

Current Landscape of Behavioral Health Services for Children with Autism Spectrum Disorder Insured by Medicaid in Washington, D.C.



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PREFACE

For years, behavioral healthⁱ services for children with Autism Spectrum Disorder (ASD) who are insured by Medicaid have been a significant concern for stakeholders across the District of Columbia, and many groups have invested significant time and effort into identifying and addressing these issues. After receiving multiple requests over time for data, resources, and recommendations pertaining to behavioral health services for children with ASD, members of Children’s National Hospital have compiled our existing knowledge into this document. This document represents a collective effort to address and bring clarity to questions about existing qualitative and quantitative data, established behavioral health systems and structures, and the lived experiences of providers working with children with ASD. This paper is not intended to encompass all aspects of care or all recommendations that would be needed to ensure a well-functioning system of care and focuses primarily on the experiences of health care providers. The goal of this paper is to further advance systemic efforts to improve evaluation and treatment services and systems for children with Medicaid who have or are suspected of having Autism Spectrum Disorder in the District of Columbia.

EXECUTIVE SUMMARY

This paper summarizes the current landscape of pediatric behavioral health care for children with Medicaid who are diagnosed with or suspected of having Autism Spectrum Disorder (ASD) in the District of Columbia and provides recommendations to improve the current system of care for this population. While the District has made significant efforts to increase behavioral health care services for youth, the needs of children who have or are suspected of having ASD are distinct and worthy of special consideration. Families must navigate a multifaceted and complicated system of care and overcome significant systemic barriers to obtain an ASD diagnosis or identification and related treatment services, which contributes to inequitable outcomes. These barriers are also seen by child-serving providers across disciplines that provide care for families affected by ASD, including professionals in behavioral health care, medical care, and the education system. We recommend that the District adopt a systemic response to these needs that includes increased support for children and families, improvements in systems of coverage for services rendered, and structural changes to support equitable and timely access to necessary assessment and treatment services within the District.

ⁱ The terms "behavioral health" and "mental health" will both be used throughout this document wherever each term appears most relevant to the context.

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BACKGROUND

Autism Spectrum Disorder (ASD) is a relatively common but complex neurodevelopmental disorder characterized by deficits in social communication (such as difficulty with eye contact or body language) and restricted or repetitive patterns of behavior, interests, or activities with onset early in development.¹ The prevalence of ASD is relatively high and increasing in the United States; **according to the CDC, 1 in 54 children having a diagnosis of ASD, which equates to 1.84% of the pediatric population.**² The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is used by mental health clinicians for assessment and diagnosis of mental health disorders. This tool provides guidance on diagnostic criteria that are commonly reported to payors for insurance coverage purposes. A DSM-5 diagnosis of ASD subsumes prior DSM-IV-TR diagnoses of Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorders (PDDs).¹ Data collected from the CDC's ASD surveillance system suggests that while children can be reliably diagnosed with ASD by age two, the median age of earliest known ASD diagnosis was 4.3 years of age across states included in the study.³ Additional research suggests that children with more severe forms of ASD are detected earlier (mean age between 3.7 and 4.5 years at time of diagnosis), whereas children with mild severity and more nuanced symptoms of ASD are identified later (mean age between 5.6 and 8.6 years).⁴ Children with ASD are at increased risk of having additional psychiatric conditions including intellectual disability, speech and language disorders, developmental coordination disorders, learning disability, attention-deficit/hyperactivity disorder, mood and anxiety disorders, obsessive compulsive disorder, and sensory regulation difficulties.⁵ Children with ASD are also at increased risk of having other co-occurring medical conditions including epilepsy, sleep problems, gastrointestinal disorders, and immune dysfunction⁶; in addition, 10% of children with ASD also have other genetic and chromosomal disorders.² Given the increased risk of medical and psychiatric comorbidities, care for children with ASD should include the use of multidisciplinary teams of specialized health care providers to create a full and comprehensive treatment plan that meets the individual's needs.

Diagnostic Disparities and Inequities

ASD affects individuals from all backgrounds across all genders, races, ethnicities, and socioeconomic statuses,² but **there are notable differences in diagnosis rates and the timeliness of diagnosis among some demographic groups.** For example, ASD is diagnosed in boys four times more often than it is diagnosed in girls.² While boys are diagnosed more frequently, ASD symptoms in girls may be camouflaged by socially acceptable restricted interests or go undetected due to a lower likelihood of engaging in problematic externalizing behaviors.⁷⁻⁸ It is suggested that girls' lower rates of disruptive behavior contribute to delays in receiving diagnostic evaluations.⁹⁻¹⁰ Moreover, there are significant racial and socioeconomic disparities in timely diagnosis and treatment for children suspected of having ASD, which may be related to systemic inequities between groups.¹¹⁻¹²⁻¹³⁻¹⁴ Research has found that children who were born outside of the U.S. and children of mothers from other countries were more likely than their peers born in the U.S. or born to mothers from the U.S. to be referred for an ASD evaluation at a later age (50 months and 42 months vs. 39 months and 36 months, respectively).¹³ Hispanic or Latino/a and African-American children were more likely than White children to receive an ASD diagnosis after age four, even after controlling for other relevant factors.¹³ Recent analyses of data from nearly 600 African American children with ASD suggest that the average age

of diagnosis for African American children may be even later than initially speculated. This study reported an average age of diagnosis of 64.9 months, which was about 42 months after parents' first concerns about their child's progress and development.¹⁵ In this study, over 40% participants endorsed seeing more than one professional prior to receiving an ASD diagnosis, and about 14% reported that they saw more than six professionals before diagnosis. Surveillance reports from the CDC note that the percentage of children with an earliest known comprehensive ASD evaluation by age three was highest for non-Hispanic White children (45%), followed by non-Hispanic Black children (40%), then Hispanic or Latino/a children (39%).¹¹

Children enrolled in Medicaid have also been found to be diagnosed later than their peers without Medicaid, with an average age of 5.4 years at time of diagnosis for children enrolled in Medicaid.¹⁶ Research examining the effect of Medicaid reimbursement rates on access to care has found that families living in states with higher reimbursement rates experience less difficulty accessing care for children with ASD.¹⁷ This finding leads to the hypothesis that the delayed age of diagnosis for children enrolled in Medicaid may be driven by long wait lists resulting from low Medicaid reimbursement rates and/or scarcity of in-network providers. Additionally, children eligible for Medicaid based on a disability were found to be diagnosed 18.5 months later than those eligible for Medicaid based on socioeconomic factors; this discrepancy is likely due in part to a lack of clinical expertise in identifying ASD when a child presents with another co-occurring disability.¹⁶

Early diagnosis and subsequent early, intensive developmental and behavioral intervention can benefit the child by leveraging neural plasticity (which is the brain's ability to respond to changes, especially in early development), promoting positive parent-child interactions, and improving the child's cognitive skills, social communication, and language into adulthood.^{18 19 20 21 22} However, significant delays of up to several years may elapse between the onset of symptoms and the receipt of an official diagnosis, and many children with or who are at elevated risk for ASD do not receive needed services.²³ As noted previously, ASD can be reliably diagnosed by age two, and children who engage in intervention services for ASD earlier in their developmental course have better outcomes than those who initiate services at a later age.²⁴ Research shows that using evidence-based therapies which focus on intervening early in development, such as those using applied behavior analysis (ABA) techniques, can support development across the domains that may be affected in children with ASD.²⁵ Such domains include social-emotional development (e.g., eye contact, imitation, relationship-building), expressive and receptive language development (e.g., speaking, understanding language), and cognitive development. Delays in diagnosis and treatment can result in missed opportunities to help young children progress during critical windows of time and may lead to poorer long-term outcomes as well as greater mental and physical health burdens to society.

Process for Making a Diagnosis

For children without classic and clear-cut symptoms, it can sometimes be challenging to make a diagnosis of ASD, as there is no single available medical assessment (e.g., laboratory test, imaging scan) to definitively confirm the presence of the disorder. As noted previously, ASD can be reliably diagnosed at age two but may be diagnosed by trained clinicians as early as 18 months or younger in some cases.²⁴ There are several processes that can help detect potential ASD early on (see Figure 1), though each case varies and will follow a unique path to diagnosis.

Universal developmental monitoring or surveillance

complements developmental screening and is often the first step towards detecting children with potential ASD in the general population. Developmental monitoring, which is the observation of a child's development in comparison to expected developmental milestones, should be conducted on an ongoing basis in the home and school settings by both caregivers and educators.²⁶ The term "caregiver" is used to refer to the person who assumes responsibility for meeting the child's physical and emotional needs and could include biological, adoptive, or foster parents; guardians; or extended family members who care for the child on a regular basis. Materials designed to raise awareness, such as the CDC's "Learn the Signs. Act Early." campaign, have raised understanding about typical child development and can alert caregivers when their child's development may be off track.²⁶

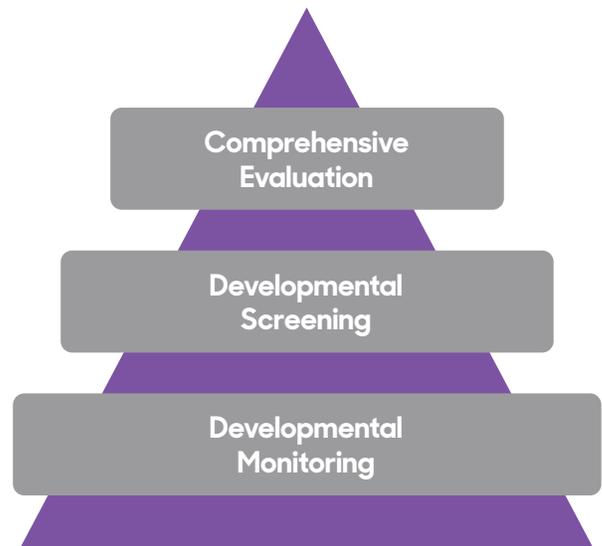


Figure 1. Processes to identify potential ASD

Developmental and mental health screening

throughout childhood is considered best practice according to the American Academy of Pediatrics (AAP) and is a component of the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services benefit required in pediatric primary care for children insured by Medicaid.²⁷

Mental health screenings are also a stipulated component of the Medicaid managed care organization (MCO) contracts in the District of Columbia. Screening refers to the systematic use of standardized tools that are designed to detect early warning signs of, or risk for, a specific condition or concern. Screening, especially in early childhood, can facilitate rapid identification of mental health and developmental concerns and facilitate linkages to care services if needed. Research suggests that surveillance without a screening tool may only have a sensitivity of 14-54%, which means that only a small proportion of children who should be identified are actually likely to be found without the use of a screening measure.²⁸ Universal screening may also help to decrease disparities since it is not based on factors related to the care provider or family and is instead administered to all children as part of routine health promotion. The AAP Bright Futures guidelines recommend that developmental screening should be conducted in pediatric primary care settings at the 9-, 18-, and 30-month well child visits, with additional and specific screening for Autism Spectrum Disorder recommended at the 18- and 24-month well child visits.²⁹ The screening requirements of EPSDT underscore the importance of regular attendance at scheduled well child visits.^{27 30} Commonly used screening tools for potential ASD in pediatric primary care are the Modified Checklist for Autism in Toddlers – Revised (M-CHAT-R) and M-CHAT Revised with Follow-Up (M-CHAT-R/F), the Survey of Well-being of Young Children (SWYC), and the Communication and Symbolic Behavior Scales Developmental Profile – Infants and Toddlers Checklist (CSBS DP-ITC). The Ages and Stages Questionnaire (ASQ), SWYC, and CSBS DP-ITC may also be used to detect other developmental concerns in young children. If results of an M-CHAT or other screening tool are elevated, or if there is any concern regarding potential signs of ASD from caregivers, educators, or health professionals, children should be referred for further evaluation. This could include

consultation with a mental health professional, referral to early intervention services, and/or a referral for a comprehensive evaluation, which could include developmental testing, ASD-specific testing, or both.

A formal, **comprehensive evaluation** is an in-depth assessment of a child's development, usually conducted by a trained specialist such as a developmental pediatrician, child psychologist, or child psychiatrist, and/or by an interdisciplinary team which could include professionals like geneticists, speech-language pathologists, or occupational therapists. Evaluations typically include a parent/caregiver interview, an observational assessment of the child's behavior, and the integration of information from vision and hearing screenings, individually-administered developmental or cognitive tests, speech and language assessments, and/or genetic testing.³¹ Evaluation results may potentially yield a diagnosis (or co-occurring or differential diagnoses) as well as a review of the child's strengths and needs. The exact components of the evaluation and the type of clinician conducting the evaluation may vary depending on whether or not the child first presents with a developmental delay, medical concern, or a family history of siblings with ASD (which may require a medical evaluation to rule out a genetic condition such as fragile X, metabolic, chromosomal disorders, or single gene mutations). Comprehensive evaluations of ASD and related, co-occurring difficulties such as learning problems, language and cognitive delays, and emotional-behavioral difficulties can be extensive, typically involving 6 to 12 hours of testing depending on the child's age, level of functioning, and referral question. A best practice diagnostic tool that assesses social functioning in a developmental context is the Autism Diagnostic Observational Schedule (ADOS-2), which is commonly used as part of the diagnostic process for ASD.³¹ Depending on an individual child's needs, diagnostic decision-making for ASD can be complex, including the involvement of professionals with specialized training and multidisciplinary teams to assess several areas of functioning during the course of a diagnostic evaluation.

PREVALENCE OF AUTISM SPECTRUM DISORDER IN WASHINGTON, D.C.

The CDC uses four national datasets to estimate the prevalence of ASD. The most widely reported prevalence rate of children with ASD in the U.S. is 1 in 54, which is derived from the CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network.³² The ADDM Network is comprised of 11 states and collects data from health and/or education records of 8-year-old children with ASD.³² Prevalence estimates vary by state, so the CDC notes that “surveillance results should be interpreted with caution due to changing composition of sites and geographic coverage over time.”³² The CDC also uses three additional datasets to provide a broader view of the prevalence of ASD at the state level, including D.C. Of note, most epidemiological studies of ASD focus on children older than three years due to the average age of first diagnosis being after age three. Among children in the ADDM Network, the National Survey of Children’s Health (2011–2012), and the National Survey of Children with Special Health Care Needs (2009–2010), evaluations occurred at or below the age of three for 43% of children, 17% of children, and 23% of children, respectively.^{33 34} Table 1 presents data from the CDC’s Autism Data Visualization Tool using the four main datasets available to estimate the prevalence of ASD at the national and local level.

Table 1. National and Local Prevalence of ASD.³²

	Medicaid Analytic eXtract (MAX)*	Autism and Developmental Disabilities Monitoring Network (ADDM)**	US Department of Education Individuals with Disabilities Education Act (IDEA)***	National Survey of Children’s Health (NSCH)****
	Ages 3-17 2012	Diagnosis by Age 8 2016	Ages 3-21 2017	Age 3-17 2017-2018
National Prevalence	0.82% (8.2/1000)	1.85% (1/54)	1.27% (12.7/1000)	2.9% CI: 2.6–3.4%
Local (D.C.) Prevalence	0.65% (6.5/1000)	N/A	1.30% (13/1000)	2.0% CI: 0.9–4.3%

Additional information regarding data (language pulled verbatim from CDC)³²

* Children 3–17 years old who had received Medicaid benefits and had at least two outpatient billing codes for ASD or one inpatient billing code in the specified year.

** Data from health and/or education records of 8-year-old children using the same methods across sites.

*** CDC used special education child count data to report the number of children 6–17 years old with ASD who are receiving special education and related services in each state.

**** NSCH annual, cross-sectional, address-based survey that collects information on the health and well-being. D.C. data should be interpreted with caution: estimate has a 95% CI width exceeding 1.2 times the estimate and may not be reliable.

While there have been no known local studies to measure the prevalence of ASD in children in D.C., Table 1 presents a range of data for consideration. **The most recent 2017–2018 data for D.C. show that between 1.3% (IDEA data) and 2.0% (NSCH data) of children in D.C. may have a diagnosis of ASD.** These data are limited in that they do not stratify prevalence rates based on demographic data such as age of diagnosis, gender, race, or ethnicity.

Estimating the prevalence of ASD in children with D.C. Medicaid is more challenging. While the 2012 MAX dataset presents ASD prevalence data for children enrolled in D.C. Medicaid (0.65%), more recent data is needed to understand the current landscape. The D.C. Department of Health Care Finance (DHCF) reports that approximately 90,000 children age 0–20 were enrolled in D.C. Medicaid in 2018 and 2019.³⁵ The prevalence rates of ASD in D.C. children presented in Table 1 were applied to the number of D.C. children enrolled in Medicaid in 2018–2019 to estimate the potential number of children enrolled in D.C. Medicaid who may have a diagnosis of ASD (see Table 2).

Table 2. Estimated Number of Children Enrolled in DC Medicaid that May Have a Diagnosis of ASD Using National Datasets.

	Medicaid Analytic eXtract (MAX)*	US Department of Education Individuals with Disabilities Education Act (IDEA)	National Survey of Children’s Health (NSCH)*
	Ages 3-17 2012	Ages 3-21 2017	Age 3-17 2017-2018
National Prevalence	0.65% (6.5/1000)	1.30% (13/1000)	2.0%* CI: 0.9-4.3%
# of Children	585	1,170	1,800 (810 – 3,870)

* NSCH annual, cross-sectional, address-based survey that collects information on the health and well-being. D.C. data should be interpreted with caution: estimate has a 95% CI width exceeding 1.2 times the estimate and may not be reliable.

If the range of prevalence estimates in Table 2 were extrapolated to the population of D.C. youth with Medicaid, **we would expect between 585 to 1,800 children enrolled in D.C. Medicaid to have a diagnosis of ASD.** Additional research specifically on Medicaid claims data is needed to analyze ASD prevalence rates in D.C. This would help determine the true prevalence rate of ASD in this population of children and improve our understanding of potential differences based on demographic variables.

One community-based case example specific to D.C. is the Children’s National Goldberg Center for Pediatric Health, which sees approximately 30% of the District’s children for pediatric primary care. The Goldberg Center is comprised of five primary care centers serving approximately 40,000 children annually. About 83% of the Goldberg Center’s 2018 patient population were D.C. residents, and 80% were enrolled in Medicaid. Among Goldberg Center patients that had at least one visit in 2018, 573 patients (1.5%) had a diagnostic code of ASD, and 984 (2.5%) patients were coded as having a developmental delay. The Goldberg Center regularly screens for ASD and developmental delays at well-child visits (WCV) using the ASQ for general development concerns at the 9-, 18-, 30- month WCVs and the M-CHAT-R for ASD-

specific concerns at the 18- and 24-month WCVs. In 2018, 21% of ASQ administrations and 5% of M-CHAT administrations across the five Goldberg Centers yielded total scores in the medium- or high-risk ranges.³⁶ Note that these percentages may be an underestimate of actual concerns in these areas, given that primary care providers often defer the administration a screening tool if the patient has a known or pre-existing diagnosis of ASD or developmental delay. Relatedly, the sensitivity of the M-CHAT with Follow-Up may be low (about 39%) in real-world settings, meaning it may not identify all children who are actually at risk of having ASD.³⁷ Nevertheless, assuming these rates remain consistent, more than 500 children annually out of those who complete screenings in the Goldberg Center would be identified as being at risk for ASD or developmental delay and would be referred for evaluation and/or additional intervention services. These data represent one local pediatric primary care medical home's quality improvement data and are not representative of all children with Medicaid in D.C. or of the entire patient population at Children's National with a suspected or confirmed diagnosis of ASD. A more comprehensive understanding of the prevalence of ASD in children with Medicaid in D.C. is needed to better understand the local context.

HEALTH CARE POLICY LANDSCAPE FOR CHILDREN WITH ASD IN WASHINGTON, D.C.

Medicaid and the Early and Periodic Screening, Diagnostic and Treatment Benefit

Approximately 70% of children in D.C. are covered by Medicaid.³⁸ Recent data show that by race, approximately 80% of Black children, 14% of children who identify as other or multi-race, and 5% of white children are covered by Medicaid in D.C.. By ethnicity, approximately 82% of covered children are non-Latino, and 18% are Latino³⁹ Federal Medicaid law recognizes the unique needs of children by requiring the delivery of comprehensive pediatric health care services to all Medicaid-enrolled children and youth under the age of 21 through provisions in the law known as Early and Periodic Screening, Diagnostic and Treatment (EPSDT).⁴⁰ With a particular focus on prevention and early detection as well as a broad mandate related to treatment, the objective – and legal requirement – is for children to get the health care, including behavioral health care, they need when they need it: the right child at the right time in the right setting.⁴¹ EPSDT guarantees that children (ages 0–20) covered by Medicaid have access to and receive services that are deemed medically necessary by a physician or other licensed healthcare provider (including a psychologist) to evaluate, diagnose, treat, correct, and/or ameliorate a physical or behavioral health condition.ⁱⁱ ⁴² Section 1905(r) of the Social Security Act (the federal authority for EPSDT) provides for coverage of all medically necessary services that are included within the categories of mandatory and optional services listed in section 1905(a), regardless of whether such services or provider types are covered under the State Medicaid Plan.⁴² Services deemed medically necessary for an individual child to evaluate, diagnose, and/or treat Autism Spectrum Disorder (ASD) are considered covered services under EPSDT, even if those services or provider types are not included in the State Medicaid Plan. By coverage, this means that the state must ensure the child receives the necessary service(s); specifics related to payment and reimbursement for the service(s) are not stipulated by EPSDT and may vary depending on the state’s Medicaid delivery system.

Federal and State Context

In July 2014, the federal Center for Medicaid and CHIP (Children’s Health Insurance Program) Services, or CMCS, issued clarifying information on approaches available under the federal Medicaid program for providing services to eligible individuals diagnosed with ASD and emphasized to state Medicaid agencies that all medically necessary services for ASD must be included under EPSDT.⁴³ Based on the CMCS 2014 guidance, it is clear that under federal law, virtually all of the services a child with ASD needs should be covered by EPSDT.⁴⁴

ii As it relates to medical necessity, the treating health care provider has a responsibility for determining or recommending that a particular covered service is needed to correct or ameliorate the child’s condition, both the state and a child’s treating provider play a role in determining whether a service is medically necessary. If there is a disagreement between the treating provider and the state’s expert as to whether a service is medically necessary for a particular child, the state is responsible for making a decision, for the individual child, based on the evidence. That decision may be appealed by the child (or the child’s family) under the state’s Medicaid fair hearing procedures.⁴¹

Prior to the 2014 guidance, states sought waivers to cover certain services or treatment modalities, but the guidance made it clear that waivers are not necessary because federal law already requires such coverage. For example, EPSDT covers the following services: licensed practitioners' services; physician services; speech, occupational, and physical therapies; private duty nursing; personal care services; home health; medical equipment and supplies; rehabilitative services; and vision, hearing, and dental services.⁴⁴ In light of this federal guidance, states have taken a variety of approaches to strengthening their state policies to improve coverage and access to ASD evaluation and treatment services.⁴⁵

Given its prevalence as a treatment modality, Applied Behavior Analysis (ABA) therapy is often a policy topic as it relates to ASD services and provider types covered by a state's Medicaid Plan (see "Intervention and Support Services" for more information on ABA). In the July 2014 CMCS guidance, ABA is never explicitly mentioned. In a subsequent CMS Frequently Asked Questions document, CMS stated that the guidance is not intended to mandate states to cover ABA. Rather, CMS will require states to meet their "longstanding EPSDT obligation . . . [by] providing medically necessary services for the treatment of ASD," but it "is not endorsing or requiring any particular treatment modality for ASD."⁴⁶ Interpretation of the guidance and FAQ document includes understanding that if states do not cover ABA therapy under EPSDT, they must cover comparable services that are expected to achieve comparable outcomes. If a particular treatment – including ABA therapy – is medically necessary to correct or ameliorate a child's ASD, and no alternative treatment is appropriate for that child, then the state Medicaid agency must cover that treatment.⁴⁷

District of Columbia Context

In the District of Columbia, approximately 90% of children served by Medicaid are enrolled in managed care organizations (MCOs), and 10% are enrolled in Fee-For-Service (FFS) Medicaid.⁴⁸ As of October 2020, children enrolled in Medicaid MCOs are insured by one of four managed care organizations: AmeriHealth Caritas of District of Columbia, CareFirst Community Health Plan District of Columbia, Health Services for Children with Special Needs (HSCSN)ⁱⁱⁱ, and MedStar Family Choice. Two of the MCOs, MedStar and CareFirst, manage their behavioral health benefit through a sub-contract with a behavioral health organization (BHO), which is another corporate entity that administers and manages the benefit. Prior to October 2020, the following Medicaid MCOs covered children in D.C.: AmeriHealth Caritas of District of Columbia, Health Services for Children with Special Needs (HSCSN), Amerigroup D.C., and CareFirst Community Health Plan District of Columbia (formerly Trusted Health Plan). Each MCO is responsible for ensuring beneficiaries receive, and render payment, to providers for office-based mental health services for children, including 1) diagnostic and assessment; 2) medication evaluation and management; 3) counseling/psychotherapy; and 4) crisis services.^{iv} ⁴⁹ To be paid under D.C. Medicaid for services covered by the MCO, providers must be in the MCO's provider network and credentialed in order to submit requests for payment after the service is rendered.

ⁱⁱⁱ HSCSN is the managed care organization for Supplemental Security Income-eligible DC youth ages 0-26.

^{iv} The Department of Health Care Finance has contracts with the managed care organizations, which include specified contractual obligations regarding behavioral health. DHCF also released a transmittal in July regarding behavioral health obligations by the MCOs.⁴⁹

DHCF pays capitation rates to the four contracted MCOs to finance the delivery of services accessed by MCO-enrolled beneficiaries within the managed care network. The MCO is responsible for paying and credentialing a provider network that offers the office-based mental health outpatient services referenced above. The remaining 10% of children are insured under D.C. Fee-For-Service Medicaid. This includes some children with disabilities not residing in an institution, some children residing in long-term care (LTC) facilities, children linked with Department of Youth Rehabilitation Services (DYRS), and children involved with the Child & Family Services Agency (CFSA). Under D.C. Fee-For-Service Medicaid, the state Medicaid agency establishes the fee levels for covered services and pays participating providers directly for each service they deliver to Medicaid beneficiaries. Beneficiaries enrolled in D.C. Medicaid Fee-For-Service have access to any Medicaid-enrolled provider. In 2019, the D.C. Department of Health Care Finance (DHCF) announced plans to move towards a fully managed Medicaid program over the coming years. This shift, which started in 2020 for adult beneficiaries, involves transitioning individuals currently in Medicaid's Fee-For-Service program to the Medicaid managed care program.⁵⁰ While children enrolled in D.C. Fee-For-Service Medicaid will eventually be moved to MCOs, a timeline and process has not been publicly announced at the time of this publication.

If a child needs more intensive in-home or community-based behavioral health services, those are provided under Mental Health Rehabilitation Services (MHRS). Mental Health Rehabilitation Services are the mental health services provided by the D.C. Department of Behavioral Health (DBH) to Medicaid-eligible individuals with serious emotional disturbance or serious mental illness. These Medicaid Rehabilitation Option (MRO) services are an expanded benefit, including services such as community support services, Community Based Interventions (CBI), Assertive Community Treatment (ACT), adult rehabilitation day services, and other activities not supported at lower levels of care.⁵¹ Mental Health Rehabilitation Services delivered through non-MCO arrangements are paid on a fee-for-service basis, even when delivered to MCO-enrolled Medicaid beneficiaries. MCO enrollees are eligible to receive home and community-based MHRS, such as community support and community-based interventions, through the DBH provider network at no financial cost to the MCO if they meet the eligibility requirements determined by DBH.⁵² Children enrolled in D.C. Fee-For-Service Medicaid or Medicaid MCOs have access to MHRS if they are eligible, and they do not need to change insurance coverage to access the service array. Children and youth with ASD and a co-occurring diagnosed mental health condition should have access to MHRS per local regulations.^{v 53 54}

In practice, many local health care providers find it difficult for children with an ASD diagnosis who have a co-occurring SED/SMI to obtain Mental Health Rehabilitation Services; this is an area for further collaboration to identify policy solutions to support those who have co-morbid conditions.

D.C. is in the midst of significant efforts to improve behavioral health policies and provision of service. On November 6, 2019, the Centers for Medicare and Medicaid Services (CMS) approved the District's Behavioral Health Transformation demonstration, effective date of January 1, 2020 (also known as the District's Medicaid

v *Per the Code of the District of Columbia, "eligible consumers of MHRS include children and youth with mental health problems."⁵³ The definition of "children and youth with mental health problems" is: "persons under 18 years of age, or persons under 22 years of age and receiving special education, youth, or child welfare services, who: (A) Have, or are at risk of having, a diagnosable mental, behavioral, or emotional disorder (including those of biological etiology) which substantially impairs the mental health of the person or is of sufficient duration to meet diagnostic criteria specified within the DSM-IV or the ICD-9-CM equivalent (and subsequent revisions), with the exception of substance abuse disorders, intellectual disability, and other developmental disorders, or seizure disorders, unless those exceptions co-occur with another diagnosable serious emotional disturbance."⁵⁴*

Section 1115 waiver). Section 1115 Medicaid demonstration waivers provide states an avenue to test new approaches in Medicaid that differ from what is required or allowed by federal statute. Waivers can provide states with considerable flexibility in how they operate their programs, including coverage of new services or delivery approaches that typically would not be allowed under current law.⁵⁵ Among a variety of changes, the District's waiver adds new community-based services designed to improve behavioral health treatment capacity.⁵⁶

One waiver provision that impacts the entire beneficiary age continuum, including children, is entitled "Psychologist and Other Licensed Behavioral Health Provider Services." This provision allows for Licensed Psychologists, Licensed Independent Clinical Social Workers (LICSWs), Licensed Professional Counselors (LPCs), and Licensed Marriage and Family Therapists (LMFTs), practicing independently, in a group practice, or in a hospital setting, to be credentialed with D.C. Medicaid and bill for outpatient behavioral health services for individuals with SMI/SED or SUD, including: assessment, diagnostic, and screening services; counseling and psychotherapy; treatment planning and care coordination; and psychological testing.⁵⁷

Prior to the 1115 waiver, D.C. Fee-For-Service Medicaid did not recognize licensed psychologists, LICSWs, LPCs or LMFTs as independent provider types to be credentialed and receive reimbursement. Certain behavioral health care providers could only become credentialed as a provider with D.C. Fee-For-Service Medicaid if they were associated with certain entities that provide mental health services including a Free-Standing Mental Health Clinic (FSMHC), a Federally Qualified Health Center (FQHC), or a Core Service Agency (CSA).^{vi} However, Medicaid managed care organizations (MCOs) in the District can and do credential certain behavioral health care providers, including psychologists and social workers associated with a hospital clinic or as an individual provider, per their contracts with the D.C. Department of Health Care Finance.⁵⁸ If a child enrolled in D.C. Fee-For-Service Medicaid needed medically necessary services from a licensed psychologist practicing in an independent practice or hospital setting, DHCF provided coverage on an as-needed basis through single case agreements between DHCF and the licensed psychologist. In practice, this policy created a higher threshold for children covered by D.C. Fee-For-Service Medicaid to obtain psychological care. A single case agreement is burdensome for families and providers, and the process is often unclear, is more expensive for Medicaid, and often results in delays regarding diagnostic and treatment services. The 1115 waiver rectified this issue for many medically necessary behavioral health care services provided by psychologists and other licensed behavioral health care providers for children covered by D.C. Fee-For-Service Medicaid, through D.C. Medicaid's recognition of these above-named provider types. Also, per the District's waiver agreement with the Centers for Medicare and Medicaid Services (CMS) this waiver service (recognition of psychologists and other licensed behavioral health care providers) will need to be incorporated into the D.C. State Plan for Medical Assistance ("State Plan") in order to make this change permanent; the waiver provisions are currently in effect for only five years. The State Plan is a comprehensive written statement that describes the nature and scope of a state's Medicaid program.

However, services provided by the clinicians specified in the waiver are not covered by the waiver when the services are associated with an Autism Spectrum Disorder diagnosis and treatment. This is due to explicit language in the District's 1115 waiver that states, "services associated with screening or treatment of Autism Spectrum disorders by these behavioral health care providers is not included."⁵⁸ In the waiver application,

^{vi} Information provided by the DC Department of Health Care Finance, Division of Children's Health Services, via phone conversations and meetings.

the District stated that it is “considering other policy interventions for ASD that will offer more comprehensive access to the services and providers needed to treat this condition.”⁵⁹ This most directly impacts children enrolled in D.C. Fee-For-Service Medicaid who have or are suspected of having ASD. The waiver covers non-ASD-related behavioral health care services provided to children with D.C. Fee-For-Service Medicaid by waiver-covered behavioral health care providers in the outlined locations of service without needing to obtain a single case agreement. **Essentially, the waiver has left unchanged current policy relative to ASD services.** Prior to the waiver, children enrolled in D.C. Medicaid MCOs should have been covered for any medically necessary service related to assessment, diagnostic, or treatment services for ASD and received those services per EPSDT. The waiver does not change this – a child enrolled in a D.C. Medicaid MCO, who is determined to need a medically necessary service, including services related to evaluation, diagnosis and treatment by a psychologist, should have that service covered by the MCO under the EPSDT authority. Similarly, prior to the waiver, children with D.C. Fee-For-Service Medicaid needed a single case agreement for services rendered by a psychologist in certain clinical settings; this remains unchanged for children with ASD. Children enrolled in D.C. Fee-For-Service Medicaid continue to need a single case agreement for medically necessary assessment, diagnostic, or treatment services for ASD when provided by a psychologist. **The waiver does NOT, in any way, categorically “carve out” or exclude ASD-related assessment, diagnostic or treatment services from the District’s EPSDT benefit.**

No further information has been provided regarding what policy interventions the District is contemplating to comprehensively address ASD. DHCF may be contemplating a broader Autism Spectrum Disorder State Plan Amendment (SPA), as specific ASD services or provider types (e.g., ABA providers) currently are not included in the District’s Medicaid State Plan. DHCF sought key stakeholder input when it was in the initial stages of developing a SPA in 2016, but public movement on a SPA has not occurred since that time.

Finally, the Departments of Health Care Finance and Behavioral Health recently announced a broad vision regarding behavioral health transformation in the District and a pathway to integrate behavioral health care services more fully into the benefits offered by District’s Medicaid managed care program. Overall, DHCF and DBH envision a three-phase approach to Medicaid behavioral health transformation. Phase I of the District’s Medicaid behavioral health transformation efforts were initiated in 2019 with DHCF and DBH’s collaboration and joint development of the 1115 Behavioral Health Transformation Waiver as well as the transition of individuals from D.C. Fee-For-Service Medicaid to the managed care program, as referenced above. In Phase II, DHCF plans to include behavioral health services as covered benefits in the District’s managed care contracts as of October 1, 2022 with the purpose of improving coordination and providing whole-person care. This is a significant announcement given that many behavioral health care services are currently administered through DBH’s provider network, including Core Service Agencies. Phase III will focus on additional efforts to integrate physical and behavioral health for Medicaid beneficiaries in the District of Columbia, which have yet to be outlined. This multi-phase process provides an important opportunity to improve access to ASD-related services for any child covered by Medicaid and to clarify which governmental agencies have ultimate accountability.

It is crucial to implement comprehensive policy solutions so that all children covered by Medicaid have limited delays in access to and seamless delivery of assessment, diagnostic, and treatment services. Children need psychological testing and evaluation services to determine if they have Autism Spectrum Disorder and/

or another Diagnostic and Statistical Manual of Mental Disorders (DSM-5)-classified neurodevelopmental disorder, such as intellectual disability. Without this determination, patients lack access to care and/or may receive care and school-related services that are not well-matched to their unique needs. As noted above, children suspected of having ASD are typically referred to specialty clinics and providers that offer the psychological service of a diagnostic evaluation. As a result, children that are unable to be referred for comprehensive evaluations are often under- or mis-diagnosed (or have diagnosis delayed, or not diagnosed at all), which impacts their access to treatment and ultimately their long-term prognosis.^{60 61} This, in turn, increases the overall economic burden related to the disease course of ASD and other DSM-5 classified disorders, as children with later diagnoses often experience more severe impairment related to persisting developmental deficits and/or comorbidities.⁶²

BEHAVIORAL HEALTH CARE LANDSCAPE FOR CHILDREN WITH ASD IN WASHINGTON, D.C.

Diagnostic Evaluations

The demand for comprehensive evaluations for ASD is high and growing. Systemic and practical factors may contribute to the gap between need for and receipt of neurodevelopmental services, such as a lack of trained neurodevelopmental specialists with expertise in ASD, lack of payment for psychologists, low reimbursement rates, confusing intake processes, overlap between different assessment clinics that causes confusion for families, long waitlists, transportation difficulties, and varying insurance coverage for the different clinics offering services. Factors associated with poverty, including limited parental education, language barriers, difficulties affording transportation, and inexperience with health care advocacy, can further impede early engagement with services.⁶³ In 2017, the Children’s National Hospital Interdepartmental Neurodevelopmental Workgroup conducted a needs assessment of internal providers to gain clarity about the barriers preventing children from accessing diagnostic evaluations. The 48 respondents were asked to rank their top areas of concern about evaluation access for children suspected of having ASD. Results of this assessment indicated that wait times for evaluations were the most concerning factor followed by referral processes, insurance gaps, psychologist reimbursement for D.C. Fee-For-Service (FFS) Medicaid, and staff capacity. While this internal survey assessed provider concerns’ with ASD evaluation processes, it did not assess parent or family concerns or the concerns of other stakeholders outside the hospital setting. This remains an important area for further investigation and understanding.

The largest provider of interdisciplinary care for children with ASD in the D.C. metro area is the Center for Autism Spectrum Disorder (CASD) at Children’s National. As of fall 2019 (prior to the pandemic), CASD received an average of 78 requests for intake evaluations and follow-up psychological testing each month, compared to 46 per month in 2014. This increase in demand for services has led to lengthening wait times despite continued clinic growth. Given numerous insurance barriers faced by clinicians, many children experience extended wait times for psychological assessments; for example, wait times for diagnostic testing at CASD can take up to 6 months and may span up to 18 months for neuropsychological testing. Of the patients seen at CASD, less than 5% are enrolled in D.C. Medicaid, including the managed care organizations (MCOs) and Fee-For-Service Medicaid. Given insurance restrictions at CASD, many children with D.C. Medicaid are seen at other clinics. Children enrolled in D.C. Medicaid have limited options for high quality evaluations as compared to their privately insured counterparts or individuals that are able to pay out-of-pocket costs without the use of insurance.

Table 3 outlines the clinics where children enrolled in D.C. Medicaid can receive comprehensive ASD evaluations. Information in Table 3 was collected by calling and emailing clinics in the D.C. metro area between October and November 2020 to determine estimated wait times for clinics that reportedly accept D.C. Medicaid plans. Lists of clinics to call were based on existing resources such as the D.C. Collaborative for Mental Health in Pediatric Primary Care’s Child and Adolescent Community Mental Health Resource Guide. While the list is comprehensive, it may not be exhaustive as there may be additional community-based clinics that were unknown at the time of publication.

Table 3. Diagnostic Evaluations for Children with D.C. Medicaid*

Clinic Name, Institution, Location	Ages Served	Wait Times (as of Oct.-Nov. 2020)
Autism and Communications Disorders Clinic, Medstar Georgetown Northwest, D.C.	0-18 yrs.	5 months
Autism Spectrum Center, Mt. Washington Pediatric Hospital Prince George’s County, M.D.	0-17 yrs.	May be as soon as 1 month
Center for Autism Spectrum Disorders, Children’s National Hospital Locations in D.C. and M.D.	0-21 yrs.	Diagnostic Evaluations: 6 mo. Neuropsychological evaluation: Preschool/kindergarten: ~9 mo. School aged: ~ 18 mo.
Child Development Program, Children’s National Hospital Northwest Washington, D.C.	0-3 yrs.	3 to 4 months
D.C. Autism Evaluation Clinic, Children’s National Hospital Northwest Washington, D.C.	0-21 yrs.	Immediate openings, then 8 months once filled
Developmental and Behavioral Clinic, HSC Health Care System Northeast Washington, D.C.	0-21 yrs.	6 to 7 months
Neurodevelopmental Pediatrics, Children’s National Hospital Locations in D.C., M.D., and V.A.	0-21 yrs.	4 to 5 months

All of the sites above endorsed being in-network for at least one D.C. Medicaid program (e.g., AmeriHealth Caritas of District of Columbia, Care First Community Health Plan, HSCSN, MedStar Family Choice, or D.C. Fee-For-Service Medicaid), but insurance would still need to be verified for each individual prior to attending an appointment to determine the individual’s covered benefits. All of the sites above endorsed offering at least some services via both telehealth and in-clinic options, sometimes on a case-by-case basis; however, a full diagnostic evaluation may not be able to be conducted over telehealth for logistical reasons (see “Autism Spectrum Disorder and the COVID-19 Pandemic” in this paper for more information). When reviewing this table, it is important to note that staff capacity varies by clinic, and each clinic has its own hours of operation and availability for ASD evaluations. Some clinics may only operate on certain days of the weeks or have specific and preset times for new patients or extended evaluations. In addition, certain clinics within this list may be specifically recommended by referring providers depending on the needs of the patient or the complexity of the case; however, those same providers may also be more difficult to access (e.g., subject to insurance barriers) or may have long wait times for recommended services. A lack of a centralized system for navigating these different clinics may also compound difficulties with timely access to services. While care coordination is essential for managing this complex system, it is unclear from available data how many Medicaid MCO beneficiaries make use of available care coordination services available through their insurance. Although some MCOs require a minimum level of contact between MCO

beneficiaries and an assigned care coordinator (e.g., HSCSN states that a care coordinator will contact beneficiaries within the first five days after enrollment and provide follow-up for up to three visits per year),⁶⁴ it is not clear how these metrics are assessed or if these expectations and implementation vary among MCOs. Given this, it is clear that **there are significant barriers to accessing services including limited service options depending on insurance, relatively remote location of some service locations, and the difficulties inherent in navigating such a complex and multifaceted system.**

Intervention and Support Services

While ASD is a lifelong condition, there are many behavioral and communication-focused therapeutic approaches, medications, and complementary and alternative medicine interventions available to support children.⁶⁵ Children diagnosed with ASD are typically referred for direct intervention services as a core part of their treatment plan. These direct services may include a combination of applied behavioral analysis (ABA) therapy, speech and language therapy, occupational therapy, physical therapy, social skills training, pharmacological intervention, cognitive behavioral therapy, and other evidenced-based, structured interventions. These interventions are usually delivered by separate providers (e.g., an occupational therapist would deliver occupational therapy while a licensed psychiatrist would oversee medication management). For the purpose of this paper, we will focus only on the direct interventions that specifically address the needs of children with ASD in the social-emotional, behavioral, and mental health domains.

However, referrals for direct services that address the child's needs in any of these areas (e.g. speech and language therapy, occupational therapy, behavioral therapy) should be made as soon as possible after concerns in the given domain are first identified. Children should not be further delayed in accessing critical services while they are on a waitlist for a comprehensive ASD evaluation in the medical or mental health sector, especially given the potential for extended wait times to evaluation and eventual diagnosis. Each of these domains represents a critical component of the child's development, and referrals to needed services should not be contingent on a diagnosis of ASD. Instead, referrals for treatment or direct interventions services in any domain should be made as soon as possible after concerns in the area are first noted.

Applied Behavior Analysis (ABA)

Recommendations from the American Academy of Pediatrics and National Research Council suggest that the most beneficial approaches for improving child outcomes are behavioral and communication approaches that provide structure, direction, and organization for the child and family.⁶⁵ Applied Behavior Analysis or ABA is one such intervention that can be individualized to the child's needs to build positive behaviors and improve skills across home, school, and community settings.^{65 66} ABA is an intervention approach that uses behavior analytic principles (such as modifying antecedents and consequences of a target behavior) to help individuals learn positive, prosocial behaviors and reduce maladaptive behaviors. For example, a behavior analyst working with a child who has behavioral outbursts would identify the factors in the environment that are making the behavior more likely to occur (e.g., what happens before

the outburst, during the outburst, and after the outburst) and would then help modify those factors in order to reduce the outbursts and increase the use of adaptive coping skills. Several comprehensive and evidence-based models for ASD treatment incorporate ABA approaches (for example, the UCLA Young Autism Program, TEACCH, LEAP, Early Start Denver Model, and Early Intensive Behavior Interventions).⁶⁷ Best practice recommendations from behavior analytic researchers agree on several critical components of ABA treatment, including that “planned, structured intervention be provided for a minimum of 20–30 [hours] per week with additional hours of informal intervention provided throughout most other waking hours” for children in the preschool years.⁶⁶ The Behavioral Analyst Certification Board (BACB) suggests that determinations regarding ABA treatment duration and focus “should be based on the medical necessity of the treatment for each individual client rather than the client’s chronological age, duration or nature of previous ABA services.”⁶⁸ In an ABA treatment model, a Board-Certified Behavior Analyst would conduct an evaluation and create an individualized treatment plan including direct client services, caregiver training, data collection/analysis, and supervision of behavior technicians. According to the BACB, the time a client spends in activities such as school and other therapies should not be counted toward or deducted from the recommended number of hours of ABA treatment provided by the behavior analyst.⁶⁸ Evidence-based care guidelines and clinical decision-making supports such as InterQual’s Behavioral Health Criteria and Milliman Care Guidelines (MCG) also provide guidance regarding medical necessity criteria for services like ABA to help providers and insurers determine what level of services are appropriate and necessary.^{69 70}

Care Navigation

Given the complexity of the service landscape and the number of specialty services that children with ASD are often recommended to receive, care navigation is a highly beneficial component of care for children with ASD.⁷¹ The term “navigator” is often used to describe an individual who supports a family or patient in establishing and maintaining their health care; other terms include a peer, family, or patient navigator, coordinator, specialist, advocate or champion.¹⁸ The scope of services and supports that navigators can provide is wide-reaching, including emotional (e.g., empowering families), informational (e.g., sharing information about ASD), instructional (e.g., stress management), instrumental (e.g., care coordination), and advocacy supports (e.g., coaching on how to advocate for specific ASD resources).¹⁴ Different models exist for conducting care navigation, including professional-led models, peer-led models (e.g., a parent who has navigated the ASD system provides support to a parent who is newer to the system), and team-led models (a combination of peers and professionals),⁷² with team-led models offering the most versatility.

Navigation has demonstrated success in targeting factors important to care engagement, such as increased knowledge of a diagnosis and its treatment as well as increased patient empowerment.^{73 74} ^{75 76} Navigation has also been associated with increased links to care, participation in recommended testing and treatment, and timeliness in obtaining health care services, even for patients at high risk for delays in care access.^{77 78} Among children referred for an ASD evaluation, working with a lay navigator was associated with greater likelihood of scheduling and completing appointments than for those who did not work with a navigator or who received navigation support later.⁷⁹ Despite the benefits of navigation, gaps within the District for care navigation services may include a lack of insurance coverage for services, limited awareness of the services or their benefits, and staff turnover.

Parent and Caregiver Support

In addition to intervention services for the child and care navigation services, parents and caregivers may benefit from supports specifically designed to meet the needs of families of children with ASD. Parents and caregivers of children with ASD experience elevated stress due in part to the permanency of the condition, a lack of societal acceptance, and a lack of support and care services.⁷⁹ It is recommended that caregivers address their own needs related to personal stress, social support, and mental health, all of which can limit their ability to engage in care.^{80 81} One local group that provides such support is D.C. Autism Parents, a non-profit organization that aims to support parents and improve the lives of all individuals affected by ASD in the District.⁸² Advocates for Justice and Education (AJE) is D.C.'s Parent Training and Information Center, which receives federal funding through the US Department of Education's Individuals with Disabilities Education Act (IDEA) and strives to ensure that parents of children with special needs are able to appropriately access educational and health care services for their child.⁸³ Each state has its own center to serve families of children with disabilities from birth through age 26. Additional natural and informal supports for parents and caregivers can be accessed through family-run and family-facing organizations such as Parent Watch, Inc. and Total Family Care Coalition as well as through other community-based, family-serving organizations. Appropriate support for families and caregivers of children with ASD is essential and should be included, if not prioritized, in the development of the child's treatment plan.

Access to ASD Treatment and ABA

With the growing prevalence of ASD, there is an increasing demand for ABA services as well as care navigation and parent/caregiver support. While ABA is often a critical component of an individual's treatment plan, access to ABA services remains one of the greatest gaps in care for children with ASD in the District, given the dearth of providers trained in this technique and the limited number of trained providers accepting D.C. Medicaid. Table 4 lists providers of ABA services in the D.C. metro area who accept D.C. Medicaid. This list is comprehensive but not exhaustive. To create this list, in 2019, contacts at AmeriHealth, Amerigroup (prior MCO), and Trusted (prior MCO) provided lists of their in-network ABA providers. These lists were cross-referenced with the D.C. Collaborative's Child and Adolescent Community Mental Health Resource Guide, and outreach to identified sites was completed. In October 2020, additional providers were added based on the in-network provider lists for ABA services from three of the four current MCOs (AmeriHealth Caritas of District of Columbia, Care First Community Health Plan, and HSCSN; an in-network behavioral health care provider list was not available for MedStar Family Choice at the time of this publication). Each agency or organization was then contacted in October and November 2020 to provide up-to-date information that was used to generate Table 4. Information from October and November 2020 calls was included to reflect recent changes in MCOs as well as updated availability during the pandemic. However, insurance coverage may change at any time, and individuals interested in receiving services should contact their own insurance providers and/or clinics to understand their covered benefits. Each agency was contacted at least three times via phone and/or email. Agencies that did not respond were not included in the table.

Of note, after calls were completed, some inconsistencies were noted between which organizations were listed as in-network providers and the information received from sites. Additionally, contacts at some

MCOs reported that some organizations or agencies for which they had in-network contracts were not listed in the table as accepting their insurance. The table only reflects the organizations that responded to the inquiry and endorsed accepting at least one D.C. Medicaid plan at the time of the call. We suspect that this approach may be reflective of families' experiences when asking agencies about insurance eligibility and thus did not include the additional organizations identified by MCOs or in-network provider lists only. This highlights that there is a discrepancy between the insurances that agencies reported accepting and the agencies that were reported to be contracted as in-network providers. This discrepancy is likely a contributing factor to the confusion surrounding referral processes and may inadvertently contribute to extended wait-times for families.

Table 4. ABA Providers that Endorsed Accepting D.C. Medicaid. *

Clinic Name or Institution, Location	Ages Served	D.C. Medicaid Plans Accepted In-Network	Wait Times (as of Oct.-Nov. 2020)
Avail Outreach ABA Springfield, V.A.	0 yrs.+	HSCSN MedStar	1 to 6 months for early morning; 12 to 18 months for after school hours
BASICS ABA Therapy, LLC Washington, D.C.	2-20+ yrs.	AmeriHealth HSCSN MedStar	Less than 6 months
Behavioral & Educational Solutions, P.C. Silver Spring, M.D.	2 yrs. +	AmeriHealth HSCSN	6 to 8 months
Capital ABA Washington, D.C.	18 mo.+	HSCSN	Approximately 6 months
Children Matter First Clarksburg, M.D.	0-10 yrs.	HSCSN	2 weeks for initial evaluation, then 1 month or more for treatment
Connection Therapy Center Washington, D.C.	0-21 yrs.	AmeriHealth CareFirst HSCSN MedStar	1 to 2 months or sooner if client is available during school hours
Continuum Behavioral Health Services McLean, V.A.	0 yrs.+	HSCSN	Immediate openings for telehealth; variable for in person
Developmental and Behavioral Clinic, HSC Health Care System Washington, D.C.	0-21 yrs.	AmeriHealth CareFirst HSCSN MedStar	5 to 6 months
Early Autism Solutions Washington, D.C.	18 mo. -12 yrs.	HSCSN	3 weeks to 1.5 months depending on needs of client
Easter Seals Washington, D.C.	6 weeks - 5 yrs.	HSCSN MedStar	Not taking new clients until January 2021
Jacob's Promise Silver Spring, M.D.	6 mo. - 13 yrs.	CareFirst HSCSN MedStar	Immediate in clinic; 2-3 months in home or less depending on location

Jeducare Services, Inc. Clinton, M.D.	3-26 yrs.	HSCSN	1 month
Learning Together, LLC Easton, M.D.	0-21 yrs.	AmeriHealth CareFirst HSCSN MedStar	Less than 1 month, or sooner if client is available during school hours
Little Leaves Locations in D.C., V.A., M.D.	Home & community: 18 mo. -12yrs. Center: 1-6 yrs.	HSCSN	3 months for in clinic; not accepting home-based clients
National Speech Language Therapy Center Locations in D.C., V.A., M.D.	18 mo. - 26 yrs.	CareFirst HSCSN MedStar	Currently cannot confirm but may vary if area schools return to in-person learning
Optimal Beginnings Bethesda, M.D.	3-18 yrs.	AmeriHealth	1 to 3 months
SPARKS Locations in M.D. and V.A.	20 mo. - 26 yrs.	AmeriHealth CareFirst FFS HSCSN MedStar	Immediate openings during school hours; more than 6 months for after school or evening hours
Step By Step Therapeutic Hyattsville, M.D.	0-21 yrs.	AmeriHealth CareFirst FFS HSCSN MedStar	Immediate openings

As seen in Table 4, children covered by Health Services for Children with Special Needs (HSCSN) have the most options available for ABA services, which is logical given that it is designed for children with special health care needs. Children covered by HSCSN are eligible for in-network services at almost all of the agencies listed above. HSCSN serves children and youth up to age 26 who live in D.C. and have an SSI-eligible disability, which includes ASD. While other payors can provide support to children with ASD, HSCSN offers services that may be particularly helpful for families of children with ASD, such as respite care and direct case management with professionals who have smaller caseloads. Conversely, D.C. Fee-For-Service Medicaid is accepted by only a few of the above agencies, none of which are located in Washington, D.C. Across clinics, there is often more availability for appointments during the daytime; however, daytime appointments often conflict with children’s school schedules and may result in a tradeoff between therapeutic services and instructional time. Again, wait times, insurance, and service location are some of the notable barriers that families may experience when trying to access ABA services for children with Medicaid in D.C.

In consideration of the pandemic, agencies were also asked about the status of in-home, clinic-based, and telehealth services. Of the 18 agencies above, 15 (83%) reported offering telehealth services, with an additional agency (6%) offering telehealth on a case-by-case basis. Thirteen agencies (76%) reported currently offering services in clinic, with one agency (6%) offering clinic-based services on a case-by-case basis. Twelve agencies (67%) reported currently offering in-home services, and two agencies (11%) reported offering in-home services on a case-by-case basis. The shift to telehealth services is likely novel for many of these agencies and merits further consideration (see “Autism Spectrum Disorder and the COVID-19 Pandemic”).

Many children with ASD are also in need of mental health services, including cognitive behavioral therapy (a short-term and solution-oriented therapy focused on changing maladaptive patterns of thoughts and behaviors leading to emotional dysregulation) and psychiatry consultation for medication management. Children with ASD may have challenges accessing these other mental health services due to limited networks of providers that will see children with co-occurring ASD and mental health concerns. For example, clinicians in the D.C. Department of Behavioral Health's Core Service Agencies are unlikely to have expertise in serving children with ASD using an ABA framework and may have difficulty serving children with significantly impairing ASD and other co-occurring mental health disorders. However, they may provide other supports such as behavior management, social skills training, and cognitive behavioral therapy as well as some more specialized modalities, such as Parent-Child Interaction Therapy. At the same time, programs may have other exclusionary criteria, such as co-occurring developmental delays, that may deter families from receiving services or lengthen wait times for children attempting to access care.

Despite the need for services, the data presented suggest that many families experience significant difficulties in accessing care and treatment for children with or who are at risk for ASD or developmental delays.^{48,49,50} This concern is particularly salient for families living in neighborhoods that experience high levels of inequities (i.e., rates of inequities that are over 20% higher than citywide averages) based on metrics such as unemployment rates, rates of residents with less than a high school degree, and proportions of households led by a single mother. Of the 28 neighborhoods with this designation in Washington, D.C., 22 are located in Wards 7 and 8; these wards are located east of the Anacostia river, and over 90% of the residents of these wards identify as Black or African American.^{84,85} Previous reports from D.C. Kids Count indicate that half of D.C. children who were insured by Medicaid were not receiving appropriate mental health services. Moreover, two-thirds of children with a developmental delay did not have a single visit with a mental health professional in the year prior.⁸⁶ Even when appointments are scheduled, long wait-times are common; fiscal year 2019 data indicate that the average wait to a diagnostic assessment at a Core Service Agency in D.C. was 22 days, with an average wait of 76 days to receive a psychiatry appointment.⁸⁷ These findings indicate that a serious and longstanding inequity in mental health care access continues to exist in D.C., disproportionately affecting outcomes for families of color and families living to the east of the Anacostia River.

Services Within the Educational System

In addition to the outpatient clinics discussed previously, there are several other avenues in the early intervention and educational systems through which children may receive developmental and psychoeducational evaluations as well as intervention services. **Strong Start**, D.C.'s Early Intervention Program administered through the Office of the State Superintendent of Education (OSSE), conducts evaluations and assessments to determine eligibility for a child to receive early intervention services. Evaluations for general developmental delays in young children (generally birth to age 3) are conducted using an early intervention framework by Strong Start under Part C of the Individuals with Disabilities Education Act (IDEA), serving children from birth until age 3 and their families and administered through OSSE.⁸⁸

A child may be eligible for Part C services if the child presents with at least a 25% delay in one area of development or if the child has a diagnosed medical condition that might result in a developmental delay, such as ASD. In school year 2017–2018, OSSE reported that 1,906 children and their families received supports from Strong Start.⁸⁹

For children between ages 3 to 5 (with some exceptions), evaluations, including evaluations for ASD specifically, may be conducted by the **Early Stages Center**, which is administered through D.C. Public Schools (DCPS). Early Stages evaluates children for eligibility under Part B of IDEA, which applies to children with disabilities beginning at age 3.⁸⁸ In fiscal year 2018, Early Stages conducted 5,140 developmental screenings, of which 1,169 (22.7%) were recommended for further evaluation.⁹⁰ Evaluations, which require parental consent, typically involve a review of available records, interviews and observations, and specific assessments chosen in alignment with the child’s identified concerns. Evaluations for children age 6 and above are typically conducted by the child’s identified public school/public charter school or school district under Part B of IDEA. Federal IDEA Part B data for the District of Columbia’s State Education Agency reported that, for school year 2018–2019, 1,895 children ages 3 to 5 were identified as having a disability, and 210 of these children were identified as having Autism.⁹¹ Relatedly, 12,218 children ages 6 to 21 were identified as having a disability, 1,048 of which were identified as having Autism.⁹¹ See Table 5 below for information about each of these mechanisms.

Table 5. Early Intervention Program and Educational Evaluations.

Organization Name	Ages Served	Population Served	Relevant Laws	Possible Evaluation Outcomes
Strong Start	0 (birth) to 3 years, or age 4 in some circumstances; can be referred until age 2 years, 10 months, 15 days	Free to D.C. residents	Individuals with Disabilities Education Act (IDEA), Part C D.C. Municipal Regulations	Identification of “developmental delays or disabilities” (not Autism specifically), development of an Individualized Family Service Plan (IFSP), and implementation of early intervention services
Early Stages	2 years, 8 months – 5 years, 10 months	Free to D.C. residents not already enrolled in Public Charter Schools	IDEA, Part B D.C. Municipal Regulations	Transition plan from Strong Start if previously identified, identification under the 13 IDEA-specified disabilities (including Autism), development of an Individualized Education Program (IEP), and provision of special education or related services as needed
DCPS or Public Charter School	3 years to 21 years	Free to D.C. residents	IDEA, Part B D.C. Municipal Regulations	Identification under the 13 IDEA-specified disabilities (including Autism), development of Individualized Education Program (IEP), and provision of special education or related services as needed

Infants and Toddlers (birth until age 3)

Early intervention specialists and educators use a system of identification based on federal education guidelines included in the Individuals with Disabilities Education Act (IDEA) of 2004.⁸⁸

Local regulations (i.e., the D.C. Municipal Regulations) offer additional guidance in alignment with IDEA. Early intervention specialists and school staff members, including educators and school psychologists, do not “diagnose” children; instead, they use a classification system based on relevant educational law. Children under age 3 within the education system may be identified as having at least a 25% delay in one area of development (e.g., physical, cognitive, communication, social-emotional, or adaptive development), or another condition that will likely result in a developmental delay, as specified within Part C of IDEA.⁸⁸ Identification of a developmental delay in this age range would make the child eligible for the development of an Individualized Family Service Plan (IFSP) and early intervention services through Strong Start. Of note, within the District, children under age 3 are not routinely screened or assessed specifically for ASD through Strong Start unless a concern for ASD is made during the referral process or if a concern arises after services are initiated. Evaluations first require parental consent and typically include behavioral observations of the child, parent input, and records reviews. Evaluations are not likely to include the ADOS-2, which is a diagnostic assessment specifically for ASD, but may include other standardized and individually administered measures of development. Decisions regarding IFSP eligibility are made by a team working together and are not at the sole discretion of any one individual. Part C early intervention services are delivered using a coaching interaction style with the purpose of promoting the child’s participation in real-life activities while supporting the parent/caregiver’s ability to improve the child’s development of new skills and strengthen current abilities throughout daily routines and activities.

Children with ASD may require special considerations that could potentially extend beyond the scope of generalized early intervention services. Regarding identification, some signs of ASD (such as difficulties with pragmatic language or inconsistencies in skill development) may be subtle, nuanced, and difficult to identify without extensive and specific expertise in this area. Therapies and interventions for children with ASD may also differ notably from the therapies and interventions recommended for children with general developmental delays, particularly if there are significant concerns about or severe difficulties with the child’s language or behavior (see “ASD Intervention and Support Services” section for more on this topic).

School-Age Children (ages 3 to 21)

Children age 3 and older within the education system are typically identified either through the Early Stages program (early childhood) or their local public school, public charter school, or public school district. Children may be identified within the school system as having one of 13 disabilities that are identified in Part B of IDEA, one of which is Autism.⁸⁸ Under Part B of IDEA, a school-age child with a disability whose disability adversely affects his or her educational performance would be eligible for special education and related services in school through the creation and implementation of an Individualized Education Program (IEP).⁸⁸ If a student is not eligible for special education and related services under IDEA Part B, the student may still be found eligible for other supports that do not include specialized instruction under Section 504 of the Rehabilitation Act of 1973. A child may be eligible for supports through the creation of a 504 Plan if

the child has a condition that impacts a major life function (e.g., communication).⁹² Education, and Welfare; Office of Civil Rights, 29 U.S.C. § 794 (Section 504 Decisions about IEPs, 504 Plans, and any other services or supports are made by a school-based team, of which the parent is a required member, and typically begin with an evaluation process as described above.

Evaluations conducted under IDEA first require parental consent.⁸⁸ Evaluations for school-age children typically include parent, teacher, and/or self-report rating scales, behavioral observations of the child, parent input, and records reviews. Evaluations also often include the administration of standardized, individually administered tests in areas like cognitive and academic functioning (for older children) and adaptive functioning (for very young children or children with developmental delays). Standardized and individually administered parent, teacher, and clinician rating scales specific to ASD are often used within Early Stages and DCPS when concerns regarding ASD are identified. The ADOS-2, which is a diagnostic assessment for ASD that is conducted directly with the child instead of using parent or teacher ratings of the child's behavior, is not routinely administered in school settings, although it is permitted for use in such evaluations.

The classification of "autism" in the school system is made by a team that includes the child's parent(s) or caregiver(s) as well as the child's educators, administrators, and related service providers. This team may also include any outside experts, such as medical professionals or family advocates who are identified and invited by the parent to participate. Any special education or related services (e.g., occupational therapy, speech therapy) that the school will provide to address concerns related to ASD are also decided upon by this team. At present, educational system personnel may or may not have specific expertise in the field of autism, though efforts are underway to expand professionals' knowledge base in this area by providing education on early indicators of possible ASD and screening measures to promote early identification.

It is important to note that a medical or mental health professional's diagnosis of ASD is not sufficient in and of itself to automatically qualify a child for special education services in the school system under IDEA Part B. When schools and early interventionists are presented with outside assessments from medical or mental health providers, schools are required to review and consider these reports when determining the child's eligibility for services. Schools may accept outside assessments outright or may choose to conduct additional assessment. In addition, schools have different criteria for classification of disabilities than medical/mental health professionals. For example, for a student to qualify for an IEP under IDEA (2004), the student's disability must be found to "adversely affect a child's educational performance," which is not a mandatory requirement in the DSM-5 criteria of ASD.⁸⁸ Thus, a child may have a diagnosis from a medical/mental health professional that does not translate into the creation of an IEP if the student's educational performance is not adversely impacted by the disability. Given the differences in perspectives, criteria, and interventions between the medical/mental health and educational systems as well as extended wait times for diagnostic evaluations in medical/mental health settings, it is recommended that all professionals with concerns about ASD make simultaneous referrals for a medical/mental health diagnostic evaluation and any needed therapeutic services while also referring families for school-based evaluations and/or school-based services. Making both types of referrals simultaneously at the first indication of concern may minimize the time that the child goes without care. It is imperative, however, that families share with all of their service professionals across settings if they are participating in parallel evaluation processes in order to improve coordination of care and ensure valid assessment results.

STAKEHOLDER INTERVIEWS

“ A child’s insurance status should not impact their ability to receive high-quality ASD services.”

Stakeholder interviews were conducted with clinicians and health care providers from several of the organizations listed in Table 3 to better understand clinicians’ perspectives on access to care for children with ASD. Of note, families of children with ASD and other relevant sectors (e.g., insurance representatives) were not interviewed, which is a limitation of the anecdotal reports discussed herein. Overall, all providers felt passionately that a child’s insurance status should not impact

their ability to receive high-quality ASD services. Interviewees identified that a historical dearth of evaluation and intervention services for individuals with ASD has negatively impacted children. Providers who were interviewed shared that many patients or clients for whom they provided direct care were often unable to access services earlier in their development, which providers attributed to factors such as longstanding lack of service availability, difficulties in accessing services even when they were available, payment/insurance barriers, and historical under-identification of ASD leading to low service utilization. Providers described how a lack of intervention services for youth with ASD may contribute to problematic and inequitable health outcomes such as delays in access to behavioral health care and increased severity of concerns at the onset of behavioral health treatment. Provider interviewees also noted that insurance reimbursement for service delivery was a major barrier to accessing behavioral health care for children with ASD, specifically among individuals with certain Medicaid plans such as D.C. Fee-For-Service Medicaid. Moreover, stakeholders expressed concerns about the quality of ABA services offered at various agencies and noted significant variability in the quality of care reported by patients across ABA sites.

Several provider interviewees recalled instances where lack of clarity on what information the different Medicaid managed care organizations (MCOs) required to make a diagnosis of ASD led to rejected insurance claims. In these cases, providers stated that they submitted evaluation reports and corresponding plans of care that were rejected by insurers who requested additional information, such as the exact score on a diagnostic instrument. Interviewees also lamented the fact that a child with an educational identification of ASD could not easily access services within the medical/mental health sector (e.g., ABA therapy from a private company that may be covered by insurance) in situations where the evaluation was completed within the school setting and there was limited documentation in the medical record to support the diagnosis. Variability in documentation requirements is not only burdensome for providers (which can lengthen waitlists) but also further delays patients from receiving intervention services like ABA, which overwhelmingly require a medical/mental health professional’s diagnosis of ASD to be considered a covered benefit under insurance.

Even when a diagnosis of ASD is made and acknowledged by insurers, providers interviewed noted several barriers that made accessing appropriate services challenging. For example, providers highlighted network adequacy issues by noting that MCOs have limited in-network ABA providers accepting new referrals. If qualified and covered providers are not readily available to accept new clients, opportunities for intervention are lost at a critical point in the child’s development. One stakeholder suggested that Medicaid beneficiaries typically have a latency of approximately six months or more from the time of a diagnosis of ASD to the time of an evaluation for ABA services. Providers also commented on the fact that families whose children are

diagnosed before age three must manage multiple transitions including first working with Strong Start and/or the child's insurance and then transitioning to Early Stages after age three. While each system serves its own purpose in accordance with its relevant regulations and laws, providers reported that the entire process, from receiving an ASD assessment to accessing evidence-based intervention, can be cumbersome, complicated, and difficult for everyone involved – including families, care coordinators, and even the providers themselves. Providers found that the complexities of this system only add to high levels of stress for recently diagnosed families, who are still adjusting to (and may be grieving) the recent diagnosis of ASD.

Providers who were interviewed also noted that there are significant systems-level challenges that occur when individuals transfer between insurance payors, and such challenges are often outside of the authority of the payors themselves. For instance, providers noted difficulty in connecting some children with HSCSN and struggled with ensuring that appropriate services were still provided or continued during the transition between payors. These system-level challenges, which may be due to confusing procedures, processes, and rules at the agency level within the District, are especially problematic given that HSCSN serves children with the most complex health care needs. HSCSN is an important resource for many families as it often provides a higher level of services for its enrollees as well as valuable benefits that enrollees may be unable to obtain from other payors. As noted above, it is also widely accepted at many clinics. While interviewees acknowledged that there are cases in which families can obtain necessary services through their original insurance providers, they saw HSCSN as a useful resource for children with ASD and their families for several reasons. First, they noted that HSCSN is intended to serve youth with a Supplemental Security Income (SSI)-eligible disability, such as ASD. Second, providers reported that families with HSCSN can more easily access specialized support services such as respite care and a care manager who can provide the needed time and expertise to help families navigate the complex care system. Given these benefits of HSCSN, providers expressed frustration about extended delays and confusing or contradictory advice about the referral process for transferring a child from their original, full-risk MCO to HSCSN. For example, despite ASD being an SSI-eligible disability, providers described some cases when children with ASD were denied the opportunity to transition to HSCSN. Interviewed providers expressed that mixed messages in the MCO transition process were especially upsetting when such transition issues translated into delays in families accessing needed services.

Some stakeholders expressed their opinion that the number of intervention hours provided through early intervention programming and in the school setting are not always sufficient to meet the child's global needs. However, it is important to consider these services in their contexts. For children served under IDEA Part B, the school's obligation under federal law is to provide access to a "free and appropriate public education," which may not encompass all of the services that the child could potentially benefit from outside of the educational setting. For young children served under IDEA Part C, early intervention services are provided in order to work with families to increase the child's participation in everyday activities and routines. Stakeholders from educational and medical specialty settings both acknowledged that there are differences in the service delivery models used in each of these settings. For example, Strong Start's use of the Natural Learning Environment Practices framework under IDEA Part C emphasizes a team-based approach that includes the parent in collaborative decision-making and collectively decides on a treatment plan. This is different from a clinical model in which services are "prescribed" or recommended by a doctor or clinician in an outpatient (ambulatory) medical or mental health care setting. Further,

early intervention service providers may use different intervention approaches from providers who are delivering care in an outpatient clinical setting. Based on provider reports, the process for obtaining ABA services in particular through both Strong Start and insurance can be confusing, especially when different providers are involved in a child's care.

As noted above, Strong Start's role as a provider of IDEA Part C services is not to diagnose conditions like ASD but rather to identify when a developmental delay exists and provide services through an IFSP to address needs that are identified by the family. Since the IFSP is a treatment plan and is viewed as such by insurers, insurers may not cover additional services beyond what has been recommended in the IFSP. One provider relayed an anecdote in which a family was trying to obtain more hours of ABA services than what was included in the IFSP, in alignment with recommendations provided by a specialty ASD clinician in ambulatory care. This provider reported that the family was denied these services by their MCO with the MCO noting, "when a member is receiving Strong Start, [insurance] does not typically authorize ABA services beyond what is recommended on the IFSP." Other stakeholders reported that, based on their own experience, they found that Strong Start does not typically provide more than 10 hours of ABA per week for some families they served. They reported that, in those cases, it was difficult for families to obtain additional services in the private sector through their insurance company. While the IFSP is created for specific purposes, payor stakeholders anecdotally report that MCOs often view the child's IFSP as setting the standard for the child's comprehensive treatment plan and thereby what insurance will cover. The result of the current system is that young children with ASD who are insured through Medicaid MCOs (which routinely use the IFSP as the treatment plan of reference and base what services will be covered on what is written in the IFSP) may be missing out on access to individualized, intensive, and evidence-based treatments during a crucial time in their development if these services are not included in the IFSP.

Community stakeholders noted that there are opportunities for improvement in communication between agencies around ASD diagnosis/identification and service delivery models within the complex landscape of mental health care in the District. Stakeholders believed that agencies that serve children with ASD may benefit from opportunities to partner with each other to understand each other's roles/responsibilities, collaborate effectively, and deliver high quality services in a timely manner. Issues raised in discussions with stakeholders included the distinction between a medical diagnosis and educational identification of ASD, the circumstances under which an ASD identification may be made across differing organizations, and difficulties in determining referral pathways for ASD-specific evaluations in the context of long wait times, restricted entry points, and lack of additional supports to guide parents through the evaluation process. These concerns were compounded by difficulties surrounding accessing recommended services depending on diagnosis and insurance. For example, in order to access ABA services, insurance providers may require a formal diagnosis of ASD, which can take several months or longer to obtain given extensive wait times and may delay time to intervention for children who would benefit from early treatment.

Transition points between service organizations and systems were also identified as an area of concern. Providers and payors anecdotally reported collaborating closely with Strong Start and Early Stages to meet the needs of young children. Clinical interviewees described that Strong Start and Early Stages serve as essential and central points of entry into the system for children living in the District. Stakeholders referenced actions taken by other states to address concerns about ASD in young children served by early

intervention, such as the piloting or implementation of universal ASD screening within early intervention to more routinely and equitably identify young children with ASD earlier in development.^{vii 93} This could include a two-stage/second stage screening process in which a brief, universal screening measure is administered to all individuals in the population of interest, and a second, more comprehensive screening measure is administered to any individuals who screen positive for elevated concerns on the universal screening measure. Stakeholders reported an interest in additional tailored trainings on ASD as well as the need for the development of a compendium of external resources for support and clear pathways for diagnostic and treatment service access.

vii For example, in Massachusetts, several Early Intervention sites joined with an academic institution to address concerns about long waitlists for ASD clinics and inequities in ASD diagnoses before age 3. The EI sites piloted a two-stage screening of ASD prior to referral for diagnostic evaluations. Under this model, stage 1 screening included the universal administration of two standardized questionnaires to parents during regularly occurring EI sessions, while stage 2 screening involved a brief (12-item) play-based observational ASD screening tool. Families could screen positive at either stage based on an elevated score on any of the screening tools administered or a parent or EI provider concern. Families identified as at risk at stage 2 screening were then referred for a comprehensive diagnostic evaluation. This model proved useful in identifying a broad range of children at risk for ASD who are typically underdiagnosed at an early age (e.g., children of color) while also ensuring rational utilization of scarce specialty resources (e.g., ASD evaluation clinics).⁹³

AUTISM SPECTRUM DISORDER AND THE COVID-19 PANDEMIC

As this paper is being published one year into the ongoing novel coronavirus (COVID-19) pandemic, we must acknowledge the impact of the pandemic on the current landscape of services for children with ASD. The COVID-19 pandemic has radically disrupted and transformed the behavioral health care system as it existed prior to COVID-19. In the early stages of the pandemic in March 2020, the vast majority (if not all) of the District's outpatient behavioral health care providers were forced to abruptly stop providing in-person services due to the risk of COVID-19 transmission from in-person care. As stay-at-home orders were implemented in states across the country, many clinicians quickly pivoted to telehealth or telemedicine services (services provided over audiovisual conferencing platforms or via phone), made possible by relaxed regulations around licensure restrictions and billing requirements. However, some services (such as ABA and therapies conducted in home) were exceedingly difficult to provide in an online environment, and services that could only be delivered in person (e.g., inpatient care) had to take extreme precautions to manage patient and provider safety.

Families faced enormous and wide-ranging stressors in response to the pandemic. Families who were personally affected by COVID-19 infections often dealt with significant illness and even unexpected death or loss, which disproportionately and inequitably affected people of color across the United States and within the District. Many families experienced significant financial burden due to job loss and unemployment as businesses closed (some of them permanently). Countless families endured major disruptions to routines and daily life caused by widespread closures of schools, work sites, places of worship, and other community spaces. Distance learning has been challenging for many families and educators, as teachers shifted their entire classrooms online and parents navigated their new roles as educators. The emotional impact of living through a pandemic has been widespread and, for many, resulted in significant stress, depressed mood, anxiety, grief, guilt, isolation, and loneliness. All of these factors were compounded by the ongoing effects of systemic racism, adverse environmental conditions, and chronic stress and adversity not buffered by adequate support. In short, all families were affected by the pandemic in some way, and many continue to be impacted even now. These barriers affected not only families but also behavioral health care providers, many of whom struggled to meet financial obligations during the pandemic but faced the probability of a drastic increase in the need for mental and behavioral health care and supports (see "Joint Letter: Addressing Behavioral Health in the District of Columbia During COVID-19").⁹⁴

While the rapid shift to telehealth may have improved access to some services for well-resourced families (e.g., families with stable internet connections, multiple internet-enabled devices, quiet and private space at home to conduct visits, and confidence in their ability to use technology), barriers to accessing care were largely exacerbated by the pandemic, especially for families with limited resources. Such barriers to care included families' need to prioritize resources toward basic necessities during the pandemic; difficulties in accessing telehealth services where they were available due to poor/no internet connection or lack of suitable devices for telehealth access; lack of accessible information and confusion about service delivery changes; and concerns related to stigma and privacy.

For children with or suspected of having ASD, the effects of the pandemic on diagnosis and treatment were especially pronounced. The pandemic caused many families to delay preventative well child visits, where important screenings (including those for ASD) occur. The pandemic shut down the educational system as it previously functioned, forcing students in the District into remote virtual school for the remainder of the 2020 spring semester and into the fall 2020 and spring 2021 semesters. Schools and primary care clinics represent vital hubs for early identification and evaluation of ASD and other behavioral health conditions, and significant disruptions to these environments may mean that behavioral health concerns go unnoticed and undetected. The pandemic greatly interfered with diagnostic ASD evaluations specifically. The ADOS-2, which is the most widely accepted instrument for ASD diagnosis, must be administered in person (face-to-face) and is not considered to be valid if conducted remotely; the instrument's publisher recommended that ADOS-2 administrations be delayed until the patient and clinician can interact in person without the use of physical barriers between patient and clinician (e.g., personal protective equipment or physical/social distancing).⁹⁵ This has made the evaluation of ASD during the pandemic particularly challenging. The early intervention and educational evaluation systems also shifted to virtual service delivery wherever possible and have yet to resume fully in-person assessment or evaluation services. For children already identified as having ASD, schools are one of the main locations for intervention delivery and service provision and serve as an important source of structure and consistency in daily life. Disruptions in school-based supports and repeated changes in routines, such as shifts between distance, hybrid, and in-person learning, may be especially challenging for children with ASD. As schools move toward more in-person learning opportunities, children with ASD may have additional considerations to be accounted for, such as potential difficulty tolerating mask-wearing due to sensory sensitivities. As noted previously, some therapeutic services for children with ASD (such as ABA) are very challenging to provide in a virtual environment and may have been temporarily halted due to the pandemic if services were unable to be provided virtually. Children with ASD, who are already at risk for other co-occurring psychiatric conditions, may be at compounded risk for poor mental health outcomes like behavior problems, self-injurious behaviors, and suicidal ideation while enduring stressors related to the pandemic. **The ramifications of the pandemic are likely to exacerbate the challenges of ensuring equitable access to care already faced by families of children diagnosed with or suspected of having ASD.**

At present, some clinics and institutions are gradually reopening for in-person services with new safety protocols including patient, family, and/or provider health screenings; use of personal protective equipment (PPE); limitations on the number of people permitted in an area; social or physical distancing requirements; increased hygiene and sanitization; and other protective measures. As some District of Columbia Public Schools (DCPS) begin re-opening, they have continued extensive distance learning practices into 2021, and many previously in-person activities remain virtual. While vaccines for the novel coronavirus have begun to be distributed at the time of this publication, it is unclear what the precise outcome of this development will be or when we, as a society, may begin to resume our pre-pandemic activities. **In sum, the COVID-19 pandemic has exposed and heightened service gaps that exist between sectors such as health care, education, and early intervention. A more seamless system across sectors could help ensure that services can be obtained year-round, regardless of setting or service modality. More mixed funding streams and accountability plans for service coverage could improve outcomes and benefit children with ASD. While much is still unknown, the COVID-19 pandemic has already greatly impacted District residents, including children with ASD, and its full impacts may not be realized for years to come.**

EFFORTS TO IMPROVE ACCESS TO CARE

Over the past decade, multiple groups across the District have come together to improve access to care for children with ASD. Several of these efforts are explored below for context and perspective, but this is not an exhaustive list of all activities in this domain. In 2010, the **D.C. Autism Task Force** was initiated as a public-private partnership with leadership from the Georgetown University Center for Child and Human Development and the Children's National Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. Its goal was to unite interested stakeholders to increase access to comprehensive neurodevelopmental evaluations for children with Medicaid in the District. This group analyzed systems-level barriers and created an inventory of the different interdisciplinary teams offering evaluations in D.C., a process for seeking assistance from the Department of Health Care Finance in resolving D.C. Medicaid access issues, and an opportunity for parents of children with ASD or suspected ASD to help improve services in D.C. This group was last convened in 2016 and was succeeded by the **Closing the Gap Initiative** with leadership from Georgetown's Department of Psychiatry. Closing the Gap aimed to understand and evaluate whether families with D.C. Medicaid had more difficulty in accessing quality ASD evaluations. The initiative began by convening national leaders in the field of ASD and systems of care, such as Vanderbilt University, in order to develop an understanding of best practices. Through discussions with community stakeholders, the initiative began investigating ways to evaluate the average age of diagnosis among D.C. residents, specifically among Medicaid beneficiaries.

In 2012, Children's National Hospital created the grant-funded **D.C. Autism Evaluation Clinic** specifically for children with D.C. Medicaid who do not or cannot receive evaluations at the Center for Autism Spectrum Disorder (CASD) or other evaluation clinics due to factors like insurance difficulties. The clinic is located at Children's National's main hospital and consists of a developmental behavioral pediatrician and a speech language pathologist. Together, clinicians can see four patients per month for 1.5-hour long visits, though more time is often needed to complete a comprehensive evaluation and provide support to families to understand their child's diagnosis. Additional time and staff support would be needed to help families navigate referrals. The care team does not include a psychologist who could conduct developmental or cognitive testing and therefore cannot provide more comprehensive psychological, neuropsychological, or psychoeducational assessments, which are particularly important for older children. While the clinic has a relatively short waitlist, it is primarily referred to by Children's National providers and through word of mouth. If the clinic were to be more widely promoted, the probable increase in demand would likewise increase wait times. This collaborative and multidisciplinary clinic was created to fill a gap in the system specifically for children with Medicaid. While it represents one step towards improving access, it remains dependent on staff availability and other internal factors for its sustainability.

In 2016, **The Autism Behavioral Communications Support** program at Children's National (now called **Beyond the Spectrum**) was created to provide both families and clinical care teams with the support and tools they need to provide the best possible care for pediatric patients with ASD who come to Children's National for medical care. The Beyond the Spectrum team provides inpatient and outpatient consultation to assess children with previously diagnosed or suspected ASD and makes recommendations about accommodations for patients with ASD and related special needs. Children served by the program routinely present with significant behavioral symptoms and communication barriers that impact their ability

to participate in medical or dental care; concerns addressed often are those that pose a high risk for injury to oneself or others, or would otherwise be linked to poor health outcomes. All children may access this service regardless of ability to pay. The team often encounters older (school age) patients with suspected ASD who never received a formal diagnosis and thus did not receive early intervention services, resulting in serious behavior problems that could have been better addressed by timely intervention. This integrated service not only provides essential consultation services but also serves as another opportunity to detect, diagnose, and intervene for children living with ASD who may have fallen through the cracks. From July 2018 to June 2019, the program saw 27 children with D.C. Medicaid where staff were able to provide support, evaluations, interventions, and additional exams as needed. Beyond the Spectrum is not listed in Table 3 as it is only available on a consultative basis to existing patients being seen at Children’s National.

In January 2017, the Child Health Advocacy Institute (CHAI) at Children’s National organized an interdepartmental and multidisciplinary group of providers – the **Children’s National Neurodevelopmental Workgroup** – in part to better understand the landscape of ASD services, determine gaps or concerns, and brainstorm solutions to clarify referral pathways for neurodevelopmental concerns. This group identified barriers to referrals for neurodevelopmental evaluations including long wait times and a lack of clarity about where to send patients internally within the hospital (including variations in insurances accepted by clinic, language capabilities of clinic staff, and clinic age limits).

To clarify referral pathways, the workgroup created an online referral guide (Figure 2) that is available to the public. It describes the various neurodevelopmental referral options within the hospital and includes details regarding ages of patients served, insurances accepted, specific services/evaluations provided, approximate wait times, and instructions for scheduling an initial appointment. This is a hospital-focused workgroup; a District-wide coalition is still needed to address similar concerns at the community level.

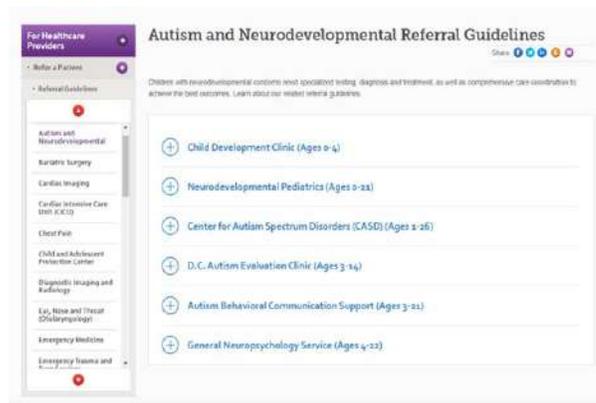


Figure 2. Children’s National ASD and Neurodevelopmental referral guidelines

In 2018, Children’s National Hospital’s Center for Autism Spectrum Disorders (CASD) and the Goldberg Center for Community Pediatric Health received internal funding from the Board of Visitors for two psychologists to receive ADOS–2 training and a corresponding testing kit/related materials with the aspiration of having embedded psychology supports for children with suspected ASD in primary care. In 2019, clinical staff from Children’s National received additional grant funding to apply the knowledge learned from these trainings to pilot the **Autism in Primary Care Initiative**. This is a novel and strategic pilot program that aims to increase early access to diagnostic ASD evaluations and to support families in navigating ASD services. Specifically, mental health clinicians already integrated into primary care clinics received training and consultative support from CASD in conducting specialized ASD evaluations, which the clinicians then provide to families in the primary care setting.

In 2019, an interdepartmental group from Children’s National Hospital received one year of internal funding from the Clinical and Translational Science Institute to conduct research and trainings to improve

community knowledge of ASD and to strengthen partnerships between Children’s National Hospital and community agencies working with young children. This project, **Expanding Autism Knowledge and Access in Community-Based Settings**, aimed to ensure that efforts to increase timely ASD identification and connections to care are co-created with community partners and are sustainable. A series of seven in-person and virtual trainings were conducted from September 2019 to May 2020 and were attended by over 250 participants from 20 agencies, including Strong Start, Early Stages, OSSE, Department of Behavioral Health/Healthy Futures, AmeriHealth, D.C. Association for the Education of Young Children, Total Family Care Coalition, Mary’s Center, and HSCSN. The trainings used a train-the-trainer model to enhance sustainability and dissemination of training content. Efforts to improve ASD care through training and professional development are promising, but such efforts require additional support and funding to ensure that community needs can be comprehensively and sustainably addressed.

As noted previously, while there are many organizations individually serving children with ASD in the District, there was no comprehensive convening group focused on addressing barriers and improving ASD care throughout the city. To address this gap, the **D.C. Autism Collaborative (DC-AC)** was launched in the summer of 2020 with 18 months of philanthropic funding from the Children’s Health Board. The DC-AC is a multidisciplinary, public-private coalition of professionals, community leaders, and parents that seeks to strategically address barriers to ASD care and advocate for solutions that will increase early and equitable access to high-quality ASD diagnosis, treatment, and coordinated care. Members of the DC-AC represent 45 different organizations across sectors including community organizations and other convening bodies, local government, education, healthcare, insurance payors, legal organizations, and advocacy groups. Four subgroups were created to address identified priorities in the following areas: Policy; Developmental Monitoring, Screening, and Evaluation; Education/Outreach and Engagement; and Early Childhood Transition Points.

In fall 2020, the Center for Autism Spectrum Disorders (CASD) at Children’s National Hospital launched **ECHO Autism**, a virtual learning network focused on ASD. The ECHO (Extension Community Healthcare Outcomes) model uses technology and case-based learning to create a forum for specialists and community providers in a particular area. This program uses a tele-mentoring format to provide access to a hub of autism specialists in order to support community providers in their work diagnosing, treating, and caring for children with ASD and their families. The multidisciplinary autism specialist team includes a pediatric psychiatrist (board certified in child, adolescent, and adult psychiatry), a developmental pediatrician, clinical psychologists, a speech and language pathologist, a social worker, and parent advocates. Participating clinicians in the community include primary care providers, subspecialty providers, early childcare providers, and others. Participants are provided with didactic trainings and real time case guidance during web-based sessions using an “all teach, all learn” approach. All participants can learn from one another’s experiences as well as network with other providers who are facing similar challenges.

While each of these programs and groups represent steps towards filling a critical need, all are susceptible to staff turnover as well as discontinuation of internal or grant funding. Some of the above efforts, such as the D.C. Autism Task Force and Children’s National Neurodevelopmental Workgroup, have been unfunded attempts to convene interdisciplinary groups of stakeholders to improve the system of care. **Systemic changes at the District level with long-term funding and support are needed in order to truly make sustainable and enduring impacts in improving access to ASD care.**

CONCLUSION

While the District has developed and expanded several city-wide programs and initiatives to address children's mental and behavioral health, these efforts have not explicitly addressed the needs of children with (or who are at risk for) ASD and their families. Prevalence rates of ASD have consistently increased over the past 15 years as evidenced by national and local data and by growing wait times and demand for ASD-related services. Navigating this landscape is extremely complex and requires extensive knowledge of multiple systems including health care, behavioral or mental health care, school systems, early intervention, and more.

As described herein, a family's journey to diagnosis often includes multiple steps that may be challenging even for the most experienced caregivers. Steps to diagnosis include the initial identification of warning signs or early symptoms by individuals in the child's life (e.g., caregivers, educators, or medical professionals); the administration of screening measures in the educational, medical, and/or mental health setting; and, eventually, a comprehensive and ASD-specific assessment – which may only occur after a significant wait time, at a specific location, and in the context of additional potential barriers (e.g., location, language, resource availability, insurance coverage, and family engagement). After the initial evaluation is complete, the often long and complicated process of securing appropriate therapeutic supports begins. The process of establishing a comprehensive treatment plan means that families must again navigate a complex system of providers from multiple disciplines to meet their child's needs across domains of development and functioning. This could mean having appointments with providers from multiple disciplines on a daily, weekly, or monthly basis such as psychology and behavioral health (ABA or other therapy for social skills, executive functioning, or other concerns), speech-language pathology (expressive and receptive language skill development), psychiatry (medication management and consultation for behavioral or mood difficulties), developmental pediatrics (a comprehensive pediatrician for children with developmental concerns), physical therapy (gross motor skill development), occupational therapy (fine and functional motor skill development), genetics (for underlying genetic concerns), social work (case management or family support), and the school system or early intervention system (development of IEP for school supports or IFSP for early intervention services).

Given these immense challenges, it is imperative that the system of care supporting children in D.C. – and specifically, those children with D.C. Medicaid – respond to these needs with increased support for children and families, improvements in systems of coverage and payment for services rendered, and structural changes to support access to needed services within the District. The burden of care should not fall solely to families to understand and maneuver this highly complex and often disjointed system of care. Data presented herein suggest that we are failing to adequately diagnose and serve children with ASD in the District – especially children insured by D.C. Medicaid. Without access to high-quality early identification, assessment, and intervention services when and where they are needed, the District's children with ASD may be overlooked, go unidentified, and ultimately miss crucial windows for intervention and treatment that could improve their outcomes into adulthood.

Recommendations

We recognize this paper is being released during a time of uncertainty due to the COVID-19 pandemic. While some of these recommendations may be more challenging to implement in the immediate recovery phase, we intend for this collective body of recommendations to serve as a guide for future systemic change to improve behavioral health services for children with ASD in the District. Below are ten recommendations to begin to address these challenges:

- 1. The District should ensure network adequacy for diagnostic and intervention services for ASD.** While MCOs are required to have network adequacy for ASD evaluations and intervention, there remain significant gaps in care. Additional information is needed to understand how DHCF is monitoring and ensuring network adequacy and why certain Medicaid MCOs are not accepted by different care providers. The District should ensure that all appropriately qualified providers are enrolled with all MCOs. In addition, D.C. should ensure there are mental health service providers available to care for children with co-occurring ASD and mental health issues as this is common and requires intervention.
- 2. Identify and implement comprehensive policy solutions that ensure adequate access to the full array of services and providers needed for ASD diagnosis and treatment.** D.C. identified the need to develop comprehensive solutions for ASD services and providers during the Section 1115 Medicaid waiver process. In other states, approaches have included a Medicaid State Plan Amendment as recommended by Centers for Medicare and Medicaid Services (CMS)^{viii}, systematically addressing training and workforce shortages, and identifying innovative approaches through telehealth. The District should use upcoming planned changes to the public behavioral health system, including behavioral health services as covered benefits in the District's Medicaid managed care contracts, as an opportunity to work with families, providers, communities, and other stakeholders to determine and begin implementation of a core set of ASD policy changes.
- 3. Standardize insurance requirements for making a diagnosis of ASD across the MCOs and increase transparency and access to this information.** The different MCOs have varying or unclear standards for what documentation is required in order to substantiate an ASD diagnosis. These discrepancies make it difficult for providers to know what documentation is needed and for families to understand what to look for in an evaluator or in written evaluation results. Moreover, an ASD identification from a school-based evaluation that includes a DSM-5 diagnosis and corresponding comprehensive psychoeducational assessment should be considered sufficient for MCOs to initiate insurance-covered treatment services.
- 4. Create a District-wide, cross-sector ASD Task Force.** This Task Force should study ASD prevalence and reimbursement rates for services, make comprehensive policy recommendations to improve gaps in care, and report its findings to the D.C. Mayor and Council. The Task Force can also explore innovative ways to ensure that critical diagnostic and early intervention services can be delivered via telemedicine. Given historical difficulty in government agencies claiming responsibility for the needs of children with ASD and the responsibility of District agencies to serve the needs of children with ASD, this Task Force could ensure the mental health, medical, and educational needs of children with ASD are met across sectors and develop a cross-government ASD strategy for D.C. This Task Force could be convened through a public-private partnership or codified in legislation and would require sustained support to have an impact.

^{viii} In a CMS document from September 2014, *Medicaid and CHIP FAQs: Services to Address Autism*, one of the FAQs was: "Do states need to submit a Medicaid state plan amendment (SPA) to offer benefits to individuals with Autism Spectrum Disorder (ASD)?" CMS responded, "In keeping with the role of the Medicaid state plan as a comprehensive written statement of the nature and scope of services available under the state's Medicaid program, a SPA is strongly encouraged to articulate the state's menu of services for ASD treatment."⁴⁶

5. **In ambulatory (medical or mental health) care settings, ASD treatment plans should be determined by specialists within the area of expertise for which they are recommending services** (e.g., speech language therapists should determine the number of speech therapy hours recommended). These decisions should not be limited by insurance restrictions, or if denied by insurance, should have the opportunity to undergo peer review with ASD specialists.
6. **Secure payment and sustainable funding for peer supports, family navigators, and care coordinators with expertise in ASD**, which are essential in helping families navigate a new diagnosis and treatment plan. These supports are even more important to fund in the wake of the COVID-19 pandemic, as these positions could further bolster workforce development while the District recovers.
7. **Secure funding to provide ongoing training and education on ASD for frontline care providers**, including primary care providers, early intervention staff, school staff, and early childhood behavioral health professionals, since individuals in these roles frequently refer children with suspected or diagnosed ASD for specialty services. Parents and caregivers of children with ASD must also be educated about ASD and engaged as partners in their children's care. The District should also look to fund models that improve access to clinical expertise, such as ECHO Autism, which has been successful in other jurisdictions.
8. **Streamline and improve the process for transitioning between MCOs** so children do not lose or delay services as they transition between insurers. The District should acknowledge the transition period when families change insurances and provide support to families in accessing services during this transition.
9. **Promote communication and diagnostic/identification reciprocity between the health care sector, educational sector, and early intervention sector for children with ASD** to make it easier for families with a classification of ASD in one system to receive acknowledgement in the other system. Streamlining processes would enable children to more quickly access the full spectrum of services available to them.^{ix}
10. **Support the implementation of universal, coordinated, and strategic developmental monitoring and screening practices across key agencies within the District of Columbia.** Universal developmental monitoring/surveillance should be adopted by systematically integrating the CDC's "Learn the Signs. Act Early." materials across agencies in the District to promote increased awareness of developmental milestones across stakeholders. Routine universal ASD screening, and potentially two-stage screening, should be implemented in programs that target young children. Screening efforts should be coordinated with organizations that can provide technical assistance and support screening implementation while ensuring that identified children can be quickly seen for comprehensive ASD evaluations.

Children's National looks forward to working with public and private partners to identify and advance meaningful systemic solutions that will improve timely access to diagnostic, treatment, and support services for children who have or are suspected of having ASD.

^{ix} While medical and educational systems operate independently, some states have explored ways to bridge communication between systems. For example, California passed the Lanterman Developmental Disabilities Act, which established regional centers for service coordination with case managers who oversee resource need and allocation for families, including awareness of school-based services. Other states (e.g., Florida, New York, Arkansas) have autism support centers that assist with resource navigation and provide coordinated trainings for families, schools, and professionals supported by varied funding mechanisms (e.g., Dept. of Education, Dept. of Developmental Services, mental health agencies, universities). Pilot programs to improve linkages between early intervention and medical settings have also shown promising results (e.g., Maine).

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