



2022 Report to Congress on Supportive Services for Individuals with Autism

Report to the U.S. House of Representatives Committee
on Appropriations (H. Rept. 117-9)

Prepared by the
National Autism Coordinator
National Institute of Mental Health
National Institutes of Health

On Behalf of the
Office of the Secretary
U.S. Department of Health and Human Services



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INTRODUCTION



AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is a developmental disability (DD) identified in 1 in 44 children¹ and approximately 2 percent of adults.² Autism contributes to differences in areas including social interaction and communication, executive functioning, sensory processing, and motor coordination. These differences can impact social relationships and other aspects of daily living. Each individual on the autism spectrum has a distinct and unique set of strengths and difficulties 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 result in additional challenges and require specialized supports across the lifespan. Data from the Centers for Disease Control and Prevention (CDC)'s Autism and Developmental Disabilities Monitoring (ADDM) Network indicate that 35 percent to 52 percent of children on the autism spectrum have co-occurring ID.^{1,3}

Autism is a lifelong disability and an individual can be affected in varying ways throughout the life course resulting in different needs at different stages of life. The combination and degree of ASD-related challenges and co-occurring physical and mental health conditions can also differ greatly from one individual to another, creating support needs for autistic individuals that can range from modest to very intensive. A wide variety of services and supports are available to help maximize health and well-being among children and adults on the autism spectrum, many of which are provided under the Individuals with Disabilities Education Act (IDEA) through age 21 (depending on state law), or the Early and Periodic Screening, Diagnostic, & Treatment (EPSDT) benefit for children under age 21 enrolled in Medicaid, or funded by Medicaid's Home and Community-Based Services (HCBS) state plan and waiver programs. Some individ-

uals with intensive needs receive long-term services and supports (LTSS) through Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), though where possible, individuals with intensive needs can receive LTSS through the HCBS program and live in home and community-based settings. Additionally, some disability services are available through managed-care or at no cost through federal, state, and local programs. However, the availability, scope, and duration of supports varies by state, and some types of supportive services may not be reimbursable. Families and individuals often require assistance in connecting to additional specialists and resources and may pay for certain supportive services out of pocket, adding additional financial strain. In many cases, individuals and families cannot afford to pay, and go without needed services. This exacerbates already significant health equity issues and disparities in the provision of quality services. The result is a "patchwork" system where families and individuals must identify available services and navigate multiple sources and sets of requirements to access services, making it challenging to access and maintain connection to the specific services and supports that they need.

Autism continues to be a top national health priority, and enhanced and expanded service options, healthcare coverage, equitable access, and systems navigation support are important areas of need and opportunity in the effort to provide a robust system of supportive services for autistic individuals and their families. Federal agencies, private research and services organizations, advocacy groups, academia, state and local agencies, and other entities engage in collaborative efforts to improve relevant services and support systems and advance the evidence base on the benefits of interventions and services. This report describes the supportive services that are beneficial to improved outcomes for people with autism and reviews existing coverage policies for these services.

Please note: The terms "individuals with autism," "individuals with ASD," "autistic individuals," and "individuals on the autism spectrum" are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. The U.S. Department of Health and Human Services (HHS) respects the different opinions within the community on the use of this language and does not intend to endorse any particular preference. In addition, the terms "autism" and "autism spectrum disorder (ASD)" are used interchangeably throughout this document unless otherwise noted. In cases where the specific DSM-5-TR defined diagnosis of autism spectrum disorder (ASD) is discussed, that term is used.

LEGISLATIVE BACKGROUND

This *2022 Report to Congress on Supportive Services for Individuals with Autism* describes supportive services and resources for individuals on the autism spectrum and their families. A summary of the research evidence base on the benefits of these services is also provided, and existing coverage policies are reviewed.

In its **report** on the fiscal year (FY) 2022 appropriations for HHS, the House Committee on Appropriations stated the following:

“The Committee is aware that treatment regimens and care plans for autism will continue throughout the life of the patient and that clinicians often spend additional time on patient care by providing supportive services or helping caregivers connect with additional specialists and resources. These additional services are not typically reimbursable. The Committee directs the Secretary to identify the supportive services that are most beneficial to improved outcomes for autism patients, review existing coverage policies for these services, and provide a report on its interim findings no later than 180 days after the date of enactment of this Act.” (House Report 117-96, Page 233)

As the scope of supportive services for people with autism and related conditions and disabilities is very broad, federal activities related to supportive services are conducted by multiple federal departments and agencies. This report was coordinated by the National Autism Coordinator (NAC), National Institute of Mental Health (NIMH), National Institutes of Health (NIH), on behalf of the Office of the Secretary of the U.S. Department of Health and Human Services (HHS), with input from the Federal Interagency Workgroup on Autism (FIWA), the support of the NIMH Office of Autism Research Coordination (OARC) and the Office of National Autism Coordination (ONAC), and in collaboration with federal agencies and offices within HHS, as well as the U.S. Departments of Defense, Education, Housing and Urban Development, Justice, Labor, Transportation, and Veterans Affairs, and the Social Security Administration. All departments, agencies, divisions, and offices contributing to this report conduct activities related to individuals with ASD and/or target intellectual and developmental disabilities (IDD) more broadly while including ASD as a significant focus. Information for FY 2022 may not be complete, as this report was in preparation during FY 2022.



OVERVIEW OF COVERAGE POLICIES FOR SUPPORTIVE SERVICES FOR PEOPLE WITH AUTISM



There are a range of supportive services in different areas that can enhance quality of life for individuals on the autism spectrum. Across the lifespan, many services are funded by Medicaid’s HCBS benefit. However, individuals may require additional supports in various areas, and alternate sources of support are needed for those who do not qualify or receive HCBS. It is estimated that the lifetime cost for an individual with autism without ID in the United States is \$1.4 million, rising to \$2.4 million for an individual with co-occurring ID.⁷ Approximately 79 percent of these costs are incurred by needed services, including non-medical services. As only some of these costs may be covered by federal benefits, private health insurance, and/or free government or community-based programs, there remains an obvious unmet need for ways to provide or support adequate, accessible, and cost-effective services to alleviate some of the financial and navigation strain on autistic individuals and their families.

While autism is a spectrum with various functional needs across individuals, all individuals who meet diagnostic criteria for ASD must have “clinically significant impairment in social, occupational, or other important areas of current functioning.”⁴ Although the need for supportive services is clear, these supports may vary from situational to comprehensive, and there is not always a clear pathway to ensuring that all of an individual’s support needs are met. This is in part due to the fact that autism can impact many different domains of functioning to different degrees, resulting in wide variation in the health and service needs from one individual on the autism spectrum to another. Some individuals may need few services and supports at different stages of their lives, while others may need many intensive services and supports throughout their lives. Thus, there is no single approach to service delivery that will satisfy the needs of all individuals on the spectrum. 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. The types of evidence that are required for coverage may vary from

one payor or service provider to the next. 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. Even with this effort, needed services and supports can be lacking or missed due to unaffordability, unavailability, lack of knowledge about the services available, or the complexity of access. They often require assistance in connecting to additional specialists and resources and may pay for certain supportive services out of pocket, causing financial strain, or forgo needed services due to unaffordability or inaccessibility, exacerbating already significant health equity issues.

Adding to the complexity of supportive service needs is the fact that an autistic individual’s service needs are likely to vary and evolve 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.⁵ Some services are targeted to young children, some to adolescents, some to adults, and some are relevant to all age groups. In addition, there are consequential changes in the expectations and legal responsibilities from childhood to adulthood that impact the types and focus of supports at different life stages.

In the United States, children with disabilities such as autism receive support from and are dependent on caregivers and systems of care that support their learning, such as the educational system. The IDEA, amended in 2004 as the Individuals with Disabilities Education Improvement Act, requires the provision of a free appropriate public education to all eligible children with disabilities ages 3-21 (depending on state law); the provision of early intervention services to eligible infants and toddlers with disabilities from birth to age 3 (or older depending on state law); and, in part, enables access to healthcare, nutritional, safety, and educational services, providing a core source of support across all communities. The role of supportive services for autism and other DD in childhood focuses on identifying and addressing challenges and building skills across key develop-

mental domains, such as communication and learning. Early intervention services such as speech/language therapy and behavioral interventions can help infants and toddlers with disabilities learn motor, social, communication, and daily living skills. Research has shown that these types of services can greatly benefit a child’s development.⁶⁻¹⁴ These services are critical, as earlier intervention has been associated with better outcomes later in life.^{15,16}

Under **IDEA** Part C, young children do not need a diagnosis of autism to begin receiving federally mandated services for related developmental issues such as speech delay and other communication and behavioral difficulties. Children with disabilities who meet the eligibility criteria qualify for special education and related services provided through the IDEA, which includes individualized services for ASD. Medicaid is required to provide ASD-related coverage for certain services and are available to the public if they meet eligibility criteria.^{17,18}

Some states offer Medicaid waiver programs, enabling states to waive the standard rules that apply to the Medicaid program to expand coverage or improve care for a target population. However, states differ in eligibility criteria for the waivers, how many people can enroll, and what services the waivers cover.¹⁹ Some states’ Medicaid HCBS waivers provide services to eligible children with ASD or DD regardless of family income and in home and community-based settings rather than in institutional or other isolated settings.^{20,21,22} Research indicates that having choices in the selection of services and service providers, as well as control over the day-to-day provision of services, strengthens the impact of the waiver services for both children and their families.²³

As ASD affects individuals across the lifespan, many individuals on the autism spectrum receive supportive services as children and continue to need services through adolescence and adulthood.²⁴ As autistic individuals age into adulthood, a frequently noted disparity is the lower availability and access to supports and services compared to those for younger children and adolescents with autism.²⁵ Approximately 50,000 youth with ASD leave high

school each year in the United States.²⁶ Needs for services such as speech/language therapy, one-to-one support, occupational therapy, medication management, and social skills training often go unmet following an exit from the educational system, as IDEA no longer applies after high school graduation or when an individual reaches the age of 22. The drop-off in services is typically referred to as the “services cliff.” Studies suggest that this drop-off in services may in fact begin to be experienced even before exiting high school, particularly for autistic individuals without co-occurring ID.²⁷ Research has found that individuals who were active users of services under IDEA receive far fewer services in adulthood, suggesting that many who may continue to need services in adulthood are not receiving them.^{28,29,30} Furthermore, studies indicate that 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 to adulthood.²¹⁻²³

Transition to adulthood has a number of implications for individuals with disabilities who may have continuing needs for support in adulthood. After exiting the school system, individuals may receive government-funded health and financial support and assistance through Medicaid and/or Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), but there may be a considerable lag in access to services resulting from re-evaluation of eligibility for Medicaid at age 18 or loss of health insurance coverage under a parent’s health insurance policy at age 26.³¹ In addition, in the United States, 18 years of age is the age of majority, or legal adulthood, where a significant change in rights and responsibilities goes into effect, unless a person is deemed incapable of making sound self-care decisions through a legal process. This transition is a significant change where individuals are expected to become self-supporting and to be increasingly responsible for their own housing, safety, self-care, vocational, and other adult needs. Accordingly, the focus shifts from building skills and learning to the logistics of having a safe place to live and, ideally, an advanced education and vocational path along with

opportunities for an engaged, healthy adult life. Individuals and families experience a divergence in what the future paths and support needs may be, and there is no longer a core source or highly-coordinated governmental system of supports such as was provided to individuals from birth through age 21. In addition, families have to transition from full-time care of a child to a new phase, which can involve facilitating growth towards adult activities and independence, and in some cases, this also means planning for lifelong supports, care, and succession planning. These dynamics add to the increasingly complicated efforts needed to navigate whatever services may be available from federal, state, and local sources. Many adult services are embedded into systems geared towards individuals with significant ID or are based on disability as defined by employment criteria. Many adults with autism, particularly those without ID, do not meet eligibility for the supports they may need to engage in employment or to support independence and daily living skills.

The adult service system is premised upon eligibility for services, usually due to significant functional or vocational limitations. Adults with autism and other DD become part of a larger “disability” community that also includes people with acquired disability due to injury, health conditions, or aging. The larger “disability” umbrella includes up to **26 percent** of adults. Thus, adults with autism face service systems that are under increased demands and may have difficulty finding providers with experience in working with autistic individuals. Adults with autism who qualify for SSI may continue to receive Medicaid coverage. Medicaid also covers LTSS, including institutional care in nursing facilities and, in some cases, non-specialized placements for people with disabilities. In the past, Medicaid coverage was generally limited to those who needed institutional care in nursing facilities, but Medicaid HCBS allows beneficiaries to receive the care they need in their homes and communities. Beyond healthcare, many adults with ASD face challenges and barriers to accessing additional services, in areas such as employment and housing. **Medicaid HCBS** can help

adults with ASD access these services by providing certain non-medical services, such as supported employment services and case management services that can help make connections to other supportive services (e.g., housing and food supports).

Depending on state policies, autistic adults who need services and supports may not be able to access them. While HCBS through the home health benefit are mandatory, additional Medicaid HCBS often depend on optional HCBS authorities such as 1915(c) waivers that require people to meet an institutional level of care. HCBS waivers allow states to limit how many people receive services, and limited waiver slots in states can also be a barrier to access. While not a true measure of unmet need as not all states screen for Medicaid eligibility prior to adding people to waiting lists, in 2021, **656,000** people across the United States were waiting for an available waiver slot. Different eligibility criteria and administrative procedures make accessing these services and supports challenging. Recent legislation has been passed in some states to decrease waiting times, but autistic adults and their caregivers continue to report unmet needs around functional skills training, employment or vocational services, housing supports, and mental and behavioral health services while waiting for HCBS.³²

The 2016-2017 Interagency Autism Coordination Committee (IACC) Strategic Plan for Autism Spectrum Disorder includes services and supports as a top priority: “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.” The scope and range of needed services is broad, and this report details the key types of ASD supportive services that may or may not be included in current coverage policies or through a variety of federal, state, and local programs. Through improved coverage, availability, and access, the opportunity to obtain high-quality services and supports will help to improve the health and well-being of individuals on the autism spectrum across the lifespan.



RESEARCH

ON SUPPORTIVE SERVICES THAT ARE BENEFICIAL TO IMPROVED OUTCOMES FOR PEOPLE WITH AUTISM



The combination and degree of characteristics can differ greatly from one autistic individual to another, resulting in a diverse array of service needs within the autism community. The following is a list of examples of the many kinds of services and supports that are accessed by individuals with autism and their families. Some services are related to health while others are related to other aspects of well-being. References are provided regarding the current evidence base in support of beneficial outcomes for each service type. Some of these services have a strong evidence base supporting their use. In contrast, other service types are newly emerging and may have little supportive evidence currently available. Some of these services are covered under health insurance programs or other federal or state benefits; some are provided at low or no cost by federal, state, and local programs; and some are not covered by health insurance or federal or state benefits and can only be accessed by paying out of pocket. Services are listed by type, but it is important to note that there are many variations in approach, intensity, duration, and setting for each type of service.³³

- Diagnostic services
- Applied behavior analysis (ABA) and other behavioral interventions
- Speech/language therapy and augmentative and alternative communication (AAC) supports
- Assistive technology, specialized medical equipment, and associated services and training
- Technology-based, robot-assisted, and artificial intelligence interventions
- Physical therapy
- Occupational therapy and sensory integration therapy
- Academic services and supports
- Mental and behavioral health services and supports
- Self- and family-directed services and supports
- Family/systems navigation
- Caregiver-, family-, and peer-mediated interventions
- Family and caregiver supports

- Support, social, and community groups
- Peer-to-peer mentoring and autistic-led support groups
- Caregiver supports and respite care
- In-home caregivers, aides, and nursing care
- Dietary and nutritional support
- Therapies for sleep disorders
- Environmental assessment and modifications
- Transportation vehicle modifications
- Empowerment, education, and advocacy training and services
- Healthcare transition (HCT) services
- Employment services, vocational rehabilitation services, job coaching
- Housing support services
- Remote services
- Recreational therapies
- Complementary and alternative interventions (e.g., music, animal-assisted, emotion regulation, and mindfulness therapies)

Diagnostic services

Timely delivery of **diagnostic services** is essential for linking individuals on the autism spectrum with needed interventions, services, and supports that improve outcomes in social and communication domains.³⁴⁻³⁷ Individuals who may be on the autism spectrum are typically referred for a diagnostic assessment, which is typically conducted through a structured parent interview using instruments such as the Autism Diagnostic Interview-Revised (ADI-R) and a clinician assessment of the individuals using the activity-based Autism Diagnostic Observation Schedule-Second Edition (ADOS-2).³⁸ However, long waitlists for diagnostic services have contributed to a two-year difference between the earliest signs of ASD and the average age of diagnosis,³⁹ with minoritized populations waiting even longer to be evaluated due to inequities in availability of health services.⁴⁰ CDC surveillance data shows improvements in earlier diagnosis of young children in recent years, though

ASD identification still varies based on race and ethnicity, geographical location, and the presence of co-occurring ID.^{41,42} The recent development of telehealth tools such as the TELE-ASD-PEDS has enabled remote diagnostic evaluation of children with signs of autism.⁴³ Such tools have been shown to be acceptable for both parents and practitioners,⁴⁴⁻⁴⁶ and may lead to further improvements in early and timely diagnosis for children with ASD.

For adults, the ADOS-2 is the standard instrument used for diagnosis of ASD. However, limited knowledge is available on the manifestations of autism in adults, and misdiagnosis is common due to a lack of standardized diagnostic criteria for adults with suspected ASD and lack of access to early medical records and developmental history that inform ASD diagnosis.^{47,48} Additionally, there is a lack of providers who are trained in diagnosing ASD in adults, resulting in even longer delays.⁴⁸ Additional research is needed to improve our understanding of how compensatory strategies, masking, and/or camouflaging of autistic traits may affect clinical presentation and diagnosis.^{49,50} Improvements to diagnostic tools and services for both children and adults will help to ensure that all individuals on the autism spectrum can access services and supports that improve health and well-being.

Applied Behavior Analysis and Other Behavioral Interventions

Applied behavior analysis (ABA) and **other behavioral interventions** can be helpful in addressing emotional and behavioral issues in autism. ABA and therapies based on its principles are the most commonly researched and practiced behavioral intervention for autism.⁵¹ Current ABA practices include the Early Start Denver Model (ESDM), Discrete Trial Training (DTT), Pivotal Response Treatment (PRT), and Early Intensive Behavioral Intervention (EIBI). The basic premise of these methods is positive reinforcement of desired behaviors to develop necessary skills and reduce undesirable or harmful behaviors, such as self-injurious behaviors. A meta-analysis of ABA studies showed that ABA resulted in significant improvements in socialization, communication, and expressive language.⁵²⁻⁵⁵ Naturalistic Developmental Behavioral Interventions (NDBIs) are based on ABA

principles but use a strengths-based model to teach skills in a naturalistic environment, such as during play or other daily activities, with natural rewards.⁵⁶ Research indicates that NDBIs can help to support social communication, language, and play skills development.⁵⁷ **Relationship Development Intervention (RDI)** is a behavioral intervention that focuses on building social and emotional skills, with primary caregivers trained as the primary therapist. Further research on RDI is needed, but one study indicates beneficial outcomes.⁵⁸ Another relationship-based behavioral intervention is Floortime, in which therapists and parents engage children through the activities each child enjoys. Research has shown benefits of Floortime for emotional development in children with autism.^{59,60} These interventions are sometimes covered by insurance.

Speech/Language Therapy and Augmentative and Alternative Communication Supports

Spoken language can be a significant barrier to communication for individuals on the autism spectrum.⁶¹⁻⁶³ **Speech-language therapy** can help people with ASD improve their abilities to communicate and interact with others.⁶⁴ This type of therapy focuses on verbal skills, such as correctly naming people and things, and better explaining feelings and emotions. Speech-language therapy can also teach nonverbal communication skills, such as using sign language or picture symbols to communicate (**Picture Exchange Communication Systems, or PECS**). A randomized controlled trial from 2012 found that speech and language therapy in a sample of school-aged children with and without autism had the greatest benefit for learning pragmatic skills, such as conversational ability, classroom learning, and social communication.⁶⁵ For older children and adolescents with developmental language disorders (which may include those with autism), research indicates that one-on-one intervention with a speech language pathologist can help to improve language skills.⁶⁶ Several **states** have begun enacting laws that require health insurers to provide coverage for autism-related healthcare services, which includes speech therapy and Augmentative and Alternative Communication (AAC) devices.

AAC supports serve as communication alternatives to speech. Some AAC supports are in the form of communication software applications that can be run on personal devices such as tablets or laptops that help individuals with autism communicate and maintain communication autonomy.⁶⁷ Research studies have demonstrated multiple benefits of using AAC for people with autism, including basic access to communication using nonspeech methods, requesting functions, and increased social communication.⁶⁸⁻⁷¹ Under IDEA, school districts are responsible for providing **assistive technology**, such as AAC, as described in a child's IEP. Learning to use AAC usually requires some kind of support or training from a professional at first. Medicaid, HCBS waivers, or private health insurance may cover the cost of AAC software, devices, and services for eligible adults with autism. The state **Assistive Technology Act** program provides information on these programs in each state and other **mechanisms for acquiring devices**, including cash loans, rent-to-own, or ways to obtain previously owned devices.

Assistive Technology, Specialized Medical Equipment, and Associated Services and Training

Individuals with autism may require **assistive technologies** and/or **specialized medical equipment**. They and their caregivers must receive education, training, and services to learn how to use and operate these devices. Examples of the types of equipment may include: AAC devices (see section on speech-language therapy above), epilepsy/seizure monitoring devices, other wearable sensors, Continuous Positive Airway Pressure (CPAP) machines to address sleep conditions,^{72,73} technologies that focus on executive function and/or socialization skills, as well as swings and other sensory/motor equipment.

Technology-based, Robot-assisted, and Artificial Intelligence Interventions

Scientific evidence for the effectiveness of **technology-based** or technology-enhanced interventions for the autistic population has increased. Telehealth, which has become widespread since the start of the COVID-19 pandemic, uses technology such as video-conferencing to allow specialists and care providers to deliver interventions remotely (see also Remote services below).⁷⁴ Extended reality (XR) technology encompasses both virtual and augmented reality, giving users an immersive and interactive environment. Rapid advancements in XR technology over the past few years have led to its application in interventions for individuals on the autism spectrum to improve social communication skills, emotion regulation and control, and daily living skills, with positive results.⁷⁵⁻⁷⁷ Virtual reality and covert audio coaching systems have also helped autistic adults develop and hone work and vocational skills and expand access to employment services.⁷⁸⁻⁸¹ **Robot-assisted technology** and **artificial intelligence (AI)** have also been used in recent years to assist individuals on the autism spectrum with developing learning and social skills.⁸²⁻⁸⁷

Physical Therapy

Physical therapy (PT) is often used by people with autism who have pervasive gross motor impairments such as poor visuomotor and bilateral motor coordination, as well as postural impairments in static and dynamic balance.⁸⁸⁻⁹¹ Impaired motor skills and atypical functional connectivity of the sensorimotor system have also been identified in older adults with autism.⁹² PT includes activities and exercises that build motor skills and improve strength, posture, and balance. Different types of PT that have been shown to be effective for children with autism include dance movement therapy⁹³ and aquatic programs.⁹⁴ Research has also shown that PT can help address gross motor delays in young children with autism.⁹⁵ Motor, physical activity, and exercise interventions have shown positive outcomes in alleviating social, behavioral, cognitive, and motor impairments in children and adults with autism.⁹⁶⁻⁹⁸

Occupational Therapy and Sensory Integration Therapy

Occupational therapy (OT) and **sensory integration therapy** can help to address the range of challenges experienced by people with ASD, including participation in and performance of activities of daily living, education, work, leisure, and social activities.⁹⁹⁻¹⁰⁰ For children with autism, OT programs often focus on play skills and learning strategies. OT services for autistic adolescents and adults often involve relevant sensory integration, relationship-building, executive functioning, self-care, and social skills interventions.¹⁰¹ OT services are the second-most used services by autistic people in the United States, behind speech and language therapy.¹⁰² Sensory integration therapy, a form of OT that helps to improve a person's sensitivities to sensory stimuli that may be overwhelming or cause discomfort, has been shown to be effective in autism and has demonstrated positive outcomes for improving individually generated goals of functioning and participation.^{103,104} OT has also been shown to positively influence dental health visits.¹⁰⁵ Autism-specific training for occupational therapists could help to improve confidence among providers and incorporation of current evidence-based practices (EBPs).¹⁰⁰

Academic Services and Supports

Autistic students have a wide array of **academic services and support** needs at varying levels of schooling, from early childhood programs all the way through post-secondary education. Interim services and supports can start early, when a child is suspected of having a delay or disability and the family is waiting for the local agency responsible for implementing IDEA to determine eligibility. Once a disability is diagnosed, children can continue to receive **individualized services and supports** to meet their needs and fully participate in the full range of activities and services. School-age children can receive services such as speech-language,

psychological, physical, and occupational therapies; academic tutoring and peer-mentoring; as well as assistive technologies, in the school setting.

School-based support can also be provided through schoolwide approaches and frameworks such as **Positive Behavioral Interventions and Supports (PBIS)** and anti-bullying programs.

Research indicates that the most common special education service received by students with ASD is speech-language therapy.¹⁰⁶ Focus on these skills is vital, as recent studies have found that social communication skills and behaviors as early as kindergarten can predict future school outcomes for ASD students.^{107,108} A recent review on the effectiveness of school-implemented interventions for autistic students from preschool to high school found that EBPs help students gain necessary academic and social communication skills. A combination of focused interventions, such as reinforcement of desired behaviors, discrete trial teaching, and visual supports, were found to be promising.¹⁰⁹ Recent studies, however, find that not all schools fully implement EBPs.¹¹⁰⁻¹¹²

Particularly for older elementary and high school students, executive functioning and self-management are important skills to learn, and research shows the built education environment can play a universal design role in optimizing outcomes for these skills in students.^{113,114} **Project-Based Learning (PBL)** is an approach that can help prepare students for the workforce by building teamwork and interpersonal skills and allow them to explore their learning and communication styles.¹¹⁵ Autistic students may continue to need academic support as they transition into and navigate through postsecondary education.¹¹⁶⁻¹²² A recent analysis found 74 postsecondary institutions that offer autism-specific support across 29 states.¹²³ Expansion of these programs to meet the needs of autistic students at two-year institutions¹²⁴ will help to foster additional opportunities for academic success.

Mental and Behavioral Health Services and Supports

Mental and behavioral health services and supports can help improve the health and well-being of people with ASD. Mental health conditions are common among individuals with ASD.¹²⁵⁻¹²⁸ Research has 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.¹²⁹⁻¹³¹ ACEs include issues such as family divorces, deaths, abuse, neglect, family illness, incarceration, substance use, discrimination, and poverty. Mental and behavioral health supports early in life, trauma-informed care, as well as social and family supports and supports provided through social workers, can play a critical role in helping to address ACEs and prevent mental health issues later in life. Such supports are important across the lifespan as well, to address mental and behavioral health challenges that persist or arise during adolescence or adulthood, such as alcohol or substance misuse.

Co-occurring mental health conditions such as anxiety, depression, and attention deficit hyperactivity disorder (ADHD) are common issues that autistic individuals report as greatly impacting quality of life and thus have been the subject of growing emphasis in the field.¹³² Access to high quality mental and behavioral health supports to address these needs among autistic individuals is essential. Mental health care for people with ASD can take many forms, including psychotropic medication, psychotherapy, or behavioral management.¹³³⁻¹³⁵ Cognitive behavioral therapy (CBT) is a common approach, which has been shown to be efficacious in autistic people.¹³⁶⁻¹³⁹ Dialectical behavioral therapy (DBT), which targets emotion dysregulation, is being used to treat eating disorders, suicidality, and self-injurious behavior in autism.¹⁴⁰⁻¹⁴²

Recent studies have also focused on “masking” or “camouflaging” behaviors in ASD, which include strategies individuals may implement to hide their autistic characteristics. Studies suggest that these

behaviors are associated with mental health challenges such as depression, stress, and anxiety.¹⁴³⁻¹⁴⁸ Studies have also suggested that autistic people are at higher risk of suicide than the general population. Progress is being made in understanding risks for suicide and developing tailored approaches to suicide prevention in autistic individuals.¹⁴⁹⁻¹⁵² Work is also being done on ways to foster elements of positive psychology (e.g., resilience, self-compassion, optimism, etc.) among autistic individuals.^{153,154} Additional research efforts are working to bridge the gap between behavioral and mental health through the validation of new tools and instruments. One such validated instrument, called the Assessment for Concerning Behavior (ACB), can help to facilitate symptom recognition by both autistic people and professionals.¹⁵⁵ The Substance Abuse and Mental Health Services Administration (SAMHSA) has published a **toolkit** to support children with IDD who have experienced trauma.

Research has also focused on the efficacious delivery of mental and behavioral health supports. Autistic people who are not receiving care through the medical home model,^{156,157} and those who have co-occurring ID, are more likely to experience unmet mental health care needs.^{158,159} Project ECHO Autism, an online learning and guided practice model, has shown the potential for community-centered mental health models to increase access to needed services.^{160,161}

Self- and Family-directed Services and Supports

Self- and family-directed services and supports prioritize participant choice, control, and flexibility. Under this type of model, the individual and/or family is involved in all service planning and decision-making activities, which gives the individual and family greater control over their care.¹⁶² As the availability of services and Medicaid waivers increase, autistic individuals and families are able to coordinate care and be more involved in decision making. For families of adults with DD, research finds that participation in a participant-directed program is associated with fewer unmet service needs, increased satisfaction with

services, and improved community functioning.¹⁶³ For families of children with ASD, research demonstrates that families feel empowered and satisfied when allowed to choose their own providers.¹⁶⁴ This is associated with lower parental stress and improved family functioning.¹⁶⁵ Recent evaluation of families of children with ASD receiving Medicaid waiver services found greater involvement in service planning and coordination and delivery of behavioral interventions for their child.¹⁶² Self-directed and person-centered planning is additionally important for adolescents and adults with autism in prioritizing personalized supports and services for transition planning, employment, and community living.¹⁶⁶⁻¹⁶⁸

Family/Systems Navigation

Families of children with autism and autistic adults often experience challenges in navigating support and service systems. **Family/systems navigation** is a case management approach that helps families and individuals identify appropriate services and overcome obstacles (e.g., transportation, language, fear, and stigma) to access necessary diagnostic and treatment services and supports.¹⁶⁹⁻¹⁷² Disparities are experienced by low-income and racial/ethnic minority individuals and families in access to autism diagnostic and treatment services.¹⁷³⁻¹⁷⁵ Research has found that children, particularly those from underserved communities, are more likely to receive diagnostic services when their primary care clinic utilized family navigation management.^{176,177} More broadly, research findings indicate that family and systems navigation services are associated with improved child and family outcomes.^{178,179}

Caregiver-, Family-, and Peer-mediated Interventions

Studies show that **caregiver-, family-, and peer-mediated interventions** can facilitate social, cognitive, and language development in children on the autism spectrum.¹⁸⁰⁻¹⁸³ These interventions can also be cost-effective and reinforce family and peer support. A parent-mediated intervention targeted to joint at-

tention outcomes in toddlers with ASD has shown positive benefits.¹⁸⁴ Mind the Gap (MTG) is an intervention focused on parent engagement that provides education about ASD, service navigation, and other topics relevant to families whose children have a new ASD diagnosis. A recent pilot feasibility study showed promising results for MTG, and a randomized controlled trial is currently underway.¹⁸⁵

Peer-mediated interventions are used to increase social skills in children with autism and have also shown beneficial outcomes.^{186,187} Peer-mediated interventions engage typically developing peers as social models to improve social initiations, responses, and interactions. For example, there is increasing research on effective strategies to teach peers to be communication partners for individuals with DD using AAC.¹⁸⁸⁻¹⁹⁰ Future research can further explore how training involving peers and the whole family (including siblings) can be helpful for facilitating the development of skills for children on the autism spectrum.^{191,192}

Family and Caregiver Supports

Family and caregiver supports provide support for the parents and other family caregivers of autistic people or those with high support needs. In focusing on the needs of a family member with high support needs while also balancing other responsibilities, family caregivers can experience stress, burnout, and reduced mental and physical well-being. Family and peer mentoring supports are intended to enhance social support and improve caregiver well-being, but additional research is needed to demonstrate the efficacy of such programs. A review of randomized and cluster randomized controlled trials of peer mentor programs for parents and caregivers suggests that mentorship programs provide neither benefit nor harm. However, those who participate in such programs have indicated that they are valuable.¹⁹³ Peer mentor training programs, such as the Military Spouse Online Autism Relocation Readiness (MilSOARR) mentor training program, have shown promising benefits for caregivers.^{194,195}

Support, Social, and Community Groups

Support, social, and community groups, as well as group therapy can be of great benefit to people with autism and their families. Autistic people experience high rates of loneliness.³¹ Community support groups for autistic people can increase social participation and assist in skill-building in a variety of areas, including leisure, recreation, and activities of daily living. A systematic review of the evidence on social participation for autistic adults found that quality of life is facilitated primarily by social skills groups and other types of support groups.¹⁹⁶ For children with autism, social skills groups have been shown to improve overall social competence and friendship quality.¹⁹⁷

Peer-to-peer Mentoring and Autistic-led Support Groups

Peer-to-peer mentoring and autistic-led peer supports have also become an increasingly common tool to provide social support, especially in college settings, and emerging research suggests beneficial outcomes.^{198,199} Social support services are also frequently used by caregivers of individuals with autism,²⁰⁰⁻²⁰² where they receive both emotional and informational support.²⁰³ Sibling groups are less common but can be helpful in providing support and teaching skills for engaging with their autistic siblings.²⁰⁴ Research suggests that social networking sites and online groups can provide important social support for individuals with autism and their families, allowing them to communicate and engage with others in a comfortable way, obtain information, and share their experiences with the community.²⁰⁵⁻²⁰⁷

Caregiver Supports and Respite Care

Caregiver supports and respite care provide short term care for a child or adult that grants relief for primary caregivers. Research indicates that caregivers of children with autism may experience impaired mental health, including anxiety and depression,^{208,209} a poorer quality of life and well-being,

and higher levels of stress as compared to caregivers of typically developing children.²¹⁰ Respite care services can be beneficial to caregivers of individuals with autism in providing support, a break from parenting demands, and allowing time for the caregiver to care for themselves.

Studies have found that the number of hours of respite care families receive is positively related to improved marital quality, as parents reported reduced stress.^{211,212} In a study of single mothers of children with autism, respite care was also found to be beneficial for maternal outcomes.²¹³ Some parents have reported using acute hospital services as an entry point to accessing respite care. Barriers to respite care are often at a systems level, as many parents are not knowledgeable about the services available to them. Parents wishing to receive respite care may also face financial barriers and long waiting lists.²¹⁴

In-home Caregivers, Aides, and Nursing Care

There is very little research on autism services provided by **in-home caregivers, health aides, or nursing care**. Though many family caregivers provide primary or supplementary care for autistic individuals, a recent study found that most healthcare providers do not meaningfully involve family caregivers as integral components to delivering person-centered care to autistic individuals.²¹⁵ As described above, the use of health aides, nursing staff, etc., to provide respite care can be beneficial to both individuals with autism and their primary caregivers.

Dietary and Nutritional Support

Studies have shown that there is a high prevalence of co-occurring gastrointestinal (GI) issues including chronic abdominal pain, constipation, acid reflux, diarrhea, food allergy, and feeding issues in autism.²¹⁶⁻²²⁰ Feeding disorders, including highly restrictive behaviors known as Avoidant Restrictive Food Intake Disorder (ARFID) or sensory based textural restrictions, are commonly seen and can contribute

to nutritional deficiencies.²²¹ Children with autism are five times more likely to have mealtime challenges such as extremely narrow food selections, ritualistic eating behaviors (e.g., no foods can touch) and meal-related tantrums.²²²

These conditions may require **dietary and nutritional support**, interventions, and/or dietary supplements (such as vitamins) to help ensure that individuals are getting adequate nutrition.³³⁵ Referral by primary care providers to GI or nutrition specialists may be helpful.²²³ Dietary interventions focused on elimination diets, such as gluten and/or casein-free diets are becoming increasingly popular^{224,225} and have shown modest clinical effect in treating children with ADHD,²²⁶ which shares some features with autism.²²⁷ Further research is needed to evaluate the beneficial effects of dietary interventions for people with autism.

Therapies for Sleep Disorders

Studies show that individuals with autism often report sleep problems, with as many as 80 percent of children²²⁸ and over 50 percent of adults²²⁹ reporting sleep-related issues. These can include symptoms of insomnia and/or circadian sleep-wake rhythm disorders, including difficulty falling asleep, increased sleep onset latency, reduced total sleep time, increased wake after sleep onset, and poor sleep efficiency.²³⁰ Subjective methods such as parent report questionnaires and objective methods such as sleep studies performed at specialized sleep clinics, which use physiological measures, are often required to diagnose sleep problems in individuals with autism.²³¹

Therapies for sleep disorders can range from widely researched behavioral and pharmacological treatments²³²⁻²³⁴ to less researched non-pharmacological interventions (e.g., lifestyle modifications, complementary and alternative medicine), over-the-counter drugs (e.g., antihistamines, melatonin, tryptophan, carnosine, iron, vitamins, and herbal remedies), and nutritional supplements.²³⁵ Identifying the specific sleep problem/disorder first and its

underlying cause(s) is critical for treatment planning.²³⁶ Future research around the neurobiological mechanisms that may underlie poor sleep in individuals with autism can help determine the efficacy and long-term effects of various therapies, as well as help improve the guidelines and clinical use of pharmaceutical and non-pharmaceutical approaches for sleep disorders.

Environmental Assessment and Modifications

Perception of sensory stimuli and processing of information coming from the environment can be a problematic issue in autism. This is highlighted by updates to the DSM-5²³⁷ and testimonies of individuals with autism that describe difficulties faced by individuals due to sensory overstimulation or understimulation, and how this can present challenges or limit daily activities.²³⁸⁻²⁴⁰ **Environmental assessment and modifications** can help to reduce distress and improve quality of life for autistic people. A systemic review on the relationship between autism and the built environment found that three main factors are important to building an autism-friendly space: sensory quality, intelligibility, and predictability/orientation.²⁴¹ Modifications to the home environment, such as through interior design and installing safety measures, can improve the well-being of children with ASD and reduce stress in their parents.²⁴² Adaptations to the sensory environment in clinical settings have also shown benefits, including soft lighting, displaying movies, and noise reduction during dental procedures.²⁴³

Transportation Vehicle Modifications

Currently, research on positive outcomes associated with **transportation vehicle modification** is scarce. It is clear, however, that transitioning from one place to another is often unsafe for autistic people without proper supports. For example, some people with developmental delays may exhibit dangerous behaviors inside a moving vehicle that place others at risk for serious injury, such as escaping child restraints, opening the door in a moving car, or other

distractions to the driver.^{244,245} One case study involving parents in Los Angeles County Public Schools revealed that school districts sometimes privatize bus transportation responsibility, but the contracting agencies are not always trained in transporting autistic students or other students with disabilities.²⁴⁶ A Swedish study of over a thousand parents found that students were not being transported according to general safety guidelines, including traveling with unfamiliar drivers and unknown passengers, which could lead to elopement.²⁴⁷ U.S.-based research is needed to determine how many school districts in the country are in compliance with disability transport regulations.

Autistic people often do not receive travel training services, and services to help autistic adults develop driving skills and attain driver's licenses are often unavailable.²⁴⁸ Difficulty with community mobility and driving skills are linked to decreased participation in education, decreased rates of employment, and loneliness and isolation.^{249,250} Further research that includes the lived experiences of autistic individuals and their caregivers is needed to ensure disability transport competency, develop driver trainings and community mobility skills, and add environmental changes to make transportation for autistic people safer, more inclusive, and more accessible.

Empowerment, Education, and Advocacy Training and Services

The autistic self-advocacy and neurodiversity movement has encouraged and increased conversation around ethical practices for services, policies, and research. **Empowerment, education, and advocacy training and services** can offer enriching community opportunities, leadership training, and volunteerism. Empowerment and advocacy training can help families learn more about autism and share that knowledge with their community.²⁵¹ Programs specifically targeted for parents of autistic individuals have been shown to increase parents' feeling of empowerment, advocacy skills, treatment enrollment for their child and positively benefit child outcomes.²⁵²⁻²⁵⁴ These

programs, and the incorporation of culturally grounded approaches, are particularly important and beneficial to minority families, as they may experience increased barriers in access to care and services.²⁵⁵⁻²⁵⁷ Advocates maintain that those developing services must engage with the neurodiversity movement and align priorities in order to achieve the best possible outcomes for autistic people.²⁵⁸ Additionally, empowerment of families and individuals with autism is essential for promoting rights-based services.²⁵⁹

Healthcare Transition Services

Healthcare transition (HCT) services can help adolescents and young adults stay connected and engaged in their care as they transfer from pediatric to adult healthcare services. These services promote health insurance retention and encourage independent management of healthcare needs. This is especially important for youth with autism, who may have special healthcare needs^{260,261} and co-occurring psychiatric and medical conditions, such as anxiety/depression, seizures, GI problems, and sleep disturbances.^{262,263} Unfortunately, transition supports are not yet a basic standard of care for all youth,²⁶⁴ and studies indicate that only a small fraction of transition-aged autistic individuals receive HCT services.^{265,266} Research has shown that for youth with ASD, access to HCT services is associated with positive social-emotional functioning, which is critical for other positive life outcomes.²⁶⁷

Employment Services, Vocational Rehabilitation Services, Job Coaching

Employment services, vocational rehabilitation services, and job coaching can increase opportunities for employment and improve employment outcomes. National data has shown that many autistic adults are unemployed or underemployed, even when compared to people with other disabilities and in spite of having needed skills and abilities for the workplace.^{268,269} Barriers to higher rates of employment for autistic adults include employer attitudes, access to services, and social communication in the workplace.^{270,271}

Some individuals with autism receive employment services through government-supported vocational rehabilitation and/or Medicaid waiver programs that assist people with disabilities to prepare for, find, and keep employment.²⁷² Adults with autism are also eligible for services through **American Job Centers**. Services can also be obtained through private job coaches and placement services.

Best practices in helping autistic adults maintain customized employment involve matching worker skills to the job setting, the job description,²⁷³ and adjustment of continued job coaching as the individual progresses.²⁷⁴ Another promising approach is through **apprenticeships**, which are paid positions that include on-the-job training and mentorship integrated with classroom instruction and usually conclude with the individual earning a nationally recognized credential. Internship programs, such as **Project SEARCH**, have also been shown to be successful in transitioning people with autism to **competitive employment**.²⁷⁵ These services are vitally important to teach autistic youth the social and vocational skills necessary to have successful outcomes after leaving the education system.

Housing Support Services

There is currently little research about the effects of different housing options on outcomes and quality of life for people with autism.²⁷⁶ It is clear, however, that there is great need among the autism community for **housing support services**. The number of young adults living with their aging parents, who may not be able to continue caring for their children in their home, continues to increase.²⁷⁷ A recent survey of parents of autistic adults revealed that support services, including housing, were not accessible, difficult to obtain, and inadequate.²⁷⁸ Autistic people may experience several challenges in independent living, including psychophysical stability and daily living, financial management, and integrated community living and housing.²⁷⁹ More broadly, recent research indicates that individuals with mental, intellectual, or developmental disabilities experience various

barriers in the rental housing market, such as receiving negative responses to requests for reasonable accommodations.

Homelessness among the autistic population is a growing cause for concern. Qualitative research indicates that ACEs, identity masking, and ableism in school settings, are among the factors that contribute to homelessness in the autistic population.²⁸⁰ Barriers to accessing services while homeless include experiences of nervousness with large groups,²⁸¹ a lack of routine and certainty,²⁸² and financial exploitation.²⁸³ **International studies** further identify risk factors of homelessness among the autistic population to include lack of support for co-occurring conditions, lower levels of support for those with less extensive support needs, and loss of employment.²⁸⁴⁻²⁸⁵ Research conducted in other countries further suggest disproportionately high prevalence of those with autistic traits among people experiencing homelessness.²⁸⁶ U.S.-based research is needed to inform our understanding of the incidence of people on the autism spectrum experiencing homelessness and ways to better support these individuals.

Remote Services

Remote services are extremely helpful to those who cannot access in-person services, whether this is due to living in rural areas, restrictions during the COVID-19 pandemic, or limitations related to disability. A small but growing evidence base demonstrates the feasibility and value of autism behavioral intervention services delivered via telemedicine.²⁸⁷⁻²⁹¹ ASD diagnosis via telemedicine is also showing preliminary accuracy and clinical utility,²⁹² as is occupational therapy.²⁹³ A systematic review of pre-pandemic remote service utilization found that telehealth has the potential to increase treatment availability, decrease diagnosis waiting times, and aid in neurodevelopmental disability monitoring.²⁹⁴ During the pandemic, caregivers of individuals with DD reported that telemedicine and tele-education were helpful when available and endorsed a need for an augmentation of these remote delivery services.²⁹⁵

Recreational Therapies

Recreational therapies cover the range of therapies that seek to improve the health and well-being of individuals on the autism spectrum through community-based sports and recreation. Research shows that participation in group sports such as soccer, basketball, or tennis can reduce social anxiety and improve social, motor, and communication skills, as well as sleep quality and developmental outcomes.²⁹⁶⁻³⁰² Results for a golf training program show similar gains in social, communication, motor, and regulatory skills.³⁰³ One study also showed that exergaming, or playing video games that require physical activity, is highly enjoyable for individuals on the autism spectrum, and social interaction while gaming may lead to additional increases in the intensity and duration of physical activity.³⁰⁴ Studies are currently underway to test the efficacy of other game-based exercise training programs in promoting the physical and mental well-being of autistic individuals,³⁰⁵ and training programs have been developed to help community coaches engage individuals on the autism spectrum to increase socialization.³⁰⁶ While additional research and larger studies are needed to determine the efficacy of different types of recreational therapies and to improve implementation, community-based sports and recreational activities can be an effective method for improving the overall health and well-being of autistic individuals.

Complementary and Alternative Interventions

There are numerous studies of **complementary and alternative interventions** for autism, which include animal-assisted, arts (music, art, drama, dance), mindfulness, and yoga therapies. Complementary and alternative approaches have become popular therapies among children and adults on the autism spectrum.^{307,308} Animals as companions, service animals, and animals in therapy (dogs, cats, and equine therapy) can benefit behavioral skills and social communication, reduce separation anxiety, and support access to employment and community living.³⁰⁹⁻³¹³ Music and drama therapy may help children with autism improve their skills in several areas, including speech production, verbal communication, theory of mind, and social interaction.³¹⁴⁻³¹⁶ Recent studies and meta-analyses suggest that mindfulness and yoga are promising interventions for improving the mental health and well-being of people with ASD and their families, but further evidence is needed to determine efficacy.³¹⁷⁻³¹⁹ Acupuncture, a form of Traditional Chinese Medicine,³²⁰ is being explored as an alternative intervention for people with autism^{321,322} but further research is needed to establish beneficial outcomes. Massage therapy is also being used to treat hypersensitivity and reduce anxiety in autism,³²³ as well as sensory-based treatment approaches using weighted blankets and vests.³²⁴

Cannabis/medical marijuana is also being increasingly used by people with autism to alleviate conditions such as insomnia, hyperactivity, epilepsy, anxiety, and chronic pain.³²⁵ There are only a few studies to date on this topic, and randomized, blind, placebo-controlled clinical trials are necessary to clarify findings on the effects of cannabis and cannabinoids in individuals with ASD is needed to increase understanding of risks and benefits and the efficacy of cannabis for symptom reduction in autism.³²⁶



CURRENT FEDERALLY SUPPORTED SERVICES, PROGRAMS, AND
COVERAGE POLICIES



This report includes information submitted by the U.S. Departments of Health and Human Services, Defense, Education, Housing and Urban Development, Justice, Labor, Transportation, and Veterans Affairs, as well as the Social Security Administration on current federally supported ASD services, programs, and coverage policies. The information submitted by each agency is provided below.

U.S. Department of Health and Human Services (HHS)

ADMINISTRATION FOR CHILDREN AND FAMILIES (ACF)

The **Administration for Children and Families (ACF)** promotes the economic and social well-being of families, children, individuals, and communities. ACF programs aim to:

- Empower families and individuals to increase their economic independence and productivity;
- Encourage strong, healthy, supportive communities to have a positive impact on quality of life and the development of children;
- Improve access to services through planning, reform, and integration;
- Create partnerships with front-line service providers, states, localities, and tribal communities to identify and implement solutions that transcend traditional program boundaries; and
- Address the needs, strengths, and abilities of vulnerable populations including people with DD, refugees, and migrants.

ACF does not currently have programs that are specifically focused on autism; however, ACF funds several offices and projects that support services and inclusion of young children with disabilities, including those with ASD.

The **ACF Office of Head Start (OHS)** promotes the school readiness of children ages birth to 5 from low-income families by enhancing their cognitive, social, and emotional development. According to the **2021 Head Start (HS) Program Information Report (PIR)**, 0.67 percent of total HS enrollment were children diagnosed with ASD. These children and their families received HS's comprehensive services

in inclusive settings. The **OHS Training and Technical Assistance Centers** carry out significant work and activities that promote inclusion of children with disabilities, including those with ASD who are served in Early Head Start (EHS) and HS settings. OHS maintains the **Head Start Center for Inclusion website**, which offers a variety of resources that support early childhood educators to ensure that children with disabilities can participate as full members of their learning communities. OHS also maintains the disabilities services section of the **Early Childhood Learning and Knowledge Center website** which includes evidence-based resources that promote early identification, referrals, family support services, cross-agency collaboration, and resources related to access and full participation of young children with disabilities in inclusive learning environments.

The **ACF Office of Planning, Research, and Evaluation (OPRE)** studies ACF programs and the populations they serve through rigorous research and evaluation projects. These include evaluations of existing programs, evaluations of innovative approaches to helping low-income children and families, research syntheses, and descriptive and exploratory studies. OPRE is currently conducting the **Study of Disability Services Coordinators and Inclusion in Head Start (2019 – 2024)** that will provide a descriptive national picture of the Disability Services Coordinators workforce for EHS and HS, including American Indian/Alaska Native (AI/AN; Region XI) and Migrant and Seasonal Head Start (Region XII) grantees. It will also explore practices and policies for working with staff, families, children, and the community. This effort will explore how EHS/HS serves children with disabilities and their families and will seek to understand how EHS/HS collaborates with services in the community, including health providers, Local Education Agencies, and Part C.

OPRE is also conducting the **Head Start Family and Child Experiences (FACES; 1997-2022)** study to provide descriptive, nationally representative information on preschool-aged children in HS in Regions I-X, and the **American Indian and Alaska Native Head Start Family and Child Experiences Survey (AI/AN FACES; 2015-2022)**, which provides representative information for HS in Region XI, including the characteristics, experiences, and development of children and their families and the characteristics of the HS programs and staff who serve them. This study collects information on whether children have a disability, what type of disability (autism is grouped into the cognitive disability category), whether the children have multiple disabilities, and how many children with a disability have an IEP or Individualized Family Service Plan (IFSP). Likewise, the **Early Head Start Family and Child Experiences Study (Baby FACES)** reports on the percentage of children in EHS programs in Regions I-X that have any special needs, the type of special needs (e.g., developmental disability or delay), and the percentage of children with an IFSP.

The **ACF Office of Refugee Resettlement (ORR)** helps eligible new populations immigrating to the United States to maximize their potential, providing people in need with critical resources to assist them in becoming integrated members of American society. Resources disseminated by ORR include ASD-related materials developed by ACF and the CDC (i.e., ***Learn the Signs. Act Early.***) to assist families with recognizing and addressing autism-related needs.

ADMINISTRATION FOR COMMUNITY LIVING (ACL)

The **Administration for Community Living (ACL)** works to increase access to community support systems for older Americans and people with disabilities. ACL was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities. ACL funds programs in all states and territories that support individuals with

disabilities, including individuals with autism, living in the community.

ACL Programs That Directly Provide or Support Provision of Supportive Services

Developmental Disabilities Council

- State Councils on Developmental Disabilities (SCDDs) are driven by people with ID/DD, families, and other key stakeholders. SCDDs in each state and territory focus on DD that are lifelong, significant and require ongoing support, such as autism. SCDDs create partnerships, collaborations, innovative programs, and equal opportunities to improve the daily lives of people with ID/DD; spark community change by bringing together people and partners to create equity in education, health, employment, and life; empower self-advocates and family leaders, influence law and policy, and educate and protect people with ID/DD; and educate decision-makers using research and lived experiences to improve the lives of people with ID/DD.
- SCDDs are catalysts for positive change. Their work removes barriers and increases opportunities for people with ID/DD so they can:
 - Participate fully and live in the community;
 - Become leaders and self-advocates, creating their own paths and helping others;
 - Access healthcare to live longer, healthier lives;
 - Complete secondary (grades 6-12) and postsecondary (after grade 12) education;
 - Find and succeed in jobs that fit their individual interests and goals;
 - Stay connected and safe during emergencies and disasters; and
 - Enjoy recreational and social activities.

UCEDD

- University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding

solutions, and advancing research related to the needs of individuals with DD and their families.

- Four core functions frame the UCEDD program: Interdisciplinary pre-service preparation and continuing education; research, including basic or applied research, evaluation, and public policy analysis; information dissemination; and community services, including direct services, training, technical assistance, and model demonstrations.
- UCEDDs support activities that address a range of issues, from early intervention to supported employment. Additional grants may be awarded to UCEDDs to conduct national training and other initiatives. Current national training initiatives are funded to address supporting people with IDD with co-occurring mental or behavioral health disabilities and community-based transitions.

Protection and Advocacy Systems

- Protection and Advocacy Systems (P&As) empower individuals with disabilities and advocate on their behalf. There are 57 P&As in the United States and its territories, and each is independent of service-providing agencies in their states. P&As are designated by the governor and provide legal advocacy to ensure the personal and civil rights of individuals with disabilities. P&As provide legal support to traditionally unserved or underserved populations to help them navigate the legal system to achieve resolution and encourage systems change. P&As engage in legal advocacy in a wide range of areas, from assisting people in accessing needed healthcare or HCBS, representing students with disabilities and their families in getting needed educational supports, and addressing disability discrimination. P&As ensure that individuals with disabilities are able to exercise their rights to make choices, contribute to society, and live independently. While their focus is most often legal, P&As also engage in a range of other efforts to promote the rights of individuals with disabilities. They often provide information and referrals, as well as training and technical assistance to service providers, state legislators, and other policymakers. They also conduct

self-advocacy training and raise public awareness of legal and social issues affecting individuals with DD and their families.

Independent Living Services

- ACL manages the Centers for Independent Living (CILs) and Independent Living Services (ILS) programs under the Rehabilitation Act, as amended. The CIL program funds 352 awards to community-based organizations that provide independent living services to individuals with disabilities. The ILS program funds 56 states and territories to sustain, expand, and improve independent living services in each state. Together these programs promote the independent living of individuals with disabilities to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into American society by enhancing consumer control; increasing use of peer support, self-help, and self-determination; ensuring equal access; and supporting individual and system advocacy.
- CILs are designed and operated by individuals with disabilities and provide independent living services for people with disabilities. CILs work to support community living and independence for people with disabilities across the nation based on the belief that all people can live with dignity, make their own choices, and participate fully in society. These programs provide tools, resources, and supports for integrating people with disabilities fully into their communities to promote equal opportunities, self-determination, and respect.
- At a minimum, centers funded by the program are required to provide the following independent living core services: information and referral; independent living skills training; peer counseling; individual and systems advocacy; and services that facilitate transition from nursing homes and other institutions to the community, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary life.
- Centers also may provide, among other services: psychological counseling, assistance in securing housing or shelter, personal assistance services,

transportation referral and assistance, physical therapy, mobility training, rehabilitation technology, recreation, and other services necessary to improve the ability of individuals with significant disabilities to function independently in the family or community and/or to continue in employment.

Caregiver Services

- ACL has **programs to support caregivers**, including the **National Family Caregiver Support Program** and the **Lifespan Respite Care Program**. ACL also manages the **RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregiving Advisory Council (FCAC)**, which was created under the RAISE Family Caregivers Act of 2018 to advise the Secretary of Health and Human Services (HHS) on effective models of both family caregiving and support to family caregivers. The Act directs the HHS Secretary to convene the FCAC, deliver a report to Congress, and develop a national family caregiving strategy. The FCAC released their first **Report to Congress** in 2021. The report describes the current landscape of family caregiving and provides 26 recommendations for how the federal government, states, tribes, territories, and communities can partner with the private sector to better support family caregivers. The **2022 National Strategy to Support Family Caregivers** was released in September 2022. It identifies more than 500 actions that communities, providers, government, and others can take to better recognize and support family caregivers. The Strategy also addresses four key principles that must be reflected in all efforts to improve the recognition, assistance, and inclusion of family caregivers and those they support.

Empowering Youth with Intellectual and Developmental Disabilities to Manage Their Healthcare Transitions

- This five-year grant, started in FY 2021 established a national, person-centered, culturally competent resource center to empower youth with ID/DD in directing their own healthcare transitions from pediatric to adult models of care. The center is working to increase self-determination, independence, and quality of life for youth with ID/DD as they transition into adult models of care. Project

activities include a national community of practice, co-led by members of the resource center's Youth Steering Committee, and a mobile app designed for youth with ID/DD to use during healthcare transitions. Anticipated outcomes of this initiative include that youth with ID/DD will lead their medical appointments and interactions with medical professionals; lead their at-home healthcare routines such as medication management; make decisions about their healthcare and wellness next steps, in consultation with providers, family members, and adult guardians; and learn how to proactively manage potential co-occurring health conditions.

Self-Advocacy Resource and Technical Assistance Center (SAR-TAC)

- This five-year grant, started in FY 2021, established a national, person-centered, culturally competent resource that empowers and supports the national self-advocacy movement for people with ID/DD. This center serves as a national resource that further strengthens statewide and local self-advocacy organizations; creates and disseminates self-advocacy resources; provides leadership development opportunities for people with ID/DD; and strengthens the network of civil rights organizations working on behalf of people with ID/DD. SAR-TAC is guided by principles of independent living, self-determination, and intersectionality. An advisory committee comprised entirely of people with ID/DD guide the work of SAR-TAC.

Center for Youth Voice, Youth Choice (CYVYC)

- CYVYC is a five-year initiative, started in FY 2020, that created a resource center on alternatives to guardianship for youth with ID/DD. CYVYC developed a national coalition of stakeholders that endorse and share information about alternatives to guardianship and conduct research on the policies and practices related to guardianship and its alternatives. The Youth Ambassador program provides support, mentorship, and leadership development to youth with ID/DD who will serve on advisory boards and as resource contacts in their states. An expected outcome of the initiative is that fewer youth are subject to guardianship.

Disability Employment Technical Assistance (TA) Center

- This five-year project was started in FY 2020. The Disability Employment TA Center provides tools and resources to ACL disability-focused grantees so that they may more effectively help individuals with disabilities (including autism) achieve meaningful employment with competitive wages in integrated settings. The Employment TA Center maximizes knowledge transfer across programs by identifying and providing training on innovative, promising, and emerging practices. Expected outcomes include improvements in competitive integrated employment and economic status for individuals with an array of abilities.

National Center to Strengthen the Direct Care Workforce

- This five-year grant will establish a national center to expand and strengthen the direct care workforce across the country. When fully operational, 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’s website will share resources from the federal government, highlight state and local model policies and best practices that can be replicated or adapted, and share training and technical assistance materials. In addition, the center will facilitate peer-to-peer sharing of lessons learned and promising practices through learning collaboratives and support collaboration between state systems, including Medicaid, aging, disability, and workforce agencies; service providers; and aging, disability, and labor stakeholders.

National Resource Center for Persons with Intellectual and Developmental Disabilities and Co-Occurring Mental Health and Related Conditions

- The grant, awarded in FY 2022 will create a national, person-centered, culturally competent resource center to increase access to supports for individuals with ID/DD and mental and behavioral health conditions, enhance system capacity, and educate

crucial system partners about the strengths and needs of individuals with ID/DD and mental health support needs. The objectives of this project are to create a Center that will provide an opportunity to elevate best practices in policy, clinical, and workforce capacity while improving the engagement of individuals with disabilities and their families in identifying effective treatment and support services. Additional project partners include the Nisonger Center at Ohio State University; the Autistic Self Advocacy Network; Green Mountain Self Advocates; the Sonoran Center; Center for Systemic Therapeutic Assessment, Resources and Treatment (START) Services; and Communication First. Project activities include Hosted Shared Learning Groups through quarterly virtual gatherings focused on individuals with co-occurring ID/DD and mental health disabilities, families, state system leaders, and professionals. Expected outcomes include the development of effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural beliefs and practices, preferred languages, and communication strategies (including the use of AAC), health literacy, and other needs, designed to increase self-determination, empowerment, and quality of life for people with co-occurring ID/DD and mental health conditions.

In FY 2022, ACL launched several initiatives to address disability equity issues:

Community Living Equity Center: HHS-2022-ACL-NIDILRR-RTCP-0026

- The **Community Living Equity Center** is a Rehabilitation Research Training Center (RRTC) to conduct research toward new knowledge and reduction of disparities in community living outcomes among people with disabilities, particularly those in underserved areas/populations, as defined by the Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. The RRTC will explore and provide detailed information about community living outcome disparities within the population of people with disabilities, across subpopulations defined by

race, ethnicity, LGBTQ+ status, or poverty status. New knowledge generated by this Center will ultimately be used toward development and implementation of evidence-based policies, practices, or interventions for achieving more equitable community living outcomes among the heterogeneous population of people with disabilities. The RRTC will serve as a national resource center in this area, and as a resource for the conduct of culturally competent disability and rehabilitation research in the community living and participation domain.

RRTC on Advancing Employment Equity for Multiply Marginalized People with Disabilities: HHS-2022-ACL-NIDILRR-RTEM-0028

- The Rehabilitation Research and Training Center on Advancing Employment Equity for Multiply Marginalized People with Disabilities is an RRTC to conduct research toward new knowledge and reduction of disparities in employment outcomes among people with disabilities, particularly those in underserved areas/populations, as defined by the Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. The RRTC will explore and provide detailed information about employment outcome disparities within the population of people with disabilities, across subpopulations defined by race, ethnicity, LGBTQ+ status, or poverty status. New knowledge generated by this Center will ultimately be used toward development and implementation of evidence-based policies, practices, or interventions for achieving more equitable employment outcomes among the heterogeneous population of people with disabilities. The RRTC will serve as a national resource center in this area and as a resource for the conduct of culturally competent disability and rehabilitation research in the employment domain.

RRTC on Equity in Health and Functioning for Adults with Physical, Cognitive, Sensory, and Developmental Disabilities from Marginalized Communities: HHS-2022-ACL-NIDILRR-RTHF-0029

- This Equity Center is for an RRTC to conduct research toward new knowledge and reduction of disparities in health and function outcomes among people with disabilities, particularly those in underserved areas/populations, as defined by the Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. The RRTC will explore and provide detailed information about health and function outcome disparities within the population of people with disabilities, across subpopulations defined by race, ethnicity, LGBTQ+ status, or poverty status. New knowledge generated by this Center will ultimately be used toward development and implementation of evidence-based policies, practices, or interventions for achieving more equitable health and function outcomes among the heterogeneous population of people with disabilities. The RRTC will serve as a national resource center in this area and as a resource for the conduct of culturally competent disability and rehabilitation research in the health and function domain.

National Center on Disability, Equity, and Intersectionality: HHS-2022-ACL-AOD-NCDE-0083

- This five-year grant will create and maintain a national resource center on disability, equity, and intersectionality to build the capacity of our communities across the nation to be more inclusive and culturally competent towards individuals with disabilities. The Center will increase knowledge and awareness of systemic ableism, racism, and other forms of discrimination experienced by individuals with disabilities, including those with marginalized identities. The Center's primary focus will be addressing systemic ableism, racism, and other forms of discrimination with a concentrated effort around health equity and other topics identified by the grantee. The Center will focus on resources to increase equitable access for people with marginalized identities by: supporting forums

for cross-cultural and cross-disability exchanges that will advance a culturally competent disability framework; translating research into action and disseminating information using multiple methods; developing tools, such as an organizational self-assessment tool, and supporting communities of practices for transforming systems and organizations; and building the next generation and future leaders of this work through engagement with youth with disabilities. The audience for the Center will include individuals with disabilities, their families, others in their support system, the DD network, independent living programs, youth with disabilities, providers, and systems of services and supports.

State Support Services, Programs, and Coverage Policies

ACL partners with all states and territories to support programs for individuals with disabilities, including individuals with autism. For this report, ACL gathered information on supportive services from their grantees. Below are examples from several states of the types of services and program activities funded by ACL that provide supportive services of benefit to individuals with autism.

MARYLAND

- Autism Stakeholder Group on Autism Related Needs: Maryland passed a law in 2021 that established a high-level position within state government - the State Coordinator for Autism Strategy. The position reports directly to the Governor's Office of Community Initiatives and leads the Stakeholder Group on Autism Related Needs. The Maryland Developmental Disabilities Council is a named member of the Group. The legislation requires the development of a strategic plan that specifies performance measures, including any national benchmarks, for monitoring and evaluating success in addressing autism-related needs in the State including, at a minimum, the following:
 - reducing the unemployment and underemployment rates of people with autism;

- improving postsecondary transition services and graduation rates;
- increasing degree-granting college admission and participation and postsecondary vocational internships and apprenticeships leading to licensure;
- increasing the availability of safe, affordable, and accessible housing;
- identifying and reducing the negative physical and mental health outcomes of people with autism, including: (i) identifying and improving caregiver and family support and respite services; (ii) evaluating need and implementation strategies for the adult autism waiver; (iii) reducing wait times for the Autism Waiver Registry; (iv) promoting social inclusion and understanding for people with autism; and (v) ensuring equitable access to diagnostic and therapeutic support services in rural areas and for underserved populations; and
- evaluating the need for and making recommendations regarding training programs for law enforcement, criminal justice professionals, or other first responders that address the effective recognition of and response to the needs of individuals with autism and their caregivers.

VIRGINIA

- The **Virginia Commonwealth University Autism Center for Excellence** provides a plethora of resources, information, training, research and technical assistance. It is an invaluable resource for both professionals and parents. Having such a resource can help bridge a number of gaps in assessments and services.

NEW YORK

New York is providing assistance to individuals and families through several means:

- The **University of Rochester, Strong Center for Developmental Disabilities, UCEDD/Leadership Education and in Neurodevelopmental and Other Related Disabilities (LEND) program** is supporting several projects and programs, including:
 - Project Title: **Clinical ECHO Autism**

- Need: Primary care providers report that they need more education and support to assess and manage children and youth with ASD and related disabilities in the medical home setting. Families trust their primary care providers and would like improved access to care that is disorder-specific in their home communities.
- The ECHO model uses tele-mentoring to promote identification and management of youth with ASD and related conditions in the primary care setting. The use of case-based learning and brief didactics builds a learning community led by a special Hub team at the University of Rochester (Developmental and Behavioral Pediatrics, psychology, family member, social worker, nutrition, Psychiatric Nurse Practitioner) with participating Spoke teams (doctors, nurse practitioners, integrated behavioral health providers) in primary care practice. By enhancing the quality of care in the medical home, children and youth with ASD and families will benefit from improved medical and behavioral health services and access to care in their communities. The ECHO model is widely used to enhance care in rural and other areas with limited specialty access.
- Unique Features: This ECHO will recruit practices from all of upstate and western New York and will encourage participation of care teams that include doctors, nurse practitioners, physician assistants, and integrated mental health providers.
- Expected Benefits: Increased knowledge, feelings of competence and quality of screening, referral and medical/behavioral care of individuals with ASD and related conditions.
- Need: Only 6-10 percent of adults with ASD obtain competitive employment. To have a meaningful impact on competitive employment rates for adults with ASD, vocational services must improve both employment matching and employment customization.
- Intervention: The customized employment process provides the framework for the Achieving Competitive Customized Employment through Specialized Services (ACCESS) intervention that is to be tested.
- Promising Practice: This process has demonstrated potential to improve employment matching in adults with ASD; however, the model has not been experimentally tested. Additionally, the employment customization component of the process has yet to be applied to adults with ASD and must be adapted to address specific challenges that this population face. An ACCESS intervention promises to improve functional outcomes by improving both employment matching and customization for job seekers with ASD.
- The overall goal is to refine and test an intervention that can be utilized by community-based Vocational Rehabilitation (VR) service practitioners to improve competitive employment outcomes for adults (age 22+) diagnosed with ASD.
- Primary goals are to: 1) Refine training, treatment, and study protocols to test the ACCESS intervention; 2) examine the feasibility and acceptability of ACCESS in an iterative open trial; and 3) examine the feasibility, acceptability, and preliminary effects of ACCESS relative to usual care in a randomized controlled pilot trial of 30 adults with ASD.
- Expected Benefits: This research study has the potential to dramatically shift current practice paradigms by informing research and policy decisions and by customizing employment placement strategies to address the specific support needs of adult job seekers with ASD using the platform of an intervention already reimbursed by VR. Given early evidence regarding the promise of customized interventions, ACCESS has the potential to yield far-reaching benefits

FLORIDA

- The following project is supported as part of the **University of South Florida, Florida Center for Inclusive Communities, UCEDD**:
 - Project Title: Achieving Competitive Customized Employment through Specialized Services (ACCESS)

for this population and the stakeholders, ultimately maintaining competitive employment outcomes.

NEW MEXICO

- The following project is supported as part of the **University of New Mexico, Center for Development & Disability, UCEDD**:
 - Project Title: Improving the Health of New Mexicans Enrolled in Medicaid Through Evidence-Based Interventions
 - Need: Expanding services not covered under existing Medicaid-related contracts.
 - Intervention: Under an agreement with the New Mexico Human Services Department and the Department of Health, the Center receives Medicaid match funds in order to expand services that cannot be covered under existing Medicaid-related contracts. Non-federal funds are matched to expand current training, technical assistance, and services. These services improve the healthcare of Medicaid-enrolled individuals statewide through: 1) training and technical assistance for Medicaid providers in identifying children with DD, including ASD, and in how to use evidence-based and/or best practice interventions; 2) case management or care coordination for specific populations; and 3) outreach and referral.

LOUISIANA

- The following project is supported as part of the **University of Louisiana, Human Development Center, UCEDD**:
 - Project Title: **Louisiana Autism Spectrum and Related Disabilities Project (LASARD)**
 - Need: In Louisiana, as in most states, there is a disparity between identified evidence-based practices for students with ASD and related disabilities and implementation in classrooms. This problem is exacerbated by the growing number of students identified with ASD and related disabilities. Educational outcomes for these students are generally less than optimal.

- Intervention: The overall goals of the LASARD Project include improving educational practices and outcomes for students with ASD and related disabilities and to develop statewide capacity to provide high quality programs for these students. The LASARD Project partners with local education agencies throughout the state to provide training and long-term job-embedded coaching in classrooms. Professional development is also provided through face-to-face workshops and webinars. The project builds the capacity of educators and school- and district-based teams to implement evidence-based practices and supports for students with ASD and related disabilities

INDIANA

- The following project is supported as part of the **University of Indiana, Institute on Disability and Community, UCEDD**:
 - Project Title: **Camp Yes And: An Improv Summer Camp**
 - Need: Strengthening communication and social skills is critical to increasing economic opportunity for youth with autism. In the United States, more than 50 percent of youth with autism do not participate in post-secondary employment or education. Stronger communication and social skills lead to increased graduation rates and improved post-secondary outcomes among teens on the autism spectrum.^{327,328} However, direct service to youth represents a one-sided approach to solving the problem. Most youth with autism lack cognitive impairments that might prevent them from succeeding in general classroom environments, but fewer than half are included in those classrooms. Many educators do not feel confident in their abilities to teach students on the autism spectrum in general education settings.³²⁹ Moreover, a single educator works with many more teens than can be served directly by a summer camp; each educator that we train has the potential to impact hundreds of teens. This camp enables educators to practice new skills and receive feedback while working hands-on with youth on the autism spectrum.

Research demonstrates that this deep professional learning leads to stronger implementation of new strategies in the classroom.³³⁰

- Intervention: Camp Yes And combines communication and social skills instruction for teens with autism and deep professional learning for general and special educators, speech-language pathologists, school psychologists, counselors, and social workers. The camp utilizes innovative instructional methods derived from improvisational theater ("improv"), a form of drama in which plot, character, and setting are created during the moment of performance. Improv has shown to be effective in strengthening these skills among youth with autism.^{331,332}
- Promising Practice: Camp evaluations have found measurable improvements in teens' social communication skills and significant decreases in their social anxiety. Evaluations also found substantial increases in educators' confidence and skill around supporting students with autism, along with a higher degree of implementation in the classroom and sharing of strategies with colleagues.

GEORGIA

- University of Georgia Community-Based Transition Planning Project (NOTE: This project has now transitioned to an implementation phase.)
 - Background: Nationally and in Georgia, individuals without a disability are twice as likely to have a bachelor's degree or higher and are two to three times more likely to be employed compared to those with a disability. Although an increasing number of students with autism are attending college, many struggle to matriculate, access services, and successfully compete for jobs following graduation.
 - Goal: The University of Georgia's College Transition Partnership Planning Project seeks to increase the proportion of college graduates with ASD who are either employed in careers related to their college majors with wages comparable to other college graduates in their field or are enrolled in a graduate school in their field of choice.
- To accomplish this goal, a partnership will be convened utilizing the Collective Impact framework to develop a comprehensive plan for an innovative, actionable pilot that focuses on providing supports to college students on the autism spectrum, which will result in successful transitions from college to employment or graduate school.
- The transition model for the pilot will be guided by a comprehensive review and analysis of relevant transition services in Georgia using a realist synthesis approach and by the input of students with autism.
- The partnership will reach consensus on the practicality and realistic likelihood that the pilot will be successful and that it will address gaps identified in the Comprehensive Review and Analysis (CRA). The quality of the partnership's design and implementation will be assessed throughout the project using developmental evaluation processes, which will inform the partnership's sustainability plan.
- Objectives:
 1. Convene Partnership
 2. Conduct Comprehensive Review and Analysis (CRA)
 3. Develop Plan for Pilot Implementation
 4. Develop Dissemination Plan
 5. Project Impact
 6. Develop Sustainability Plan
- Outcome: An innovative, practical plan for a pilot project that address problems, remedies, and solutions; identifies future partners; and can be immediately acted upon.
- University of Georgia Community-Based Transition Implementation Project
 - Goal: The goal of the Partnership is to implement the model developed during the Planning year for a sustainable, culturally competent, innovative pilot project focused on providing supports for young autistic adults that result in their successfully transitioning from college to employment or graduate school.

- The objectives include:
 1. Continue to utilize the Collective Impact framework to convene and facilitate the Partnership.
 2. Guided by the Partnership, implement the plan for a pilot project at Emory University focused on culturally competent services and supports for a diverse group of young autistic adults who are transitioning from college to employment or graduate school.
 3. Conduct a process evaluation of the pilot implementation, identify challenges/barriers encountered, and problem-solve to overcome those challenges/barriers.
 4. Refine/improve the pilot implementation based on evaluative feedback.
 5. Evaluate the Partnership and utilize evaluation findings to improve the Partnership.
 6. Reach consensus on how the findings from the implementation of the pilot at Emory can be replicated at Georgia State University and the University of Georgia; begin implementation.
 7. Conduct a summative evaluation of the pilot implementation to determine success in meeting the project outcomes.
 8. Disseminate project findings and products.
 9. Develop a plan to sustain the pilot project and the Partnership.
- Expected Benefits: Autistic college graduates secure jobs in their field of choice or are accepted into graduate school. Products include a replication blueprint and short videos.

Cross Departmental Partnership

The **Housing and Services Resource Center** is a partnership led by ACL between HHS and HUD. The Center was created for people who work in the organizations and systems that provide housing resources and homelessness services, behavioral and mental health services, independent living services and other supportive services, and others who are working to help people live successfully and stably in the community (see page 59 for more detail).

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

The mission of the **Agency for Healthcare Research and Quality (AHRQ)** is to produce evidence to make healthcare safer, higher quality, more accessible, equitable, and affordable and to work within HHS and with other partners to make sure that the evidence is understood and used. AHRQ does not receive funds from the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019 but does support research to determine the effectiveness and outcomes of interventions for individuals with ASD. This is achieved through funding extramural, investigator-initiated research, promoting the development of practice improvement tools that apply and use the latest scientific evidence into advancing care delivery, and use of data and analytics to evaluate health and healthcare, in line with their mission. Some of these are described below, and further details can be found on the AHRQ website.

- **AHRQ's Digital Healthcare Research Program:** AHRQ's Digital Healthcare Research Program's mission is to produce and disseminate evidence about how the evolving digital healthcare ecosystem can best advance the quality, safety, and effectiveness of healthcare for patients and their families. The Digital Healthcare Research Program at AHRQ provides foundational research to ensure that digital healthcare systems are designed and implemented in ways that improve quality and safety, while not resulting in excessive burden on physicians and other members of the care team. Current research areas include usability, consumer-focused digital healthcare, clinical decision support, safety, patient-reported outcomes, and care transitions.
- **U.S. Preventive Services Task Force (USPSTF):** Since 1998, AHRQ has been authorized by the U.S. Congress to convene the Task Force and to provide ongoing scientific, administrative, and dissemination support to the Task Force. The U.S. Preventive Services Task Force is an independent, volunteer panel of national experts in prevention and evidence-based medicine. The Task Force

works to improve the health of people nationwide by making evidence-based recommendations about clinical preventive services such as screenings, counseling services, and preventive medications. All recommendations are published on the Task Force’s website and/or in a peer-reviewed journal. Task Force members come from the fields of preventive medicine and primary care, including internal medicine, family medicine, pediatrics, behavioral health, obstetrics and gynecology, and nursing. Their recommendations are based on a rigorous review of existing peer-reviewed evidence and are intended to help primary care clinicians and patients decide together whether a preventive service is right for a patient's needs. Each year, the Task Force makes a **report to Congress** that identifies critical evidence gaps in research related to clinical preventive services and recommends priority areas that deserve further examination. More information on these reports is available on the Task Force website.

- **The Effective Health Care Program:** The Effective Health Care (EHC) Program funds individual researchers, research centers, and academic organizations to work with AHRQ to produce patient-centered outcomes research (PCOR) for clinicians, consumers, and policymakers. PCOR is designed to inform healthcare decisions by providing evidence on the effectiveness, benefits, and harms of different treatment options. The EHC Program reviews and synthesizes published and unpublished scientific evidence, generates new scientific evidence and analytic tools, and translates research findings into useful formats for various audiences. Stakeholders are involved throughout the research process to improve research results and ensure findings are relevant to users’ distinct concerns.

Recent research projects that seek to improve the health and well-being of individuals with ASD are described below for the period of FY 2018-2022.

PA-20-072 Stakeholder-Partnered Implementation Research and Innovation Translation (SPIRIT) Program: Vulnerable Populations Cared for by Learning Health Systems During the COVID-19 Pandemic

Grant number: 3K12HS026407-03S1

Institution: University Of California, Los Angeles (UCLA)

Summary: As a collaboration among UCLA, Kaiser Permanente Southern California, the Department of Veterans Affairs (VA) Greater Los Angeles Healthcare System, and the Los Angeles County Department of Health Services, the AHRQ-PCORI K12 program, Stakeholder-Partnered Implementation Research and Innovation Translation (SPIRIT), is designed to prepare outstanding postdoctoral scholars for academic research careers focused on rapid and sustainable uptake of new scientific discoveries and innovations that improve the design, delivery, and outcomes of care for chronic diseases at the individual, population, and healthcare system levels. This supplement to the SPIRIT K12 Program leverages existing K12 Scholar projects and expands the specific aims of their ongoing research to develop high-impact new knowledge concerning COVID-19 and the ongoing pandemic. Three current K12 scholars are proposing supplemental work that address health issues that have arisen due to COVID-19. These projects address how different vulnerable populations with healthcare needs, including adults with diabetes, children with ASD, and Veterans with severe mental illness, are managing during the stay-at-home orders during the COVID-19 pandemic and evaluate their experiences with one solution for healthcare provision, telehealth, during stay-at-home orders. PUBLIC HEALTH RELEVANCE: Through mentored research career development of the next generation of interdisciplinary team members, leaders, and innovators in dissemination and implementation science and learning health systems, the SPIRIT K12 Program will advance our knowledge of delivery and implementation strategies for proven interventions in real-world practice and community settings. This supplement to the SPIRIT K12 Program leverages existing K12 Scholar projects and expands the specific aims of their ongoing research to develop high-impact new knowledge concerning COVID-19 and the ongoing pandemic.

Ambulatory Pediatric Safety Learning Lab

Grant number: 5R18 HS026644-04

Institution: Boston Children's Hospital

Summary: After almost two decades of research and quality improvement, hospitalized children in the United States are safer from healthcare-related harm. The vast-majority of healthcare, however, is provided in the clinic and at home, and few studies in this context have demonstrated how to improve safety. Children are especially vulnerable to preventable harm caused by healthcare for many reasons, including weight-based medication dosing, handoffs between caregivers, and their limited ability to communicate evolving symptoms. At home, two in five children with chronic disease have a medication error. Of these, 3.6 percent are injured due to these errors—the same rate as hospitalized children. Among the 165,000 children with type 1 diabetes (T1D) nationally, 20 percent have poor glycemic control. The leading cause of death before age 30 among individuals with T1D is acute complications (e.g., severe hypoglycemia, diabetic ketoacidosis). One in 68 children have ASD. Of these children, 40 percent take antipsychotic medications, and most are not screened for complications. Management of chronic conditions with families is complex and offers a myriad of opportunities for system failures to occur that can lead to patient harm. We have identified three key opportunities to reduce the two most egregious harms in this setting—medication errors and treatment delays—in two different conditions. The Ambulatory Pediatric Patient Safety Learning Lab aims to:

1. Redesign processes for adjustment of medication dosing based on clinical information gathered by the patient/family to prevent medication errors. (This will be studied in type 1 diabetes)
2. Create processes for patient/family medication monitoring and communication with clinic to prevent adverse drug events. (This will be studied in children with ASD on antipsychotics)
3. Design a workflow to plan for, detect, and prompt management of serious illness among children with chronic conditions at home. (This will be studied in both populations)

This learning lab integrates design and systems engineering—in collaboration with Mad*Pow, and University of Wisconsin Systems Engineering Initiative for Patient Safety—with Cincinnati Children’s expertise in

patient-centered research and implementation. The overarching goal is to redesign systems of care and coordination between the clinic and home to eliminate harm due to healthcare in these settings. Problem analysis will include ethnography in the home and clinic, interviews, FMEAs, and digital diaries. We will implement all interventions together in the simulated environment and evaluate using a randomized factorial trial. Finally, we will implement in our clinical system with qualitative and quantitative evaluation. The intent is to develop a scalable model which leverages health systems and patient/family strengths to ensure safe healthcare among all children. Upon completion of this proposal, our team is perfectly poised to scale this nationally through the Solutions for Patient Safety (SPS) Network and improve pediatric ambulatory safety across the United States. PUBLIC HEALTH RELEVANCE: Management of chronic conditions with families is complex and offers a myriad of opportunities for system failures to occur that can lead to patient harm; such failures can have lethal results. We have identified key opportunities to reduce the two most egregious harms in this setting—medication errors and treatment delays—in children with two model conditions, type 1 diabetes and ASD. In collaboration with Mad*Pow, an award-winning design firm, and University of Wisconsin Systems Engineering Initiative for Patient Safety, we will redesign processes for management of medications and serious illnesses between the clinic and home, and prepare to disseminate nationally through our networks.

Enabling large-scale research on autism spectrum disorders through automated processing of EHR using natural language understanding

Grant number: R21HS024988-01A1

Institution: University of Arizona

Summary: With increasing use of electronic medical records for a variety of patients, a large investment is being made in a resource still vastly underused. Especially in mental health, where problems are highly individualized, requiring personalized intervention, and often accompanied by rich data not easily captured in structured templates, the need for extracting information from free text in existing records for use as large-scale stand-alone datasets or in combination with other data is real. Without scalable and effective

computational approaches to capture this data, much time, effort, and money is used to create limited-use records that instead could be leveraged into precious data sources to inform existing research and lead to new insights, progress, and treatments. Our broad, long-term goal is processing free text in electronic health records (EHR) in mental health. We focus on ASD, a particularly interesting example of both shortcomings and opportunities. ASD's prevalence has increased over the years, and estimates range from 1 in 150 in 2000 to 1 in 68 in 2010. These numbers are based on surveillance using EHR. The increasing prevalence is not well understood, and hypotheses range from changing diagnostic criteria to environmental factors. The lines of inquiry used to find cures are similarly broad and range from brain scans and genetics, resulting in large structured datasets, to highly individualized therapies, resulting in rich but unstructured data. Currently the text information in the electronic records is not being leveraged on a large scale. The proposed project continues our preliminary work and uses a data-driven approach to create human-interpretable models that allow automated extraction of relevant structured data from free text. The DSM is the starting point for identifying features. A database of thousands of records is leveraged to design and test the algorithms. The two specific aims are: 1) design and test natural language processing (NLP) algorithms to detect DSM criteria for ASD in free text in EHR, and 2) demonstrate feasibility and usefulness of the models for large-scale analysis of ASD cases, which is inconceivable today with current approaches. Our methods include analysis of free text in electronic records and end-user annotations to create a large gold standard of instances of DSM criteria for ASD, application of machine learning and rule-based approaches to create human-interpretable models for automated annotation of diagnostic patterns in textual records, and demonstrate usefulness with new research (e.g., Automatically detect ASD vs. no-ASD status for challenging cases; evaluate prevalence of symptoms over time). Through NLP algorithms, this project has the potential to significantly shift away from the current paradigm of attempting to understand ASD by relying on small-scale data from individual interventions and

lack of integration between different data sources, to leveraging information from existing large-scale data sources to propose novel analyses and hypotheses.

Screening for Autism Spectrum Disorder in Young Children

The USPSTF posted the draft research plan (RP) for public comments in Feb. of 2021. The final research plan was posted June of 2021. The review will look at the following key questions:

1. Does screening for ASD in children ages 12 to 36 months improve:
 - a. Access and timing of ASD evaluation, diagnosis, and intervention?
 - b. Developmental, functional, and quality of life outcomes?
2. What is the accuracy of screening instruments to detect ASD in children ages 12 to 36 months?
3. What are the harms of screening for ASD in children ages 12 to 36 months and their families?
4. Do interventions targeting young children with ASD improve developmental, functional, and quality of life outcomes?
 - a. To what extent is the timing of intervention initiation (by age and in relation to the establishment of an ASD diagnosis) associated with ASD-related outcomes?
5. What are the harms of interventions for ASD in young children?

A full explanation of the RP can be found on the **USPSTF website**. The EPC is currently working on the evidence review. Unfortunately, we are not able to share information on when the evidence review will be completed or when we anticipate the draft recommendation statement will be ready for public comment.

Comparative Effectiveness of Therapies for Children with Autism Spectrum Disorders (PCORTF 13.8) Contract number: 290-15-00003I-5

Summary: Two reports were produced; **Interventions Targeting Sensory Challenges in Children with Autism Spectrum Disorder - An Update**; and **Medical**

Therapies for Children with Autism Spectrum Disorder - An Update.

- **Interventions Targeting Sensory Challenges in Children with Autism Spectrum Disorder - An Update:**

This report included studies comparing interventions incorporating sensory-focused modalities with alternative treatments or no treatment. Studies had to include at least 10 children with ASD ages 2–12 years. Two investigators independently screened studies and rated risk of bias. We extracted and summarized data qualitatively because of the significant heterogeneity. We also assessed strength of the evidence (SOE). This report identified 24 unique comparative studies (17 newly published studies and 7 studies addressed in our 2011 review of therapies for children with ASD). Studies included 20 randomized controlled trials, 1 nonrandomized trial, and 3 retrospective cohort studies (3 low, 10 moderate, and 11 high risk of bias [ROB]). Populations, intervention approaches, and outcomes assessed varied across studies. Relative to usual care or other interventions, sensory integration–based approaches improved measures related to sensory and motor skills in the short term (3 RCTs with high, moderate, and low ROB and 1 high ROB retrospective cohort study). Environmental enrichment improved nonverbal cognitive skills in treated children compared with standard care in two small randomized controlled trials (low and moderate ROB). Four small randomized controlled trials (2 moderate and 2 high ROB) of auditory integration–based approaches reported mixed results. Studies of music therapy (4 randomized controlled trials—1 low, 2 moderate, and 1 high ROB—and 1 high ROB nonrandomized trial) used different protocols and addressed different outcomes, precluding synthesis. Massage improved ASD symptom severity and sensory challenges versus a waitlist control condition (7 studies, 5 with likely overlapping participants, 3 moderate and 4 high ROB). Additional randomized controlled trials (moderate and high ROB) of interventions with sensory-related components (tactile stimulation exercises, weighted blankets) reported few significant differences between treatment groups.

- **Medical Therapies for Children with Autism Spectrum Disorder — An Update:**

To evaluate the comparative effectiveness and safety of medical interventions (defined broadly as interventions involving the administration of external substances to the body or use of external nonbehavioral procedures to treat symptoms of ASD for children with ASD). The report included comparative studies of medical interventions that included at least 10 children with ASD. Two investigators independently screened studies and rated risk of bias. We extracted and summarized data qualitatively given significant heterogeneity. We also assessed strength of the evidence (SOE) and considered cumulative data from eligible studies included in our 2011 review of medical therapies and newly published studies.

HHS OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION (ASPE)

The **Assistant Secretary for Planning and Evaluation (ASPE)** is the principal advisor to the HHS Secretary on policy development and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis. The **Office of Behavioral Health, Disability, and Aging Policy (BHDAP)** within ASPE focuses on policies and programs that support the independence, productivity, health and well-being, and long-term care needs of people with disabilities, older adults, and people with mental and substance use disorders. The Division of Disability and Aging Policy is responsible for policy and data development, coordination, research, and evaluation of policies and programs focused on the functioning and well-being of persons with disabilities and older adults. The Division is the focal point for crosscutting disability and aging collaboration within HHS and across the federal government. Alzheimer’s disease and related dementias and IDD, including ASD, are notable areas of engagement and expertise. Descriptions are provided for some current projects related to autism.

- ASPE initiated development of the **Dataset on Intellectual and Developmental Disabilities**, a linked dataset which will enable researchers to analyze relationships between various sociodemographic information, need for home and community-based services, service utilization, service expenditures, and person-centered outcomes prior to and during the COVID-19 pandemic for individuals with ID/DD.
- ASPE published a brief on **Child and Adolescent Mental Health During COVID-19**, which identifies children with disabilities among the most disproportionately affected by a mental health condition during COVID-19 and describes policy considerations for schools and early childhood service providers.
- ASPE published the report **Health Insurance Coverage Among Working Age Adults with Disabilities**, which tracked changes in health insurance coverage for this population from 2010-2018. From 2010-11 to 2017-18, the proportion of U.S. adults with disabilities who lacked health insurance coverage for a full year was nearly halved, falling by about 46 percent from 17 percent to 9 percent. There was also an increase of about 14 percent in the proportion of adults with disabilities who had continuous coverage, from about 71 percent to 81 percent. These improvements were concentrated immediately after 2014, when the largest Affordable Care Act (ACA)-driven insurance expansions first took effect. Coverage gains were particularly large for Medicaid, coinciding with the ACA's Medicaid expansion program that took effect in most states starting in 2014. Having coverage for only part of the year, however, remained more than 50 percent more common for adults with disabilities (10 percent in 2017-18) than those without disabilities (6 percent in 2017-18) throughout the study period. The American Rescue Plan of 2021 (ARP) expanded subsidies for Marketplace plans (since extended through 2025 under the Inflation Reduction Act), which has the potential to increase coverage further for adults with disabilities. An estimated 532,000 uninsured adults with disabilities (about 67 percent) now have access to a zero-premium plan after premium tax credits on Healthcare.gov, an increase of 16.8 percentage points from pre-ARP estimates.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

CDC Efforts Focused on Autism Spectrum Disorder

CDC data published in 2021 found that about 1 in 44 children aged 8 years in the CDC's **Autism and Developmental Disabilities Monitoring (ADDM) Network** have ASD.³³³ These data also found, for the first time, no overall difference in the number of Black and Hispanic children identified with ASD compared to White children. In terms of early identification, more children aged 4 years are being evaluated and diagnosed with ASD than in the past.³³⁴ This highlights the importance of CDC's ADDM Network in tracking changes in ASD diagnoses to inform policy and clinical practice. CDC analyses of ADDM Network data also provide updated information on the variability in the community prevalence of ID; recent analyses indicate that 39 percent of children with ID also have ASD.³³⁵

CDC's investments in modernizing ASD surveillance activities are leading to more timely and actionable data to help children and their families.^{336,337} Beginning in surveillance year 2018, the ADDM Network updated its methods for monitoring ASD, which expanded tracking progress in early identification, decreased costs, led to faster reporting, and allowed sites to incorporate additional data sources. ADDM Network sites recently piloted a statewide expansion of ASD monitoring that requires fewer resources and provides the first-ever local data on ASD or other DD to some communities.

CDC continues to maintain and update its **Autism Data Visualization platform** that lets users explore available data on the prevalence, demographics, and other characteristics of children with ASD from four major data sources (ADDM Network, Special Education, Medicaid, and National Survey of Children's Health). The website was launched in April 2019 and has garnered over 110,000 page views as of October 2022. This platform provides an easy way to access national, state, and community-specific **data** that can inform programs, policies, and practices to address health disparities and improve the health and

well-being of children with ASD. CDC regularly updates a public-facing **list** of all published ASD prevalence studies that provide structured information on the population characteristics, study design, measurement of ASD, and prevalence estimates.

As children with ASD age into adolescence and adulthood, there are gaps in understanding their challenges and needs. In 2020, CDC completed the first-ever follow-up among children with ASD at age 16 years who were previously identified by the ADDM Network at age 8 years to better understand health needs and diagnostic practices in this transition period (publication under review). These results will be shared with healthcare and service providers, educators, researchers, and policymakers to inform equitable allocation of services and support for adolescents with ASD.

CDC's Study to Explore Early Development (SEED)

is a case-control study of children aged 2–5 years with ASD compared to children with other DD, and to children from the general population. It is the largest U.S. study of young children with ASD. SEED helps us learn more about risk factors for ASD and describes the behavioral phenotypes, co-occurring health conditions, and healthcare services and needs of children with ASD or with other developmental disabilities.³³⁸ With the release of **data** from the final phase, data are now available for over 6,000 children, including over 1,800 children with ASD.

SEED data have shown that many children (~60 percent) with ASD who use psychotropic medications have not received behavior therapy, despite recommendations from the American Academy of Pediatrics that behavior therapy should be used as a first-line treatment.³³⁹ SEED data also have been used to examine use of community-based services for preschool-aged children and the importance of having insurance.³⁴⁰ Findings show nearly 40 percent of children are not receiving supportive services; children on public insurance alone (versus public and private) are the least likely to receive community-based behavioral therapy and most likely to receive psychotropic medication. SEED data can inform care and treatment decisions related to use of psychotropic

medications,³⁴¹ GI symptoms,³⁴² and behaviors,³⁴³ such as wandering,³⁴⁴ pica,³⁴⁵ and resistance to toilet training.³⁴⁶

In 2020, CDC leveraged SEED infrastructure to collect **information** on the impact of COVID-19 on services, behaviors, and health during 2020 to help inform public health strategies for young children with and without ASD (aged 5–9 years) and their families during public health emergencies. These data have been used to compare children with ASD to children with other DD and to children from the general population regarding their experiences with disruptions to regular healthcare, developmental services, and IEP/504 plans and IDEA accommodations. Analyses are ongoing for the following topics: changes in daily living skills and behavior problems from before to after the onset of the pandemic; use of telehealth services and parent training for delivering therapies; factors associated with childhood resiliency; response to mitigation strategies and infection; and the impact of COVID on parental mental health.

In FY 2021, CDC completed **SEED Teen**, a follow-up study of original SEED participants at ages 12–16 years, and reported preliminary data indicating adolescents with autism were **90 percent** more likely to have additional mental health or other conditions and three times more likely to have unmet healthcare service needs compared with children in the general population. CDC used lessons learned from SEED Teen to inform the SEED Follow-Up study that was launched in July 2021. Data collected in the SEED Follow-Up study will facilitate analyses on early adult outcomes of individuals with ASD (e.g., health, functioning, and service use and needs) and factors associated with developmental trajectories. Additional components of the SEED Follow-Up study are in-person examination of cognitive abilities of individuals with and without ASD and analysis of existing data and biospecimens from preschool-aged participants and their families.

CDC's **Learn the Signs. Act Early. (LTSAE)** program encourages early, ongoing, and family-engaged developmental monitoring of all children and early identification of developmental delays so that children

and their families can receive the services and support they need. CDC's LTSAE program routinely engages early care educators, healthcare providers, and other professionals to support parents in regular developmental monitoring and action on concerns about their child. CDC supports **Act Early Ambassadors**, now in 47 states, the District of Columbia, Guam, Puerto Rico, and the Federated States of Micronesia, to promote and integrate early and ongoing developmental monitoring into early childhood systems and programs at the state and local levels, such as childcare, home visiting, and WIC (Special Supplemental Nutrition Program for Women, Infants, and Children) programs. Over the past year, technical assistance and collaborative learning opportunities were provided to WIC staff from 22 states and one territory; 19 states are promoting CDC's free Milestone Tracker app; and WIC staff from 44 states have participated in training on early development. CDC's LTSAE program also collaborates with the American Academy of Pediatrics to target messaging to pediatric healthcare providers about the importance of developmental monitoring, screening, referral, and follow-up. The LTSAE program develops and promotes training and materials to support healthcare and other providers' roles in assuring these services.

With the addition of Coronavirus Aid, Relief, and Economic Security (CARES) Act funds, CDC bolstered the LTSAE program to address challenges to early identification and access to supports for children with autism and other developmental disabilities due to the COVID-19 pandemic. In Fall 2020, CDC, in collaboration with the Association of University Centers on Disabilities, completed a rapid needs assessment across 43 Act Early response state teams to inform strategies to mitigate the impact of the COVID-19 pandemic on early identification of developmental delays within early childhood systems. Most (over 90 percent) of 349 respondents indicated that COVID-19 had highly impacted early identification, 48 percent reported decreases in the number of children served, and up to 66 percent had transitioned to virtual/remote hybrid delivery service. The 43 Act Early response teams developed and implemented state work plans to increase parent-engaged developmental

monitoring and early action on concerns about children, bolstering early childhood systems and delivery of essential health services. Act Early Ambassadors also promoted and distributed materials and tools to improve resiliency of very young children (birth to age 5) and their families during the COVID-19 pandemic, aligning with CDC's response efforts. With ongoing CARES Act funds in 2022, CDC-funded COVID Act Early Response teams continued to address the gaps and challenges identified in the needs assessment, expanding and evaluating the impact of their efforts to improve early identification and connect children with services and supports during COVID-19.

In FY 2023, CDC will continue to support surveillance, research, and LTSAE activities that help us better understand ASD and how we can best support children and families, including addressing health inequities and supporting children and families in public health emergencies. CDC will also continue contributing to the enhanced understanding of children with ASD as they reach adolescence to inform critical periods in development and transition to adulthood.

Disability and Health

Up to **26 percent** of American adults, or up to one in four, have at least one developmental or other disability.³⁴⁷ Disabilities can range from those present from childhood and lasting a lifetime to those that are later onset, possibly temporary, and associated with other health conditions. Disabilities may include difficulty with movement, hearing, seeing, communicating, concentrating, remembering, caring for oneself, or making decisions. The annual healthcare costs associated with disabilities are nearly \$868 billion—over 36 percent of all healthcare expenditures for adults residing in the United States.³⁴⁸ As a group, people with disabilities are much more likely to be physically inactive, to smoke cigarettes, be overweight, have heart disease or diabetes, and are less likely to receive preventive healthcare services.^{349,350} CDC aims to foster access to preventive services so that people with disabilities can live healthy lives.

In alignment with CDC CORE Health Equity goals, CDC aims to increase inclusion of people with disabilities, including ASD, in public health data to better evaluate health disparities, better target health prevention and promotion activities, and to evaluate health and other outcomes. These efforts include increased collaborations to include the **HHS Disability Data Standard** in public health data collection systems and to enhance the use of administrative and survey data in identifying people with disabilities. CDC is working to ensure people with disabilities are included in ongoing surveillance efforts by developing, testing, and disseminating syndromic surveillance definitions to identify people with disabilities and monitor emerging public health threats. People with disabilities are often disproportionately negatively impacted by disasters, yet disability is frequently underrepresented in data used to guide decision-making and resource allocation during public health emergencies.³⁵¹ Absent available demographic information on disability, diagnostic code-based definitions could be used to identify people with disabilities; however, there is no uniform standard for measuring disability using this method. CDC, in collaboration with the Association of State and Territorial Health Officials (ASTHO) and the CDC's National Syndromic Surveillance Program, is creating diagnostic code-based definitions to identify emergency department visits by people with disabilities. The goal of this project is to build public health capacity to monitor the health and well-being of people with disabilities before, during, and after public health emergencies. This work will have a sustainable impact on national, state, and local response capacity to detect and monitor the health and well-being of people with disabilities during current and future public health emergencies.

National Programs on Health Promotion for People with Disabilities

CDC funds two **National Programs on Health Promotion for People with Disabilities**—the National Center on Health, Physical Activity, and Disability (NCHPAD) and Special Olympics—to work with people with mobility limitations (ML) and ID, respectively. These national organizations support the development,

implementation, evaluation, and dissemination of non-research activities aimed at raising knowledge and awareness of the health needs of people with ML and/or ID; developing and disseminating health promotion models, strategies, tools, and health promotion materials; providing training and education to healthcare professionals; and promoting the adoption of healthy behaviors aimed at reducing health disparities for people with ML and ID.

Improving the Health of People with Mobility Limitations

CDC's partnership with NCHPAD primarily focuses on reducing health disparities and improving the health of people with ML by delivering health promotion programs to people with ML and expanding the capacity of healthcare and community-based providers to serve the health needs of people with ML.

NCHPAD developed a comprehensive, evidence-based set of wellness modules that help tailor health promotion programs to the unique needs of people with a range of disability and mobility issues. NCHPAD identified existing evidence-based programs that fit under seven chronic condition focus areas: High Blood Pressure, Type 2 Diabetes, Chronic Heart Disease, Mental Health, Obesity, Asthma & Chronic Obstructive Pulmonary Disease, and Physical Inactivity. Seventeen programs that NCHPAD previously adapted have been mapped to these seven chronic condition focus areas. CDC also partners with NCHPAD to promote MENTOR (Mindfulness, Exercise and Nutrition To Optimize Resilience), an initiative created to bridge the gap between healthcare and post-healthcare public health practice for individuals who have recently accessed the healthcare system for treatment related to a new or existing disability, new secondary health condition, or a condition likely to result in a disability. NCHPAD's healthcare-to-wellness national network and the creation of seven specialty (chronic disease) programs partnerships will assist in screening patients with mobility limitations and registering them in NCHPAD's national registry for participation in the online MENTOR program and/or one of the seven specialty programs.

Improving the Health of People with Intellectual Disabilities

Special Olympics provides year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with ID. CDC funds the Special Olympics Healthy Athletes® and Healthy Communities Programs to provide Special Olympics athletes with increased access to free health screenings, education, services, supports, and referrals for follow-up healthcare as well as year-round health promotion and disease prevention programs.

CDC’s partnership with Special Olympics focuses on reducing barriers to inclusive health services and programs, challenging misperceptions, eliminating stigma, and improving the health of people with ID by the following:

- Training healthcare professionals to conduct and support Healthy Athletes® screening events throughout the United States.
- Increasing the availability of data during and after screening events using digital health technology to evaluate effectiveness and provide critical health information on this population.
- Providing disability awareness training to healthcare professionals, community wellness partners, schools, and other collaborators who have limited or no experience working with people with ID.

CDC and Special Olympics support people with ID in the following ways:

- Conducting Healthy Athlete screenings to assess risk for chronic disease and mental health conditions.
- Expanding screening information to include healthcare utilization patterns.
- Evaluating virtual/online options for hearing assessments.
- Expanding programming for young children.

- Developing and piloting a new model for healthcare referral/coordination.
- Collaborating with university-based partners on health indicator data collection.
- Delivering a multidisciplinary training curriculum in academic institutions.

Disability and Health Data System

CDC’s **Disability and Health Data System (DHDS)** is an online interactive source of state, regional, and national data on the health and demographics of adults with disabilities. States rely on this information to understand the health status and needs of their population with disabilities and to tailor health protection programs for this population. Through DHDS, states can easily identify prevalence of disability status by approximately 30 measures of health (e.g., smoking, physical activity, obesity, hypertension, heart disease, and diabetes) and can leverage this information to inform policies and practices that address health disparities and support people with disabilities.

CDC is using the existing dataset to drive programmatic decisions and inform strategies for a Medicaid analysis project to examine the impact of COVID-19 on people with IDD, specifically to identify the following:

- Changes in patterns of healthcare access and service use over time, including uptake of telemedicine and tele-mental health.
- Changes in new conditions acquired during the COVID-19 pandemic.

In 2022, CDC updated DHDS to include the latest 2020 Behavioral Risk Factor Surveillance System data on U.S. adults with disabilities, including cognitive, mobility, vision, self-care, independent living, and hearing. CDC also regularly updates and makes publicly-available **state fact sheets** that provide an overview of disability in each state.

State Disability and Health Programs

CDC currently invests in 10 State Disability and Health Programs to improve health outcomes among people with ML and ID. Through 2021, these **programs** reached 3.2 million people nationwide through the implementation of 39 evidence-based strategies and interventions focusing on physical activity, nutrition, diabetes, and other health topics significant for this population. The state programs strengthen partnerships and design, create, and implement programs to improve the health of people with disabilities in their states. In 2021, CDC began a new five-year cycle with an increased focus on engagement with high-quality routine preventive healthcare, adoption of healthy lifestyle behaviors, and early identification, management, and control of chronic disease and mental health conditions among people with IDD and people with ML.

Additionally, CDC has partnered with ASTHO and the National Association of County and City Health Officials (NACCHO) to embed 28 disability specialists in state, territorial, and local health departments' public health emergency preparedness and response programs to ensure issues impacting people with disabilities are considered in planning and response efforts. CDC supports the NACCHO Disability Specialists Program by funding salaries of 10 public health workers specialized in emergency preparedness and disability inclusion to enhance local health departments' capacity inclusion of people with disabilities in public health preparedness, response, data collection, and programs.

Finally, CDC supported a technical assistance and training center to disseminate COVID-19 emergency preparedness and response resources, along with the development of a central, online repository of practice-based materials on emergency preparedness tailored for people with disabilities, caregivers, and the emergency and healthcare providers who serve them. Through these efforts, an online toolkit called **Public Health is for Everyone** now contains over 100 COVID-19 resources relevant to people with disabilities.

CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)

The **Centers for Medicare & Medicaid Services (CMS)** is committed to strengthening and modernizing the nation's healthcare system to enhance quality, accessibility, and improved outcomes in the most cost-effective manner possible. CMS administers several programs that are available to individuals with disabilities, including those with ASD.

Medicaid

- States establish and administer their own **Medicaid** programs and determine the type, amount, duration, and scope of services within broad federal guidelines. Federal law requires states to provide certain mandatory benefits and allows states the choice of covering other optional benefits. Therefore, there is variation across states in terms of the scope of coverage offered in each Medicaid program.
- Examples of mandatory benefits include services like inpatient and outpatient hospital services, physician services, laboratory and x-ray services, and home health services, among others. Optional benefits include services like prescription drugs, case management, physical therapy, occupational therapy, and HCBS.
- Individuals with ASD could receive some of these mandatory and optional services based on their individual assessed needs.
- Services and supports for individuals with ASD can be covered under Medicaid through a variety of authorities including section 1905(a) of the Social Security Act.
 - CMS does not endorse or require any particular treatment modality for ASD. State Medicaid agencies are responsible for determining what services are included within a menu of both mandatory and optional services for eligible individuals. Medicaid may cover a variety of services and supports, such as case management, rehabilitative services, and physical, occupational, and speech therapies.

Some ASD treatment modalities, or components of such treatment modalities, are within the scope of the federal Medicaid program under the following benefit categories: section 1905(a)(6) services of Other Licensed Practitioners (OLP), section 1905(a)(13) Preventive Services, and section 1905(a)(11) Therapies. States may provide services to address ASD under each of these benefit categories.

- ASD services could also be provided by states under optional programs found at section 1915(i) state plan HCBS, section 1915(c) HCBS waiver programs, 1915(k) Community First Choice state plan programs, and section 1115 demonstration programs. **HCBS** are types of person-centered care delivered in the home and community. A variety of health and human services can be provided. HCBS programs address the needs of people with functional limitations who need assistance with everyday activities, like getting dressed or bathing. HCBS are often designed to enable people to stay in their homes, rather than moving to a facility for care.
 - Examples of health care that can be provided under HCBS include:
 - » Home health care such as:
 - Skilled nursing care
 - Therapies: Occupational, speech, and physical
 - Dietary management by registered dietician
 - Pharmacy
 - » Durable medical equipment
 - » Case management
 - » Personal care
 - » Caregiver and client training
 - » Health promotion and disease prevention
 - Examples of services to support daily living that are supported under HCBS include:
 - » Assistance with acquisition, retention, or improvement in self-help, socialization, and adaptive skills
 - » Day habilitation services
 - » Home-delivered meal programs
 - » Congregate meal sites
 - » Personal care (dressing, bathing, toileting, eating, transferring to or from a bed or chair, etc.)
 - » Transportation and access
 - » Home repairs and modifications
 - » Home safety assessments
 - » Homemaker and chore services
 - » Information and referral services
 - » Telephone reassurance
 - » Supported employment services
 - » Adult daycares
 - » Senior centers
 - Some of the benefits of HCBS include:
 - » Cost effectiveness: usually less than half the cost of institutional care.
 - » Culturally responsive: spiritual and cultural activities and support available.
 - » Familiarity: patient enjoys the comfort of their own home or small residential facility in the community.
 - » Some waivers permit family members to be paid caregivers.
- In August 2022, CMS released guidance on a new **optional Medicaid health home benefit** for children with medically complex conditions available starting October 1st that helps state Medicaid programs provide Medicaid-eligible children who have medically complex conditions, including severe autism, with person-centered care management, care coordination, and patient and family support. CMS anticipates that the new benefit will help these children receive the care they need, including across state lines. The services provided under the new benefit include providing access to the full range of pediatric specialty and subspecialty medical services, including services from out-of-state providers, as medically necessary. States with approved Medicaid state plan amendments (SPAs) to cover the new health home benefit will receive a

15 percentage point increase in federal matching for their expenditures on health home services during the first two FY quarters that the SPA is in effect. CMS also has committed to offer ongoing technical assistance to states about implementation of the new optional benefit.

- Also in August 2022, CMS announced key actions to strengthen and expand access to high-quality, comprehensive healthcare for children, including children with autism, across the country. CMS issued new guidance reminding states of their mandate to cover behavioral health services for children in Medicaid and urging states to leverage every resource to strengthen mental health care for children, including expansion of school-based healthcare. HHS also issued a proposed rule that, for the first time ever, would require states to report certain quality measures to strengthen Medicaid and the Children’s Health Insurance Program (CHIP) to ensure that the millions of children and families enrolled in these programs have access to the highest quality of care. These actions are part of **HHS’ ongoing efforts** to support the Biden-Harris Administration’s call to address the nation’s mental health crisis, including its impact on children.
- In July 2022, CMS released the first-ever HCBS quality measure set to promote both consistent quality measurement within and across state Medicaid HCBS programs and health equity among the millions of older adults and people with disabilities who need long-term services and supports, including individuals with autism.
- Through section 9817 of the American Rescue Plan Act of 2021, states are investing over \$25 billion in activities to enhance, expand, and strengthen Medicaid HCBS, including to expand access to services and improve quality of care for individuals with autism. Of this funding, states are investing over \$8 billion in a broad range of activities to enhance, expand, and strengthen Medicaid HCBS for people with ID/DD, including individuals with autism. For example, states are reducing waiting lists for services and expanding access to

employment supports for people with ID/DD, and providing specialized training to direct support professionals to improve the care provided to people with autism.

- On July 7, 2014, CMS released an **Informational Bulletin** providing information on the options available under the federal Medicaid program for furnishing services to eligible individuals with ASD. The Informational Bulletin outlines the Medicaid coverage categories that are available to cover services to treat ASD. The Bulletin also discusses requirements related to services for individuals under the age of 21 eligible for EPSDT coverage, and how states currently furnishing more limited coverage of services to treat ASD under a section 1915(c) waiver or section 1915(i) Medicaid state plan amendment may have to transition those individuals to EPSDT coverage.
- It is important to note that EPSDT is a mandatory benefit extended to all Medicaid-eligible individuals under the age of 21. The program makes children eligible for benefits through section 1905(r) of the Social Security Act, which requires the provision of any medically necessary healthcare services listed in section 1905(a) of the Act. This mandate includes services to address ASD. The EPSDT mandate expires at an individual’s 21st birthday, and the benefits a state makes available for adults would then take over, which could result in a smaller scope of services offered to an adult with ASD.
- For states with managed care plans, those plans are expected to offer the services they are contracted with the state to provide, including those specific to ASD, without adding unnecessary barriers to service access.
- Federal law requires that state Medicaid programs, including Medicaid managed care plans, ensure adequate access to timely care, including by keeping an adequate network of providers.
- Individuals eligible for Medicaid via the adult group receive a benefit package that includes the Essential Health Benefits required in the Market-place, as described below.

Children’s Health Insurance Program (CHIP)

- CHIP provides comprehensive benefits to children. States have flexibility to design their own program within federal guidelines. States may choose between a Medicaid expansion program, a separate CHIP, or a combination of both types of programs.
- Medicaid Expansion CHIP programs provide the same Medicaid benefit package as provided for children under each state’s Medicaid program. Please see the *Medicaid* section for discussion of ASD coverage in this context.
- Similar to Medicaid, states that establish and administer their own separate CHIP programs determine the type, amount, duration, and scope of services within broad federal guidelines. Federal law requires states to provide certain mandatory benefits and allows states the choice of covering other optional benefits. Therefore, there is variation across states in terms of the scope of coverage offered in each separate CHIP program. For example, some states specifically include coverage of ABA as part of their CHIP benefits available for the screening, diagnosis, and treatment of individuals with ASD.
 - All separate CHIPs must provide well-baby and well-child care, dental coverage, behavioral health care, and vaccines. **Section 2103(c)(5) of the Social Security Act** requires coverage of mental health services (including behavioral health treatment) necessary to prevent, diagnose, and treat a broad range of mental health symptoms and disorders, including substance use disorders. Additional information is available in State Health Official letter # 20-001.
- All Marketplace health plans and most other private insurance plans must cover preventive services for children without charging a copayment or coinsurance. This includes **autism screening** for children at 18 and 24 months.
- Health plans cannot put a lifetime dollar limit on most benefits an individual receives. The law also does away with annual dollar limits a health plan can place on most benefits for most health plans, and no Marketplace health plans can have annual or lifetime dollar limits. Prior to the Affordable Care Act, many plans set a dollar limit on what they would spend for covered benefits during the time individuals were enrolled in the plan, leaving individuals on the autism spectrum and their families to pay the cost of all care exceeding that limit.
- Young adults can remain covered under their parents’ insurance up to at least the age of 26. For a young adult with autism or related conditions and their family, that means more flexibility, more options, and greater peace of mind.
- Individuals on the autism spectrum and families of children on the autism spectrum now have expanded access to affordable **insurance options** through the Health Insurance Marketplace and expansion in Medicaid.
- Most health plans sold in the individual and small group markets, including the Marketplace, must cover “essential health benefits,” including hospitalizations, preventive services, and prescription drugs, to help ensure that individuals have the coverage needed to stay healthy. Health insurers will also have annual out-of-pocket limits to protect families’ incomes against the high cost of healthcare services.

The Affordable Care Act/Marketplace

The Affordable Care Act contains important provisions for individuals with autism and related conditions and their families:

- Most health insurance plans are no longer allowed to deny, limit, exclude, or charge more for coverage to anyone based on a **pre-existing condition**, including **autism and related conditions**.
- All non-grandfathered individual and small group plans, including all Marketplace health plans, must provide habilitative and rehabilitative services as essential health benefits. Services in these categories generally include occupational therapy, physical therapy, and speech therapy. Plans must also cover mental and behavioral health services, though the exact services covered may vary by state and issuer.

- ABA therapy is specifically included in many Marketplace health plans.
- Marketplace health plans cannot impose limits on coverage of habilitative services and devices that are less favorable than any such limits imposed on coverage of rehabilitative services and devices. They also cannot place combined visit limitations on habilitative and rehabilitative services and devices.
- Benefits vary by state and issuer, but coverage for other benefits, such as peer supports, assistive technology, housing support, etc., are frequently not covered.

Additional Resources

- **HHS.gov: The Affordable Care Act and Autism and Related Conditions**
- **The National Council of States Legislatures webpage (August 2021): Autism and Insurance Coverage State Laws**
- **Autistic Self-Advocacy Network (ASAN): Health Insurance and Medicaid Coverage for Autism Services: A Guide for Individuals and Families (July 2015)**
- On September 24, 2014, CMS released a set of **Frequently Asked Questions (FAQs)** to respond to questions raised by states and stakeholders regarding autism services. Additional questions may be directed to the autism services mailbox at **AutismServicesQuestions@cms.hhs.gov**.
- In January 2014, CMS released a report entitled **Autism Spectrum Disorders (ASD) State of the States of Services and Supports for People with ASD**, which provides a nationwide summary of state services for people with ASD and policies related to people with ASD. The report provides information on existing programs and policies in all 50 states and the District of Columbia. The report stemmed from the IACC's 2010 and 2011 Strategic Plans. (Note: Due to the size of this report, smaller files of state profiles organized by geographical region and the background information are also available upon request from the Contracting Officer's Representative listed on the report cover.)

- In 2010, CMS released an environmental scan of the scientific evidence regarding the efficacy, effectiveness, safety, and availability of ASD-related psychosocial services and supports for children, transitioning youth, and adults with ASD. This report, entitled **Autism Spectrum Disorders Services: Final Report on Environmental Scan**, describes findings from the literature review, including data on the evidence base for interventions for individuals with autism across the age span as well as data on the significant costs associated with caring for individuals with autism.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

HRSA Programs That Directly Provide or Support Provision of Supportive Services

- HRSA/Maternal and Child Health Bureau (MCHB) provides funding to grantees for family caregiver and systems navigation services. The Innovations in Care Coordination for Children and Youth with Autism and Other Developmental Disabilities Program provides funding to entities to provide family navigation services in medically underserved areas and with medically underserved populations. The goal of the family navigation services is to reduce barriers to early diagnosis and treatment of autism/DD and to increase self-efficacy of families receiving family navigation services in navigating the system of care and services for autism/DD. The family navigators provide time-limited services to families of children with autism and other DD or who have increased likelihood of developing autism/DD to address a variety of needs including:
 - Strengthening the family-professional partnership between the families and the clinicians providing care to their children;
 - Improving families' awareness of resources and services for their children;
 - Reducing delays in accessing specialty and sub-specialty services (e.g., developmental behavioral pediatricians, child neurologists, child psychologists, occupational therapists, speech language therapists, etc.);

- Helping to minimize barriers to accessing community-based services (e.g., transportation, financial, etc.);
- Coordinating care between multiple providers;
- Promoting care that is culturally and linguistically competent; and
- Helping to facilitate transition across settings and providers, and from pediatric to adult systems of care.
- HRSA/MCHB’s **Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** and **Developmental Behavioral Pediatrics (DBP)** Training Programs provide training to healthcare and related professionals to screen, refer, and provide services for children with autism/DD. In the context of training, these programs support a range of services and interventions and coordination of care to improve the health and well-being of individuals with autism/DD.
- More information about HRSA/MCHB-funded Autism CARES Act Programs can be found at: mchb.hrsa.gov/programs-impact/autism.
- The HRSA-funded **State Public Health Coordinating Center for Autism (SPHARC)** provides technical assistance to CARES grantees and state maternal and child health (MCH) programs who may offer gap filling supportive services to individuals on the autism spectrum and their families. In addition, state MCH programs may support gap filling services as needed. Particularly, those technical assistance and supportive services are related to:
 - Caregiver training for family-mediated interventions
 - Transition healthcare
 - Family and peer mentoring supports
 - Caregiver respite services
 - Family caregiver and systems navigation services
 - Individual- and family-directed services and personal supports (self-direction)
 - Empowerment, education, and advocacy training and services
 - Telehealth

HRSA Policies for Healthcare Coverage of Supportive Services for People on the Autism Spectrum

The HRSA-funded SPHARC and the **Catalyst Center** assist HRSA-funded Autism CARES grantees and state Title V MCH Programs to understand the support services and related policies available to individuals on the autism spectrum and their families. In some cases, the grantees facilitate provider training or family/self-advocate perspective to those delivering services to individuals with autism. Empowerment, education, and advocacy training are often custom delivered to meet a need. Support services offered vary by state or jurisdiction and by the age of the person who needs the services. For example, Parts B and C of IDEA offer early intervention services by age categories. Part C covers birth through 36 months of age, and Part B applies to supportive services for children ages 3 through 21 years of age. Parts B and C are closely tied to the school setting, and the school or other partners may administer IDEA federal funds. It is common for a school setting to only administer Part B, and an early childhood organization may administer Part C. Additionally, public schools are federally mandated to identify, locate, and evaluate all children for developmental delay through **IDEA’s ChildFind** service. Generally public schools coordinate with education, public health, and community organizations for extensive outreach. As persons with autism leave school settings, adult services are provided through different systems for career support and healthcare. Healthcare support services variations often depend upon the payor type of the insurance coverage. For instance, public health insurance (such as Medicaid-managed care or fee-for-service) may have different coverage than private payors of healthcare coverage, and state or jurisdiction policies for this population greatly influence the supportive services available.

INDIAN HEALTH SERVICE (IHS)

The **Indian Health Service (IHS)** is responsible for providing federal health services to American Indians and Alaska Natives (AI/AN). The provision of health services to members of federally recognized Tribes grew out of the special government-to-government relationship between the federal government and Indian Tribes. This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders. The IHS is the principal federal healthcare provider and health advocate for American Indian people, and its goal is to raise their health status to the highest possible level. The IHS provides a comprehensive health service delivery system for approximately 2.6 million American Indians and Alaska Natives who belong to 574 federally recognized Tribes in 37 states.

The IHS mission is to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level. The IHS vision is to promote healthy communities and quality healthcare systems through strong partnerships and culturally responsive practices.

Indian Children's Program (ICP)

As part of the IHS mission to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level, IHS is committed to providing education, training, consultation, and resources to clinicians treating patients with neurodevelopmental disorders, including ASD, through the IHS **Indian Children's Program (ICP)**. In 2016, the ICP transitioned under the IHS Telebehavioral Health Center of Excellence (TBHCE) to become a national program. The TBHCE currently provides training and support to healthcare providers regarding behavioral health, family, and social issues facing AI/AN youth diagnosed with neurodevelopmental disorders, including ASD. These services are available to all IHS, Tribal, and urban Indian organization providers and include no-cost continuing education credits. Currently, IHS has **28 webinars** on ASD and autism-

related topics available any time to any healthcare provider providing care to AI/AN patients.

In response to COVID-19, IHS provided three webinars to assist healthcare providers in supporting families of children with ASD and other neurodevelopmental disorders during the COVID-19 pandemic. Topics in the IHS COVID-19 Response Webinar Series included:

- Supporting Safety for Families of Children with Neurodevelopmental Disorders during COVID-19;
- Emotion and Behavior Regulation Support for Families of Children with Neurodevelopmental Disorders during COVID-19; and
- Learning Support for Families of Children with Neurodevelopmental Disorders during COVID-19

In 2021, IHS hosted a webinar training series on ASD to develop healthcare providers' skills to treat individuals with ASD. Topics included:

- Introduction to Autism Spectrum Disorder;
- Screening and Diagnosis of Autism Spectrum Disorder;
- After an Autism Spectrum Diagnosis: Next Steps;
- Applied Behavior Analysis for Autism Spectrum Disorder; and
- Supports for Transition-Aged Individuals with Autism Spectrum Disorder

In observance of World Autism Day on April 2, 2022, IHS hosted a special workshop entitled "**Exploring Mindfulness and Dance Movement Therapy for Children with Autism Spectrum Disorder**." The workshop provided healthcare providers, family members, and other interested participants with information on how dance movement therapy and mindfulness interventions can be treatment approaches for children with autism. The workshop was a fun, interactive experience for families and healthcare providers to learn and practice specific mindfulness and dance movement therapy techniques, thereby increasing their therapeutic skill set with children with autism to create accepting and caring home and healthcare environments.

NATIONAL INSTITUTES OF HEALTH (NIH)

The **National Institutes of Health (NIH)** is the nation's medical research agency. NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. As part of this mission, NIH supports scientific research to better understand the causes and mechanisms underlying ASD, improve methods of early identification and diagnosis, and develop and improve interventions and services, including behavioral, communication, and daily living skills interventions, to improve overall health among children, adolescents, and adults with ASD. NIH makes coordinated efforts to invest in a wide range of ASD research. Information on aggregate NIH funding for autism can be found on NIH's **Research Portfolio Online Reporting Tools (RePORT)** under **Categorical Spending for Research, Condition, and Disease Categorization (RCDC)**. Though NIH is not involved in health service coverage decisions, NIH-supported research on interventions and services contributes to the overall evidence base that is available for use by agencies and organizations that make decisions related to health service coverage. Some examples of NIH-funded autism services research are provided below.

Research on Outcomes

NIH supports studies on the impact of various interventions and services on outcomes for individuals with ASD. For example, a study supported by the National Institute of Deafness and Other Communication Disorders (**P50DC018006**) is examining whether adding an oral-motor focused intervention to a social-communication intervention will improve language outcomes in minimally-verbal children with ASD. Children who have ASD often receive services through school systems. An NIH-supported longitudinal analysis of services, ranging from physical or speech therapy to personal care or respite services over 14 years, found that people with ASD received significantly fewer services after high

school. The decrease in services was greater for those who had ASD and ID than it was for those who only had ASD.²⁹ Scientists funded by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) are working to address long-term outcomes of children with ASD. For example, one group of researchers is assessing the long-term outcomes of children with ASD at ages 14 to 15 who received early intensive behavioral intervention in the preschool years (**R01HD087302**). In addition, the Autism ACTION Network, a new interdisciplinary network of eight institutions, is conducting research on evidence-based interventions in real world settings, which aim to engage families to access resources and support when they first learn their child has signs of ASD and to coach families to embed evidence-based intervention strategies for toddlers with ASD in everyday activities (**5R01HD093055**).

Research on Detection

ASD Pediatric Early Detection, Engagement, and Services (PEDS) Network: Beginning in 2014, the National Institute of Mental Health (NIMH) supported five research grants that composed the ASD PEDS Network (**R01MH104302, R01MH104355, R01MH104400, R01MH104423, R01MH104446**). ASD PEDS researchers tested strategies for universal screening coupled with referral to and engagement in services when indicated for children with ASD from 12 to 36 months of age. The researchers also examined the issues surrounding coordination among different settings including primary care and community service agencies. The ASD PEDS investigators compiled information across their individual studies and identified common implementation strategies (e.g., developing stakeholder relationships and provider trainings) and barriers (e.g., inefficient systems of care, difficulty engaging families in the interventions, provider attitudes, and organizational culture). They found that despite diverse settings and a variety of innovation content, common facilitators and challenges exist in implementing innovations to enhance access to early ASD screening, diagnosis, and treatment.³⁵² Findings from one of the ASD PEDS projects suggest that an ASD diagnosis becomes stable starting at age 14 months and overall is more stable than any other

diagnostic category including language or developmental delay.³⁵³ Furthermore, once a child is identified as having ASD, there is an extremely low chance that he or she will test within typical levels at age 3. This finding opens the opportunity to test the impact of very early age treatment of ASD. Main findings from a second ASD PEDS project suggest that utilizing “family navigators” to engage caregivers in recommended services improved the likelihood of diagnostic ascertainment among children from racial/ethnic minority, low-income families who were detected in primary care as at-risk for ASD.³⁵⁴ NIMH is currently funding a longitudinal study to identify long-term outcomes from two ASD PEDS projects (**R01MH121595** and **R01MH121599**). The study is following two cohorts of children: those who were diagnosed with autism through early universal screening programs (at well-baby check-up) and those who did not participate in an early detection program yet were diagnosed at a later time. The study is testing the impact of early screening on long-term outcomes, which include autism symptoms; cognitive, social, behavioral, and academic functioning; family well-being and parent mental health; and treatment engagement.

NICHD also funds research on the detection of autism. One study (**5R01HD039961**) is investigating the best age to initiate screening with the Modified Checklist for Autism in Toddlers (M-CHAT), as well as accuracy of physician surveillance and factors associated with disparity in effective ASD screening and surveillance. Another study (**5R03HD090365**) is focusing on implementation of the M-CHAT in the context of a large urban reschool sample. In addition, NICHD is funding research to develop a telehealth screening protocol for systematically screening, assessing, and monitoring symptomatic infants from a distance, which will increase families' access to specialized evaluations and decrease the significant waiting time between parents' first concerns and infants' first evaluation (**5R21HD100372**).

Research on Identifying and Addressing the Needs of Transition-Aged Youth and Adults with ASD

NIMH supports services research projects on transition-aged youth and adults with ASD. “Transition-aged youth with ASD” refers to individuals with ASD who, in the coming months or years, will age out of the services and supports delivered via K-12 education and other child/adolescent service systems. Research projects include a focus on improving competitive employment outcomes, strategies for achieving self-management of co-occurring health conditions, improving understanding of social relations, and engaging siblings of adults with ASD in future planning to achieve optimal long-term outcomes (**R34MH111556**, **R34MH111536**, **R34MH111531**, **R34MH111491**, **R34MH111489**). NIMH is also addressing the need for more research aimed at fostering effective and developmentally appropriate services for adults and transition-aged youth by enriching the pool of autism researchers focused on this specific population, through career development and enhancement awards (**RFA-MH-20-420/-421**). One NIMH-funded career enhancement award recipient is examining a strength-based intervention to improve job interview skills in transition-aged youth with ASD (**K18MH122847**).

Interagency Autism Coordinating Committee

NIH also manages the **Interagency Autism Coordinating Committee (IACC)**, a federal advisory committee authorized under the Autism CARES Act of 2019 to provide advice to the HHS Secretary on issues related to autism. The Committee, currently composed of over **40 federal officials and public stakeholders** representing a wide range of views and expertise, is charged with providing a **Strategic Plan** to guide federal autism efforts. The IACC holds three full committee meetings per year, where it hosts public discussions and presentations on issues of importance to the autism community and hear public comments. Issues related to autism services and supports, family, and caregiver challenges are discussed in this forum and are highlighted in committee documents such as the **IACC Strategic Plan for Autism Spectrum Disorder**.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

The **Substance Abuse and Mental Health Services Administration (SAMHSA)** leads public health efforts to advance the behavioral health of the nation. SAMHSA's mission is to reduce the impact of substance misuse and mental illness on America's communities. SAMHSA-funded activities broadly impact the health and well-being of individuals with mental health conditions, including those with ASD, and their families.

SAMHSA Programs That Directly Provide or Support Provision of Supportive Services

Mandated by Congress, SAMHSA's **block grants** are noncompetitive grants that provide funding for substance misuse and mental health services. While they are not autism-specific, they can support a broad array of services for children with mental health conditions/serious emotional disturbances and substance use disorders.

SAMHSA is responsible for two block grant programs:

- **Substance Abuse Prevention and Treatment Block Grant (SABG):** The SABG program provides funds and technical assistance to all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, six Pacific jurisdictions, and one tribal entity. Grantees use the funds to plan, implement, and evaluate activities that prevent and treat substance misuse and promote public health.
- **Community Mental Health Services Block Grant (MHBG):** The MHBG program provides funds and technical assistance to all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and six Pacific jurisdictions. Grantees use the funds to provide comprehensive, community-based mental health services to adults with serious mental illnesses and to children with serious emotional disturbances and to monitor progress in implementing a comprehensive, community-based mental health system. Grantees use the block grant programs for prevention, treatment, recovery support, and other services to supplement Medicaid, Medicare, and private insurance services. Specifically, block grant recipients use the awards for the following purposes:
 - Fund priority treatment and support services for individuals without insurance or for whom coverage is terminated for short periods of time.
 - Fund those priority treatment and support services that demonstrate success in improving outcomes and/or supporting recovery that are not covered by Medicaid, Medicare, or private insurance.
 - Fund primary prevention by providing universal, selective, and indicated prevention activities and services for persons not identified as needing treatment.
 - Collect performance and outcome data to determine the ongoing effectiveness of behavioral health promotion, treatment, and recovery support services.

U.S. Department of Defense (DoD)

The **U.S. Department of Defense (DoD)** is charged with coordinating and supervising all Defense agencies and functions of the government concerned directly with national security and the U.S. Armed Forces. This report provides details on research and service and support activities in the Department of Defense and the Military Health System (MHS) TRICARE program.

U.S. ARMY

The **DoD Autism Research Program (ARP)** was first established through language in the 109th U.S. Congress, House of Representatives Conference Report (H.R. 5631) in FY 2007 with an appropriation of \$7.5 million for research on ASD in the military. Following in FY 2008 through FY 2020, the DoD ARP has continued through the Defense Health Program with additional appropriations. The ARP focuses on improving the lives of those living with ASD by funding innovative and highly impactful research. Through the program's Areas of Interest, the ARP focuses on ways to improve diagnosis, treatment, and studying psychosocial factors for affecting key lifetime transitions to independence and a better life for those with autism and their families. Two of the ARP's Areas of Interest focus on funding research related to supportive services for people with autism:

- Interventions promoting success in key transitions to adulthood for individuals living with ASD
- Healthcare provider-focused training or tools to improve healthcare delivery for individuals with ASD across the lifespan and the continuum of care (i.e., primary care, urgent/emergent care, and disaster relief)

The ARP has three open grant opportunity solicitations for work in these Areas of Interest described above (Opportunity numbers: **W81XWH-22-ARP-IDA**, **W81XWH-22-ARP-CTA**, and **W81XWH-22-ARP-CDA**).

MILITARY HEALTH SYSTEM (MHS)/TRICARE

The **Military Health System (MHS)** serves active duty service members, their families, along with eligible military retirees and their dependents. The MHS administers the **TRICARE** program, which is the medical benefits package that serves the population through a direct government-owned facilities as well as through services purchased from the private sector. TRICARE offers comprehensive medical care to over 9.6 million beneficiaries, including approximately two million children. This also includes over 35,000 MHS beneficiaries (in FY 2020) diagnosed with ASD.

Through TRICARE, the MHS provides physician and other licensed independent provider services, pharmacy coverage, psychosocial treatment, psychological testing, occupational therapy, physical therapy, and speech and language pathology for the treatment of ASD to all eligible TRICARE beneficiaries.

A separate but related TRICARE program, the **Extended Care Health Option (ECHO)**, offers supplemental services to Active-Duty Family Members (ADFM) with a qualifying physical or psychologically disabling condition, including ASD. ECHO services may include respite care, durable equipment, incontinence supplies, and home health services.

Currently, ABA services are authorized for coverage under the Comprehensive Autism Care Demonstration (ACD). Approximately 16,000 TRICARE eligible beneficiaries are currently enrolled in the ACD (for FY 2021). In 2021, the Department published a policy revision that included a number of improvements to the ACD, including enhanced support to parents and caregivers, improved care coordination, and improved outcomes, with the focus always being on helping military beneficiaries diagnosed with ASD, and their families, to reach their maximum potential.

All ABA services for military beneficiaries are provided through a contracted network of civilian providers. Several military medical treatment facilities also offer programs to support beneficiaries diagnosed with ASD and their families. These initiatives include:

- The Fort Belvoir Community Hospital (FBCH) Autism Resource Center, which is designed to provide resources for beneficiaries newly diagnosed with ASD and their families;
- The Joint Base Lewis McChord Center for Autism Resources, Education and Services (JBLM CARES) program, which provides patient-centered care services for beneficiaries diagnosed with ASD and their families during the transition period of locating purchased care services; and
- Deployment of the Play & Language for Autistic Youngsters (PLAY) Project, first launched within the MHS at Wright Patterson Air Force Base (WPAFB), which provides training of a portable parent-focused early childhood intervention to beneficiaries diagnosed with ASD.

In addition to medical services covered under the TRICARE Basic medical benefit, covered ECHO benefits, and the ACD, the DoD also offers non-medical services through the Exceptional Family Member Program, (i.e., non-medical respite) and Military OneSource (i.e., non-medical counseling and non-clinical resources) to support beneficiaries with a diagnosis of ASD and their family members.

U.S. Department of Education (ED)

The mission of the **U.S. Department of Education (ED)** is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access. ED supports programs to develop and implement evidence-based practices for services to infants, toddlers, children, youth, and postsecondary students, as well as programs for individuals with disabilities who have graduated from high school or a postsecondary institution and are seeking vocational rehabilitation services. ED supports ASD-related services and supports through programs administered by the Office of Special Education and Rehabilitative Services (OSERS). An overview of these programs is provided below.

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES (OSERS)

The mission of the **Office of Special Education and Rehabilitative Services (OSERS)** is to improve early childhood, educational, and employment outcomes and raise expectations for all people with disabilities, their families, their communities, and the nation. OSERS houses two offices that provide supportive services for people with disabilities, including autism: the Office of Special Education Programs (OSEP) and the Rehabilitation Services Administration (RSA).

Office of Special Education Programs (OSEP)

The **Office of Special Education Programs (OSEP)** within OSERS is responsible for overseeing the administration of the IDEA.

Part B of the IDEA:

- The IDEA Part B grants to states provide funding to ensure that eligible children with disabilities ages 3 through 21 (depending on state law) receive a free appropriate public education (FAPE) in the least restrictive environment. Children with autism can be eligible to receive special education and related services under Part B of the IDEA.
- Special education and related services are individualized for each eligible child with a disability. The services and supports are listed on a child's IEP.
- Under the IDEA statute, "related services" are defined as: transportation and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation including therapeutic recreation, social work services and school nurse services designed to enable a child with a disability to receive FAPE as described in the IEP of the child; counseling services, including rehabilitation counseling; orientation and mobility services; and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children. The term does not include a medical device that is surgically implanted or the replacement of such device.
- Assistive technology services and devices can also be identified on a child's IEP. Under the IDEA statute this is defined as: any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability. The term does not include a medical device that is surgically implanted, or the replacement of such device. The term "assistive technology service" means any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device.
- Local educational agencies can use federal IDEA funds to pay for services and supports, in addition to state and local funds. They could also work with Medicaid to access funds to pay for related Medicaid health services.

Part C of the IDEA:

- The IDEA Part C grants to states provide funding to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities from birth to age 3 (or older depending on state law) and their families. Infants and toddlers with autism can be eligible to receive early intervention services under Part C of the IDEA.
- Early intervention services are individualized for each eligible infant and toddler with a disability. The services are listed on a child’s individualized family services plan (IFSP).
- Under the IDEA statute early intervention services include:
 - Family training, counseling, and home visits;
 - Special instruction;
 - Speech-language pathology and audiology services, and sign language and cued language services;
 - Occupational therapy;
 - Physical therapy;
 - Psychological services;
 - Service coordination services;
 - Medical services only for diagnostic or evaluation purposes;
 - Early identification, screening, and assessment services;
 - Health services necessary to enable the infant or toddler to benefit from the other early intervention services;
 - Social work services;
 - Vision services;
 - Assistive technology devices and assistive technology services; and
 - Transportation and related costs that are necessary to enable an infant or toddler and the infant’s or toddler’s family to receive another service described in this paragraph.

- Early intervention service providers can put a system of payments in place that includes billing public (Medicaid) or private insurance and charging family fees. They can use federal IDEA funds to pay for early intervention services, in addition to state and local funds.

Part D of the IDEA:

The IDEA has provisions for national activities, which includes funding discretionary grants to support the implementation of the IDEA. Discretionary grants include support for parent training and information centers; personnel development; technical assistance and dissemination; professional development through the State Personnel Development Grant program; and technology, media, and educational materials program. Information on grants funded by OSEP can be found in the OSEP **Discretionary Grants Database**.

OSEP submits an annual **Report to Congress** on the progress made toward the provision of FAPE to all children with disabilities and the provision of early intervention services to infants and toddlers with disabilities. Information on the implementation of the IDEA can be found in the *Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act*. OSEP also supports a variety of data technical assistance centers that are funded through an IDEA Part B statutory provision related to improved data quality.

Rehabilitation Services Administration (RSA)

The **Rehabilitation Services Administration (RSA)** is a component of OSERS and provides leadership and resources to assist state and other agencies in providing vocational rehabilitation and other services to individuals with disabilities, including those with ASD, to maximize their employment, independence, and integration into the community and the competitive labor market.

RSA is established by Congress as the principal federal agency authorized to carry out Titles I, III, VI, and VII, as well as Section 509 of the Rehabilitation Act of 1973, as amended by Title IV of the Workforce Innovation and Opportunity Act. The Rehabilitation

Act provides the statutory authority for programs and activities that assist individuals with disabilities in the pursuit of gainful employment, independence, self-sufficiency, and full integration into community life. Additionally, RSA administers programs and activities under the Randolph-Sheppard Act, as amended. The RSA Commissioner and RSA Deputy Commissioner provide overall direction and leadership to RSA's two Divisions:

- **State Monitoring and Program Improvement Division**
- **Training and Service Programs Division**

RSA Programs develop and implement comprehensive systems of vocational rehabilitation, supported employment, and independent living services for older individuals who are blind through the provision of services, training, and advocacy to maximize the employment, independence, and integration of individuals with disabilities in their communities.

RSA accomplishes its mission by:

- Administering formula and discretionary grant programs authorized by Congress;
- Evaluating, monitoring, and reporting on the implementation of federal policy and programs and the effectiveness of vocational rehabilitation, supported employment, independent living, and other related programs for individuals with disabilities;
- Providing technical assistance and disseminating information to public and private nonprofit agencies and organizations; and
- Coordinating with other federal agencies, state agencies, and the private sector including professional organizations, service providers, and organizations of persons with disabilities for the review of program planning, implementation, and monitoring issues.

The largest program RSA administers is the State vocational rehabilitation (VR) program. This program funds State VR agencies to provide employment-related services for individuals with disabilities so that they

may prepare for and engage in competitive, integrated, and gainful employment that is consistent with their strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice. For more than 100 years, the VR program has supported individuals with physical disabilities to prepare for and enter the workforce. In 1943, the program expanded to serve individuals with psychiatric disabilities, a category which includes mental health-related disabilities and developmental and intellectual disabilities. Nationwide, the VR program serves more than one million individuals with disabilities each year. More than 91 percent of the people who use State VR services have significant physical or psychiatric disabilities that seriously limit one or more functional capacities (mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) (Section 7(21)(A)(i) of the Rehabilitation Act). These individuals often require multiple services over an extended period. For them, VR services are indispensable for attaining employment and increased independence.

State VR agencies may provide a wide variety of services to individuals with disabilities, including career counseling, work-based learning experiences (e.g., internships, apprenticeships, and short-term employment), financial support for vocational training and postsecondary education, rehabilitation technology and training, transition and pre-employment transition services, supported employment services, transportation, and other services and supports necessary for individuals with disabilities to achieve employment. The VR program is administered by 78 VR agencies, which cover the 50 States, the District of Columbia, the Commonwealth of Puerto Rico, American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, and the U.S. Virgin Islands. In addition to receiving federal VR program appropriations, a VR agency may receive program income from other sources, such as reimbursements from the Social Security Administration (SSA) for individuals served through the VR program who are SSDI beneficiaries or SSI recipients who achieve paid employment at a level of earnings high enough to be terminated from receiving their SSDI or SSI benefits.

Another key program administered by RSA is the Supported Employment Services program (SE program), through which RSA provides supplemental funds to State VR agencies, in conjunction with Title I VR State grant funds, to provide supported employment services to individuals with the most significant disabilities. Supported employment means competitive integrated employment, including customized employment, or employment in an integrated work setting in which individuals with the most significant disabilities, including youth with the most significant disabilities, are working on a short-term basis toward competitive integrated employment (Section 7(38) of the Rehabilitation Act). Supported employment is recognized as an effective strategy in assisting individuals who, because of the nature and severity of their disability, need ongoing support services to engage in and maintain competitive integrated employment. Such supports may include regular monitoring at the worksite from the time of job placement until transition to extended services.

RSA also administers the American Indian Vocational Rehabilitation Services (AIVRS) program, RSA provides grants to governing bodies of Indian Tribes located on federal and state reservations (and consortia of such governing bodies) to establish and operate tribal vocational rehabilitation programs to deliver VR services to American Indians with disabilities who live on or near such reservations. AIVRS grant awards are made through the competitive process for a period of up to five years to provide a broad range of VR services including, where appropriate, services traditionally used by Indian Tribes, designed to assist American Indians with disabilities to prepare for and engage in gainful employment.

RSA submits an annual **Report to the President and Congress** that describes the activities of RSA as the principal agency carrying out Titles I, III, VI, and specified portions of Titles V and VII of the Rehabilitation Act of 1973, as amended by the Workforce Innovation and Opportunity Act. RSA is responsible for preparing and submitting these reports under Section 13 of the Rehabilitation Act. More information about the programs mentioned above and other activities of the RSA can be found in the annual *RSA Report to the President and Congress*.

U.S. Department of Housing and Urban Development (HUD)

The **Department of Housing and Urban Development (HUD)** works to strengthen the housing market in order to bolster the economy and protect consumers, meet the need for quality affordable rental homes, utilize housing as a platform for improving quality of life, and build inclusive and sustainable communities free from discrimination. HUD-funded activities broadly impact the well-being of individuals with disabilities, including those with ASD, and their families.

HUD administratively enforces several civil rights laws prohibiting housing discrimination, including the Fair Housing Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act (ADA). With few exceptions, the Fair Housing Act covers housing throughout the country.

Section 504 of the Rehabilitation Act

Section 504 provisions apply to recipients of HUD financial assistance, including the Community Development Block Grant, Public Housing, Multifamily, Housing Choice Voucher, and other programs. HUD's Section 504 regulations (at 24 CFR § 8.4c) permit exclusion of persons without disabilities from the benefits of a program if the program is limited by federal statute or Executive Order to individuals with disabilities and also permits exclusion of a specific class of individuals with disabilities from a program if the program is limited by federal statute or Executive Order to a different class of individuals. However, HUD does not have disability-specific programs, such as housing specifically for persons with ASD.

Section 811 Supportive Housing for Persons with Disabilities

The HUD Section 811 program provides funding to develop and subsidize rental housing with the availability of supportive services for very low- and extremely low-income adults with disabilities. The program supports two major types of assistance: (1) capital grants and project-based rental assistance for

nonprofit developers to build, rehabilitate, or acquire small group homes or scatter site housing units with the availability of supportive services for very low-income persons with disabilities and (2) project-based rental assistance for state housing agencies in partnership with state Health and Human Services/Medicaid agencies to provide housing for extremely low-income persons with disabilities with access to appropriate supportive services.

In August 2020, HUD awarded **over \$74 million** in grants to 12 state housing agencies to support affordable rental housing for extremely low-income persons with disabilities. The awards will support up to five years of rental assistance for approximately 2,400 units of housing in buildings participating in project rental assistance through the Section 811 program. HUD also awarded **\$54.7 million** in capital advance and project rental assistance grants to 15 community organizations through the Section 811 program. The grants were awarded to organizations who will create permanent supportive housing models that will be at the forefront of design, service delivery, and efficient use of federal resources. Awardees must promote long-term housing security and facilitate community integration of persons with disabilities. In 2020, HUD issued an **eviction moratorium** and offered additional funds to properties receiving project-based rental assistance under the **Section 811 program**, as part of the Coronavirus Aid, Relief, and Economic Security (CARES) Act.

Eviction Protection Grant Program

In May 2022, HUD announced \$20 million in new grants for its **Eviction Protection Grant Program**, doubling the amount originally allocated for the launch of the Program in November 2021. HUD awarded grants to 11 additional organizations (10 organizations selected in November 2021) to help non-profits and governmental entities provide legal assistance to low-income tenants at risk of or subject to eviction.

Housing Choice Voucher Program

The Housing Choice Voucher (HCV) program is the federal government's largest rental assistance program. The program provides housing assistance to around 2.3 million very low-income families, older adults, and people with disabilities to afford decent, safe, and sanitary housing in the private rental market. HCVs are administered locally by around 2,100 public housing agencies (PHAs).

- **Mainstream Voucher Program:** Mainstream vouchers assist very low-income adults with disabilities with tenant-based rental assistance. Participants receive a voucher and are free to choose any housing in the private rental market that meets the requirements of the program. Similar to the regular housing choice voucher, Mainstream vouchers are administered locally by PHAs. The 2017, 2018, and 2019 Appropriations Acts funded new Mainstream vouchers. Since 2018, HUD has awarded over \$500 million in funding to PHAs to support 50,000 new Mainstream vouchers. Under the authority of the CARES Act, HUD allocated nearly \$77 million for Mainstream vouchers in May 2020 and another \$87 million in November 2020. In June 2022, HUD announced the availability of \$40 million in carryover funding for additional **Mainstream Vouchers** to support community living for persons with disabilities, and later in July 2022, HUD awarded over \$36 million in mainstream vouchers and fees to support community living for people with disabilities. Since April 2021, HUD, alongside the HHS, has provided **technical assistance** to help PHAs that administer Mainstream Vouchers for non-elderly persons with disabilities to strengthen their partnerships with state agencies that assist persons with disabilities to transition from institutional settings to the community.
- **Emergency Housing Voucher Program:** The Emergency Housing Voucher (EHV) is a special program available through the American Rescue Plan Act that has provided 70,000 housing choice vouchers to local PHAs. The program assists individuals and families who are experiencing homelessness, at

risk of homelessness, recently homeless, or victims of domestic violence, dating violence, stalking, sexual assault, or human trafficking. In 2021, HUD awarded \$1.1 billion – 70,000 vouchers – for 626 PHAs administering the HCV Program.

- HUD has additional **special purpose voucher programs** that serve people with disabilities:
 - **Vouchers for Non-Elderly Persons with Disabilities:** Since 1997, HCVs have been awarded under different special purpose voucher program types to serve very low-income non-elderly adults with disabilities (NED).
 - **HUD-VASH:** The **HUD-Veterans Affairs Supportive Housing (HUD-VASH)** Program combines HUD's HCV rental assistance for homeless Veterans with case management and clinical services provided by the VA. VA provides these services for participating Veterans at VA medical centers, community-based outreach clinics, through VA contractors, or through other VA designated entities.
 - » In August 2022, HUD awarded \$841,113 in **Tribal HUD-VASH expansion grants** to three Tribally Designated Housing Entities to help house 45 Native American Veterans experiencing or at risk of experiencing homelessness.
 - » And later, in September 2022, HUD awarded 28 **Tribal HUD-VASH renewal awards**, totaling more than \$9 million, to provide rental assistance and supportive services to Native American Veterans experiencing or at risk of homelessness.
 - **Family Unification Program and Foster Youth to Independence:** The **Family Unification Program (FUP)** is a program under which HCVs are provided to eligible families and youths involved in the child welfare system. The **Foster Youth to Independence (FYI)** initiative makes HCV assistance available to youth at least 18 years and not more than 24 years of age who left foster care or will leave foster care.

Public Housing

Public housing was established to provide decent and safe rental housing for eligible low-income families, older adults, and persons with disabilities. Public housing comes in all sizes and types, from scattered single-family houses to high rise apartments for older adults. There are approximately 900 thousand households living in public housing units, managed by some 2,700 PHAs.

Project Based Rental Assistance

HUD has provided over 1.2 million low-income families with decent, safe, and affordable housing via Project Based Rental Assistance (PBRA), including older adults and people with disabilities, to continue to live independently. When paired with quality voluntary supportive services, PBRA can help low-income individuals with disabilities obtain and maintain community-based stable housing and avoid institutional settings.

Homeless Assistance Programs

Individuals with disabilities are over-represented among people experiencing homelessness. Homelessness assistance programs provide funding to states and local governments and nonprofit providers to serve individuals and families across the United States who are affected by homelessness.

- **Continuum of Care Program.** The **Continuum of Care (CoC)** program promotes community-wide commitment to the goal of ending homelessness. The program provides funding for efforts by nonprofit providers and state and local governments to quickly rehouse homeless individuals and families while minimizing the trauma and dislocation caused to homeless individuals, families, and communities by homelessness. The program connects individuals and families served to wraparound services provided through federal mainstream programs administered by federal agencies, such as Medicaid, behavioral health supports, Temporary Assistance for Needy Families (TANF), domestic violence supports, Child

Care and Development Fund (CCDF), Head Start and Early Head Start, Healthy Start, and the Federal Home Visiting Program. Through provision of re-housing services and **wraparound supports**, the CoC program optimizes **self-sufficiency** among individuals and families experiencing homelessness.

In FY 2021, HUD provided over **\$2.6 billion** in funding for homeless assistance through its CoC programs, which include a variety of approaches to providing both emergency and long-term affordable housing and supportive services. This total included over \$1.7 billion specifically for **Permanent Supportive Housing** with funding provided to 4,056 local housing projects.

People with disabilities are significantly over-represented among people experiencing unsheltered homelessness, and in June 2022, HUD issued a **first-of-its-kind funding package** as a targeted effort to reduce unsheltered homelessness and homelessness in rural areas. This funding package includes \$322 million in grants, including \$54.5 million set-aside for rural areas, to fund homeless outreach, permanent housing, supportive services, interim housing, planning, and data costs. In addition, HUD announced the availability of an additional \$43 million for special purpose housing vouchers to public housing authorities that partnered with CoC organizations that will receive grant funds through this funding package.

In August 2022, HUD announced the availability of **\$2.8 billion** in competitive funding to homeless services organizations across the country for supportive services and housing programs for people experiencing homelessness.

Youth Homelessness

The Youth Homelessness Demonstration Program (YHDP) is an initiative designed to reduce the number of youth experiencing homelessness. The goal of the YHDP is to support selected communities, including rural, suburban, and urban areas across the United States, in the development and implementation of a

coordinated community approach to preventing and ending youth homelessness. In March 2022, HUD made \$72 million in **YHDP funding** available to up to 25 communities nationwide.

Housing and Services Resource Center

The **Housing and Services Resource Center** is part of a partnership between HUD and HHS to make community living a reality for all. This partnership will expand accessible, affordable housing; help people exit homelessness; improve HCBS; and address the institutional bias in America's long-term care system. The Center was created for people who work in the organizations and systems that provide housing resources and homelessness services, behavioral and mental health services, independent living services and other supportive services, and others who are working to help people live successfully and stably in the community.

The goal of the Center is to foster collaboration and cross-sector partnerships, in order to streamline access to services, better leverage resources, and ultimately make community living possible for more people. People can use the Housing and Services Resource Center website to:

- Learn about how to develop and expand partnerships;
- Quickly find tools designed for community collaborations;
- Increase knowledge to support people with disabilities, older adults, and people experiencing homelessness to get and/or keep affordable and accessible housing and voluntary services; and
- Discover innovative models and strategies.

Housing Discrimination

The Fair Housing Act protects people from discrimination when they are renting or buying a home, getting a mortgage, seeking housing assistance, or engaging in other housing-related activities. Additional protections apply to federally assisted housing. The Fair Housing Act prohibits discrimination in housing because of race, color, national origin, religion, sex (including gender identity and sexual orientation), familial status, and disability.

In June 2022, HUD allocated over \$30 million in funding for state and local fair housing enforcement agencies across the country under the Department's **Fair Housing Assistance Program (FHAP)**. HUD also issued guidance on the investigation of housing discrimination complaints that allege discrimination based on a housing provider's use of criminal records in tenant screening that specifically discusses how such practices can result in disability discrimination.

In July 2021, HUD announced that it made \$19.4 million available through HUD's **Fair Housing Initiatives Program (FHIP)** to fair housing organizations to conduct activities that address discriminatory housing practices related to the COVID-19 pandemic. The funds, which were provided through the American Rescue Plan Act of 2021, will allow private fair housing enforcement organizations to respond to fair housing inquiries and complaints, conduct fair housing testing, and implement education and outreach activities related to the COVID-19 pandemic. The funds are also being used to address fair housing issues affecting individuals and families experiencing housing instability, including those who may face displacement due to discriminatory evictions and foreclosures.

In September 2021, HUD awarded **\$47.4 million** to fair housing organizations across the country under its FHIP. The grants will support the efforts of 120 state and local fair housing organizations working to address and prevent violations of the Fair Housing Act and helping to end discrimination in housing.

Affirmatively Furthering Fair Housing

In addition to barring housing discrimination, the Fair Housing Act requires HUD and its funding recipients, such as local communities receiving HUD funds, to take affirmative steps to remedy fair housing issues such as segregated neighborhoods, lack of housing choice for protected class groups (including persons with disabilities), and unequal access to housing-related opportunities. In 2023, HUD issued a major Proposed Rule to restore the Affirmatively Further Fair Housing mandate. As stated by HUD, the rule, “aims to remedy the effects of the long history of discrimination in housing, will help to foster opportunity in communities across the country where every resident can thrive,” and to, “spur HUD program participants to take action in order to ensure members of protected classes have equitable access to affordable housing opportunities.” Under the proposed rule, HUD grant recipients would be required to prepare an **Equity Plan**, to “be developed following robust community engagement, would contain their analysis of fair housing issues confronting their communities, goals, and strategies to remedy those issues in concrete ways, and a description of community engagement.” Additionally, HUD is committed to providing communities that receive HUD funding with the technical support they need to meet their long-standing fair housing obligations.

U.S. Department of Justice (DOJ)

The **U.S. Department of Justice (DOJ)** ensures fair and impartial administration of justice for all Americans. The **Bureau of Justice Assistance** funds several programs that provide resources and services to individuals with autism and their families. Below are details about some specific programs.

- DOJ provides **subject expertise** to all of their **Justice and Mental Health Collaboration Program** Partnerships, and Connect and Protect Law **Enforcement Behavioral Health Response** grantees, on responding to people with intellectual and developmental disabilities (IDD).
- Organizations can request **Free Training and Technical Assistance through the Arc**.
 - Any state, locality, or federally recognized tribal government, as well as organizations such as non-profit behavioral health organizations, criminal justice agencies, and service providers, can request assistance from the **Center for Justice and Mental Health Partnerships**.
 - The goal of the center is to connect jurisdictions with the resources, knowledge, and skills necessary to improve responses to people at the intersection of criminal justice and behavioral health systems. Support can range from reviewing training protocols to sharing information on best practices and advising on program design, among other types of support.
- **Collaborative Comprehensive Case Plans** offer web-based tools and resources to better integrate behavioral health and needs information into comprehensive case plans that actively engage the participant and reflect a balanced and collaborative partnership between criminal justice, behavioral health, and social service systems.
- The **Police-Mental Health Collaboration** framework is intended to help jurisdictions advance comprehensive, agency-wide responses to people with mental health needs in partnership with behavioral health systems. The framework is accompanied by the PMHC toolkit and the PMHC self-assessment tool. The tool walks agencies through a series of questions to assess the status of their efforts and generates a unique action plan to strengthen that work.
- The **Academic Training Initiative** through the University of Cincinnati is a national initiative to enhance police engagement with people with behavioral health conditions and developmental disabilities.
 - The goals of the initiative are to:
 - » Raise awareness in the policing community about the nature and needs of people with behavioral health (BH) conditions and IDD;
 - » Provide training and resources on BH, IDD, and crisis response; and
 - » Support the use of evidence-informed, best practices in these responses.
 - Through the **Collaborative Crisis Response and Intervention Training Program**, the Bureau of Justice Assistance seeks applications for funding support to law enforcement on how to effectively partner with mental health, substance use disorder, and community service agencies to promote public safety and ensure appropriate responses to individuals who have behavioral health conditions, intellectual disabilities, developmental disabilities, or physical disabilities.

- The **Justice and Mental Health Collaboration Program** provides grants directly to states, local governments, and federally recognized Indian tribes to improve responses to people with mental health conditions who are involved in the criminal justice system. JMHCP funding requires collaboration with a mental health agency.
 - Communities across the country have used JMHCP funding to implement systemwide reforms that span first contact with the justice system to reentry and return to the community. This includes funding for crisis stabilization units, mental health courts, universal mental health screening and assessment in jail, permanent supportive housing, and community corrections mental health caseloads.
 - The program supports **14 Law Enforcement-Mental Health Learning Sites** who serve as peer resources to grantees and communities across the country.
- **Home Safe, The Kevin and Avonte Program:** Reducing Injury and Death of Missing Individuals with Dementia and Developmental Disabilities through the International Association of Chiefs of Police
 - This program supports local jurisdictions' efforts to reduce the number of deaths and injuries of individuals with forms of dementia such as Alzheimer's disease or developmental disabilities such as autism who, due to their condition, wander from safe environments.

U.S. Department of Labor (DOL)

The **U.S. Department of Labor (DOL)** works to foster full access to gainful employment opportunities for all Americans, including youth and adults with disabilities. DOL also seeks to advance career pathways for youth and adults through its support for workforce development and job training programs, including apprenticeships. The Office of Disability Employment Policy (ODEP) at DOL develops and influence policies and practices that increase the number and quality of employment opportunities for people with disabilities. Its work aligns with DOL's priorities of driving diversity, equity, inclusion, and accessibility (DEIA). DOL's Employee Benefits Security Administration (EBSA) works to ensure that participants and beneficiaries in Employee Retirement Income Security Act of 1972 (ERISA)-covered plans with ASD can access treatment to improve their lives, including through enforcement of the Mental Health Parity and Addiction Equity Act (MHPAEA).

Initiatives at the Office of Disability Employment Policy (ODEP)

Enhancing policies and practices to foster supports and services for people on the autism spectrum and improve their access to gainful employment and careers represents a major priority at ODEP. Launched in 2021, ODEP runs the three-year, \$2.9 million project on **Research Support Services for Employment of Young Adults on the Autism Spectrum (REYAAS)**. The REYAAS project recognizes gainful employment as a key social determinant of health and a major contributor to quality of life.

The REYAAS project has released a **project fact sheet**; a **literature review on programs, models, and support strategies**; and a **literature review on program effectiveness**. The REYAAS project has also conducted a series of listening sessions on key facilitators and barriers to employment. These sessions involved youth and young adults on the autism spectrum, direct service providers, employers, advocates and policymakers, educators, and researchers. The REYAAS

project released a **summary report** of these listening sessions that discussed barriers and facilitators to employment and careers.

Through this work, the REYAAS project seeks to learn more about promising practices, approaches, strategies, and policies to improve access to gainful employment for autistic people. This knowledge can help enhance and increase access to work-based learning, including internships and apprenticeships, jobs, and careers for young adults on the autism spectrum. It also aims to understand how to best support autistic workers in the workplace, including for mental and physical health at work. The project emphasizes the full inclusion of people on the autism spectrum who have diverse support and access needs, needs for services, communication styles, and backgrounds. It informs ODEP's work to enhance policies and practices that can drive access to gainful employment and career pathways for people with disabilities that match skills and talents.

Since 2020, ODEP has managed the \$6 million **Partnership on Inclusive Apprenticeship (PIA)** to help enhance career access through work-based learning. PIA advances policies and practices to foster pathways for career seekers with disabilities, including people who are neurodivergent. It places a major emphasis on driving apprenticeships in key high-growth, high-demand fields, such as information technology (IT), healthcare, and clean energy and financial services.

PIA provides outreach and technical assistance for intermediaries from industries, employers, providers of services, and all other interest groups. It has hosted the **Apprenticeship for All Podcast Series** (currently at 18 episodes) and released **resources for apprentices with disabilities** on starting career paths and **disclosing disabilities** and seeking work supports. PIA has released an **Equal Employment Opportunity Toolkit** and a spotlight on **success stories** for apprentices with disabilities, including

neurodivergent people. It has also released resources for employers and intermediaries, such as a **guides to designing inclusive apprenticeship programs** and fostering **accessible on-the-job training**.

Supported by ODEP, the **Job Accommodation Network (JAN)** provides free, expert, and confidential guidance on job accommodations and work supports for people with disabilities. JAN provides assistance to workers and job seekers, supervisors and managers, providers of services, family members, and all other stakeholders. They can connect with JAN specialists by calling, emailing, or using live chat. JAN offers resources at its website on a wide range of disabilities, including **autism, ADHD**, and other forms of neurodivergence. Its website also shares resources for issues such as disclosure, job coaching, and assistive technology in the workplace.

Managed jointly by ODEP and the DoD, the **Workforce Recruitment Program (WRP)** is a recruitment and referral program. WRP connects employers from the federal and private sectors with college students and recent graduates with disabilities, including people who are neurodivergent, for internships and permanent jobs. WRP candidates can annually apply through their school campuses and then take part in elective informational interviews with federal workers who serve as volunteer recruiters. The Office of Personnel Management (OPM) recognizes WRP as a model strategy in its guidance to federal agencies regarding the recruitment and hiring of people with disabilities. Since the program's expansion in 1995, thousands of students and recent graduates have received temporary and permanent opportunities for gainful employment through the WRP.

The **Partnership on Employment & Accessible Technology (PEAT)** advances inclusion and access for the emerging and future workplace in the United States. PEAT helps support workers and job seekers with disabilities, employers, and all others by fostering policies and practices that can support full access at the forefront. It provides

accessibility toolkits for issues such as teleworking, staff training, and workplace policies. It also shares resources on the emerging future of work, such as on equal access and inclusion for automated vehicles, equitable broadband, and the increasing use of artificial intelligence and extended reality in the workplace.

Launched in 2019, the **Center for Advancing Policy on Employment for Youth (CAPE-Youth)** helps address barriers that youth and young adults with disabilities may face. It focuses on their transition from youth systems into adulthood and barriers that can result in lower employment outcomes, educational attainment, and community participation than their peers. CAPE-Youth works to improve employment outcomes by helping states build capacity in their youth service delivery and workforce systems. It conducts research, develops partnerships, and shares best and promising practices.

CAPE-Youth also helps states identify new ways to expand career pathways, work-based learning, strategic partnerships, and coordination of systems. **The Guideposts for Success: Framework for the Future** drives the work of CAPE-Youth by outlining the five key domains for programs and services. These five domains consist of preparing for careers, school life, engagement with families, youth development and leadership, and connecting activities.

Federal initiatives at ODEP that interconnect healthcare and employment include the **Retaining Employment and Talent after Injury/Illness Network (RETAIN)**, which launched in 2018. The RETAIN demonstration projects facilitate the development of approaches and strategies for people to stay at work and return to work after an injury or illness. Funded by ODEP and the SSA, RETAIN has supported demonstration grants to eight state teams in Phase 1. The goals of the RETAIN initiative include ensuring retention of employment and participation in the labor force for people who acquire or may likely develop disabilities that inhibit their ability to work.

RETAIN also focuses on decreasing long-term work absence; this emphasis includes reducing the need for SSDI and SSI. The RETAIN initiative is highly relevant for people on the autism spectrum: Research shows that many people on the autism spectrum have secondary conditions that can affect their physical and mental health and wellness. Additionally, people on the autism spectrum may meet the eligibility criteria for SSDI and SSI. In 2021, the RETAIN initiative awarded four-year, Phase 2 grants to five of the state teams from Phase 1 to build upon their success in supporting stay-at-work and return-to-work for people with disabilities.

ODEP launched the **Advancing State Policy Integration for Recovery and Employment (ASPIRE) initiative in 2020**. ASPIRE seeks to support and expand access to competitive, integrated employment for people with mental health conditions. It assists seven states that are working to integrate their policies, programs, and funding systems to expand evidence-based mental health services for people with mental health conditions. ASPIRE emphasizes the use of best and promising practices, such as the Individual Placement and Support Model of Supported Employment.

ODEP's State Exchange on Employment & Disability (SEED) initiative is a unique state-federal collaboration that supports state and local governments to develop and implement disability-inclusive policies and best practices that lead to increased employment opportunities for people with disabilities, including those who are neurodivergent. SEED supports partnerships and collaborations with 19 state and local intermediary organizations that reach more than 7,000 legislators, 50 governors, 50 lieutenant governors, 1,400 mayors, and 3,000 county governments. By leveraging its intermediary partners, the SEED collaborative supports states' needs through: testimony and expertise; state priority mapping, data collection, and policy analysis; and policy development and implementation support. State policy options range from examining state disability employment policies and expanding transportation options for job seekers with disabilities to providing incentives for the private sector to employ people with disabilities and fostering youth transition policies.

In addition to policy development work with states and federal agencies, ODEP shares key resources and information on employment topics through its **website**. ODEP's **Autism webpage** provides resources and information for employers, job seekers and transition-aged youth on the autism spectrum, service providers, and policymakers. Likewise, ODEP's website offers topic resource pages on issues, such as **Mental Health** and **Health Care**.

Ensuring Compliance with MHPAEA for ASD

EBSA enforces Title I of the Employee Retirement Income Security Act of 1974, including the requirements of MHPAEA, with respect to two million private employment-based group health plans, which cover approximately 137 million participants and beneficiaries. MHPAEA generally provides that financial requirements (such as coinsurance and copays) and treatment limitations (such as visit limits) imposed on mental health or substance use disorder (MH/SUD) benefits cannot be more restrictive than the predominant financial requirements and treatment limitations that apply to substantially all medical/surgical benefits in a classification. In addition, MHPAEA prohibits separate treatment limitations that apply only to MH/SUD benefits. EBSA has issued guidance to emphasize that plans and issuers must ensure that treatment limitations on benefits for ASD do not violate the requirements of MHPAEA.* This includes benefits for ABA therapy.

EBSA is committed to ensuring that participants and beneficiaries in ERISA-covered plans with ASD can access treatment to improve their lives. Vigorous enforcement of MHPAEA has been one of the agency's top enforcement priorities, with EBSA working with health insurance issuers and other service providers to group health plans to obtain widespread corrections of violations affecting multiple group health plans. In a recent enforcement action, EBSA investigated exclusions of coverage for ABA therapy, a primary treatment for ASD, by service providers to self-insured plans. As a result of these investigations, several large service providers have made changes to provide coverage of ABA therapy for their self-insured plan clients, affecting close to a million and a half participants.**

* See FAQs about Mental Health and Substance Use Disorder Parity Implementation and the 21st Century Cures Act Part 39, Q1, available at <https://www.dol.gov/sites/dolgov/files/EBSA/about-ebbsa/our-activities/resource-center/faqs/aca-part-39-final.pdf> and <https://www.hhs.gov/guidance/document/affordable-care-act-implementation-faqs-final-set-39>.

** See 2022 MHPAEA Report to Congress, pages 21 and 39, available at <https://www.dol.gov/sites/dolgov/files/EBSA/laws-and-regulations/laws/mental-health-parity/report-to-congress-2022-realizing-parity-reducing-stigma-and-raising-awareness.pdf>

U.S. Department of Transportation (DOT)

The **U.S. Department of Transportation (DOT)** works to deliver the world's leading transportation system, serving the American people and economy through the safe, efficient, sustainable, and equitable movement of people and goods. DOT-funded research and activities broadly impact the well-being of individuals with disabilities, including those with ASD, and their families and help ensure access to important supports including disability employment, recreational activities, community living, and respite for family caregivers. One example of DOT funding that can help fund transportation that provides such access is the **Section 5310 Enhanced Mobility of Seniors and Individuals with Disabilities Program**.

The **National Aging and Disability Transportation Center (NADTC)** was established by the DOT in 2015. NADTC promotes the availability and accessibility of transportation options that meet the needs of older adults, people with disabilities, and caregivers. The mission of NADTC is to:

- Serve professionals in the fields of transportation, aging, disability, human services, and caregiving.
- Provide resources, training, and information through an information and referral hotline, website, as well as both distance and online training.
- Empower communities across the country to implement or improve innovative transportation programs at the local level.
- Support older adults, people with disabilities of all ages, and their families to help them find the best mobility options in their communities to reach their destinations of choice.

The **National Rural Transit Assistance Program (RTAP)** operates under a cooperative agreement between the **Federal Transit Administration (FTA)** and the **Neponset Valley Transportation Management Association**, and its mission is to address the training and technical assistance needs of rural and tribal transit operators across the nation and to support

state RTAP programs. The National RTAP provides technical assistance related to ASD and travel, including an Easterseals Project Action Consulting presentation during a session of the 2017 National RTAP Technical Assistance Conference and response to a recent technical assistance request for autism training for school bus drivers.

On February 11, 2020, NIMH sponsored a free **webinar** which featured presentations by the National Center for Mobility Management and the FTA on transportation and mobility services for youth with autism transitioning out of high school. The webinar helped users leverage mobility resources and develop connections with transportation providers and services.

The **DOT's Accessible Transportation Technologies Research Initiative (ATTRI)** was a joint multi-modal, multi-agency initiative, co-led by the Federal Highway Administration, FTA, and Intelligent Transportation Systems Joint Program Office, with support from the **National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)** within HHS/ACL, and other federal partners. The ATTRI Program developed and implemented transformative applications to improve mobility options for all travelers, particularly those with disabilities. ATTRI research focused on removing barriers to transportation for people with visual, hearing, cognitive, and mobility disabilities. Technologies and creative service models funded by ATTRI offer all Americans enhanced travel choices and accessibility at levels once only imagined. DOT awarded application development funding for Wayfinding and Navigation, Pre-trip Concierge & Virtualization, and Safe Intersection Crossing, with NIDILRR awarding a grant in the Robotics and Automation technology area. Taken together, the four technology areas help break down barriers along the Complete Trip, ensuring **equal access** to the transportation network, and the benefits of mobility for all.

U.S. Social Security Administration (SSA)

The mission of the **Social Security Administration (SSA)** is to ensure equity and accessibility in delivering services by improving customer experience and addressing systemic barriers to participation in SSA's programs. SSA administers two disability programs authorized under the Social Security Act – the **Social Security Disability Insurance program (SSDI)** and the **Supplemental Security Income program (SSI)**. The SSDI and SSI programs provide assistance to people with disabilities. Under these programs, the SSA evaluates claims relating to ASD for both adults (aged 18-64 years) and children (aged <18 years). While these two programs are different, the medical requirements are the same. Individuals may claim benefits under both programs concurrently.

- The **SSDI** program pays benefits to the disabled individual and certain **family members** if the beneficiary is “insured,” i.e., they have worked long enough – and recently enough – and paid Social Security taxes on their earnings. Those receiving SSDI benefits also generally are eligible for Medicare after a 24-month qualifying period. The first 24 months of disability benefit entitlement is the waiting period for Medicare coverage.
- The **SSI** program provides financial assistance to meet basic needs for food, clothing, and shelter to adults and children with disabilities who have limited income and resources. SSI is funded by general tax revenues. In most states, SSI recipients qualify for Medicaid automatically without the need to fill out a Medicaid application or qualify after applying.
- As of **December 2021**, approximately 418,000 individuals with a primary impairment of ASD – approximately 215,000 children (under 18 years of age) and 203,000 adults (18-64 years of age) – received SSI payments; children received an average monthly payment of \$678 and adults received an average monthly payment of \$652. In addition, approximately 110,000 SSDI beneficiaries had a primary impairment of ASD, of whom 27 percent

were workers and 73 percent were adult children; workers received an average monthly payment of \$804 and adult children received an average monthly payment of \$957. Out of approximately 275,000 total adult recipients with a primary impairment of ASD, 62 percent received SSI only, 26 percent received SSDI only, and 12 percent received both SSI and SSDI.

- In calendar year 2020, the latest year for which data is available, SSA processed 22,979 first-time adult and 29,505 first-time child claims for ASD. Of those claims, 71 percent of adult claims and 73 percent of child claims met requirements following initial determination/reconsideration and were allowed benefits, compared to 39 percent and 47 percent, respectively, for all impairments.

SSA also runs the **Ticket to Work** program. This is a free and voluntary program that connects eligible individuals with free employment services. It is available to everyone age 18 through 64 who receives SSDI and/or SSI benefits because of his or her disability. Of the 342,369 SSDI and/or SSI beneficiaries with either a primary or secondary diagnosis of ASD who were either receiving payments or whose payments were suspended due to their wage income in 2020, 89,701 (26.2 percent) had participated in the Ticket to Work program and used either Employment Networks or State VR Agency services at some point while receiving benefits.

U.S. Department of Veterans Affairs (VA)

The **Department of Veterans Affairs (VA)** is committed serving and honoring America's veterans by ensuring access to timely, high quality benefits and services. As part of this commitment, the VA's Veterans Health Administration delivers **healthcare** to the more than nine million enrolled veterans each year, including veterans with autism or other disabilities, through the largest integrated healthcare network in the United States, with 1,298 health care facilities. In addition, the **Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA)**, a health benefits program which provides coverage to the spouse or widow(er) and children of veterans not eligible for TRICARE, allows ABA as a covered health benefit.



SUMMARY AND CONCLUSION



Autism affects an estimate of 1 in 44 children¹ in the United States and approximately two percent of adults.² In addition to the social and communication challenges experienced by people on the autism spectrum, some also have language or intellectual disabilities or co-occurring physical and mental health conditions. These co-occurring conditions can include epilepsy, GI, sleep, mental and physical health conditions. Specialized supportive services can help to improve skills and alleviate co-occurring conditions, promote and facilitate learning, preempt and/or address behavioral challenges, promote health, improve quality of life, and optimize independence over the lifespan.^{355,356} Supportive services for people with autism include behavioral interventions, mental health services, speech/language therapy, physical therapy, employment services, social groups, advocacy training, and many more. Supportive services are also beneficial to the caregivers and family members of individuals with autism, including respite care, support and sibling groups, and family/systems navigation services.

This report provides an overview of the evidence base for positive outcomes linked to receipt of these services and many more. The report also includes information submitted by the Departments of Health and Human Services, Defense, Education, Housing and Urban Development, Justice, Labor, Transportation, and Veterans Affairs, as well as the Social Security Administration, on their specific programs and efforts in support of services for people with autism and/or disabilities. In this final section, the report provides a summary of the different pathways of coverage for services, as well as identification of ongoing areas of need.

PATHWAYS TO COVERAGE OF SERVICES FOR PEOPLE WITH AUTISM

This report reviews several different pathways to obtaining coverage of services for people with autism. The types of services covered, duration, intensity, and eligibility requirements vary under different

forms of coverage, which may further vary by state. Below, we provide a summary of the services coverage options available to individuals with autism and their families.

Medicaid, administered by CMS, is jointly operated between the states and the federal government. It provides healthcare coverage for individuals below certain income thresholds. Income and eligibility requirements can vary by state. The SSI program is an important Medicaid eligibility pathway for people with ID/DD. Most children enrolled in Medicaid receive services through a **Medicaid health plan**, such as a health maintenance organization (HMO) or other insurance company. The state Medicaid agency and the Medicaid health plan determines which services are “medically necessary” and which providers can be reimbursed for services. Services typically covered include case management, physical, occupational, and speech therapies, and ABA. The **EPSDT Medicaid benefit** mandates the provision of all medically necessary healthcare services found in section 1905(a) of the Social Security Act, including screening, diagnostic, and treatment services, to Medicaid beneficiaries under the age of 21.

When a child receives extended care in an institutional setting, Medicaid disregards family income as an eligibility requirement and makes the determination based solely on the child’s income. The **Tax Equity and Fiscal Responsibility Act (TEFRA/Katie Beckett State Plan Option)** of 1982 (PL No. 97-248, Section 134), makes it possible to do the same for a family whose child requires care at the level provided in an institution, but who can safely be cared for at home, as long as it is cost neutral to the state to do so. Under TEFRA/Katie Beckett, states can disregard income eligibility requirements and provide Medicaid coverage if a child with a disability (including autism) requires a level of care that could be reasonably provided in a hospital, skilled nursing facility, or an intermediate care facility for individuals with ID. Currently, 18 states and the District of Columbia have chosen to implement the TEFRA/Katie Beckett State Plan Option.

Head Start and Early Head Start programs are free, federally funded programs designed to promote school readiness for children from low-income families. Head Start and Early Head Start work closely with the IDEA Part B funded early childhood program and the IDEA Part C early intervention program. They cover children ages birth to age 5. These programs are required to serve children with special needs, which may include children with autism. **Early Head Start programs** offer services to infants with significant disabilities and their families. Families must **apply** in order to enroll their child in a Head Start Program.

Section 504 of the Rehabilitation Act of 1973 is a federal law designed to protect the rights of individuals with disabilities. **Section 504 regulations** require a school district to provide a FAPE to each qualified student with a disability who is in the school district's jurisdiction, regardless of the nature or severity of the disability. The Office for Civil Rights (OCR) of ED enforces Section 504 in programs and activities that receive federal financial assistance from the ED. OCR also enforces IDEA, which was first enacted in 1975 and most recently revised in 2004 as the **Individuals with Disabilities Education Improvement Act (IDEA)**. IDEA extends the prohibition against discrimination to the full range of state and local government services, programs, and activities (including public schools) regardless of whether they receive any federal financial assistance. IDEA mandates that children with various disabilities, including autism, are entitled to a public education that meets their individual needs in the “least restrictive environment” possible. The IDEA provides states with federal grants to support early intervention programs. For children with autism younger than 3 years, **early intervention services**, such as speech therapy, ABA, occupational therapy, physical therapy, and family training can be received through these programs. For children 3 years and older, special education services are provided by the local school district through their special education department. School-based services are available until children graduate from high school and based upon the unique needs of the individual. These services may include supports such as speech therapy,

occupational therapy, physical therapy, academic tutoring, behavioral supports during the school day, peer-to-peer mentoring, and transition services. A student’s IEP describes the needs of the child and how these needs will be met within the context of the school district.

Waiver programs are used to deliver some kinds of services for people with disabilities. A waiver program approved by the CMS allows states to waive certain provisions to allow Medicaid services to be delivered in a different place, to people with different needs, or different income levels. Nearly all states and the District of Columbia offer **HCBS Medicaid Waivers**, which are fee-for-service programs.

These must follow federal guidelines and are available to people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting. State HCBS Waiver programs must: 1) Demonstrate that providing waiver services won’t cost more than providing these services in an institution, 2) Ensure the protection of people’s health and welfare, 3) Provide adequate and reasonable provider standards to meet the needs of the target population, and 4) Ensure that services follow an individualized and person-centered plan of care. States can waive certain Medicaid program requirements under HCBS Waivers, including comparability of services criteria and income eligibility requirements. 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.³⁵⁷ HCBS Waivers can help to meet the service needs of people with autism and decrease their unmet healthcare needs.³⁵⁸⁻³⁶⁰ 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 individuals and their families.³⁶¹ In light of the heightened demand for autism services and long waiting lists, some states developed waivers specifically for children with ASD; the development of adult autism-specific waivers are less frequent.^{355,362-364} This **website** provides a complete list of Medicaid waivers for each state.

If a family earns too much to qualify for Medicaid and their child is not covered under a group health plan or other creditable health insurance, publicly funded health insurance may be obtained through **CHIP**. CHIP is administered **by states**, according to federal requirements. The program is funded jointly by states and the federal government. Every state administers its own CHIP program with broad guidance from CMS. Coverage for ABA and other autism services varies by state.

An additional way for families and individuals to pay for autism supportive services is through the **Achieving a Better Life Experience (ABLE) Act**. The ABLE Act was signed into law on December 19, 2014. The ABLE Act amended the federal tax code to allow families the opportunity to set up tax-exempt 529A savings accounts for disability-related expenses. Account funds are generally not considered for the SSI program, Medicaid, and other federal means-tested benefits. **ABLE accounts** enable people with autism and their families to save for housing, education, transportation, medical and other expenses related to their disability. This allows individuals with disabilities, including autism, to save for their future needs without losing access to other resources. Forty states, including the District of Columbia, offer ABLE programs.

The SSDI and SSI programs are also available to provide assistance to people with disabilities. The SSDI program pays benefits to the disabled individual and certain family members. Everyone eligible for SSDI benefits is also eligible for Medicare after a 24-month qualifying period. In addition, the SSI program provides financial assistance to meet basic needs for food, clothing, and shelter to adults and children with disabilities who have limited income and resources and is funded by general tax revenues. In most states, SSI recipients qualify for Medicaid.

For U.S. services members, retirees, and their families, **TRICARE** covers many **services** for beneficiaries with autism. These include occupational therapy, physical therapy, physician services, psychological

services, psychological testing, prescription drugs, and speech therapy. TRICARE covers ABA for all eligible beneficiaries diagnosed with autism through the TRICARE **Comprehensive Autism Care Demonstration (ACD)**. To qualify for the ACD, active duty service members must enroll in the **Exceptional Family Member Program (EFMP)** and register in the **Extended Care Health Option (ECHO)**. In addition, the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) is a health benefits program that provides coverage to the spouse or widow(er) and children of veterans not eligible for TRICARE. CHAMPVA allows ABA as a covered health benefit.

Individuals with autism and their families also have the option to obtain private insurance coverage through health insurance plans run by private insurance companies. Based on data from the 2019 National Survey of Children's Health, a recent study estimates that about 44 percent of children with ASD are covered by private insurance.³⁶⁵ For working-age adults with disabilities, health insurance was dramatically improved by insurance expansions driven by the **Affordable Care Act in 2014**. However, it is possible that the COVID-19 pandemic has resulted in disruptions to employment that have impacted private insurance coverage. By 2019, **all 50 U.S. states** had enacted private autism insurance mandate legislation requiring coverage of autism-related services. Forty-seven of these states clearly specify coverage for ABA in their mandates.³⁶⁵ On their **website**, the National Conference of State Legislators provides detailed information about insurance coverage state laws as they specifically pertain to people with autism. The intent of private insurance mandate legislation was to cover a larger breadth of services that include medically necessary services available for the treatment of ASD. Despite these mandates, studies indicate that many privately insured children with ASD are primarily treated through publicly funded systems.^{366,367}

FEDERALLY FUNDED PROGRAMS AND RESEARCH ON SERVICES FOR PEOPLE WITH AUTISM

As reviewed in this report, there are many examples of federal activities focused on services and supports for individuals on the autism spectrum and their families:

- The Administration for Children and Families (ACF) Office of Head Start (OHS) maintains the disabilities services section of the **Early Childhood Learning and Knowledge Center website**, which provides evidence-based resources such as the **Disability Services Coordinator Orientation Guide**.
- The Administration for Community Living (ACL) funds programs in all states and territories that support individuals with autism in a variety of ways, including areas such as social skills, transportation, employment, and caregiver supports (programs vary by state).
- The Centers for Medicare & Medicaid Services (CMS) administers Medicaid and CHIP.
- The Health Resources and Services Administration (HRSA) funds the **State Public Health Coordinating Center for Autism (SPHARC)**, which provides technical assistance and supportive services for autism in a variety of areas.
- The Indian Health Service (IHS) provides education, training, consultation, and resources to clinicians treating patients with neurodevelopmental disorders, including ASD, through the IHS Indian Children's Program (ICP).
- The Substance Abuse and Mental Health Services Administration (SAMHSA) funds block grants that can support a broad array of services for children with mental health conditions, including autism.
- The Office of Special Education Programs (OSEP) within the Department of Education (ED) is responsible for overseeing the administration of IDEA, through which many children with autism receive early intervention services and special education and related services.
- The Rehabilitation Services Administration (RSA), within the Department of Education (ED), provides leadership and resources to assist state and other agencies in providing vocational rehabilitation and other services to individuals with disabilities, including those with ASD, to maximize their employment and independence.
- The Department of Housing and Urban Development (HUD) provides funding to develop and subsidize rental housing with the availability of supportive services for very low- and extremely low-income adults with disabilities.
- The Bureau of Justice Assistance within the Department of Justice (DOJ) provides free technical assistance to organizations such as non-profit behavioral health organizations, criminal justice agencies, and service providers on responding to people with intellectual and developmental disabilities.
- The Department of Labor (DOL)'s Office of Disability Employment Policy (ODEP) conducts policy development work with states and federal agencies to support the integrated employment of people with disabilities.
- The Department of Transportation (DOT) has developed and implemented transformative applications to improve mobility options for people with disabilities.
- The Social Security Administration (SSA) administers two disability programs authorized under the Social Security Act; the SSDI and SSI.
- The Department of Veterans Affairs (VA) delivers healthcare to the more than nine million enrolled veterans each year, including veterans with autism or other disabilities, Veterans Health Administration, in addition to the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA), which allows ABA as a covered health benefit.

Federal departments and agencies are also funding research efforts related to the provision of supportive services and interventions for individuals with autism:

- The Office of the Assistant Secretary for Planning and Evaluation (ASPE) within the U.S. Department of Health and Human Services (HHS) has several ongoing projects that provide analysis of service utilization by people with disabilities, including autism.
- The U.S. Department of Defense (DoD) Autism Research Program (ARP) is funding research on interventions promoting success in key transitions to adulthood and healthcare provider-focused training or tools to improve healthcare delivery for individuals with ASD.
- The Defense Health Agency (DHA) has been working with the Congressionally Directed Medical Research Program (CDMRP) to better understand the impact of ABA services for people with autism.
- The National Institutes of Health (NIH) supports work to connect families to resources when they first receive a diagnosis through the Autism ACTION Network, as well as the ASD Pediatric Early Detection, Engagement, and Services (PEDS) Network, which has a number of service-related research projects currently underway.

ONGOING AREAS OF NEED

As reviewed above, there are numerous ongoing service-related federal efforts and multiple pathways to obtaining coverage of certain services for children and adults with autism. Coverage and the services received is affected by the insurance policies in place at the state (i.e., HCBS waivers, insurance mandates) and federal level (i.e., Medicaid, CHIP), an individual's or family's ability to spend out-of-pocket, as well as their familiarity with and comfort level with navigating the service system.^{368,369,370} The difficulty of obtaining coverage for supportive services is further compounded by the fact that different rules are instituted in different states, which may have different eligibility criteria, age caps, and dollar limits. This complexity is well illustrated by the eligibility requirement of a formal diagnosis for receipt of certain services; documentation of a diagnosis that is useful in one context may not meet eligibility requirements in another context, and different states and programs may have different requirements. This can be a major stumbling block

for many families. Certain supportive services may only be covered once they have cleared a time and resource-intensive review to establish a base of efficacy, but this does not reflect the full range of services that are being used by members of the autism community. Future research is needed to establish the evidence base of efficacy for some of the services that individuals are currently using and find helpful in their daily lives and in alleviating co-occurring conditions. Some of these services are not covered by health insurance or federal or state benefits and can only be accessed by paying out of pocket.

Family Navigation

The complexity of the supportive services landscape points to one important area of need: family navigation supports to help families identify and coordinate care among the various providers, service types, and forms of coverage. Services are often fragmented among many different providers and in some cases, families may not be aware of the types of supports that are available to them. Families who are already facing significant functional impairments and disability-associated life stressors may have to shoulder additional burden of navigating complicated gate-keeping requirements before even identifying whether appropriate supports and services are actually available in their community. In some instances, providers may receive conflicting guidance on whether or not they are able to serve a person with autism, or if they should be referred to other services specific for those with DD. As a result, autistic individuals' co-occurring conditions, such as mental health conditions, may go unaddressed. Family navigation services have been found to be effective in improving access and adherence to services over time,³⁷¹ but tools designed specifically for families following a diagnosis of autism are currently limited.³⁷² To be offered starting in October 2022, a new Medicaid health home benefit for children with medically complex conditions is a step towards meeting this need. This benefit will help state Medicaid programs provide person-centered care management, care coordination, and patient and family support. Fragmentation of the service system may be further improved by enhanced “wrap-around” or “continuum

of care” services. Wrap-around services refer to the practice of providing all the various services that an individual may need over time across different areas in their life (e.g., home, school, community). Wrap-around service delivery is a team-based, collaborative case management approach where a number of professionals work together to provide a holistic program of supports. This coordinated approach can help to improve outcomes for individuals and their families.^{373,374}

Consistency of Coverage

Given the different forms of coverage for autism-related services, researchers are beginning to evaluate whether the type of healthcare 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 with federally funded health insurance.³⁷⁵ Additional work has found that children with ASD enrolled in Medicaid were more likely to have visits to occupational therapists, physical therapists, and behavioral therapists compared to children with private insurance.³⁷⁶ Furthermore, research indicates that children with ASD-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.²⁰ A recent scoping review found preliminary evidence that HCBS waivers for people with IDD benefit states economically, reduce unmet healthcare needs, increase parental ability to continue working, and reduce racial disparities in care access.³⁷⁷ Further research in this area is needed in order to ensure consistency of care and services received by individuals with autism and their families.

Workforce Shortages

A significant barrier in accessing services is the shortage in the workforce of **direct support professionals (DSPs)**. Autistic individuals and their families face difficulties in accessing providers with expertise in working with people with autism and sufficient training in related areas, such as AAC.³⁷⁸⁻³⁸¹ 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. 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.

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.³⁸²⁻³⁸³ 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. Addressing these issues within the DSP profession would greatly improve the availability of supportive services for people with autism of all ages.

More training programs for service professionals in every service field would be helpful in addressing shortages. For example, there is a need for increased training for those involved in the provision of mental health services to address the unique needs of people with autism. An enhanced workforce focused on preventative care could help to reduce the number of individuals with autism who may not access services until they are in acute or crisis care.^{384,385} Federal agencies such as HRSA and ACL fund **programs** to provide training for direct support professionals, but more programs and program capacity are needed to meet the growing needs of the autism and disability communities.

Diagnostic Services

As reviewed earlier in this report, an additional area of ongoing need is the long gap between referral and diagnostic assessment. Long waitlists have resulted in a two-year difference between the earliest signs of ASD and the average age of diagnosis,³⁹ with minoritized populations waiting even longer to be evaluated.⁴⁰ Shortages in healthcare providers in

underserved geographic areas, time-consuming evaluations, and the high cost of care contribute to disparities in diagnosis.³⁸⁶ Individuals attempting to obtain a diagnosis in adulthood also experience long wait times. A survey of 77 adults diagnosed with ASD found that participants were self-diagnosed for an average of 3.25 years before they received a formal diagnosis.³⁸⁷ Self-diagnosis can be problematic because it relies on information available on the internet, which may not be accurate and lead to misdiagnosis, unrealistic expectations for treatment, increasing anxiety, and promoting distrust of professionals.³⁸⁸ However, the dearth of providers who can accurately diagnose autism in adults make it difficult for individuals who suspect they may be on the autism spectrum to access diagnostic services.³⁸⁹ Medical home models, a tiered system of developmental screening and early ASD evaluation, and other clinical models have been tested to reduce the gap between referral and diagnosis.³⁹⁰⁻³⁹³ Recent developments leveraging new technologies in telemedicine can also help to remediate these problems and increase access to diagnostic services.³⁹ 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.

Waitlists for Services

People in need of HCBS often face barriers to accessing services, such as long waitlists for Medicaid HCBS waiver slots. HCBS allows states to **limit** how many people receive services and states may manage costs by limiting services to a finite number of beneficiaries which as noted earlier, can create a barrier to access. It is estimated that individuals with ID/DD spend **48 months** on a waiting list before enrolling in a Medicaid HCBS waiver. Parents of children with autism cite long waitlists as a top concern in obtaining services.³⁹⁴ For adults with autism, a recent study found that the waiting list for receiving HCBS through Medicaid is months long, resulting in unmet needs for functional skills supports, employment or vocational services, housing supports, and mental and behavioral

health services.³⁹⁵ It is important to note that while 656,000 people across the United States were reported to be on waiting lists in 2021, this is not a true indication of unmet need as not all states screen for Medicaid eligibility prior to adding people to waiting lists and over half of people on waiting lists for HCBS **may not be eligible** to receive those services. Recent legislation has been passed in some states to decrease waiting times (e.g., Maryland), but further targeted efforts may be required to meet increasing demand and reach particularly underserved populations, including minority racial/ethnic groups, individuals who may be more isolated, and as they age away from the supports provided throughout childhood and adolescence.³⁹⁵

The Services Cliff

Aging out of the supportive services system provided in schools under IDEA and under Medicaid's EPSDT benefit is a top concern for individuals with autism and their families. Most individuals will continue to need some types of services or supports in adulthood, but many do not qualify for adult services.²⁶ This is often described as "falling off the services cliff," referring to the dramatic decline in access to services during the transition to adulthood.³¹ 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.²⁶ As individuals with autism progress into adulthood, there are a variety of areas and challenges that could be improved through increased coverage for supportive services. These include unemployment, underemployment, economic vulnerability, and premature mortality.^{396,397} Compared to their peers with other types of disabilities, young adults with autism have the lowest rate of employment, at 58 percent.²⁶ People who are unemployed are at risk of "falling through the cracks" in healthcare coverage and not receiving the services they need. The disconnect between the mental health and DD services systems increases the likelihood of individuals "falling through the cracks"; because mental health services are based around serious mental illness, people with autism are often not eligible unless they have a diagnosed co-occurring

mental health issue. Furthermore, DD services are often based on ID and IQ, and a person with autism who does not qualify based on those criteria thus would not be eligible to receive those supportive services. Autistic adults also face many barriers in accessing appropriate physical healthcare.³⁹⁸

Services for Older Adults

Further research is needed to identify and understand the full range of health and social support services needed by older autistic adults in areas such as continued support related to autistic traits, co-occurring mental health difficulties and physical health challenges, communication, social connection, daily living skills, and long term supports in the absence of family caregivers or adequate long term planning.³⁹⁹⁻⁴⁰¹ While there are many existing programs providing services and supports for older adults with disabilities, research and evaluation are needed to determine if those services and supports need to be adapted to meet the specific needs of autistic individuals. As many older autistic adults may not actually be diagnosed, having services that are adapted to meet the functional needs of a broad range of individuals, including autistic individuals, is especially important to help ensure that each individual will be able to receive appropriate services that correspond to their needs.

Racial, Ethnic, and Geographic Disparities

Racial, ethnic, and geographic disparities in autism are well-established,⁴⁰² with many disparities present in areas related to service provision and accessibility.⁴⁰³ Family- and neighborhood-level socioeconomic status (SES), as well as racial and ethnic minority status, are strongly related to disparities in **access** to quality autism care.⁴⁰⁴ Families living in low-SES neighborhoods and rural areas are more likely to be located in a service “desert,” areas of low service availability and fewer providers.⁴⁰⁵ Research has found that Black and minoritized families with autism are not as quickly enrolled in services in the first years of life following a diagnosis,^{406,407} and non-white children in general are diagnosed, referred, and screened later than their white peers, resulting in delayed onset of

treatment.⁴⁰⁸ Minority families are also under-represented in evidence-based treatments and services in autism.^{406,409,410} Language barriers have been noted as a factor in the lower number of hours of direct services received by non-English speaking families compared to English-speaking families.⁴¹¹ For example, a substantially lower percentage of Latino children receive school-based occupational therapy and physical therapy as compared with non-Latino white children.⁴¹² 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 providers⁴¹³ and consider diverse experiences, preferences, and values in the design and provision of autism services for families and their children.⁴¹⁴

Impacts of COVID-19

Lastly, it is important to acknowledge the known and unknown impacts of the COVID-19 pandemic on the services and supports of people with autism and other disabilities. **A recent report** found that fewer disability benefit claims were filed during the pandemic, as well as claims by certain vulnerable populations.⁴¹⁵ People with disabilities experience **systemic inequities** in healthcare access, social determinants of health, morbidity, and mortality compared to people without disabilities.⁴¹⁶ **The COVID-19 pandemic** exacerbated existing inequities for people with disabilities, who have been disproportionately impacted with increased infections, hospitalizations, and death, in addition to interruptions in essential services and supports and social isolation. At the same time, the pandemic ushered in rapid policy and service adaptations that increased accessibility for some, such as through the use of telehealth.

The paragraphs above briefly review areas of ongoing need and opportunity in the realm of supportive services for individuals with autism. Further in-depth detail and research can be found in the IACC Strategic Plan for Autism Spectrum Disorder, which outlines priority areas for enhanced research, services, and policy issues.

Conclusion

Individuals with autism have complex medical, behavioral, educational, and social service needs. Because the combination and degree of characteristics can differ greatly from one individual to another, there are many **diverse service needs** among the autism community. Often services are provided through a range of government agencies and providers that frequently require integration and collaboration between healthcare, education, employment, and social support sectors.⁴¹⁷⁻⁴¹⁸ As reviewed in this report, there are multiple pathways to obtaining service coverage and numerous federal programs and efforts underway related to autism services. Despite these efforts, available funds are limited and individuals and families may be unable to access or afford the full scope of services that could help to improve their health and well-being or that of their loved one in all relevant areas. Often a “patchwork” of service provision and coverage is needed in order to begin to meet the service needs of an individual. Navigating the requirements among different options for eligibility and coverage can be challenging.

A heightened focus on diversity, equity, inclusion, and accessibility across public and private sectors has opened the doors to opportunities for considering ways to improve equity of supportive services access and quality, as well as inclusion of people with autism and other disabilities across many segments of life. In addition, many autistic adults have become actively engaged in advocacy and have expanded disability rights to include neurodiversity and have pushed service providers and researchers to truly include

their perspectives, experiences, and interests. Both in the United States and across the globe, the rights and inclusion of people with disabilities has taken on key importance in health equity with a call to support each person in their strengths and challenges through services and supports that enhance quality of life.

As described in the recent *2021 Report to Congress on the Health and Well-Being of Individuals with Autism Spectrum Disorder*, the Federal Interagency Workgroup on Autism (FIWA) developed recommendations to improve the health and well-being of individuals on the autism spectrum. Several of these recommendations specifically focused on services, including, increased federal coordination in providing services and supports; optimized behavioral and other therapeutic interventions; and recognition of caregiver mental health and support needs. Coupled with the information provided in the present report, these recommendations highlight the ongoing need for improvements in supportive service quality, coverage, and delivery. Moving forward, coordination of federal activities, service providers, and engagement with the autism community through avenues such as the IACC, the activities of the National Autism Coordinator, and federal partnerships with state and local governments and private organizations will continue to play critical roles in ensuring that federal departments and agencies are able to be responsive to the evolving needs of the community and emerging opportunities to improve supportive services for people on the autism spectrum and their families.



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