

**UNITED STATES DISTRICT COURT  
EASTERN DISTRICT OF NEW YORK**

**C.K.** through his next friend **P.K.**; **C.W.**  
through her next friend **P.W.**, for themselves  
and those similarly situated,

**Plaintiffs,**

**v.**

**Mary T. Bassett**, in her official capacity as  
Commissioner of the New York State Department  
of Health; **Ann Marie T. Sullivan**, in her official  
capacity as Commissioner of the New York State  
Office of Mental Health,

**Defendants.**

C/A No. \_\_\_\_\_

**CLASS ACTION COMPLAINT FOR INJUNCTIVE  
AND DECLARATORY RELIEF**

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## NATURE OF THE CASE

1. This action arises out of New York State’s well-known and longstanding failure to provide Medicaid-eligible children with legally required mental health care.

2. The Named Plaintiffs are Medicaid-eligible children with mental health conditions who require intensive home and community-based mental health services in order to correct or ameliorate their conditions while remaining safely at home and in their communities. They bring this action on behalf of themselves and two classes of similarly-situated children against Defendants Mary T. Bassett, M.D., in her official capacity as Commissioner of the New York State Department of Health (“DOH”), and Ann Marie T. Sullivan, M.D., in her official capacity as Commissioner of the New York State Office of Mental Health (“OMH”).

3. New York’s most marginalized children are facing a mental health crisis. The State’s mental health system for Medicaid-eligible children is languishing in a state of dysfunction, providing inadequate, inaccessible, and woefully underfunded mental health services.

4. While federal law requires Defendants to provide timely access to an array of intensive home and community-based mental and behavioral health services, the reality is that these critical services are either not being provided at all, not being provided in sufficient quantity, frequency, and duration, or not being provided in a timely manner. For thousands of children comprising the “EPSDT Class” (defined in ¶¶ 52, 168), these failures by the State violate the Medicaid Act. For thousands of children comprising the “ADA Class” (defined in ¶¶ 52, 169), Defendants’ failures also violate Title II of the Americans with Disabilities Act (the “ADA”) and Section 504 of the Rehabilitation Act (“Section 504”).

5. Medicaid-eligible children have the right to receive medically necessary mental health services under the Early and Periodic Screening, Diagnostic, and Treatment Services

(“EPSDT”) provisions of the Medicaid Act. 42 U.S.C. § 1396a(a)(10)(A); 42 U.S.C. § 1396a(a)(43); 42 U.S.C. § 1396d(a)(4)(B); 42 U.S.C. § 1396d(r). They also have the right to receive such medically necessary mental health services in a timely manner under the Reasonable Promptness provision of the Medicaid Act. 42 U.S.C. § 1396a(a)(8). Defendants’ failure to provide or arrange for such mental health services for New York’s Medicaid-eligible children, and their failure to make them available on a timely basis, violate the EPSDT and Reasonable Promptness provisions of the statute.

6. Specifically, under the EPSDT provisions of the Medicaid Act, Defendants are required to provide or arrange for certain intensive home and community-based mental health services (“IHCB-EPSDT Services”) for Medicaid-eligible children for whom such services are a medical necessity. The required IHCB-EPSDT Services include:

- (a) **Intensive Care Coordination** – an assessment and service planning process conducted through a child and family team that coordinates services across multiple systems that serve the child and family, and manages all the care and services they need. This includes assessment and service planning, assistance in accessing and arranging for mental health services (including mobile crisis services), coordinating multiple mental health services, advocating for the child and the child’s family, monitoring the child’s progress, and transition planning, as required under 42 U.S.C. §§ 1396d(a)(13), 1396d(a)(19), and 1396n(g)(2).
- (b) **Intensive, home-based behavioral services** – intensive behavioral services and supports coverable as rehabilitation services as required under 42 U.S.C. § 1396d(a)(13), including individualized therapeutic interventions, provided on a frequent and consistent basis, that are designed to improve behavior and are delivered to children and families in the child’s home or any setting where the child is naturally located.
- (c) **Mobile Crisis Services** – intervention services that can respond to a child’s acute mental health emergency quickly and wherever needed coverable as rehabilitative services and targeted case management as required under 42 U.S.C. §§ 1396d(a)(13), 1396d(a)(19), and 1396n(g)(2).

7. New York State purports to include certain IHCB-EPSDT Services as part of a package of services called Children and Family Treatment and Support Services, but these

services do not comprise all of the required IHCB-EPSDT Services, and in any event are not actually provided to all eligible children for whom they are medically necessary. New York does not have sufficient numbers of practitioners available to provide the required services to the class members who are entitled to them, and to provide these services in sufficient quantity, frequency, and duration, and in a timely manner. Defendants also fail to maintain processes for monitoring the extent to which children are unable to obtain these required services and identifying the need for corrective action.

8. State officials have known about these gaps in care for years, but have failed to address them.

9. Without access to the services they need to remain in their homes, children with mental health disabilities also are unnecessarily segregated in residential treatment facilities, residential treatment centers, psychiatric centers, and other segregated settings, or are at serious risk of institutionalization. Defendants thus fail to provide mental health services to these children in the “most integrated” setting, which would enable them to interact with their communities to the fullest extent possible, as required by the ADA and Section 504. *See* 42 U.S.C. § 12132 *et seq.*; 29 U.S.C. § 794; *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 (1999).

10. Plaintiffs’ ADA and Section 504 claims are based on Defendants’ failure to provide Medicaid-eligible children with the IHCB-EPSDT Services listed above, as well as additional services defined by DOH as “Home and Community-Based Services,” which are services that the State agreed to fund under a federal waiver of certain Medicaid-related funding restrictions (the “HCBS Waiver Services”). The HCBS Waiver Services are specifically designed to prevent children from being unnecessarily institutionalized and allow them to remain

in their homes and communities. But here again, Defendants have failed to implement these HCBS Waiver Services in any meaningful way, and these services are not actually available to the children who are eligible for them.

11. The impact of these statutory violations on Medicaid-eligible children is devastating. In the absence of the intensive home and community-based mental health services they need, and to which they are legally entitled, their mental health conditions continue to deteriorate, causing disruption and harm to the children, their education, their families and relationships, their future adulthood, and their very lives. Without adequate services, families in crisis often have no alternative but to rely on hospital emergency rooms to provide short-term care that fails to address the child's underlying conditions. Children also are unnecessarily placed in psychiatric hospitals and similar institutions for extended periods, where they are separated from their families and communities and fail to thrive. Too many children are stuck in a vicious cycle of repeated emergency room visits and repeated institutionalization, without receiving the intensive home and community-based services they actually need for their conditions to improve.

12. Defendants' violations disproportionately affect LGBTQIA+ youth, youth from low-income families, and people of color who already face myriad struggles that harm their mental and behavioral health, including discrimination in all its manifestations.

13. As but one example, without intensive home and community-based mental health services, children experiencing mental health crises are often confronted by law enforcement as the only available emergency responders, a situation fraught with danger, particularly for youth of color.

14. Plaintiffs seek declaratory and injunctive relief to enforce the Medicaid Act, the ADA, and Section 504, and to require Defendants to undertake the steps necessary to cure the violations of these statutes described more particularly in this Complaint.

### **JURISDICTION AND VENUE**

15. This action is brought under 42 U.S.C. § 1983 because Defendants, and each of them, acting under color of state law, have deprived the Named Plaintiffs, and the class members they represent, of rights secured by federal statutory law.

16. This action arises under the Medicaid Act, Title II of the ADA, and Section 504. Accordingly, this Court has jurisdiction over the subject matter of this action under 28 U.S.C. § 1331 (federal question jurisdiction) and 28 U.S.C. § 1343 (civil rights jurisdiction).

17. Venue is proper in this district pursuant to 28 U.S.C. § 1391(b) because Defendants are sued in their official capacity and perform their official duties by and through offices within the district and thus reside therein, and a substantial part of the events and omissions giving rise to the claims herein occurred in this district. One of the Named Plaintiffs resides in this District.

### **PARTIES**

#### **I. NAMED PLAINTIFFS**

##### **A. Plaintiff C.K.**

18. Plaintiff C.K. is a biracial, 15-year-old Medicaid recipient from Suffolk County, New York, who has been diagnosed with multiple mental and behavioral conditions. He brings this action through his mother, P.K.

19. C.K. loves working with animals, visiting animal shelters, listening to music, playing video games, and watching football.



20. C.K.'s mental and behavioral health conditions first became evident when he was a young child. At three years old, he was diagnosed with Attention Deficit Hyperactivity Disorder ("ADHD"). C.K. has since been diagnosed with the following additional conditions: Bipolar Disorder, Depression, Anxiety, Intermittent Explosive Disorder, Oppositional Defiant Disorder, and Avoidant/Restrictive Food Intake Disorder.

21. C.K. has been prescribed medications, including psychotropic medications. He is currently receiving Concerta and Prozac. Over the years, he has also been prescribed Risperdal, Depakote, Zoloft, Abilify, Lithium, and Seroquel.

22. C.K.'s mental health has been negatively affected by Defendants' failure to provide IHCB-EPSDT Services, and to provide such services in a timely manner and in the quantity, frequency, and duration he needs and to which he is legally entitled.

23. Qualified professionals have determined that C.K.'s mental health conditions have substantially limited his ability to engage in major life activities, including his functioning in family, school, and community activities.

24. A licensed practitioner of the healing arts has recommended that C.K. receive IHCB-EPSDT Services, including community psychiatric supports and treatment, psychosocial rehabilitation, and family peer support services (*see* ¶ 111 below).

25. In addition, C.K. was determined eligible to receive HCBS Waiver Services, including community self-advocacy treatment and supports, pre-vocational services, and respite services (*see* ¶ 124 below). Respite services are intended to provide C.K. with short-term assistance, in either planned or crisis situations, to address his mother's need for temporary relief from her primary caregiver responsibilities.

26. C.K.'s mother, P.K., has repeatedly sought IHCB-EPSDT Services and HCBS Waiver Services in order to keep C.K. safely at home.

27. Since he was first hospitalized for mental health reasons at the age of four, C.K. has cycled in and out of hospitals, emergency rooms, and residential treatment centers. For example, by the time he was nine years old, C.K. had been sent to a community residence and soon thereafter to a residential treatment center. By the time he was 10 years old, C.K. had experienced approximately 16 hospital stays for mental health treatment. Between August 2017 and August 2019, when he was 10 to 12 years old, C.K. was again placed in a residential treatment center for his mental health conditions. Between July 2020 and January 2021, C.K. was hospitalized for psychiatric treatment on several occasions, and from April to June 2021, C.K. was again placed in a community residence for adolescents because of his mental health conditions and related behaviors. On July 20, 2021, C.K. was readmitted to a psychiatric hospital as an inpatient for two weeks. He was then placed in a partial hospitalization program for two more weeks where he was in a treatment program during the day at a psychiatric hospital and was sent home at night. The out-of-home placements in the past two years were typically the result of C.K.'s suicidality and suicidal ideation.

28. In the absence of IHCB-EPSDT Services and HCBS Waiver Services, C.K. has repeatedly engaged in self-harm and expressed suicidal thoughts both in the community and in residential settings.

29. For example, in September 2021, C.K. jumped out of a car he was riding in with P.K. and ran into traffic in an effort to be hit by another passing car. When brought to the emergency room, C.K. expressed that another round of hospitalizations would do him no good, and that what he needed were services to teach him coping skills.

30. C.K. has not received timely access to the IHCB-EPSDT Services and HCBS Waiver Services that he was recommended as needing two and a half years ago.

31. Upon his discharges from residential treatment centers and hospitals, C.K. has each time returned home without receiving the IHCB-EPSDT Services he needs to succeed in the community. In fact, services were either not provided at all or were delayed and sporadic. The IHCB-EPSDT Services that C.K. needs are simply not available.

32. For example, following his discharge from a residential treatment center in August 2019, C.K. waited six months to receive one of the IHCB-EPSDT Services determined medically necessary for him and nine months to receive another. C.K. did not receive other IHCB-EPSDT Services and the HCBS Waiver Services for which he was eligible. In light of C.K.'s mental health conditions and the urgency of his mental health needs, the long delay in providing C.K. any IHCB-EPSDT Services – along with the failure to provide C.K. with other IHCB-EPSDT services at all – was inappropriate and unreasonable, causing C.K. further harm.

33. Although C.K. has been assigned to various care managers through provider groups known as “Health Homes,” C.K. has never been provided the intensive care coordination he needs and which is required under the Medicaid Act. The Health Homes have merely sent referrals for various uncoordinated IHCB-EPSDT Services and HCBS Waiver Services to mental health providers and reported back to C.K.'s mother.

34. Defendants have failed to provide or arrange for medically necessary IHCB-EPSDT Services for C.K. They have also failed to provide HCBS Waiver Services specifically designed to allow him to remain in his home. Although C.K. is now living at home, C.K.'s mental health has continued to deteriorate and he has been placed at serious risk of institutionalization. Without the IHCB-EPSDT Services and HCBS Waiver Services to which he

is entitled, C.K. will continue to be at serious risk of becoming unnecessarily institutionalized and his condition will continue its downward spiral.

35. C.K. desires to receive intensive mental health services in his home and other community-based settings.

**B. Plaintiff C.W.**

36. Plaintiff C.W. is a Black, 13-year-old Medicaid recipient from Monroe County, New York, who has been diagnosed with multiple mental and behavioral conditions. She brings this action through her family member and guardian, P.W., with whom C.W. has lived since she was an infant, and who has been her primary caregiver.

37. C.W. is an active, engaging youngster who enjoys drawing, arts and craft activities, including building things, dance, and gymnastics. C.W. also likes participating in other sports, watching TV, and playing video games.

38. C.W.'s mental and behavioral health conditions first became evident when she was a young child; she was first diagnosed with ADHD nearly a decade ago, and C.W. has since been diagnosed with the following conditions: Psychotic Disorder – Unspecified Schizophrenia Spectrum and Other Psychotic Disorder; Reactive Attachment Disorder; ADHD; Generalized Anxiety Disorder; Intermittent Explosive Disorder; Trauma and Stressor-Related Disorder; Oppositional Defiant Behavior; Other Specified Anxiety Disorder; Chronic Stress Disorder; and Other Specified Persistent Mood Disorder.

39. C.W. has long been prescribed and has taken psychotropic medication. As a young child, C.W. was prescribed Clonidine to treat impulsivity. Since then, C.W. has had an extensive history of receiving multiple other psychiatric medications. For example, by June 2019, C.W. was taking Clonidine, Sertraline (Zoloft), Risperidone, and Adderall (to treat her

ADHD). At any given time from February 2020 to November 2021, C.W. was taking three to five psychotropic medications concurrently. Most recently, C.W. has been prescribed Seroquel XR, Lithium Carbonate, and Intuniv.

40. C.W.'s mental health has been negatively affected by Defendants' failure to provide IHCB-EPSDT Services, and to provide such services in a timely manner and in the quantity, frequency, and duration she needs and to which she is legally entitled.

41. Qualified professionals have determined that C.W.'s mental health conditions have substantially limited her ability to engage in major life activities, including her functioning in family, school, and community activities.

42. A licensed practitioner of the healing arts has recommended that C.W. receive IHCB-EPSDT Services, including community psychiatric supports and treatment services (*see* ¶ 111 below).

43. C.W.'s guardian P.W. has repeatedly sought intensive therapeutic interventions in order to keep C.W. safely at home.

44. In September and December 2018, P.W. was informed that C.W. was on a waiting list for home and community-based skill building mental health services. In January 2019, P.W. was informed that C.W. had been referred instead for psychosocial rehabilitation services under Children and Family Treatment and Support Services (*see* ¶ 111 below). Four months later, C.W. still had not received any services. As a result, C.W. cycled in and out of comprehensive psychiatric emergency programs ("CPEP") five times, often waiting many hours before seeing a doctor, only to be told to go home without receiving any treatment.

45. When one IHCB-EPSDT Service, community psychiatric supports and treatment, was finally provided in May 2019, C.W. received this service only sporadically – fewer than ten

times by September 2019 when the provider left her job and the services ceased. No provider has since provided C.W. the medically necessary IHCB-EPSDT Services she needs and is legally entitled to receive.

46. Given the nature of C.W.'s mental health conditions and the urgency of her mental health needs, Defendants' long delay in providing C.W. any IHCB-EPSDT Services and their failure to provide her with necessary IHCB-EPSDT services have caused C.W. harm.

47. In the absence of adequate treatment and services, C.W.'s mental health and behavioral conditions continued to deteriorate, resulting in her becoming verbally and physically aggressive. C.W. fought with her guardian and also experienced episodes of self-harm and suicidality. From March to April 2020, C.W. was admitted twice to an inpatient psychiatric unit, once for one week and once for two weeks. During her hospitalizations, staff placed her in seclusion, and restrained her with physical and chemical (medication) restraints.

48. Defendants have failed to provide or arrange for medically necessary IHCB-EPSDT Services for C.W. or provide her with HCBS Waiver Services, all of which would improve her condition and enable her to remain at home. Due to the lack of these services, C.W.'s stability and emotional state continued to decline. P.W. was advised to place C.W. in a residential treatment facility and to medicate her. The IHCB-EPSDT Services that C.W. needs are simply not available.

49. In April 2020, C.W. was admitted to a residential treatment facility. Staff members at the facility reported that C.W. struggled at night with anxiety, often requesting that someone sit outside her door so she could fall asleep. A psychological evaluation stated that:

“[C.W.] is easily upset, is sad, changes mood quickly, and often says ‘I hate myself,’ ‘I can’t do anything right,’ and ‘Nobody likes me.’ . . . [S]he reported ‘I don’t like myself, how I am, I feel ugly and stupid, like a person who is not supposed to be.’”

50. On top of everything else, C.W.'s weight increased significantly after her admission to the facility. C.W.'s condition continued to deteriorate. In October 2021, C.W. was then moved to an intensive treatment unit, an even more restrictive inpatient setting. C.W. has now languished in residential care for almost two years. Without the medically necessary intensive home and community-based mental health services to which she is entitled, C.W. will continue to remain institutionalized and her condition will continue to get worse.

51. C.W. desires to receive mental health services in her home and other community-based settings.

### **C. The Proposed Classes**

52. Each Named Plaintiff is a member of and represents both of the following classes:

a. The EPSDT Class is defined as all current or future Medicaid-eligible children in New York State under the age of 21 (a) who have been diagnosed with a mental health or behavioral condition, not attributable to an intellectual or developmental disability, and (b) for whom a licensed practitioner of the healing arts has recommended IHCB-EPSDT Services to correct or ameliorate their conditions.

b. The ADA Class is defined as all current or future Medicaid-eligible children in New York State under the age of 21 (a) who have been diagnosed with a mental health or behavioral condition, not attributable to an intellectual or developmental disability, that substantially limits one or more major life activities, (b) for whom a licensed practitioner of the healing arts has recommended IHCB-EPSDT Services to correct or ameliorate their conditions or who have been determined eligible for HCBS Waiver Services, and (c) who are segregated, institutionalized, or at serious risk of becoming institutionalized.

## II. DEFENDANTS

53. Defendant Mary T. Bassett, M.D., who is being sued only in her official capacity, is the Commissioner of DOH.

54. DOH is the “single state agency” responsible for oversight and implementation of the Medicaid program in New York and compliance with all federal requirements. *See* 42 U.S.C. § 1396a(a)(5); 42 C.F.R. § 431.10; N.Y. Soc. Serv. Law § 363-a(1)-(2).

55. As the state agency charged with administering the Medicaid program, DOH has “inherent authority to protect the quality and value of services rendered by providers” in that program. *See Matter of LeadingAge N.Y., Inc. v. Shah*, 32 N.Y.3d 249, 262 (2018)(citation omitted).

56. Defendant Bassett is responsible for overseeing the Medicaid program and all of its policies and practices, including its contracts with managed care plans to carry out the State’s responsibility to provide Medicaid covered services, including IHCB-EPSDT services. N.Y. Soc. Serv. Law §§ 364(2), 364-j, 367-a. DOH is also responsible for regulating and setting Medicaid reimbursement rates for all Medicaid services.

57. The Commissioner of DOH also sets standards for “health home” services, New York’s manner of ostensibly providing care coordination, including their structure and eligibility conditions. N.Y. Soc. Serv. Law § 365-l.

58. With regard to providing mental health services to Medicaid recipients, DOH delegates certain responsibilities to OMH pursuant to a cooperative agreement between the agencies, as required by state regulations. N.Y. Soc. Serv. Law §§ 364-a(2), 365-m.

59. Defendant Ann Marie T. Sullivan, M.D., who is being sued only in her official capacity, is the Commissioner of OMH.



60. OMH develops, licenses, and regulates Medicaid-funded programs serving individuals with mental illness. N.Y. Mental Hyg. Law §§ 7.07(a), 7.09, 7.15.

61. OMH is further charged with ensuring that the care and treatment of individuals with mental illness is of “high quality and effectiveness.” N.Y. Mental Hyg. Law § 7.07(c).

62. Defendant Sullivan is responsible for ensuring that services for people with mental illness are periodically evaluated, “that departmental budget requests reflect such evaluations,” and for creating rules and regulations regarding the evaluation criteria and methods used. N.Y. Mental Hyg. Law § 31.01. State law further entrusts Defendant Sullivan with the authority to adopt regulations to implement “any matter under [her] jurisdiction.” N.Y. Mental Hyg. Law § 7.09(b).

63. Defendants Bassett and Sullivan are also responsible for promulgating rules and regulations for the operation and funding of programs that expand the existing home and community-based system of mental health services. N.Y. Mental Hyg. Law § 41.49.

## **STATEMENT OF FACTS**

### **I. STATUTORY BACKGROUND**

#### **A. The Medicaid Act and the EPSDT Mandate**

64. Medicaid is a cooperative federal-state program that directs federal funding to states to assist them in providing medical assistance to low-income individuals. 42 U.S.C. § 1396(a). States that choose to accept federal funding and participate in the Medicaid program must adhere to the minimum federal requirements set forth in the Social Security Act and its implementing regulations. *See generally* 42 U.S.C. § 1396a(a); 42 C.F.R. § 431.1 *et seq.*

65. To participate in Medicaid, a state must submit and have approved by the Secretary of Health and Human Services a state plan for medical assistance. 42 U.S.C. §§ 1396a, 1396d(a).

66. New York has chosen to participate in Medicaid.

67. The Social Security Act also requires states to provide services in a timely manner. Assistance must be “furnished with reasonable promptness to all eligible individuals.” 42 U.S.C. § 1396a(a)(8); 42 C.F.R. § 435.930(a).

68. “[E]arly and periodic screening, diagnostic, and treatment services . . . for individuals who are eligible under the plan and are under the age of 21” are among the mandatory categories of medical assistance. 42 U.S.C. § 1396d(a)(4)(B). The EPSDT mandate requires states to provide or arrange for such health care, treatment, or other measures that are necessary to correct or ameliorate children’s physical and mental impairments and conditions. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a)(4)(B), 1396d(r)(5).

69. The Medicaid Act explicitly requires every participating state to implement an EPSDT program that:

- (a) provides or arranges for screening services “in all cases where they are requested,” 42 U.S.C. § 1396a(a)(43)(B); and
- (b) provides or arranges for corrective treatment, the need for which is disclosed by such child health screening services, 42 U.S.C. § 1396a(a)(43)(C).

*Rosie D. v. Romney*, 410 F. Supp. 2d 18, 26 (D. Mass. 2006).

70. Under the EPSDT mandate, states must provide and arrange for all of the treatment services covered in 42 U.S.C. § 1396d(a) for Medicaid-eligible children when necessary to “correct or ameliorate . . . mental illnesses and conditions discovered by . . . screening services, whether or not such services are covered under the State plan.” 42 U.S.C. § 1396d(r)(5).

71. Case management services (42 U.S.C. §§ 1396d(a)(19), 1396n(g)) and any “remedial services . . . recommended by a physician or other licensed practitioner of the healing arts . . . for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level” (42 U.S.C. § 1396d(a)(13)(C)) are just some of the home and community-based services that states must provide.

72. Although states may contract with organizations, including managed care entities, to oversee the delivery of services, and may arrange services through provider networks, states retain responsibility for ensuring compliance with Medicaid requirements, including the EPSDT mandates. 42 U.S.C. §§ 1396a(a)(5), 1396a(a)(43), 1396u-2. States must ensure that managed care organizations have the capacity to offer “an appropriate range of services and access to preventive and primary care services” for all enrolled beneficiaries and to maintain “a sufficient number, mix, and geographic distribution” of service providers. 42 U.S.C. § 1396u-2(b)(5).

**B. The ADA, Section 504, and the Integration Mandate**

73. Title II of the ADA, 42 U.S.C. § 12131 *et seq.*, prohibits public entities from discriminating against or excluding a “qualified individual with a disability” from participation in the “benefits of the services, programs, or activities of a public entity” “by reason of such disability.” 42 U.S.C. § 12132; 28 C.F.R. § 35.130.

74. Implementing regulations for Title II of the ADA require public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d).

75. New York State’s mental health service system and Medicaid programs are public entities and, therefore, mental health services must be provided in the most integrated setting appropriate to an individual’s needs.

76. The U.S. Supreme Court has held that “unjustified institutional isolation of persons with disabilities is a form of discrimination” and that the ADA requires states to “provide community-based treatment for persons with mental disabilities when treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.” *Olmstead*, 527 U.S. at 600, 607.

77. Section 504, 29 U.S.C. § 794, imposes identical requirements on programs and activities that receive federal financial assistance. *See, e.g.*, 45 C.F.R. § 84.4(b)(2) (“most integrated setting” regulation).

78. This requirement of the ADA and Section 504 is often referred to as the “integration mandate.”

79. An “integrated setting” is one that “enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.” 28 C.F.R. part 35, App. B.

80. The Department of Justice has further defined “segregated settings” under *Olmstead* as having the “qualities of an institutional nature” and include, but are not limited to:

(1) congregate settings populated exclusively or primarily with individuals with disabilities; (2) congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals’ ability to engage freely in community activities and to manage their own activities of daily living; or (3) settings that provide for daytime activities primarily with other individuals with disabilities.

81. Since *Olmstead*, courts have held that the ADA and Section 504 also prohibit states from placing people with mental illness “at serious risk of institutionalization or segregation,” even if they reside in the community. *See, e.g., Davis v. Shah*, 821 F.3d 231, 262-

263 (2d Cir. 2016); *United States v. Mississippi*, 400 F. Supp. 3d 546, 553 (S.D. Miss. 2019) (collecting decisions).

## **II. THE NEED FOR INTENSIVE HOME AND COMMUNITY-BASED MENTAL HEALTH SERVICES IN NEW YORK**

### **A. Defendants' Longstanding Failure to Provide Medicaid-Eligible Children with Adequate Mental Health Services**

82. Defendants have long failed to provide adequate mental health services, including IHCB-EPSDT Services, and to provide such services in sufficient quantity, frequency, and duration, and in a timely manner, to meet the needs of New York's Medicaid-eligible children.

83. The federal government has recognized the importance of IHCB-EPSDT Services. The Department of Justice has concluded that “[i]n-home and community-based services effectively support children with mental health conditions and can reduce reliance on segregated residential treatment,” thereby “maintaining [children’s] connection to their families and communities.” The Centers for Medicare and Medicaid Services (“CMS”) and the Substance Abuse and Mental Health Services Administration (“SAMHSA”) have explained that home and community-based services have resulted in “[i]mproved clinical and functional outcomes” for children and “significant improvement in the quality of life for . . . children, youth, and family,” including “[r]educed costs of care,” “[i]mproved school attendance and performance,” “[i]ncrease in behavioral and emotional strengths,” “[m]ore stable living situations,” “[r]educd suicide attempts,” and “[d]ecreased contacts with law enforcement.”

84. There are over 2,200,000 children and adolescents enrolled in Medicaid in New York State, tens of thousands of whom are eligible to receive IHCB-EPSDT Services.

85. The mental health treatment needs of New York's Medicaid-eligible youth have long been at crisis levels. More than one in ten teenagers in the State suffer a major depressive

episode, there are surges of youth visiting New York’s emergency rooms due to mental health crises, and suicide has long been one of the leading causes of death for youth aged five to 19.

86. Certain groups of Medicaid-eligible children, including LGBTQIA+ youth, are disproportionately affected by New York’s lack of adequate mental health services. For example, lesbian, gay, and bisexual youths consider suicide at three times the rate of their non-LGBTQIA+ peers.

87. Children of color also suffer disproportionately from inadequate mental health care, including disproportionate risks of suicide. In October 2020, the U.S. Department of Health and Human Services reported to Congress on “African American Youth Suicide” in response to a Congressional committee finding that “African American children aged 5 to 12 are dying by suicide at nearly twice the rate of their white counterparts.” The report concluded, among other things, that “[l]ower rates of current or past mental health problems despite higher rates of past suicide attempts suggests that Black youth have limited access to and/or utilization of mental health services.”

88. The Centers for Disease Control and Prevention found that Black high schoolers in New York State were nearly twice as likely as their white peers to have engaged in a suicide attempt that resulted in an injury, poisoning, or overdose.

89. Defendants are aware of the extent of the mental health crisis in New York. In a December 2019 report, OMH acknowledged that “1 in 10 youth have a serious emotional disturbance,” (often referred to as “SED”), but only “20% of children with SED” receive the “specialty mental health treatment” that they need. OMH further stated that: “A majority of youth in juvenile justice settings and other ‘cross system[s]’ . . . have SED[s]”; “1 in 5 teens experience clinical depression”; and “[s]uicide is the 2[nd] leading cause of death for 15-24 year-

olds.” Mental illness also leads to failure in school. In fact, OMH reported that “[a]pproximately 50% of students with a mental illness age 14 and older drop out of high school.” What’s more, “[h]alf of all lifetime cases of mental disorders begin by age 14.”

90. In the same report, OMH also acknowledged the substantial need for “[m]ore [mental health] services available to children from birth to age 21 (including children under 5 and for young adults 18 to 21).” The report likewise acknowledged New York’s obligation to treat Medicaid-eligible children with mental illness in the least restrictive setting.

91. Defendants have known for at least a decade that New York’s Medicaid system fails to meet the mental and behavioral health needs of the State’s Medicaid-eligible children.

92. As early as 2011, a Behavioral Health Reform Work Group appointed pursuant to then-Governor Andrew Cuomo’s executive order documented numerous deficiencies in the delivery of behavioral health services to Medicaid-eligible children: “Despite the significant spending on behavioral health care, the system offers little comprehensive care coordination even to the highest-need individuals, and there is little accountability for the provision of quality care and for improved outcomes for patients/consumers.” The Work Group also found that the “average time between onset and treatment of mental illness in children . . . is approximately nine years.”

93. The Children’s Subgroup of the Behavioral Health Reform Work Group found, among other things, that “current systems are ‘siloes’” and the “current behavioral healthcare system for children and their families is underfunded.” The Children’s Subgroup emphasized that “harmful and costly developmental trajectories continue to be formed early in life.”

94. These longstanding and ongoing deficiencies were also confirmed by a 2015 report, titled “Redesigning Children’s Behavioral Health Services in New York’s Medicaid

Program,” issued by the Medicaid Institute, which is part of the United Hospital Fund. That report noted that:

- The delivery of behavioral health services is “piecemeal and fragmented.”
- “Families are often served by a disjointed, overlapping, non-comprehensive and costly series of services. Medicaid redesign must better align systems to yield continuity of care, access, and cost-efficiency, and promote greater integration of primary care and behavioral health.”
- New York’s Medicaid system for children’s behavioral health results in “uncoordinated and fragmented care, as well as unmet needs for those wait-listed or ineligible for waiver services . . . .”
- “[The] design and its resulting fragmented services array is insufficiently flexible to meet many children’s constantly changing [behavioral health] needs, complicating the goal of connecting kids to the right services in the right amount at the right time.”
- “Significant systems gaps” include “waiting too long to treat children, giving them treatment because it is available rather than appropriate, and using a ‘siloed’ approach to care that does not, by its very nature, take into account the entire child and his or her context within a family unit.”

95. The Medicaid Institute report concluded that “a full array of services is required” to meet the needs of Medicaid-eligible children in light of “the wide variety of [behavioral health] diagnoses,” but that the numbers of Medicaid behavioral health providers are not sufficient “to meet the expected demand.” “Currently, in New York, children have long waits to see a child psychiatrist.” “[T]here is a shortage of specially trained [behavioral health] practitioners who can prescribe medications.” “[T]here is a dearth of practitioners schooled in the latest therapeutic models.” “Turnover rates are high.” And, while there is “broad agreement” about the need to develop the array of behavioral health services for children, “there is no momentum, dedicated resource or formal effort to make this a reality.”



**B. The Limited Home and Community-Based Mental Health Services Supposedly Available in New York Do Not Include Critically Important Required Services**

96. Recognizing the need for substantial improvements, New York amended its Medicaid plan starting in 2019 to include some additional EPSDT services that children in New York are supposed to receive in their homes and communities. New York also obtained federal approval for HCBS Waiver Services to reach Medicaid-eligible children who would be at risk of unnecessary institutionalization in the absence of the waiver services. However, the services referenced in the state plan do not include all the required IHCB-EPSDT Services. As a result, Defendants deprive Medicaid-eligible children of access to the services they need and are legally entitled to receive.

97. In the remainder of this section, the Complaint first describes how the services included in the State's Medicaid plan or provided by the State fall short of the IHCB-EPSDT requirements (¶¶ 100 to 120), after which the limited HCBS Waiver Services are described (¶¶ 121 to 125). Section III then describes how Defendants have failed to provide or arrange for even these limited services to be sufficiently available to meet the needs of Medicaid-eligible children.

98. Plaintiffs' claims under the Medicaid Act (set forth at ¶¶ 181 to 186), on behalf of themselves and the EPSDT Class members, are based on Defendants' failures to arrange for or provide IHCB-EPSDT Services.

99. Plaintiffs' claims under the ADA and Section 504 (set forth at ¶¶ 187 to 206), on behalf of themselves and the ADA Class members, are based on Defendants' failures to arrange for or provide both IHCB-EPSDT Services and HCBS Waiver Services.

**1. IHCB-EPSDT Services**

**a. Intensive Care Coordination Services**

100. Intensive care coordination is a critical component of IHCB-EPSDT Services.

Intensive care coordination is a robust form of case management that includes: an assessment and service planning process conducted through a child and family team, which includes the child and family, and their formal and informal support network; assistance accessing and arranging for services; coordinating multiple services, including crisis services; advocating for the child and family; monitoring and follow-up activities; and transition planning.

101. Children with severe or complex mental health issues need intensive care coordination to ensure they receive the mental and behavioral health treatment and other medically necessary services they need while living in their homes and communities. CMS, the federal agency under the U.S. Department of Health and Human Services (“HHS”) that oversees Medicaid, and SAMHSA, the agency within HHS that leads public health efforts to advance the behavioral health of the nation, recognize that intensive care coordination is vitally important. In their guidance to states, they acknowledge that intensive care coordination should include: “assessment and service planning,” “accessing and arranging for services,” “coordinating multiple services,” “access to crisis services,” “advocating for the child and family,” and “monitoring progress.”

102. Intensive care coordination is a covered service under Medicaid as a case management service and rehabilitative service. *See* 42 U.S.C. §§ 1396d(a)(13), 1396d(a)(19), 1396n(g)(2); 42 C.F.R. §§ 440.130(d), 440.169, 441.18.

103. In New York State, some limited form of care coordination for Medicaid-eligible children is ostensibly arranged by care managers employed by provider groups known as “Health Homes.” But the care coordination provided by Health Homes is not at all intensive.

104. New York’s Health Homes do not provide the intensive care coordination services that children with severe or complex mental health conditions need and that EPSDT requires Defendants to provide. They do not provide planning and treatment through a child and family team, and do not provide intensive care coordination including care management and skill-based rehabilitation in the home and community where children and their families and caregivers need such services.

105. Multiple counties have explained that the State simply does not provide intensive care coordination. For example,

- Westchester County noted in its 2021 local service plan that “Children’s Mental Health services [have] been impacted by Health Home . . . implementation. Specifically those children and families who had been served under Intensive Case Management and were reduced to Health Home Care Management level of care. These are children with serious mental health issues whose needs were met by intensity of [Intensive Case Management] visits and services. We have experienced many Health Home/Care Management programs not being able to meet their level of service need and respond in a timely and efficient way.”
- In 2020, Montgomery County noted that “Care management via [Health] Homes and the loss of traditional ICM/SCM services has been terribly executed. Patients are not able to get the level of care they need to keep them from the hospital due to caseload sizes and the additional responsibilities of unqualified care managers who may not have any experience in the MH/SUD systems. This is further complicated now that the Children’s Health Homes has been [enacted]. Patients and families contin[ue] to struggle with understanding the services and as providers there is a lot of confusion as to how a care manager can help families.”
- Schoharie County similarly reported that New York’s “Care Coordination model is focused on referral and service linkage, without the previous Case Management focus on engagement and skill building. The loss of the targeted case management program and transition into the Medicaid Health Home Care Management has resulted in adults and children receiving less adequate services for their needs.”

106. Rather than providing intensive care coordination, Health Homes act merely as a referral system, often simply informing families that services are unavailable or subject to waitlists. *See* ¶¶ 136-138, 163 below.

107. Thus, New York’s Medicaid-eligible children do not receive the intensive care coordination that they need and are legally entitled to receive.

**b. Intensive, Home-Based Behavioral Services**

108. IHCB-EPSDT Services also include home and community-based individualized intensive behavioral services and supports coverable as rehabilitation services, including therapeutic interventions, provided on a frequent and consistent basis, that are designed to improve behaviors associated with a child’s mental health conditions.

109. Intensive home-based behavioral services are provided to children and families in their homes or any settings where the children are naturally located. Intensive home-based behavioral services, like other IHCB-EPSDT Services, are medically necessary for children with severe or complex mental health conditions.

110. New York’s Medicaid plan purports to provide for certain intensive behavioral services as part of a package of mental health services referred to as Children and Family Treatment and Support Services (“CFTSS”).

111. CFTSS services were incorporated in the State’s Medicaid Plan starting in January 2019 as part of the State’s multi-year Medicaid “redesign,” supposedly to address the substantial deficiencies in New York’s mental health system for children. The intensive behavioral services ostensibly offered in the package of CFTSS services include the following:

- (a) Community psychiatric supports and treatment, a multi-component service that consists of intensive interventions and rehabilitative supports;
- (b) Psychosocial rehabilitation, *i.e.*, services that build a child’s social and interpersonal skills, daily living skills, and ability to achieve community integration;
- (c) Family peer support services, *i.e.*, services provided to parents and families by people with similar-lived experiences that include support, self-advocacy skills, and parent skill development; and

- (d) Youth peer support services, *i.e.*, services provided to children by people with similar lived experiences to set goals, build skills, and become successful participants in their treatment regimes.

112. To facilitate the child's ability to receive services in the home or where the child otherwise is naturally located, CFTSS ostensibly provides for an array of mental health services, including assessments, to be provided by licensed mental health practitioners other than medical doctors, such as psychotherapists, clinical social workers, therapists, and counselors.

113. To receive any one of the CFTSS services, children must either be referred directly to a CFTSS provider or first be assessed by a licensed practitioner of the healing arts, and then referred to the appropriate CFTSS service. Under the State's Medicaid Plan, anyone can refer a child for this initial assessment, including a parent, pediatrician, or county worker.

114. For a child to be eligible for a CFTSS service, the CFTSS provider or licensed practitioner of the healing arts must determine that the service is medically necessary for the child. Upon that determination, New York's Medicaid program is required to provide that service to the child as part of the child's EPSDT benefit.

115. Despite these requirements, Defendants have failed to provide or arrange for these services for the members of the EPSDT Class and the ADA Class. As alleged more fully in Section III of this Complaint, these required CFTSS services either do not exist at all, do not exist in sufficient quantity, frequency, or duration, or are not timely made available to the children for whom they have been deemed medically necessary.

116. Moreover, in the absence of the requisite intensive care coordination discussed above, providing individual, isolated CFTSS services to a child will be insufficient to meet that child's needs. Without intensive care coordination, no person or entity is responsible for coordinating the various, multiple aspects of the child's mental health care as is medically necessary and required under the Medicaid Act.

**c. Mobile Crisis Services**

117. Mobile mental health crisis services are another critical component of IHCBS-EPSSDT Services.

118. For children experiencing a mental health crisis, a mobile, onsite, in-person response should be available at times or places necessary to meet the needs of the child for the purpose of identifying, assessing, and stabilizing the situation and reducing any immediate risk of harm.

119. The mobile crisis response should be delivered wherever the crisis occurs, including in the child's home, school, or community.

120. Here again, New York State's Medicaid Plan provides for mobile crisis intervention services as one of the services theoretically available under CFTSS, but Defendants have failed to implement mobile crisis intervention services in any meaningful way, and such services are largely unavailable to the children who need and are legally entitled to them.

**2. HCBS Waiver Services**

121. In addition to the IHCBS-EPSSDT Services described above, New York purports to provide critical mental health services as part of its package of HCBS Waiver Services.

122. HCBS Waiver Services are services authorized through a waiver under Section 1915(c) of the Social Security Act allowing New York to spend federal Medicaid dollars on these services notwithstanding the existing Medicaid rules prohibiting the use of federal funds for these purposes.

123. HCBS Waiver Services are designed to provide support for children with mental health needs "at risk of admission to institutional levels of care." As such, to be eligible for these

services, children must be capable of receiving services in the community but at risk of being admitted to more restrictive settings to receive mental health treatment.

124. By stated policy, HCBS Waiver Services include the following:

a. Planned and Crisis Respite Care, *i.e.*, short-term relief for caregivers of children suffering with mental health issues, including in crisis situations, without which the child would need a higher level of care due to caregiver burnout and/or the temporary inability of the caregiver to provide the required assistance to the child; and

b. Caregiver/Family Supports and Services, *i.e.*, providing caregivers training and education to better meet the mental health needs of children.

125. As with the IHCBS-EPSDT Services described above, Defendants also fail to provide HCBS Waiver Services to meet the needs of the ADA Class. HCBS Waiver Services either do not exist at all, do not exist in sufficient quantity, or are not timely made available to the children and their caregivers who need them. Children deprived of any HCBS Waiver Services for which they are eligible, by definition, are children with severe or complex mental and behavioral health issues who either have been institutionalized or who are at serious risk of institutionalization.

### **III. NEW YORK'S ONGOING FAILURE TO PROVIDE IHCBS-EPSDT SERVICES AND HCBS WAIVER SERVICES NECESSARY TO MEET THE NEEDS OF MEDICAID-ELIGIBLE CHILDREN**

126. Despite the compelling need for IHCBS-EPSDT Services and HCBS Waiver Services, Defendants fail to provide these services in sufficient quantity, frequency, and duration to meet the needs of the State's Medicaid-eligible children.

127. Defendants likewise have failed to implement policies and practices statewide to ensure that the services are provided to meet the mental health care needs of the EPSDT and

ADA Class members. As a result, there remains a lack of IHCB-EPSDT Services and HCBS Waiver Services, and these services are frequently unavailable, inaccessible, inadequate, and subject to lengthy waiting lists. Medicaid-eligible children thus remain without the services they need and to which they are entitled as a matter of law.

128. The extensive, statewide, and ongoing failure to provide mental health services to Medicaid-eligible children has been well-documented by multiple sources, including counties, mental health providers, advocates, independent studies, and Defendants' own data, admissions, and records.

**A. Defendants Fail to Provide Class Members with the IHCB-EPSDT Services and HCBS Waiver Services They Need**

129. It is widely recognized throughout the state that Defendants fail to provide adequate intensive home and community-based mental health services to Medicaid-eligible children. Critical mental health services, to the extent they are even available, are fragmented and uncoordinated, leaving desperate families on their own to attempt to coordinate their children's care and to cobble together any mental health services they can. In sum, IHCB-EPSDT Services and HCBS Waiver Services remain illusory in the state.

130. This shortage of services afflicts communities across the state. In October 2020, for example, New York's Regional Planning Consortium ("RPC"), a statewide network of community stakeholders and managed care organizations, found that, in multiple regions, there were no "active providers for CFTSS and HCBS [Waiver Services]"; that children were "waiting many months for services"; and that providers were "only serving within their agencies and [were] not accepting community referrals."

131. At an August 2020 meeting, stakeholders identified access and capacity issues as a "top area" needing focus, noting that "services that [the State] said families would have access



to are not being provided,” for example, crisis intervention through CFTSS. In a November 2020 letter to Defendant Sullivan, the RPC’s parent organization, the New York State Conference of Local Mental Hygiene Directors, emphasized the need to support “increasing capacity needs and the struggling workforce.”

132. Recent reports from New York’s individual regions include similarly grim assessments. For example, the Southern Tier reported that multiple providers identified the lack of available staffing as a predominant barrier to providing services. Central New York complained about “providers with increased job vacancies leading to increased burnout and turnover from existing care managers due to high caseloads.” The Mohawk Valley region stated that there “is difficulty in connecting clients” to CFTSS and HCBS Waiver Services “due to limited providers of these services in this region and long wait-lists for agencies who do provide services.” The Finger Lakes region further highlighted problems resulting from “the inadequacy of response to people experiencing urgent behavioral health problems, with the default responders inappropriately being solely law enforcement.”

133. Data from the past few years confirm that New York is failing to meet the needs of Medicaid-eligible children for IHCB-EPSDT Services for in-home behavioral support services, despite the existence of New York’s CFTSS program.

134. OMH projected that approximately 200,000 children would be eligible for CFTSS services. As of October 2020, however, only 8% of the anticipated number of children had received any CFTSS services.

135. In New York City in 2020, fewer than 6,000 children received any type of CFTSS service, including only 2,394 children who received community psychiatric supports and

treatment services and only 1,898 children who received psychosocial rehabilitation services, out of approximately 1.2 million children on Medicaid in the five boroughs.

136. Data also confirm that New York State is failing to provide children with intensive care coordination services required under Medicaid’s EPSDT provisions. Instead, New York provides community-based care management that is woefully inadequate to address children’s complex mental and behavioral health conditions, and further underscores the State’s failure. *See* ¶¶ 103 to 107.

137. New York Health Homes’ community-based care management services do not provide the intensive care coordination services required by the Medicaid Act. They are not adequate or appropriate to meet the needs of class members.

138. The little care management that Health Homes do provide remains inaccessible for the overwhelming majority of Medicaid-eligible children. In 2015, New York estimated that about 174,000 children would be eligible to receive community-based care management to be provided by Health Homes, including more than 100,000 children with mental health and substance abuse issues. OMH data from 2019, the most recent available, show that only 11% of the anticipated number of eligible children were enrolled in Health Homes. By February 2021, the New York State Coalition for Children’s Behavioral Health reported that fewer than one in five of the children the State estimated to be eligible were in fact enrolled.

139. Critical mobile crisis intervention services, ¶¶ 6, 117-120, are also not provided to Medicaid-eligible children who experience mental health crises or emergencies. Counties across the State report a lack of mobile crisis services for youth in their communities.

140. For example, in 2021 Monroe County reported that “[i]n the children’s service system, alternatives to emergency room use, including respite and crisis services for youth, are

scarce. . . . [C]risis service through CFTSS became available in January 2020, but there are no local providers who have been designated [to provide the service].” One New York region even reported the existence of *waitlists* for crisis intervention services for youth in Albany, Saratoga, and Schenectady Counties – an illegal and dangerous oxymoron.

141. Without the mobile crisis services required under the IHCBS-EPSTDT Services array, children having mental health crises are placed at further risk when law enforcement personnel are the only available emergency responders to the mental health crisis. Police officers are not trained or qualified to provide mental health treatment, and are not a substitute for mental health professionals providing the onsite mental health assistance that is needed. A law enforcement response to a mental health crisis is also a situation fraught with danger, particularly for youth of color.

142. Defendants also do not provide HCBS Waiver Services to all the children who need them or are eligible to receive them.

143. OMH also projected that approximately 65,000 children would be eligible for HCBS Waiver Services. As of July 2020, however, only approximately 10% of that number were even enrolled in HCBS Waiver Services.

144. Each year, all 57 counties and New York City are required to submit local services plans for mental hygiene services detailing the mental health needs of their population and reporting goals, objectives, and strategies to meet those needs. As further evidence of the State’s failure, in their 2020 and 2021 local services plans, several counties decried the unmet needs of children, starkly describing that access to community-based mental health services for children had worsened over the past year, rising to “*near-crisis levels in our community.*”

**B. Defendants Also Fail to Provide Class Members with These Necessary Services in a Timely Manner**

145. The State also fails to provide Medicaid-eligible children in New York with IHCBS-EPSDT Services and HCBS Waiver Services in a timely manner.

146. New York's local officials and stakeholders confirm that IHCBS-EPSDT Services and HCBS Waiver Services are not provided timely and that there are long delays to obtain these mental health services. In 2020 and 2021, counties reported not only an increased need for mental health services for children and youth, but also that services were not sufficiently available to meet those needs.

147. Across the state, counties report growing waitlists for IHCBS-EPSDT Services and HCBS Waiver Services. Schenectady County, for example, reported "lengthy waitlists" for both CFTSS and HCBS Waiver Services.

148. Other children eligible for IHCBS-EPSDT Services or HCBS Waiver Services are told that providers are "closed" and cannot take referrals.

149. Counties reported that the CFTSS and HCBS waiver programs are a "real challenge" and are a "main area of concern," and that while such services "began to roll out in January 2019, [they] have not been readily accessible." One county noted "[t]here are major concerns regarding [HCBS Waiver Services]. While [there is] a need for higher level of care, very few youth are actually receiving the services. The referral rate is low and staffing difficulties impact a youth being able to obtain the services and supports they need."

150. In addition, there are significant delays in accessing the assessment programs that determine whether a child or youth qualifies for HCBS Waiver Services. There "continues to be difficulty getting . . . connected to HCBS [Waiver Services] in a timely manner." For example, in the third quarter of 2020, the RPC featured the story of a child who "has not been able to get

connected to HCBS [Waiver Services] for a year since transitioning home from a Residential Treatment Center.”

151. In November 2020, a Long Island provider said that “wait lists are often worse than what is reported. Since [her agency] de-designated 11 months ago, they have children still not receiving HCBS [Waiver] Services due to waiting. There are 9 (out of 18) youth that have not been re-established with a respite provider in 11 months.”

152. Defendants’ failures further affect children and youth in New York’s rural regions who already face challenges of accessing mental health care in geographically-isolated communities.

153. RPC reporting in 2020 noted that “[t]imely access to behavioral health care has been a challenge in rural regions.” For example, Mohawk Valley’s Children and Families Subcommittee pinpointed the following recurring issues: “Waitlists, availability, and agencies not prepared to provide[] services remain a constant issue . . . . In Fulton & Montgomery Counties there are no services available[; m]inimal luck connecting children with services[; and d]ifficulty in recruiting staff. Otsego County sees a similar problem. The relative rural area our region is made up of proves difficult in connecting services and the capability to provide services via telehealth.”

154. Across the State, in rural and urban areas, in towns, villages, and cities, IHCBS-EPSTD Services and HCBS Waiver Services are not timely available for the Medicaid-eligible children who need them.

**IV. DEFENDANTS' CONDUCT RESULTS IN SEGREGATION, INSTITUTIONALIZATION, AND SERIOUS RISK OF INSTITUTIONALIZATION FOR CLASS MEMBERS**

155. Deprived of mental health services in their homes and communities, New York's children in need of IHCB-EPSDT Services and HCBS Waiver Services deteriorate to the point of becoming segregated or placed at serious risk of institutionalization. They cycle in and out of emergency rooms, psychiatric hospitals, residential treatment centers, residential treatment facilities, CPEPs, and other segregated placements even though they are eligible to receive mental health services at home and in their communities.

156. Children who do not get the IHCB-EPSDT Services and HCBS Waiver Services they need and for which they are eligible decompensate to the point of requiring placement in unnecessarily segregated and out-of-home placements.

157. One Long Island provider reported "seeing a trend of hospitalizations and out-of-home placements for kids who are on waiting lists." In such situations, the "child has been connected and could be receiving [home and community-based] services, but they are on waiting lists," thus making home discharge ineffective for the continued treatment of the child's mental health issues and potentially dangerous for the child and the family, with the likely need for readmittance to a hospital or other psychiatric institution.

158. In 2020 and 2021, thousands of Medicaid-eligible children who should have been receiving intensive home and community-based services were at increased risk of segregation and institutionalization. For example,

- The RPC reported that the centralized referral systems for children's mental health services "have seen an increase in out-of-home placement referrals and have found that many of these children never received CFTSS and are unknown to their system. . . There is no longer a system in place to keep track of the status of all the children requiring services, especially those waiting for CFTSS and HCBS."

- Numerous counties similarly expressed concerns about children spending hours or even days in the emergency room, “only to be sent home due to no bed space in NYS . . . .”
- In Monroe County, “alternatives to emergency room use, including respite and crisis services for youth, are scarce,” leaving youth whose needs could be met with a lower level of care with few options.
- Clinton County explained: “Community trends do show that there may be an increase in emergency room utilization given the lack of recruitment and retention of community staff that may assist with averting crisis.”

159. OMH’s own data reflect the degree to which children rely on emergency rooms for mental health reasons, with the State seeing tens of thousands of such visits each year. OMH data also show that in 2019, within 90 days after discharge from psychiatric inpatient hospitals, 10-25% of children were readmitted and 21-34% visited emergency rooms. Statewide, the percentage of children who visited an emergency room within 90 days of discharge from a psychiatric inpatient hospital increased from 23% in 2013 to 30% in 2019.

160. All too often, there appear to be only two outcomes for class members in crisis and their families, even after prolonged periods spent waiting in the emergency room: go home with no services in place or be hospitalized for inpatient psychiatric treatment that could be located many miles away across the state, making family visitation very difficult, time-consuming, and prohibitively expensive for low-income families.

161. Several counties report that in some cases, when immediate crisis symptoms subside, children are simply discharged from emergency rooms with no services provided whatsoever. One county reported that “[t]here have been instances where a youth has spent months on the emergency room floor” without mental health services. “Children are often sent home without appropriate care or are maintained in ER for days.” One county referred to a

“revolving door” of children being discharged from the emergency room without proper services in place only to have their next crisis land them in the emergency room once again.

162. The cost and harm of these wholly ineffective emergency room visits vastly outweigh the cost and benefit of providing home and community-based services *before* a child’s mental health issues rise to crisis-levels necessitating admittance to hospitals or other institutional settings.

163. In January 2021, Saratoga County summarized in stark terms how “CFTSS and HCBS services were designed to reduce risk of hospitalization and out-of-home placement, but those services have not been available,” resulting in increased segregation and risk of institutionalization:

“CFTSS and HCBS services need to be available before we can determine if they are sufficient to meet the needs of the children and adolescents in Saratoga County. The SPOA [Single Point of Access] process was efficient in managing the available services prior [to] the Medicaid Redesign, Health Homes and unbundling of [the] HCBS Waiver. The most at risk youth were prioritized for available services and lower level services were offered to fill the gap until the appropriate level of service became available. At this time, we are able to offer Care Management to an increased number of youth but ***the critical support services the [Care Managers] refer to are not available. CFTSS and HCBS services were designed to reduce risk of hospitalization and out-of-home placement, but those services have not been available. Subsequently, youth and families are utilizing Mobile Crisis, Police Departments, Emergency Departments, inpatient hospitalization and request for out-of-home placement to manage on-going cris[es].***”

164. The increased segregation of children in mental health institutions and other segregated settings has serious ramifications for both the EPSDT Class and the ADA Class. Without a sufficient array of IHCBS-EPSDT Service providers, children in the EPSDT Class are at risk that they will not be able to obtain the IHCBS-EPSDT Services they need, and that, as a result, they will be unable to remain in their homes and communities and will be unnecessarily placed in psychiatric hospitals and similar facilities.



165. For children in the EPSDT Class, IHCB-EPSDT Services are a medical necessity; mental health services provided in an institution or other segregated setting are not a substitute for the IHCB-EPSDT Services that children in the EPSDT Class are entitled to receive under the Medicaid Act, and which they need to thrive. Children in the EPSDT Class are often stuck in a vicious cycle of repeated institutionalizations, followed by inadequate mental health care in the community when discharged, without ever receiving the IHCB-EPSDT Services they actually need for their conditions to improve.

166. Without IHCB-EPSDT and HCBS Waiver Services, children in the ADA Class are also subject to unnecessary institutionalization and segregation when they could be better treated in their homes and communities. Defendants thus fail to provide Medicaid services to these children in the “most integrated” setting as required by the ADA and Section 504, even though they have long sought such services. Children in the ADA Class, like children in the EPSDT Class, are subject to the vicious cycle of repeated, ineffective, and unnecessary institutionalization and segregation.

### **CLASS ALLEGATIONS**

167. The Named Plaintiffs properly maintain this action as a class action pursuant to Rules 23(a) and 23(b)(2) of the Federal Rules of Civil Procedure.

168. As noted above, the EPSDT Class is defined as all current or future Medicaid-eligible children in New York State under the age of 21 (a) who have been diagnosed with a mental health or behavioral condition, not attributable to an intellectual or developmental disability, and (b) for whom a licensed practitioner of the healing arts has recommended IHCB-EPSDT Services to correct or ameliorate their conditions.

169. Also as noted above, the ADA Class is defined as all current or future Medicaid-eligible children in New York State under the age of 21 (a) who have been diagnosed with a mental health or behavioral condition, not attributable to an intellectual or developmental disability, that substantially limits one or more major life activities, (b) for whom a licensed practitioner of the healing arts has recommended IHCB-EPSDT Services to correct or ameliorate their conditions or who have been determined eligible for HCBS Waiver Services, and (c) who are segregated, institutionalized, or at serious risk of becoming institutionalized.

170. The deficiencies in mental health care described above, and the resulting risks to the children in the EPSDT and ADA Classes, arise from Defendants' statewide policies and practices, including the following:

a. Defendants' failure to maintain a sufficient array of IHCB-EPSDT Services and HCBS Waiver Services throughout the state to meet the needs of the children in the EPSDT and ADA Classes, and their failure to implement adequate practices to reasonably ensure a sufficient array of IHCB-EPSDT Services and HCBS Waiver Services throughout the state;

b. Defendants' failure to implement adequate practices to reasonably ensure that the children in the EPSDT Class are able to obtain the IHCB-EPSDT Services to which they are entitled, and with reasonable promptness, including processes for monitoring the extent to which class members are unable to obtain such services and identifying the need for corrective action.

c. Defendants' failure to implement adequate practices to reasonably ensure that the children in the ADA Class are able to obtain IHCB-EPSDT Services and HCBS Waiver Services in the least restrictive environment and most integrated setting appropriate to their needs, and are not unnecessarily segregated and placed at serious risk of institutionalization

because IHCB-EPSDT Services and HCBS Waiver Services are unavailable, including processes for monitoring the extent to which children in the ADA Class are unable to obtain IHCB-EPSDT Services and HCBS Waiver Services and are unnecessarily institutionalized, and identifying the need for corrective action.

d. Defendants' failure to ensure that mental health service providers serving Medicaid-eligible children are sufficiently available to provide IHCB-EPSDT Services and HCBS Waiver Services to meet the needs of the children in the EPSDT and ADA Classes, and their failure to implement adequate practices to reasonably ensure that mental health service providers are sufficiently available to meet the needs of the EPSDT and ADA Classes.

171. These policies and practices arise from the action and inaction taken by Defendants. The policies and practices, and their consequences, have been so widespread and consistent that Defendants should be deemed to have acquiesced to them.

172. As a result of the policies and practices described above, the children in the EPSDT Class are subject to serious harm and risk, including the following: (a) they are being denied the IHCB-EPSDT Services to which they are entitled under the Medicaid Act; (b) they are being denied IHCB-EPSDT Services with reasonable promptness as required by the Medicaid Act; and (c) they are exposed to significant risk of imminent future violations of the EPSDT and Reasonable Promptness provisions of the Medicaid Act.

173. The children in the ADA Class are further subject to the following harm and risks: (a) they are unable to obtain Medicaid Services in the least restrictive environment and the most integrated setting appropriate to their needs; (b) they are unnecessarily segregated; (c) they are placed at serious risk of institutionalization; and (d) they are exposed to significant risk of imminent future violations of the ADA and Section 504.

174. The EPSDT Class and the ADA Class are each sufficiently numerous to make joinder impracticable. There are approximately 2,200,000 children on Medicaid in New York State, tens of thousands of whom are entitled to receive IHCB-EPSDT Services and/or HCBS Waiver Services. For example, as noted above, Defendants estimated that 200,000 youth would be eligible for IHCB-EPSDT Services through CFTSS, but only a fraction have received even one CFTSS service. Defendants estimated that 65,000 youth would be eligible for HCBS Waiver Services, but only a fraction are even enrolled in HCBS. Other factors that make joinder impracticable include the fluid nature of each class, the geographically diverse class members, the limited financial resources of class members, the unknown identity of future class members, and Defendants' discretion with respect to service provision.

175. There are questions of fact and law common to the claims of all EPSDT Class members, including the following:

a. Whether Defendants' failure to provide necessary IHCB-EPSDT Services throughout the state and implement adequate practices to reasonably ensure sufficient IHCB-EPSDT Services are available, and the resulting risk that EPSDT Class members will be unable to obtain the necessary IHCB-EPSDT services, or to obtain such services with reasonable promptness, violates the Medicaid Act.

b. Whether Defendants' failure to implement adequate coordination, policies, and other practices to reasonably ensure that the EPSDT Class members are able to obtain the IHCB-EPSDT Services to which they are entitled, and with reasonable promptness, and the resulting risk that EPSDT Class members will be unable to obtain those services, or to obtain them with reasonable promptness, violates the Medicaid Act.

c. Whether Defendants' failure to ensure that sufficient qualified providers of IHCB-EPSDT Services are available to meet the needs of Medicaid-eligible children and which services they are legally entitled to, with reasonable promptness, violates the Medicaid Act.

d. Whether the Named Plaintiffs and EPSDT Class members are entitled to declaratory and injunctive relief to vindicate their statutory rights.

176. There are questions of fact and law common to the claims of all ADA Class members, including the following:

a. Whether Defendants' failure to make available Medicaid services to members of the ADA Class in the most integrated setting appropriate to their needs, thereby segregating members of the ADA Class or placing them at serious risk of institutionalization, violates the ADA and Section 504.

b. Whether Defendants' failure to administer and provide IHCB-EPSDT Services and HCBS Waiver Services that meet the needs of the ADA Class to receive mental health services in the most integrated setting appropriate to their needs violates the ADA and Section 504.

c. Whether Defendants' failure to provide a sufficient array of IHCB-EPSDT Services and HCBS Waiver Services throughout the State and to implement adequate practices to reasonably ensure a sufficient array of these services, such that members of the ADA Class are able to obtain mental health services in the most integrated setting appropriate to their needs and instead are segregated or placed at serious risk of institutionalization, violates the ADA and Section 504.

d. Whether Defendants' failure to implement adequate coordination and other practices to reasonably ensure that ADA Class members are able to obtain Medicaid services in the least restrictive environment and most integrated setting appropriate to their needs, violates the ADA and Section 504.

e. Whether the Named Plaintiffs and the ADA Class members are entitled to declaratory and injunctive relief to vindicate their statutory rights.

177. Each Named Plaintiff is a member of both the EPSDT and ADA Classes. The claims that the Named Plaintiffs raise are typical of those of the EPSDT and ADA Classes, as each EPSDT and ADA Class member's claim would arise from the same course of events, and each class member would make similar legal arguments to prove Defendants' liability. The remedies sought by the Named Plaintiffs are the same remedies that would benefit the EPSDT and ADA Classes: an injunction requiring Defendants to take affirmative acts to cure their violations of law and provide or arrange for the provision of sufficient IHCB-EPSDT Services and HCBS Waiver Services, for the Named Plaintiffs and the EPSDT and ADA Classes.

178. The Named Plaintiffs will fairly and adequately represent the interests of the EPSDT and ADA Classes. There are no conflicts among the Named Plaintiffs and any members of the EPSDT or ADA Classes. The "Next Friends" are dedicated to representing the best interests of the Named Plaintiffs.

179. The undersigned counsel have extensive experience in litigating civil rights and class action lawsuits, including those involving the rights of children, youth, and adults with mental health conditions.

180. Defendants have acted or refused to act on grounds that are generally applicable to the EPSDT and ADA Classes, and injunctive and declaratory relief is appropriate respecting the EPSDT and ADA Classes each as a whole.

**CLAIMS FOR RELIEF**

**FIRST CAUSE OF ACTION  
(Violations of the EPSDT Provisions of the Medicaid Act,  
by Plaintiffs C.K., C.W., and the EPSDT Class)**

181. The Named Plaintiffs incorporate each and every allegation of the Complaint as if fully set forth below.

182. Defendants, while acting under color of state law, violate the EPSDT provisions of the Medicaid Act by failing to provide or arrange for the Named Plaintiffs and the EPSDT Class members to receive IHCB-EPSDT Services that are medically necessary to correct or ameliorate their mental health conditions. 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).

183. Defendants' acts and omissions described above violate 42 U.S.C. § 1983 by depriving the Named Plaintiffs and members of the EPSDT Class of their statutory rights.

**SECOND CAUSE OF ACTION  
(Violations of the Reasonable Promptness Provision of the Medicaid Act,  
by Plaintiffs C.K., C.W., and the EPSDT Class)**

184. The Named Plaintiffs incorporate each and every allegation of the Complaint as if fully set forth below.

185. Defendants, while acting under color of state law, violate the Reasonable Promptness provision of the Medicaid Act by failing to provide or arrange for the Named Plaintiffs and the EPSDT Class members to receive IHCB-EPSDT Services with "reasonable promptness" in violation of 42 U.S.C. § 1396a(a)(8).

186. Defendants' acts and omissions described above violate 42 U.S.C. § 1983 by depriving the Named Plaintiffs and the members of the EPSDT Class of their statutory rights.

**THIRD CAUSE OF ACTION  
(Violations of the ADA, by Plaintiffs C.K., C.W., and the ADA Class)**

187. The Named Plaintiffs incorporate each and every allegation of the Complaint as if fully set forth below.

188. Title II of the ADA provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” 42 U.S.C. § 12132.

189. Title II of the ADA also requires that “[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d).

190. The Named Plaintiffs and members of the ADA Class have mental impairments that substantially limit one or more major life activities, or have a record of such impairments, and therefore have a disability as defined by the ADA, 42 U.S.C. § 12102, and its implementing regulations, 28 C.F.R. § 35.108.

191. The Named Plaintiffs and members of the ADA Class are “qualified individuals with disabilities” as defined by the ADA, 42 U.S.C. § 12131(2), and its implementing regulations, 28 C.F.R. § 35.104.

192. The Named Plaintiffs and members of the ADA Class are qualified to receive services in the most integrated community-based settings that meet their mental health needs.

193. Defendants, named in their official capacities, are each a public entity as defined by the ADA, 42 U.S.C. § 12131(1), and its implementing regulations, 28 C.F.R. § 35.104.



194. By failing to provide IHCBS-EPSTDT Services and HCBS Waiver Services, and failing to adequately implement and administer the State's mental health service system, Defendants discriminate against the Named Plaintiffs and the ADA Class by denying them the opportunity to receive the Medicaid services they need in integrated settings, thus causing them to be unnecessarily segregated or placed at serious risk of institutionalization in violation of Title II of the ADA.

195. Defendants fail to make reasonable modifications to their policies, practices, and procedures that are necessary to avoid discrimination against the Named Plaintiffs and the ADA Class on the basis of their disabilities. 28 C.F.R. § 35.130(b)(7).

196. Serving the Named Plaintiffs and the ADA Class in the most integrated settings appropriate to their needs and making reasonable modifications, can be reasonably accommodated and would not fundamentally alter the nature of the Defendants' services, programs, or activities.

197. Defendants fail to administer services, programs, and activities for the Named Plaintiffs and the ADA Class in the most integrated setting appropriate to their needs. 28 C.F.R. §§ 35.130(d), 35.152(b)(2).

198. Defendants violate the rights of the Named Plaintiffs and the ADA Class under Title II of the ADA, 42 U.S.C. § 12131, *et seq.*, and its implementing regulations.

**FOURTH CAUSE OF ACTION**  
**(Violations of Section 504, by Plaintiffs C.K., C.W., and the ADA Class)**

199. The Named Plaintiffs incorporate each and every allegation of the Complaint as if fully set forth below.

200. Section 504 provides that “[n]o otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the

participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” 29 U.S.C. § 794(a).

201. The Named Plaintiffs and members of the ADA Class have mental impairments that substantially limit one or more major life activities, or have a record of such impairments, and therefore have a disability for purposes of Section 504 and its implementing regulations, 45 C.F.R. § 84.3(j).

202. The Named Plaintiffs and members of the ADA Class are qualified individuals with disabilities for purposes of Section 504 and its implementing regulations, 45 C.F.R. § 84.3(l)(4).

203. The Named Plaintiffs and members of the ADA Class are qualified to receive services in the most integrated community-based settings that meet their mental health needs.

204. Defendants operate programs or activities that receive federal financial assistance for purposes of Section 504, 29 U.S.C. § 794(b), and its implementing regulations, 45 C.F.R. § 84.3(k).

205. By failing to provide IHCBS-EPSDT Services and HCBS Waiver Services, and failing to adequately implement and administer the State’s mental health service system, Defendants discriminate against the Named Plaintiffs and the ADA Class members by denying them the opportunity to receive the Medicaid services they need in integrated settings, thus causing them to be unnecessarily segregated or placed at serious risk of institutionalization in violation of Section 504.

206. Defendants violate the rights of the Named Plaintiffs and the ADA Class Members under Section 504, 29 U.S.C. § 794, and its implementing regulations.

**PRAYER FOR RELIEF**

WHEREFORE, the Named Plaintiffs respectfully request that the Court:

- a. Assert subject matter jurisdiction over this action;
- b. Order that the Named Plaintiffs may maintain this action as a class action pursuant to Rule 23(a) and Rule 23(b)(2) of the Federal Rules of Civil Procedure and appoint the undersigned as class counsel pursuant to Rule 23(g) of the Federal Rules of Civil Procedure;
- c. Declare unlawful, pursuant to Rule 57 of the Federal Rules of Civil Procedure, Defendants' conduct as alleged herein as a violation of the rights of the Named Plaintiffs, the EPSDT Class members, and the ADA Class members under: (i) the EPSDT and Reasonable Promptness Provisions of the Medicaid Act, 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r), 1396a(a)(8); (ii) Title II of the ADA, 42 U.S.C. § 12101 *et seq.*; and (iii) Section 504, 29 U.S.C. § 794;
- d. Grant permanent injunctive relief requiring Defendants to:
  - i. establish and implement policies and practices to ensure the timely provision of intensive home and community-based mental health services to the Named Plaintiffs, the EPSDT Class members, and the ADA Class members;
  - ii. promptly make available the IHCB-EPSDT Services and HCBS Waiver Services for which the Named Plaintiffs, the EPSDT Class members, and the ADA Class members are eligible; and
  - iii. establish and implement policies and practices to ensure that Defendants do not discriminate against the Named Plaintiffs and the ADA Class members, and that Defendants provide them the Medicaid services for which they are eligible in the most integrated setting appropriate to their needs;

- e. Retain jurisdiction over Defendants until such time as the Court is satisfied that Defendants have implemented and sustained this injunctive relief;
- f. Award reasonable attorneys' fees and costs pursuant to 28 U.S.C. § 1920, 42 U.S.C. § 12205, 42 U.S.C. § 1988, and Federal Rules of Civil Procedure 23(e) and (h); and
- g. Grant such other relief as the Court may deem just and proper.

Dated: March 31, 2022

Respectfully submitted,

**CHILDREN'S RIGHTS, INC.**



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