditions in autistic populations using both private- and public-insurance datasets,[51, 52] more timely and comprehensive data can serve to further highlight the impact of these conditions on the service system. Further, research has suggested that the prevalence rates of co-occurring conditions in autism may differ depending on the age group and study design.[53] Without robust and accurate prevalence data, health care providers and systems may not be able to effectively implement targeted interventions to address the needs of their communities. Additionally, the lack of comprehensive data tracking may present a barrier to the long-term monitoring of outcomes and trajectories for autistic individuals with co-occurring conditions. Coupled with a potential lack of evidence-informed resource allocation, this may also present barriers to accessible health care provision for this population.

While longitudinal studies have explored the trajectories of certain co-occurring conditions from childhood into adolescence as well as early adulthood,[54] additional longitudinal studies are needed to identify risk and resilience factors for the profile of co-occurring conditions that may occur across the lifespan, including in older adulthood.[55] Development of profiles for co-occurring conditions into late adulthood can also serve to highlight areas of service disparities and lack of services access for aging autistic populations.

Research has also highlighted the importance of adapting traditional research approaches to better serve the needs of autistic individuals. For example, community based participatory research, which entails a partnership approach to research that equitably involves community members, representatives of community organizations, and academic researchers in all aspects of the research process, is an approach that can result in more equitable results. A review of community-based participatory research (CBPR) found it to be an effective model for building partnerships between researchers, communities, and those with lived experience to improve healthcare and skills development in autism care.[56] Additionally, efforts to adapt survey instruments for autistic adults reveal barriers, such as confusing vocabulary, imprecise response options, and ableist language.[57] These issues were addressed through modifications like simplifying sentence structure, adding hotlinks for clarification, and including autism-specific items. This participatory approach to research and instrument design is essential for ensuring more accurate data collection and improving health interventions tailored to autistic individuals.

Equitable Access to Diagnostic Services

Validation of diagnostic and assessment tools for co-occurring conditions in autism continues to be an area of potential research and challenge. Additionally, for children falling below the diagnostic threshold for ASD, research has emphasized the importance of accessible and accurate assessment tools and diagnostic procedures that can identify communication disabilities and mental health conditions.[58] This is particularly relevant for co-occurring mental health conditions beyond anxiety and depression, where much of the current research on assessment tools has been concentrated, potentially leaving gaps in understanding and diagnosing other mental health conditions in autistic individuals.[59-61] As mentioned, the accurate diagnosis of co-occurring conditions is needed for the timely access of appropriate services.[62] Additionally, research suggests the need to ensure that assessment measures accurately capture the unique manifestations of autism and co-occurring conditions for women and girls.[63, 64] Research on gender-based differences in the efficacy of assessment tools could yield more equitable access to health care for autistic individuals of all genders.

Research has suggested that individuals who received their diagnosis of autism in adulthood had a greater number of co-occurring mental health diagnoses than individuals who were diagnosed with autism in childhood.[65] This underscores the importance of early identification, which may result in better mental health for autistic individuals. Given research data on the lived experiences of autistic adults regarding perceived barriers to adult diagnosis,[66] it is vital to explore pathways to improved access to autism diagnosis across the lifespan and subsequent access to mental health interventions and services to promote health and well-being of autistic individuals.

Equitable Access to Health Coverage

Many autistic individuals may rely on a combination of Medicaid, Children's Health Insurance Program (CHIP), and other public insurance programs for needed health care coverage. Drexel University’s 2023 National Autism Indicators Report on Medicaid and Autism highlights Medicaid’s critical role as a safety net, particularly for autistic individuals with co-occurring conditions, emphasizing the need for comprehensive coverage.[67] However, one in four autistic youth lose their Medicaid coverage as they transition into adulthood, with only half regaining coverage.[68] Additionally, privately insured families are more likely to report inadequate coverage for needed care compared to those with public insurance.[69] The variability of state mandates and coverage underscores the need for continued work towards providing consistent, comprehensive autism services across insurance types. There are also gaps in the literature regarding how co-occurring conditions, apart from intellectual disability, affect the employment opportunities of autistic individuals, as well as whether subsequent underemployment or unemployment creates barriers to accessing healthcare services due to insufficient or absent employer-based health insurance coverage. Further, the parents of children with intellectual disability and autism relying on public health insurance, such as Medicaid and CHIP, are significantly more likely to experience workforce absence and unemployment compared to those with private insurance, with uninsured parents facing even higher unemployment rates.[70] Further research is needed to explore the impacts of housing stability and financial security on the overall well-being of autistic individuals and their families, as these factors play a crucial role in ensuring equitable access to health care and support services.

Future Directions

Integrated and Personalized Care Models

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.[71] Among their recommendations, the authors suggested early interventions for co-occurring conditions, highlighting the importance of timely action in the absence of more comprehensive assessments. Development of patient-centered, integrated health care models are needed, with an emphasis on efficient coordination of services and effective communication between providers and the families they serve. Improving the coordination of services can lead to the reduction the barriers for accessibility of services across many autistic populations, including traditionally underserved populations.

In addition to integrated care models, allied health fields such as occupational therapy (OT) play a crucial role in enhancing the quality of life for autistic individuals through targeted, evidence-based interventions. The American Occupational Therapy Association (AOTA) released an evidence-based practices guidelines framework in 2024 that describes how OT interventions can help support health and well-being among autistic people. The 2024 Occupational Therapy Practice Guidelines emphasize multidisciplinary approaches that promote meaningful participation, neurodiversity-affirming practices, and the need for greater support in daily living activities, particularly for autistic youth.[72]

Telehealth and Technological Innovations

Technical advances and uptake of telehealth in the last decade have facilitated access to health care services for many individuals in the autism community.[73] Leveraging this innovation could also serve to alleviate some access issues, especially for individuals in rural areas as well as in communities with limited access to specialized providers that may be needed for the care and management of co-occurring conditions.

A systematic review of pre-pandemic remote service utilization found that telehealth has the potential to increase treatment availability, decrease diagnosis waiting times, and aid in neurodevelopmental disability monitoring.[74] During the pandemic, caregivers of individuals with DD reported that telemedicine and tele-education were helpful when available and endorsed a need for an augmentation of these remote delivery services.[75] Consensus among health care providers and community experts have resulted in best practice guidelines for telehealth care tailored to adults with developmental disabilities, focusing on improving care quality, communication, support collaboration, equitable access, and safety.[76]

Innovations in health care delivery models should be coupled with increased specialized training for health care providers who interact with a wide variety of autistic populations. For example, programs such as the ECHO Autism LINKS program, which combines pediatric primary care provider training with family navigation, showed promising feasibility and preliminary efficacy in improving providers' ability to develop expertise in new content areas and work independently, as well as provide high quality family support to underserved communities.[77] Virtual provider training networks like this one will ensure that the future health care workforce is adequately equipped to provide competent, personalized, and accessible care for autistic individuals with co-occurring conditions.

Patient-Provider Interactions

Overview

The patient-provider interaction plays a central role in health care provision for autistic individuals with co-occurring conditions, shaping the overall quality of care and serving to facilitate optimal health outcomes. Establishment of positive interactions between autistic patients and the health care providers who serve them involves effective communication and trust building to understand the unique needs and concerns expressed by the individual.

Communication Practices

Research suggests autistic individuals may find inter-personal communication with health care providers particularly challenging, as socio-communicative differences are characteristic of autism itself.[78] Additionally, systematic reviews in the field of health care provider interactions suggest that health care providers often do not engage in effective communication with autistic patients to communicate using communication styles preferred by autistic people. One such study found that over half of their autistic adult study respondents indicated difficulties in communicating (e.g., not feeling understood, communicating when anxious, producing speech) with their doctor.[79] Those same autistic adults indicated a preference for online or written communication in advance of appointments. Additionally, differences in non-verbal communication can contribute to miscommunications during health care provider treatment or examinations where provider questions or prompts may be misinterpreted by autistic patients.[80] Parents of autistic children report that providers may often minimize their concerns about their child's co-occurring conditions or dismiss them altogether as another trait of their child's autism.[81] Continued research on patient experiences can further enrich the field in the optimal provision of health care for autistic individuals. Knowledge gaps remain in terms of the experiences and preferences across the different provider disciplines. The combination of both additional provider- and patient-focused research can further strengthen the patient-provider relationship across the numerous co-occurring conditions that affect individuals with autism.

Given the need for additional autism-specific provider trainings intended to increase provider knowledge in autism mentioned in the preceding section of this chapter, additional communication factors that can improve patient-provider interactions include the use of accessible language and accommodations, as well as skill in incorporating caregiver/support perspectives into care.[82] Further, shifting towards strengths-based perspectives in discussing autism and co-occurring conditions can have positive effects towards the meaningful considerations of autistic perspectives in medical care.[83, 84] The combination of this positive communication, personalized care, and ensuring that patients feel heard serve as necessary precursors for the development of strong, positive patient–provider relationships.[85] Through positive communication practices, the involvement of patients and their families as active decision-makers in their medical planning can serve to empower autistic patients to advocate for their needs and preferences, ultimately enhancing long-term health outcomes.

Accommodating Sensory and Processing Needs

Perspectives from those with lived experiences have highlighted the need for structural changes to health care systems to facilitate access to health care services for autistic patient and their caregivers. Autistic patients may often prefer additional time to process information and instructions, respond to questions, or process sensory stimuli.[82] In order to facilitate optimal patient-provider interactions, it is essential for health care providers to recognize and accommodate these differences and ensure additional supports are provided to autistic patients based on their individual needs. A review of studies in this field identified the need for experimental or quasi-experimental methodologies to examine how the adoption of structural changes to health care systems affect patient experiences and quality health outcomes compared with a comparison group.[86]

Researchers have emphasized the inclusion of diversion stimuli (e.g., sensory toys for children in waiting rooms) and adjustments to meet logistical and sensory concerns for inpatient settings.[87] These can include changes to health care facilities (e.g., adding sensory/quiet locations), appointment scheduling processes (e.g., flexibility in clinic appointment timing), and insurance coverage policies.[88, 89] Further exploration of the provision of care across diverse populations is discussed in the subsequent section on disparities in care provision. Embedding aspects of cultural competency, culturally responsiveness, and cultural humility into the practices of specialists who deal with co-occurring conditions in autism can enhance provider knowledge, confidence, and self-efficacy in working with diverse patients with an array of sensory and processing needs.[90]

Provider Training Needs

From the provider perspective, health care providers have often indicated the complexity of interacting with autistic patients and parents, citing lack of their knowledge of autism as a hindrance in establishing positive interactions.[91] Encouragingly, a few health care provider disciplines have developed recommendations to promote positive interactions with autistic individuals. For example, dental professionals have emphasized the need for basic training about special care dentistry and autism at an undergraduate level, as well as highlighting the benefits of working collaboratively with autistic patients and their caregivers to gain valuable insights, in developing the treatment plans to address a patients' dental issues.[92] Gastroenterologists have also stressed the need to understand how GI distress can present differently in autistic populations, as well as the need for comprehensive nutritional evaluations due to the high incidence of food aversions and/or the use of exclusionary diets.[93]

Across the literature, a noticeable knowledge gap includes the lack of clinical guidelines for the wide range of specialists that an individual with autism and co-occurring conditions may encounter across their lifespan. As noted in previous chapters in this *Strategic Plan Update*, there are a wide variety of specialized health care professionals that autistic patients may encounter, including neurologists, psychologists, geneticists, speech-language pathologists, among others. Additional research on these providers and their experiences with autistic patients could serve to further develop policies and procedures towards enabling positive patient-provider interactions. The perspectives of certain specialized providers, such as mental health professionals, can potentially be extrapolated to universal therapeutic practices across specializations.[94]

There is a dearth in research focused health care delivery for autistic individuals with ID.[95] Given the common co-occurrence and prevalence of ID in autistic children,[96] this knowledge gap represents an area of opportunity for additional research in the future. Further, similar to the needs of provider training centered on autism, research suggests that additional training is needed for health care professionals around autism and ID, as well.[97] The lack of research including this population may serve as a hindrance towards the development of patient-centered care and interventions addressing the complex co-occurring conditions outlined in this *Strategic Plan Update*.

Trauma-Informed Care

The integration of trauma-informed principles into patient-provider interactions has emerged as a novel model in the delivery of compassionate, patient-centered health care,[98] including for individuals with disabilities. For example, in populations with ID, researchers have suggested the role of psychological trauma in the development of dental anxiety and poor oral health, and the use of trauma-informed care can ameliorate dental health care experiences for this population.[99]

Although the literature is quite limited with regard to research on specific co-occurring conditions and the effects of previous trauma for autistic individuals, increased awareness has been given to the intersection of autism and post-traumatic stress disorder (PTSD) in the delivery of effective care practices.[100] Most research to date has focused on adverse events in childhood and prevalence rates of post-traumatic stress related to accidents, disasters, violence, and/or abuse.[101] However, research has also explored, to a more limited extent, how the accumulation of lower-level stressful life events (such as moving, change in environment, or bereavement) can also contribute to PTSD in autistic people.[102, 103] Future research can help to understand the principles of trauma-informed care and the importance of this practice in the comprehensive and responsive care for all autistic patients.

Future Directions

Progression in the optimization of patient-provider interactions will necessitate the empowerment of autistic patients and their caregivers towards advocating for their specific needs, gaining broader health knowledge, and increasing service utilization. The use of patient/family empowerment strategies have been examined on a limited basis.[104-106] For example, the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit is an online set of tools for autistic adults, supporters, and healthcare providers. The centerpiece of the Toolkit is the Autism Healthcare Accommodations Tool, which allows autistic adults to create a personalized accommodations report to give to their healthcare provider. Preliminary testing of the Toolkit has found it to reduce barriers to healthcare for autistic adults and improve patient-provider communication.[107] Future research can expand on these strategies to respond to the unique needs of autistic patients with co-occurring conditions. As research continues in the field of provider trainings on autism knowledge, knowledge-sharing of best-practices will serve to enrich the field to provide responsive care that respects the needs and preferences of their patients' diverse backgrounds and experiences.

Considerations for Individuals with Complex and High Support Needs

Overview

There has been growing discussion within the community of potential ways to better meet the needs of individuals with complex and high support needs (e.g., autistic individuals with co-occurring intellectual and/or communication disability, requiring intensive or 24 hour supports, or with multiple co-occurring physical or mental health conditions) and their caregivers. In general, individuals with these higher support needs and their caregivers are underrepresented in autism research,[108] as well as in health care models.[109] There exist significant disparities in the health care utilization and higher unmet needs expressed in individuals with communication disabilities compared to individuals without communication disabilities.[110]

Diagnostic Overshadowing

Diagnostic overshadowing refers to the potential for health care providers to attribute behaviors to a known condition, such as autism, while overlooking other co-occurring physical or mental health conditions.[111] Ongoing research has contributed growing awareness of potential diagnostic overshadowing and how it can contribute to difficulties in ASD diagnosis in populations with complex medical conditions.[112] It can lead to missed diagnoses of co-occurring conditions due to the assumption that all signs and behaviors are related to the primary diagnosis of autism, rather than exploring the possibility of additional health issues. The co-occurrence of physical and mental health conditions along with autism may complicate the differential diagnosis process, as these conditions can often overlap in their clinical presentations.[113] Enhanced provider training in recognizing co-occurring conditions and understanding the nuances between manifestations of conditions can improve diagnostic accuracy and reduce the likelihood of overshadowing. Further, autistic individuals with genetic syndromes, multiple chronic conditions, or additional disabilities may need access to multiple specialized health providers, access to multiple service systems (i.e., developmental disability and mental health) and need more supportive services.[114]

Communication Supports

Qualitative research among autistic individuals with significant communication disabilities also highlight the need for personalized communication strategies and accommodations during health care visits to facilitate effective communication, including coordination between patients and providers on preferred communication style prior to visits.[115-117] Further, a research case study found that adolescents who have co-occurring communication difficulties were able to avoid communication breakdowns when paired with health care professionals who understood their differences and tailored their interaction style to meet the needs of their patients.[118]

Many autistic individuals may utilize AAC approaches, including low- or high-tech devices and other communication supports. The benefits of AAC use to meet the needs of diverse communications needs for autistic individuals across the spectrum has gained prominence through the lived experiences of AAC users.[119] As health care provision shifts towards the inclusion of telehealth and remote consultation models, AAC users should factor into provider considerations around accommodations to meet the communication needs of their patients. For example, qualitative research suggests that although telehealth models have proven to increase accessibility of services, there are also challenges regarding information transfer over the telephone or videoconferencing, particularly for AAC users who may be non-speaking.[120] Research recommendations have also suggested the importance of incorporating AAC users into the design, development, and testing of telehealth applications[121] to strengthen health care provision for autistic individuals who utilize these communication supports.

Addressing Health Disparities

Delivering high-quality, responsive health care to people on the autism spectrum with co-occurring ID necessitates an understanding of their unique needs and barriers to care. Research suggests that autistic youth with co-occurring ID may be more likely to experience unmet mental health care needs and receive poorer quality of care than others in the broader autism population.[122, 123] Prevalence estimates conducted from the CDC's ADDM Network suggest that around one-third of children diagnosed with ASD had co-occurring ID, with disparities across racial/ethnic groups.[96, 124] Although the literature on health care insurance in this population is limited, a study found that a dual diagnosis of ID and autism may help maintain continuous insurance coverage during the transition period from adolescence to adulthood.[125]

Satisfaction with Health Care Systems and Services

Qualitative feedback on the health care experiences of autistic patients with co-occurring conditions have noted similar themes around the areas of lower satisfaction, decreased perceived quality of care, and poor patient-provider communication as a barrier to access to quality care.[126] These issues are particularly pronounced for those with ID, where the challenges in diagnosing co-occurring conditions can be exacerbated by communication difficulties and behavioral issues that complicate medical interactions.[87] For instance, non-speaking individuals may struggle to convey symptoms or discomfort effectively, which can lead to misdiagnoses or overlooked co-occurring conditions. Moreover, behavioral issues such as anxiety or agitation during medical visits can further hinder accurate assessments and effective communication between patients and providers.

Similarly, qualitative feedback from caregivers of children with co-occurring ID indicate that health services typically do not meet their child's needs and that the constant battle to obtain appropriate health services can lead to a sense of hopelessness around the possibility of having positive health experiences.[127] As such, these perspectives of families and caregivers are also critical in developing relevant and effective health care-related supports and services to optimize health and well-being across the lifespan for autistic individuals with high support needs. Further, strengthening the health care system can improve the experiences of families who may often experience inefficiency while navigating and bouncing between various systems such as disability services and mental health care. Enhanced coordination and integration across these systems could alleviate some of the systemic challenges faced by these families.

Caregiver Long-Term Planning

As individuals with autism and co-occurring high-support needs age, families may face significant uncertainty in planning for care after parents can no longer provide it.[128] The number of adults with autism living with their aging caregivers continues to increase, highlighting a growing concern about the future provision of care.[129] Further research is needed to identify and understand the full range of health and social support services required by older autistic adults, particularly in areas such as continued support related to autistic traits, co-occurring mental health difficulties, physical health challenges, communication, social connection, and daily living skills.[130, 131] This is especially critical in the absence of family caregivers or adequate long-term planning. The current gaps in research emphasize the importance of developing robust long-term support systems to ensure continuity of care and quality of life for autistic individuals as they age,[132] particularly when familial support is no longer available.

Knowledge Gaps and Barriers to Research Progress

Research on populations with high-support needs have centered on qualitative feedback on service and support use. Additional longitudinal studies detailing the general health trajectories of this group would serve to inform policies and practices around the care provision to address other co-occurring conditions outlined in previous chapters of this *Strategic Plan Update*.[133, 134]

Meaningful Inclusion in Research

Further research, including longitudinal studies, on the barriers to health care provision across the life course (e.g., adolescence, transition into adulthood, aging populations, etc.) can serve to fill the existing knowledge gaps around this population. Given the need to include people with high support needs and their caregivers as meaningful participants in the research process, methodological considerations in the research process are needed to effectively support this population and ensure ethical considerations are suitably addressed. As these groups have been often excluded for research on autism, inclusive research designs and approaches are necessary to ensure generalizability of health outcome findings in autism research, especially to medically vulnerable populations such as those with high-support needs.[135] For example, processes such as supported decision-making have been explored for the ethical inclusion of people with disabilities in clinical research.[136]

Unmet Needs and Provider Perspectives in High-Support Autism Care

As mentioned previously, although qualitative studies have highlighted barriers to quality care, and a few population-based studies have provided data on the prevalence of co-occurring conditions and characteristics of this population, there remains limited understanding of the complex needs faced by high-support populations and their caregivers. For example, a CDC study using population-based surveillance data from the ADDM Network estimated the percentage of autistic children with co-occurring high-support needs (i.e., defining this criteria as either nonverbal or minimally verbal or had an IQ less than 50) and described their sociodemographic and clinical characteristics, finding a higher likelihood of seizure disorders, among other findings.[137] Due to the wide spectrum of need and the heterogeneity among this population alone, providers may lack understanding about how best to address the needs of high-support autistic individuals and their caregivers. Although universal principles around the provision of family- and person-centered care still apply to this population, there is limited research on provider experiences interacting with higher-support families, particularly in specialized medical fields that are pertinent to the range of co-occurring conditions autistic patients may encounter.

Future Directions

Given the prevalence of co-occurring ID among autistic individuals, specific diagnostic tools or interventions for other co-occurring conditions could be developed to assist in the provision of competent health care at an early stage. Recognizing that co-occurring health conditions may present differently or need modified approaches for diagnosis in populations with high support needs is a critical in terms of provider knowledge and ability to deliver high-quality, person-centered care. Recognizing the communication differences that arise and providing the flexibility needed to allow communication best-practices to be deployed in health care settings remains the goal for quality health care provision to this population with complex health care needs.

The development and dissemination of evidence-based practices will serve to optimize health outcomes in the long-term, ensuring that the health care workforce is prepared to deliver the comprehensive and high-quality health care that is needed by all people on the autism spectrum, including individuals with high support needs. Further, research in the field of genetics, environmental interactions, and etiology of co-occurring conditions can also serve to inform future interventions and supports that are responsive to the needs of this population. Coupled with enhanced provider trainings outlined in previous sections, the health care system can be strengthened to better meet the needs of autistic individuals with high-support needs.

Promoting Equity and Reducing Disparities

Overview

Underrepresented and underserved populations within the autism community may include various groups identified by demographic factors (e.g., sex/gender presentation & orientation, race, ethnicity, age, language preference, socioeconomic status, geography, etc.). Across the lifespan, common barriers to quality health care experienced by individuals with autism overall include scarcity of resources/health care in diverse languages, shortage and high-cost of autism-related health care services, and limited awareness or knowledge of best health care pathways for autism and co-occurring conditions.[28]

While studies on underrepresented populations have highlighted disparities in autism diagnosis and access to care, there is a lack of studies that focus on the unique needs of those with intersectional identities (i.e., identities that can contribute to some level of social disadvantage and, when combined, intensify those disadvantages). For example, autistic adults, particularly those from racial and ethnic minority groups, experience higher rates of medical and psychiatric conditions compared to their non-autistic peers, with disparities such as lower mental health diagnoses and higher obesity rates among Black and Hispanic autistic individuals, highlighting the need for further research on intersectional health disparities.[138] Understanding how the social determinants of health intersect with health care experiences for those with medically complex conditions is essential to tailoring interventions to the needs of the population and providing support services effectively. Further, while population-based prevalence studies have shed light on disparities in certain co-occurring conditions along racial and ethnic groups, further disaggregation of racial and ethnic data may assist in identifying in-group differences and disparities, allowing for enhanced tailored services to populations most at need. Consideration should also be given to qualitative research and mixed methods approaches that may further highlight disparities not yet captured in quantitative studies.

Racial, Ethnic, Gender, and Socio-Economic Disparities

Racial, ethnic, and geographic disparities in autism are well-established, with many disparities present in areas related to service provision and accessibility.[139, 140] Medicaid data suggest that co-occurring health conditions among autistic adults, which occur more often than in non-autistic peers, differ based on race and ethnicity.[141] Similarly, presentation of certain co-occurring conditions, such as mental health conditions, may present differently for women and girls, highlighting the need for improved diagnostic practices to address gender-related disparities.[142] Research has found that Black and minoritized families with autism are not as quickly enrolled in services in the first years of life following a diagnosis,[143, 144] and non-white children in general are diagnosed, referred, and screened later than their white peers, resulting in delayed onset of treatment.[145] Families from minoritized racial and ethnic groups are also under-represented in evidence-based treatments and services in autism.[144, 146, 147]

Autistic individuals who identify as sexual and/or gender minorities may also face higher levels of stress, mental health conditions, and reduced quality of life compared to their peers, with sexual minority autistic adults reporting significantly poorer mental health and lower quality of life than their heterosexual counterparts, underscoring the need for mental healthcare providers to address these intersecting identities and associated social stressors.[148, 149] Further, individuals on the autism spectrum who identify as LGBTQIA+ may experience higher unmet health care needs and compounded health disparities, exacerbated by inadequate health insurance coverage and provider networks.[150, 151]

Family- and neighborhood-level socioeconomic status (SES), as well as racial and ethnic minority status, are strongly related to disparities in access to quality autism care.[152] Families living in low-SES neighborhoods and rural areas are more likely to be located in a service "desert," areas of low service availability and fewer providers.[153] A study on primary care provider access in underserved autistic populations found that parents accessing safety-net clinics feel uncertain about their knowledge of autism and screening practices, potentially leading to missed opportunities for crucial screening and subsequent access to services, highlighting the socioeconomic barriers to health care access.[154] Given the care coordination required for co-occurring conditions, research on improving health literacy and addressing caregiver supports through family navigation services can assist in the reduction of disparities.

Social Determinants of Health

Addressing the causes of 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, educational attainment, geographic proximity to providers/specialists, crime and victimization, etc.) on the lifelong health outcomes of autistic individuals. Collecting this data on measures of social determinants of health among autistic populations with co-occurring conditions and incorporating it into interpretations of prevalence figures of conditions can serve to facilitate the development of effective public health equity initiatives aimed at addressing these disparities.[155]

Geographic Disparities in Health Care Provision

Reducing geographic disparities in the health care provision for individuals with autism and co-occurring conditions is a complex challenge. Research has shown that despite consistent referrals to supportive services, families of individuals with autism in rural and underserved areas received less than half of the recommended services due to long waitlists and limited availability, highlighting the pressing need for improved access to developmental and behavioral services and ongoing efforts to address barriers such as travel, waitlists, and scheduling challenges.[156] Studies have also suggested uneven distribution of specialized health care resources, with rural and remote areas often facing shortages of qualified professionals and limited access to specialized services.[157]

Addressing these challenges requires research efforts that delve into the geographical disparities in access to care, explore telehealth solutions, and develop strategies to enhance health care infrastructure and service delivery in rural communities. For example, research efforts have emphasized the importance of addressing these disparities through various strategies, including incentivizing health care professionals to practice in underserved regions,[158] implementing telehealth programs to facilitate remote consultations and interventions,[159] and enhancing community-based resources and supports.[160] However, despite these efforts, significant gaps persist in access to care across different geographical regions, underscoring the ongoing need for targeted interventions and programmatic initiatives to promote equitable health care provision for rural individuals with autism and co-occurring conditions.

Cultural and Linguistic Sensitivity

Research underscores the significance of culturally sensitive and linguistically appropriate care in addressing the diverse health care needs of the autistic community effectively.[161] Challenges during health care provision, such as miscommunication and unfamiliarity with cultural norms, can serve to hinder adequate care for culturally and linguistically diverse (CLD) autistic individuals.[162] Studies emphasize the importance of health care providers possessing the necessary knowledge and skills to navigate cultural nuances and communicate effectively with individuals and families from varied cultural backgrounds.[163-165] There is a need to increase cultural competency among service providers[166] and consider diverse experiences, preferences, and values in the design and provision of autism services for families and their children.[164]

Caregivers from CLD populations often state the need for greater involvement in their child's medical interventions, highlighting the importance of open communication, frequent quality interactions, and bilingual capabilities in care settings.[90] A study of a Latino families in Northern California indicated higher health care utilization among government-insured participants, significant language and health literacy barriers for Spanish-speaking caregivers, and digital literacy challenges, suggesting the need for culturally tailored, multilingual, and accessible resources to improve autism care equity.[167] This finding on the underutilization of services and disparities in health access reflect previous findings suggesting that private health insurance plans may be inadequately covering needed health services, including services for co-occurring conditions.[168] Similarly, parent training programs for autism have been effective in empowering and engaging parents of Black children, but culturally adapted interventions are crucial for addressing disparities in service access and diagnosis among Black autistic children, with ongoing needs for trust-building and increased representation in the provider community.[166]

Participatory Research Approaches

Additional research is needed to examine the experiences of caregivers and families of autistic individuals with co-occurring conditions, particularly in underrepresented communities. Understanding the unique challenges faced by caregivers, such as caregiver burden, mental health concerns, and access to support services, is vital for developing holistic and family-centered interventions. Doing so, however, will require concerted efforts to prioritize the voices and experiences of underrepresented communities in research agendas, foster interdisciplinary collaborations, and employ participatory research methodologies that center the needs and priorities of autistic individuals from diverse backgrounds. In addition to acting as research participants, the diverse perspectives from members of the autism community can serve to inform research priorities moving forward, to ensure that the research aligns with the needs and desires of those with lived experience.

Future Directions

In September 2023, the National Institute on Minority Health and Health Disparities (NIMHD) designated people with disabilities as a population with health disparities for research supported by the National Institutes of Health. This health disparity designation helps to encourage research specific to the health issues and unmet health needs of this population. Additionally, NIH issued a notice of funding opportunity focused on new and innovative approaches and interventions aimed at the intersection of disability, race and ethnicity, and socioeconomic status on health care access and health outcomes. This serves to complement other initiatives undertaken by the federal government aimed at improving equity for people with disabilities, including those on the autism spectrum. 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. Further, addressing the disparities among these underrepresented groups will not only serve to improve their health outcomes but will also provide best-practices that are applicable to all populations in the autism community with co-occurring conditions.

Impact of COVID-19

Overview

The *2021-2023 IACC Strategic Plan* included a comprehensive chapter on “COVID-19 and the Autism Community,” including the impact of the pandemic on the physical and mental health of the autistic community. The pandemic may have served to exacerbated existing shortages of health care providers and other direct care workers who interact with autistic individuals and provide health services. Further, research suggests that the presence of co-occurring conditions in autism may increase the risk of worse health outcomes related to COVID-19 (coronavirus disease 2019) infection,[169-172] particularly for those living in congregate settings.[173] Research also suggests potential exacerbation of neuropsychiatric traits among those with co-occurring conditions due to the lasting effects of long COVID.[174]

While existing studies have offer valuable qualitative insight into broader health care disparities and disruptions following the initial stages of the pandemic, there remains limited research into the experiences, outcomes, and health care utilization patterns of this population in the years following initial lockdown measures, particularly among the wide range of co-occurring conditions outlined in this *Strategic Plan Update*. Additionally, methodological limitations and challenges in data collection and analysis further complicate efforts to assess the impact of COVID-19 on health care provision for individuals with autism, as many studies may rely on retrospective or cross-sectional data, which might not capture the full dynamic nature of the pandemic's effects over time.[175] While qualitative research has provided insight into caregiver stress and burnout following initial pandemic-related shutdowns and service disruptions,[176] additional research on targeted interventions to support and enhance caregiver well-being are also needed.

Disruption of Services

Societal and public health pandemic mitigation strategies, such as stay-at-home orders and masking requirements, may have increased strain on family caregivers, such as increased demands on caregiver mental health,[176] and disrupted routines for health care provision. Although all children faced missed or delayed services regardless of developmental diagnosis, one study found that during the initial phase of the pandemic, more autistic children faced delayed specialty services than children in the general population, reporting difficulty obtaining care due to challenges with telehealth and difficulty wearing masks.[177] Additionally, provider turnover or shortages, mandated community resource and nonessential service closures, and social distancing requirements further added to this reduction in access to specialized services needed to adequately address co-occurring conditions among autistic individuals.[178]

The provision of behavioral health services, outpatient psychiatry visits, and access to specialized psychiatric facilities, was also significantly disrupted during the COVID-19 pandemic. Many services transitioned to telehealth modalities, posing challenges such as limited observation capabilities and reduced monitoring of vital signs, exacerbating concerns about medication management, medication shortages, increased risk of mental health crises, and difficulty accessing specialized psychiatric facilities due to infection control measures and staffing shortages.[179] The rapid evolution of the pandemic and the continually shifting health care landscape experienced during the early phase of the pandemic pose logistical challenges to conducting rigorous research on this topic. Delays in data collection, disruptions in research protocols, and changes in health care delivery models necessitated flexibility and adaptability in study design and implementation. However, as researchers adapted to the challenges presented by the pandemic, research efforts continued with the goal of assessing the long-term impact of COVID-19 on health care provision for individuals with autism and co-occurring conditions.

Telehealth Adaptations and Challenges

The COVID-19 pandemic prompted rapid adaptation of health care services with the widespread adoption of telehealth presenting both opportunities and challenges, particularly in the diagnosis and treatment of co-occurring conditions among autistic individuals. Previous research has suggested telehealth for providing direct therapy for autism demonstrated efficaciousness in teaching new skills, with positive feedback from caregivers and clinicians, though further research is needed to confirm these results and address challenges in underserved areas.[180, 181] Telehealth evaluations for autism diagnoses in young children also showed high satisfaction rates among providers and caregivers, indicating their potential to increase access and reduce wait times.[182] Further, case studies from the perspective of providers and their experiences with telehealth indicate the added benefit of these technologies in allowing for rapid interdisciplinary approaches to care provision, due in part to the ability to rapidly connect to multiple providers across a range of specialties needed to care for a child with complex co-occurring conditions.[183, 184] However, it must be noted that qualitative research from the perspectives of caregivers also suggest that while some caregivers of children with autism and co-occurring mental and behavioral conditions may prefer online consultations with providers, some parents of autistic children with co-occurring physical conditions indicate a preference towards direct, in-person consultations, highlighting divergent, individual-level preferences in health care delivery based on the nature of the co-occurring condition.[185]

In the context of lessons learned from the pandemic, clinicians navigating telehealth approaches to autism and co-occurring condition diagnostic services can weigh the advantages, including increased accessibility and potential for observation in multiple contexts, against the challenges, such as difficulties in engaging individuals with higher support needs, technological limitations, and the need for validation of telehealth diagnostic methods.[186] While telehealth offers promise for addressing barriers to access and efficiency in diagnostic evaluations, its implementation necessitates ongoing refinement and consideration of long-term sustainability, underscoring the importance of continued innovation and adaptation in health care practices beyond the pandemic era. Further, the uptake of telehealth practices for health care delivery has also raised concerns over technological reliability and accessibility barriers for socioeconomically underserved populations, highlighting the need for ongoing research and innovation to optimize telehealth delivery for individuals with autism. Comparative studies assessing the long-term health outcomes of virtual versus in-person health care services can inform evidence-based practices and guide the development of innovative health care delivery models tailored to the needs of autistic patients with co-occurring conditions.

Disparities in Health Care Access and Equity Challenges

In addition to considerations on the benefits and challenges associated with novel telehealth delivery models, noted disparities in access to health care resources and services among individuals with autism from underserved communities, including racial and ethnic minorities, low-income families, and rural populations continue to exist.[187] These communities may often face barriers such as limited access to health care facilities, transportation challenges, and other societal barriers, exacerbating existing inequities in health care provision.[188] The pandemic may have also served to magnify these challenges, underscoring the urgent need to address systemic inequalities in health care access and delivery. Addressing these COVID-related health inequities and promoting equity in health care provision for individuals with autism and co-occurring conditions following the pandemic era requires a multifaceted approach that acknowledges the intersectionality of social determinants of health, systemic barriers, and individual needs. A crucial component of this approach is ensuring equitable representation in clinical trials and research studies, which is vital for developing interventions that are both inclusive and effective across diverse populations.[189]

Future Directions

The COVID-19 pandemic provided an opportunity to learn about what kinds of health care 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 health care services and supports for optimal health and well-being. While the acute phase of the pandemic may have passed, stakeholders from medically complex populations with disabilities, such as autistic individuals with co-occurring conditions, have stated the need to promulgate measures undertaken during the pandemic that would serve to protect vulnerable populations, such as telehealth flexibility.[190] Future directions can prioritize the integration of telehealth services and remote service options into routine health care delivery models, ensuring continued access to care for individuals with autism and co-occurring conditions. Moreover, efforts should focus on enhancing the competence and accessibility of these novel health care services to meet the diverse needs of the autism community, including populations with higher support needs. As emphasized in previous sections, community-based and family/patient-centered approaches to health care provision are important, as they emphasize the coordination of medical, behavioral, and social services to support the comprehensive health and well-being of individuals with autism and co-occurring conditions. Collaboration among health care providers, policymakers, and community members will be essential in shaping the future of health care provision for this population utilizing the lessons learned through the COVID-19 pandemic, with an emphasis on equity and inclusion.

Federal Agency Activities & Initiatives

Federal agencies, as well as private funders, are conducting activities and funding research to improve health care service provision for autistic people with co-occurring conditions. Activities include a webinar held by the National Institute of Mental Health (NIMH) focused on health care transition, a part of an overarching webinar series focused on transition aged youth. Further, the Administration for Community Living (ACL) has projects focused on empowering youth with intellectual and developmental disabilities to manage their healthcare transitions, and projects supporting the direct health care workforce. Several Centers for Disease Control and Prevention (CDC) Several Centers for Disease Control and Prevention (CDC) funded research initiatives have focused on areas related to health care provision, such as increasing the inclusion of people with disabilities, including those with autism, in public health data to better evaluate health disparities, target disease prevention and health promotion activities, and enhance the use of administrative and survey data for identifying people with disabilities through increased collaborations and funding of national programs and state initiatives focused on improving health outcomes and access to care (National Programs on Health Promotion for People with Disabilities; State Disability and Health Programs). The Health Resources and Services Administration (HRSA) is also funding research projects, such as the Autism Transitions Research Project (ATRP), to explore health care transitions for autistic individuals.

The HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) continues work on the Integrated Dataset on Intellectual and Developmental Disabilities, which links sociodemographic information with health care service data to analyze outcomes for individuals with intellectual and developmental disabilities, including autism. Additionally, the Department of Justice (DOJ) is involved in activities related to crisis response and access to medical diagnostic equipment for people with disabilities, such as the Justice and Mental Health Collaboration Program (JMHCP). The Department of Health and Human Services (HHS) introduced the HHS Roadmap for Behavioral Health Integration, aiming to integrate behavioral health care into broader health and social services systems. Additionally, ACL launched The Link Center, a resource hub for people with intellectual and/or developmental disabilities, including those with mental health conditions. The Administration for Children and Families (ACF) also launched a webpage to engage parents with disabilities and learning differences.

Efforts to ensure health care accessibility include manuscripts by the Agency for Healthcare Research and Quality (AHRQ) on health insurance coverage among families and children with autism (PMID: 33113106; PMID: 33076792). The Centers for Medicare & Medicaid Services (CMS) has enacted final rules to ensure access to Medicaid services and continuous coverage for children under Medicaid and the Children's Health Insurance Program (CHIP). To enhance patient-provider interactions, HRSA supports the LEND and DBP programs, as well as DBPNet. The Substance Abuse and Mental Health Services

Administration (SAMHSA) supports initiatives like the National Child Traumatic Stress Network, focusing on resilience and tailored trauma-focused cognitive behavioral therapy (CBT) for children with disabilities, and the Technology Transfer Centers (TTC) Program, focused on strengthening the specialized healthcare workforce. Educational efforts include the Department of Education's initiatives to bolster mental health services in schools.

Efforts to reduce disparities include CDC research on developmental monitoring for low-income children (PMID: 34988863), HRSA research investments, including AIR-B and Autism FIRST, focused on underserved populations, and an NIH Autism Centers of Excellence focused on advancing equitable strategies across the life course, awarded to Drexel University. Further, NIH recently designated people with disabilities as a population with health disparities, paving the way towards additional research in this population. The impact of COVID-19 on autistic individuals is also a significant area of federal focus. The IACC Coronavirus Resources page, AHRQ's Stakeholder-Partnered Implementation Research and Innovation Translation (SPIRIT) Program, and CDC's Act Early Response to COVID-19 initiative all address the unique challenges faced by this population during the pandemic. ASPE's reports on COVID-19 data collection and infrastructure improvements for patient-centered outcomes research further inform policies to mitigate adverse effects. The Department of Education has also previously funded research to accelerate pandemic recovery in special education.

Summary

The provision of high-quality, person-centered health care to autistic people is a critical step towards ensuring positive long-term health outcomes for this population. The medical complexity presented by co-occurring condition may necessitate the coordination of health care providers across different specialty fields. Further, ensuring that these providers are properly trained, feel knowledgeable to interact with autistic patients from all diverse backgrounds and abilities, and are widely accessible to the community remains the goal for health care system optimization. Innovations in design of health care settings and processes can help improve the healthcare user experience for autistic people. The proliferation and use of technology platforms following the COVID-19 pandemic can also serve to further bolster options for preferred health care delivery models for this medically complex community. Finally, ensuring that the perspectives of people with lived experience are centered in the research and health services priorities moving forward will ensure that future innovation in health care provision research reflect the needs and desires of this community.

Conclusion

Since the IACC issued its first Strategic Plan in 2009, which highlighted the need to understand the biological mechanisms of autism and its co-occurring conditions, much progress has been made in describing and understanding the range of health conditions that co-occur in individuals on the autism spectrum. Unanswered questions and unmet service needs, however, continue to drive the need for deeper understanding of these conditions and greater availability and quality of services and supports to meet the needs of autistic individuals navigating life with co-occurring health needs.

The discussions of the IACC in the last 5 years, including the Working Group on Improving Health Outcomes, have emphasized a number of key themes. Importantly, the Committee has reiterated the need for more research to understand the full scope of co-occurring conditions in autistic individuals, including their prevalence, symptoms and features, trajectory, and underlying biological mechanisms in relation to the core symptoms of autism. Further research is needed to understand the safety and effectiveness of treatments and interventions for use in autistic people. Studies must aim to understand the needs of transition-age autistic youth, adults of all life stages, girls and women, underserved racial and ethnic populations, and individuals with high support needs, which are often under-represented in autism research. Additionally, studies to improve research and services must incorporate the perspectives of autistic individuals and their families. By including their voices in the process, the results will be more impactful, accessible, and responsive to the specific needs of autistic individuals and their families.

It is also clear that information on the frequency and features of co-occurring conditions in autism needs to be more effectively disseminated to health care practitioners and other service providers. Practitioners may require specific training to confidently and appropriately address the physical and mental health needs of both autistic children and adults. Commonly, symptoms of treatable physical or mental illness go unaddressed because they are misinterpreted as “just part of autism” or underlying disability. Healthcare system resources can be targeted to further develop much-needed training tools for practitioners, tools to improve screening and diagnosis, and tools to help patients and their families navigate their health conditions.

Lastly, policy adjustments are needed to reduce systems and financial barriers and enhance care coordination. Federal and state governments must collaborate more effectively to implement and manage autism services. Existing infrastructure can be leveraged to enhance access to services and collect additional data on service access and service provision. This information would help build a high-quality evidence base on methods to improve screening and diagnosis, interventions, and other outcomes. Increased investments are also needed to link providers and provide better coordination across the range of primary care, services, and community resources that are used by autistic people and their families. Collectively, these efforts will help to improve the experiences of autistic individuals in the health system.

The discussions of the IACC and the Working Group highlight the critical need to understand the healthcare system barriers, the autistic perspective in research, and the biological factors that underly the health outcomes of people with autism. There are many opportunities for scientific advancement and novel treatment approaches to improve the health and well-being of autistic individuals, both early in life and through adulthood. The IACC stresses the importance of including diverse members of the autism community in discussions to better understand and address autism health-related issues, including researchers, clinicians, service providers, autistic adults, family members, and federal agency representatives. The IACC will continue to address these challenges for autistic individuals and their families in its future activities and will strengthen its commitment to fostering collaboration, striving for equity, and addressing the needs of the full autism community.

Appendix I: References

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Chapter 4: Co-Occurring Mental and Behavioral Health Conditions

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Chapter 5: Co-Occurring Intellectual, Communication, Developmental, and Learning Disabilities

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Chapter 6: Health Care Service Provision

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Appendix II: Request for Public Comment Analysis

Table 1. The 39 types of co-occurring conditions, examples of each type of co-occurring condition, and the number of responses that mentioned each type of co-occurring condition. Individual responses may be coded to zero, one, or more categories.

Co-Occurring Condition	Examples	Number of Responses
Anxiety	Generalized anxiety disorder, phobias, selective mutism	595
Attention-Deficit/Hyperactivity Disorder (ADHD)		447
Cardiovascular Conditions	High blood pressure, heart disease	27
Communication Issues	Non-verbal, minimally verbal, selective mutism	379
Dental Health	Dental and oral health issues	31
Depression and Mood Disorders	Depression, bipolar disorder, mania, dysthymia	413
Dysautonomia	Postural orthostatic tachycardia syndrome (POTS)	88
Emotion Dysregulation	Meltdowns, outbursts, rejection sensitivity, Disruptive mood dysregulation disorder (DMDD)	157
Epilepsy/Seizure Disorders	Epileptic or non-epileptic seizures	97
Feeding and Eating Conditions	Anorexia, bulimia, disordered eating, orthorexia, pica, ARFID	141
Gastrointestinal (GI) Issues	Acid reflux, Crohn's disease, chronic intestinal pseudo-obstruction (CIP/CIPO), gastritis, gastroparesis, irritable bowel syndrome, bowel incontinence, constipation, gastroesophageal reflux disease (GERD), heartburn	416
Gender Dysphoria		19
Genetic Syndromes	Fragile X syndrome, Tuberous sclerosis complex, Rett syndrome, Phelan-McDermid syndrome, Down syndrome	13
Immune Conditions	Mast Cell Activation Syndrome (MCAS), allergies, chronic colds and infections, immunodeficiency, autoimmune disorders	91
Intellectual Disability		156
Joint/Connective Tissue, Musculoskeletal, Orthopedic Conditions	Ehlers Danlos Syndrome (EDS, hEDS), hypermobile spectrum disorder, Klippel Feil syndrome, osteopenia, hypotonia, Marfan syndrome, scoliosis, muscle weakness	207
Learning and Memory	Dyslexia, dysgraphia, memory loss, confusion, prosopagnosia/prosopamnesia, topological agnosia/topographical disorientation, aphantasia/mind blindness, brain fog, dementia	257
Neurological Conditions	Migraines, headaches, Tourette Syndrome and other tic disorders	78

Nutritional and Metabolic Issues	Vitamin deficiencies/processing, blood sugar regulation, obesity/weight management, hormone imbalances, diabetes	79
Obsessive Compulsive Disorder (OCD)		106
Obstetrical/Gynecological	Pre-menstrual dysphoric disorder (PMDD), adenomyosis, polycystic ovarian syndrome (PCOS)	33
Other Developmental Disability	General developmental delays, Fetal alcohol spectrum disorder (FASD)	89
Other Neurodivergence		9
Other Psychiatric Disorders	Paranoia, schizophrenia, homicidal ideation, catatonia, dissociative disorders, alexithymia	60
Pain and Fatigue	Pain tolerance/intolerance, fibromyalgia, chronic pain, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Complex regional pain syndrome (CRPS), high or low pain tolerance, Small Fiber Neuropathy	154
Pathological Demand Avoidance (PDA)		143
Personality Disorders	Borderline personality disorder (BPD), narcissistic personality disorder, empathy deficit disorder (EDD)	20
Respiratory/Lung Conditions	Asthma, difficulty breathing	9
Self-Injurious/Aggressive Behavior	Skin picking, self-harm, conduct disorders, head banging, damaging property, potential harm to others	317
Sensory and Motor Issues	Sensory sensitivity (lights, sounds, foods, etc.), sensory processing disorder, hearing loss, vision problems, poor interoception, motor control, dyspraxia, clumsiness, vestibular issues, balance, apraxia	597
Sexual Dysfunction		6
Skin Conditions	Eczema, rash, psoriasis	26
Sleep Disorders	Sleep apnea, delayed phase sleep syndrome, insomnia, hypersomnia	513
Stress Disorders	Post-Traumatic Stress Disorder (PTSD), complex PTSD (C-PTSD)	94
Substance Misuse/Addiction	Substance use disorder, alcohol use, drug use, gambling, gaming, and other forms of addiction	32
Suicidal Ideation		210
Urological Conditions	Urine retention, urinary incontinence	15

Table 2. The 20 categories of impact of co-occurring conditions, examples of each category, and the number of responses that mentioned each category of impact. Individual responses may be coded to zero, one, or more categories.

Impact	Examples	Number of Responses
Academic Challenges	Difficulty learning or retaining knowledge, difficulty taking notes in class, difficulty engaging in class	202
Adverse Side Effects	Medication resistance, polypharmacy/overmedicated, forced hospitalization/institutionalization, ineffective or harmful treatments/interventions, treatments for the incorrect condition, unsure of which medication to prioritize	123
Bias/Stigma	bias, ableism, stigma, infantilization, discrimination, bullying, lack of understanding	217
Burnout	Lack of energy, lack of motivation	123
Daily Living Skills	Hygiene issues (brushing teeth, etc.), self-care, preventative care, feeding oneself, cleaning one's spaces	203
Difficulty Communicating	To health care/service providers, to caregivers; includes difficulty communicating needs	345
Difficulty Finding Providers	Difficulty finding qualified/trained, appropriate, or available providers, not enough day programs for individuals with high support needs, seeking emergency care because of lack of options, difficult transition from pediatric to adult care, long waitlists, providers being dismissive of concerns, difficulty/unwillingness to consider symptoms as separate from autism, misdiagnosis	386
Emotional Challenges	Dissatisfaction, unhappiness, lack of self-worth, disconnection/dissociation, shame	151
Employment/Financial	Unemployment, underemployment, difficulty maintaining employment, housing instability/homelessness; applies to the individual with autism	214
Executive Function	Difficulty with transitions/change, lack of self-efficacy, difficulty making appointments, impulse control, emotional control, flexible thinking, working memory, self-monitoring, planning and prioritizing, task initiation, organization, avoidance	209
Household Dynamics	Caregiver injury, caregiver burnout/stress/isolation/mental health concerns, impact on caregiver employment, altered household finances/benefits, separation/divorce, altered schedules to accommodate appointments for autistic individual, impact on siblings	107
Inaccessibility	Lack of accommodations, sensory issues, lack of appropriate accommodations for full participation; applies to medical facilities, workplaces, etc.	204
Insurance Coverage	Lack/loss of benefits, includes health insurance, Social Security	44

Masking	Hiding autistic traits from others	88
Overstimulation	Sensory overload	129
Reduced Health and Well-being	Disruption in daily routines (e.g., absences from school/work), untreated concerns become exacerbated, restrictions on activities/independence (e.g., inability to drive)	189
Rumination/Perseveration	“Getting stuck” on a topic or idea	27
Safety Concerns	Abuse, neglect, elopement, concern about interacting with the community (e.g., law enforcement), use of stoves/ovens, drowning, challenging behaviors, inability to live independently due to safety concerns, property destruction	144
Social Challenges	Maintaining friendships, romantic relationships, isolation/loneliness, mistrust of others, overly trusting of others	335
Stress/Trauma	Trauma from negative experiences in the past, stress over dealing with consequences of co-occurring condition (e.g., GI issues), not being understood	129

Table 3. The 10 categories of research needs related to co-occurring conditions in autism, examples of each category of need, and the number of responses that mentioned each category of research need. Individual responses may be coded to zero, one, or more categories.

Research Need	Examples	Number of Responses
Q1. Screening and Diagnosis	Update autism screening and diagnostic instruments	124
Q2. Biology	Research on specific co-occurring conditions, biological factors that link autism to co-occurring conditions, underlying factors that influence autistic traits and/or co-occurring conditions	449
Q3. Genetic and Environmental Factors	Genetic and environmental factors that influence co-occurring conditions (e.g., large genetic studies to identify contributing factors)	84
Q4. Interventions	Interventions and therapeutics for co-occurring conditions, managing chronic conditions	310
Q5. Services and Supports	Research on practitioner and provider training, caregiver supports, educational supports, dissemination of interventions in the community	284
Q6. Lifespan	Research on adults (includes screening and diagnosis, interventions specifically or adults), transition-age needs, housing, community integration and acceptance	169
Q7. Infrastructure and Prevalence	Prevalence of co-occurring conditions, research infrastructure needs (data banks, bio banks, research workforce),	48
CC1. Sex and Gender	Autism in females, LGBTQIA+ issues, menopause	123
CC2. Promoting Equity and Reducing Disparities	Reduced disparities for underserved populations (ex., race/ethnicity, high support needs)	178
Inclusion of Lived Experience in Research	Community-based participatory research, increase in autistic researchers	118

Table 4. The eight categories of services and supports needs related to co-occurring conditions, examples of each category of need, and the number of responses that mentioned each category of services and supports needs. Individual responses may be coded to zero, one, or more categories.

Services and Supports Needs	Examples	Number of Responses
Accessibility of Services/Interventions	AAC, telehealth/remote services, reducing geographic/SES disparities, internet connectivity, reduced waitlists, increased accommodations, improved accessibility of interventions	541
Acute Care/Crisis Management	Emergency/crisis management, more inpatient mental health care options	47
Better/Personalized Services	More program options (day programs, residential facilities), better educational plans, adapting existing interventions for autistic individuals, services for adults	447
More Benefits/Insurance Coverage	Better insurance coverage, universal basic income, universal healthcare, increased social security benefits	573
Provider Training	Improved provider training and patient-provider interactions, reduced ableism/stigma etc., trauma-informed care, increased understanding of autism and co-occurring conditions, cultural competency, transition to adult care, being collaborative with patients with disabilities towards a diagnosis	575
Support for Caregivers	Respite care, caregiver mental health care, support for siblings, caregiver education and training	107
Systems Improvements	Better coordination of systems, better systems navigation, better case management, addressing systemic barriers for marginalized populations, increase workforce development and capacity, better pay for providers	382
Training for Autistic Individuals	Employment training, goal setting, daily living skills, psychoeducation	77

Table 5. The 13 categories of impact the COVID-19 pandemic had on autistic individuals, examples of each category of impact, and the number of responses that mentioned each impact. Individual responses may be coded to zero, one, or more categories.

COVID-19 Impact	Examples	Number of Responses
Benefit of Remote Technologies	Increased use of telehealth, Zoom, mobile apps for grocery delivery, curbside pickup, etc.	491
Benefits of Reduced Social Obligations	Reduced obligations, reduced pressure to mask certain behaviors, social benefits of face masks	203
Caregiver Hardships	Burnout, stress	47
Concerns about Public Health Guidelines and Society	Difficulty wearing masks, inaccessible/not useful public information, concern about de-prioritization of disabled people in health care processes, concern about "push" for people to go back to in-person work, Fear from infection, lack of trust in others to adhere to public guidelines, concern about societal changes (increased anger, etc.)	248
COVID Infection	Long COVID, recurring COVID infection	97
Decreased Availability of Services	Staff shortages, closures of programs, service disruptions, inability to meet with a provider in a timely fashion	297
Delayed Health Care	Put off going to the dentist, seeing the doctor for routine care or a new health issue	51
Delayed Research Progress		3
Disruption of Routines/Regression	Learning loss, loss of skills, disruptions due to end-of-pandemic restrictions	276
Economic Hardships	Job loss, loss of health insurance, housing instability, food insecurity	53
Hardships of Increased Isolation	Reduced social interactions and opportunities	310
Lack of In-Person Services	Increased use of Telehealth, Zoom, etc.	166
New or Exacerbated Health Challenges	Anxiety, depression, fatigue (new or exacerbated)	313

Appendix III: 2018-2019 IACC Health Outcomes Working Group Member Roster

Note: Affiliations for Working Group members are listed as they were in 2018-2019. Affiliations may have changed.

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