Chapter 5: Services and Supports

What Services and Supports Are Needed to Maximize Health and Well-Being?

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

Introduction

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

There have been notable advancements in the services research portfolio from 2008 to 2020. In 2020, 9% ($34.8 million) of autism-related research funding from Federal agencies and private organizations addressed issues related to services and supports.[1] This reflects significant growth from 2008, when 2% of total funding ($4.2 million) was directed to research on services. There have been advances in recent years regarding the direction and priorities of autism services research and the incorporation of different perspectives, especially from those with lived experience.[2] This includes research focused on supportive services post-diagnosis and during times of transition, self-directed care, increased access to services and supports, identifying optimal ways to support the acquisition of life skills, research addressing disparities in underrepresented groups, and measuring the health, wellbeing, safety, and mortality of people with autism. Although there has been some growth in services research funding over the years, there is still a need for translation of findings to community practice, as the quality and accessibility of services for people on the autism spectrum remains uneven, particularly in lower-resource settings. [3] Members of the autism community have continued to voice the need for more services research that can significantly impact the current service infrastructure and those living with autism today. Adequate and sustained funding allocated towards services research will be needed to achieve the Question 5 Recommendations of the *IACC Strategic Plan*.

Every individual on the autism spectrum has a distinct and unique set of strengths and challenges and may need varying levels of support in different areas. For example, some individuals on the autism spectrum have accompanying language and/or intellectual disabilities (ID) or other co-occurring physical or mental health conditions that may require specialized or more intensive services supports across the lifespan. A wide variety of services and supports are available to help maximize health and well-being among children and adults on the autism spectrum. Although some of these may be covered by insurance or offered at no cost through federal and state programs, families and individuals often require assistance in connecting to additional specialists and resources and may be required to pay for certain supportive services out of pocket. The result is a "patchwork" system where families and individuals must identify available services and navigate multiple sources and sets of requirements, making it challenging to access and maintain connection to the specific services and supports that they need. Recent research has identified ongoing unmet needs for adequate, cost-effective services to alleviate some of the financial strain on autistic individuals and their families.[4] In addition, research has revealed that families with a member on the autism spectrum are more likely to experience poverty and outcomes such as food insecurity due to additional cost of care, disparate access to needed services, and loss of income resulting from parental job loss, and that this was heightened as a result of the COVID-19 pandemic[5, 6]. This highlights the need for continued efforts to strengthen the system of services and supports available to assist individuals with autism and their families.

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

Education System

Schools are one of the primary settings where children with autism receive intensive supports and services.[7] With the growing number of autistic students entering the education system, there is a need to standardize the methods by which eligibility for services is determined. The *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. IDEA classifies autism as a "developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance." However, many states, and even school districts within a given state, can differ in their interpretation of the "educational impact" required for an autism classification according to IDEA, given limited guidance to define this concept.[8] Research has highlighted discrepancies between educational eligibility for autism-related services as compared to clinical diagnoses of autism, where more girls than boys may be lost in educational vs. clinical diagnoses.[9] This inconsistency may result in the absence or lack of services provided to students with autism, or access to services under different eligibility criteria.[10] In order to match students with effective services and supports, classification systems need to be sensitive to the characteristics that are most valid and distinguish between students with autism-related traits and those without.[11] Determining eligibility criteria for appropriate, tailored educational supports and services remains an area of opportunity for continued research.

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

Currently, the public education system is not adequately preparing students with autism for adulthood. Research suggests that Individualized Education Program (IEPs) for students with autism in their final year of school may not be consistently meeting the standards outlined by law or best practice recommendations necessary for successful transition from high school.[16-18] Less is known around the preparation of autistic students enrolled in charter, private, and home schools. Before students graduate from high school, curricula could focus on building skills for students to be successful in the workplace, including introducing Project-Based Learning (PBL) and encouraging students to seek out paid apprenticeships. PBL helps prepare students for the workforce by building teamwork and interpersonal skills and allows them to explore their learning and communication styles. Studies show that project-based, team-centered problem-solving can help individuals build skills at their own pace and increase engagement.[19, 20] This could be due to the fact that PBL allows students to use practical thinking as they make decisions and discover solutions about issues that interest them.[21] Other programs, such as Unstuck and On Target, can help students build executive functioning skills, which are also essential for maximizing post-secondary outcomes.

Apprenticeships are paid positions that include on-the-job training integrated with classroom instruction and usually conclude with the individual earning a nationally recognized credential.[22] The Office of Disability Employment Policy (ODEP) 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.[23] Further research is needed to develop best practices to help youth with autism develop the life and vocational skills necessary to support successful outcomes after exiting the education system.

Healthcare System

Insurance Coverage

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

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

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

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

Research is also beginning to evaluate whether the type of health care coverage has an impact on the services an individual receives. A recent study found that privately insured children with autism are less likely to have health insurance plans that covered a fuller range of needed services compared to children on public insurance.[35] Additional work has found that children with autism enrolled in Medicaid were more likely to have visits to occupational therapists, physical therapists, and behavioral therapists compared to children on private insurance.[32] Furthermore, research indicates that children with autism-related HCBS Waivers are more likely to have outpatient visits and less likely to have inpatient visits and long-term treatment than children without HCBS Waivers.[36] A recent review found preliminary evidence that HCBS waivers for people with intellectual and developmental disabilities benefit states economically, reduce unmet healthcare needs, increase parental ability to continue working, and reduce racial disparities in care access.[25] Despite these promising developments, it is estimated that approximately 30% of children with autism still do not receive the services they need.[37] Further research in this area is needed in order to ensure consistency of care and services received by individuals with autism and their families.

Service Delivery Models

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

Mental Health Services and Supports

Co-occurring mental health conditions are more prevalent in the autism population than in the general population,[42] including anxiety disorders, depressive disorders, bipolar and mood disorders, schizophrenia, and attention-deficit/hyperactivity disorder.[43] Recent studies have also focused on “masking” or “camouflaging” behaviors in autism, which include strategies individuals may use to hide their autistic characteristics so they can fit in better socially. Masking creates stress for the individual, however, and can lead to mental health issues and burnout. Studies suggest that these behaviors are associated with mental health challenges such as depression, stress, and anxiety.[44-49] Research has also suggested that autistic children experience a greater number of adverse childhood experiences (ACEs) in their family and community environments that may later impact their mental and physical health.[50-52] ACEs include issues such as family divorces, deaths, abuse, neglect, family illness, incarceration, or substance abuse, discrimination, and poverty. Autistic students have reported that mental health issues interfere with their success in school and that they have difficulty identifying and accessing needed supports.[53-55] For both children and adults with autism, access to high quality mental and behavioral health supports to address these needs among autistic individuals is essential[56, 57]. Studies have also suggested that autistic people are at higher risk of suicide than the general population.[58] Progress is being made in understanding risks for suicide and developing tailored approaches to suicide prevention in autistic individuals.[59-61] Additional research efforts are working to bridge the gap between behavioral and mental health through the validation of new tools and instruments that can facilitate symptom recognition by both autistic people and professionals.[62]

Dental Care

Autistic individuals may struggle with maintaining healthy dental hygiene.[63, 64] This could be due to a combination of sensory issues related to sights, sounds, and smells while in dental provider offices, communication issues, and poor dental habits at home.[65] For some autistic individuals, intravenous (IV) sedation for dental procedures may be necessary, but the cost for anesthesia administration may not be covered by insurance, creating a burden for some families. Further, autistic children may have major risk of developing tooth decay, periodontal lesions, and alterations of the oral microbiome due to the aforementioned sensory issues, as well as oral trauma due to self-injury.[66] Many of these issues can be reduced through preventative approaches, such as personalized educational models, as well as environmental alterations to dental offices to accommodate sensory issues related to autism. Research is beginning to evaluate the effectiveness of environmental alteration approaches (e.g., dimmed lights, images shown on ceilings, calming music, and tactile pressure using weighted vests).[67] Additional work is needed to determine how to scale these approaches in various community service settings. Trainings for families to use with their children and for autistic adults, as well as trainings for dental health providers are emerging and may be one helpful approach.[68, 69] The National Institute for Dental and Craniofacial Research publication of a *Practical Oral Care Guide for People with Autism* is one example of recent educational efforts to address oral health in individuals on the autism spectrum.[70] In a recent study funded by NIDCD, researchers discussed how collaboration between dentists and occupational therapists to optimize the dental clinic environment and help autistic patients emotional regulation and familiarization with dental procedures can create an approach that works well for individuals with autism.[65, 70] For autistic adolescents and young adults, transition to different insurance coverage remains as a potential barrier to continued dental care, with the potential risk of a drop in coverage for a prolonged period of time or a lack of coverage for a particular procedure.[71] Additional research is needed in the area of improving access to cosmetic dental procedures and the physical and mental health benefits of these procedures.

Appropriate Services to Address Health and Safety Concerns

Many autistic people have coexisting mental and physical conditions.[72] These higher rates of health complications throughout the life course may result in elevated risk of early mortality. Research shows the causes of death to be diverse, including chronic conditions (such as cancer and seizures), accidents (such as choking on food and accidental poisoning), and health complications due to medication side effects.[73] Additionally, the research suggests that even though autistic individuals die more by suicide and present with more self-harm than do their non-autistic peers, the association can be explained by co-occurring mental health conditions.[74, 75] To address these significant health disparities, it is necessary to increase implementation of services, evidence-based approaches, and trauma-informed care.[76-78] Additional research around improved access to appropriate preventative mental health services and supports across the lifespan may also ameliorate mortality rates seen in the autistic population. Victimization remains a concern among autistic populations, particularly with regard to sexual violence, physical and online bullying/harassment, financial exploitation, and maltreatment.[79-81] Professionals and providers must be properly trained to provide optimal support for autistic populations experiencing victimization. In addition, there is a need for more training and supports to help autistic people learn how to recognize exploitative behavior, advocate for themselves, and seek help from others when needed. Individuals with communication challenges, intellectual disabilities, and/or high support needs may be particularly susceptible to victimization, health complications, and early mortality. Services to address health and safety issues must therefore be appropriately tailored to meet the needs of these subsets of the autism community.

There also is a need for the healthcare system to emphasize increasing access to health services in underserved populations and cultural competency among service providers. Language barriers have already been noted as a factor in the decreasing number of hours of direct services received by non-English speaking families compared to English-speaking families.[82] For example, a substantially lower percentage of Latino children receive school-based occupational therapy (OT) and physical therapy (PT), and a moderately lower percentage receive PT outside of school compared with non-Latino White children.[83] Additional research is needed to improve access to supports and services for families with limited English proficiency. Further, there is a need to understand and consider diverse experiences, preferences, and values in the design and provision of autism services for families and their children.[84]

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

Law Enforcement and Safety

Law enforcement plays a key role in responding to incidents involving the safety of individuals with autism and developmental disabilities. Wandering, or elopement, behavior presents safety risks for some autistic individuals and is one type of safety-related issue that often involves law enforcement. Approximately one in four children with autism exhibit wandering behaviors away from supervision each year, with about one in five cases resulting in fatalities.[88] Most of the adverse incidents resulting from wandering episodes include unintentional drowning and motor vehicle accidents. For example, in incidents of unintentional drowning near bodies of water around a child's residence, wandering was the most commonly reported activity that precipitated this outcome.[89] Improvements in swim skills have been observed in autistic children participating in learn-to-swim programs, however, additional focus must be provided on ensuring all autistic individuals have access to these swimming instruction programs.[90] Because the risk for elopement increases with the severity of autism and with co-occurring intellectual disabilities, many of the individuals at greatest risk have limited language and may not be able to tell first responders their names, addresses, or phone numbers if they get lost.[91]

In 2017, Congress passed Kevin and Avonte's Law, honoring the memory of two boys with autism, Kevin Wills and Avonte Oquendo, who drowned while wandering. The U.S. Department of Justice has led the implementation of Kevin and Avonte's Law, supporting numerous grant awards for wandering prevention and training of law enforcement departments across the U.S. on how to manage cases of wandering by children with autism and other developmental disabilities to maximize speed and safe return home of the children.[92, 93] In addition, The Department of Justice and Vera Institute have collaborated on a program called Serving Safely to train law enforcement on how to have safe interactions with individuals with mental illnesses and developmental disabilities in a variety of different law enforcement situations.[93] Additional resources are needed to adequately support and train caregivers and service providers on the risks of wandering. Such resources could include increased access to tracking technologies, improved IEP changes to address wandering, swim instructor trainings that focus on the needs of autistic students, and additional support from pediatricians on wandering mitigation strategies.[94, 95] Additionally, more research is needed in the utilization of outdoor programs to encourage physical activity outdoors and for the purposes of environmental exploration. Trainings that familiarize autistic individuals with how to safely interact with law enforcement and the use of ID cards and medical bracelets to help alert law enforcement to the needs of autistic people they may encounter have also increased the level of education of autistic people, their families, and law enforcement to increase the chances for positive and productive interactions.

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

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

People on the autism spectrum may have a wide range of support needs that evolve over the course of their lifespan. Due to the wide range of needs within the autism community, corresponding supports and services should optimally be tailored to the needs of each autistic individual. The concept of quality of life (QOL) serves as a conceptual and assessment framework to develop person-centered planning as a basic principle to guide professional practice.[103] Validated QOL assessment instruments are used to measure personalized support trajectories to ensure that autistic individuals achieve optimal outcomes in the domains of life that they decide are most important to themselves and their families.[104] However, additional research is needed around the use of QOL measurements, the outcomes associated with person- and family-centered planning, and a shift away from deficits-based models of autism.[105]

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

The role of networks of support (i.e., family caregivers, providers, healthcare workers, etc.) in ensuring patient-centered care has been an emerging topic 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.[109] In addition, the lived experience provided from patient- and family-centered care would be ideal in identifying systemic issues and "on the ground" solutions for local healthcare providers to optimize the supports and services offered to individuals with disabilities in their facilities.[110]

Navigation Services

Family navigation can serve as an important support system for families of individuals on the autism spectrum. Family navigators are professionals who engage with families to enhance access to early identification and services via shared navigation plans that help meet the family's priorities and goals when navigating systems of support. These navigation services have been found to be effective in improving access and adherence to services over time.[111] Comprehensive evidence-based family navigation services consist of key components including individually tailored, family-centered care coordination. [112] Typically, family navigation is designed to assist under-resourced families in navigating potentially complex systems of care. Tools designed specifically for the development of shared navigation plans for families following a diagnosis of autism are currently limited.[113] In addition, the effectiveness of family navigation is related to multiple factors, including service timing, family factors, case management, and presumed service needs. As a result, these navigation services may be implemented differently across different health care delivery systems, resulting in highly variable initial outcomes and family experiences.[114] However, the evidence of the feasibility, acceptability, and potential efficacy of family navigation services at increasing access and reducing time to autism-related diagnostic services has warranted additional research and focus on this service. Additionally, family navigation may help support autistic parents of young children, some of whom may be diagnosed as autistic as well.[115] There is a noted dearth in research around the service and support needs of autistic parents and the strategies that may help them serve as caregivers, highlighting an area for future research.

Caregiver Supports

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

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

Sibling perspectives are often missing from the discourse around caregiver supports. Sibling support groups are often the least commonly reported family support service available. [122] Further, although siblings generally report interactions ranging from promoting their sibling’s development (e.g., promoting academic skills) to providing more targeted support for autism-related functional limitations, there is evidence of more extensive caregiving roles and parent-like roles among racially and ethnically diverse siblings.[123] Additionally, there is evidence that broad support for the non-autistic sibling of individuals with autism can potentially provide long-term benefits for both siblings, including decreased stress, improves social skills, and improved self-efficacy.[124] Privately funded programs for support of siblings and sibling caregivers are emerging,[125] but there are more opportunities to develop this area to meet the needs of siblings of autistic individuals who may have a lifelong role in supporting their sibling.

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

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

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

Ongoing Areas of Need

Accessibility and Waitlists

The availability of services and supports is a key measure of their quality. Long waitlists have resulted in a two-year difference between the earliest signs of autism and the average age of diagnosis,[138] with minoritized populations waiting even longer to be evaluated.[139] Depending on state policies, autistic adults who need services and supports may spend time on long waiting lists as well. These autistic adults and their caregivers report unmet needs around functional skills training, employment or vocational services, and mental and behavioral health services while waiting for HCBS services.[140] Recent legislation has been passed in some states to decrease waiting times.[141] Further disparities have been noted, as recent research suggests that the socioeconomic status of a neighborhood is a factor in availability and proximity of services.[142] Because many services for autism are delivered via outpatient models, logistic barriers, such as transportation, childcare, and job accommodations, must be addressed to enhance families' ability to appropriately access services.[143] While there are indications that telehealth may be one way to deliver diagnostic services more efficiently to cut down on the wait time, further research is needed to establish the validity of diagnostic assessment through telehealth tools for children and adults and train and increase the number of service providers across a range of geographical and socioeconomic settings to connect individuals to timely diagnostic services.[144-147]

Families from racial/ethnic minority backgrounds are under-represented in evidence-based interventions and services in autism.[148-150] Language barriers have 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. For example, a substantially lower percentage of Latino children receive school-based occupational therapy and physical therapy as compared with non-Latino white children.[83] Additional research is needed to improve access to supports and services for families from diverse backgrounds and for whom English is not their primary language. Further, there is a need to increase cultural competency among service providers[151] and consider diverse experiences, preferences, and values in the design and provision of autism services for families and their children.[84]

The "Services Cliff"

As the need for services and supports remains a constant throughout the lives of people on the autism spectrum, ensuring high-quality services is key to achieving positive outcomes. As autistic youth transition to adulthood, a frequently noted disparity is the steep drop-off in the amount of supports and services available for adults compared to those available to younger children and adolescents with autism, particularly those offered through the school system under IDEA. [150] Unmet needs such as speech/language therapy, one-to-one support, occupational therapy, medication management, and social skills training often follow an individual's exit from the educational system and entry into the adult service system[152]. This drop-off in service availability and utilization upon reaching adulthood is typically referred to as the "services cliff.".[153, 154] Autistic individuals with co-occurring intellectual disability may be especially vulnerable to the effects of falling off the services cliff.[155] Youth with autism and co-occurring intellectual disability may already be more likely to experience unmet mental health care needs and receive poorer quality of care than the broader autistic population.[156] Most autistic individuals will continue to need some types of services or supports in adulthood, but many do not qualify for adult services.[157] It is estimated that approximately 26 percent of young adults on the autism spectrum receive no services – services which could help them become employed, continue their education, or live more independently.[157] Avoiding a lapse in service provision during this critical time of transition into adulthood is an area of ongoing concern for the autism community.[158, 159] More coordination of adult services is needed, as well as availability of adult services system navigators to assist autistic adults and caregivers in coordinating adult service plans.

Independent Living, HCBS, Transportation, and Self-Determination

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

There is a wide array of private and state-funded services aimed at supporting individuals with autism in competitive employment.[162] The efficacy and standardization of employment related supports and career readiness services across states has not been adequately examined. The Supplemental Security Income (SSI) program provides monthly financial assistance to individuals with disabilities who meet federally defined income, asset, and medical eligibility criteria. There has been a steady increase in the number of SSI recipients with autism in recent years, despite overall declines in total SSI awards given to adults with mental disorders.[163] However, variations in SSI awards across states could lead to substantial differences in access to other benefits, including Medicaid and vocational rehabilitation services, which often depend on SSI receipt.[164]

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

Services and support needs around transportation and community mobility for autistic individuals can vary, depending on their geographic area and individual goals, among other factors. Autistic individuals may encounter challenges in obtaining a driver's license, driving confidence and driving performance compared to neurotypical peers.[167] Additionally, access to public transportation is a predictor of improved community participation, as well as a significant predictor of a greater number of support service utilization.[168] Additional research is needed around strategies to facilitate public transportation travel training, although studies have begun examining travel planning mobile applications and related technologies in facilitating safe travel.[169] Transportation needs are an under-recognized barrier to increasing independence in general, and strategies to increase independence in mobility are needed.[167, 170, 171]

The right to self-determination includes decisions around housing and activities of daily living. This aspect of choice remains important in a person’s ability to participate fully in their community of choice through independent living and residential supports. There is evidence that incorporating characteristics of self-determination into residential support programs may offer autistic young adults the skills to live independently.[172] Finding affordable housing options as autistic adults age remains an issue of importance throughout the lifespan in order to avoid homelessness. There is a dearth of research around the types of homelessness autistic people experience and what barriers autistic people face when trying to exit homelessness.[173] Further, autistic traits may be over-represented among homeless people and autistic homeless people may show a distinct pattern of characteristics and needs, although further research is needed in this area.[174] Most state developmental disability agencies fund services in the areas of transportation and residential supports.[175] However, supports and resources for improving community participation regardless of residential status remains an area of need.[176] The Housing and Services Resource Center was launched in December of 2021, through a partnership between the U.S. Department of Health and Human Services and the U.S. Department of Housing and Urban Development, with the goal of affordable, accessible housing in community settings. The Center will seek to implement a federally coordinated approach to providing resources, program guidance, training, and technical assistance to public housing authorities and housing providers for various populations, including autistic adults.

Services for Individuals with Intensive Support Needs

Due to the wide array of needs and levels of needs across the autism spectrum, the supports needed by an individual can vary greatly from person to person. Autistic people with co-occurring intellectual disability and/or language disability are among those who often need more intensive supports and services across the lifespan.[177] Additional research is needed to identify how best to support autistic people who may require these kinds of services, which can include full time family or staff care. appropriate employment, day programs, medical services, daily life skills training, occupational therapy, communications supports, and other kinds of services. Their families may need additional supports as well including respite care. The lived experiences of autistic individuals with higher support needs, their caregivers, and providers may often be missing from studies analyzing broader trends in services and supports. However, individuals with fewer perceived or less intensive support needs may still require services and supports at various points of their lives and throughout various domains in life. For example, an independent autistic adult who may appear to have few support needs may go through periods when they need significant support in the area of mental or physical health or during major life transitions. As a result, all individuals on the autism spectrum need access to appropriate supports and accommodations tailored to their individual needs. In addition, thoughtful planning of public spaces and activities with attention to the principles of universal design, so that they are sensitive to the needs of individuals with various kinds of disabilities, including physical, intellectual and developmental, social, and sensory disabilities, can be helpful for everyone. For example, access to augmented and alternative communication (AAC) modalities and options for written communication in group activities, sensory-friendly environments, and automated or live captioning may be beneficial not only for individuals on the autism spectrum, but for people with other kinds of disabilities or people who do not have disabilities. Disability-friendly environments provide options for more community participation for everyone.

Workforce Training and Development

A significant barrier in accessing services is the shortage in the workforce of direct support professionals (DSPs)[178]. DSPs support people with disabilities to participate fully in their communities, in areas such as caregiving, support with daily activities of living, mobility assistance, accessing resources, emotional support, and employment support[179]. Because of these shortages, families may have to drive long distances to see providers and may experience delays or gaps in access to therapies and services[180]. Despite rising demand for DSPs, it is estimated that the median wage for direct care is approximately $13.00 per hour, with a significant proportion living below the federal poverty level and almost half relying on some form of public assistance[181-183]. DSPs are faced with a physically and emotionally demanding workload with limited training and inadequate supervision, leading to low job satisfaction and high rates of turnover. In 2018, 14 percent of DSPs reported not having health insurance and 71.3 percent reported having their own medical debt[184]. Addressing these issues within the DSP profession would greatly improve the availability of supportive services for people with autism of all ages.

Additional workforce-related barriers for autistic individuals and their families include difficulties accessing properly trained providers with expertise in working with people with autism.[181, 185-187] Over the past decades, several states have enacted laws requiring health insurers to provide coverage for autism-related child health care services, including physical and behavioral health care; speech, occupational, and physical therapy; and applied behavioral analysis (ABA).[188] Although these state insurance mandates have been associated with a modest increase in certain aspects of the workforce (i.e., board certified behavior analysts), there are still severe workforce shortages in several professions that are critical in providing services to individuals with autism.[189] Primary care providers have often reported a lack of knowledge around a diagnosis of autism and the services and supports that may be required.

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

There have also been several recent initiatives seeking to further enhance the care primary care providers deliver for children with autism, including initiatives offering tele-mentoring of providers like Project ECHO (Extension for Community Healthcare Outcomes), and guided curricula for providers like the Autism Case Training (ACT) curriculum advanced by the Centers for Disease Control and Prevention. [190] 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 increase access to health services through research-based screening and diagnostic procedures.[191]

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

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

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

Coordination of Services

An autistic individual's service needs are likely to vary at different points across the lifespan. Service providers, health professionals, educators, and direct support staff continually change across the lifetimes of people on the autism spectrum.[175] As autism-related services and supports become more specialized, there is a growing need for effective care coordination with providers across systems of care.[195] The interdisciplinary nature of the care required by autistic individuals will often necessitate different types of providers working in tandem to optimize positive outcomes. Supportive services may be obtained through a variety of sources: government-funded health insurance, private health insurance, out-of-pocket, federal, state and local services programs, or grants and foundations. In some cases, services are offered based on functional needs, rather than clinical diagnosis. Individuals with autism and their caregivers often put a great deal of time and effort into piecing together a "patchwork" of supportive services through many different payors and providers in order to obtain adequate services and supports to address different areas of need. There is evidence that current measures of care coordination in national and state samples may fail to capture lower income, under resourced members from underrepresented racial and ethnic groups.[196] Additional systematic barriers faced by many families include differences in the type and number of services supported by insurance plans and inequities and disparities in type and number of services available among geographic location. These complexities in the service system require proactive navigation to access early screening and other timely services.

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

Summary

Across their lifespan, autistic people may need a wide range of services and supports to maximize positive outcomes and promote overall health and wellbeing. The Committee continues to highlight the need for researchers to focus on developing practical, affordable, and culturally competent services and support approaches that can be used in a variety of settings. Whenever possible, these approaches should prioritize the implementation and efficient delivery of evidence-based practices within the communities of choice of each autistic individual. Effectively supporting caregivers, increasing the direct care services workforce, and enhancing workforce training are all vital to improving service delivery, especially to meet the needs of diverse populations and individuals across the autism spectrum. The 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 health, well-being, and positive outcomes for autistic individuals with all types and levels of disabilities and abilities.

Recommendations

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

Examples:

- Develop, test, and implement effective services that increase the supply and quality of care.
- Support research to identify best practices, including systematic evidence-based collaborative approaches and federal policies, that can be applied in a variety of settings, including low-resource settings.
- Develop approaches that scale up the use of evidence-based practices in a variety of community-based settings and address the gaps between research and practice.

RECOMMENDATION 2. Address disparities in service provision and improve access to services for all, including low resource and underserved communities and individuals and families with high support needs.

Examples:

- Support research to understand and develop strategies to address health disparities, health inequities, and disparities in services access and utilization for underserved and underrepresented populations, including families with low socioeconomic resources, youth and adults with high support needs, and those who are racial/ethnic minorities. Develop culturally competent service provision strategies, improve the quality of care to encourage utilization, and increase person-centered care as well as other best practices to reduce disparities.
- Develop approaches for systems navigation, caregiver supports, and other strategies that reduce stress on the individual and family system and increase accessibility of services.

RECOMMENDATION 3. Improve service delivery to ensure quality and consistency of services across many domains with the goal of maximizing the probability of positive outcomes and improving the value that individuals get from services.

Examples:

- Support training of general and specialty medical, dental, and mental healthcare and service providers in how to work successfully with patients with autism, including autistic adults with high support needs.
- Emphasize person- and family-centered planning to achieve individual goals.
- Expand the diversity and cultural competence of the service provider workforce.
- Develop improved metrics and measurement tools for health outcomes of people with autism across the lifespan, including individuals with high support needs.
- Quantify outcomes in order to inform effective service models.
- Continue research into determinants of service quality, including accessibility, continuity, and flexibility of services

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