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Supporting Healthy Futures: Capitalizing on Medicaid's EPSDT Medical Necessity Standard

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Supporting Healthy Futures: Capitalizing on Medicaid's EPSDT Medical Necessity Standard

Teressa Colhoun*

Abstract

Youth mental health is in crisis. Children report increased rates of suicidal ideology, depression, and anxiety. Diagnosis rates soar. Pediatric mental health care remains difficult to access. When services are accessible, they are costly—often sending families into medical debt.

This Note discusses Medicaid's Early and Periodic Screening, Diagnostic, and Treatment ("EPSDT") benefit. Specifically, it studies the EPSDT benefit's creation, structure, and administration. This Note focuses on the context in which the EPSDT benefit operates, particularly how health care financing models impact benefit administration. It suggests that the EPSDT benefit has the capacity to address crucial gaps in pediatric mental health care. However, this Note summarizes key issues in the benefit's current administration. Specifically, it articulates how EPSDT's medical necessity standard is manipulated by states to deny coverage to children, despite their providers' opinion that such treatment is necessary. It further

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discusses inconsistencies that exist when courts are asked to apply the EPSDT benefit's medical necessity standard in coverage determination challenges.

This Note ultimately advocates for consistency and predictability in medical necessity standards, so that children receive coverage for crucial health care services. It urges three possible solutions to address the EPSDT benefit's current shortcomings: First, it suggests federalizing a definition for medical necessity. Next, it advocates for the establishment of a consistent burden shifting framework to apply in courts where coverage determinations are being challenged on the basis of medical necessity. Finally, it proposes the implementation of a specialized patient advocacy model. Ultimately, these solutions share a common goal: to capitalize on the potential of the EPSDT benefit's broad promise to cover medically necessary services so that children can access much needed care, particularly given the ongoing youth mental health crisis.

Table of Contents

INTRODUCTION 847

I. THE CHILD MENTAL HEALTH CRISIS 852
   A. *The Mental Health Crisis Plaguing Children and Adolescents* 853
   B. *Unique Considerations for Mental Health Care* 856

II. MEDICAID 861
   A. *Basic Principles of Medicaid* 861
   B. *Traditional Medicaid Coverage* 863
   C. *Medicaid Cost and Benefit Delivery* 863

III. MEDICAID'S EPSDT BENEFIT 868
   A. *Legislative History and Development* 869
   B. *Medicaid's EPSDT Benefit Structure* 875
   C. *Adult Medicaid Versus EPSDT* 877
   D. *Administering EPSDT Through Managed Care* 878
   E. *Mental Health and EPSDT* 880

IV. MEDICAL NECESSITY UNDER EPSDT 883
   A. *Federal Guidance* 883

B. *State and Managed Care Parameters for Medical Necessity* 886

V. EPSDT LITIGATION 887
A. *Background on EPSDT Litigation* 888
B. *Over Reliance on the Adult Medicaid Standard in EPSDT Cases* 889
C. *Provider Deference in EPSDT Medical Necessity Determinations* 893

VI. ADDRESSING THE VARIATION IN MEDICAL NECESSITY 895
A. *Federalizing the Medical Necessity Definition* 895
B. *Establishing a Judicial Test for the ESPDT Medical Necessity Standard* 901
C. *Making Patient Advocates Available for Families* Receiving EPSDT Services 903

CONCLUSION 906

INTRODUCTION

In October 2021, the American Academy of Pediatrics ("AAP"), the American Academy of Child and Adolescent Psychiatry ("AACAP"), and the Children's Hospital Association ("CHA") jointly declared a "National State of Emergency in Children's Mental Health."[1] Then, in December 2021, U.S. Surgeon General Vivek Murthy referred to a youth "mental health pandemic."[2] More recently, Dr. Murthy referred to mental health as "the defining public health crisis of our time."[3] Scholars and the media frequently discuss the substantial

1. *AAP-AACAP-CHA Declaration of a National Emergency in Child and Adolescent Mental Health*, AM. ACAD. PEDIATRICS, https://perma.cc/DRA5-WY6R (last updated Oct. 19, 2021).

2. U.S. PUB. HEALTH SERV., PROTECTING YOUTH MENTAL HEALTH: THE U.S. SURGEON GENERAL'S ADVISORY 40 (2021) [hereinafter SURGEON GENERAL'S ADVISORY], https://perma.cc/X6K4-LX9U (PDF).

3. Vivek H. Murthy, *U.S. Surgeon General: Loneliness Is at Heart of Growing Mental Health Crisis*, UCLA HEALTH (June 29, 2023), https://perma.cc/AX7F-739K.

impacts of COVID-19,[4] environmental justice issues,[5] mass shootings,[6] social media,[7] and social movements[8] on youth mental health. Politicians across party lines also acknowledge the youth mental health crisis.[9]

4. *See, e.g.*, Ashley Abramason, *Children's Mental Health Is in Crisis*, AM. PSYCH. ASS'N (Jan. 1, 2022), https://perma.cc/CR9T-WKYA ("As the United States approaches 2 full years of the COVID-19 pandemic, mental illness and the demand for psychological services are at all-time highs—especially among children."); Karen Nikos-Rose, *Online Learning in COVID-19 Detrimental to Teen Mental Health, School Satisfaction, Performance*, U.C. DAVIS (Nov. 30, 2022), https://perma.cc/KQW9-WGD7 ("Youth participating in virtual learning also reported feeling less social connection and higher rates of mental health problems, in comparison to their peers who could attend school in-person or in a hybrid model."); All Things Considered, *A Closer Look at the Declining Mental Health of Kids*, NPR, at 2:20 (May 6, 2023), https://perma.cc/E7UM-E9LY (discussing declines in mental health that occurred as a result of the pandemic).

5. *See, e.g.*, Emma Pennea et al., *The Nexus of Climate Change, COVID-19, and Environmental Justice on Children's Health,* 12 J. APPLIED RSCH. ON CHILD., no. 1, 2021, at 1, 1 ("Extreme weather events and declines in both air and water quality have resulted in escalating threats of mortality, morbidity, displacement, food insecurity, and mental health problems.").

6. *See, e.g.*, MAYA ROSSIN-SLATER, SURVIVING A SCHOOL SHOOTING: IMPACTS ON THE MENTAL HEALTH, EDUCATION, AND EARNINGS OF AMERICAN YOUTH, STAN. INST. FOR ECON. POL'Y RSCH. 2 (2022), https://perma.cc/HGG8-SV8M (PDF) ("Several studies demonstrate that school shootings have detrimental effects on the mental health and educational outcomes of surviving youth.").

7. *See* Mary Yang, *3 Reasons Why Seattle Schools Are Suing Big Tech Over a Youth Mental Health Crisis*, NPR, https://perma.cc/HB95-7UDY (last updated Jan. 11, 2023) (discussing a 2023 lawsuit filed against the companies behind TikTok, Instagram, Facebook, Snapchat, and YouTube alleging that "students are being recommended harmful content online, exacerbating a mental health crisis, and social media companies are allowing it to happen").

8. *See, e.g.*, Alexandra Rothstein, *The Importance of Black Kids' and Teens' Mental Health During the Trial of Derek Chauvin in the Death of George Floyd*, CHILD.'S MINN. (Apr. 20, 2021), https://perma.cc/5U2L-TA6X (explaining that George Floyd's murder likely negatively impacted many children's mental and emotional health).

9. For example, in the fall of 2023, "U.S. Senators Amy Klobuchar (D-MN) and Katie Britt (R-AL) introduced the *Youth Mental Health Research Act*. . . . Companion legislation is led in the House of Representatives by Congresswoman Bonnie Watson Coleman (D-NJ), Congressman Brian Fitzpatrick (R-PA), Congresswoman Grace Napolitano (D-CA), and Congressman Tom Kean, Jr. (R-NJ)." *Klobuchar, Britt Introduce Bipartisan Legislation to Improve Youth Mental Health*, U.S. SEN. AMY KLOBUCHAR (Oct. 19, 2023), https://perma.cc/MAV9-79S5.

Despite widespread awareness of the youth mental health crisis, the issue continues to worsen.[10] Data suggests that the number of children in the United States who experienced at least one major depressive episode increased between 2021 and 2022.[11] Experts advocate for change to address the current crisis and improve future outcomes.[12]

Medicaid, as the largest public health program in the United States,[13] has the unique capacity to address pressing public health matters. Because Medicaid provides coverage to millions of children, the program has the potential to directly address health issues affecting youth, including the mental health crisis.[14] Specifically, Medicaid's Early and Periodic Screening, Diagnosis, and Treatment[15] ("EPSDT") benefit

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10. *See* Alan Mozes, *Mental Health of America's Children Only Getting Worse*, U.S. NEWS & WORLD REP. (Mar. 14, 2022), https://perma.cc/YE57-X48Z ("[A]nxiety, depression and behavioral problems appear to be on the rise, while the amount of time kids spent being physically active or getting preventive care has been on the decline.").

11. *See* MADDY REINERT ET AL., MENTAL HEALTH AM., 2022: THE STATE OF MENTAL HEALTH IN AMERICA 25 (2021), https://perma.cc/4699-ETJ4 (PDF) ("The number of youth experiencing MDE increased by 306,000 (1.24%) from last year's dataset.").

12. *See, e.g.*, *Academy of Pediatrics, American College of Emergency Physicians, and Emergency Nurses Association Call for Strategies to Improve Care for Children, Adolescents Seeking Urgent Help for Mental, Behavioral Health Concerns*, AM. ACAD. PEDIATRICS (Aug. 16, 2023), https://perma.cc/782L-W94L ("The time is now to improve access to emergency care for the rising numbers of children and adolescents seeking help for mental and behavioral health emergencies. Strategies to address challenging circumstances that affect prehospital services, the surrounding community and, ultimately, patient care are needed.").

13. *See Medicaid*, AM. HOSP. ASS'N, https://perma.cc/Q4GN-UTNP (last visited Feb. 7, 2024) ("Medicaid is the nation's largest single source of coverage . . . ."); *September 2023 Medicaid & CHIP Enrollment Data Highlights*, MEDICAID.GOV, https://perma.cc/D8ET-LRXR (last visited Jan. 30, 2024) (noting that, as of September 2023, "81,408,432 individuals were enrolled in Medicaid").

14. *See Early Periodic Screening, Diagnosis, and Treatment*, HEALTH RES. & SERVS. ADMIN., https://perma.cc/27W7-QJLK (last visited Feb. 15, 2024) ("Medicaid covers one-third of children age 1–6, and more than 40% of school-age children and adolescents . . . ."); Yael Cannon, *A Mental Health Checkup for Children at the Doctor's Office: Lessons from the Medical-Legal Partnership Movement to Fulfill Medicaid's Promise*, 17 YALE J. HEALTH POL'Y, L. & ETHICS 253, 271 (2017) ("More than 42 million children now receive their healthcare through the Medicaid program.").

15. 42 U.S.C. § 1396d(r).

mandates "comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid."[16] The benefit requires states to cover all services that "correct or ameliorate" a child's diagnosed conditions.[17] Additionally, the EPSDT benefit explicitly includes coverage for mental health screenings and services.[18] Because mental health care is ameliorative by nature, the EPSDT benefit has the capacity to play a crucial role in confronting the youth mental health crisis.

However, Medicaid's EPSDT benefit, as it is currently administered and interpreted, does not fulfil its potential of effectively addressing the youth mental health crisis.[19] The benefit's medical necessity standard is easily manipulated to limit the scope and amount of coverage that children can receive.[20] Medicaid is largely a state administered program, so state agencies have varying methods for determining what care will qualify as medically necessary for EPSDT recipients.[21] Furthermore, when families bring judicial challenges to coverage determinations, courts across the country apply inconsistent standards to the medical necessity inquiry.[22] As a result, despite all receiving health coverage via the EPSDT benefit, children are subject to different standards for health coverage determinations based on where they live.[23] In some states, the state agency responsible for administering Medicaid and EPSDT has substantial say in what care will be deemed

16. *Early and Periodic Screening, Diagnostic, and Treatment*, MEDICAID.GOV [hereinafter *Early and Periodic Screening*], https://perma.cc/EKU9-UUSH (last visited Jan. 30, 2024); *see also* 42 C.F.R. §§ 441.50–441.60 (2024); John B. v. Menke, 176 F. Supp. 2d 786, 790 (M.D. Tenn. 2001) ("The purpose of EPSDT is to ensure that underserved children receive preventive health care and follow-up treatment.").

17. 42 U.S.C. § 1396d(r)(5).

18. *See id.*

19. *See* Jane Perkins & Sarah Somers, *Medicaid's Gold Standard Coverage for Children and Youth: Past, Present, and Future*, 30 ANN. HEALTH L. & LIFE SCIS. 153, 169 (2021) (noting that EPSDT form responses indicate that over half of eligible children are not receiving mental health services).

20. *See, e.g.*, Moore *ex rel.* Moore v. Reese, 637 F.3d 1220, 1226–30 (11th Cir. 2011) (describing a state Medicaid agency's decision to limit the number of hours of care that a child would receive, although the child's provider deemed more hours medically necessary).

21. *See infra* Part IV.B.

22. *See infra* Parts V.B–C.

23. *See infra* Parts IV–V.

medically necessary, potentially overriding a treating physician's opinion.[24] In other states, the child's treating physician gets substantial deference to make determinations of medical necessity.[25] These inconsistencies contradict the stated federal purpose of the EPSDT benefit—to provide broad coverage to children across the country.

The following hypothetical illustrates the inconsistencies: A child is diagnosed with pre-verbal trauma and post-traumatic stress disorder ("PTSD"). Their doctor says they require eye movement desensitization and reprocessing ("EMDR") therapy.[26] In Iowa, the child might receive EPSDT coverage for EMDR. However, in Florida, the state agency might employ a third-party business to review the doctor's EMDR request. The reviewer will not meet with the child but will determine that EMDR is not medically necessary based solely on the child's medical records. The child in Florida is left in limbo. Perhaps the child's family will endure an administrative appeals process and subsequent litigation. In the meantime, the child's symptoms worsen. Alternatively, the family might not have the financial resources to challenge the determination, in which case the child will either go without care or receive less effective services. Either way, the child is not receiving timely and necessary services. This hypothetical illustrates the nonsensical inequalities that exist across the EPSDT benefit.

This Note assesses the possibility of establishing a more equitable public health care system that can help address the child mental health crisis by examining Medicaid's EPSDT benefit, specifically, the medical necessity standard. Part I of this Note provides a background on the issue of youth mental health and will address the characteristics that make mental health care and services unique. Part II establishes background on Medicaid, and Part III analyzes its EPSDT benefit before comparing EPSDT to adult Medicaid. Finally, Part III examines the unique ways in which EPSDT specifically contemplates providing behavioral health care services to recipients.

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24. *See infra* Part V.B.

25. *See infra* Part V.C.

26. *Cf. EMDR Therapy*, CLEVELAND CLINIC, https://perma.cc/Y55V-YPCR (last updated Mar. 29, 2022) (describing EMDR as "relatively new—but very effective" and subject to "ongoing research").

Next, Part IV analyzes ESPDT's medical necessity standard. This analysis surveys federal guidance regarding the standard and then considers how states apply that guidance in practice. Part V then explores judicial construction of EPSDT's medical necessity standard, comparing varied judicial approaches in applying the standard.

Ultimately, Part VI of this Note presents three potential solutions. First, it argues that the EPSDT medical necessity standard should be made uniform through federal legislative action.[27] Specifically, there must be a distinct medical necessity standard applied in EPSDT cases. Second, it suggests a judicial solution.[28] This Note urges the establishment of a clear test for judges to apply in EPSDT medical necessity litigation. Third, it proposes a programmatic solution whereby patient advocates trained specifically on the EPSDT benefit's nuances help families navigate medical necessity challenges.[29] Finally, this Note concludes with an assessment of the potential for the ESPDT benefit to support young people, especially as the mental health crisis they face continues to worsen.

I. THE CHILD MENTAL HEALTH CRISIS

"Mental health" is a vague term that is often used to describe several conditions.[30] These conditions range from depression and anxiety to Attention-Deficit Hyperactivity Disorder ("ADHD") and autism spectrum disorder.[31] Treatment

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27. *See infra* Part VI.A.

28. *See infra* Part VI.B.

29. *See infra* Part VI.C.

30. *See Behavioral Health*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://perma.cc/WG3V-3S5R (last visited Feb. 15, 2024) ("Behavioral health includes the emotions and behaviors that affect your overall well-being. Behavioral health is sometimes called mental health and often includes substance use."); SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., BEHAVIORAL HEALTH INTEGRATION 1 [hereinafter SAMHSA, BEHAVIORAL HEALTH INTEGRATION], https://perma.cc/QX9K-ZASM (PDF) (last visited Feb. 8, 2024) ("The term 'behavioral health' in this context means the promotion of mental health, resilience and wellbeing; the treatment of mental and substance abuse disorders; and the support of those who experience and/or are in recovery from these conditions, along with their families and communities.").

31. *See What Is Children's Mental Health?*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://perma.cc/AU9V-FNAT (last updated July 26, 2023)

and services to support children who struggle with these conditions vary, depending on the particular needs of each child.

As described below, mental health conditions that are improperly diagnosed or mistreated during childhood can have lifelong impacts on individuals.[32] Thus, in addressing the current youth mental health crisis, it is important to understand the unique characteristics of certain mental health conditions and treatments, as well as the pitfalls of our current approach to pediatric mental health care that may have led to the "mental health pandemic."[33]

A. *The Mental Health Crisis Plaguing Children and Adolescents*

Statistics on pediatric and adolescent mental health are worsening at alarming rates in the United States.[34] Several studies and surveys have found that children are documenting higher rates of mental health symptoms and diagnoses, including depression, anxiety, and suicidal ideation.[35] Unsurprisingly, child mental health worsened during the

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("Among the more common mental disorders that can be diagnosed in childhood are attention-deficit/hyperactivity disorder (ADHD), anxiety (fears or worries), and behavior disorders.").

32. *See infra* Part I.B.

33. SURGEON GENERAL'S ADVISORY, *supra* note 2, at 40.

34. *See supra* notes 1–12 and accompanying text; *see also* Rebecca H. Bitsko et al., *Mental Health Surveillance Among Children—United States, 2013–2019*, MORBIDITY & MORTALITY WK. REP. SUPPLEMENTS, Feb. 25, 2022, at 1, 1 (concluding that child mental health is a "substantial public health concern" in the United States).

35. *See* SURGEON GENERAL'S ADVISORY, *supra* note 2, at 8

> [I]n recent years, national surveys of youth have shown major increases in certain mental health symptoms, including depressive symptoms and suicidal ideation. From 2009 to 2019, the proportion of high school students reporting persistent feelings of sadness or hopelessness increased by 40%; the share seriously considering attempting suicide increased by 36%; and the share creating a suicide plan increased by 44%. Between 2011 and 2015, youth psychiatric visits to emergency departments for depression, anxiety, and behavioral challenges increased by 28%. Between 2007 and 2018, suicide rates among youth ages 10-24 in the US increased by 57%. Early estimates from the National Center for Health Statistics suggest there were tragically more than 6,600 deaths by suicide among the 10-24 age group in 2020.

COVID-19 pandemic.[36] However, even as the country has returned to normal, trends in child mental health remain disturbing.

The increased documentation of mental health issues is attributable to several factors. For example, efforts at reducing the stigma surrounding mental health might have made children more willing to seek medical attention for mental health symptoms.[37] Furthermore, the COVID-19 pandemic increased stress, social isolation, and social turmoil for many children.[38] These circumstances have all been linked with an increased prevalence of mental health issues.[39] Ultimately, the rapid increase in child mental health conditions and symptoms culminated in the declaration of a national emergency in child and adolescent mental health in 2021.[40]

Current mental health infrastructure in the United States, particularly for pediatric patients, is not well equipped to address the increased demand for services.[41] Even before the

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36. *See COVID-19 Pandemic Associated with Worse Mental Health and Accelerated Brain Development in Adolescents*, NAT'L INST. MENTAL HEALTH (Jan. 26, 2023), https://perma.cc/VY97-7TMW ("Compared to the pre-pandemic group, adolescents assessed after the pandemic shutdowns reported more symptoms of anxiety and depression and greater internalizing problems. Their brains showed . . . reduced volume in the hippocampus and amygdala, which are involved in accessing memories and regulating responses to fear and stress . . . ."); SURGEON GENERAL'S ADVISORY, *supra* note 2, at 9 (describing the impacts of COVID-19 on children's mental health and concluding that "rates of psychological distress among young people, including symptoms of anxiety, depression, and other mental health disorders, have increased"); *see also Pandemic Accelerated Youth Mental Health Crisis*, HARV. T.H. CHAN SCH. PUB. HEALTH (July 29, 2022) [hereinafter *Pandemic Accelerated Crisis*], https://perma.cc/VJ2H-V4S7 ("COVID's effect on children's mental health depends on a range of factors including age, family circumstances, pre-existing conditions, and innate susceptibility . . . .").

37. *See, e.g.*, *What Is Stigma?*, NAT'L ALL. ON MENTAL ILLNESS, https://perma.cc/F33J-KS55 (last visited Feb. 8, 2024) (discussing ongoing efforts and strategies to reduce the stigma surrounding mental health).

38. *See* SURGEON GENERAL'S ADVISORY, *supra* note 2, at 9.

39. *See id.*

40. *See U.S. Surgeon General Issues Advisory on Youth Mental Health Crisis Further Exposed by COVID-19 Pandemic*, U.S. DEP'T HEALTH & HUM. SERVS. (Dec. 7, 2021), https://perma.cc/3G9V-MZ6N.

41. *See* David Axelson, *Beyond A Bigger Workforce: Addressing the Shortage of Child and Adolescent Psychiatrists*, PEDIATRICS NATIONWIDE (Apr. 10, 2020), https://perma.cc/KWA5-PPN4 (arguing that the United States "does

COVID-19 pandemic, mental health professionals often lacked the capacity to meet the demand for their services.[42] Data collected from 2007 through 2017 showed that "less than half of the 7.7 million children in the United States with an identifiable mental health condition [were] receiving services from any mental health provider, much less a psychiatrist."[43] As the population seeking these services continues to increase, many children still struggle to access care.[44] As a result, advocates call for a robust response from the government.[45] Specifically, these advocates demand changes to the public health care system, as it is likely that mental health issues will continue to affect children at alarming rates.[46]

Certain populations are at higher risk for confronting mental health issues during childhood and adolescence. Children with disabilities, LGBTQ+ youth, or those who identify as members of a minority group are at a heightened risk for mental health issues, as are those from lower socioeconomic backgrounds.[47] Because barriers to access are heightened for

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not have enough child and adolescent psychiatrists" resulting in barriers to access for patients, such as long wait times for appointments).

42. *See* Rebecca Bonanno, *The U.S. Must Invest in the People Who Care for Children's Mental Health*, N.Y. TIMES (Sept. 9, 2022), https://perma.cc/5NRD-RUNG ("Even before 2020, many children and teenagers with behavioral struggles were not receiving services. The reasons included lack of financial resources, the stigma of mental health issues and, of course, the shortage of therapists trained to work with children.").

43. Axelson, *supra* note 41.

44. *See* Elizabeth Wright Burak, *CMS Reminds States EPSDT Requirement Includes Behavioral Health, Offers Specific Strategies*, GEO. UNIV. MCCOURT SCH. PUB. POL'Y CTR. FOR CHILD. & FAMS. (Aug. 19, 2022), https://perma.cc/Y8GY-69F8 ("CMS's data show declining access to mental health services for children after the onset of the pandemic.").

45. *Cf.* Jen Christensen, *Almost Half of Children Who Go to ER with Mental Health Crisis Don't Get the Follow-Up Care They Need, Study Finds*, CNN (Feb. 13, 2023), https://perma.cc/ZUT9-5RHG (explaining that, although there was a "surge of children turning up in emergency departments with mental health issues" during the pandemic, "there just doesn't seem to be enough" follow-up care available to ensure long-term positive health outcomes).

46. *See Pandemic Accelerated Crisis*, *supra* note 36 (arguing that efforts to address child mental health post COVID-19 need to "shift up toward preventative care and secondary and early intervention" because there is "no going back to a pre-pandemic 'normal'" regarding child mental health).

47. *See* SURGEON GENERAL'S ADVISORY, *supra* note 2, at 11.

many of these populations, Medicaid's EPSDT benefit plays a particularly essential role in supporting these children.[48] In short, effective administration of the EPSDT benefit has the potential to positively impact populations who are most in need of the services that it purports to cover.

B. *Unique Considerations for Mental Health Care*

Several factors make diagnosing mental health conditions a complex process. Physical health conditions often present clear and ascertainable symptoms, making conditions easy to identify. In contrast, mental health symptoms and conditions are often more amorphous and difficult to identify.[49] What might initially appear to be normal behavior or feelings for a child may be symptoms of a larger behavioral health issue.[50] For example, most children feel "sad, anxious, irritable, or aggressive at times, or they occasionally find it challenging to sit still, pay attention, or interact with others. In most cases, these are just typical developmental phases. However, such behaviors may indicate a more serious problem in some children."[51] Once

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48. *See* Stacy Hodgkinson et al., *Improving Mental Health Access for Low-Income Children and Families in the Primary Care Setting*, PEDIATRICS, Jan. 2017, at 1, 3

> Despite resounding evidence of the deleterious effects of poverty on the psychological well-being of children and families, there is a vast unmet need for mental health services in this population. It is estimated that among children experiencing poverty who are in need of mental health care, <15% receive services, and even fewer complete treatment.

49. *See Mental Illness in Children: Know the Signs*, MAYO CLINIC (Jan. 27, 2024) [hereinafter *Know the Signs*], https://perma.cc/SUA6-2A8Q (explaining that identifying youth mental health conditions is difficult because "the symptoms of a condition may depend on a child's age" and "[y]oung children may not be able to express how they feel or explain why they are behaving a certain way"); Bitsko et al, *supra* note 34, at 1 ("[N]o comprehensive surveillance system for children's mental health exists and no single indicator can be used to define the mental health of children or to identify the overall number of children with mental disorders.").

50. *See* NAT'L INST. MENTAL HEALTH, CHILDREN AND MENTAL HEALTH: IS THIS JUST A STAGE? (2021), https://perma.cc/9SFR-3MQR (PDF) (describing how the complexities of juvenile behavior make distinguishing typical child development from potential serious health problems).

51. *Id.*

identified, symptoms often overlap among conditions, making the diagnosis process lengthy.[52]

Even once a child is diagnosed with a mental health condition, obtaining effective treatment is often complicated. As with physical health conditions, treatment for mental health conditions depends on the nature of the specific condition and effective treatment varies widely on a case-by-case basis.[53] Hence, effective treatment looks different for each child.[54]

Effective treatment of mental health disorders is complicated and often requires more than strictly medical care. Environmental factors, such as trauma or exposure to tobacco, in addition to genetic factors, all contribute to mental health conditions.[55] Thus, a child suffering from a mental health condition might benefit from the collaboration of a range of individuals and professionals, including medical providers in addition to the central adults in the child's life, like parents and teachers.[56] For serious mental health issues, treatment can include a combination of several types of therapy, medication,

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52. *See, e.g.*, U.S.C. & S.C. DEP'T SOC. SERVS., SYMPTOMS THAT OVERLAP WITH CHILD TRAUMA AND MENTAL ILLNESS, https://perma.cc/2VMW-AZ4G (PDF) (last visited Feb. 8, 2024) (identifying symptoms of several mental health disorders that overlap with symptoms of childhood trauma, demonstrating that identifying the cause of a given symptom can be challenging).

53. *See Therapy to Improve Children's Mental Health*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://perma.cc/8Q3S-K97U (last updated Mar. 8, 2023) (explaining that there are typical treatments for "most common childhood conditions, like ADHD, behavior disorders, anxiety, or depression" but there is more variation for treating more specific child health disorders); *see, e.g.*, *Know the Signs*, *supra* note 49 (describing psychotherapy and medication as "common treatments for children who have mental health conditions," but noting that individual treatment plans are required for each case).

54. *See Therapy to Improve Children's Mental Health*, *supra* note 53 ("Therapy is most effective if it fits the needs of the specific child and family.").

55. *See Inheriting Mental Disorders*, AM. ACAD. PEDIATRICS., https://perma.cc/GHS5-UFDN (last updated Nov. 21, 2015) ("Mental disorders are the result of both genetic and environmental factors.").

56. *See What Is Children's Mental Health?*, *supra* note 31 (describing parents, healthcare professionals, and teachers as all playing significant roles in managing care and providing support to children with mental health disorders); *Know the Signs*, *supra* note 49 (emphasizing the unique role that parents play in supporting youth with mental health conditions, including by participating in forms of therapy that involve the parents and parent training programs).

and other interventions.[57] The result is an elaborate system of variables that all influence whether a child will receive effective treatment and how long it will take to obtain such treatment.

Social, economic, and a host of other factors further complicate one's ability to access mental health care. A general lack of understanding regarding the nature and potential seriousness of mental health conditions also makes treatment difficult to access.[58] For instance, though mental health conditions are often chronic, they are frequently treated as if they are acute.[59] Further, society generally accepts the seriousness of many physical health conditions.[60] In response, society has prioritized making treatment available.[61] In contrast, enduring stigmatization of mental health conditions perpetuates a system where access to care is relatively limited for many of these conditions.[62] Finally, the cost of child mental health care is often a prohibitive force for individuals seeking care.[63] Many families who are able to access care face significant

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57. *See Types of Treatment*, ASS'N FOR CHILD.'S MENTAL HEALTH, https://perma.cc/55H8-563F (last visited Feb. 8, 2024) (summarizing the range of therapies employed to treat mental health disorders and explaining that the decision of treatment is made on an individual basis).

58. *See* Lauren Jett, *Mental Illnesses Are Common, but Care Is Lacking*, HARV. MED. SCH. (Nov. 5, 2019), https://perma.cc/N62H-U8ZX

> Although mental illness is widespread—25% of adults in developed countries experience significant mental health problems each year—the treatment is outdated and lacking. Kessler says that mental disorders are treated as acute, episodic ailments instead of chronic illnesses. "We're waiting for the equivalent of a heart attack—the suicides, the overdoses, or violent outbursts—to occur before we do anything," Kessler told Brigham Health.

59. *See id.*

60. *See id.*

61. *See id.*

62. *See id.* (explaining that "mental health treatment has taken longer to advance than other medical fields" and the stigma around mental health illness contributes to ongoing accessibility challenges); *supra* notes 41–46 and accompanying text; *see also Mental Health: Overcoming the Stigma of Mental Illness*, MAYO CLINIC (May 24, 2017), https://perma.cc/FN6Z-LKPG (explaining that stigma around mental health is common and describing impacts of such stigma on patients suffering from mental health conditions).

63. *See* Yuki Noguchi, *Paying for Mental Health Care Leaves Families in Debt and Isolated*, NPR (Oct. 19, 2022), https://perma.cc/F2RP-PNR2 (describing the circumstances of several families who ended up in medical debt

medical bills.[64] In fact, many end up in debt as a result of medical bills for pediatric mental health services.[65]

Although often discussed separately, mental and physical health are closely related topics. Children who have mental health conditions tend to have additional chronic health conditions, such as asthma or epilepsy, more frequently than children without mental health conditions.[66] Similarly, individuals with chronic health conditions report higher rates of mental health struggles.[67] Successful treatment of mental health conditions can have positive impacts on physical health and vice versa.[68] Accordingly, the EPSDT benefit, which covers both physical and mental health services, plays a quintessential role in overall health outcomes for children.[69]

The impacts of untreated or improperly treated mental health conditions are difficult to overstate. Because childhood involves significant physical, social, and emotional developmental milestones, mental health issues during youth and adolescence—particularly those left untreated—often result

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because of high costs and a lack of public or private insurance coverage for behavioral health care services).

64. *See* Yuki Noguchi, *Kids' Mental Health Care Leaves Parents in Debt and in the Shadows*, KFF HEALTH NEWS (Oct. 19, 2022), https://perma.cc/2TXM-WHSM (describing a situation where a teen's mental health services cost his parents $12,500 per month).

65. *Cf. id.* ("A recent KFF poll . . . found that about 100 million Americans have some kind of health care debt, and 20% of those owe money for mental health services.").

66. *See* Ruth Perou et al., *Mental Health Surveillance Among Children—United States, 2005–2011*, MORBIDITY & MORTALITY WK. REP. SUPPLEMENTS, May 17, 2013, at 1, 2.

67. *See* SAMHSA, BEHAVIORAL HEALTH INTEGRATION, *supra* note 30, at 1 ("[P]ersons with physical health conditions such as asthma and diabetes report high rates of substance use disorders and serious psychological distress.").

68. *See id.* at 2 (explaining that treatment of physical illness can positively impact mental health outcomes and similarly, "treatment of mental and substance use disorders can lead to improved physical health for those with behavioral health conditions").

69. *See* Robin Rudowitz et al., *10 Things to Know About Medicaid*, KAISER FAM. FOUND. (June 30, 2023), https://perma.cc/5LVQ-3M3M ("Longstanding research shows that Medicaid eligibility during childhood is associated with positive effects on health and effects beyond health such as improved long-run educational attainment.").

in ongoing physical and mental health issues later in life.[70] Untreated mental health conditions can also impact several areas of a child's life, such as their academic success or involvement in the juvenile justice system.[71] On a societal level, the cost of untreated mental health conditions is staggering, estimated at over $100 billion annually in the United States.[72] Thus, prevention, early diagnosis, and comprehensive treatment for mental health issues are crucial to ensuring positive health outcomes, both in the present and later in life.[73] Accordingly, the EPSDT benefit, which promises preventative and comprehensive health coverage, has the potential to play a substantial role in addressing youth mental health needs and supporting healthy futures.

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70. *See What Is Children's Mental Health?*, *supra* note 31 ("Being mentally healthy during childhood means reaching developmental and emotional milestones and learning healthy social skills and how to cope when there are problems."); Bitsko et al., *supra* note 34, at 17 (examining the immediate and long-term effects of mental health disorders on children); Vikki Wachino et al., *The Kids Are Not All Right: The Urgent Need to Expand Effective Behavioral Health Services for Children and Youth*, BROOKINGS (Dec. 22, 2021), https://perma.cc/KQ2H-FRXV ("Children who have experienced mental health challenges are more likely to experience mental illness, addiction, and other chronic medical conditions as adults . . . ."); *see also* Laura Weiss Roberts et al., *Premature Mortality Among People with Mental Illness: Advocacy in Academic Psychiatry*, 41 ACAD. PSYCHIATRY 441, 441 (2017)

> Earlier this decade, Druss et al. published a 17-year follow-up study of US data and found that people with mental disorders died 8 years earlier on average than people without these disorders. Similarly, in 2006, the National Association of State Mental Health Program Directors issued a report concluding that people with severe mental illness died 25 years earlier on average than the general population. Updated information from the World Health Organization states that the life expectancy of people with severe mental disorders is decreased by 10 to 25 years.

71. *See Recognizing Mental Health Problems in Children*, MENTAL HEALTH AM., https://perma.cc/4HR9-HF4Y (last visited Jan. 30, 2024) ("Untreated mental health problems can disrupt children's functioning at home, school and in the community. Without treatment, children with mental health issues are at increased risk of school failure, contact with the criminal justice system, dependence on social services, and even suicide.").

72. *About Mental Illness*, NAT'L ALL. ON MENTAL ILLNESS, https://perma.cc/U96T-BF59 (last visited Feb. 15, 2024).

73. *See* SURGEON GENERAL'S ADVISORY, *supra* note 2, at 8 (asserting that mental health issues are a "leading cause of disability and poor life outcomes" for young people and describing that "about half" of "children with [a] treatable mental health disorder" did not receive treatment for their condition).

II. MEDICAID

Medicaid is a robust and complex public health care program.[74] The EPSDT benefit is just one small component of a much larger system of public health care benefits. Accordingly, a basic understanding of Medicaid's history, purpose, and structure, provided below, is helpful for understanding the EPSDT benefit.

A. *Basic Principles of Medicaid*

In 1965, Medicaid was established to provide medical insurance coverage to low-income Americans.[75] Eligibility requirements were initially very strict.[76] Medicaid only served a limited population and covered fairly basic services.[77] Subsequently, Medicaid has changed significantly, now covering a broader population.[78] However, the general purpose of the

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74. The U.S. Government Accountability Office admits that "Medicaid is complex." *All About Medicaid*, U.S. GOV'T ACCOUNTABILITY OFF. (July 14, 2016), https://perma.cc/7T9P-7FKQ. This Note only provides a broad overview of Medicaid before analyzing EPSDT's medical necessity standard. Readers are encouraged to seek additional resources that focus on other aspects of Medicaid.

75. Social Security Amendments of 1965, 42 U.S.C. §§ 1396–1396w-7.

76. *See* Anne-Marie Foltz, *The Development of Ambiguous Federal Policy: Early and Periodic Screening, Diagnosis and Treatment (EPSDT)*, 53 MILBANK Q. 35, 38–39 (1975)

> Each state set its own standards for medical need just as it set standards for eligibility for welfare, but it was intended to include those who were categorically eligible and who faced high medical expenses although they were not poor enough to receive welfare payments. Children under 21 could also be included in any state's Medicaid program regardless of categorical eligibility, but only 17 states chose this option.

77. *See* Rudowitz, *supra* note 69 (explaining that Medicaid eligibility was initially highly restrictive as to *only* cover those individuals and families receiving cash assistance); *see also* Foltz, *supra* note 76, at 39

> Services provided under the 1965 Title XIX legislation included inpatient and outpatient hospital services, and physician's and other remedial services. Preventive care or screening services were not spelled out in the legislation (Social Security Act, Section 1905a). They could be provided, but in practice, most states did not reimburse for them.

78. *See Status of State Medicaid Expansion Decisions: Interactive Map*, KAISER FAM. FOUND. (Dec. 1, 2023), https://perma.cc/FH8N-8UYX (explaining

program remains the same to this day: to provide health insurance coverage to those in need. In short, today Medicaid is a government program that "provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults," and qualifying individuals with disabilities.[79]

Medicaid is a product of "cooperative federalism,"[80] where states and the federal government each play a role in program operation. Currently, every state has a dedicated administrative agency tasked with operating their state Medicaid program.[81] State Medicaid programs are designed as follows: a state drafts a state plan and the Centers for Medicare and Medicaid Services ("CMS") reviews the state plan for compliance with federal requirements.[82] States may also apply for waivers of some of the federal statutory requirements for their plan.[83] Once CMS approves the state plan, the program is funded jointly by the state and federal government.[84] As a result of this operational structure, Medicaid programs, specifically the benefits offered, vary considerably among states.[85]

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that many states expanded their Medicaid eligibility requirements after the Affordable Care Act was passed).

79. *Medicaid*, MEDICAID.GOV, https://perma.cc/BE9F-5JHA (last visited Feb. 10, 2024).

80. Wisc. Dep't of Health & Fam. Servs. v. Blumer, 534 U.S. 473, 495 (2002).

81. *See, e.g.*, *Cardinal Care: Virginia's Medicaid Program*, DEP'T MED. ASSISTANCE SERVS., https://perma.cc/2LJM-2KPC (last visited Feb. 10, 2024) (promoting Virginia's state Medicaid program); *TennCare Medicaid*, DIV. TENNCARE, https://perma.cc/DU28-VE2H (last visited Feb. 10, 2024) (describing Tennessee's state Medicaid program).

82. *See Medicaid State Plan Amendments*, MEDICAID.GOV, https://perma.cc/8NHQ-MVTK (last visited Feb. 10, 2024) (explaining the state plan is an agreement between the state and federal government regarding Medicaid eligibility, coverage, and financing for that state's population).

83. *See Waivers*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://perma.cc/QC7A-Y2GW (last visited Feb. 10, 2024) (describing the purpose and nature of the Medicaid waiver program and the steps that states must follow to apply for a Medicaid program waiver).

84. *See* 42 C.F.R. § 441.55; *see also Medicaid*, *supra* note 79.

85. *See* 42 C.F.R. § 441.57 (allowing states to exercise some discretion in offering services that are not mandatory); Rudowitz, *supra* note 69 ("Subject to federal standards, states administer Medicaid programs and have flexibility

B. *Traditional Medicaid Coverage*

In terms of coverage, states have substantial flexibility in deciding the particular benefits that their Medicaid program will cover. The federal government sets a floor for coverage that must be offered, and states determine the extent of any additional benefits that will be covered.[86] Certain benefits are mandatory, meaning that states operating a Medicaid program *must* cover these services.[87] For example, the EPSDT benefit is mandatory.[88] All states operating Medicaid programs must provide the benefit to Medicaid enrollees under the age of twenty-one.[89] Other services are optional.[90] States can decide whether and to what extent they will cover these services.[91] For example, dental coverage is an optional service.[92] States may choose to cover dental services for adult Medicaid enrollees, however they are under no legal obligation to do so. As a result, Medicaid coverage varies considerably across states.

C. *Medicaid Cost and Benefit Delivery*

Medicaid is costly. As previously discussed, it is a joint program between the federal government and the states. Consistent with this design, the program is jointly funded by the federal government and each state.[93] For fiscal year 2021, Medicaid spending totaled $728 billion.[94] The federal

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to determine what populations and services to cover, how to deliver care, and how much to reimburse providers.").

86. *See* 42 U.S.C. § 1396d.

87. *See, e.g.*, *id.* § 1396d(a)(3)(A) (requiring states to cover X-ray services); *see also Mandatory & Optional Medicaid Benefits*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://perma.cc/98T5-372G (last visited Feb. 10, 2024) (listing the mandatory benefits that states are required to provide in their Medicaid programs, including family planning services and physician services).

88. *See* 42 U.S.C. § 1396d(a)(4)(B); *id.* § 705(a)(5)(F)(i).

89. *See id.* § 1396d(a)(4)(B); *id.* § 705(a)(5)(F)(i).

90. *See Mandatory & Optional Medicaid Benefits*, *supra* note 87.

91. *Id.*

92. *See* 42 U.S.C. § 1396d(a)(10).

93. *See* Elizabeth Williams et al., *Medicaid Financing: The Basics*, KAISER FAM. FOUND. (Apr. 13, 2023), https://perma.cc/3H7H-ZXXH.

94. *Id.*

government paid 69% of this total, while states collectively paid 31%.[95] The amount each state spends on Medicaid depends on several factors, including population size, benefits offered, and cost of care.[96] Though actual spending varies by state,[97] the program generally accounts for a significant portion of each state's budget.[98] Because of federal Medicaid spending, the program is also a major source of federal funding to the states.[99] Nationally, children, who make up approximately half of Medicaid enrollees, account for only a limited percentage of program expenditures.[100]

Medicaid's high costs are the result of the program's design. Under traditional Medicaid, states pay for medical services on a fee-for-service basis.[101] When health coverage is financed via fee-for-service, a doctor or health care provider is reimbursed for

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95. *Id.*

96. *See id.* ("Variation in spending across the states reflects considerable flexibility for states to design and administer their own programs—including what benefits are covered and how much providers are paid—and variation in the health and population characteristics of state residents.").

97. *Cf.* KAISER COMM'N ON MEDICAID & THE UNINSURED, MEDICAID FINANCING: AN OVERVIEW OF THE FEDERAL MEDICAID MATCHING RATE (FMAP) 2 (2012), https://perma.cc/YJ8R-TMFC (PDF) (explaining how federal and state funds are calculated).

98. *See* Williams et al., *supra* note 93

> The federal share of spending for services used by people eligible through traditional Medicaid, which includes individuals who are eligible as children, low-income parents, because of disability, or because of age (65+), is determined by a formula set in statute. The formula is designed so that the federal government pays a larger share of program costs in states with lower average per capita income. The resulting "federal medical assistance percentage" or "FMAP" varies by state and ranged from 50 percent to 78 percent for FFY 2023.

99. *See id.* (noting that Medicaid is "the largest source of federal revenues for state budgets").

100. *See* Robin Rudowitz et al., *Children's Health Coverage: Medicaid, CHIP and the ACA*, KAISER FAM. FOUND. (Mar. 26, 2014), https://perma.cc/NXX2-VP7R ("Because children typically have low health care costs, they only account for about 20% of Medicaid program spending, even though they represent nearly half of all Medicaid enrollees.").

101. *See Provider Payment and Delivery Systems*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://perma.cc/WM7L-6PSG (last visited Feb. 10, 2024).

each individual service they perform.[102] Requests for payment are made after services are provided.[103] Providers are financially motivated to provide as many services as possible, in order to earn more money.[104] Under this model, providers have generally been afforded great deference and inquiries into the "medical necessity" of the course of action prescribed have been limited.[105] This financing structure resulted in massive costs for states operating Medicaid programs.[106]

As a response to unfettered costs, states have increasingly turned to managed care tools, such as Managed Care Organizations ("MCOs"),[107] to administer their Medicaid

102. *See Fee for Service*, HEALTHCARE.GOV, https://perma.cc/YS4G-UPFK (last visited Feb. 10, 2024) ("A method in which doctors and other health care providers are paid for each service performed. Examples of services include tests and office visits.").

103. *See* Aaron Seth Kesselheim, Note, *What's the Appeal? Trying to Control Managed Care Medical Necessity Decisionmaking Through a System of External Appeals*, 149 U. PA. L. REV. 873, 879 (2001) (summarizing the basic tenants of the fee-for-service model and noting that because payment comes subsequent to services under the model, payers were less likely to review the medical necessity of services).

104. *See* Katie Cavender, *Changing Health Care Payment Structures*, HARV. MED. SCH. (Mar. 8, 2023), https://perma.cc/4XSW-6ERZ ("The fee-for-service model trains teams to deliver care in a way that directly aligns with how they are paid . . . .").

105. *See* Kesselheim, *supra* note 103, at 879 ("[F]ee-for-service insurers by nature examined the medical necessity of a particular treatment only after the patient had received it. . . . [T]raditional insurers usually abided by the health care provider's judgment as to the proper medical care, rarely denying payment for services.").

106. *See* John A. Flippen, *The Early and Periodic Screening, Diagnostic, and Treatment Program and Managed Medicaid Mental Health Care: The Need to Reevaluate the EPSDT in the Managed Care Era*, 50 VAND. L. REV. 683, 687 (1997).

107. Managed care organizations are defined as "integrated entities in the healthcare system, which endeavor to reduce healthcare expenditures costs." Joseph Heaton & Prasanna Tadi, *Managed Care Organization*, NAT'L LIBR. MED., https://perma.cc/WM4X-5C8B (last updated Mar. 6, 2023). There are several types of MCOs, including health maintenance programs, preferred provider organizations, and point of service organizations. *Id.* Though each iteration varies slightly, they all operate with the goals of saving money while providing medical coverage. *Id.* Notably, managed care has also become increasingly popular in the private-market. *See* Kesselheim, *supra* note 103, at 880 ("[M]anaged care organizations grew in popularity among purchasers of health insurance because of the managed care industry's promise to rein in the costly excesses of the fee-for-service insurance system."); *see also Private Payer Summary*, AM. ASSOC. FOR MARRIAGE & FAM. THERAPY,

programs.[108] The theory underlying this trend is that managed care gives states greater control over Medicaid costs.[109] States contract with MCOs who used capitated rates[110] to shift the financial risk of care to a private source.[111] The capitated rate is calculated based on a host of factors and varies across states.[112] Under the capitated rate model, providers are paid *before* they provide services.[113] Thus, unlike the fee-for-service model, providers are not financially motivated to prescribe as many services and treatments as possible. Instead, providers are now

https://perma.cc/X7GR-9QG7 (last visited Feb. 11, 2024) (estimating that about two-thirds of Americans receive their insurance through some form of managed care).

108. *See* OFF. INSPECTOR GEN., DEP'T HEALTH & HUM. SERVS., OEI-05-93-00290, MEDICAID MANAGED CARE AND EPSDT 1 (1997), https://perma.cc/HFB3-DKUU (PDF) ("State Medicaid agencies have turned to managed care to rein in escalating health care costs, difficult to do in a fee-for-service environment . . . ."); *Managed Care*, MEDICAID.GOV, https://perma.cc/K6PU-9TSR (last visited Feb. 11, 2024) (noting that states use MCOs to administer their Medicaid programs); *see also Provider Payment and Delivery Systems*, *supra* note 101 ("In 2019, 83 percent of all Medicaid beneficiaries were enrolled in some form of managed care.").

109. *See Provider Payment and Delivery Systems*, *supra* note 101 ("Managed care provides states with some control and predictability over future costs. Compared with FFS, managed care can allow for greater accountability for outcomes and can better support systematic efforts to measure, report, and monitor performance, access, and quality.").

110. According to CMS, capitation is "[a] way of paying health care providers or organizations in which they receive a predictable, upfront, set amount of money to cover the predicted cost of all or some of the health care services for a specific patient over a certain period of time." *Capitation and Pre-payment*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://perma.cc/E39V-4GMY (last visited Feb. 11, 2024). "Instead of being paid for each health care service or product, health care providers participating in these models may be paid a set amount of money per patient, for a set amount of time, for a certain set of services." *Id.*

111. *See* Flippen, *supra* note 106, at 684 (rationalizing the shift from fee-for-service to managed care based on the fact that "capitated rates . . . require that private managed care organizations ('MCOs') bear the risk of providing services to the Medicaid population and attempt to profit from a flat-rate system").

112. *See* MEDICAID & CHIP PAYMENT & ACCESS COMM'N, MEDICAID MANAGED CARE CAPITATION RATE SETTING 3–4 (2022), https://perma.cc/32CZ-RFF7 (PDF) (identifying several factors used to calculate the capitated rate for Medicaid managed care, including baseline costs, rate cells, future cost projections, and non-benefit costs).

113. *See supra* note 110.

motivated to provide as few services or treatments as possible.[114] As a result, costs are presumed to be more manageable and predictable for states.[115] Beyond its simple financial impact, the managed care model fundamentally changes medical decision-making. Physicians are accorded less deference than under the fee-for-service model, as utilization reviews are consistently implemented to ensure lower health care costs.[116]

The operational details of Medicaid managed care vary by state, as there are various types of managed care delivery systems.[117] Broadly speaking, to implement managed care, states contract with MCOs, who in turn, provide health care

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114. *Cf.* Patrick C. Alguire, *Understanding Capitation*, AM. COLL. PHYSICIANS, https://perma.cc/ZL4P-C6NF (last visited Feb. 11, 2024)

> It is not unusual for large groups or physicians involved in primary care network models to also receive an additional capitation payment for diagnostic test referrals and subspecialty care. The primary care physician will use this additional money to pay for these referrals. Obviously, this puts the primary care provider at greater financial risk if the overall cost of referrals exceeds the capitation payment, but the potential financial rewards are also greater if diagnostic referrals and subspecialty services are controlled.

115. Cost predictability under the MCO model is attributable to the capitated rate. Because rates are capitated, once the state enters a contract with an MCO, the cost to the state is set. *See Capitation and Pre-payment*, *supra* note 110. If health care costs exceed that amount, the MCO—not the state—bears the burden of the additional cost. *See* Flippen, *supra* note 106, at 684.

116. *See* Kesselheim, *supra* note 103, at 880–81

> MCOs restrained "the kind, volume, and manner in which services are provided" either directly through rules and organizational controls limiting the options available to health care providers or indirectly by modifying health care providers' behavior through financial incentives. MCOs implemented cost-saving strategies across the entire spectrum of health care delivery, including fixing payments for services and limiting access to more expensive medical specialists. Most significantly, however, MCOs worked to eliminate excessive services through a stronger commitment to reviewing care recommended by physicians and refusing to authorize treatments deemed unnecessary.

117. For a survey of the common types of managed care delivery systems that Medicaid uses, see *Provider Payment and Delivery Systems, supra* note 101. States commonly use comprehensive-risk based managed care, primary care case management, and limited-benefit plans. *See id.*

coverage to Medicaid recipients.[118] Notably, it is not uncommon for a single state to contract with several MCOs to provide coverage to their Medicaid enrollees.[119] As a result, Medicaid enrollees within the same state may receive their health coverage from separate MCOs.[120] The terms of contracts between a state and each individual MCO may vary, resulting in different coverage parameters for enrollees within a single state.[121]

While this payment delivery model appears compatible with adult Medicaid and arguably makes costs more predictable for states,[122] as discussed below, the use of managed care delivery is more controversial in the context of the EPSDT benefit.

III. MEDICAID'S EPSDT BENEFIT

The inclusion of the EPSDT benefit in state Medicaid programs is mandatory.[123] The development of the EPSDT

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118. *See Managed Care*, *supra* note 108 ("Medicaid managed care provides for the delivery of Medicaid health benefits and additional services through contracted arrangements between state Medicaid agencies and managed care organizations (MCOs) that accept a set per member per month (capitation) payment for these services.").

119. *See, e.g.*, *Medicaid MCO Enrollment by Plan and Parent Firm, 2021*, KAISER FAM. FOUND. [hereinafter *MCO Enrollment by Plan*], https://perma.cc/6RFG-T89K (last visited Feb. 11, 2024) (identifying several MCOs that each state contracts with to administer their Medicaid programs); *see also* Elizabeth Hinton & Jada Raphael, *10 Things to Know About Medicaid Managed Care*, KAISER FAM. FOUND. (Mar. 1, 2023), https://perma.cc/4RHN-4NFC ("States contracted with a total of 285 Medicaid MCOs as of July 2020.").

120. *See MCO Enrollment by Plan*, *supra* note 119 (surveying the Medicaid managed plan organizations that operated in 2021 and showing how many individuals were enrolled in each plan).

121. *See* SARA ROSENBAUM ET AL., COMMONWEALTH FUND, HOW STATES ARE USING COMPREHENSIVE MEDICAID MANAGED CARE TO STRENGTHEN AND IMPROVE PRIMARY HEALTH CARE 1 (2020), https://perma.cc/53KQ-KQTW (PDF) (noting that Medicaid managed care contracts "can vary enormously both in their details and in the degree to which the purchaser sets specific expectations versus broader aims").

122. Note that managed care generally remains controversial, despite being widely implemented. Advocates in the private market debate the "controversy created by the strategy MCOs use to limit medical services," yet the model persists. Kesselheim, *supra* note 103, at 881.

123. *See* 42 U.S.C. § 1396d(a)(4)(B); *supra* notes 87–89 and accompanying text.

benefit and its role in treating mental health conditions certainly impacts the current youth mental health crisis. Specifically, EPSDT's comprehensive promise to cover all medically necessary services—even those that do not "correct" a condition but only "ameliorate" a condition—inspires hope that mental health services will be covered.[124] This Part of the Note addresses several aspects of the EPSDT benefit, including the benefit's history and current administration and delivery.[125] Ultimately, it assesses why the EPSDT benefit is crucial for addressing child mental health care needs.[126]

A. *Legislative History and Development*

The EPSDT benefit's legislative history illustrates the government's intent to confer a comprehensive benefit to children. When the Medicaid Act[127] was passed in 1965, few people qualified for Medicaid coverage.[128] At the time, states could specifically choose whether and to what extent children would receive health benefits.[129] There was no requirement that children receive any minimum coverage.[130] Further, there was limited federal guidance regarding what type of care a state Medicaid program must cover beyond basic hospital and physician services.[131] For example, there was no requirement that preventative care be covered by a state Medicaid program.[132] Indeed, the language of the initial statute likely barred states from covering preventative care for some enrollees, such as children, without also providing the same

124. 42 U.S.C. § 1396d(r)(5).

125. *See infra* Parts III.A–D.

126. *See infra* Part III.E.

127. Social Security Amendments of 1965, 42 U.S.C. §§ 1396–1396w-7.

128. *See* Rudowitz, *supra* note 69 (explaining that Medicaid initially only covered Americans receiving cash assistance from the federal government but has since been expanded to cover more populations).

129. *See* Foltz, *supra* note 76, at 39.

130. *See id.*

131. *See id.* (explaining that the 1965 legislation contemplated covering "inpatient and outpatient hospital services, and physician's and other remedial services").

132. *See id.* ("Preventive care or screening services were not spelled out in the legislation (Social Security Act, Section 1905a). They could be provided, but in practice, most states did not reimburse for them.").

coverage for adults.[133] It would soon become evident that change was necessary.

While Medicaid was still in its infancy, the federal government recognized that the public health care program was not effectively serving children. In 1963, President John F. Kennedy established a task force to study youth health.[134] Published in 1964, the study found that one-third of males could not enroll in the armed services due to physical or mental health conditions.[135] This jarring statistic directed public and political attention to the state of child health care.[136] Later, in a 1967 letter to Congress, President Johnson vigorously advocated for comprehensive health benefits for children.[137] He referenced both the prevalence of untreated physical and mental health conditions among young people and their potential to impact individuals into adulthood.[138] His message was simple:

133. *See* Sara Rosenbaum, *When Old Is New: Medicaid's EPSDT Benefit at Fifty, and the Future of Child Health Policy*, 94 MILBANK Q. 716, 716 (2016) ("[B]ecause of a basic Medicaid requirement that similarly situated beneficiaries be treated similarly, any state that tried to add more benefits for children likely would have been barred from doing so.").

134. *See id.* at 717 (noting that President John F. Kennedy established a task force to assess health issues preventing men from joining the armed services shortly before his assassination).

135. *See* PRESIDENT'S TASK FORCE ON MANPOWER CONSERVATION, ONE-THIRD OF A NATION: A REPORT ON YOUNG MEN UNQUALIFIED FOR MILITARY SERVICE 1 (1964), https://perma.cc/3LMT-P7FX (PDF) ("One third of all young men in the nation turning 18 would be found unqualified if they were to be examined for induction into the armed forces. Of these, about one-half would be rejected for medical reasons. The remainder would fail through inability to qualify on the mental test.").

136. *See, e.g.*, Rosenbaum, *supra* note 133, at 717 (describing how studies of the health of military service members and a study about the wellbeing of children attending government-supported Head Start preschools contributed to executive concern about the status of children's health care).

137. *See* Lyndon B. Johnson, *Special Message to the Congress Recommending a 12-Point Program for America's Children and Youth* (Feb. 8, 1967), https://perma.cc/C533-NNBB

> Recent studies confirm what we have long suspected. In education, in health, in all of human development, the early years are the critical years. Ignorance, ill health, personality disorder—these are disabilities often contracted in childhood: afflictions which linger to cripple the man and damage the next generation. Our nation must rid itself of this bitter inheritance. Our goal must be clear—to give every child the chance to fulfill his promise.

138. *See id.*

government has a responsibility to invest in children in order to ensure individual and societal wellbeing in the future.[139]

Legislators quickly responded to President Johnson's request that health policy focus on the unique and significant needs of children. They introduced legislation that would provide preventative and comprehensive health benefits for children.[140] The House Ways and Means Committee debated the pending legislation, focusing their dialogue on the cost of a comprehensive and preventative health care benefit for children.[141] Legislators did not discuss the mechanics of establishing a preventative health care benefit, nor the specific services that the benefit would cover.[142] Ultimately, the amendments creating the EPSDT benefit passed in the House with relatively few alterations from the draft's initial form.[143] Later that year, the Senate Finance Committee held hearings on the EPSDT legislation.[144] Again, hearings only sparsely addressed the practical details of the EPSDT benefit, and no changes were made to the House version of the benefit.[145] The ease with which the legislation passed in Congress came at the expense of attention to detail, which would cause several issues later.[146]

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139. *See id.* ("The future of many of our children depends on the work of local pub[lic] health services, school boards, the local child welfare agencies and local community action agencies.").

140. *See* 42 U.S.C. § 1396d(r); WILBUR J. COHEN & ROBERT M. BALL, SUMMARY AND LEGISLATIVE HISTORY OF THE SOCIAL SECURITY AMENDMENTS OF 1967, at 3 (1968), https://perma.cc/EN7C-GUXD (PDF) (explaining that the amendments were proposed as a result of President Johnson's concern that public health care for children be made more robust); *id.* at 18–19 (noting briefly the key components of the amendments that addressed child health care).

141. *See* Foltz, *supra* note 76, at 44 ("During each phase, the issues of program cost and administration were taken up . . . .").

142. *See id.* ("[Q]uestions of scope of services and eligible population were . . . frequently ignored.").

143. *See id.* at 46–47.

144. *See id.* at 48–50.

145. *See id.*

146. *See id.* at 40–41

> The establishment of a program of preventive services for children confronted the federal government with four major questions which had to be resolved in the course of legislation, administration, and implementation of the program. These questions were: (1) Which

On January 2, 1968, President Johnson officially signed EPSDT into law, requiring states to provide preventative health services and comprehensive coverage to children under the age of twenty-one.[147] Many of the details regarding benefit administration remained undefined. Instead, the Department of Health, Education and Welfare ("HEW")[148] was tasked with developing regulations and guidelines to practically implement the benefit, a process that would take several years.[149] Due to the lack of guidance, when initially enacted, states exercised considerable flexibility in their EPSDT program administration.[150] However, even without program details fully worked out, the EPSDT benefit initially appeared to be a novel tool, capable of drastically improving health care coverage for many children.[151] Eventually, in 1973, the ESPDT benefit was fully implemented in accordance with final HEW guidelines and regulations.[152]

> children were to be reached? (2) What would be the extent and quality of health services offered? (3) How much could or should be spent on the program? and (4) Through what administering agency was the program to be implemented? The cost would, of course, affect both the extent and quality of care and the numbers of children to be reached. These four questions do not seem to have been addressed in an orderly or exhaustive fashion by those planning the program. As a result, the program that has became known as EPSDT created considerably more controversy during the five years after it was signed into law by President Johnson in 1968 than it did during its eight-month legislative gestation.

147. *See id.* at 49.

148. Note that HEW later became the modern U.S. Department of Health and Human Services ("HHS"). *See HHS Historical Highlights*, U.S. DEP'T HEALTH & HUM. SERVS. (Jan. 21, 2021), https://perma.cc/3XNR-85AZ.

149. *See* Foltz, *supra* note 76, at 50 (explaining that ESPDT became law in January 1968, yet was set to be implemented later, giving HEW time to develop regulations and guidelines).

150. *See* S.D. *ex rel.* Dickson v. Hood, 391 F.3d 581, 590 (5th Cir. 2004) ("[T]he original EPSDT health care, services and treatment provision was optional and not described in detail in the statute, many states had chosen not to provide EPSDT-eligible children all the care and services allowable under federal law.").

151. *See* Rosenbaum, *supra* note 133, at 716 (noting that when EPSDT was first established, it "came to be understood as a special children's coverage standard with no counterpart in either public or private insurance").

152. *See* Foltz, *supra* note 76, at 35 ("[F]inal guidelines were issued in 1972, and full implementation was deferred until July 1973.").

Not long after the EPSDT benefit was fully implemented, it became clear that the benefit was not being administered effectively.[153] Several amendments were subsequently made to the EPSDT benefit. Most notably, in 1989, Congress amended the EPSDT benefit through the Omnibus Budget Reconciliation Act ("OBRA").[154] The 1989 changes to the statute codified the truly broad and comprehensive scope of the EPSDT benefit, particularly regarding what services states must cover.[155] States were now required to provide "[s]uch other necessary health care . . . described in [the Act's § 1936d(a) definition of 'medical assistance'] to c*orrect or ameliorate* defects . . . illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan."[156] As discussed below, this change significantly broadened the scope of services that states were now required to cover for children.[157] In short, the 1989 OBRA amendment appeared to codify the original intent of offering a preventative and comprehensive health care benefit for children.

Although lawmakers frequently discuss Medicaid reform, legislators have passed no subsequent amendments that would meaningfully change the EPSDT benefit.[158] Attempts made to limit the EPSDT benefit's broad scope have been unsuccessful.[159] Today, EPSDT remains a powerful benefit,

153. *See* Rosenbaum, *supra* note 133, at 718 ("The course of implementation was challenging. Early on, systemic federal and state resistance was the norm. Later, numerous lawsuits were mounted to enforce EPSDT's extraordinary coverage guarantee.").

154. Pub. L. No. 101-239, 103 Stat. 2106 (1989) (codified as amended in scattered sections of 42 U.S.C.).

155. *See* Rosenbaum, *supra* note 133, at 718–19 (describing the force of the 1989 amendments in truly defining the scope of coverage to be mandated under the EPSDT).

156. 42 U.S.C. § 1396d(r)(5) (emphasis added).

157. *See infra* Part III.B.

158. *See* Alice Sardell & Kay Johnson, *The Politics of EPSDT Policy in the 1990s: Policy Entrepreneurs, Political Streams, and Children's Health Benefits*, 76 MILBANK Q. 175, 197–98 (1998) (describing failed legislative efforts aimed at narrowing the scope of and reducing the cost of the EPSDT benefit).

159. *See id.* at 176–77 (describing attempted reforms that would have essentially abolished the EPSDT benefit during the 1990s); *see also id.* at 187 (noting that, although EPSDT costs are high, reforms like the 1989 amendment are unlikely to be the sole cause of increased program costs).

often cited as being more comprehensive than even private health insurance.[160]

Over the years, courts have also continued to characterize the EPSDT benefit as ensuring broad access to preventative and comprehensive health care for children.[161] Courts support these assertions with references to the benefit's legislative history, congressional intent, and the 1989 amendments.[162] They recognize the utility of the EPSDT benefit, especially for the most vulnerable children.[163] CMS has embraced a similar interpretation, asserting, "The goal of EPSDT is to assure that individual children get the health care they need when they need it—the right care to the right child at the right time in the

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160. *See* COMMONWEALTH FUND, COMPARING EPSDT AND COMMERCIAL INSURANCE BENEFITS 1 (2005), https://perma.cc/HKX2-V6D4 (PDF) (explaining the significant differences between EPSDT and private insurance, and concluding that EPSDT is broader in terms of coverage than most private insurance plans).

161. *See* Salazar v. District of Columbia, 954 F. Supp. 278, 303 (D.C. Cir. 1996) ("The purpose of the EPSDT program is to ensure that poor children receive comprehensive health care at an early age, so that they will develop fewer health problems as they get older."); Mitchell v. Johnston, 701 F.2d 337, 348 (5th Cir. 1983) ("[T]he legislative history of EPSDT demonstrates a clear congressional desire to require participating states to provide eligible children with a comprehensive *preventive* dental program."); Katie A. *ex rel.* Ludin v. Los Angeles County, 481 F.3d 1150, 1159 (9th Cir. 2007) ("The legislative history of the EPSDT provisions simply indicates a Congressional purpose to provide a broad program of health care to poor children . . . .").

162. *See* cases cited *supra* note 161; *see also* Ekloff v. Rodgers, 443 F. Supp. 2d 1173, 1180 (D. Ariz. 2006) ("EPSDT was foreseen as 'the largest preventive health program for children.'" (quoting H.R. 3299, 101st Cong. § 4213 (1989))).

163. *See, e.g.*, Stanton v. Bond, 504 F.2d 1246, 1251 (7th Cir. 1974)

> Indiana's somewhat casual approach to EPSDT hardly conforms to the aggressive search for early detection of child health problems envisaged by Congress. It is difficult enough to activate the average affluent adult to seek medical assistance until he is virtually laid low. It is utterly beyond belief to expect that children of needy parents will volunteer themselves or that their parents will voluntarily deliver them to the providers of health services for early medical screening and diagnosis. By the time an Indiana child is brought for treatment it may too often be on a stretcher. This is hardly the goal of "early and periodic screening and diagnosis." EPSDT programs must be brought to the recipients; the recipients will not ordinarily go to the programs until it is too late to accomplish the congressional purpose. (citation omitted).

right setting."[164] As discussed in Part VI however, this comprehensive and broad view of health care for children—seemingly embraced by courts and regulators and expressly found in the EPSDT's legislative history—often remains unfulfilled. As a foundation for this forthcoming analysis, the following subpart details the EPSDT benefit's structure.

B. *Medicaid's EPSDT Benefit Structure*

Any state that operates a Medicaid program is required to provide the EPSDT benefit.[165] EPSDT is the essential Medicaid benefit that ensures children can access important preventative screenings and comprehensive care. Currently, estimates assert that over forty-two million children receive health care coverage through the EPSDT benefit.[166] States must provide *all* children who are eligible for Medicaid with the EPSDT benefit until the age of twenty-one.[167] Thus, the EPSDT benefit is a crucial tool for ensuring that a large population of children access health care services.

EPSDT's name spelled-out summarizes the purpose and goals of the benefit. Problems should be identified *early*; children should be evaluated at *periodic* intervals; child beneficiaries should receive physical, mental, developmental, dental, hearing, and vision *screenings* to identify prospective health issues; *diagnoses* should be made; and *treatment* provided for any health problems identified.[168]

The periodic screening requirement involves having providers conduct screenings at age-appropriate intervals based on standards set by the pediatric medical and dental communities.[169] By evaluating children regularly with

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164. CTRS. FOR MEDICARE & MEDICAID SERVS., EPSDT—A GUIDE FOR STATES: COVERAGE IN THE MEDICAID BENEFIT FOR CHILDREN AND ADOLESCENTS 1 (2014) [hereinafter EPSDT: A GUIDE FOR STATES], https://perma.cc/BR6D-NG9R (PDF).

165. *See Mandatory & Optional Medicaid Benefits*, *supra* note 87.

166. Cannon, *supra* note 14, at 271.

167. *See* Perkins & Somers, *supra* note 19, at 156.

168. *See Early and Periodic Screening*, *supra* note 16 (describing the general structure of the EPSDT benefit).

169. *See* Perkins & Somers, *supra* note 19, at 165 ("The law requires that qualified providers perform each of the four types of screens at different

age-appropriate screenings, the EPSDT benefit strives to prevent medical conditions from occurring or reoccurring.[170] States must also cover visits that are "inter-periodic."[171] In other words, if a child presents with symptoms, the EPSDT benefit should cover their visit with a provider who can examine, diagnose, and treat them—even if the visit is not a routine check-up.[172]

The EPSDT benefit promises to cover services and treatment for conditions identified during periodic or inter-periodic screenings. Under federal law, states must provide EPSDT recipients with the "necessary health care, diagnostic services, treatment, and other measures described in subsection (a) to *correct or ameliorate* defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan."[173] By using the phrase "correct or ameliorate," the EPSDT benefit imposes a broad requirement on states regarding medical necessity.[174] Instead of only covering services that correct ailments, the benefit is intended to cover services that "ameliorate" or "make more tolerable" conditions that

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intervals in accordance with periodicity schedules that meet the standards of pediatric medical and dental practice.").

170. *See* U.S. DEP'T HEALTH & HUM. SERVS., HHS LETTER TO STATES 2 (2013), https://perma.cc/HX4S-MR8L (PDF) ("The preventive thrust of EPSDT helps to ensure that health problems, including behavioral health issues, are identified and treated early, before problems become more complex and their treatment more costly.").

171. Perkins & Somers, *supra* note 19, at 165.

172. *See id.* ("EPSDT also requires coverage of 'inter-periodic' screens, which are visits to a health care provider at 'such other intervals, indicated as medically necessary, to determine the existence of an illness or condition.'" (citation omitted)).

173. 42 U.S.C. § 1396d(r)(5) (emphasis added); *see also* GARY SMITH ET AL., U.S. DEP'T HEALTH & HUM. SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 10 (2000), https://perma.cc/UP7A-CQMB (PDF) (asserting that EPSDT requires "states to cover all treatment services, *regardless of whether or not those services are covered in the state's Medicaid plan*").

174. *See* L. Kate Mitchell, *The Promise and Failures of Children's Medicaid and the Role of Medical-Legal Partnerships as Monitors and Advocates*, 30 HEALTH MATRIX 175, 194 (2020) ("EPSDT is unique in its preventive focus and in its expansive definition of medical necessity, which includes services that both correct and *ameliorate* a medical condition.").

children experience.[175] The EPSDT benefit's medical necessity standard is broad, especially when compared to private insurance or adult Medicaid standards.[176] This uniqueness is particularly important for children who have mental health conditions because they often require an array of costly, ameliorative services.[177]

C. *Adult Medicaid Versus EPSDT*

As described above, Medicaid programs in each state serve as an important source of health insurance for qualifying adults. Because EPSDT is a distinct benefit for a defined population—children—understanding the relationship between Medicaid, generally, and EPSDT is crucial to a thorough analysis of the programs.

States are expected to have more uniformity across their EPSDT benefit programs than across their adult Medicaid programs because there are more federal program requirements for administering the EPSDT benefit.[178] For example, all state EPSDT programs must include coverage for hearing screenings and related treatment.[179] However, coverage for hearing disorder services is optional for adult Medicaid.[180] Thus, in any given state, *all* children should receive hearing screening and service coverage. However, the same coverage for adults will vary across states. Additionally, CMS explicitly states, "The EPSDT benefit is more robust than the Medicaid benefit for adults."[181] In short, states cannot deny EPSDT coverage for a

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175. EPSDT: A GUIDE FOR STATES, *supra* note 164, at 10.

176. *See infra* Part III.C.

177. Unlike many physical health conditions, which can be treated and cured with medication, "[m]edication does not outright cure mental illness. However, it may help with the management of symptoms." *Mental Health Treatments*, MENTAL HEALTH AM., https://perma.cc/C76W-PGAV (last visited Feb. 12, 2024).

178. *See Early and Periodic Screening*, *supra* note 16 (summarizing the requirements for states implementing the EPSDT benefit).

179. *See id.*

180. *See Mandatory & Optional Medicaid Benefits*, *supra* note 87 (classifying "speech, hearing and language disorder services" as optional benefits).

181. EPSDT: A GUIDE FOR STATES, *supra* note 164, at 1.

service on the basis that the specific service is not covered for their adult Medicaid population.[182]

Moreover, the medical necessity standard for the EPSDT benefit is much broader than the medical necessity standard for adult Medicaid. The EPSDT benefit's language requires that states cover services that either *correct or ameliorate* a child's condition.[183] For example, instead of just covering common services like treatment for asthma or the common cold, the EPSDT benefit has covered services such as "specially adapted devices like car seats."[184] Though car seats will almost certainly not correct a child's medical condition, they are covered because they ameliorate the symptoms of a condition.[185] However, as discussed throughout this Note, a study of the EPSDT benefit reveals that the benefit's unique medical necessity standard is frequently ignored or undermined as to make its impact trivial.[186]

D. *Administering EPSDT Through Managed Care*

As discussed above, states customarily administer their Medicaid programs through managed care relationships. Just as states have turned to managed care to finance adult Medicaid, they frequently use MCOs to deliver the EPSDT benefit to children.[187] Indeed, most children covered by Medicaid receive their services through managed care.[188]

The differences between adult Medicaid and EPSDT warrant unique considerations that states must bear in mind

182. *See* 42 U.S.C. § 1396d(r)(5) (requiring coverage for necessary services "*whether or not* such services are covered under the State plan" (emphasis added)).

183. *Id.*

184. Mitchell, *supra* note 174, at 194.

185. *See id.*

186. *See infra* Parts IV–V.

187. *See* Kelly Whitener, *Three Ways to Ensure EPSDT Works in Managed Care*, GEO. UNIV. MCCOURT SCH. PUB. POL'Y CTR. FOR CHILD. & FAMS. (Jan. 9, 2017), https://perma.cc/Q9PN-M7Q9; *see also supra* notes 108–119 and accompanying text.

188. *See* Whitener, *supra* note 187 ("Nearly 9 out of 10 children in Medicaid and CHIP receive services through some type of managed care arrangement . . . .").

when they contract with MCOs to provide EPSDT coverage.[189] As noted, managed care allows a state to better predict and manage the cost of their Medicaid program.[190] Accordingly, managed care makes both logical and practical sense in the context of adult Medicaid because each state has substantial flexibility in what services they will provide.[191] However, as described above, states do not have this same flexibility in operating their EPSDT programs. EPSDT's medical necessity requirement imposes a broad obligation to provide all services that a child needs.[192] States cannot solely rely on cost when evaluating coverage determinations for children.[193] Thus, the fundamental principles underlying MCOs—cost savings and predictability—are incompatible with the principles on which the EPSDT benefit is founded.[194]

Given the seemingly contradictory goals of the EPSDT benefit and managed care, CMS has published specific guidance to states on the subject of EPSDT delivery via managed care.[195] Because the EPSDT benefit is mandatory and has strict program requirements, states must ensure that MCOs administering their EPSDT program comply with all federal requirements.[196] Thus, contracts between the state Medicaid

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189. *See* Flippen, *supra* note 106, at 689–91 (explaining that, because "[m]any managed care providers are not accustomed to dealing with the EPSDT's undefined benefits package," they struggle to contract appropriately with states to deliver the breadth of services required by the benefit).

190. *See supra* notes and 107–115 accompanying text.

191. Generally speaking, managed care works for Medicaid because the delivery tool can adequately balance a state's interest in saving money while improving access to health care and health care outcomes. *See generally* ROSENBAUM ET AL., *supra* note 121.

192. *See supra* notes 173–176 and accompanying text.

193. *See infra* Part IV.B.

194. *See* Victor M. Jones, *To Bryce Gowdy, with Love: Prioritizing Medicaid's "EPSDT" Mandate for America's Most Vulnerable Youth*, 48 S.U. L. REV. 127, 193 (2020) ("The aims of EPSDT 'to offer a comprehensive, high-quality health benefit,' are at odds with the underlying cost-saving goals of managed care." (citation omitted)).

195. *See generally* VIKKI WACHINO, CTR. FOR MEDICAID & CHIP SERVS., THE EARLY AND PERIODIC SCREENING, DIAGNOSTIC AND TREATMENT (EPSDT) BENEFIT FOR CHILDREN AND YOUTH IN MANAGED CARE (2017), https://perma.cc/CL6H-VCV2 (PDF).

196. *See id.* at 1.

agency and MCOs must be carefully drafted.[197] CMS suggests language for defining medical necessity in these contracts and encourages states to incorporate this definition into their contracts with MCOs.[198]

Despite CMS's attempts to support states that administer the EPSDT benefit via managed care, the delivery method remains controversial. Indeed, as of 2020, although most states contract with MCOs to deliver their EPSDT benefit, only nine states specifically describe the EPSDT benefit's medical necessity standard in their contracts with the MCOs.[199] This imprecision may be due to the inherent incompatibility between managed care and the EPSDT benefit. Ultimately, the lack of clarity in MCO contracts and the contradictory goals of MCOs and the EPSDT benefit harm children seeking care, especially for mental health services that are expensive, comprehensive, and ameliorative.

E. *Mental Health and EPSDT*

The EPSDT benefit's language specifically promises coverage for mental health care. Even in the 1960s when Medicaid and the EPSDT benefit were first established, mental health issues were recognized as a problem affecting American youth.[200] Based on the data that initially prompted the development of a federal health insurance program for kids, the

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197. *See* Whitener, *supra* note 187 (explaining that it is crucial that state Medicaid agencies are precise and careful when they contract with managed care).

198. *See* WACHINO, *supra* note 195, at 2

> To assure consistency and that the state plan reflects the statutory requirements, we encourage states to consider including the following language in their state Medicaid plan: All medically necessary 1905(a) services that correct or ameliorate physical and mental illnesses and conditions are covered for EPSDT-eligible beneficiaries ages birth to twenty-one, in accordance with 1905(r) of the Social Security Act.

199. *See* ROSENBAUM ET AL., *supra* note 121, at 3 ("In their contracts, nearly all states specify an adult medical necessity standard that MCOs are expected to apply. Fewer states (nine) describe Medicaid's special pediatric medical necessity standard.").

200. *See* Perkins & Somers, *supra* note 19, at 157–59.

EPSDT benefit specifically contemplated covering mental health screenings and services for children.[201]

Prevention, a core tenant of the EPSDT benefit, is particularly important for children, whether they display mild mental health symptoms or they are diagnosed with a serious mental health condition.[202] The purpose of preventative health care services is easily understood in the context of vaccinations; when vaccinating a child against a given disease, the goal is to prevent the child from experiencing the condition later in life. In the behavioral health context, preventative care is less common and more difficult to understand.[203] Despite being uncommon, methods of preventative mental health care for kids do exist. Age-appropriate screenings for conditions like depression[204] or other behavioral health assessments are prime examples. Accordingly, the EPSDT benefit offers an avenue to ensure that children receive these preventative screenings and any associated services or treatment.

Ameliorative services are also extraordinarily important for mental health treatment, positioning the EPSDT benefit nicely to make a positive impact. By nature, many mental health treatments and services are not intended to correct a child's condition.[205] Instead, the purpose of these services is to ameliorate a child's condition—reducing symptoms and enhancing their quality of life and day-to-day function.[206] For example, medication might not cure a child's mental health condition, but it can improve the child's symptoms.[207] In other

201. *See Early and Periodic Screening*, *supra* note 16.

202. *See supra* notes 165–175 and accompanying text.

203. *See* Ashten R. Duncan et al., *An Emerging Preventive Mental Health Care Strategy: The Neurobiological and Functional Basis of Positive Psychological Traits*, FRONTIERS IN PSYCH., Oct. 2021, at 1, 1 ("Even with the expanding burden of the COVID-19 pandemic on mental health, our approach to mental health care remains largely reactive rather than preventive.").

204. *See Preventive Care Benefits for Children*, HEALTHCARE.GOV, https://perma.cc/8AZJ-CJ9E (last visited Feb. 12, 2024).

205. *See Information About Mental Illness and the Brain*, NAT'L LIBR. MED. (2007), https://perma.cc/WB5W-QP7F ("At this time, most mental illnesses cannot be cured, but they can usually be treated effectively to minimize the symptoms and allow the individual to function in work, school, or social environments.").

206. *See id.*

207. *See Different Types of Mental Health Treatment*, FAMILYDOCTOR.ORG, https://perma.cc/K8KZ-Y9YC (last updated Apr. 2023) ("Medicines for mental

words, coverage for ameliorative services is crucial for addressing mental health needs.

Additionally, because behavioral health services are expensive, Medicaid plays an important role in ensuring that children who need such services get affordable access.[208] EPSDT intends to cover even more services than private insurance, so it is an important source of funding for children with costly health care needs.[209] This payment for services is extremely important for the vulnerable children that EPSDT covers, particularly because they are unlikely to receive coverage from another form of health insurance.[210]

Finally, this promised behavioral health care coverage is especially important because children who are insured by Medicaid, and thus receive EPSDT coverage, tend to have more emotional or behavioral health care needs than children covered by private health insurance.[211] Bearing this in mind, CMS has devoted considerable efforts to emphasizing the important role that EPSDT can play in preventing and treating mental health conditions in youth.[212]

Even so, the scope, breadth, and volume of behavioral health services that are made available to an individual EPSDT enrollee depend on whether the state Medicaid agency is willing to provide coverage for the requested behavioral health service

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disorders make changes to brain chemicals that are involved in emotions and thought patterns. Medicines don't cure psychiatric conditions or health problems. But they can improve your symptoms. They can make other treatments, such as counseling, more effective.").

208. *See Ten Things to Know About Medicaid's Role for Children with Behavioral Health Needs*, KAISER FAM. FOUND. (June 19, 2017) [hereinafter *Medicaid's Role for Children with Behavioral Health Needs*], https://perma.cc/RG72-AH6L ("[Medicaid] also covers services that are excluded from private coverage or for which private coverage is limited for children with private insurance.").

209. *See* Rudowitz, *supra* note 69 (describing EPSDT as "especially important for children with disabilities" because private insurance is often inadequate to meet their needs).

210. *See supra* note 160 and accompanying text.

211. *See Medicaid's Role for Children with Behavioral Health Needs*, *supra* note 208 ("Larger shares of Medicaid children with special health care needs report emotional or behavioral difficulties, compared to those with private insurance only.").

212. *See supra* note 170 and accompanying text. *See generally* EPSDT: A GUIDE FOR STATES, *supra* note 164.

at all.[213] Furthermore, state Medicaid agencies continue to debate the effectiveness of several types of treatment and therapy for mental health conditions so coverage for these services is far from guaranteed, even under the purportedly robust EPSDT benefit.[214] This results in uncertainty regarding if services will be covered and to what extent they will be covered for children.

IV. MEDICAL NECESSITY UNDER EPSDT

EPSDT's medical necessity standard is a powerful mechanism. When applied consistently with federal law, it can play a meaningful role in ensuring children have access to all the health care services they may need. This Part begins by analyzing federal law and guidance for the EPDST benefit's medical necessity standard, assessing how federal guidance currently undermines the purpose of the federal law's language.[215] Then, this Part analyzes how states and managed care providers apply the medical necessity standard in practice.[216]

A. *Federal Guidance*

The Medicaid Act does not define what "medically necessary" means for the EPSDT benefit.[217] As amended in

213. *See* AMY CLARY & BARBARA WIRTH, NAT'L ACAD. FOR STATE HEALTH POL'Y, STATE STRATEGIES FOR DEFINING MEDICAL NECESSITY FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS 3–5 (2015), https://perma.cc/E34F-LCGD (PDF) (describing the variance in state medical necessity parameters and how this variance impacts whether children in a given state will be provided coverage for particular behavioral health services).

214. *See id.* at 5 (listing several types of services and treatments that EPSDT coordinators often cite as needing to be more researched before they are clearly considered medically necessary by states, including applied behavioral analysis for children with autism, behavioral health services, psychological testing, and therapeutic horseback riding).

215. *See infra* Part IV.A.

216. *See infra* Part IV.B.

217. *See* Moore *ex rel.* Moore v. Reese, 637 F.3d 1220, 1232 (11th Cir. 2011) (describing the process of defining medical necessity as a "judicially accepted component of the federal legislative scheme"); Q.H. v. Sunshine State Health Plan, Inc., 307 So. 3d 1, 9 (Fla. Dist. Ct. App. 2020) ("The Medicaid Act does not define the terms 'necessary' or 'medically necessary.'" (citing 42 U.S.C. § 1396d)).

1989, the statute only requires that EPSDT cover "necessary health care, diagnostic services, treatment, and other" services "to *correct or ameliorate* defects and physical and mental illnesses and conditions discovered by the screening services, *whether or not* such services are covered under the State plan."[218] This language is as close as federal law comes to defining medical necessity for purposes of EPSDT. States must cover services that correct or ameliorate conditions, which, as noted above, is a broad requirement.[219] This definition also illustrates the difference between adult Medicaid and EPSDT, specifically mandating that states cover necessary services, even if those services are not covered by their adult Medicaid plan.[220]

Federal guidance is limited in interpreting the medical necessity standard set forth in the federal law. In 2014, CMS published federal guidance on EPSDT.[221] The thirty-eight-page publication devotes a mere three pages to the EPSDT benefit's medical necessity standard, in a section titled "Permissible Limitations on Coverage of EPSDT Services."[222] The guidance establishes that states cannot have "inflexible limits" on services that they will cover for EPSDT beneficiaries.[223] CMS states that "determination of whether a service is medically necessary for an individual child must be made on a case-by-case basis, taking into account the particular needs of the child."[224] For example, a state could impose a soft limit on the annual number of covered physical therapy visits for children.[225] However, if, upon review of an individual child's case, it were to be determined that additional physical therapy services were medically necessary to correct or ameliorate a diagnosed condition, those services would have to be covered.[226]

218. 42 U.S.C. § 1396d(r)(5) (emphasis added).

219. *See supra* note 174 and accompanying text.

220. *See supra* notes 178–182 and accompanying text.

221. *See generally* EPSDT: A GUIDE FOR STATES, *supra* note 164.

222. *Id.* at 23.

223. Perkins & Somers, *supra* note 19, at 167; *see also* EPSDT: A GUIDE FOR STATES, *supra* note 164, at 24 (establishing that states can't have hard limitations on the amount of services children may receive).

224. EPSDT: A GUIDE FOR STATES, *supra* note 164, at 23.

225. *See id.* at 24.

226. *See id.*

This 2014 CMS guidance provides several explicit methods that states may use to limit coverage for EPSDT recipients. Notably, CMS explicitly allows states to impose prior authorization requirements for treatment.[227] This allows state Medicaid agencies to review treatment decisions before providing coverage for these services. Additionally, states can choose whether or to what extent they will cover experimental treatments.[228] Because federal law and regulations do not define the term "experimental treatment," guidance is limited here.[229] Indeed, states are free to define "experimental treatment" for their Medicaid program.[230] The guidance also explains that coverage determinations cannot be made solely based on cost.[231] However, states "may consider the relative cost effectiveness of alternatives as part of the prior authorization process."[232] Thus, states are allowed to deny coverage if there is a less expensive alternative treatment that is "equally effective and actually available."[233] This guidance fails to establish how to evaluate whether two treatment options are "equally effective." In practice, states rely on these guidelines to push the outward boundaries towards limiting the scope of coverage provided by their EPSDT program.[234]

227. *See id.* ("States may impose utilization controls to safeguard against unnecessary use of care and services.").

228. *See id.* at 24–25 ("EPSDT does not require coverage of treatments, services, or items that are experimental or investigational. Such services and items may, however, be covered at the state's discretion if it is determined that the treatment or item would be effective to address the child's condition.").

229. *Id.* at 25.

230. *See id.* ("The state's determination of whether a service is experimental must be reasonable and should be based on the latest scientific information available. Medicare guidance on whether a service is experimental or investigational is not determinative of the issue and may not be relevant to the pediatric population.").

231. *See id.*

232. *Id.*

233. *Id.*

234. *See, e.g.*, Q.H. v. Sunshine State Health Plan, Inc., 307 So. 3d 1, 12–13 (Fla. Dist. Ct. App. 2020) (describing Florida's attempt to overly-rely on CMS's grant of prior authorization power to deny EPSDT coverage, even upon appeals).

B. *State and Managed Care Parameters for Medical Necessity*

Ultimately, states define medical necessity for their EPSDT programs within parameters set by federal law and guidelines described above. Each state and Washington D.C. independently defines the parameters for medical necessity for their EPSDT benefit.[235] Some states, like California, simply use the federal definition for medical necessity from the Medicaid Act.[236] Other states impose more parameters in their medical necessity definitions for purposes of EPSDT, relying on the 2014 CMS guidance.[237] For example, some states, like Mississippi, adopt the position that services are not medically necessary if they are experimental or cost more than other services that would result in the same outcome.[238]

As previously noted, many states administer their EPSDT benefit through managed care organizations.[239] Under these circumstances, states define medical necessity in their contract with each individual MCO.[240] Consequently, different MCOs operating EPSDT plans within the same state might use different standards or rules for medical necessity.[241]

CMS addressed the issue of ESPDT administered by managed care organizations in the 2014 guidance and again in 2017[242] as concerns regarding the effectiveness of EPSDT via

235. *See State Definitions of Medical Necessity Under the Medicaid EPSDT Benefit*, NAT'L ACAD. FOR STATE HEALTH POL'Y (Apr. 23, 2021) [hereinafter *State Definitions of Medical Necessity*], https://perma.cc/LYH5-L7VN (surveying various state definitions for medical necessity under EPSDT).

236. *See* CAL. WELF. & INST. CODE § 14059.5(b)(1) (West 2024) ("For individuals under 21 years of age, a service is 'medically necessary' or a 'medical necessity' if the service meets the standards set forth in Section 1396d(r)(5) of Title 42 of the United States Code."); *see also* 42 U.S.C. § 1396d(r)(5) (defining medical necessity for EPSDT at the federal level).

237. *See supra* notes 227–233 and accompanying text.

238. *See* 23-5 MISS. CODE R. § 5.1 (LexisNexis 2024) (noting that care does not qualify as medically necessary in Mississippi if it is experimental, more conservative, or "substantially less costly" treatment exists); *see also State Definitions of Medical Necessity*, *supra* note 235 (listing examples of state EPSDT medical necessity definitions).

239. *See supra* notes 187–199 and accompanying text.

240. *See* ROSENBAUM ET AL., *supra* note 121, at 3.

241. *See supra* note 121 and accompanying text.

242. *See generally* WACHINO, *supra* note 195.

managed care grew.[243] The 2014 guidance established the permissibility of managed care in the EPSDT context.[244] The 2017 guidance sought to clarify the details of those arrangements.[245] Specifically, managed care providers administering the EPSDT benefit must define medical necessity in a way that is consistent with the federal definition.[246] However, the guidance only *encourages* states to use the federal language describing medical necessity from the Medicaid Act when contracting with these providers.[247] Just as states maintain flexibility in setting parameters for their EPSDT medical necessity definitions, managed care providers do as well.[248]

The state and managed care variation in medical necessity is significant. The result is that the method for determining medical necessity varies across and even within states. Because medical necessity is often hotly debated in the context of mental health care, this variation is particularly significant for children seeking coverage for these services. This variation in medical necessity results in different coverage decisions for children and gives rise to legal battles.

V. EPSDT LITIGATION

One tool to address discrepancies in EPSDT's medical necessity standard is litigation. This Part discusses the

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243. *See* Jones, *supra* note 194, at 193

> The aims of EPSDT "to offer a comprehensive, high-quality health benefit," are at odds with the underlying cost-saving goals of managed care. . . . [T]his conflict is particularly noticeable in the area of children's mental health care. Afterall, CMS instructs that "a state may not deny medically necessary treatment to a child based on cost alone." (citations omitted).

244. *See* EPSDT: A GUIDE FOR STATES, *supra* note 164, at 29–31.

245. *See generally* WACHINO, *supra* note 195.

246. *See id.* (detailing the three steps that states should take when drafting managed care contracts to ensure that their programs are administered in compliance with federal requirements); *see also* Whitener, *supra* note 187 (explaining that CMS "regulations require MCO . . . contracts to define medical necessity in a way that is consistent with EPSDT").

247. *See* WACHINO, *supra* note 195, at 2.

248. *See supra* notes 240–241 and accompanying text.

background of EPSDT litigation,[249] courts' reliance on adult Medicaid standards,[250] and the importance of granting providers deference on decisions of medical necessity in EPSDT cases.[251] With the lack of uniformity across state EPDST programs, judicial challenges are also failing to protect children's mental health.

A. *Background on EPSDT Litigation*

EPSDT litigation is common when children fail to receive services guaranteed by the Medicaid statute. Early litigation was brought to require states to provide the EPSDT benefit.[252] Litigation has since been brought to enforce various aspects of the EPSDT benefit, including the "reasonable promptness" provision and the adequate access to screenings requirement.[253]

Litigation has also been used to clarify the standard for medical necessity under the EPSDT benefit. Because parameters for medical necessity vary across and within states, families sometimes seek judicial redress for their child's medical necessity coverage determinations.[254] Litigation typically arises as the result of a denial of coverage for care that a child's medical provider has determined is medically necessary.[255] This customarily occurs when a state Medicaid agency imposes strict criteria that a child must satisfy to qualify for coverage.[256] For example, if the child does not precisely satisfy each piece of prior authorization criteria, then the state is expected to engage in an

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249. *See infra* Part V.A.

250. *See infra* Part V.B.

251. *See infra* Part V.C.

252. *See, e.g.*, Stanton v. Bond, 504 F.2d 1246, 1251 (7th Cir. 1974) (explaining that states cannot take a "casual approach" to enacting the EPSDT benefit because Congress called for the "aggressive search for early detection of child health problems" when enacting the statute).

253. *See, e.g.*, Health Care for All, Inc. v. Romney, No. Civ.A. 00-10833, 2005 WL 1660677, at *8–*9 (D. Mass. July 14, 2005) (analyzing the "reasonable promptness" provision of the EPSDT benefit).

254. *See supra* notes 235–238 and accompanying text.

255. *See, e.g.*, Q.H. v. Sunshine State Health Plan, Inc., 307 So. 3d 1, 3 (Fla. Dist. Ct. App. 2020) (appealing the state Medicaid agency's denial of coverage for services).

256. *See, e.g.*, *id.* at 5–8 (analyzing strict prior authorization criteria that resulted in the denial of services for a child).

individualized review of their medical needs to determine medical necessity.[257] After an administrative appeal process results in an unfavorable outcome for the enrollee, the child's parent or guardian may bring a lawsuit seeking judicial review of the state Medicaid agency's denial.[258]

This makes judges the ultimate gatekeepers, determining whether children will obtain coverage for the medical care that their treating physician has recommended. As discussed below, when faced with this critical task, courts have produced inconsistent outcomes.[259] Their conflicting analyses have done very little to clarify the EPSDT benefit's medical necessity standard. This leaves children, their parents, and providers in a vulnerable position—often waiting for an extended period while litigation is ongoing—with unpredictable outcomes regarding the child's health care.[260]

B. *Over Reliance on the Adult Medicaid Standard in EPSDT Cases*

Some courts interpret medical necessity as treatment which the child's provider recommends but that is also reviewed by the state Medicaid agency, which ultimately determines the necessity of a particular treatment.[261] At times, the

257. *See, e.g.*, *id.* at 3–4 (providing an example of when a child's prior authorization for growth hormone treatment was denied because she failed to meet all the criteria for pediatric growth hormone deficiency).

258. *See, e.g.*, *id.* at 5–8 (laying out the administrative appeal process in Florida). It is notable that litigation statistics likely do not reflect the accurate population of EPSDT recipients who have their coverage denied and are unhappy with the result. Because the economic and noneconomic costs of litigation are high, parents might decide to forego recommended treatment for their children or to cover the costs for more minor treatments out-of-pocket.

259. *See infra* Parts V.B–C.

260. *See, e.g.*, Hunter v. Chiles, 944 F. Supp. 914, 920 (S.D. Fla. 1996) (noting that the plaintiff spent six years attempting to get Medicaid coverage for the services that his physician recommended).

261. *See* Moore *ex rel.* Moore, 637 F.3d 1220, 1235 (11th Cir. 2011) ("[T]he treating physician and the state both have roles to play in determining medical necessity, and the treating physician's opinion is not dispositive."); *Q.H.*, 307 So. 3d at 9 (arguing that both the treating physician and state officials ought to take part in determining what is medically necessary for each beneficiary); *see also* Hunter *ex rel.* Lynah v. Cook, No. 08-CV-2930, 2013 WL 2252917, at *4 (N.D. Ga. May 22, 2013) (relying on the analysis in *Moore*, of *Rush v. Parham*, 625 F.2d 1150 (5th Cir. 1980), an adult Medicaid case, to parse the

state-reviewer does not examine the child but, rather, reviews medical notes and draws a conclusion about the medical necessity of the proposed services.[262] Under these conditions, states fail to ensure that EPSDT medical necessity determinations are made based on an individualized review, as promised by law.[263] Despite inconsistencies with the EPSDT benefit's promise, this appropriation of ultimate decision making authority to the state is notably consistent with judicial interpretation of the permissible medical necessity standard of states' adult Medicaid programs, in which states have wide latitude in making coverage determinations.[264]

Indeed, several courts have overly relied on adult Medicaid caselaw in setting the standard for medical necessity in EPSDT

roles of the treating physician and the state in EPSDT medical necessity determinations).

262. *See, e.g.*, Jacobus v. Dep't of PATH, 857 A.2d 785, 789 (Vt. 2004) (noting that Vermont's reviewer never examined the children demanding coverage and simply examined medical notes and applied them to a list of criteria to determine that the requested services were not medically necessary).

263. *See id.* (concluding that having a state reviewer "[s]imply reapplying the listed criteria is not an individualized review" to make a medical necessity determination for purposes of EPSDT).

264. The leading Supreme Court case interpreting the medical necessity standard dealt with adult Medicaid. *See* Beal v. Doe, 432 U.S. 438 (1977). This case considered whether therapeutic abortion, a highly controversial medical service, should be covered under a state Medicaid plan for adults. *Id.* at 443–44. The case involved a question regarding what role the treating physician played in making medical necessity determinations. *Id.* at 448. "Under the Pennsylvania program, financial assistance is not provided for medically necessary abortions unless two physicians in addition to the attending physician have examined the patient and have concurred" in the medical necessity decision. *Id.* The majority refrained from explicitly defining the role of the treating physician in making medical necessity determinations; however, a three-justice dissent noted "the paramount role played by the attending physician in the abortion decision." *Id.* at 454 (Brennan, J., dissenting).

cases.[265] For example, in *Moore v. Reese*,[266] the Eleventh Circuit reviewed a state's denial of at-home nursing care for an EPSDT beneficiary.[267] The child's lifelong doctor determined that she required ninety-four hours of private nursing services at home each week.[268] The state engaged a private entity to review this determination for medical necessity.[269] Upon review, the state determined that the child only qualified for eighty-four hours of care per week, ten hours short of what her provider determined.[270] On appeal, the Eleventh Circuit parsed the roles of the treating physician and the state agency in determining medical necessity.[271] The court summarized government publications and ultimately cited a string of cases to address the question.[272] Specifically, the court summarized three medical necessity cases that involved adults covered by Medicaid.[273] All three cases were decided before the 1989 OBRA amendment that codified the contemporary medical necessity standard for

265. *See* D.U. v. Seemeyer, No. 13-CV-1457, 2018 WL 1010486, at *9 (E.D. Wis. Feb. 20, 2018) (relying on *Rush v. Parham*, 625 F.2d 1150 (5th Cir. 1980), an adult Medicaid case, in interpreting the medical necessity standard in an EPSDT case, and according a more limited role for the child's treating physician in determining what is medically necessary); M.A. v. Norwood, 133 F. Supp. 3d 1093, 1103 (N.D. Ill. 2015) (analyzing adult Medicaid cases and giving roles to both the treating physician and state Medicaid agency in determining the medical necessity standard in EPSDT cases).

266. 637 F.3d 1220 (11th Cir. 2011).

267. *See id.* at 1223 ("This appeal concerns the extent to which a state Medicaid agency may review Moore's treating physician's determination of medical necessity under 42 U.S.C. § 1396d(r) of the Medicaid Act.").

268. *See id.* at 1224–26 (describing the child's longstanding relationship with her physician and his methodology for determining how many nursing hours she would require).

269. *Id.* at 1226–28.

270. *Id.* at 1226.

271. *See id.* at 1235 (explaining that the court had to decide "what happens when [the] treating physician and the state's medical expert disagree about what amount of nursing hours are medically necessary").

272. *See id.* at 1235–55 (analyzing CMS and state publications and caselaw to develop "guiding principles" for the roles of providers and the state in making medical necessity determinations).

273. *See id.* at 1242–53 (grounding their analysis on *Beal v. Doe*, 432 U.S. 438 (1977), *Curtis v. Taylor,* 625 F.2d 645 (5th Cir. 1980), *Rush v. Parham*, 625 F.2d 1150 (5th Cir. 1980), three cases that discuss medical necessity in the adult Medicaid context).

the EPSDT benefit.[274] The court summarized just a single EPSDT case that construed the 1989 amendment and then noted that it would not be relevant to the current analysis.[275]

The Eleventh Circuit's misplaced overreliance on adult Medicaid caselaw resulted in the expansion of the state's role, as opposed to the treating physician's role, in determining medical necessity for EPSDT beneficiaries.[276] Indeed, in *Moore*, the court held that the state and physician both have roles to play in medical necessity decisions.[277] But it is the state that makes the ultimate determination.[278]

The *Moore* court, and several others, have relied heavily on *Rush v. Parham*[279] when constructing the medical necessity standard under EPSDT.[280] *Rush* did not involve EPSDT but, rather, involved coverage determinations for traditional, adult Medicaid.[281] Specifically, the *Rush* court reasoned that the state has a considerable role and responsibility in determining medical necessity because of Congress's intent in drafting the Medicaid statute.[282] Accordingly, under adult Medicaid, the *Rush* court held "that the physician is required to operate within such reasonable limitations as the state may impose."[283] However, both the legislative history of the EPSDT benefit and the 1989 OBRA amendment are plainly distinct from the

274. *See id.*

275. *See id.* at 1253–55 (discussing *Pittman ex rel. Pope v. Secretary, Florida Department of Health & Rehabilitative Services*, 998 F.2d 887 (11th Cir. 1993)); *id.* at 1254 ("*Pittman* does not help answer the question presented here.").

276. *See id.* at 1258 ("[T]he district court erred in granting summary judgment for Moore and too narrowly limiting [the state Medicaid agency's] role.").

277. *See id.* at 1257 (noting that, although the state must take into account the treating physician's determination, the state can nonetheless conduct its own review and limit services).

278. *See id.*

279. 625 F.2d 1150 (5th Cir. 1980).

280. *See supra* note 272 and accompanying text.

281. *See Rush*, 625 F.2d at 1152.

282. *See id.* at 1155 (noting that Congress intended that the states play a role in setting standards for medical assistance in the context of medical necessity coverage determinations).

283. *Id.* at 1156.

legislative history of traditional adult Medicaid.[284] Accordingly, when courts like the *Moore* court apply *Rush*, or similar cases, in the EPSDT context, they fail to account for the distinct nature and legislative purpose of the EPSDT benefit.

Moore, and several other courts, have engaged in this reasoning and analysis to ultimately expand the role of the state in making medical necessity determinations for children enrolled in EPSDT.[285] In its expanded role, the state can easily limit or deny coverage. This adversely impacts children who are then left without coverage for medical services recommended by their doctors.

C. *Provider Deference in EPSDT Medical Necessity Determinations*

Other courts afford physicians more deference in addressing questions of medical necessity under the EPSDT benefit. For example, in *Pediatric Specialty Care, Inc. v. Arkansas Department of Human Services*,[286] the Eighth Circuit required coverage for services where the child's provider deemed them medically necessary.[287] In *Hunter v. Chiles*,[288] a United States district court reasoned that treating physicians are "experts."[289] When a treating physician acts within generally accepted standards of medical care, the state Medicaid agency "cannot deny coverage to anyone because of speculation that other payors may exist."[290] In both *Pediatric Specialty Care, Inc* and *Hunter*, treating physicians play the primary role in making medical necessity determinations and states are limited in their ability to challenge those decisions.

These courts emphasize EPSDT's legislative history. For example, the Fifth Circuit explained that the "1989 amendment was clearly a response to the disappointing performance of the

284. *See supra* notes 128–157 and accompanying text.

285. *See supra* note 261 and accompanying text.

286. 293 F.3d 472 (8th Cir. 2002).

287. *See id.* at 481 (giving deference to the provider in determining what care is medically necessary and requiring the state to reimburse providers for that care).

288. 944 F. Supp. 914 (S.D. Fla. 1996).

289. *Id.* at 922.

290. *Id.*

EPSDT treatment function as optional and within each state's discretion."[291] Accordingly, unlike under adult Medicaid, "the plain words of the statute and the legislative history make evident that Congress intended that the health care, services, treatment and other measures that must be provided under the EPSDT program be determined by reference to federal law, not state preferences."[292] When courts consider this specific legislative history and Congressional intent, they reach a different outcome than courts who rely primarily on caselaw decided before the 1989 OBRA amendment, like the court in *Moore*.

Similarly, in some class action lawsuits, courts have deferred to treating physicians, allowing them the final say in the medical necessity determination. In *Collins v. Hamilton*,[293] the Seventh Circuit held that a state Medicaid agency must pay for services if "deemed 'medically necessary' by an EPSDT screening."[294] Likewise, in *Rosie D. v. Romney*,[295] the court concluded that "if a licensed clinician finds a particular service to be medically necessary to help a child improve his or her functional level, this service must be paid for by a state's Medicaid plan pursuant to the EPSDT mandate."[296] The *Rosie D.* court discussed the 1989 OBRA amendment at length in reaching this conclusion:

> On December 19, 1989, Congress restated and deepened its commitment to eligible children by amending the Medicaid statute to promise that persons under twenty-one years of age would receive *all* reasonably necessary medical care regardless of ability to pay. From today's perspective, the scope of this commitment seems breathtaking: no Medicaid-eligible child in this country, whatever his or her economic circumstances, will go without treatment deemed medically necessary by his or her clinician.[297]

291. S.D. *ex rel.* Dickson v. Hood, 391 F.3d 581, 592 (5th Cir. 2004).
292. *Id.*
293. 349 F.3d 371 (7th Cir. 2003).
294. *Id.* at 376.
295. 410 F. Supp. 2d 18 (D. Mass. 2006).
296. *Id.* at 26.
297. *Id.* at 22.

Treating physicians do not exercise their practice of medicine without limitation under this approach. These courts still consider whether the provider's determinations of medical necessity is "consistent with generally accepted professional medical standards as determined by Medicaid; is reflective of the level or service that can be safely furnished, and there is no equally effective and more conservative or less costly treatment available; and is furnished in a manner not primarily intended for convenience."[298] However, as long as substantive medical decisions are made appropriately, the states must provide coverage for the medically necessary services as deemed required by a child's treating physician.

VI. ADDRESSING THE VARIATION IN MEDICAL NECESSITY

As is, children who receive health care coverage from the EPSDT benefit are subject to different health coverage outcomes depending on where they live. The variation in medical necessity standards across states and managed care organizations continues to result in legal action.[299] Courts further conflate EPSDT and adult Medicaid, confusing the already imprecise medical necessity standard for children.[300]

Change is necessary. If changes are effective, the EPSDT medical necessity standard can be leveraged to produce more equitable health outcomes. This is especially important for children who struggle with mental health issues and who require significant medical services and treatment. This Part suggests three potential solutions—one legislative, one judicial, one programmatic—to address inequities that might result in better, more equitable health coverage outcomes for youth.

A. *Federalizing the Medical Necessity Definition*

Establishing a clear, consistently-applied federal definition for medical necessity is paramount to the success of the EPSDT benefit. As the benefit is interpreted now, the issue of dissimilarity in the medical necessity standard is a prohibitive force in ensuring that children receive the treatment or services

298. Hunter v. Chiles, 944 F. Supp. 914, 922 (S.D. Fla. 1996).

299. *See supra* notes 261–298 and accompanying text.

300. *See supra* notes 265–285 and accompanying text.

that they require.[301] To ensure that recipients get the promised coverage, federal lawmakers should establish a clear definition for medical necessity for the EPSDT benefit.

A uniform definition for medical necessity should reflect the EPSDT benefit's congressional intent. Legislative history supports a broad reading of the Medicaid EPSDT benefit that assures preventative and comprehensive care for children.[302] This definition should be patently distinct from the meaning of medical necessity under the general adult Medicaid program that a given state operates. Should litigation arise regarding coverage determinations, lawmakers should include clear language stating that this standard, not the adult standard, must apply.

The mechanics of the definition must embody Congress's intent. First, the definition should codify the role of the treating physician as the primary decision-maker when it comes to medical necessity determinations for children. The medical provider best understands the individual child's medical needs. Thus, they are better equipped than state agency employees or judges at treating conditions. This is particularly significant in the context of mental health care.

As discussed in Part I of this Note, improper treatment of mental health conditions can have detrimental consequences for the rest of a child's life. For example, the decision to prescribe contact lenses versus glasses for a particular child is unlikely to have long-term effects on the child's health; debates regarding course of treatment between a child's provider and a state agency are unlikely and the impact minimal. However, the decision to provide community-based mental health services versus inpatient treatment can have more devastating effects on the child's imminent condition, as well as their outcomes later

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301. *See supra* note 260 and accompanying text.

302. *See* Katie A. *ex rel.* Ludin v. Los Angeles County, 481 F.3d 1150, 1159 (9th Cir. 2007) ("The legislative history of the EPSDT provisions simply indicates a Congressional purpose to provide a broad program of health care to poor children . . . ."); S.D. *ex rel.* Dickson v. Hood, 391 F.3d 581, 592 (5th Cir. 2004) (analyzing the legislative history of the EPSDT benefit and subsequent amendments and concluding that states must cover all necessary medical services); Ekloff v. Rodgers, 443 F. Supp. 2d 1173, 1181 (D. Ariz. 2006) (describing the legislative history of EPSDT and determining that it supports a broad reading of the state's obligations to offer necessary medical treatment to children).

in life.[303] These services are costly and likely to cause more debate between a physician and a state agency.[304] Accordingly, codifying the provider as the primary decision-maker is consistent with the requirement that EPSDT medical necessity determinations be made on a case-by-case basis, individualized for each child.[305]

Next, the definition should include a clear delineation of permissible coverage limitations. Currently, federal guidance outlines several examples of ways that states can limit coverage via their medical necessity standards.[306] However, states can creatively set parameters that push the boundaries of these possible limitations. To address this, the federal definition of medical necessity should explicitly articulate the *only permissible* limitations for coverage determinations. For example, instead of vaguely suggesting that states can impose "soft" limits on coverage determinations,[307] the definition should articulate what "soft" limits are permissible. This will, in turn, minimize the ability of states to creatively administer their programs around federal requirements. Similarly, this definition should bar states from imposing prior authorization requirements. These requirements are often arbitrary and incompatible with the individualized nature of the EPSDT benefit.

Codifying the definition will allow states to more effectively contract with MCOs to administer their EPSDT services. As is, states often fail to contract carefully with MCOs when they attempt to deliver EPSDT services privately.[308] By federalizing the definition, states and MCOs can avoid variation in the standard that is applied, as the definition to be used in contracts will be established.

By establishing a uniform definition for medical necessity, legislators can reduce the likelihood that children and families will need to turn to the courts for judicial resolution of adverse coverage determinations. This is important for several reasons.

303. *See supra* notes 70–73 and accompanying text.

304. *See supra* notes 208–210 and accompanying text.

305. *See supra* note 224 and accompanying text.

306. *See supra* notes 221–233 and accompanying text.

307. *See supra* notes 221–226 and accompanying text.

308. *See supra* note 199 and accompanying text.

On a practical level, families and children seeking coverage for benefits under the EPSDT benefit may lack necessary resources to obtain legal representation and navigate the legal system.[309] Moreover, limiting the role of the courts in these determinations will likely allow children to access coverage in a timelier manner, which is often crucial to receiving effective and meaningful medical care and is also a cornerstone of the EPSDT benefit. Finally, given the ongoing volatility of the private right of action under the Medicaid Act as a whole, it is prudent to ensure that the EPSDT benefit operates as efficiently and effectively as possible without increasing or maintaining the role of courts in simple coverage determinations.[310]

Codifying a clear definition will also be beneficial in the cases that do result in litigation. Courts will know what standard must govern their analysis. Because this standard will

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309. *See supra* note 258.

310. The Medicaid Act does not explicitly confer a private right of action in its text. *See* Wilder v. Va. Hosp. Ass'n, 496 U.S. 498, 521 (1990) ("The Medicaid Act contains no . . . provision for private judicial or administrative enforcement."). Instead, litigants commonly utilize § 1983 challenges to enforce their rights under the law. *See, e.g.*, *id.* at 504–05. For several years, federal circuits disagreed regarding the availability of a private right of action to enforce various provisions of the Medicaid Act. *See, e.g.*, *id.* at 524 (finding a private right of action under § 1983 to enforce rights under the Medicaid Act); Robin Rudowitz & Laurie Sobel, *What Is at Stake for Medicaid in Supreme Court Case Health & Hospital Corp v. Talevski?*, KAISER FAM. FOUND. (Oct. 28, 2022), https://perma.cc/CBL8-SE37

> Federal circuit courts have generally upheld private enforcement of rights for Medicaid enrollees (particularly in cases where the state has denied . . . EPSDT benefits, enrollment, or care in the least restrictive setting). On the other hand, courts have also ruled that providers and enrollees do not have enforceable rights to sue for inadequate payment rates.

Generally, a private right of action has been available to litigants trying to enforce EPSDT provisions. *Id.* In 2023, the United States Supreme Court reaffirmed the right to bring § 1983 challenges under federal laws that do not explicitly confer a private right of action, like the Medicaid Act. *See* Health & Hosp. Corp. of Marion County v. Talevski, 599 U.S. 166, 192 (2023) (holding that nursing home residents had a private right of action to enforce rights under the Federal Nursing Home Reform Act when their care is being paid for by Medicaid). "The Talevski decision preserves Section 1983 rights in Medicaid unwinding and other situations in which vital federal rights conferred by Medicaid are harmed." Sara Rosenbaum & MaryBeth Musumeci, *U.S. Supreme Court Preserves Medicaid Beneficiaries' Rights*, COMMONWEALTH FUND (June 15, 2023), https://perma.cc/ES6Q-C8UM.

be federally-imposed, courts will apply the same standard in each case. This will eliminate the current inconsistencies apparent in litigation.

Because Medicaid is largely a state-administered program, federalizing the EPSDT medical necessity definition is likely to receive criticism as defying principles of federalism.[311] However, there is no constitutional prohibition against federalizing the EPSDT medical necessity definition.[312] In fact, outside the context of Medicaid, medical standards are largely uniform. For example, national standards govern the practice of medicine, and these standards are accepted by courts across the country in medical malpractice litigation.[313] Federal law, in contexts other than Medicaid, has also shifted towards nationalizing medical care.[314] Accordingly, it is clear that, outside the context of Medicaid, some level of nationalization with regard to the

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311. *But see* Nicole Huberfeld, *Federalizing Medicaid*, 14 U. PA. J. CONST. L. 431, 473–79 (2011) (explaining how Medicaid financing and standards of medicine in other areas of law are already federalized and arguing that Medicaid ought to be federalized).

312. Constitutional challenges are likely whenever the federal government acts in an area where states hope to maintain autonomy. This is particularly true where, as under this suggestion, the federal government's action would likely result in increased costs for the states, a byproduct of requiring states to cover the costs of more medical services and treatments. *See* Mitchell, *supra* note 174, at 206–07 (describing the current Medicaid system, under which states capitalize on the flexibility afforded to them in designing their state plan to cut costs). However, such challenges to the proposed solution are meritless.

The Spending Clause affords Congress the authority to "to pay the [d]ebts and provide for the common [d]efence and general [w]elfare of the United States." U.S. CONST. art. I. § 8, cl. 1. And under the Necessary and Proper Clause, Congress can "make all laws" necessary to carry out its obligations, including promoting "general welfare." *Id.* cl. 18. Court precedent illustrates that promoting "general welfare" includes establishing and funding national programs, like Medicaid. *See* Helvering v. Davis, 301 U.S. 619, 645 (1937) (holding that the federal government's operation of Social Security benefits for elderly Americans was constitutional). Taken together, these constitutional principles afford Congress the ability to follow the proposed conduct.

313. *See* Huberfeld, *supra* note 311, at 476–77 (describing national licensing exams that doctors must pass to practice in the United States, as well as the shift in medical malpractice litigation from relying on local standards of practice to national standards of practice in determining the appropriate standard of care).

314. *See, e.g.*, Emergency Medical Treatment and Labor Act, 42 U.S.C. § 1395dd.

practice of medicine has been accepted. In fact, the localized regulation of medical decision-making in Medicaid is unique—acceptable for Medicaid beneficiaries but not acceptable for the general public. Thus, federalizing a small component of one particular Medicaid benefit is not as radical a change as it may seem on its face.

Similarly, this approach does not fully restrict states from regulating pediatric providers. For example, fraud and abuse laws[315] will still apply and states can review medical provider's work for compliance with these laws. Doctors will remain subject to other standards, like acting in accordance with the appropriate standard of care.[316] Thus, while codifying a federal definition for medical necessity may impact states' ability to control the costs of their EPSDT programs, it will not eliminate the states' roles in exercising oversight over the medical field.

Ultimately, if federal lawmakers establish a comprehensive, uniformly applied definition of medical necessity for the EPSDT benefit, CMS and state Medicaid agencies will be able to better administer the benefit. This benefits the children that EPSDT seeks to support, allows providers to treat their patients most effectively, and allows the

315. For example, the False Claims Act ("FCA") makes it unlawful for medical providers to knowingly submit false or fraudulent Medicare or Medicaid claims to the government. 31 U.S.C. § 3729. The knowledge standard includes instances where the medical provider acts with "deliberate ignorance" or "reckless disregard of the truth or falsity of the information." *Id.* § 3729(b)(1)(A)(ii)–(iii). FCA violations may result in both civil and criminal penalties. *See id.* § 3729(a)(1)(G); 18 U.S.C. § 287.

316. The "standard of care" is a concept in medical malpractice litigation that requires physicians to perform their duties in a way that a reasonable provider with the same training would. *See* Kipfinger v. Great Falls Obstetrical & Gynecological Assocs., 525 P.3d 1183, 1195–96 (Mont. 2023) (analyzing the standard of care element in medical malpractice litigation). It places fault on those who do not practice at the requisite level. *See id.* at 1195 ("[T]he breach element of a medical malpractice claim generally requires proof, in the form of qualified expert testimony on a more probable than not basis, that the alleged error or omission breached, i.e., deviated from, the applicable standard of medical care."). Previously, the standard of care was determined by local standards. *See, e.g.*, Hall v. Hilbun, 466 So. 2d 856, 866 (Miss. 1985), *superseded by statute on other grounds*, MISS. CODE ANN. § 85-5-7 (2024) (defining the locality rule as requiring physicians to perform services with the reasonable care that a physician "standing in the same neighborhood or locality" would). The locality rule faced criticism as medical training, resources, and uniform standards are now common. *Id.* at 870.

benefit to live up to its intended purpose of providing broad health care coverage for America's youth.

B. *Establishing a Judicial Test for the ESPDT Medical Necessity Standard*

As explained above, children who are denied coverage based on a lack of medical necessity frequently turn to the courts for redress. Because of the practical challenges of establishing a federal definition of medical necessity, setting a judicial test or standard for judges to apply in EPSDT litigation may be the most feasible solution to addressing health coverage disparities for EPSDT beneficiaries. This solution comes at lower political costs and still ensures increased uniformity for children across the United States.

To ensure fair results, the judicial test for medical necessity in EPSDT litigation should impose a burden shifting framework.[317] First, a child should establish that they were denied coverage for services that a medical provider determined were medically necessary. Once established, this should give rise to an inference of impropriety on behalf of the state. Then, the burden should shift to the state to show why the proposed treatment or services are *not* medically necessary. Judges should require state agencies to show that they have engaged in a case-by-case review of the child's circumstances. This review should involve a direct medical examination of the child by a licensed medical professional, as opposed to routine reviews of medical records by nonmedical professionals. Finally, if the state is successful in its showing, the burden should shift back to the child to demonstrate that care is in fact medically necessary. This might be done via a showing that the state's

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317. This type of burden shifting framework is utilized in several contexts. For example, in the employment context, the McDonell Douglas burden shifting framework allows employees to bring discrimination claims when there is no direct evidence of discrimination. *See* McDonnell Douglas Corp. v. Green, 411 U.S. 792, 802 (1973). This framework allows complex, fact-specific cases to be litigated fairly. *See id.* at 802 n.13 ("The facts necessarily will vary in Title VII cases, and the specification above of the prima facie proof required from respondent is not necessarily applicable in every respect to differing factual situations."). The complexity and fact-specific nature of Title VII claims is similar to the complexity and fact-specific nature of medical necessity determinations discussed throughout this Note.

evidence was insufficient or that the state failed to fully address the specific needs of the child.

In applying this test, courts should act consistently with the caselaw described above, where they provide significant deference to the child's treating physician.[318] This provider, who often has treated the child for a significant period of time, is "the expert" when it comes to making medical treatment decisions.[319] They are more familiar than state agency bureaucrats with the child's needs, condition, and the likelihood of effective treatment. Accordingly, their opinion should be given substantial weight.

This solution provides significant improvements from the current system. First, it will ensure that judges stop applying the adult Medicaid standard for medical necessity in EPSDT cases. This is consistent with the legislative history of the benefit and will allow the benefit to fulfill its promise of broad and comprehensive coverage for children.[320] Additionally, it will minimize the role that judges play in making important health care coverage determinations for children. Instead, medical practitioners, who are experts in the field, will rightfully be responsible for making medical necessity determinations. Taken together, these benefits are likely to produce more predictable and equitable health care coverage outcomes for children.

But this test will not address the root cause of the issue. The existing variation that states have in their parameters for medical necessity, including variation across their MCO contracts, will endure. However, once families and children seek judicial redress, the process will be more efficient and meaningful if the courts have a standard to apply in these cases. Judicial application of the burden shifting framework will ultimately produce more equitable outcomes that are consistent with the legislative intent of providing a comprehensive benefit to children.

318. *See supra* notes 286–298 and accompanying text.

319. Hunter v. Chiles, 944 F. Supp. 914, 922 (S.D. Fla. 1996).

320. *See supra* Part III.A.

C. *Making Patient Advocates Available for Families Receiving EPSDT Services*

The health care system is complicated. The complexities and nuances of health care coverage and benefits are only exacerbated in the context of specific benefits, like EPSDT. While the two proposed solutions discussed above are broad and likely would make a large impact, this third proposed solution may offer a more immediate response to the issue. This subpart suggests that dedicated patient advocates, made accessible to children covered by the EPSDT benefit and their guardians, will make the most immediate impact in terms of navigating issues related to medical necessity and coverage denials.

Patient advocates are an important resource for patients as they navigate the health care system.[321] They serve in a wide array of capacities. Traditionally, patient advocates help patients understand their medical bills, access their medical records, and, when appropriate, apply for financial assistance.[322]

Patient advocates are employed in a variety of capacities.[323] For example, many hospitals employ patient advocates.[324] These individuals work with patients who are receiving services at the hospital.[325] Similarly, private employers increasingly make patient advocates available to their employees and their family members.[326] Sometimes, these advocates are available to

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321. *See Why Healthcare Advocacy Is Important*, TUL. UNIV. SCH. PUB. HEALTH & TROPICAL MED. (Mar. 1, 2021), https://perma.cc/N7B3-JJE4 (explaining that, because "52 percent of patients in the U.S. cannot navigate the healthcare system's complexity without help," patient advocates are an important resource for patients and family members).

322. *See generally Find a Patient Advocate*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://perma.cc/8K9Z-CXHL (last visited Feb. 14, 2024).

323. *See Why Healthcare Advocacy Is Important*, *supra* note 321 ("Employers, insurance companies, and hospitals may also offer patients health advocates.").

324. *See, e.g.*, *Patient Advocates*, SENTARA, https://perma.cc/727T-H4MN (last visited Feb. 14, 2024) (advertising the availability of patient advocates to assist patients "with problem solving" and helping patients by "facilitat[ing] questions, concerns and complaints").

325. *See id.*

326. *See, e.g.*, *Why Healthcare Advocacy Is Important*, *supra* note 321.

employees whether or not the employee participates in the employer's health insurance plan.[327]

Likewise, the U.S. Department of Veterans Affairs ("VA") makes patient advocates available at every VA medical center.[328] These advocates are a resource for all VA benefit recipients at all stages of care.[329] Whether the patient disagrees with a medical provider's care plan or is concerned about billing, they can obtain a patient advocate to answer questions and support them as they resolve issues.[330]

Medicaid's EPSDT benefit does not have a dedicated patient advocate system that is comparable to the patient advocate systems often found in the context of private employer-sponsored insurance or VA benefits. Instead, EPSDT dialogue often refers to the role of lawyers and doctors as advocates for their patients in the medical legal partnership ("MLP") model.[331] However, unlike the VA system, where each clinic has at least one patient advocate, MLPs are not available at every clinic that treats children covered by EPSDT.[332] Indeed, MLP availability is not yet widespread.[333] Thus, while the MLP

327. *See, e.g.*, *Health Advocate*, PRINCETON U., https://perma.cc/F6KP-ZZUZ (last visited Feb. 14, 2024).

328. *See Patient Advocates*, U.S. DEP'T VETERANS AFFS., https://perma.cc/5VBN-HTJQ (last updated May 11, 2015).

329. *See id.*

330. *See id.*

331. The term Medical Legal Partnerships ("MLP") refers to "[a] concerted collaborative effort among lawyers and health care providers to identify EPSDT implementation issues and advocate for appropriate review and coverage standards." Mitchell, *supra* note 174, at 210. MLPs integrate legal and medical work through a method of reciprocity. *See id.* Doctors identify patient's "health-harming legal needs" and lawyers advocate for the patients. *Id.* at 211. These partnerships are undeniably valuable in ESPDT administration. *See id.* at 216 ("MLPs are uniquely suited to identify and address EPSDT implementation issues because they provide a framework for meaningful education and collaboration among experts on Medicaid law and pediatric care."). This Note does not purport to discuss the MLP model or the potential extent of its benefit to EPSDT recipients in depth but encourages readers to become familiar with the model as another avenue to address the shortcomings of EPSDT administration and coverage.

332. *Cf. id.* at 216–30 (providing some examples of MLPs that operate in the EPSDT context and explaining how the model can be applied on a widespread basis to benefit more EPSDT recipients).

333. For example, the Health Service Resource Administration funds nearly 1,400 health centers across the country. *Health Center Program: Impact*

advocacy model may eventually be effective for administration of EPSDT's benefit, MLPs have not been implemented widely enough to address the needs of EPSDT beneficiaries.

Instead of relying on MLPs, the traditional patient advocacy model utilized by employer-sponsored insurance plans and present in the VA health benefit system should be replicated for EPSDT program administration. Dedicated professionals with knowledge of EPSDT requirements and administration should be made readily available to guardians and children. Though it would be impractical to make these advocates available at every medical office that treats EPSDT beneficiaries, as is the case under the VA model, these advocates should be made available at the state level. Each state should employ enough advocates to address the needs of benefit recipients. The roles of these advocates should not be conflated with social workers or other support staff that already work with families in the realm of social services. Instead, patient advocates should have a distinct role in health care coverage.

Initially, implementing the patient advocate model might seem costly and impractical. However, despite front-end costs, such as paying salaries to advocates, it is likely that both administrative and litigation costs will decrease over time. Patient advocates can explain how medical necessity determinations are made in language that parents can understand. In turn, parents will be better informed when making decisions regarding if and how they would like to proceed in the case of an unfavorable medical necessity determination. This will benefit both EPSDT recipients and the state.

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and Growth, HEALTH RES. & SERVS. ADMIN., https://perma.cc/5EZ7-BLF6 (last visited Feb. 19, 2024). Many children and Medicaid recipients receive services at these federally funded centers. *See id.* (noting that, in 2022, one in nine children received care at these centers as well as "[m]ore than 24.2 million uninsured, Medicaid, and Medicare patients"). However, the National Center for Medical-Legal Partnership reports that MLPs operate at only 163 HRSA-funded health centers. *FAQs*, NAT'L CTR. FOR MED.-LEGAL P'SHIP, https://perma.cc/U6M6-8HFU (last visited Feb. 19, 2024). This disparity illustrates that, despite the functionality of MLPs, they are still not available with enough frequency for the EPSDT population to rely on them.

CONCLUSION

Varied medical necessity standards and interpretations across EPSDT are problematic, especially for the increasing population of children suffering from mental health conditions. Given the amorphous nature of many mental health conditions, the meaning of medical necessity is particularly important to these children. Whereas what is medically necessary to address routine physical conditions, like a broken bone, is relatively straightforward, what is medically necessary to address chronic medical issues, including serious mental health conditions, is much more complex. Oftentimes, these pediatric patients require ameliorative services, a hallmark of the EPSDT benefit. Thus, EPSDT coverage is crucial for ensuring their health and wellbeing.

However, federal law and guidance regarding medical necessity for the EPDST benefit is vague and the term is not well-defined. Accordingly, states have substantial flexibility in defining medical necessity for EPSDT. Cunning states have capitalized on this flexibility by setting parameters that significantly limit the ease with which children can access coverage for services that their providers have deemed medically necessary. When this occurs, families have often turned to the judicial system for redress. However, courts sometimes empower states to restrict medically necessary coverage. In short, given the continued dissimilarity in legal, administrative, and judicial construction of the medical necessity standard, EPSDT fails to satisfy its purpose.

Change is necessary. Federal legislators should consider amending the Medicare and Medicaid Act to include a distinct, clear definition of medical necessity under EPSDT. This will reduce the variation in medical necessity that produces the current inequalities. There should also be a clear judicial test to be applied in EPSDT medical necessity litigation. This test should clearly identify the standard under which these cases should be reviewed, and it should be patently different from the standard applied in adult Medicaid cases. Finally, the patient advocate model poses a viable solution to address medical necessity challenges, avoiding litigation altogether. Given the magnitude of the youth mental health crisis, implementing all or any combination of these solutions will likely produce positive impacts on the health of children covered by the EPSDT benefit.