

## Question 5: What Services and Supports Are Needed to Maximize Quality of Life?

**Aspirational Goal:** Develop and implement high-quality, evidence-based, and widely accessible services and supports that maximize quality of life and health across the lifespan for all people on the autism spectrum and their families.

### Introduction

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

Research on services and supports historically focuses on self-directed care, access to care and systems navigation, coordination of funding and services among state and local agencies, community-based supports, and the need to better measure the health and wellbeing, safety, and mortality of people with autism. There have been several notable advancements in the services research portfolio across the decade from 2008 to 2020 due in part to IACC recommendations. In 2020, 9% (\$34.8 million) of autism-related research funding from Federal agencies and private organizations addressed issues related to services and supports.<sup>1</sup> Although there has been a trend of incremental growth over the past few years, there has been insufficient movement to prioritize research that would significantly impact the current service infrastructure and those individuals currently living with autism.<sup>2</sup> A lack of adequate, sustained funding allocated towards services research may therefore present a barrier towards meeting the Objectives previously identified in past versions of the *IACC Strategic Plan*.<sup>3</sup>

There have been advances in recent years regarding the direction and priorities of autism services research and the incorporation of key stakeholder perspectives.<sup>4</sup> This includes research focused on public services (particularly support services post-diagnosis and during times of transition), increasing access to services and supports, and identifying optimal ways to improve life skills. Further, federal agencies such as the Health Resources and Services Administration's Maternal and Child Health Bureau have leveraged innovative platforms to provide specialized training for professionals and access to health services through research-based screening and diagnostic procedures.<sup>5</sup> Despite this enhanced focus, services for people on the autism spectrum remain uneven, particularly in lower-resource settings.<sup>6</sup> There are many opportunities to bridge gaps between research and tangible services and supports in various domains of life for all people with autism. For example, workforce availability for autism-related services is limited in terms of overall numbers, time available, and knowledgeability, with the greatest unmet need observed among minorities and in rural settings.<sup>7</sup>

Recent research has also contributed to our understanding of the economic costs associated with autism services and supports across the lifespan. Researchers estimate that the lifetime cost for an individual with autism without intellectual disability in the United States is \$1.4 million, rising to \$2.4 million for an individual with co-occurring intellectual disability.<sup>8</sup> Approximately 79% of these costs are incurred by needed services. Thus, there remains an obvious unmet need for adequate, cost-effective services to alleviate some of the financial strain on autistic individuals and their families. The opportunity to access high-quality services and supports will help to improve the health and wellbeing of many individuals on the autism spectrum.

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

## Education System

Schools are one of the primary settings where children with autism receive intensive supports and services.<sup>9</sup> With the growing number of autistic students entering the education system, there is a growing need to standardize the methods by which students are determined to be eligible for services. Research has highlighted a notable discrepancy between educational eligibility for autism-related services as compared to clinical diagnoses of autism.<sup>10</sup> This inconsistency may result in the absence or lack of services provided to students with autism, or access to services under different eligibility criteria.<sup>11</sup> In order to match students with effective services and supports, classification systems need to be sensitive to the characteristics that are most valid and distinguish between students with specific autism-related traits and those without.<sup>12</sup> The *No Child Left Behind Act* and the *Individuals with Disabilities Education Improvement Act* (IDEA) both state that students with autism must have access to high-quality, research-based interventions that help support them in the least restrictive instructional environment that can meet their learning needs. The IDEA classifies autism as a “developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child’s educational performance.” However, many states, and even school districts within a given state, can differ in their interpretation of the “educational impact” required for an autism classification according to the IDEA, given the limited guidance to define this concept.<sup>13</sup> Determining eligibility criteria for appropriate, tailored educational supports and services remains an area ripe for continued research.

More tools are necessary for educators and the public to gain a greater understanding of the wide range of outcomes that exist and the evidence-based practices most effective for teaching students with autism.<sup>14</sup> Research suggests that an educator’s individual attitudes about evidence-based practices (EBPs) can influence their use of EBPs with children with autism in public schools.<sup>15</sup> Strategies targeted at individual provider (teachers and staff) attitudes towards these practices might improve the rates of utilization of these EBPs in classrooms. Additionally, optimal leadership (i.e., principals, administrators, etc.) behaviors are associated with a positive school climate for EBP implementation.<sup>16</sup> Previous federally funded programs such as the [National Professional Development Center on ASD](#) have shown improved outcomes when students are the recipients of EBPs. However, given the number of EBPs that teachers and classroom staff are expected to use simultaneously, future research should aim to shed light on strategies to implement numerous EBPs in various settings, with the goal to improve educational outcomes and mitigate failed implementation.<sup>17</sup>

Research studies have begun to focus on the mental health of students with autism. Co-occurring mental health conditions are more prevalent in the autism population than in the general population,<sup>18</sup> including anxiety disorders, depressive disorders, bipolar and mood disorders, schizophrenia, suicidal behavior disorders, and attention-deficit/hyperactivity disorder.<sup>19</sup> These can occur among all age groups; however, the majority occur in younger individuals, most of whom are involved in the education system. Autistic students have reported that these co-occurring conditions interfere with their success in school, but that they have difficulty identifying and accessing the supports that they need.<sup>20-22</sup> These studies have mainly focused on adolescents and college-aged young adults, and further work is needed to provide insight to the experiences of younger students as well.

Currently, the public education system is not adequately preparing all children with autism for adulthood. Individualized Education Program (IEPs) for students with ASD in their final year of school may not be consistently meeting the standards outlined by law or best practice recommendations necessary for successful transition from high school.<sup>23-25</sup> After graduating high, students are typically expected to attend college. However, people with disabilities experience certain barriers to post-secondary education, so an exploration of alternate transition goal could be helpful. Before students even graduate high school, curricula could focus on building skills for students to be successful in the workplace, including introducing Project-Based Learning (PBL) and encouraging students to seek out paid Apprenticeships. PBL helps prepare students for the workforce by building teamwork and interpersonal skills and allows them to explore their learning and communication styles. Studies show that project-based, team-centered problem-solving can help individuals build skills at their own pace and increase engagement.<sup>26,27</sup> This could be due to the fact that PBL allows students to use practical thinking as they make decisions and discover solutions about issues that interest them.<sup>28</sup> Apprenticeships are paid positions that include on-the-job training integrated with classroom instruction and usually conclude with the individual earning a nationally recognized credential.<sup>29</sup> The Office of Disability Employment Policy (ODEP), through the National Apprenticeship Act of 2021, funds the [Partnership on Inclusive Apprenticeship \(PIA\)](#) which provides technical assistance around inclusive recruiting, teaching, and on-the-job training practices. Mentorship plays a large role in the experience of apprentices, as many of them have limited exposure to the industry.<sup>30</sup> It is vitally important to teach youth with autism the social and vocational skills necessary to have successful outcomes after leaving the education system.

## Healthcare System

There have been several advancements in the field of healthcare service and support delivery in recent years. One important funding stream for reimbursement of services provided to individuals with autism is the Medicaid program. Jointly operated between the states and the Federal government, Medicaid provides healthcare coverage for individuals below certain income thresholds and encompasses a wide array of benefits, such as case management; physical, occupational, and speech therapies; and rehabilitative services that are often used by individuals with autism. The [Early and Periodic Screening, Diagnostic and Treatment \(EPSDT\)](#), the child health portion of Medicaid, mandates the provision of medically necessary services found at section 1905(a) of the Social Security Act to Medicaid beneficiaries under the age of 21. EPSDT ensures that children and adolescents receive appropriate mental health, developmental, and specialty health services. Outside of Medicaid, there may be large disparities in insurance coverage and reimbursement rates based on differences in state health coverage mandates.

Insurance coverage remains an important component to ensuring access to and utilization of autism services and supports. By 2019, all 50 U.S. states had enacted private autism insurance mandate legislation requiring coverage of autism-related services.<sup>31</sup> Further, forty-seven of these states clearly specify coverage for ABA in their mandates.<sup>32</sup> These insurance reform mandates have proven effective, with no significant differences between privately and publicly insured children on receiving developmental services and behavioral treatment.<sup>33,34</sup> However, disparities remain with privately insured children with autism being less likely to have health insurance plans that covered a fuller range of needed services compared to children on public insurance.<sup>33</sup>

The medical home model of care, developed by the American Academy of Pediatrics, is a family-centered teams approach to providing and coordinating medical care and facilitates communication of condition-specific needs and smooth transitions between providers/offices.<sup>35</sup> Research has shown that

the medical home model facilitates access to care for autistic children. Parents of autistic children who participate in a medical home report fewer unmet needs than those who did not.<sup>36</sup> Autistic young adults who participated in a medical home were also three times as likely to receive healthcare transition services as those without a medical home.<sup>37</sup> Research also shows that the presence of a medical home is associated with increased parent reports of shared health care decision-making, receipt of preventive pediatric care, and reduced frustration in accessing services.<sup>38</sup> This suggests that a medical team approach to pediatric care can facilitate the provision of organized and coordinated healthcare supports and services for people with autism and their families.

[Medicaid Home and Community Based Services \(HCBS\) waivers](#) can help to meet the service needs of people with autism and decrease their unmet healthcare needs.<sup>39</sup> Further, having choices in the selection of services and service providers, as well as control over day-to-day provision of services, strengthens the impact of the waiver services for both children and their families.<sup>40</sup> Among states that have enacted autism-specific waivers in the past decade, additional attention may benefit older adults on the autism spectrum, many of whom may need ongoing services and supports for maximal independence and life course outcomes.<sup>41</sup>

### Appropriate Services to Address Health and Safety Concerns

Autistic people are more likely to have coexisting mental and physical conditions. These higher rates of health complications throughout the life course may result in elevated risk of early mortality. Research shows the causes of death to be diverse, including chronic conditions (such as cancer and seizures), accidents (such as choking on food and accidental poisoning), and health complications due to medication side effects.<sup>42</sup> Additionally, the research suggests that even though autistic individuals die of suicide and present with more self-harm than do their non-autistic peers, the association can be explained by co-occurring mental health conditions.<sup>43,44</sup> To address these significant health disparities, it is necessary to increase implementation of services, evidence-based approaches, and trauma-informed care.<sup>45-47</sup> Additional research around improved access to appropriate preventative mental health services and supports across the lifespan may also ameliorate mortality rates seen in the autistic population.

Wandering, or elopement, behavior presents additional safety risks for some individuals with autism. Approximately one in four children with autism exhibit wandering behaviors away from supervision each year, with about one in five cases resulting in fatalities.<sup>48</sup> Additionally, individuals with autism spectrum disorder (ASD) are a high-risk group with an increased risk for drowning.<sup>49</sup> Most injuries sustained from wandering episodes include drowning and motor vehicle accidents. Because the risk for elopement increases with the severity of autism and with co-occurring intellectual disabilities, many of the individuals at greatest risk have limited language and may not be able to tell first responders their names, addresses, or phone numbers if they get lost.<sup>50</sup> In 2017, Congress passed [Kevin and Avonte's Law](#), honoring the memory of two boys with autism, Kevin Wills and Avonte Oquendo, who drowned while wandering. The National Autism Association (NAA) also produces information and resources on prevention and management of wandering for parents and clinicians.<sup>51</sup> Additional resources are needed to adequately support and train caregivers on the risks of wandering. Such resources could include increased access to tracking mechanisms, improved IEP changes to address wandering, and additional support from pediatricians on wandering mitigation strategies.<sup>52</sup>

There is a need for the healthcare system to emphasize increasing access in underserved populations and cultural competency among service providers. Language barriers have already been noted as a factor in the decreasing number of hours of direct services received by non-English speaking families compared to English-speaking families.<sup>53</sup> For example, a substantially lower percentage of

Latino children receive school-based occupational therapy (OT) and physical therapy (PT), and a moderately lower percentage receive PT outside of school compared with non-Latino White children.<sup>54</sup> Additional research is needed to improve access to supports and services for families with limited English proficiency. Further, there is a need to understand and consider diverse experiences, preferences, and values in the design and provision of autism services for families and their children.<sup>55</sup>

Overall, it is important to continue to support research to test quality services and supports as well as evidence-based interventions that can be scaled up and implemented in any community setting and be accessible through medical coverage. Although additional research in the utilization of community-based organizations is needed, studies suggests that with greater adoption, implementation, and sustained utilization of evidence-based practices within community-based care settings, there can be significant improvement of appropriate service delivery to individuals with autism.<sup>56,57</sup> Additionally, efforts to improve access to quality autism-related mental health services would require explicit attention to the organization and financing of these mental health services.<sup>58</sup>

### Ensuring Individualization, Choice, Person-Centered Planning, and Self-Direction

People with autism may encounter a wide range of support needs across their lifespan. Due to the heterogeneity within the autism community, corresponding supports and services should optimally be tailored to the needs of each autistic individual. The concept of quality of life (QOL) serves as a conceptual and assessment framework to develop person-centered planning as a basic principle to guide professional practice.<sup>59</sup> Validated QOL assessment instruments would be necessary for the measurement of personalized support trajectories to ensure that autistic individuals achieve optimal outcomes in the domains of life that they decide are most important to themselves.<sup>60</sup> However, additional research is needed around the use of QOL measurements, the outcomes associated with person-centered planning, and the shift away from deficits-based models of autism.<sup>61</sup>

There have been advancements in the incorporation of person-centered planning, particularly for transition-to-adulthood planning. Within healthcare transition, patient autonomy is frequently cited as the ideal goal during transition planning, citing positive health outcomes over time.<sup>62</sup> Additionally, shared decision-making models are more frequently being seen as a benchmark measure within a successful healthcare transition protocol for autistic individuals.<sup>63</sup> Additional research is needed around guardianship and alternatives to maximize self-determination and preserve choice.

The role of networks of support (i.e., family caregivers, providers, healthcare workers, etc.) in ensuring patient-centered care has been an emerging topic within academia. For example, while family caregivers provide 70-90% of care for autistic people living in the community, most healthcare providers do not meaningfully involve family caregivers as integral components to delivering person-centered care to autistic individuals.<sup>64</sup> In addition, the lived experience provided from patient- and family-centered care would be ideal in identifying systemic issues and “on the ground” solutions for local healthcare providers that can serve to optimize the supports and services offered in their facilities.<sup>65</sup>

### Caregiver Supports

One of the most frequently identified unmet needs by parent caregivers in the literature is the need for respite care, which is typically a service that allows primary caregivers to take some time away and leave the child in the care of other formal and informal caregivers.<sup>66</sup> Parent caregivers of children with developmental disabilities are more likely to develop mental health conditions, such as anxiety and depression, over the course of their caregiving.<sup>67</sup> In 2018, Congress passed the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#), paving the way for a national strategy to

support caregivers, including respite options. The development of these respite options must prioritize accessibility and affordability to achieve maximal utility.

Sibling perspectives are often missing from the discourse around caregiver supports. Sibling support groups are often the least commonly reported family support service available.<sup>68</sup> Further, although siblings generally report interactions ranging from promoting their sibling's development (e.g., promoting academic skills) to providing more targeted support for autism-related functional limitations, there is evidence of more extensive caregiving roles and parent-like roles among racially and ethnically diverse siblings.<sup>69</sup> Additionally, there is evidence that broad support for the non-autistic sibling of individuals with autism can potentially provide long-term benefits for both siblings, including decreased stress, improves social skills, and improved self-efficacy.<sup>70</sup>

There is a need to improve access to support resources in rural areas for caregivers of individuals with autism. Caregivers of individuals with autism report high levels of stress, social isolation, and poor mental health.<sup>71</sup> Social and emotional support may buffer negative effects of stress for caregivers of individuals with autism, however, those living in rural areas may be disadvantaged due to social isolation and increased distance from resources.<sup>72</sup> Healthcare professionals, including nurses, can play a fundamental role in supporting, educating, and connecting caregivers to other support services. It is important to identify and implement efficient and cost-effective ways to deliver evidence-based practices for autism to rural communities. Lessons learned during the COVID-19 pandemic highlight the potential benefit of telehealth supports and services for caregivers in rural settings in increasing behavioral parent training and navigation of complex health systems.<sup>73-75</sup>

Accessible services and supports for caregivers from underrepresented groups remains an area in need of additional attention. Addressing individual, family, and systemic barriers to autism-related service access for members of racial and ethnic minorities requires dedicated resources, implementation of explicit strategies and policies, and incorporation of the principles of cultural and linguistic competence.<sup>76</sup> Discrimination based on race and ethnicity continues to present an obstacle to many caregivers. For example, research shows that Black caregivers continue to face more obstacles such as systemic bias and interpersonal racism when seeking supports and services compared to White caregivers of autistic individuals.<sup>77-79</sup> Additionally, many families may forego family employment due to the long-term care of a child. These lost earnings were estimated to reach about \$18,000 per year, with families from underrepresented groups being disproportionately affected.<sup>80</sup> Affordable, evidence-based services available in culturally competent methods should be a priority for the benefit of caregivers from racial or ethnically underrepresented groups.

Family navigation can serve as an important support system for families of children with autism. Family navigators are professionals who engage with families to enhance access to early identification and services via shared navigation plans that help meet the family's priorities and goals when navigating systems of support. These navigation services have been found to be effective in improving access and adherence to services over time.<sup>81</sup> Comprehensive evidence-based family navigation services consist of key components including individually tailored, family-centered care coordination.<sup>82</sup> Typically, family navigation is designed to assist under resourced families in navigating potentially complex systems of care. Tools designed specifically for the development of shared navigation plans for families following a diagnosis of autism are currently limited.<sup>83</sup> In addition, the effectiveness of family navigation is related to multiple factors, including service timing, family factors, case management, and presumed service needs. As a result, these navigation services may be implemented differently across different health care delivery systems, resulting in highly variable initial outcomes and family experiences.<sup>84</sup> However, the evidence of the feasibility, acceptability, and potential efficacy of family navigation services at increasing access and reducing time to autism-related diagnostic services has warranted additional research and focus on this service.

Caregiver supports for parents of aging children with autism remains an area in need of additional research and focus. Aging parents of adult children with autism often experience declining health, as well as shrinking informal social support systems, while caregiver burden remains constant or increases.<sup>85</sup> In addition, costs associated with caring for an adult (e.g., medical care, paying for respite care, transportation, etc.) can increase over time, while aging parents' income may either remain constant or decrease, particularly as they face health challenges and changes in income due to retirement.<sup>86</sup> As the growing number of people with autism enter late stages of adulthood, supports for aging caregivers remains an area of urgent need and additional research.

## Outcomes, Quality of Services, and Service Needs

As the need for services and supports remains a constant throughout the lives of people on the autism spectrum, ensuring high-quality services is key to achieving positive outcomes. As autistic individuals age into adulthood, a frequently noted disparity is the dwindling amount of supports and services available compared to those available to younger children and adolescents with autism.<sup>87</sup> Unmet needs such as speech/language therapy, one-to-one support, occupational therapy, medication management, and social skills training often follow an exit from the educational system. This is typically referred to as the "service cliff" of autism-related services.<sup>88,89</sup> The potential losses in services and supports may occur more often for autistic individuals with co-occurring intellectual disability.<sup>90</sup> Youth with autism and co-occurring intellectual disability may already be more likely to experience unmet mental health care needs and receive poorer quality of care than the broader autistic population.<sup>91</sup> Avoiding a lapse in service provision during this critical time of transition into adulthood is an area of ongoing concern for the autism community.

The availability of services and supports is a key measure of their quality. Depending on state policies, autistic adults who need long-term services and supports may spend time on long waiting lists. These autistic adults and their caregivers report unmet needs around functional skills training, employment or vocational services, and mental and behavioral health services while waiting for HCBS services.<sup>92</sup> Recent legislation has been passed in some states to decrease waiting times.<sup>93</sup> Further disparities have been noted, as recent research suggests that the socioeconomic status of a neighborhood is a factor in availability and proximity of services.<sup>94</sup> Because most services for children with autism are delivered via outpatient models, logistic barriers, such as transportation, childcare, and job accommodations, must be addressed to enhance families' ability to appropriately access services.<sup>95</sup> Further research is needed on the quality and availability of services and supports.

Autistic individuals often report difficulty with achieving positive outcomes associated with independent living and employment.<sup>96</sup> Services and supports aimed at facilitating independent living for adults with autism should consider the challenges to independent living include autism symptomology, limited independent living skills, financial constraints, and lack of community integration and housing options.<sup>97</sup> There is a wide array of private and state-funded services aimed at supporting individuals with autism in competitive employment.<sup>98</sup> The efficacy and standardization of employment related supports and career readiness services across states has not been adequately examined.

## Housing, Supports, And Other Services Across a Continuum of Need

The right to self-determination includes decisions around housing and activities of daily living. This aspect of choice remains important in a person's ability to participate fully in their community of choice through independent living and residential supports. There is evidence that incorporating characteristics of self-determination into residential support programs may offer autistic young adults the skills to live independently.<sup>99</sup> Finding affordable housing options as autistic adults age remains an

issue of importance throughout the lifespan in order to avoid homelessness. Most state developmental disability agencies fund services in the areas of transportation and residential supports.<sup>100</sup> However, supports and resources for improving community participation regardless of residential status remains an area of need.<sup>101</sup> The [Housing and Services Resource Center](#) was launched in December of 2021, through a partnership between the U.S. Department of Health and Human Services and the U.S. Department of Housing and Urban Development, with the goal of affordable, accessible housing in community settings. The Center will seek to implement a federally coordinated approach to providing resources, program guidance, training, and technical assistance to public housing authorities and housing providers for various populations, including autistic adults.

The Supplemental Security Income program provides monthly financial assistance to individuals with disabilities who meet federally defined income, asset, and medical eligibility criteria. There has been a steady increase in the number of Supplemental Security Income (SSI) recipients with autism in recent years, despite overall declines in total SSI awards given to adults with mental disorders.<sup>102</sup> However, variations in SSI awards across states could lead to substantial differences in access to other benefits, including Medicaid and vocational rehabilitation services, which often depend on SSI receipt.<sup>103</sup>

Due to the heterogeneous nature of the autism spectrum, the support needs can vary drastically from person to person. There have been discussions around the more intensive supports and services required by autistic people with co-occurring intellectual disability and minimal language and their caregivers.<sup>104</sup> While there has been discordance in how to refer to autistic people who fall under this category of needs (e.g., “persons with high support needs,” “profound autism,” “severe autism,” “low functioning,” etc.), additional research is needed to identify how best to support autistic people who may require these services. The lived experiences of autistic individuals with higher support needs, their caregivers, and providers may be missing from studies analyzing broader trends in services and supports.

## Workforce Training and Development

Over the past decades, several states have enacted laws requiring health insurers to provide coverage for autism-related child health care services, including physical and behavioral health care; speech, occupational, and physical therapy; and applied behavioral analysis (ABA).<sup>105</sup> Although these state insurance mandates have been associated with a modest increase in certain aspects of the workforce (i.e., board certified behavior analysts), there are still workforce shortages in several professions that are critical in providing services to individuals with autism.<sup>106</sup> Primary care providers have often reported a lack of knowledge around a diagnosis of autism and the services and supports that may be required. Additionally, parents have often reported difficulties in accessing specialty care. Against this backdrop, there have been several recent initiatives seeking to further enhance the care primary care providers deliver for children with autism, including tele-mentoring initiatives like Project ECHO (Extension for Community Healthcare Outcomes), and guided curricula like the [Autism Case Training \(ACT\)](#) curriculum advanced by the Centers for Disease Control and Prevention.<sup>7</sup> Further, the National Council on Disability (NCD)’s Health Equity Framework recommends requiring comprehensive disability clinical-care curricula in all US medical, nursing and other healthcare professional schools and requiring disability competency education and training of medical, nursing and other healthcare professionals.<sup>107</sup> More information is needed, however, about the uptake of these initiatives and their impact on the services being received by autistic individuals.

Some autistic individuals may have contact with law enforcement and the broader criminal justice system and it is important that their needs are recognized and that appropriate services are provided.<sup>108</sup> Current research suggests that young adults with autism were not overrepresented in the



juvenile and adult justice systems, received similar charges and charge outcomes, and were as likely to reoffend as their peers.<sup>109</sup> However, by age 21, approximately 20% of youth with autism had been stopped and questioned by police and nearly 5% had been arrested.<sup>110</sup> Effective training models for law enforcement built around understanding and recognizing traits of autism, increasing practical skills around typical autistic behaviors (i.e., stimming, communication differences, etc.), and cultural responsiveness with regard to autistic people from underrepresented groups may improve stakeholder perceptions during these interactions and improve outcomes.<sup>111-114</sup>

Community health workers are often health workers who are also trusted members of the community they serve. They may serve a critical role in building community and individual knowledge through outreach and community education. These partnerships have also proven effective at building community trust and partnerships with underrepresented groups for the purposes of culturally sensitive recruitment into academic research.<sup>115</sup> Community health workers have been utilized in various communities to convey knowledge around autism and connect families to resources in their communities. Less is known around evidence-based provider trainings for the effective development of community health workers.

The literature on services and training the workforce relevant to providing services for older age autistic adults is minimal and represents a gap in the knowledge base. Caregivers employed by retirement homes and/or other long-term care facilities may be ill-prepared to accommodate the needs of the autistic population.<sup>116</sup> There is not enough known around the specific issues related to caring for this older population, and as such, this topic may be missing from the research literature and general conversation on services and policy relevant to autism.

## Coordination of Services

As autism-related services and supports become more specialized, there is a growing need for effective care coordination with providers across systems of care.<sup>117</sup> The interdisciplinary nature of the care required by autistic individuals will often necessitate different types of providers working in tandem to optimize positive outcomes. There is evidence that current measures of care coordination in national and state samples may fail to capture lower income, under resourced members from underrepresented racial and ethnic groups.<sup>118</sup> There may be other systematic barriers for families such as differences in the type and number of services supported by insurance plans and inequities and disparities in type and number of services available among geographic location. These complexities in the service system require proactive navigation to access early screening and other timely services.

Individuals with autism may require services provided through different agencies and paid for through different systems. Care delivered across these systems often is inefficiently and ineffectively coordinated. Additionally, the financial strain on families can differ depending on the type and coverage of their individual health insurance plans.<sup>119</sup> With the variance in the amount of co-occurring health conditions that may accompany a diagnosis of autism, care coordinating is needed to navigate appropriate coverage of certain services and supports.<sup>120</sup>

## Summary

Across their lifespan, autistic people may need a wide range of services and supports to maximize their positive outcomes and promote overall health and wellbeing. The Committee continues to highlight the need for researchers to focus on developing practical, affordable, and culturally humble services and support approaches that can be used in a variety of settings. These approaches should prioritize the implementation and efficient delivery of evidence-based practices within the communities of choice of each autistic individual. Effectively supporting caregivers and improving workforce training should remain a vital component of service delivery, especially when meeting the needs of diverse

populations. The service and support landscape across the United States remains complex and can seem like a daunting undertaking to successfully navigate through. Ensuring the delivery of high-quality, accessible supports and services throughout the lifespan should remain a priority in the pursuit of optimal quality of life for autistic people.

## Objectives

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

**Examples:**

- Identify best practices, including systematic evidence-based collaborative approaches, to scale up existing services and increase access to evidence-based interventions in communities.
- Test and implement effective healthcare services that increase the supply and quality of care.
- Develop approaches that scale up the use of evidence-based practices in the educational setting and address the gaps between research and practice.

**Objective 2. Improve systems navigation and develop effective services and supports for caregivers.**

**Examples:**

- Support research to understand and develop strategies to address health disparities, health inequity, and disparities in services access and utilization for underserved and underrepresented populations. Underserved communities include families with low socioeconomic resources, youth and adults with high support needs, and those who are racial/ethnic minorities.
- Develop culturally humble service provision strategies, improve the quality of care and perception of quality of care to encourage utilization, and increase person- and family-centered care as well as other best practices to reduce disparities.

**Objective 3. Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services.**

**Examples:**

- Develop better metrics and measurement tools for health outcomes of people with autism across the lifespan.
- Develop, test, and implement metrics and measurements for autism services, as well as Federal, state, and local programs.
- Quantify outcomes in order to inform effective service models.
- Continue research into determinants of service quality, including accessibility, continuity, and flexibility of services

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