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Policy Approaches to Improving Coverage of Dyslexia Screening, Testing and Treatment

Ross Margulies, Partner
Alexander Somodevilla, Associate
Steven Chen, Manager
Manatt Health

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About Celebrate Dyslexia

Celebrate Dyslexia was founded in 2019 with the mission to foster a community that celebrates, educates, and empowers the one in five with dyslexia. Founded by Jasmin Dean, a mother of three sons with dyslexia, the organization has remained dedicated to creating innovative programming and resources for one in five students with dyslexia across medical, educational, and celebratory initiatives to create a long-lasting impact for the next generation. Celebrate Dyslexia is proud to have impacted approximately 100,000 individuals including students, parents, medical professionals, educators, and community members. For more information, see <https://celebratedyslexia.org/>.

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Ross Margulies

Partner

Manatt Health

202.585.6626

rmargulies@manatt.com

Alexander Somodevilla

Associate

Manatt Health

202.585.6543

asomodevilla@manatt.com

Steven Chen

Manager

Manatt Health

202.624.3362

sschen@manatt.com

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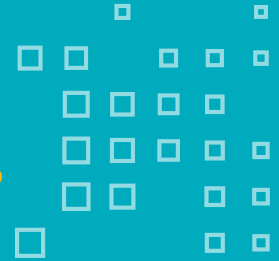


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Executive Summary

Dyslexia is a neurobiological disorder affecting up to one in five children, including over 80% of those with learning disabilities.¹ Despite its widespread prevalence, many children are not properly screened or tested and often miss out on evidence-based interventions to address the associated challenges. For those that do receive a proper and timely diagnosis, treatment options are often difficult to navigate, unaffordable, and out of reach, leading to poor educational outcomes and increased likelihood of unemployment and criminal justice involvement.² In California alone, the estimated societal cost of dyslexia was estimated to be \$12 billion in 2020 and \$1 trillion over the next 60 years.³

Immediate action is required to ensure that children with dyslexia receive the comprehensive services and supports they need. Dyslexia must be recognized as a medical condition, with screening, testing, and treatment fully integrated into our health care system and covered by public and private health insurance, rather than being limited to the domain of educational and self-pay services.

To address resource gaps and improve access to dyslexia screening, testing, and treatment services (“dyslexia services”), advocates should collaborate with relevant stakeholders to:

- a. **Increase Public Awareness.** Educate communities and policymakers about the prevalence and impact of dyslexia, including the benefits of early diagnosis and intervention.
- b. **Update Diagnosis Codes.** Advocate for the modernization of ICD-10-CM diagnosis codes for dyslexia to align with current scientific understanding.
- c. **Push for USPSTF Recommendations.** Advocate for the United States Preventive Services Task Force (USPSTF) to assess the evidence and develop recommendations for early childhood dyslexia screening during primary care visits.
- d. **Seek CMS Clarification.** Engage with the Centers for Medicare and Medicaid Services (CMS) to clarify guidelines on Medicaid coverage for dyslexia services, including under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit.
- e. **Advocate for State Coverage Mandates.** Engage in targeted state advocacy to expand requirements for insurance coverage of dyslexia services.

These actions will help ensure that children with dyslexia receive the care and resources essential to their success, benefiting not only children and their families, but society as a whole.

Objective

This white paper explores opportunities to improve insurance coverage of dyslexia screening, testing and treatment services (“dyslexia services”). We begin by defining dyslexia and outlining the fragmented patient journey across educational and self-pay services, highlighting the associated human and economic toll. Next, we assess the current statutory and regulatory landscape regarding dyslexia coverage at both federal and state levels, including under public insurance, private insurance, and self-pay options. We also profile recent efforts to adopt coverage mandates, including New York’s S5481. Finally, we offer actionable recommendations to improve coverage of essential dyslexia services and identify potential collaborators for future advocacy efforts.

Background

What is Dyslexia?

Dyslexia is defined as “an unexpected difficulty in reading for an individual who has the intelligence to be a much better reader, most commonly caused by a difficulty in the phonological processing (the appreciation of the individual sounds of spoken language), which affects the ability of an individual to speak, read, and spell.”^{4,5} Similar to other neurodevelopmental conditions such as attention deficit hyperactivity disorder (ADHD) and autism, dyslexia is neurobiological in origin, characterized by distinct neural signatures that reflect difficulties in phonological and orthographic processing.⁶ Children with dyslexia generally have decreased brain activation and less gray matter in certain brain regions associated with reading skills.⁷ As a result of these functional and structural differences, dyslexia can lead to poor academic performance, diminished self-esteem and a lack of motivation.⁸ Dyslexia affects upwards of 20% of the population and 80–90% of those with learning disabilities.⁹ Its occurrence spans across gender, socioeconomic status, and racial groups, showing similar rates in diverse backgrounds.¹⁰

Signs and Symptoms

Dyslexia manifests a wide range of characteristics in those it affects, with these challenges evolving from childhood to adulthood. In early childhood, children with dyslexia often struggle with foundational reading skills, including phonological awareness, letter identification, letter-sound knowledge and rapid naming.¹¹ Among the pre-literate population, this translates into challenges with language acquisition, letter-sound recognition, color and number identification, handwriting, fine motor skills, and sight word recognition.¹² As these children mature, they may continue to face challenges in language organization, memorization, spelling, and persistent difficulties in reading, writing and motor skills (dyspraxia), and mathematics (dyscalculia), along with executive function issues, and memory problems.¹³ These patterns have been validated across languages.¹⁴

Some dyslexic learners may exhibit strengths in cognitive and socioemotional tasks, which can sometimes result in misdiagnosis or underdiagnosis of dyslexia. These individuals may excel in verbal reasoning, working memory, and language-related tasks, despite encountering difficulties in phonological awareness, rapid naming tasks, and other literacy issues.

In addition to learning challenges, children with dyslexia frequently report mental health problems as co-morbidities. Dyslexia is associated with higher rates of depression, anxiety, sleep disturbances, and social withdrawal.^{15,16,17} Furthermore, between 15–40% of children with dyslexia may also have ADHD.^{18,19}

The following characteristics are associated with dyslexia:

1. Difficulty with the development of phonological awareness and phonological processing skills
2. Difficulty accurately decoding nonsense or unfamiliar words
3. Difficulty reading simple words in isolation
4. Inaccurate and labored oral reading
5. Lack of reading fluency
6. Various degrees of learning the names of letters and their associated sounds
7. Difficulty with learning to spell
8. Difficulty in word finding and rapid naming
9. Variable difficulty with aspects of written composition
10. Variable degrees of difficulty with reading comprehension

Table SEQ Table 1* ARABIC 1. From F. Roitsch & S. Watson (2019). An Overview of Dyslexia: Definition, Characteristics, Assessment, Identification, and Intervention. *Science Journal of Education*, 7(4).

Current Patient Journey and Challenges

Screening, Testing and Diagnosis

Identifying and intervening for dyslexia as early as possible is critical for effective remediation.²⁰ Prevention and early phonological awareness intervention programs targeted at children in kindergarten through 2nd grade can significantly enhance reading skills, elevating many struggling readers to average reading levels.²¹ Research indicates that effective early intervention can dramatically reduce the expected incidence of reading disabilities—defined as reading below grade level—from 12–18% down to just 2–6%.²² Another study found that 90% of children with reading difficulties will achieve grade level in reading if they receive help in the 1st grade.²³ Conversely, children identified as reading disabled after 2nd grade often struggle to catch up to their peers; 75% of children whose help is delayed to age nine or later continue to struggle throughout their school career.^{24,25}

Although numerous screening tools exist for dyslexia, many children do not receive adequate assessments. Federal law mandates that schools identify and evaluate children with learning disabilities, leading to the traditional view that dyslexia screenings fall under the educational system’s purview.²⁶ Educators are expected to look for indicators of phonological difficulties through a child’s history, observations and specific tests.²⁷ However, formal screenings are frequently overlooked and lack the necessary quality due to insufficient training and resources.²⁸ Additionally, educators may hesitate to make a formal medical diagnosis of dyslexia, complicating the identification process.^{29,30,31,32}

Comprehensive neuropsychological evaluations conducted by trained physicians are considered the gold standard for assessing learning disabilities, including the diagnosis of dyslexia.³³ Neuropsychologists utilize a multifaceted approach to evaluate children, employing advanced imaging techniques to assess altered brain function or development, analyzing medical and educational histories, and conducting various assessments to arrive at a thorough diagnosis. These comprehensive evaluations not only pinpoint indicators of dyslexia but also uncover any attentional or emotional issues that may contribute to or arise from learning difficulties. Moreover, they play a crucial role in identifying the most effective evidence-based interventions and accommodations tailored to address each child’s unique learning challenges.

While neurophysiological evaluations for dyslexia can be effective, they are often prohibitively expensive, rarely covered by health insurance, and not included in standard well-child visits, creating significant barriers to access. As explained in further detail below, private health plans generally do not recognize dyslexia and other learning disabilities as medical conditions, meaning they do not consider neurophysiological evaluations for dyslexia as necessary medical treatment.^{34,35} CMS has also not issued policy guidance related to coverage of dyslexia screening under state Medicaid programs.³⁶ As a result of these policies—or lack thereof—the substantial costs associated with neurophysiological evaluations render them unaffordable for many families, severely limiting access to essential dyslexia screening and intervention.

Treatment

Once diagnosed, children with dyslexia should receive appropriate treatments using educational tools to enhance the ability to read. Specially trained learning disability educators develop and implement intervention plans for children with dyslexia. Educational interventions typically emphasize structured literacy, which teaches word-identification and decoding strategies in a systematic and explicit manner. Structured literacy approaches include the following core elements: phonology (sound structure of spoken words), sound-symbol association, syllables, morphology, syntax and semantics.³⁷ Evidence strongly suggests that structured literacy programs can improve reading skills among children with dyslexia.³⁸

Teachers need to be trained on structured literacy and the instructional strategies essential to success for these students. Unfortunately, access to structured literacy programs is relatively poor, particularly among public institutions, where 60% of elementary school teachers have not received training to teach these foundational reading skills.³⁹ Only 5,000 professionals are certified to provide structured literacy instruction, and most are only available through private institutions, which can often be unaffordable for many families.^{40,41,42}

The Individuals With Disabilities Education Act (IDEA) and the Rehabilitation Act of 1973

There are two federal laws in place to protect the rights of children with disabilities to receive free and appropriate public education (FAPE): The IDEA and Section 504 of the Rehabilitation Act of 1973.

IDEA. The IDEA is a federal law that ensures FAPE to eligible children with disabilities throughout the nation and ensures special education and related services for those children. Administered by the Department of Education, IDEA is the primary federal funding source supporting the education of children with disabilities, and it is designed to meet the individual education needs of students with disabilities as adequately as the needs of nondisabled students are met. IDEA provides formula grants to states to support special education and related services and early intervention services, and discretionary grants to state educational agencies, institutions of higher education, and other nonprofit organizations to support research, demonstrations, technical assistance and dissemination, technology development, personnel preparation and development, and parent training and information centers. As of the 2022–23 school year, IDEA supported more than eight million eligible children across the country, with 32% diagnosed with specific learning disabilities such as dyslexia.^{43,44} In FY 2024, Congress allocated approximately \$15.4 billion for IDEA funding.⁴⁵

Under the IDEA, students with disabilities who require special education and related services have an Individualized Education Plan (IEP) which stipulates the services (educational and health care-related) a student will receive as part of the FAPE they are entitled to receive under federal law. While Medicaid and Children’s Health Insurance Program (CHIP) are generally the payer of last resort for health care services, when services are included in a student’s IEP, Medicaid is responsible for payment ahead of any federal IDEA funds.⁴⁶ Notably, IDEA’s IEP requirements specifically extends to specific learning disabilities, which is defined to include dyslexia.⁴⁷ States also often use IDEA funds to further develop technical capabilities and infrastructure with respect to providing services for

students with dyslexia. For example, Texas recently allocated \$275,000 per year for the state's Regional Education Service Centers Dyslexia and Related Disorders Coordinators Program for two years, with \$125,000 per year allocated from Texas' General Revenue and \$150,000 per year allocated from federal funds distributed under IDEA.⁴⁸ This allocation must be used to assist the program in the proper identification of students with dyslexia and support in how to best serve those students. Notably, Texas' program provides screenings for dyslexia and other supports for children, families and educators. Texas Region 20's Education Service Center provides consulting services for school districts within the region. Consultants can provide schools with specialized literacy programs and other interventions for students with dyslexia, or training programs and workshops for educators.⁴⁹

It should be noted that some state agencies and disability advocacy groups have criticized IDEA for failing to meet its promise of providing adequate funding to states to ensure students with disabilities receive FAPE, often requiring states to allocate a disproportionate amount of their own funds towards this effort. For example, California allocated \$11.2 billion funding to provide services required by IDEA between 2013 and 2014, but only about 10% of that came from federal IDEA funding.⁵⁰

When IDEA was first established in 1975, Congress pledged to provide 40% of the national average per-pupil expenditure to help states meet new requirements under IDEA. However, not even half of this percentage has ever been met.⁵¹ IDEA's consistent underfunding is especially concerning given the increasing costs of special education, further straining state budgets and the public school system.⁵²

Rehabilitation Act of 1973. Section 504 of the Rehabilitation Act is a civil rights law that protects individuals from discrimination on the basis of disability in programs and activities that receive federal financial assistance, including public schools. Students with disabilities who require certain accommodations due to their disability may qualify for a 504 Plan, which spells out the accommodations the child with disabilities will be provided in the educational setting.

A child can have a 504 Plan in addition to or instead of an IEP. State Medicaid programs can provide coverage for the accommodations provided under a child's 504 Plan. In these cases, however, Medicaid is the payer of last resort, meaning that schools and local education agencies (LEAs) may bill Medicaid only after they bill any outside legally liable third parties. In circumstances where an LEA meets its Section 504 obligations to an IDEA-eligible child with a disability through an IEP, Medicaid would be the payer of first resort for any Section 504 accommodations included in the IEP, as discussed above.

Summary of Current State

Dyslexia is often underdiagnosed and misunderstood, impacting a significant portion of the population and leading to challenges in reading and writing, as well as various secondary effects. Current systems frequently leave children with dyslexia navigating a fragmented array of educational and self-pay services, creating substantial barriers to accessing quality care. On average, families incur an additional \$15,000 each year for dyslexia interventions—and, in California alone, the societal cost of dyslexia was estimated at \$12 billion in 2020, with projections suggesting it could escalate to \$1 trillion over the next 60 years.⁵³ These figures underscore the urgent need for action to address the health, educational and economic impacts of dyslexia.

A new paradigm is essential to provide comprehensive support for children with dyslexia. This approach must recognize dyslexia as a medical condition, integrating screening and treatment into the health care system to ensure that affected individuals receive the necessary care and resources. By addressing these gaps, we can improve the quality of life for millions of children and their families.

Potential Coverage Pathways

Relevant Sources of Health Care Coverage in the United States

A new paradigm which seeks to expand access to and increase affordability of dyslexia services by integrating these services into our health care system must address the health insurance coverage of such services. There are a variety of public and private sources of health care coverage and payment that could facilitate access to dyslexia services. These include Medicaid, commercial health insurance, and tax-advantaged accounts such as HSAs and FSAs. However, as explained in further detail below, each of these pathways currently present their own difficulties, and the existing frameworks governing each option do not go far enough in ensuring the reliable pathway to coverage and access that children with dyslexia require.

Medicaid

Medicaid is a public health insurance program for low-income individuals, individuals with disabilities, the elderly, and pregnant women and children, which is jointly financed by the federal government and states, and administered by states within broad federal guidelines. Notably, Medicaid covers one-third of children ages 1–6, and more than 40% of school-age children and adolescents.⁵⁴ While Medicaid eligibility for children in this income range varies by states, on average states cover children in families earning less than 148% of the federal poverty level. Medicaid is therefore a significant source of coverage for children with dyslexia and the predominant source of coverage for low-income children with dyslexia.

Children enrolled in Medicaid can potentially access dyslexia services via two pathways: a) the EPSDT benefit; and b) Medicaid School-Based Services (SBS). However, as explained in more detail below, there is currently a lack of definitive requirements and guidance for both pathways, which results in uncertainty, lack of awareness and education, disparate coverage policies, and ultimately low utilization of Medicaid-covered dyslexia services for the most vulnerable children.

EPSDT. State Medicaid programs are required to provide comprehensive preventive health care services for children under age 21 who are enrolled in Medicaid through the EPSDT benefit.⁵⁵ Under EPSDT, children and youth under the age of 21 (referred to here as “children”) are entitled to coverage of all medically necessary preventive, diagnostic, and treatment services that are coverable under Medicaid, including services that are optional for adults, and even if such services are not specifically outlined in the state’s Medicaid plan or coverage policies.⁵⁶

Under the EPSDT benefit, states are required to cover periodic well-child preventive screening visits, which must include, at a minimum, a comprehensive health and developmental history, an unclothed physical exam, immunizations, laboratory tests, and health education and guidance for parents and children.⁵⁷ According to the CMS, “Well-child visits, referred to in statute as screening services, are the foundation of EPSDT coverage and are a crucial entry point for identifying concerns and conditions that require follow-up care. These visits are intended to be comprehensive and include age-appropriate screenings, referrals to diagnostic and specialty services, and referrals to establish ongoing dental, vision, and hearing care.”⁵⁸

Furthermore, states must also provide coverage of such medically “necessary health care, diagnostic services, treatment, and other services” described in the Medicaid statute “**to correct or ameliorate** defects and physical and mental illnesses and conditions, whether or not such services are covered under the State plan.”⁵⁹ CMS “interprets the “correct or ameliorate” requirement to mean that a service does not need to cure a condition in order to be covered under EPSDT as a medically necessary service. Thus, services that maintain or improve a child’s current health condition are also covered under EPSDT because they “ameliorate” a condition—i.e., they prevent a condition from worsening or prevent development of additional health problems. As such, services such as physical and occupational therapy are covered when they have an ameliorative, maintenance purpose.”⁶⁰

Under a plain reading of the EPSDT statutory language, it would appear that both dyslexia screening and treatment would be covered for Medicaid enrolled children under the benefit. Dyslexia screening is an “age-appropriate screening” for children enrolled in Medicaid, and dyslexia screening during a well-child visit can be crucial to ensure that the child is referred to appropriate “diagnostic and specialty services.” Dyslexia treatment also arguably falls under the EPSDT’s broad umbrella of coverage, as it is a medical necessary service that can “correct or ameliorate” the symptoms affecting children with dyslexia.

Notwithstanding the above, we could not identify any definitive CMS guidance directing states with respect to coverage and provision of dyslexia services under the EPSDT benefit. While CMS recently released updated guidance to state Medicaid agencies regarding operational and other requirements associated with the EPSDT benefit, the guidance did not touch on the provision of dyslexia services, or even learning disorders generally.⁶¹

Neither did we identify widespread and consistent state practice of including specific references to dyslexia services in state statutes, Medicaid State Plans or sub-regulatory coverage guidance with respect to coverage of such services under the particular state’s Medicaid EPSDT benefit. We note, however, that the lack of explicit references to dyslexia services across the states does not necessarily mean that the services **wouldn’t** be covered under the state’s Medicaid program, and may just be a function of the structure and underlying authority of the EPSDT benefit, which requires that qualifying services be covered **even if** they are

not specifically outlined in the state’s plan or elsewhere in state coverage policies. In any event, the ambiguity inherent in the benefit is arguably part of the problem. If providers, patients and their caregivers are not adequately informed of the scope of a state’s covered services, they will naturally be less inclined to pursue and provide such a service. **For this reason, explicit coverage policies, either in a Medicaid State Plan or federal or state policy guidance, where appropriate, are absolutely vital to ensure that low-income children enrolled in the Medicaid program are able to access the dyslexia services they desperately require.**

School-Based Services. State Medicaid programs can also cover SBS, which are critical health and health-related services provided to students and their caregivers in the school setting by personnel employed by a school or LEA. SBS covered by Medicaid and the CHIP can fall into either or both of two categories: General health care services provided to Medicaid-eligible children, either under the EPSDT benefit or other state plan authority; and IEP services provided to Medicaid eligible children with disabilities.⁶²

Medicaid-covered SBS can encompass a wide range of services, including preventive services (e.g., immunizations, screenings); behavioral health services (e.g., mental health and substance use disorder (SUD) services); physical and occupational therapy; and disease management for chronic diseases (e.g., obesity, asthma).⁶³ Providing these services to children at schools can increase access and utilization overall, as it limits disruption to caregivers’ work schedules or concerns with transportation to a health care facility, and reduces the stigma of accessing certain services, such as behavioral health services.⁶⁴

CMS has clarified previously and emphasized in recent guidance that states can use Medicaid and CHIP funding to pay for SBS for all Medicaid- and CHIP-enrolled children—not only those who qualify for special education—and can pay for any service within schools that could otherwise be provided and that Medicaid would cover outside the schools.⁶⁵ Furthermore, in 2022, CMS also reminded state Medicaid programs that although EPSDT determines the benefits that must be covered for children and youth enrolled in Medicaid, it does not specify the **settings** in which such services must be provided. In many instances, the benefits can be provided in schools and early education settings in ways that support the child and enhance both health and educational outcomes.⁶⁶ Thus, **states could choose to provide coverage of EPSDT services, which arguably covers dyslexia screening and treatment as discussed above, in the school setting—which could be crucial in removing access barriers, increasing utilization, and reducing burden on working parents.**

However, it should be noted that, in practice, schools and LEAs often encounter difficulties operationalizing SBS, and children often encounter issues accessing services in the school setting for a variety of reasons, including:

1. in many cases, schools must wait for an order or referral from the child’s physician or other licensed provider before providing otherwise covered services;
2. schools are often unfamiliar with certain operational and administrative complexities associated with SBS, including billing requirements, parental consent, patient confidentiality, and Medicaid third-party liability;
3. schools and state Medicaid agencies often use different, field-specific jargon;
4. the disparate and intersecting funding requirements for Medicaid and CHIP and for educational programs are complex; and
5. coverage varies by state because of the discretion state Medicaid agencies have in determining what SBS are covered by Medicaid and CHIP and how they are financed.⁶⁷

CMS has recently issued guidance to help address and alleviate some of these issues,⁶⁸ but many of the underlying issues remain, including the efficacy of advancing medical screening and treatment in the educational setting.

Commercial Insurance

Another important source of health coverage in the United States is commercial insurance, which includes policies purchased on the Affordable Care Act (ACA) individual marketplace, group health plans, and employer-sponsored health plans. In 2021, 61.9% of U.S. children were commercially insured.⁶⁹ However, dyslexia is not considered a “medical condition” by most commercial health plans today. Dyslexia services are instead generally considered “educational” in nature, and most forms of insurance will not cover services that are non-medical and educational in nature.⁷⁰

With the exception of employer-sponsored plans federally regulated under the Employee Retirement Income Security Act (ERISA), state governments generally have wide latitude to regulate the health insurance policies issued within each state. As such, in instances where stakeholders identify gaps in coverage for certain health conditions, state legislatures often respond by adopting laws that require commercial plans to provide coverage for certain items or services for those patient populations. For example, as of this writing, most states have laws that require health plans in the state to provide coverage for autism spectrum disorder (ASD) screening and/or treatment services.⁷¹ Alabama is noteworthy in that the state enacted a law that requires large group health plans to cover screening, diagnosis, and treatment of ASD for children 18 years of age or under,⁷² and subsequently adopted a separate law explicitly extending these requirements to the state’s Medicaid Program, although ASD and related services would arguably fall under general EPSDT coverage policies even without such an explicit coverage requirement.⁷³

We conducted a search of state laws and regulations to assess the extent to which states have adopted policies that require commercial health plans operating in their state to provide coverage of dyslexia services. As part of our search, we did not identify any state that has adopted a policy that explicitly requires commercial health plans to cover dyslexia services. Some states, like Vermont, require plans to provide coverage for “early and childhood developmental disorders,” which are defined as “mental or physical impairment or combination of mental and physical impairments that results in functional limitations in major life activities, accompanied by a diagnosis defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM) or the International Classification of Disease (ICD).”⁷⁴ Vermont’s law explicitly references “autism spectrum disorder” but does not provide any other examples of specific conditions that must be covered. Notably, it also specifically **excludes** “learning disabilities.” Although dyslexia is arguably an “impairment[] that results in functional limitations in major life activities,” the DSM currently defines dyslexia as a “specific learning disorder with impairment in reading”⁷⁵ and, as explained below, current ICD-10 diagnosis codes do not adequately capture dyslexia as a medical condition, which make it unlikely that it would be covered under a state statute like Vermont’s.⁷⁶

An additional factor contributing to this paucity of relevant state laws is that most states approach dyslexia services in the educational setting. For example, Texas explicitly requires that students enrolled in public schools in the state “shall be screened or tested, as appropriate, for dyslexia and related disorders at appropriate times in accordance with a program approved by the State Board of Education.”⁷⁷

As explained above, approaching dyslexia services in the context of the educational setting has been insufficient and has left too many children underdiagnosed, undertreated, and left behind. Securing coverage and access to dyslexia screening and treatment thus requires a fundamental transformation of the status quo, which pulls dyslexia out of the educational setting and appropriately places screening and treatment in the medical setting where it belongs. The first step in this transformation necessarily requires health insurance coverage of these services, but the current state landscape remains resistant to change.

Efforts to Codify Dyslexia Insurance Requirements In New York State

Some states, however, appear to be trending in the right direction. A recently enacted New York law provides an illustrative example of an effort to codify in the state's insurance code certain plan requirements to cover dyslexia services, but also highlights some of the obstacles that stakeholders can encounter as part of this endeavor.

The Dyslexia Diagnosis Access Act requires commercial health plans in the state to provide coverage for comprehensive neuropsychological examinations for dyslexia.⁷⁸ It is the first state law of its kind to require health plans to cover dyslexia testing. This new law represents a major breakthrough with respect to efforts to transform the status quo and adopt a new paradigm for dyslexia screening which approaches this issue from a medical perspective, in part by securing health insurance **coverage** of these services. That said, it should be noted that, although a monumental first step, the legislation focuses solely on dyslexia **screening** and does not address insurance coverage of **treatment**, which is pivotal.

Even with the law's apparent limitations, it received strong opposition from various stakeholders, particularly from health plans in the state, when the bill language was under consideration by the New York legislature. The primary contention made by opponents of the bill lies in their view that dyslexia testing is a "language-based learning disability," and not a medical treatment appropriate for health insurance coverage.⁷⁹ Opponents also argued that the bill's requirements result in an "unfunded mandate" on health plans that will "increase premium costs, and further stretch healthcare resources."

In efforts to rein in the impact the bill, opponents offered various amendments which were included in the final language enacted into law, and which: a) require that a referral be made by a physician before testing is covered; b) require that the screening be done only by a health professional licensed, certified, or authorized under the state's education code to provide such screening and acting within their scope of practice, which has the potential to severely limit the scope of health professionals who can provide the screening; and c) allow health plans to implement restrictive utilization management protocols before the service will be covered, which can provide plans with discretion to deny a service request if deemed not medically necessary under the plan's coverage criteria.⁸⁰

The New York law became effective January 1, 2025.

Health Savings Accounts/Flexible Spending Arrangements

Another coverage pathway that can increase access to dyslexia services may be found in the use of HSAs and FSAs.⁸¹ HSAs/FSAs are advantageous from a tax perspective on multiple fronts, as individuals are able to contribute funds on a pre-tax basis into these accounts, and HSA/FSA distributions used to pay for qualifying expenses are tax-free.⁸²

Individuals are generally able to use funds from HSAs/FSAs for “Qualified Medical Expenses.” IRS guidance defines a Qualified Medical Expense as “the costs of diagnosis, cure, mitigation, treatment, or prevention of disease, and for the purpose of affecting any part or function of the body.”⁸³ Medical care expenses must be primarily designed to alleviate or prevent a physical or mental disability or illness. When assessing eligibility of an item or service as a Qualified Medical Expense, the IRS asks whether the item or service would have been purchased “but for” its medical purpose.

IRS Publication 502 outlines different examples of items and services the agency will consider as “qualified medical expenses” for purposes of HSA/FSA eligibility.⁸⁴ Notably, Publication 502 directs readers searching for “Learning Disabilities” to the Publication’s section on “Special Education.” The section on Special Education states the following:

You can include in medical expenses fees you pay **on a doctor’s recommendation** for a **child’s tutoring** by a teacher who is specially trained and qualified to work with children who have learning disabilities **caused by mental or physical impairments, including nervous system disorders**. You can include in medical expenses the cost (tuition, meals, and lodging) of attending a school that furnishes special education to help a child to overcome learning disabilities. Overcoming the learning disabilities must be the primary reason for attending the school, and any ordinary education received must be incidental to the special education provided.⁸⁵

A few aspects of this language are noteworthy, and arguably limit the scope of this category. First, the language does not explicitly refer to **screening** services, and thus potentially leaves out a vital part of the dyslexia services framework. Second, the reference to a “doctor’s recommendation” indicates that such tutoring services would not be eligible as a Qualified Medical Expense without a Letter of Medical Necessity (LOMN) from a physician (which would likely require some sort of screening and diagnosis as a prerequisite).

Publication 502 also provides examples of what the IRS considers to be “Special Education” for purposes of this category: a) teaching Braille to a visually impaired person; b) teaching lip reading to a hearing disabled person; or c) giving remedial language training to correct a condition caused by a birth defect. Given these examples, it is unclear whether dyslexia screening and treatment would necessarily rise to the level of “Special Education” as the IRS conceptualizes the term (i.e., in the context of blind and deaf children, and children with birth defects). It is noteworthy, however, that at least some HSA administrators and third-party resource’s view dyslexia **treatment** as qualifying as eligible as a Qualified Medicaid Expense with a LOMN, finding that “treatments that specifically treat the medical condition of dyslexia are eligible to be reimbursed through consumer-directed healthcare accounts like FSAs, HSAs and HRAs.”⁸⁶

Notwithstanding the above, we note that the potential of HSAs/FSAs to expand access and affordability to dyslexia services for vulnerable children may be limited. FSAs are only available through an employer, have relatively low employer contribution limits, do not carry over year over year, and do not transfer with an individual if they change employers. Furthermore, although HSAs can be established and maintained outside of an employment context, nearly all HSAs are employment-based plans, with a very small fraction being directly purchased on the individual market, which creates barriers to access for individuals with employers who do not offer HSAs. As a result, only about one in six privately insured adults has access to an HSA.⁸⁷ HSAs are also disproportionately held by wealthier individuals who utilize HSAs as another form of investment vehicle.⁸⁸ There are also racial disparities to consider, as Hispanics and African Americans are less likely to be enrolled in an HSA than non-Hispanic whites.⁸⁹ As such, although some families may be able to derive some benefit from HSAs/FSAs, the scope of their impact is limited by the practical reality that these options are simply unavailable for many families in need.

Relevant Organizations

Expanding awareness of and insurance coverage for dyslexia services will require engagement with several stakeholders and organizations that play a critical role in the realm of health care coverage in the United States. There are three organizations worth noting upfront: 1) the CMS, 2) the USPSTF, and 3) the CDC National Center for Health Statistics (NCHS), ICD-10 Coordination and Maintenance Committee.

CMS. CMS is the federal agency tasked with administering the Medicaid program. CMS enforces federal Medicaid requirements and works with state Medicaid agencies on the State Plan Amendments (SPAs) and waiver programs that establish the scope of services, coverage, and payment terms that govern a particular state's Medicaid program. In deciding whether to approve a particular SPA or waiver, CMS is ultimately responsible for ensuring compliance with federal requirements.

CMS also often issues guidance documents outlining the agency's expectations with respect to Medicaid program requirements. CMS also issues guidance documents and letters to state Medicaid agencies clarifying the agency's views regarding specific policy areas, often encouraging states to pursue different options that would advance certain policy priorities of the agency. As noted above, CMS recently issued new EPSDT guidance to "provide states with the information they need to meet EPSDT requirements." CMS also recently issued a letter to state Medicaid agencies, encouraging them to adopt programs that address the health related social needs of their beneficiaries.⁹⁰

USPSTF. The USPSTF is an independent panel of non-Federal experts in prevention and evidence-based medicine that makes evidence-based recommendations about clinical preventive services, including screening, counseling, and preventive medications.⁹¹ The USPSTF assigns letter grades (A-I) to each recommendation statement based on the strength of the evidence and the balance of benefits and harms of a specific preventive service.

USPSTF recommendations play a pivotal role in the scope of private insurance coverage in the U.S. By way of background, under Section 2713 of the ACA, private health plans (including employer plans governed by ERISA) must provide coverage for a range of recommended preventive services and may not impose cost-sharing (such as copayments, deductibles, or co-insurance) on patients receiving these services. Under this

requirement, insurers must cover without cost-sharing any evidence-based items or services that have in effect a rating of “A” or “B” in the current USPSTF recommendations.⁹² USPSTF recommendations also play an important role in the Medicaid program, as state Medicaid programs are required to cover any clinical preventive services that are assigned a grade A or B by the USPSTF.⁹³

Given the above, an “A” or “B” recommendation from the USPSTF can expand both access and affordability of relevant preventive services for individuals enrolled in commercial health plans and state Medicaid programs. In our review, we did not identify any USPSTF recommendations directly applicable to dyslexia screening or treatment. However, there are several current USPSTF recommendations pertinent to children and adolescents that are illustrative. For example, the USPSTF issued a “B” recommendation for “screening for anxiety in children and adolescents aged 8 to 18 years,” concluding “with moderate certainty that screening for anxiety in children and adolescents aged 8 to 18 years has a moderate net benefit.”⁹⁴ USPSTF also issued a “B” recommendation for screening for Major Depressive Disorder for adolescents.⁹⁵

Notably, for both of these recommendations, USPSTF concluded that “the evidence is insufficient” for relevant screening for **younger** age groups, generally finding that evidence on the accuracy of screening tools and the effects of screening and treatment in this younger group is lacking, and the balance of benefits and harms cannot be determined. Furthermore, it should be noted that stakeholders recently submitted a recommendations request for the USPSTF to consider screening for speech and language delay and disorders in children aged five years and younger without signs or symptoms. The USPSTF concluded that the evidence is insufficient to assess the balance of benefits and harms of screening for speech and language delay and disorders in children who do not present with signs or symptoms or parent/caregiver concerns. Although “USPSTF found adequate evidence on the accuracy of screening tools to detect speech and language delay and disorders,” it noted that “there was limited and inconsistent evidence on the effectiveness of interventions on intermediate outcomes such as speech and language domains (e.g., fluency, articulation, and expressive and receptive language) and health outcomes (e.g., improved school performance, social/emotional function, or quality of life).” This additional scrutiny with respect to evidence of screening accuracy and treatment effectiveness for younger children could present obstacles in securing a USPSTF recommendation on dyslexia services for younger children.

CDC NCHS, ICD-10 Coordination and Maintenance Committee. The CDC’s NCHS, ICD-10 Coordination and Maintenance Committee is responsible for making clinical modifications to the ICD-10-CM (the International Classification of Diseases, Tenth Revision, Clinical Modification in the United States).⁹⁶ The ICD-10-CM is a standardized system used to code diseases and medical conditions (morbidity) data.⁹⁷ Health care providers use ICD-10-CM codes when diagnosing patients, which allows researchers and health care providers to accurately define and track the patient population, which also helps advance screening and treatment options.

Currently, there are two ICD-10 CM codes that reference and purport to capture dyslexia:

“F81.0 Specific reading disorder ‘Backward reading’ Developmental dyslexia Specific learning disorder, with impairment in reading Specific reading retardation Excludes 1: alexia NOS (R48.0) dyslexia NOS (R48.0).”

“R48 Dyslexia and other symbolic dysfunctions, not elsewhere classified Excludes 1: specific developmental disorders of scholastic skills (F81.-) R48.0 Dyslexia and alexia.”⁹⁸

However, both ICD-10-CM codes suffer from significant flaws. The F81.0 code is not consistent with the most recent scientific data regarding dyslexia, as it is outdated and untrue to define dyslexia as “backward reading.” Moreover, the code does not accurately capture the cause of dyslexia as a condition of neuroanatomy, genetics, and genetic environmental origin, despite studies finding neurobiological evidence that dyslexia results from abnormal development of white matter negatively impacting the normal left hemisphere language network.⁹⁹ Furthermore, dyslexia is not a condition due to developmental delay, but is instead a neurological diagnosis that is lifelong. The R478 code suffers from similar issues, is insufficiently specific and includes other symbolic dysfunctions.

Recommendations

Given the above, shifting the paradigm for coverage and access to dyslexia services will require a multi-faceted approach that engages with a variety of disparate levers across the health care spectrum, including private stakeholders, patient advocacy groups, and federal and state legislatures and government agencies.

Collaboration with Stakeholders

Collaboration among advocates and other relevant stakeholders is important to increase education and awareness of dyslexia and the need for increased affordability and access to dyslexia services. Given many of the existing barriers outlined above, this collaboration can focus on dispelling common misconceptions of dyslexia as a problem that should be approached exclusively in the educational context and reframing the issue as one that is inherently medical, given dyslexia’s neurobiological origins.

Engagement with a diverse set of stakeholders will be important to advancing this mission, and there is a wide array of stakeholders, including professional societies, patient advocacy groups, and Members of Congress, that can serve as important partners. Below is a non-exhaustive list of stakeholders to consider engaging:

1. American Academy of Pediatrics
2. American Academy of Family Physicians
3. Child Neurology Society
4. National Alliance for Medicaid in Education
5. Disability rights organizations
6. Other dyslexia patient organizations
7. Sympathetic members of Congress and state legislatures, including the House Dyslexia Caucus

Engagement with a diverse set of stakeholders will be vital, as it can emphasize the various different perspectives relevant to the issue, allow for identification of the full scope of additional barriers to dyslexia services, and facilitate the formulation of a comprehensive, deliberative approach to removing those barriers, which can incorporate the recommendations further highlighted below.

ICD-10 Code Application

One barrier discussed in this White Paper involves the lack of an ICD-10 diagnosis code that accurately captures dyslexia as a medical diagnosis. An appropriate diagnosis code can be a prerequisite for any initiative wishing to expand awareness, research, screening and treatment options, and payor coverage of a particular diagnosis.

Advocates have previously submitted applications to the ICD-10 Coordination and Maintenance Committee for a new ICD-10 code unique to dyslexia. ICD-10 diagnosis code applications are often an iterative process that requires extensive communication with the CDC's NCHS and health care coding experts. It is common for the CDC's NCHS to work with requestors and make recommendations for improving an application for resubmission and future consideration.

ICD-10 diagnosis code applications submitted by a diverse group of stakeholders are more likely to be successful. Advocates should seek to collaborate with major professional societies (e.g., American Academy of Pediatrics) and other groups to submit a new ICD-10 diagnosis code application that incorporates feedback received to date by the CDC's NCHS and expands on the growing need for an ICD-10 diagnosis code unique to dyslexia to allow researchers and health care providers to better define and track this patient population.

USPSTF Recommendation

Under the existing governing framework, a USPSTF recommendation of "A" or "B" can expand both access and affordability of dyslexia screening for individuals enrolled in commercial health plans. As such, advocates can collaborate with appropriate stakeholders to submit a nomination for the USPSTF to consider issuing an A or B recommendation for dyslexia screening services. There is precedent for USPSTF recommendations in the context of screening for anxiety in children and adolescents aged eight to 18 years, although we note that the USPSTF has been less receptive with respect to nominations for services for younger children, finding insufficient evidence to support the efficacy of screening and related services for this age group. Given the importance of dyslexia screening and diagnosis in early childhood, any such nomination put forward to the USPSTF should highlight the strength of existing evidence supporting the accuracy of dyslexia screening tools and the benefit of dyslexia screening for younger children.

Centers for Medicare & Medicaid Services Engagement

It will be important for dyslexia advocates to collaborate with relevant stakeholders to engage with CMS to provide education regarding dyslexia as a medical condition and request that the agency issue appropriate guidance to state Medicaid agencies regarding potential pathways for expanding Medicaid coverage of dyslexia screening and treatment, including through the EPSDT benefit, as applicable.

In its recently issued EPSDT guidance, CMS noted that the agency plans to continue working with all states to ensure adherence to EPSDT requirements, including through technical assistance webinars and planned future guidance. This can provide a viable opening for advocates to engage the agency and request that

CMS issue guidance dedicated to the scope of EPSDT coverage of certain learning disabilities, including dyslexia. Explicit CMS guidance affirming the scope of EPSDT coverage of dyslexia services can provide state Medicaid agencies with the needed clarity to adopt explicit coverage policies in this context.

Advocates can also consider engaging with the agency regarding the current efficacy of the Medicaid SBS pathway with respect to dyslexia screening, diagnosis, and treatment and identify specific policies for CMS to consider to make this a more viable pathway for vulnerable children with dyslexia, including through the provision of additional federal funding to better equip state Medicaid agencies and LEAs to employ and train relevant professionals to provide these services in a school setting. Such engagement should also emphasize that the educational setting may not always be the appropriate pathway for certain children with dyslexia, and highlight the need for a holistic approach that also integrates dyslexia services into hallmarks of the EPSDT program, such as periodic well-child visits.

We note that there are several different approaches to engaging with CMS. It is often useful to collaborate with a bipartisan group of “champion” members of Congress who sit on a committee with jurisdiction over the issue. In this case, this can include the Senate Committee on Health, Education, Labor & Pensions (HELP). A letter from the Senate HELP Committee to CMS that outlines existing barriers to access for children with dyslexia and that calls on the agency to act on specific policy proposals can serve as an effective entry point to CMS engagement and collaboration.

Targeted State Advocacy

Given that states have a great deal of discretion to adopt policies with respect to their own Medicaid programs and the regulation of commercial insurance plans in the state, targeted state advocacy will also be crucial. Advocates can identify particular states with influential champions at the local and state legislature, and executive levels who are passionate about the issue, perhaps due to personal connection to dyslexia, and willing to advance state-level policies to expand coverage and access to dyslexia services.

At the state executive branch level, such targeted state advocacy can include working with the state Medicaid agency to adopt or expand explicit coverage policies for dyslexia services, including under the state’s EPSDT benefit. This may require working with the state Medicaid agency in its efforts to receive appropriate federal approval for such coverage expansion, if applicable. These efforts can also include conversations with the relevant state’s education agency to discuss ways to improve the provision of dyslexia services in the educational setting, where appropriate.

At the legislative level, such targeted state advocacy can include working with the state legislature to advance legislation that would require the state’s Medicaid program, as well as commercial health insurance plans under the state’s regulatory purview, to provide coverage of dyslexia services to children in the state, much like states have done in the context of ASD.

We note that, as we’ve seen in New York’s Dyslexia Diagnosis Access Act, any such initiative that is specific to dyslexia is likely to face some level of opposition from different stakeholders in the state, particularly health insurance plans that would be required to comply with any new coverage requirement. As such, conversations and collaboration with these stakeholders may also be required to ensure a successful legislative process and enacted law that establishes and protects the full scope of dyslexia services children require.

Conclusion

The current paradigm, by which dyslexia is primarily approached in the educational setting, is leaving far too many children behind. Many children are not properly screened or provided evidence-based interventions for dyslexia, which can, in any event, be unaffordable for most families. A new paradigm is needed, which recognizes dyslexia as a medical condition and fully integrates dyslexia screening, diagnosis, and treatment into our health care system, with comprehensive coverage by public and private health insurance.

Expanding awareness and insurance coverage for dyslexia services requires a multi-pronged, collaborative policy advocacy approach with various stakeholders, including CMS, USPSTF, CDC, professional societies, and other patient advocacy groups. Successful advocacy and implementation of the policy approaches recommended herein will help ensure that children with dyslexia receive the care and resources they and their families require.

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76. See also, e.g., CT Gen Stat § 38a-488a.

77. See TEC § 38.003; see also 70 Okl.St. Ann. § 1210.520.

78. New York State Assembly, A2898-A/S5481-A. <https://www.nysenate.gov/legislation/bills/2023/A2898/amendment/A>.

79. See Blue Cross and Blue Shield Plans, Memorandum in Opposition of A2898A (May 21, 2023). <https://nysblues.org/wp-content/uploads/2023/07/MIO-A.2898A-Carroll-Dyslexia-Testing.pdf>; see also New York Health Plan Association, Memorandum in Opposition of S.5481/A.2898.A (May 20, 2024).

80. Manatt correspondence with key legislative stakeholders.

81. There are several different types of FSAs, including the Health Care Flexible Spending Account, Limited Expense Health Care FSA, and Dependent Care FSA.

82. Some employers also offer Health Reimbursement Arrangements (HRAs), which differ in that employees are unable to contribute funds into their HRA.

83. Internal Revenue Service, Publication 502, Medical and Dental Expenses (2023). <https://www.irs.gov/publications/p502>.

84. *Id.*

85. *Id.* (emphasis added).

86. See Lively, *Dyslexia Treatment* (last visited December 4, 2024). <https://livelyme.com/whats-eligible/dyslexia-treatment> (referencing HSA Store, <https://hsastore.com/hsa-eligibility-list/d/dyslexia-treatment>).
87. G. Lukens, *Expanding Health Savings Accounts Would Boost Tax Shelters, Not Access to Care*, Center on Budget and Policy Priorities (June 22, 2023). <https://www.cbpp.org/research/health/expanding-health-savings-accounts-would-boost-tax-shelters-not-access-to-care>.
88. According to recent surveys, thirty-five percent of HSA wealth is owned by only 7% of account holders. See Devenir Research, *2021 Year-End HSA Market Statistics * Trends Executive Summary* (March 2022), <https://www.devenir.com/wp-content/uploads/2021-Year-End-Devenir-HSA-Research-Report-Executive-Summary.pdf>; see, also, M. Miller, *HSAs May Work Best as Tax Shelters*, Morningstar (May 17, 2023). <https://www.morningstar.com/alternative-investments/hsas-may-be-best-used-tax-shelters>.
89. National Health Interview Survey, 2007–2018.
90. Letter from Anne Marie Costello, Acting Deputy Administrator and Director, Center for Medicaid & CHIP Services, to State Health Officials, SHO #21-001, Regarding Opportunities in Medicaid and CHIP to Address Social Determinants of Health (SDOH) (January 7, 2021). <https://www.medicaid.gov/federal-policy-guidance/downloads/sho21001.pdf>.
91. USPSTF, *Understanding how the U.S. Preventive Services Task Force (USPSTF) Works* (February 2023). https://www.uspreventiveservicestaskforce.org/uspstf/sites/default/files/inline-files/understanding-how%20the%20tf-works-2022-update_3.pdf.
92. It should be noted that as of this writing, there exists some uncertainty with respect to the continued viability of this statutory requirement. In the case *Braidwood Management Inc. v. Becerra*, plaintiffs challenged the ACA's USPSTF requirement, arguing that USPSTF panel members were unconstitutionally appointed. In June 2024, the United States Court of Appeals for the Fifth Circuit agreed with the plaintiffs, but limited relief only to the named plaintiffs for now (as opposed to a national injunction). As such, the USPSTF requirement remains in effect as of this writing, but this could change depending on the outcome of future proceedings in that case.
93. SSA § 1905(a)(13).
94. USPSTF, Final Recommendation Statement: Anxiety in Children and Adolescents: Screening (October 11, 2022). <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/screening-anxiety-children-adolescents>.
95. USPSTF, Final Recommendation Statement: Depression and Suicide Risk in Children and Adolescents: Screening (October 11, 2022). <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/screening-depression-suicide-risk-children-adolescent-s#fullrecommendationstart>.
96. CDC, National Center for Health Statistics, *ICD-10 Coordination and Maintenance Committee* (June 7, 2024). <https://www.cdc.gov/nchs/icd/icd-10-maintenance/index.html>.
97. CDC, National Center for Health Statistics, *ICD-10-CM* (June 7, 2024). <https://www.cdc.gov/nchs/icd/icd-10-cm/index.html>.
98. CDC. *International Classification of Disease, Tenth Revision, Clinical Modification (ICD-10-CM)*, (2021). www.cdc.gov/nchs/icd/icd10cm.htm.
99. See, e.g., Price C. *A review and synthesis of the first 20 years of PET and fMRI studies of heard speech, spoken language and reading. Neuroimage. 2012; 62:816–847. [PubMed: 22584224]*; see also Vandermosten M, Boets B, Wouters J, Ghesquière P. *A qualitative and quantitative review of diffusion tensor imaging studies in reading and dyslexia. Neurosci Biobehav Rev. 2012; 36:1532–1552. [PubMed: 22516793]*; see also Maisog JM, Einbinder ER, Flowers DL, Turkeltaub PE, Eden GF. *A meta-analysis of functional neuroimaging studies of dyslexia. Ann N Y Acad Sci. 2008; 1145:237–259. [PubMed: 19076401]*.

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