



AUTISM AND MEDICARE:

When “more” is sometimes less

More adults with autism are becoming covered by Medicare, almost always in addition to existing Medicaid and/or private insurance. This paper examines the challenges to accessing autism treatment under Medicare and the additional barriers it sometimes creates to maintaining access to treatments covered by secondary insurance. The paper then identifies a range of possible reforms for remedying gaps in health insurance coverage for autistic adults who have Medicare as their primary insurance.

The Insurance Resource Center for Autism and Behavioral Health
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EXECUTIVE SUMMARY

While for many years, diagnosis and treatment of Autism Spectrum Disorder (ASD or autism) focused on children and adolescents, there is now a broad consensus that autism is a lifelong condition that requires treatment throughout the lifespan by qualified health care providers. Over the past decade, public and private health insurance dramatically expanded coverage for the diagnosis and treatment of autism, resulting in a major systemic change from previous years. Autistic individuals have benefited greatly from this expansion of access to necessary health care.

Once a disabled adult has received Social Security disability benefits for 24 months, they are automatically enrolled in Medicare, which often becomes their primary health insurance. As autistic individuals transition to Medicare, they are experiencing new barriers to health insurance coverage and, in some cases, the disruption of access to ongoing, beneficial treatments.

Although disabled individuals between the ages of 21 and 64 have been covered by Medicare for many years, the program remains principally focused on the needs of seniors, age 65 and older. As such, Medicare has not adequately expanded its coverage to meet the needs of its disabled population. This is particularly true with respect to mental/behavioral health treatments, as Medicare is not subject to the requirement of mental health parity that applies to most private insurance and Medicaid.

This paper seeks to understand the challenges faced by autistic adults in obtaining coverage for medically necessary treatments through Medicare and secondary insurance. Our initial research points to significant gaps in Medicare's coverage of autism treatments and in the categories of health professionals permitted to bill Medicare for medically necessary treatments that meet the needs of adult autistics. In addition, Medicare's administrative practices are impeding beneficiaries' access to their secondary insurance (private insurance or Medicaid). Autistic adults' problems with accessing behavioral health and other medical treatments are compounded by a shortage of health care professionals with the training necessary to accommodate their unique needs. To some extent, these shortages are systemic, but low rates of provider participation can also be attributed to Medicare's low reimbursement rates, inadequate time constraints, and excessive administrative red tape.

We conclude by identifying various paths to remedying gaps in health insurance coverage for autistic adults who have Medicare as their primary insurance. To accomplish meaningful change, we anticipate the need to engage directly with state and federal policymakers, as well as key personnel within the Centers for Medicare and Medicaid Services (CMS).

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INTRODUCTION

In recent decades, Autism Spectrum Disorder (ASD or autism) has gone from being considered a rare condition, estimated in the early 1990s to affect fewer than 10 in 10000 children,¹ to a condition affecting a significant portion of the population. Using 2020 data, the Centers for Disease Control and Prevention (CDC) estimated the prevalence of autism in 8-year-olds to be 1 in 36.² As it is most frequently diagnosed in early childhood, the initial focus of autism treatments has been on children, from birth through adolescence. However, there is a broad consensus that many of the functional limitations experienced by children with autism¹ continue into adulthood, as does the need for treatment by qualified health care providers. A summary of autism treatments prepared by the National Institutes of Health-National Institute for Childhood and Human Development states, “Many people with ASD benefit from treatment, no matter how old they are when they are diagnosed. People of all ages, at all levels of ability, can often improve after well-designed interventions.”³ In a similar vein, the CDC notes, “ASD affects each person differently, meaning that people with ASD have unique strengths and challenges and different treatment needs. Treatment plans usually involve multiple professionals and are catered to the individual.”⁴

Over the last decade, public and private insurance dramatically expanded coverage for the diagnosis and treatment of autism, resulting in major systemic change from previous years. In Massachusetts, this change began with the passage of two landmark bills – An Act Relative to Insurance Coverage for Autism, known as “ARICA” (2010),⁵ and the Autism Omnibus Bill (2014).⁶ Under ARICA, most private health insurers in Massachusetts are required to provide coverage for the diagnosis and treatment of ASD (with no age limit). The Autism Omnibus Bill extended this requirement to the state’s Medicaid program, MassHealth, through age 21.⁷ Autistic individuals have benefited greatly from this systemic change, which expanded their access to necessary health care.

Generally, people become eligible for Medicare beginning at age 65. However, for younger disabled adults, the receipt of Social Security benefits triggers Medicare eligibility at a much earlier age. Many autistic adults under age 65 obtain Social Security benefits based on disability. They may obtain Social Security Disability Insurance (SSDI) either on their own work record or, more commonly, through the Disabled Adult Child (DAC) benefit once a parent begins receiving Social Security benefits.⁸ After a 24-month waiting period, these individuals are automatically enrolled in Medicare, which in most cases becomes their primary medical insurance provider.⁹ While people with disabilities are a sizeable Medicare cohort (roughly 12% in 2022),¹⁰ Medicare’s focus remains on individuals 65 and older, who have long been its core constituency.¹¹ Medicare’s authorized treatments and the associated eligible providers reflect the medical needs of the principal target population and often do not align well with the needs of disabled adults, including individuals with autism.

¹ Please note: The use of identity-first language (“an autistic adult” or “an autistic”) and person-first language (“an adult with autism”) is a personal choice. The authors considered the range of views regarding language use and endeavored to respect all views by alternating a variety of styles.

As autistic individuals transition to Medicare, many are discovering new barriers and experiencing disruptions in their coverage for medically necessary health services. Individuals who have transitioned to Medicare are encountering the following obstacles:

- There is an acute shortage of Medicare-eligible providers that offer behavioral health treatment for autistic individuals.
 - Many providers of behavioral health services for autistic individuals are licensed professionals not currently eligible to enroll as Medicare providers;
- Medicare does not specifically include coverage for behavioral health treatments for ASD;
- Medicare’s administrative practices – in particular, failure to issue denials which trigger secondary payments – are preventing autistic adults from accessing timely benefits from secondary insurers.

In addition, having Medicare as primary insurance can compound the obstacles faced by autistic adults in accessing medically necessary services, even when it covers a specific service. As an example, Medicare covers therapeutic treatments such as occupational and speech/language therapy, but Medicare’s complex billing requirements and low reimbursement rates exacerbate the systemic shortages of providers who are qualified to meet the unique needs of the disabled adults with autism.

This paper examines the challenges faced by autistic adults in obtaining coverage for medically necessary treatments through Medicare and secondary insurance and explores the options for overcoming these obstacles.

AUTISM AND BEHAVIORAL HEALTH COVERAGE UNDER MEDICARE

Medicare and the challenges faced by autistic adults in obtaining behavioral health treatments

It is widely acknowledged that necessary treatment for mental and behavioral health conditions is not available to many who are in need.¹² The Association of American Medical Colleges reports, using NIH data, that “more than 150 million people live in federally designated mental health professional shortage areas. Within a few years, the country will be short between 14,280 and 31,109 psychiatrists, and psychologists, social workers, and others will be overextended as well.”¹³ With an overall shortage of traditional mental health professionals, many of them opt not to take any insurance,¹⁴ and the problem is particularly acute with respect to Medicare and Medicaid, largely because of low reimbursement rates.¹⁵

Those covered by Medicare by virtue of disability have a higher prevalence of cognitive and mental health impairments than the traditional 65+ Medicare beneficiaries.¹⁶ For this reason alone, the general shortage of mental health professionals disproportionately burdens this population. However, autistic adults face additional challenges in finding qualified behavioral health providers. It is well-understood that the functional impairments that result from ASD vary widely among affected individuals.¹⁷ A patient may have limited language or complete fluency, average or higher cognitive ability or an intellectual disability, sensory sensitivities, or anxiety – to name just a few. The unique profile of each autistic individual adds to the complexity of finding a suitable behavioral health provider.

Autistic individuals who have the ability to self-report about their experiences have provided key insights into the barriers in accessing behavioral health care, including:

- provider-level characteristics, like the limited availability of providers trained in autism,
- patient-level characteristics, like challenges with expressive and/or receptive language, and
- system-level characteristics, like environments that are not accommodating to sensory needs.¹⁸

At the other end of the spectrum, autistic individuals with an intellectual disability and significant language impairment are unable to access mental health treatments that rely primarily on verbal interactions. These individuals rely on behavioral treatments such as Applied Behavior Analysis (ABA), modified Cognitive Behavior Therapy (MCBT), and Dialectical Behavior Therapy (DBT), as alternatives to traditional talk-based therapies. Training in these alternative approaches is uncommon among the professional provider groups authorized to bill Medicare. Moreover, autistic individuals with an intellectual disability and/or significant language impairment are not likely to be good candidates for integrating treatment of behavioral health into primary health care. Even if the primary care doctor has experience treating individuals with intellectual disability and limited language (which is often not the case), the time allocated for a standard office visit is likely insufficient to permit the addition of effective behavioral health treatment.¹⁹

Qualified providers of behavioral health treatments outside current Medicare-authorized categories

With a growing autistic population in need of behavioral health treatments, these services are often provided by licensed professionals that are not eligible to become Medicare providers. By focusing on the behavioral health needs of autistic individuals, these professional providers have developed expertise that is often lacking in the general practice of traditional mental health professionals. Innovative approaches are often required to meet the complex behavioral health needs of adult autistics. Even when a service is nominally covered by Medicare, the practice of specifically delineating which types of providers can bill for each covered service inhibits non-traditional pairings of treatments and providers.

Until recently, Medicare has permitted mental health services to be provided only by psychiatrists or other doctors, clinical psychologists, clinical social workers, clinical nurse specialists, nurse practitioners, and physician assistants.²⁰ The Consolidated Appropriations Act of 2023 broadens provider eligibility in the behavioral health field to include services provided by a credentialed (master's or doctoral degree) state-licensed mental health counselor.²¹ Medicare's inclusion of mental health counselors will enable some autistic individuals to continue receiving behavioral health treatment from providers they relied upon prior to their transition to Medicare. However, the expansion does not include certain providers (e.g., licensed applied behavior analysts (LABAs), board-certified behavioral analysts (BCBAs)) that specialize in behavioral health treatments that have been shown to benefit individuals with autism. As such, adults covered by Medicare are likely to continue to suffer from the shortage of qualified clinicians.

Prior to becoming eligible for Medicare, Caitlin, a young autistic adult who uses an Assistive Communication Device, was receiving Cognitive Behavior Therapy (CBT) from a Licensed Mental Health Provider who accepted MassHealth. Once on Medicare, Caitlin could no longer access her MassHealth coverage for this ongoing, effective treatment. First, the Licensed Mental Health Provider was not eligible to be a Medicare provider and so could not submit a claim to Medicare that would trigger a denial. Moreover, MassHealth indicated that since Medicare did cover CBT, Caitlin should seek treatment with a provider eligible to bill Medicare for this treatment. Caitlin's family caretaker explained that it had been extremely difficult to find a provider who could work effectively with her daughter and that she had not been able to identify any Social Workers (the Medicare-approved providers for CBT) whose practice encompassed the needed treatment. In this case, Medicare's lack of flexibility with respect to eligible providers, exacerbated by MassHealth's rigid adherence to its third-party liability rules with respect to treatments nominally but not effectively covered by Medicare, resulted in Caitlin being cut off from a necessary and proven behavioral health treatment.

Medicare's authorized billing codes fail to encompass behavioral health treatment specific to ASD

The Healthcare Common Procedure Coding System or "HCPCS" is "a collection of standardized codes that represent medical procedures, supplies, products and services. The codes are used to facilitate the processing of health insurance claims by Medicare and other insurers."²² Within HCPCS, the Current Procedural Terminology (CPT-4) is a numeric coding system maintained by the American Medical Association (AMA) that consists of descriptive terms and identifying codes primarily used to identify medical services and procedures furnished by physicians and other health care professionals."²³

As a defined benefit program, Medicare delineates the specific treatments it covers by reference to specific CPT codes. Medicare's billing codes for mental and behavioral health focus largely on the treatment of conditions that occur within the general population. Some of these conditions are common, as well, in autistic adults. If, for example, an adult autistic seeks treatment for a comorbid condition, such as anxiety or depression, and assuming that the treatment can be effectively administered by an enrolled provider, there will be a billing code that permits the provider to be reimbursed by Medicare. However, ABA and other commonly prescribed behavioral health treatments for autism that are covered in Massachusetts by private insurance and, up to age 21, by MassHealth, are not among Medicare's current billing codes. The omission of billing codes specific to autism treatments is yet another obstacle to ensuring appropriate behavioral health coverage for autistic adults.

Medicare’s administrative practices obstruct access to benefits from secondary insurers

A high proportion of those who obtain Medicare retain Medicaid coverage; such individuals are referred to as “dual-eligibles,” because they meet eligibility for both Medicare and Medicaid. In addition, some autistic adults who obtain Medicare continue to be covered under a parent’s private insurance. For dual-eligibles or those covered by an employer-sponsored plan of an employer with fewer than 100 employees, Medicare becomes the primary insurer.²⁴ Secondary insurers commonly require a denial of coverage by the primary insurer before paying a claim. However, under Medicare’s current administrative procedures, there is no efficient mechanism for non-covered providers to obtain a denial, as they cannot bill Medicare in the first place. Similarly, Medicare does not issue a denial when an enrolled provider submits a claim using a non-recognized billing code. In both cases, the autistic adult (or a caretaker acting on their behalf) is blocked from accessing insurance coverage that they relied upon prior to receiving Medicare.

Key informants²⁵ identified possible “work-arounds” to obtain a denial:

- CMS Form 1490, “Patient’s Request for Medical Payment”
 - This form is available for initiating requests for payment when 1) the provider or supplier has refused to file a claim for Medicare Covered Services; 2) the provider or supplier is unable to file a claim for the Medicare Covered Services; or 3) the provider or supplier is not enrolled with Medicare. If Medicare does not cover the service or the provider is not qualified to bill Medicare, the submission of CMS Form 1490 will trigger a denial (a prerequisite to accessing coverage from secondary insurers).
 - There are serious drawbacks to this approach that make it burdensome to use, particularly for ongoing treatments: 1) completing this form and assembling the supporting paperwork is time-consuming (there is no electronic submission alternative); 2) using this approach injects a significant time lag for reimbursement (CMS processing on the order of 60 days on top of subsequent processing by secondary insurance); 3) the denial only applies to a specific occurrence of the treatment and does not carry over to subsequent, similar treatments; 4) in Massachusetts, submissions (via Form 1490S) are processed by a third-party contractor who is inaccessible to consumers and their advocates.²⁶

For several years, Carlos has been benefitting from Applied Behavioral Analysis therapy, provided by a Board-Certified Behavior Analyst. Pursuant to Massachusetts law, this therapy is covered by his parent’s employer-sponsored private insurance, without age limitation. Upon obtaining Medicare coverage, Carlos’s private insurer refused to pay for this therapy pending a denial from Medicare. The BCBA was not eligible to enroll as a Medicare provider; moreover, there was no Medicare billing code associated with this treatment. Accordingly, the provider was unable to submit a bill to Medicare for this treatment and receive a denial. This resulted in a months-long stalemate, during which Carlos was faced with mounting bills and the provider went unpaid. After an extensive delay, the private insurer agreed to pay if the provider transmitted each claim with a cover letter stating that “[provider] does not participate with Medicare for the time period of the claim (itemizing each day of service) and that [provider] has never had a relationship with Medicare.”

- CMS Form 855I, “ Medicare Enrollment Application - Physicians and Non-Physician Practitioners”
 - The form is used “to enroll in the Medicare program and receive a Medicare billing number.” It is over twenty pages long (not including instructions) and requires comprehensive information about the practitioner’s qualifications, business model, etc. Ostensibly, a provider could submit this form for the purpose of getting a letter from Medicare that confirms the provider’s ineligibility to enroll (effectively, a blanket denial).
 - It is neither in Medicare’s interest nor that of providers and their patients to employ such a time-consuming and complex process to confirm a known lack of eligibility.

Clearly, all parties involved would benefit from a less burdensome administrative solution.

MEDICARE PRACTICES THAT EXACERBATE CHALLENGES FOR ACCESSING THERAPIES AND PRIMARY CARE

Medical care from Speech/Language Pathologists (S/LPs) and Occupational Therapists (OTs)

In addition to behavioral health treatments, autistic adults may rely on therapies provided by speech and language pathologists (S/LPs) and occupational therapists (OTs). Professionals in these fields often have more experience than physicians in working with autistic individuals and adapting therapies to their needs. Although professionals in these provider groups also work with seniors, the skills and approaches required for effective treatment are not the same in these two populations. Moreover, younger adults with disabilities are likely to seek out community or home-based services, whereas speech, occupational, and physical therapies for older adults frequently occur in a hospital or rehabilitation setting.²⁷

Because they are in high demand and short supply, SL/Ps²⁸ and OTs²⁹ in private practice (as opposed to institutional settings) have the option to take only private-pay clients and not those who rely on insurance. While the overall shortage of SL/Ps and OTs cannot be directly attributed to Medicare, this is another area in which higher reimbursement rates and greater flexibility with respect to coverage for autism-related services could significantly increase access.

Medical care from Primary Care Physicians

Although the primary care physician has a crucial role in adult patient care, many primary care physicians are not well-prepared to serve their autistic patients. A literature review on this topic identifies several key barriers in primary health care for adults with an Intellectual or Developmental Disability (I/DD) and/or autism, including a lack of specialized training, poor attitudes toward this population, ineffective patient-doctor communication, emotional discomfort or fear on the part of the autistic adult (of medical procedures, of negative

judgment, etc.), the autistic individuals' lack of involvement in decision-making, and failure to provide adequate time for the office visit.³⁰ Failure to address these barriers within primary care leads to poorer overall health outcomes in this population.³¹ Medicare cannot single-handedly address these systemic challenges, but it can address the time limitation problem by ensuring that PCPs are permitted to bill for longer office visits when treating an autistic patient.

In order to fulfill its obligations as the primary insurer of the many autistic adults, CMS must take a proactive role in expanding access to providers, by ensuring that reimbursement rates are sufficient to attract qualified practitioners and that providers can take additional time, if necessary, to meet patients' needs. CMS should also lend support to initiatives that help expand training of health care professionals to work effectively with autistic adults.

MEDICARE AND BARRIERS TO HEALTH CARE EQUITY

Health care equity for disabled adults

In reflecting on the current state of coverage for people with disabilities, the Kaiser Family Foundation has observed that:

despite broader access to public and private coverage and improvements in Medicare benefits brought about by the ACA, people with disabilities are likely to face ongoing challenges if their coverage, including Medicare, does not provide the services and supports they need to live as independently and productively as possible. Evidence points to a consistent pattern of differences in the health care experiences of younger beneficiaries with disabilities and those of older Medicare beneficiaries, with younger beneficiaries encountering significantly more cost-related barriers to care than older beneficiaries. Given high rates of health problems and relatively low incomes among Medicare's beneficiaries under age 65 with disabilities, the needs of this relatively vulnerable population require careful attention in ongoing Medicare policy discussions.³²

A literature review on health care outcomes for individuals with I/DD attributes markedly poorer health outcomes in this population to "a cascade of disparities" in the health care system.³³

The Centers for Medicare & Medicaid Services (CMS) has recently intensified its focus on the disparities in health care that affect persons with disabilities, among other groups. In its "Framework for Health Equity 2022–2032," CMS states:

We strive to identify and remedy systemic barriers to equity so that every one of the people we serve has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes.

This Framework challenges us to incorporate health equity and efforts to address health disparities as a foundational element across all our work, in every program, across every community. We are designing, implementing, and operationalizing policies and programs that support health for all the people served by our programs, eliminating avoidable differences in health outcomes experienced by people who are disadvantaged or underserved, and providing the care and support that our enrollees need to thrive.³⁴

It would be within the scope of this initiative for CMS to examine and address policies and programs that have resulted in gaps in provider access and treatment coverage for autistic individuals who obtain Medicare coverage as young adults.

Medicare and Mental Health Parity

The Mental Health Parity and Addiction Equity Act (MPHAEA) passed Congress in 2008. Mental health parity refers to requirements for health insurers to cover mental health and substance use disorder services on terms that are equal to those offered for medical and surgical services. The mandate for mental health parity applies both to quantitative (e.g., number of visits covered) and non-quantitative (e.g., requirements for pre-authorization; progress requirements) treatment limits.³⁵ These requirements apply to most private health insurance plans and most Medicaid plans.³⁶ Unfortunately, fifteen years later, requirements for mental health parity have not yet been applied to Medicare.

In their recent detailed and thoughtful analysis of gaps in Medicare's coverage of Substance Use Disorder (SUD) treatments, authors from the Legal Action Center conclude that "[a]pplication of the Parity Act to Medicare would ensure that beneficiaries with SUDs do not experience discrimination in their health care coverage and would promote greater access to SUD prevention and treatment."³⁷ The authors identify multiple structural barriers to care that would be eliminated by applying the Parity Act to Medicare, including, among other things, authorizing care delivery and reimbursement for licensed counselors, requiring adequate networks of providers and facilities that furnish specialized treatment to Medicare beneficiaries, and supporting the establishment of reimbursement rates and policies comparable to those for medical services.³⁸ The application of mental/behavioral health parity to Medicare would similarly eliminate these and other barriers to accessing coverage of necessary autism treatments.

As there is no logical basis to assume that the policy objectives of a parity requirement do not apply equally to Medicare as to other forms of insurance, it seems likely that assumptions about cost form the principal barrier to extending parity to Medicare. The Legal Action Center has challenged the assumption that incorporating parity requirement into Medicare would substantially increase costs, with a detailed study conducted by health economists at RTI International. The study showed that the cost of covering unmet needs for SUD coverage (residential programs, intensive outpatient programs, and licensed and certified counselors)

would largely be offset by reduced costs from treating medical conditions caused by SUD and from fewer SUD-related hospitalizations and emergency department visits.³⁹

Advocacy in support of extending parity to Medicare continues, and there has been some progress on the legislative front. For example, under the 2023 Consolidated Tax Act, Congress directed the Government Accountability Office to study and report on mental health coverage relative to medical/surgical coverage under Medicare Advantage plans (relative to private insurance and Medicare fee-for-services plans).⁴⁰ Legislation has also been introduced to require parity under Medicare Part C (Medicare Advantage plans) and Part D (prescription drug coverage).⁴¹

ONE CARE AND DUAL-ELIGIBLES WITH AUTISM (AGES 21-64)

Many autistic adults enrolled in Medicare are also covered by Medicaid (in Massachusetts, MassHealth). Dual-eligibles may choose to receive these two coverages separately – in which case MassHealth is secondary to Medicare – or they may enroll in One Care.⁴² One Care is a managed care plan, available to dual-eligibles in Massachusetts that qualify for Medicare by virtue of disability (ages 21 to 64). One Care is legally required to cover all of the benefits included in both Medicare and MassHealth and may include additional coverages. Those additional benefits are specified in a 3-way contract between MassHealth, CMS, and the private insurers that were competitively chosen as Medicare-Medicaid Providers (MMPs). Periodic review of program performance has resulted in amendments to program coverage. For example, amendments have included the expansion of behavioral health diversionary services to offer support in community settings as a means of preventing the need for hospitalization.⁴³ One Care could ensure better health care outcomes for autistic adults by expanding coverage to include medically necessary autism treatments.

While expanding One Care to cover autism treatments could offer a useful option to some autistic adults, there are some significant limitations to this approach. The plan currently specifies that “[b]eneficiaries who have any other comprehensive private or public insurance, receive home and community-based service (HCBS) waiver services, or reside in an intermediate care facility for individuals with intellectual disabilities are not eligible to enroll in One Care.”⁴⁴ This group includes many autistic adults, including those with intensive behavioral health support needs. In addition, the choice of One Care providers is quite limited: statewide, there are only three insurance companies that offer One Care, and in many counties coverage is only available from one of these carriers. Consequently, in choosing to enroll in One Care, an individual must be willing to accept the limitations of that company’s provider network. While this trade-off may work well for some individuals, it remains a non-solution for others.

SUMMARY AND RECOMMENDATIONS

The foregoing analysis suggests several possible paths for remedying the existing gaps in health insurance coverage for autistic adults who have Medicare as their primary insurance. The following list identifies a range of possible reforms, the potential impact of each reform, and

the challenges associated with implementation. Discussions with state and federal policymakers, as well as key personnel within CMS, may reveal additional options.

- Remove the age cap on MassHealth (Medicaid) coverage of autism treatments
 - Would prevent disabled autistic adults from losing access to many behavioral health treatments at age 21
 - Recognizes that therapies considered “medically necessary” for children and adolescents continue to be medically necessary for adults
 - In Massachusetts, likely requires state legislation and federal approvals
 - Because Medicaid remains payer of last resort for dual-eligibles, resolution of issues and administrative barriers pertaining to Medicare’s coverage (or lack of coverage) of autism treatments and providers would still be necessary

- Reform Medicare administrative mechanisms to facilitate access to secondary insurance
 - Create a mechanism for denial of claims relating to treatments not covered by Medicare or by providers not eligible for enrollment, so that beneficiaries can access their secondary insurance
 - In tandem with removing the cap on MassHealth (Medicaid) coverage, this would go a long way toward providing equivalent coverage to what currently exists in Massachusetts for autistic children and adolescents
 - No state or federal legislation necessary
 - Ask CMS Medicare-Medicaid Coordination Office to study and address obstacles faced by dual-eligible autistic adults.

- Expand One Care coverage to include autism treatments as defined in ARICA/Omnibus Autism bill
 - Consideration of additional benefits for target populations are within One Care’s mandate (and are often promoted as a key feature of One Care)
 - Limitations include:
 - Individuals on HCBS waivers or covered by other comprehensive public or private insurance are currently not eligible to enroll in One Care
 - Managed care offerings may have more restrictive networks, which could offset the benefits of expanded coverage

- Medicare coverage expansion
 - Broaden Medicare benefits to cover diagnosis and treatment of autism
 - Establish additional billing codes for autism treatments
 - Expand provider eligibility to include licensed professionals with expertise in autism treatments (e.g., LABAs, BCBAs)
 - Extend behavioral/mental health parity to Medicare
 - As an intermediate step, CMS Center for Innovation⁴⁵ could:
 - Authorize a demonstration that expands coverage of autism treatments;

- Study ways to expand health care equity for individuals with ASD, for example, by permitting greater flexibility in the types of providers eligible to offer covered autism treatments
- Initiatives to expand access to health care professionals with expertise regarding autism
 - Increase reimbursement rates to encourage additional participation by providers
 - CMS controls rate-setting for authorized services; however, CMS budget must be authorized by Congress
 - Authorize payment for longer appointments, as necessary, to accommodate the special needs of disabled adults
 - CMS-sponsored research and demonstration projects should support training (in medical schools, nursing programs, etc., as well as through continuing education initiatives)
 - Address network adequacy with respect to providers of autism treatments

¹ See, e.g., Wing, L (1993) The Definition and Prevalence of Autism: A Review, *European Child and Adolescent Psychiatry*, 2(2), 61-74. <http://www.mugsy.org/wing.htm>. (“Sixteen published epidemiological studies, using specified criteria and methods, carried out in different places and at different times, reported age-specific prevalence rates of autism varying from 3.3 to 16.0 per 10,000. ... The most consistent findings [were] in the range 4.3 to 4.9 per 10,000.”)

² Maenner MJ, Warren Z, Williams AR, Amoakohene E, Bakian AV, Bilder DA, Durkin MS, Fitzgerald RT, Furnier SM, Hughes MM, Ladd-Acosta CM, McArthur D, Pas ET, Salinas A, Vehorn A, Williams S, Esler A, Grzybowski A, Hall-Lande J, Nguyen RHN, Pierce K, Zahorodny W, Hudson A, Hallas L, Mancilla KC, Patrick M, Shenouda J, Sidwell K, DiRienzo M, Gutierrez J, Spivey MH, Lopez M, Pettygrove S, Schwenk YD, Washington A, and Shaw KA. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ*. 2023 Mar 24;72(2):1-14. doi: 10.15585/mmwr.ss7202a1.

³ National Institutes of Health, National Institute of Child Health and Human Development, What are the treatments for autism. Retrieved June 16, 2023 from <https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments>.

⁴ Centers for Disease Control and Prevention, What is Autism Spectrum Disorder. Retrieved June 16, 2023 from <https://www.cdc.gov/ncbddd/autism/facts.html>

⁵ An Act Relative to Insurance Coverage for Autism, 2010 Mass. Acts 207.

⁶ Autism Omnibus Law, 2014 Mass. Acts 226.

⁷ For more detailed information about the insurance coverage required under these bills, see The Insurance Resource Center for Autism and Behavioral Health, Fact Sheet, Insurance Coverage for Autism Treatments in Massachusetts: Overview and FAQs, at massairc.org.

⁸ To receive SSDI under a parent’s work record, an adult child must have a disability that began before age 22 and the parent must be receiving Social Security benefits. Social Security Administration, Disability Benefits | How You Qualify, Retrieved June 16, 2023, at <https://www.ssa.gov/benefits/disability/qualify.html>.

⁹ See, Center for Medicare Advocacy, Medicare Coverage for People with Disabilities, Retrieved June 16, 2023 at <https://medicareadvocacy.org/medicare-info/medicare-coverage-for-people-with-disabilities/>; see also, Centers

for Medicare and Medicaid Services, Medicare and Other Health Benefits: Your Guide to Who Pays First, <https://www.medicare.gov/sites/default/files/2021-10/02179-Medicare-and-other-health-benefits-your-guide-to-who-pays-first.pdf>.

¹⁰ CMS Fast Facts, March 2023, CMS Program Data – Populations, <https://data.cms.gov/sites/default/files/2023-03/CMSFastFactsMar2023.pdf>.

¹¹ See, Cubanski, J, Neuman, T, and Damico, A, Medicare’s Role for People Under 65 with Disabilities, Kaiser Family Foundation, Issue Brief, August 2016, <https://www.kff.org/medicare/issue-brief/medicares-role-for-people-under-age-65-with-disabilities/>.

¹² MENTAL HEALTH CARE: Access Challenges for Covered Consumers and Relevant Federal Efforts, United States Government Accountability Office, Report to the Chairman, Committee on Finance, U.S. Senate, March 2022, at <https://www.gao.gov/assets/gao-22-104597.pdf>.

¹³ Weiner, S, (2022, August 9). A growing psychiatrist shortage and an enormous demand for mental health services, Association of American Medical Colleges, <https://www.aamc.org/news/growing-psychiatrist-shortage-enormous-demand-mental-health-services>; GAO Report, MENTAL HEALTH CARE: Access Challenges for Covered Consumers and Relevant Federal Efforts.

¹⁴ Acceptance of insurance by psychiatrists and the implications for access to mental health care, JAMA Psychiatry. 2014 February ; 71(2): 176–181. doi:10.1001/jamapsychiatry.2013.2862; Chaminou, N (2023) Therapists who don’t accept insurance, Psychology.org, <https://www.psychology.org/resources/therapists-who-dont-accept-insurance/>

¹⁵ Ochieng, N, Schwartz, K, and Neuman, T (2020, October 22) How Many Physicians Have Opted-Out of the Medicare Program? Issue Brief, Kaiser Family Foundation. <https://www.kff.org/medicare/issue-brief/how-many-physicians-have-opted-out-of-the-medicare-program/>; Giliberti, M, (2023, February 10), Fix the foundation: Unfair rate setting leads to inaccessible mental health care. Mental Health America. <https://mhanational.org/blog/fix-foundation-unfair-rate-setting-leads-inaccessible-mental-health-care>.

¹⁶ Cubanski, J, Neuman, T, and Damico, A, Medicare’s Role for People Under 65 with Disabilities.

¹⁷ National Institute of Mental Health, Autism Spectrum Disorder, <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd>

¹⁸ Gilmore, D, Longo, A, Krantz, M, Radford, D and Hand, BN, Five Ways Providers Can Improve Mental Healthcare for Autistic Adults: A Review of Mental Healthcare Use, Barriers to Care, and Evidence-Based Recommendations, Curr Psychiatry Rep. 2022; 24(10): 565–571. Published online 2022 Aug 15. doi: 10.1007/s11920-022-01362-z.

¹⁹ Krahn, G.L., Hammond, L., and Turner, A, A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities, Mental Retardation and Developmental Disabilities Research Reviews, 12:70-82 (2006). (Article begins with an account of a primary care appointment by an individual with a complex medical condition (including ID/D), in which, due to time constraints, the physician was unable to address the principal symptoms that prompted the visit).

²⁰ Cubanski, J, Freed, M, and Neuman, T, FAQs on Mental Health and Substance Use Disorder Coverage in Medicare, updated January 2023, Kaiser Family Foundation.

²¹ Cubanski, J, Freed, M, and Neuman, T, FAQs on Mental Health and Substance Use Disorder Coverage in Medicare, updated January 2023; see also, <https://www.federalregister.gov/documents/2022/11/18/2022-23873/medicare-and-medicaid-programs-cy-2023-payment-policies-under-the-physician-fee-schedule-and-other>.

²² Centers for Medicare and Medicaid Services, “HCPCS Coding Questions,” https://www.cms.gov/medicare/coding/medhcpcsgeninfo/hcpcs_coding_questions)

²³ Centers for Medicare and Medicaid Services, “HCPCS Coding Questions,” https://www.cms.gov/medicare/coding/medhcpcsgeninfo/hcpcs_coding_questions). A second set of codes is used primarily to identify products, supplies, and services not included in the CPT-4 codes, such as ambulance services and durable medical equipment, prosthetics, orthotics, and supplies (DMEPOS) when used outside a physician’s office.

²⁴ Centers for Medicare and Medicaid Services, Medicare and Other Health Benefits: Your Guide to Who Pays First.

²⁵ Interviews with Majda Abbas, Esq. and Mary McGinley, Esq., Greater Boston Legal Services, and Sarah Schmitz, President, Comprehensive Billing Consultants.

²⁶ Interview with Majda Abbas, Esq. and Mary McGinley, Esq., Greater Boston Legal Services.

²⁷ See, e.g., Improving Access to Community-based Speech Pathology Services, Brigham Bulletin, Retrieved 6/19/2023 at <https://bwhbulletin.org/2020/01/16/improving-access-to-community-based-speech-pathology-services/>

²⁸ AMN Healthcare, What's Driving the Demand for Speech-Language Pathologists? October 18, 2022. Retrieved at <https://www.amnhealthcare.com/amn-insights/news/speech-language-pathologists/> (“The demand for speech-language pathologists (SLPs) is rising, with projected job growth at 21% through 2031, according to the Bureau of Labor Statistics.”).

²⁹ Lin, V, Zhang, X, and Dixon, P, Occupational Therapy Workforce in the United States: Forecasting Nationwide Shortages, 2015 September;7(9):946-954.

³⁰ Krahn, G.L., Hammond, L., and Turner, A, A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities; see also, Iezzoni, LI, Rao, SR, Ressler, J., Bolcic-Jankovic, D, Agaronik, ND, Donelan, K, Lagu, T, and Campbell, EG, Perceptions Of People With Disability And Their Health Care, Health Affairs, 40:2, February 2021, <https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.01452>

³¹ Id.

³² Cubanski, J, Neuiman, T, and Damico, A, Medicare’s Role for People Under 65 with Disabilities.

³³ Krahn, G.L., Hammond, L., and Turner, A, A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities.

³⁴ CMS Framework for Health Equity 2022–2032, <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>

³⁵ See, Centers for Medicare and Medicaid Services, “Warning Signs - Plan or Policy Non-Quantitative Treatment Limitations (NQLs) that Require Additional Analysis to Determine Mental Health Parity Compliance,” <https://www.cms.gov/ccio/resources/regulations-and-guidance/downloads/mhpeachecklistwarningsigns.pdf>.

³⁶ For a detailed explanation of how mental health parity applies to various forms of Medicaid coverage, see Musumeci, M,) Behavioral Health Parity and Medicaid, Issue Brief, Kaiser Family Foundation, June 2015.

<https://www.kff.org/report-section/behavioral-health-parity-and-medicaid-issue-brief/>; see also, Pestaina, K, Mental Health Parity at a Crossroads, Kaiser Family Foundation, August 2021, <https://www.kff.org/private-insurance/issue-brief/mental-health-parity-at-a-crossroads/>.

³⁷ Steinberg, D and Weber, E, Medicare Coverage of Substance Use Disorder Care: A Landscape Review of Benefit Coverage, Service Gaps and a Path to Reform, Legal Action Center, February 2021.

³⁸ Id.

³⁹ The Cost of Adding Substance Use Disorder Services and Professionals to Medicare, prepared for the Legal Action Center by Parish, W and Mark, TL, RTI International, August 2022.

⁴⁰ In Section 4130 of the 2023 Consolidated Appropriations Act, H.R. 2617 (ENR), Congress directed the Government Accountability Office to conduct a study that “compares the mental health and substance use disorder benefits offered by Medicare Advantage plans (including specialized MA plans for special needs individuals)” with other (non-mental health/SUD) benefits offered by such Medicare Advantage plans and with the mental health and substance use disorder benefits under the original Medicare fee-for-service program (parts A and B).

⁴¹ Interview with Deborah Steinberg, Legal Action Center; see, U.S. Senate Committee on Finance, News Release (March 22, 2023), Wyden, Bennet Introduce Bill to Increase Access to Mental and Behavioral Health Care for Kids, Seniors, and Low-Income Americans, <https://www.finance.senate.gov/chairmans-news/wyden-bennet-introduce-bill-to-increase-access-to-mental-and-behavioral-health-care-for-kids-seniors-and-low-income-americans>

⁴² Massachusetts One Care Preliminary Fourth Evaluation Report, Summer 2021, ES-1, <https://innovation.cms.gov/data-and-reports/2021/fai-mass-er4>. (“The Medicare-Medicaid Coordination Office and the Innovation Center at the Centers for Medicare & Medicaid Services (CMS) have created the Medicare-Medicaid Financial Alignment Initiative (FAI) to test, in partnerships with States, integrated care models for Medicare-Medicaid enrollees. The demonstration in Massachusetts, known as One Care, was implemented October 1, 2013.”).

⁴³ Massachusetts One Care Preliminary Fourth Evaluation Report, Summer 2021, 2-2.

⁴⁴ Massachusetts One Care Preliminary Fourth Evaluation Report, Summer 2021, ES-1.

⁴⁵ Centers for Medicare and Medicaid Services, About the Medicare-Medicaid Coordination Office. The goals of this office include “1. Providing dual eligible individuals full access to the benefits to which such individuals are entitled to under the Medicare and Medicaid programs; 2. Simplifying the processes for dual eligible individuals to access

the items and services they are entitled to under the Medicare and Medicaid programs; 3. Improving the quality of health care and long-term services for dual eligible individuals. 4. Increasing dual eligible individuals' understanding of and satisfaction with coverage under the Medicare and Medicaid programs; 5. Eliminating regulatory conflicts between rules under the Medicare and Medicaid programs; 6. Improving care continuity and ensuring safe and effective care transitions for dual eligible individuals; 7. Eliminating cost-shifting between the Medicare and Medicaid program and among related health care providers; [and] 8. Improving the quality of performance of providers of services and suppliers under the Medicare and Medicaid programs.” Retrieved June 20, 2023 from <https://www.cms.gov/medicare-medicaid-coordination/medicare-and-medicaid-coordination/medicare-medicaid-coordination-office>