Chapter 6: Lifespan

How Can We Address the Needs of People on the Autism Spectrum throughout the Lifespan?

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

Introduction

Based on population and prevalence estimates, approximately 70,700-111,600 autistic youth turn 18 each year in the United States.[1] According to 2017 data from the Centers of Disease Control and Prevention (CDC), an estimated 1 in 45, or close to 2%, of adults in the United States have autism.[2] Given the growing size of the population of youth and adults diagnosed with autism, there are significant concerns about how this increase will affect the transition and adult disability service systems. Research to understand the unique needs of this growing population is required in order to develop services and programs that facilitate opportunities for people on the autism spectrum to lead healthy and fulfilling lives.

The U.S. does not have a coordinated services system for adults with disabilities that mirrors the system for children with disabilities that is mandated by the Individuals with Disabilities Education Act (IDEA). Once a young adult ages out of school-based services, they and their families are required to navigate the adult services environment, with its many sets of rules and systems, including healthcare, disability entitlements, higher education, employment supports, day programs, housing options, and home and community-based services, among others. State developmental disabilities departments and mental health services departments are two major sources of services for people with disabilities who qualify. Individuals on the autism spectrum sometimes do not meet eligibility requirements for services provided through the states if they do not have an intellectual disability, even though they may have significant needs. Given these barriers and complexities, often autistic adults end up not receiving services that they need.

As autistic youth transition into adulthood, studies have shown that they develop co-occurring physical and mental health conditions at higher rates than their neurotypical peers.[3-5] Unfortunately, they may not be able to find adult medical providers with training in autism or developmental disabilities. They may also have challenges finding affording suitable housing, as well as employment or programs that provide enrichment. What is known about the progression from middle adulthood into older adulthood is even less. We do know that often there are multiple transitions that occur later in life; from employment to retirement, from independent housing to living with family members or from living with family members to living alone in an institutional environment, or from parent caregivers to siblings or other designated caregivers. Without adequate supports, these transitions have the potential to cause further decline in older adults, including accumulating physical and mental health challenges, or conditions such as poverty or homelessness if appropriate planning is not in place.

Issues related to adulthood were highlighted by the IACC in the first *IACC Strategic Plan* in 2009. Since then, there has been some growth and progress in research and development of services focused on adults with autism. Programs and research on transition age youth and young adulthood related to education, employment, housing, and other key issues have emerged. More work is needed in this area, as well as on middle age and older adulthood. The variability of support needs across the autism spectrum necessitates an individualized approach to effectively prioritize and meet the needs of each aging autistic adult at different life stages. Across their lifespan, autistic adults report higher than average unmet needs, with receipt of autism-specific services often decreasing with age.[6] The needs of autistic adults who require intensive long term supports is an understudied area that needs more focus. Understanding the factors that contribute to health and well-being across all communities, including those with intellectual disabilities or other high support needs and those are members of communities that have been historically underserved, is critical. Learning more about the needs of adults across the lifespan will aid in the development of improved services and programs that facilitate opportunities for people on the autism spectrum to meet their personal goals, engage in meaningful activities and relationships, and experience health and a sense of well-being.

Progress in the Field and Areas of Ongoing Need

Diagnosis and Developmental Trajectories of Autism in Adulthood

There are currently no published national estimates of the percentage of autistic individuals who received an autism diagnosis in adulthood. Autism may be misdiagnosed or particularly difficult to identify in adults due to a lack of standard diagnostic criteria.[7] The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), Module 4 is the most commonly used instrument for diagnosing autism in adults.[8] While the ADOS-2 has proven to be accurate in identifying adults with autism, the social communication difficulties it measures may not be unique to ASD.[9] As the use of DSM-5 becomes more widespread in the coming years, there is an opportunity for researchers to evaluate the effect of DSM-5 criteria on rates of adult autism diagnosis in real-life settings.[10] Additional research is needed to determine more robust standardized diagnostic criteria for autistic adults. As discussed in Chapter 1, the development of diagnostic measures for non-English speakers, as well as culturally-grounded provision of diagnostic assessments, is needed in order to better reach minority and underserved adult populations. Another important issue for future research is that psychiatric assessment traditionally relies on self-report, whereas autism formal diagnostic practices rely more on direct observation in structured clinical settings and/or caregiver report. Childhood caregivers may not be available or may have difficulty recalling specific behaviors that occurred many decades ago. Exclusive reliance on self-report may not be ideal, due to possible limitations in insight, communicative difficulties, or over-reporting.

Current understanding of the different manifestations of autism in adulthood is limited. Research has shown that there are continuities and changes over time in the developmental trajectory of each individual with autism[11-14]. Longitudinal studies have found that some adults with autism show "improvement" in autism severity and continued growth in social skills.[15] However, the apparent decreases in autistic characteristics may be due to the fact that diagnostic instruments designed for use with children do not adequately query the types of behaviors or symptomology most relevant to adults. Furthering the field's understanding of the developmental profile of autism at all ages will be critical to achieving accurate diagnostic evaluation of autism in adulthood.

State-funded services and support programs often require documentation of an autism diagnosis prior to a certain age. This makes it difficult for a person diagnosed in adulthood to access state-funded autism-related supports. Obtaining a diagnosis in the absence of appropriate services and supports may be detrimental to well-being for some individuals. Research in this area is needed to educate adults self-referring for diagnosis about the possible benefits and disadvantages of obtaining an autism diagnosis. For example, there is a lack of research in identifying the prevalence of autism among military veterans or active military personnel, although there is preliminary data suggesting a connection between autism-related traits and suicidal ideation/behaviors in active military personnel.[16]

The developmental trajectory of women on the autism spectrum across the lifespan has also not been sufficiently examined, potentially resulting in an underdiagnosis of autism in women. Studies have identified high rates of co-occurring mental health conditions among autistic women, with age of diagnosis being an important moderator.[17] A delayed or missed diagnosis may leave autistic women more likely to miss early intervention opportunities to address potential mental health issues early on. Additionally, the literature is limited on the experiences of women with co-occurring intellectual disability. However, there is emerging evidence on the differences in cognitive abilities and social awareness in autistic women, potentially leading to "camouflaging" of core autistic traits.[18] Studies involving self-reported camouflaging behavior and mental health symptoms in autistic and non-autistic youth and adults have found associations between higher levels of camouflaging behaviors and higher levels of symptoms such as stress, anxiety, depression, and suicidal ideation. [19-21] However, because these studies have been mostly cross-sectional, causality has not been demonstrated.

Physical and Mental Health

There is a growing body of literature on health and wellbeing in autistic adults[4, 22-25]. It is now known that adults on the autism spectrum are disproportionately affected by health issues such as immune conditions, gastrointestinal and sleep disorders, epilepsy, obesity, dyslipidemia, hypertension, and diabetes. Rarer conditions, such as stroke and Parkinson's disease, were also significantly more common among adults with autism. Mental health conditions are also prevalent, the most common being anxiety, depression, bipolar disorder, obsessive compulsive disorder, and schizophrenia. Suicidal ideation and death by suicide have been reported at rates higher than the general population.[26-28] Perhaps as a result of these increased physical and mental health issues, the average life expectancy of non-autistic individuals was about 70 years of age, in comparison to only 54 years for autistic individuals.[26] Those autistic individuals with intellectual disability died even younger, on average at just under 40 years.

The impact of these issues on overall wellbeing and mortality were not well known until recent years. This was due in part to the relatively small number of studies of autistic adults and the lack of epidemiological studies detailing medical issues across the lifespan. In addition, there are very few screening and diagnostic instruments adequately validated for detecting and diagnosing physical and mental health conditions in autistic individuals.[29] Furthermore, autistic adults are frequently prescribed medications that are associated with side effects that may affect their physical health such as weight gain, although more research is needed to determine the extent of these issues.[30] Further large-scale research is needed in order to grow our limited understanding of the co-occurring physical and mental health issues that may be experienced by autistic individuals in adulthood and old age.

In addition, more research is needed to understand what factors may contribute to physical and mental health promotion, wellness, and prevention of chronic and acute health conditions in autistic people. Activities that have benefits for neurotypical people, such as exercise,[31] healthy diet,[32] yoga, mindfulness,[33,34] high quality sleep, social engagement, and other similar practices may be avenues of further study to better understand how they may also increase wellness for individuals on the autism spectrum, particularly if tailored to their unique needs.[35] Further research is needed to understand what activities, health practices, and social and physical environmental factors contribute to optimal health and wellbeing for people on the autism spectrum, and if translated to health practice could have the potential to increase well-being and reduce premature mortality among autistic individuals.

Healthcare

A lack of accessible healthcare services in autistic adults can contribute to increased emergency department use, and reduced self-efficacy.[36] The COVID-19 pandemic may hasten the pace of research in the field of telehealth for the provision of healthcare in autistic adults (detailed further in the chapter on COVID-19). Additional research is needed to determine effectiveness of these telehealth models in providing increased access to specialized healthcare in for autistic adults. Research has found that mental health trajectories are associated with individual (e.g., adaptive functioning) and contextual (e.g., neighborhood-specific) variables, which may inform ecological approaches to care, the identification of risk factors, and treatment planning for autistic adults[37]. The role of trauma-informed care in recognizing the compounding effects of daily stressors and significant sources of trauma,[38] and identifying creative ways to support meaningful social contact in accepting environments have been explored in autistic youth- and adolescent-focused research. This remains an emerging area for prospective research among autistic adults with co-occurring mental healthcare needs.

There is a need to increase access to sex education or reproductive health care during adolescent and adult healthcare provision in ways that will be meaningful and beneficial for life course outcomes.[39-41] Common misperceptions about autism include the idea that autistic people are asexual or abstain from sexual behaviors. However, autistic people may often seek intimate partnerships, including sexual relationships, without adequate sexual education in preparation for adulthood or parenthood. Provider misconceptions and poor communication between providers, autistic individuals, and caregivers may also lead to key routine health procedures, such as Pap smears, being overlooked.[42] In particular, transition-aged autistic youth demonstrated the lowest utilization of obstetrics/gynecology services, compared to similar aged youth in the general population and those with other special healthcare needs,[43] highlighting this gap in service utilization, particularly among female adolescents. Additionally, the population of autistic transition-aged youth that identify as LGBTQIA+ require unique healthcare services and may benefit from specialized healthcare models[44].

Service Delivery

A greater awareness of the co-occurring physical and mental health conditions that may accompany an autism diagnosis has led to a growing appreciation of the need for lifelong care for adults with autism. The lack of funding for adult disability services may hamper efforts meant to facilitate and incorporate accommodation, inclusion, and independence for people on the autism spectrum. In addition, long wait times for enrollment and limited access to services across each state can have negative effects on lifelong outcomes for autistic adults.[45] Further, states also differ in how they manage waiting lists: some require assessment for Medicaid eligibility prior to adding an individual to the waiting list, while others place individuals on the waiting list without assessing eligibility.[46] Autistic adults who may be more vulnerable to poorer outcomes in adulthood due to socioeconomic status or membership in a racial/ethnic minority group also have the greatest difficulty accessing needed services.[47] To effectively meet the Aspirational Goal of greater inclusion and self-determination for all autistic adults across their lifespan, especially for those who are most vulnerable, a significant investment in quality and accessible adult disability services is needed, particularly with an eye towards an active reduction of the historic barriers to services.

An effective method to increase the quality of services provided to autistic adults across the lifespan is through the training of the provider workforce, across many disciplines, on adult-specific provision of care. As discussed in Question 5 of the *Strategic Plan*, few adult care providers have received formal training on how to support adults with autism, and as a result, report less confidence in their abilities to interact with autistic adults. Many autistic adults may often receive their healthcare in pediatric settings, due to a lack of adult providers who feel competent and comfortable treating them. Further, social communication challenges between adult autistic patients and healthcare providers may serve as a critical barrier to care.[48] Provider trainings should emphasize improved access to up-to-date information and research and skills training relevant to diagnosis, assessment, and interventions for autistic individuals.[49] Further, among medical and pediatric trainees across all educational levels, awareness for sensory and behavioral issues present among autistic children was low.[50] This knowledge gap is significantly more pronounced in providers that treat autistic adults. As such, there is a need for training grants and initiatives focused on training professionals who will be working with adults to detect, diagnose, and address mental and physical health-related needs in this population.

Given that most adults with autism have complex needs that bring them into contact with multiple public service systems, there is an urgent need for research and initiatives focused on care coordination, interagency collaboration, strategies for integrating extant funding streams, and community-based collective impact strategies. For the transition-age autistic youth age frame, researchers have effectively applied a systems perspective to understand how factors related to service systems, as well as individual and family-level factors, impact the transition to adult healthcare services with disabilities.[51] This systems-based approach was useful in identifying strategic systems changes which could promote better outcomes, and similar approaches could be used to improve autism service systems among older adults with autism.[52] Focusing on a wide range of stakeholder perspectives in the autism community, including service providers, service users, family members, and caregivers, research on adult autism services could provide unique insight into system changes which could improve service delivery outcomes for this population.

Community Integration, Support Groups, and Community-Based Services

Adolescents and adults with autism experience high rates of loneliness.[53] Further, autistic adults with co-occurring mental health conditions, intellectual disability, lower incomes, and those living in supported living facilities report participating in fewer, personally meaningful community activities.[54] Increased community engagement and integration can be a key way to facilitate social participation and assist in skill-building in a variety of areas, including leisure, recreation, and activities of daily living. Quality of life and overall health and wellbeing are positively impacted by participation in social skills groups and other types of community support groups.[55,56] Empowerment, education, and advocacy training services offered within the community can offer enriching opportunities for participation, leadership training, and volunteerism. These programs, and the incorporation of culturally grounded approaches, are particularly important and beneficial to families from racial/ethnic minority backgrounds, as they may experience increased barriers in access to care and services.[57,58,59] It is important to note that autistic adults with high support needs and/or co-occurring intellectual disability have not been sufficiently included in the literature on community participation across the lifespan, limiting the generalizability of this research to all autistic adults.

Growing awareness of the benefits of community engagement and community-based services is reflected in forthcoming updates to federal regulations. By 2023, the Centers for Medicare & Medicaid Services will require states to be in compliance with new requirements for individuals receiving Medicaid services to spend more time participating in communities, rather than in isolated settings.[60] It will therefore be necessary to expand the availability of day programs and other opportunities for community engagement. As more emphasis is placed on the provision of community-based services, research and policy priorities should similarly emphasize the perspectives and interests of autistic adults across the lifespan and across the spectrum of need. Additionally, emphasis should be placed on supporting multi-generational autistic families (i.e., autistic parents with autistic children) in engaging in the community-based services of their choice.

Employment Services and Vocational Skills

Research has found that only about a third of autistic adults enter the labor force.[61] Many autistic adults are unemployed or underemployed, even when compared to people with other disabilities and in spite of having needed skills for the workplace.[62,63] Barriers to higher rates of employment for autistic adults include employer attitudes, access to services, and social communication in the workplace.[64,65,66, 67] Studies also suggest that sustaining continued employment is a challenge for individuals with ASD.[68,69] This may be particularly true for adults with ASD who have co-occurring ID, who are at even greater risk of unemployment.[70,71] Studies of the unemployment and underemployment in autistic adults have been limited by small sample sizes and other factors. Additional research is needed to fully understand employment status stratified by support and service needs, and by income level/economic status.

Promising approaches of supported and competitive integrated employment for autistic adults across the spectrum include matching worker skills to the job setting and description, and adjustment of continued job coaching as the individual progresses.[72-78] Another promising approach is through apprenticeships, which include on-the-job training and mentorship and typically conclude with the individual earning a nationally recognized credential. Internship programs have also been shown to be successful in transitioning people with autism to competitive employment.[79,80] Access to these pathways should be widely accessible to all individuals on the autism spectrum. In order to provide ongoing support for employed autistic adults, job-site training and access to workplace learning should remain best practices to optimize positive outcomes. Further, studies have not yet adequately measured employment outcomes in middle aged and older adults seeking continued employment. Additional research is needed in emerging practices such as technology and customized employment in order to support autistic adults in building lifelong careers in their field of choice. Capacity-building in employment support for autistic adults is recommended based on a lack of evidence guiding existing vocational services.[74] To that end, evidence-informed resources and curricula for employment-support personnel such as job coaches are needed in building proficiency and standards of practice.

Securing competitive employment remains an ongoing challenge for many individuals on the autism spectrum, particularly young adults. While there remain very few studies examining comprehensive interventions for autistic individuals seeking employment, there have been some intervention research focused on specific critical components of the employment process, such as: work-specific social skills; the use of assistive technology to teach work skills and organizational skills; pre-employment interview skills; and video modeling to teach specific work skills. [72] However, these studies have been mostly quasi-experimental and have generally involved autistic individuals with above average cognitive abilities and life skill functioning. [81] Additional research is needed to identify evidence-based interventions are needed for individuals with high support needs, such as co-occurring intellectual disability. The development of effective employment readiness practices and interventions will also require high-quality, rigorous research, ideally with randomized control trial (RCT) designs. [82] Additionally, the high variation across states around vocational rehabilitation (VR) service use and outcomes for transition-aged autistic youth highlights the impact of state-level VR policies on employment outcomes for autistic job-seekers. [83] These VR services (e.g., job placement, on-the-job support, on-the-job training, maintenance, information referral, etc.) were significantly associated with competitive employment, however disparities remain for those with lower educational levels, those who have received cash benefits, and underrepresented racial and ethnic groups. [84, 85] Additionally, fostering early work experiences (e.g., community-based, school-sponsored, paid, unpaid) during high school remains an area in need of continued focus for disability employment policy at federal and state levels.[86] Research is also needed to better understand job retention among autistic individuals, not just job attainment.

Communication Supports and Accommodations

Communication challenges associated with a diagnosis of autism may persist into adulthood, significantly impacting the quality of life of autistic adults if no adequate supports are readily accessible. About 13,000 non-speaking youth with autism turn 18 each year in the United States.[87] In some cases, they may rely on alternative and augmentative communication (AAC) methods.[88, 89] AAC provides an effective means of communication for many autistic individuals and can involve low-tech options such as gestures, writing, drawing, pointing to photos/words, etc., or high-tech options such as speech-generating devices. While one approach is not likely applicable to all non-speaking autistic individuals, there might also be different points in the individual's lifespan at which AAC is more or less beneficial to speech production. [90-92] Additional research may be beneficial to help determine what AAC transitions (e.g., moving from low tech to high tech or from AAC to speech) look like for some people, as well as what targeted interventions seem best for functional communication across a person's lifespan. Additionally, professionals in the field of communication have a better understanding of communication in autism and the potential application of AAC than in previous decades. However, many in the community, particularly caregivers of older autistic adults, may be unaware of the available range of AAC options or see the value in communication services and AAC interventions.[93] Further, additional research is needed around the availability and accessibility of live captioning and other communication supports geared at helping autistic individuals process information. Recent research has also argued for a paradigm shift away from individual support that changes behaviors, toward a system that provides support at an environmental level (e.g., peer mentoring, adapting tasks, using individual strengths).[94]

In addition to communication supports, individuals on the autism spectrum may need accommodations to facilitate participation in various domains of daily living. For example, although universities and institutions for higher learning are required under federal law to provide accommodations for students with disabilities, many students with autism frequently report the need for further accommodations specific to the unique features of autism, such as: sensory friendly spaces and practices, educational practices designed for multiple learning preferences, support groups, and increased awareness and acceptance of self-stimulatory behaviors.[95] Although these accommodations may not be strictly academic in nature, it remains important for university disability accommodations offices to remain aware of self-reported accommodations preferences among students with lived experience. Similar, requesting workplace accommodations may present distinct challenges for individuals with autism compared to others with more visible or physical disabilities. For example, disclosing a diagnosis of autism may be a complex and nuanced task for individuals who may already fear stigma and discrimination.[96, 97] Additional research is needed around exploring the process around efficacious disclosures and accommodations and how these processes may potentially vary according to demographic factors (e.g., race/ethnicity, gender, age, etc.), level of support need, and industry type.

Housing Services and Transportation

Residential services and housing supports are discussed in more detail in Chapter 5, but they are important to mention here in that these services must also be integrated with other adult-specific services as part of a coordinated system of services and care for adults with autism. Members of the autistic community and caregivers have voiced the need for additional research and policies to support aging autistic adults, many of whom continue to live with their family of origin, as their caregivers reach retirement age.[98] There is growing research detailing the increased risk of homelessness faced by autistic individuals[99-101]. These studies highlighted the need for those providing housing services to properly understand traits of autism and the potential need for specialized housing supports. There is also a need for research on transportation access for autistic adults, including for commuting to work and traveling to school, healthcare services, and community life activities[102]. Yet, evidence to support the development of targeted programs and support is lacking in this area.[103-105]

Continuing Education and Enrichment Across the Lifespan

Pursuing postsecondary education can be important in fostering independence, self-determination, and employment success[106]. It is estimated that approximately 45% of autistic young adults will enroll in a university, college, or technical/vocational school in the coming years.[107] However, of the students entering post-secondary education, completion rates for autistic students remains lower than that of their neurotypical peers. [108] Students on the spectrum often report inadequate disability related services and supports and poorer physical and mental health outcomes including loneliness and anxiety.[109, 110] Despite previous research indicating autistic students' preferences for academic support services while in post-secondary educational settings, few quality studies have delved into this area.[111] For autistic students with co-occurring intellectual disability, additional supports are needed to improve independent living skills. Additional research on promoting college readiness in the autistic students is needed to maximize positive outcomes.

Across the lifespan, autistic adults may require additional life skills building with a focus towards independence, self-determination, and community participation. However, for middle-aged and older adults with autism, the scale of need for social skills services in these populations vastly outweighs the current evidence-based offerings.[112] Ongoing education and enrichment activities should remain a priority in the support of autistic adults as they navigate complex service systems and pursue optimal life outcomes. The emergence of virtual-based social skills interventions for adults also presents unique opportunities for future research.[113]

Safety, Victimization, and Interactions with Law Enforcement

Safety issues remain a key concern among the autism community. Much of the existing research has focused on autistic children and adolescents (e.g., wandering/elopement,[114] peer victimization,[115] etc.). However across the lifespan, autistic adults continue to be at heightened risk for safety issues, including negative interactions with law enforcement.[116] Autistic adults are more likely to experience victimization such as property crime, maltreatment, teasing/emotional bullying, and sexual assault by peers.[117] This may hold particularly true for adults with high support needs. Among autistic women, the rates of self-reported sexual violence range from between two to three times as high as the rates among women in the general population.[118] Research is needed to further understand the experiences of victimization in across the lifespan as well as the other safety risks among racial/ethnic groups (e.g., Black and Latinx communities), gender minorities, and autistic individuals with co-occurring ID. Research has suggested that autistic children experience a greater number of Adverse Childhood Experiences (ACEs) in their family and community environments.[119,120, 121] Longitudinal research is needed to examine the long-term impacts of ACEs and the way in which they may impact the mental and physical health of people with autism in adulthood.[122]

Recent advancements have been made in the tracking and reporting of cases of abuse and neglect. The Administration for Community Living (ACL)'s National Adult Maltreatment Reporting System (NAMRS) provides a comprehensive, national reporting system for adult protective services (APS) programs. The goal of NAMRS is to provide consistent, accurate national data on the exploitation and abuse of older adults and adults with disabilities, as reported to APS agencies. In addition, the Centers for Medicare & Medicaid Services requires States to implement an incident reporting system to protect the health and welfare of the Medicaid beneficiaries who receive services in community-based settings or nursing facilities. However, during prior audits, the U.S. Department of Health and Human Services' Office of Inspector General (OIG) found that some States did not always comply with Federal and State requirements for reporting and monitoring critical incidents such as abuse and neglect. Additional research and reports should illuminate whether improvements have been made in the facilitation of incident reporting for individuals with disabilities, including those with autism.

Autistic individuals may interact with law enforcement officers as victims of crime, witnesses to crime, or suspects of crime. Unfortunately, the majority of law enforcement officers report receiving no formal training for interacting with autistic individuals.[123] Law enforcement officers may use physical force unnecessarily or escalate problem behavior when attempting to gain the compliance of individuals with autism, particularly in individuals from racial/ethnic minority populations.[124] There are currently a limited number of programs to improve safety for individuals on the autism spectrum. In some communities, policy officers, judges, and first responders receive specific training on autism. Despite this, the current research is insufficient to inform evidence-based programs to ensure safety among adults on the autism spectrum in all areas of life. Research is needed to support the development of specialized training programs for law enforcement officers and first responders to develop a better understanding of autism, address implicit biases, and improve awareness of safety issues.[125]

Financial Planning

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

Special Considerations for Transition Age Youth with Autism

In the years since the release of the *2016-2017 IACC Strategic Plan*, research on the transition to adulthood for autistic youth has continued to reflect findings of suboptimal outcomes compared to non-autistic peers regarding employment, continuing education, relationships, independent living, and physical and mental health. According to a 2015 report[53], 26% of young adults on the autism spectrum did not receive any services; services that could have helped them gain employment, continue their education, and live more independently. Individuals from minority backgrounds have even poorer outcomes in these measures[126]. Along the varying spectrum of needs, challenges in social cognition and executive function can cause difficulties in the expectations around adulthood become increasingly complex and supportive services are less readily available.[3, 127] Interventions and services such as college readiness programs, social skills training, and supported employment interventions are becoming increasingly utilized as part of the pathway to successful transition to adulthood. Additional studies are needed to fully assess outcomes during the transition period for autistic young adults, including population-level approaches.[128, 129]

Although existing interventions often focus on skills for independence, members of the autistic community still mention the need for more person-centered strategies tailored to the individuals' unique goals and challenges. [130] Further, interventions that focus on enhancing cognitive and language skills as well as teaching daily life skills are vital in nurturing independence among autistic adolescents. [131] Ongoing assessment of adaptive behaviors can help identify areas that are in need of improvement and help to identify goals that can be targeted across environments. [132] Further research is needed to explore the use of virtual modalities, remote instruction, and person-centered strategies for the support of daily life skills.

Despite the need for high quality healthcare into adulthood, there is ample evidence that healthcare services for autistic youth are frequently disrupted during this transition period. There is a notable decline in service utilization across office/outpatient and inpatient settings but stable use in emergency and home settings as autistic youth transition from pediatric to adult healthcare.[133] More than 1 in 4 autistic adolescents lost Medicaid coverage during the transition into adult healthcare services and fewer than half subsequently regained it.[134] The transition from pediatric to adult systems of healthcare has been noted as a particularly challenging period for children and adolescents with disabilities.[135, 136] The American Academy of Pediatrics (AAP) notes that this critical intersection between pediatric and adult healthcare systems requires that high-quality, developmentally appropriate healthcare services be available in an uninterrupted manner as the person moves from adolescence to adulthood. This requires the careful coordination of patient, family, and provider responsibilities.[137] Unfortunately, a coordinated approach to HCT is infrequently implemented for autistic youth.[138-140] Further, successful transition of autistic youth to the adult healthcare system requires the availability of transition services. Yet despite facing complex healthcare needs, such services are often simply unavailable to autistic youth, and many in this age group have difficulty finding adult providers on their own.[141] Communication, social, and physical challenges already experienced by this population may compound these difficulties.[142, 143] It is therefore critical to increase the availability of transition services in order to facilitate a straightforward and coordinated transition to adult health care.

Special Considerations for Autistic Adults with High Support Needs

Given the heterogeneity of autism, there are a wide range of supports and services that a particular individual may need as they age into adulthood and beyond. Research indicates that adults with high support needs face poorer outcomes compared to their neurotypical peers or autistic adults with lower support needs (i.e., higher adaptive skills and cognitive ability)[70, 144-146]. There has been growing discussion within the community on potential ways to better meet the needs of individuals with high support needs (e.g., autistic individuals with co-occurring intellectual and/or language disability requiring intensive supports) and the generalizability of currently available adult autism services to this population.[147] There is current limited knowledge on the services and supports that would benefit autistic adults with co-occurring intellectual disability across multiple domains of life. Currently available outcome measures can be further refined to accurately capture positive outcomes (e.g., social experiences, daily skills and experiences, autonomy, etc.) that are relevant to autistic populations with high support needs.[148,149] The perspectives of families and caregivers are critical in developing relevant and effective supports and services to optimize quality of life and wellbeing across the lifespan for autistic individuals with high support needs.

Special Considerations for Older Adults with Autism

In recent years, studies have begun to identify a high prevalence of health conditions (e.g., autoimmune conditions, obesity, cardiovascular disease, gastro-intestinal disorders, sleep disorders, psychiatric conditions) as autistic individuals age into midlife and beyond.[4,150, 151,152,153] Several studies have pointed to elevated rates of neurodegenerative diseases such as Parkinson's disease and related issues (e.g., stiffness, tremor) in adults with autism.[4, 154, 155] In addition, prevalence of early-onset dementia is 2.6 times higher among autistic adults.[156] Research has begun to elucidate the neural and other biological mechanisms, as well as social environmental factors, that may underlie these elevated rates of co-occurring health conditions. Studies have found specific age-related changes in the brains of autistic adults in terms of both cortical thickness and brain volume.[157-159] Further work is needed, particularly longitudinal studies of lifespan trajectories, to gain a better understanding of the biology of aging in autism as well as associated medical conditions and co-occurring mental health issues. More research is also warranted to better understand the unique challenges of aging in autism. For example, in one study of the developmental trajectories of individuals with autism as they aged found that in comparison with people with intellectual disability alone, autistic individuals lost their activities of daily living skills faster and more markedly, suggesting that autism may lead to greater levels of disability.[160] A critical question to tackle is the interplay between nature (biology) and nurture (lifestyle, services access, experience) and how these contribute to the physical and mental health outcomes observed for older autistic adults. Additional research is also needed on screening, diagnosis, and assessment tools for older adults; menopause in older autistic women;[161] as well as the effects of long-term psychotropic drug use.

In providing care for aging autistic adults, most geriatric healthcare providers do not have adequate expertise or knowledge about autism, and there is currently no knowledge base about best medical practices that may be specific to this population. Additional work is needed at the systems level to design interventions that can be implemented by geriatric health practitioners in community settings. In addition, enhanced mechanisms to support clinical and research training are needed to support and expand the expertise of healthcare professionals in working with aging adults with autism.[162]

An additional area in need of enhanced focus is the available service and support networks for aging adults with autism. Many adults with autism live with their families.[163,164] Older individuals with ASDs whose social and care needs family members have met can lose these supports with the death or incapacity of their parents or siblings.[162] There is a lack of evidence that existing models of care can meet the needs of older autistics adults, and growing concerns that the current long-term care workforce is not trained to address the unique needs of aging adults with autism.[162] Further research, including population based studies, are needed to identify and understand the unique needs of older adults on the autism spectrum so that services can be tailored to address their needs. Supportive services to provide assistance to families and individuals in planning for older adulthood, succession planning, and establishment of financial, housing, and services-related supports are also critical to ensure that older autistic adults have a viable plan for long-term care. Due to advances in autism research and services, the aging autism population of today is likely to be somewhat different from the aging autism population that we will see in 20 years' time. Thus, ongoing evolution of the system of supports and continually updated provider training will be critical to ensure that the changing (and potentially expanding) needs of the population are met.

Inclusion of Autistic Adult Lived Experience in Research, Services, and Policy

In recent years, autistic academics have called for increased community participation in autism research.[165-167] A shift has occurred toward more inclusive research agendas and intervention programs that engage directly with autistic individuals and their families, including their perspectives in conceptualizing research goals and intervention outcomes.[168, 169] There is growing focus on societal accommodation, rather than removal of the differences, that make individuals with autism unique.[128, 169] Community-based participatory research hinges on meaningful and trusting relationships with members of the autism community; relationships that may take time to develop but are essential for research that is equitable, respectful, and aligns with community priorities.[170] As effective participatory research often takes more time and is more expensive than traditional research, systemic shifts within the autism research establishment are needed in order to facilitate more frequent and more equitable engagement with community partners.[167, 171] These include greater education and training of autism research stakeholders, adjustments in the evaluation of grant proposals, and extension of funding cycles and project timelines. Several organizations, such as the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) have formed successful academic-community partnerships composed of autistic and non-autistic academic scientists and community partners to conduct research relevant to the needs of adults on the autism spectrum.[172, 173] As service delivery systems and governmental policies are refined to meet the needs of autistic adults, the meaningful participation of autistic lived experiences will be critical in ensuring that the perspectives of all adults on the autism spectrum are adequately addressed.

Conclusions

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

It is unlikely that meaningful progress toward the Aspirational Goal will be made without substantially increasing funding for autism research and services focused on adults across the lifespan. Research focused on adult issues has lagged far behind other types of autism-related research, comprising only 3% of all autism research spending in 2018. [174] Fundamental questions around the developmental trajectories and life outcomes of adults with autism remain unanswered. As adult-specific services and supports are developed and implemented across multiple communities, additional research and programming targeted toward addressing the unique needs of autistic adults is necessary in order to ensure that these interventions and services remain effective and efficient across multiple domains of adult life. A strengthened level of support for this work will be needed in order to meet the current and growing needs of the population.

Recommendations

RECOMMENDATION 1: Support development and coordination of integrated services to help people on the autism spectrum successfully transition to adulthood and progress through the lifespan with appropriate services and supports.

Examples:

- Use population-level data to understand unmet needs, disparities in access and outcomes, emerging usage trends, cost issues, and the effectiveness of adult services in achieving their desired outcomes.
- Develop improved adult service models and coordination across agencies and systems (e.g., education, vocational rehabilitation, employment, housing, healthcare, social services, communication supports, law enforcement, older adult services).
- Develop strategies for reducing socioeconomic or racial/ethnic disparities in service access and related outcomes for autistic adults.

RECOMMENDATION 2: Support research and develop and implement approaches to improve physical and mental health outcomes across the lifespan, with the goal of improving safety, reducing premature mortality, and enhancing health and well-being.

Examples:

- Develop approaches for diagnosing autism in adults.
- Develop services approaches to address autism and co-occurring physical and mental health conditions in adults, as well as approaches to promote wellness throughout the lifespan.
- Conduct large-scale longitudinal studies across adulthood into older age to examine trajectories of physical and mental health conditions, and address the additive and interactive effects of biological, cognitive, behavioral, and environmental factors that lead to co-occurring conditions.
- Engage adults on the autism spectrum and their families in collaborative and participatory research to better understand adult needs, provide input on research plans, and conduct research that addresses community-based health priorities.
- Identify social determinants of health that impact autistic adults, including those in underserved populations, and strategies to improve outcomes.
- Conduct long-term follow-up studies examining the effects of interventions and services delivered in childhood on later adult outcomes.

RECOMMENDATION 3: Support research, services activities, and outreach efforts that facilitate and incorporate accessibility, as well as acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum.

Examples:

- Support research and programs on accessibility, acceptance, accommodation, inclusion, and universal design, including barriers, impacts, and best practices.
- Support research on person centered planning, self-direction, independent living, and community integration.
- Support efforts to increase the accessibility of research, services and supports programs by providing plain or easy read program guidance, simplified processes, accessible forms, remote access, accommodations for different communication modalities, and other disability-friendly procedures and processes to increase the ease of access for autistic individuals and their families.

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