

## Chapter 6: Lifespan

*How Can We Meet 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 of autism, approximately 70,700-111,600 autistic youth turn 18 years old each year in the United States. <sup>1</sup> 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. <sup>2</sup> Given the growing size of the population of autistic adults, it is urgent to develop an effective array of adult services to meet the needs of autistic adults across the lifespan, including those with the highest support needs. As mentioned in the previous chapter, the “service cliff” that people with autism experience as they transition from the school-based service system to the adult service system presents significant concerns. The U.S. does not have a coordinated system of services for adults with disabilities that mirrors the service system for children with disabilities mandated by the Individuals with Disabilities Education Act (IDEA), which makes available a free appropriate public education to eligible children with disabilities nationwide and ensures special education and related services to those children. . Once a young adult ages out of the school-based service system, they and their families are required to navigate the adult services environment on their own, with its many separate systems and sets of rules set by states and various service agencies. State developmental disabilities departments and mental health services departments are two major sources of services for people with disabilities who qualify. Individuals with autism sometimes do not meet eligibility requirements for services provided through the state developmental disabilities programs if they do not have an intellectual disability, however, even though they may have other characteristics and conditions that are barriers to them being able to move directly to employment. Some people with autism also do not qualify for services provided through the mental health system. Individuals and families must navigate through the healthcare system, the disability entitlement system, higher education, employment supports or day programs, housing options, and home and community-based services, among others. With the barriers presented by having to navigate the many services and their requirements, and the difficulty qualifying for some services, many young adults end up not receiving services that they need – services that would have been continuations of what they received when they were in school. According to the 2015 National Autism Indicators Report on Transition into Young Adulthood, 26% of young adults on the autism spectrum received no services – services that could have helped them gain employment, continue their education, or live more independently. As autistic adults continue into adulthood, studies have shown that they develop co-occurring physical and mental health conditions at a higher rate than their neurotypical peers, and they may continue to struggle to maintain employment and needed services. What is known about the transition from middle adulthood into older adulthood is even less.

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 adulthood in autism, though the growth has been very modest and is not on par with the need. Some of the knowledge gaps are just starting to be filled, but there is much more work to be done. 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 needs of autistic adults who require intensive long term supports throughout their lives and rely on family caregivers is also an understudied area that needs more focus. Understanding the factors that contribute to challenges and the factors that contribute to improved health and well-being across all communities, including those with 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 and will help the community to develop 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 lead healthy and fulfilling lives.

### Transition to Adulthood

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. 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.<sup>7,8</sup> 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. However, population-level approaches are needed in order to fully measure outcomes during this transition period for autistic young adults.<sup>9</sup>

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.<sup>10</sup> 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.<sup>11</sup> 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.<sup>12</sup> Further research is needed to explore the use of virtual modalities, remote instruction, and person-centered strategies for the support of daily life skills

Securing competitive employment remains an ongoing challenge for many young adults with autism. While there remain very few studies examining comprehensive interventions for transition-aged youth with autism 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.<sup>13</sup> However, these studies have been mostly quasi-experimental and have generally involved autistic individuals with above average cognitive abilities and life skill functioning.<sup>14</sup> Due to this gap in the literature and in policies and practices, evidence-based interventions are needed for transition-aged autistic youth 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.<sup>15</sup> 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 youth.<sup>16</sup> 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.<sup>17, 18</sup> 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.<sup>19</sup>

Pursuing postsecondary education can be important in fostering independence, self-determination, and employment success. It is estimated that of the autistic children transitioning into adulthood within the next few years, approximately 45% will enroll in a university, college, or technical/vocational school.<sup>20</sup> However, of the students entering post-secondary education, completion rates for autistic students remains lower than that of their neurotypical peers.<sup>21</sup> Students on the spectrum will often report struggles with inadequate disability related services and supports related to their unique needs, poorer physical and mental health outcomes, more depressive symptoms and episodes of loneliness, suicidal ideation, and heightened symptoms of anxiety.<sup>22, 23</sup> 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.<sup>24</sup> For autistic students with co-occurring intellectual disability, additional supports around independent living skills may be needed. However, this population remains insufficient researched in the literature around promoting college readiness in autistic students.

There is currently a limited number of studies that delve into access to sex education or reproductive health care services during the transition period into adult services.<sup>25</sup> Common perceptions about autism often include the idea that autistic people are asexual or abstain from sexual behaviors. However, research shows autistic people may often seek intimate partnerships, including sexual relationships, without adequate sexual education in preparation for adulthood or parenthood. This highlights a gap in education and creates an opportunity for transition services to connect with autistic transition-aged youth in ways that will be meaningful and beneficial for life course outcomes.<sup>26, 27</sup> Provider misconceptions and poor communication between providers, the transition-aged youth, and caregivers may also lead to key routine health procedures, such as Pap smears, being overlooked.<sup>28</sup> Transition-aged autistic youth also demonstrated the lowest utilization of obstetrics/gynecology services, compared to similar aged youth in the general population and those with other special healthcare needs,<sup>29</sup> highlighting this gap in service utilization, particularly among female adolescents.

Additionally, the literature suggests that there may be a sizeable population of autistic transition-aged youth that identify as LGBTQIA+, though there are no conclusive studies determining the prevalence of autistic youth with alternative gender or sexual orientation.<sup>30</sup> Nevertheless, this population may require unique healthcare services and may benefit from specialized healthcare transition models.

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.<sup>31</sup> More than 1 in 4 autistic adolescents lost Medicaid coverage during the transition into adult healthcare services and fewer than half subsequently regained it.<sup>32</sup> The transition from pediatric to adult systems of healthcare has been noted as a particularly challenging period for children and adolescents with disabilities.<sup>33, 34</sup> 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.<sup>35</sup> Unfortunately, a coordinated approach to HCT is infrequently implemented for autistic youth.<sup>36-38</sup>

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.<sup>39</sup> These studies on healthcare utilization and expenditures in relation to non-autistic peers also reflect the complex healthcare needs typically associated with autism and commonly co-occurring physical and mental health conditions. This complexity poses additional challenges for autistic youth as they navigate the transition to adult healthcare systems, particularly when co-occurring conditions may compound the communication, social, and physical challenges already experienced by this population.<sup>40, 41</sup>

### Adult-Specific Services and Supports

As autistic individuals progress through adulthood, they may require a wide range of ongoing adult-specific services and supports, creating unique age-specific challenges in navigating service sectors. 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 many of their prioritized services receipt decreasing with age.<sup>42</sup> Although the evidentiary base to address these unmet needs and adult-specific programs and supports have improved in recent years as members of the autistic community have expressed specific research priorities, more research is needed across many domains of life.

### Community-Based Services and Community Integration

While a focus of the literature has been on reporting overall outcomes in adulthood, less attention has been paid to understanding how autistic adults integrate into the community, the benefits of participation, and the barriers and facilitators that may influence participation. Without a deep

understanding of the participation interests of this growing group, there is a risk of a variety of adverse outcomes for autistic adults, their families, and service providers. Community participation can occur in a variety of ways, including leisure activities, recreation, activities of daily living (e.g., shopping), and participation in support groups, including online activities. The wide range of support needs across the autism spectrum may also complicate blanket solutions for improving meaningful participation in community activities. For example, 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.<sup>43</sup> Further, autistic adults with higher support needs, such as co-occurring intellectual disability, have not been sufficiently included in the literature around community participation across their lifespan, limiting the generalizability of this research to all autistic adults. Overall, community participation has been found to improve life satisfaction and subjective well-being, and decrease loneliness, with interventions aiming to improve engagement in the community also reporting significant improvements in overall wellbeing.<sup>44</sup> 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.<sup>45</sup> 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. Additionally, emphasis should be placed on supporting multi-generational autistic families (i.e., autistic parents with autistic children) in effectively integrating into their communities of choice.

#### Continuing Education Across the Lifespan

The literature around continuing education, social and behavioral skills building, and post-secondary education has been mainly focused on primary and secondary school-aged children and adolescents, as well as transition-aged autistic young adults. 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.<sup>46</sup> Ongoing education 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.<sup>47</sup>

#### Employment Services and Vocational Skills

Although federal legislation has mandated enhanced services for transition-aged autistic young adults, many adults continue to face unemployment after leaving secondary education settings. Studies have consistently found that only about a third of autistic adults enter the labor force.<sup>48</sup> Among these adults, the aspects of supported employment are a strong, evidence-based method for securing competitive integrated employment across the lifespan,<sup>49</sup> although studies have not 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 also securing competitive integrated employment helping autistic adults to build lifelong careers in their field of choice. Additionally, capacity-building in employment support for autistic adults is recommended, based on a reported insufficiency of, and a lack of evidence guiding, existing vocational services,

particularly among older autistic adults.<sup>50</sup> 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. Autistic adults with co-occurring intellectual disability face employment outcomes that are significantly less positive than among the wider autistic adult population. However, independence in daily living skills was a robust predictor of employment in autistic adults with co-occurring intellectual disability, highlighting potential for additional interventions and services in this area to maximize employment outcomes for these individuals.<sup>51</sup> 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, internships and apprenticeships have proven to be meaningful pathways towards career-building in autistic adults. Access to these pathways should be widely accessible to all individuals on the autism spectrum.

### Safety/Victimization/Law Enforcement Interactions

In recent years, the autistic community has raised concerns over issues around safety and has flagged this area for prioritization in the research agenda, yet the literature on this topic in autistic adults remains limited. Much of the research focused on safety issues (e.g., wandering/elopement,<sup>52</sup> peer victimization,<sup>53</sup> suicidality<sup>54</sup> etc.) has centered around autistic children and adolescents. However, across the lifespan, autistic adults with high support needs, such as those with co-occurring intellectual disability, continue to be at heightened risk for safety issues such as wandering.<sup>55</sup> Autistic adults are also more likely to experience victimization such as property crime, maltreatment, teasing/emotional bullying, and sexual assault by peers.<sup>56</sup> Among adult autistic women in particular, the rates of self-reported sexual violence ranges from between two to three times as high as the rates among women in the general population.<sup>57</sup> Careful research is needed to further understand the experiences of victimization in adulthood 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 intellectual disability. Additionally, 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. 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 any improvements have been made in the facilitation of incident reporting. Further, while there are few systems that track 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.

Research focused on adults in the criminal justice system is also important to understand precipitating factors for criminality or adverse interactions with law enforcement. Autistic adults may interact with law enforcement officers as victims of crime, witnesses to crime, or suspects of crime. However, a majority of law enforcement officers will often report receiving no formal training for interacting with autistic individuals.<sup>58</sup> Further, 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.<sup>59</sup> The relatively limited research around training programs indicates that additional research is needed around the potential for specialized training programs for law enforcement officers to address these issues.<sup>60</sup>

### Health and Healthcare

The literature on health and healthcare needs of autistic adults throughout the lifespan is also similarly limited, as the bulk of the research on physical and mental health outcomes have focused on children and adolescents with autism. Reported prevalence rates of co-occurring mental health conditions in autistic individuals vary, depending on ascertainment method (e.g., clinical diagnosis, surveillance or administrative records, caregiver- or self-report).<sup>61, 62</sup> In addition, there are very few screening and diagnostic instruments adequately validated for detecting and diagnosing mental health disorders in autistic individuals. Nevertheless, the data consistently suggest considerable levels of co-occurring mental health conditions or symptoms in autistic adolescents and young adults, and a significant mental health care need in this population as they age into adulthood. In autistic adults, the most commonly reported mental health conditions are anxiety, depression, bipolar disorder, obsessive compulsive disorder, and schizophrenia.<sup>61, 63</sup> Suicidal ideation and death by suicide have been reported at rates higher than the general population, although rates vary greatly depending on the method of ascertainment.<sup>64-66</sup> Furthermore, mental health trajectories were 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.<sup>67</sup> The role of trauma-informed care in recognizing everyday trauma and identifying creative ways to support meaningful social contact in accepting environments had been explored in autistic youth- and adolescent-focused research but remains an emerging area for prospective research among autistic adults with co-occurring mental healthcare needs.

Co-occurring physical health conditions are also a concern for autistic adults. This can include higher rates of chronic conditions such as cardiovascular disease and higher risk of early mortality, as well as co-occurring epilepsy, sleeping disorders, and feeding and gastrointestinal issues.<sup>68</sup> Additionally, 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. A further lack of accessible healthcare services in autistic adults can also lead to reduced satisfaction with care, increased emergency department use, and reduced self-efficacy.<sup>69</sup> Similar as to with mental health conditions, more validated and psychometrically sound assessment tools are needed to accurately measure a variety of areas of physical health and quality of life across the lifespan for autistic adults.<sup>70</sup> The COVID-19 pandemic may likely hasten the pace of research in the field of telehealth for the provision of healthcare in autistic adults. Additional research in order to determine effectiveness of these telehealth models at providing increased access to needed specialized healthcare in adults is needed, although there is evidence for the rapid feasibility of these models as evidenced by the aforementioned COVID-19 pandemic.

### Housing Services and Transportation

Residential services and housing supports are discussed in more detail in Question 5 of the *Strategic Plan*, 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.<sup>71</sup> 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. Yet, evidence to support the development of targeted programs and support is lacking in this area.<sup>72, 73</sup>

### 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.<sup>74</sup> In some cases, they may rely on alternative and augmentative communication (AAC) methods.<sup>75, 76</sup> 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.<sup>77-79</sup> Additional research may be beneficial and determining 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, the literature reveals 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.<sup>80</sup> 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); and conceptualizing autism using the social, rather than medical, model of disability.<sup>81</sup>

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.<sup>82</sup> 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.<sup>83,84</sup> 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.

### Adult Diagnosis

Longitudinal studies demonstrate clear evidence that autism-related service and support needs continue well into adulthood. Although there are estimated prevalence rates for adults living with autism within the United States,<sup>2</sup> there are currently no known national estimates for the percentage of autistic individuals who received an autism diagnosis in adulthood. Further, autism may often be misdiagnosed or be particularly difficult to identify in adults through a formal diagnosis due to a lack of standard diagnostic criteria for adults with suspected autism.<sup>85</sup> As the use of DSM-5 becomes more widespread, there is an opportunity for researchers to evaluate the effect of DSM-5 criteria on rates of adult autism diagnosis in real-life settings.<sup>86</sup>

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), Module 4 is considered a "gold-standard" instrument for diagnosing autism in adults.<sup>87</sup> While the ADOS-2 has proven highly accurate at identifying adults with autism, the social communication difficulties it measures may not be unique to just a diagnosis of ASD.<sup>88</sup> Although the ADOS-2 doesn't serve as a stand-alone diagnostic measure, additional research is needed to determine more robust standardized diagnostic criteria for autistic adults. Such research will need to consider that adult 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 occurring many decades ago. Exclusive reliance on self-report may also not be ideal, due to possible limitations in insight, communicative difficulties, or over-reporting of autism characteristics to achieve secondary gain (e.g., involvement in legal system, to obtain financial assistance).

An important gap in the research to improve adult diagnosis involves the limited knowledge around the manifestations of autism in adults. Understanding the developmental profile of autism at all ages is key in an accurate diagnostic evaluation of individuals with suspected autism. Research has shown that there are continuities and changes over time in the developmental trajectory of each individual with autism. Longitudinal studies have also found that some adults with autism show "improvement" in autism severity compared to estimates obtained during earlier childhood or young adulthood, as well as a constant progression of social skills into adulthood.<sup>89</sup> However, these apparent "decreases" in autistic characteristics may simply reflect that case that instruments designed for use with children do not adequately query the types of behaviors or symptomology most relevant to adults with autism.

Considering that state-funded support programs often require documentation of an autism diagnosis prior to a certain age, it is unlikely that someone diagnosed in middle adulthood would be able to access

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 risks 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.<sup>90</sup> The benefits and risk of obtaining an adult diagnosis of autism while in active duty or as a veteran remains an area for future research.

The developmental trajectories of women on the autism spectrum across their lifespan have also not been sufficiently examined, potentially resulting in an underdiagnosis of autistic women. While there has been inconsistent evidence around sex-related differences in executive functioning in autistic individuals, considerable evidence does exist demonstrating higher rates of co-occurring mental health conditions among autistic women, with age of diagnosis being an important moderator.<sup>91</sup> A delayed or missed diagnosis of autism may leave these autistic women more likely to miss early intervention opportunities for these mental health co-occurring conditions. 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.<sup>92</sup> 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.<sup>93-95</sup> However, because these studies have been mostly cross-sectional, causality has not been demonstrated.

### Service Delivery for Adults

A greater awareness of 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. A lack of funding for adult disability services may hamper efforts meant to facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society. In addition, extraordinarily long wait times for enrollment<sup>96</sup> and access to needed services across each state can have negative effects on lifelong outcomes for autistic adults. Further, states also differ in how they operate waiting lists. Some states 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.<sup>97</sup> 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.<sup>98</sup> 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.<sup>99</sup> 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.<sup>100</sup> Further, among medical and pediatric trainees across all educational levels, awareness for sensory and behavioral issues present among autistic children was low.<sup>101</sup> This knowledge gap is significantly more pronounced in provider's comfort around adults with autism. 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.<sup>102</sup> 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.<sup>103</sup> 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.

### Services and Supports for Adults with High Support Needs

The heterogeneity of autism has meant that there are a wide range of supports and services needed for adults on the autism spectrum. Consequently, there has been discussion within the community around the needs of individuals with high support needs (i.e., autistic individuals with co-occurring intellectual and language disability requiring intensive supports) and the generalizability of adult autism services research portfolio on this high-support population.<sup>104</sup> As discussed across Questions 5 and 6 of the *Strategic Plan*, the literature is limited for the services and supports that would benefit autistic adults with co-occurring intellectual disability across multiple domains of life. Typically utilized outcome measures indicate 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). However, measures would need to be refined or tailored to accurately capture positive outcomes (e.g., social experiences, daily skills and experiences, autonomy, etc.) within autistic populations with high support needs.<sup>105</sup> The gaps in the literature for autistic adults with high support needs and their caregivers may often leave many within this community feeling alienated from the current autism research agenda.<sup>106</sup> The research on services and supports may not feel relevant to caregivers of adults with high support needs, given the immediacy of actionable, intensive supports

needed for this population. Due to the presence of co-occurring intellectual and language disability within autistic adults with higher support needs, the perspectives of families and caregivers is critical in gaining further insight into the development of relevant and effective supports and services to optimize quality of life and wellbeing across the lifespan.

### Outcomes for Older Adults with Autism

The absence of literature in the field of geriatric medicine and psychiatry and autistic adult outcomes has led to a dearth of knowledge on optimal services and supports for a growing, aging population. Studies have suggested that people on the autism spectrum have a high prevalence of health conditions (e.g., immune conditions, cardiovascular disease, sleep disorders, psychiatric conditions) in midlife and old age, regardless of intellectual disability status.<sup>107, 108</sup> Geriatric care providers often are unaware of the best practices for healthcare in autistic older adults who may present with multiple, chronic health conditions. Additional work is needed at the systems level to identify health disparities and design interventions that can be implemented by geriatric health practitioners in community settings. Additional research is also needed on menopause in autism, as this remains a gap in the literature for older autistic women.<sup>109</sup> These potential discoveries in optimal outcomes for older adults (e.g., effect of long-term psychotropic drug use, caregiver training, etc.) would be greatly facilitated by the utilization of longitudinal research study designs that track adults as they age into late adulthood, as well as potential oversampling in these studies as well.

### Inclusion of Lived Experiences in Research, Services, and Policy

In recent years, a shift has been advocated toward for more inclusive research agendas and intervention programs that engage directly with the autism community, including considerations of their perspectives in conceptualizing desirable research goals and intervention outcomes, and a focus on societal accommodation, rather than removal of the differences that make individuals with autism unique.<sup>9, 110</sup> Although there may be agreement between autism researchers and community members about the need and desire to conduct more participatory research, research systems may not be designed for participatory research, given the lack of training, support, and funding to pursue this at a systems level.<sup>111</sup> 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 respectful autism research that aligns with community priorities.<sup>112</sup> However, several organizations, such as the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) successfully bring together the academic community and the autistic community to conduct research projects relevant to the needs of adults on the autism spectrum using the principles of community based participatory research. 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 knowledge gaps are adequately addressed in the research portfolio.

## Summary

There is a growing evidence base documenting the challenges faced by autistic adults in acquiring needed disability services, accessing healthcare, finding appropriate competitive employment or vocational activities, long term supports, community integration, and achieving other positive outcomes in adulthood. However, critical knowledge gaps remain in our understanding of the full range of need across the entire autism spectrum, across all levels of ability and disability, sex/gender, race/ethnicity/culture, and age. It remains unclear how much of the current knowledge regarding how to best achieve the Aspirational Goal would translate to autistic adults and families who are underrepresented in the literature. Thus, studies could 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 on the autism spectrum.

It is unlikely that we will make meaningful progress toward the Aspirational Goal 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.<sup>113</sup> 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.

## 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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