

UNITED STATES DISTRICT COURT  
WESTERN DISTRICT OF MISSOURI  
CENTRAL DIVISION

S.J., by and through her next friend, S.S.; )  
C.T.; P.W. a minor child by and through )  
her next friend, C.W.; S.E.S., a minor child )  
by and through her next friend, J.L-S.; T.S., )  
a minor child, by and through his guardian, )  
M.S.; S.A., minor child by and through her )  
next friend, M.A.; R.R., a minor child by )  
and through his next friend, M.D.; B.B., a )  
minor child by and through her next friend )  
C.B.; I.B., a minor child by and through her )  
next friend, A.B.; and Caring for Complex )  
Kids Coalition, )

Civil Action No. \_\_\_\_\_

Plaintiffs. )

v. )

JENNIFER TIDBALL, in her official )  
capacity as Acting Director of Missouri )  
Department of Social Services, and )  
MISSOURI DEPARTMENT )  
OF SOCIAL SERVICES, )

Defendants. )  
\_\_\_\_\_ )

**COMPLAINT**

**INTRODUCTION**

1. This case seeks declaratory and injunctive relief to compel the Missouri Department of Social Services and its acting director, Jennifer Tidball, to arrange for the private duty nursing care services that Defendants have authorized as medically necessary for Medicaid-enrolled children with medically complex conditions.

2. Plaintiffs S.J., C.T., P.W., S.E.S., T.S., S.A., R.R., B.B., and I.B. are children

under the age of 21 with medically complex conditions who are enrolled in Medicaid. Plaintiff Caring for Complex Kids Coalition is an association of parents and caregivers of medically complex children who live in Missouri.

3. Plaintiffs are alive because of dramatic advances in medical science over the past few decades. They are dependent on medical technologies and associated nursing care to stay alive—ventilators to breathe, tracheostomy tubes to clear airways, gastrostomy tubes to receive nutrition. They require assistance with activities of daily living like toileting, dressing, eating, and moving. Because of their medical and survival needs, Defendants have determined that in-home nursing services are medically necessary for Plaintiffs and authorized these services so that these children may live safely in their homes and with their families.

4. The Medicaid Act requires Defendants to “arrang[e] for (directly or through referral to appropriate agencies, organizations, or individuals)” treatment that the child needs to “correct or ameliorate” their conditions. 42 U.S.C. §§ 1396a(a)(43)(C), 1396d(r)(5). Covered services include private duty nursing. *Id.* at §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(b), 1396d(r).

5. Due to systemic deficiencies in their policies, practices, and procedures, Defendants are failing to arrange for the private duty nursing services they have determined the Plaintiffs need.

6. Defendants’ deficient policies, practices, and procedures related to arrangement of private duty nursing services also violate the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act (Section 504). 42 U.S.C. § 12132; 29 U.S.C. § 794(a). Because of these violations, Plaintiffs are not receiving medically

necessary, in-home nursing services, leaving them at a serious risk of institutionalization and, in some cases, needing admission into an institutional setting.

### **JURISDICTION AND VENUE**

7. This is an action for declaratory and injunctive relief to enforce Plaintiffs' rights under provisions of the Medicaid Act, the ADA, and Section 504.

8. Jurisdiction is based on 28 U.S.C. §§ 1331 and 1343.

9. At all times relevant to this action, Defendants have acted under color of law.

10. This Court is authorized to award Plaintiffs' requested declaratory relief and injunctive relief under 28 U.S.C. §§ 2201-2202 and Fed. R. Civ. P. 65.

11. Venue is proper in the Western District of Missouri pursuant to 28 U.S.C. § 1391(b).

### **PARTIES**

12. Plaintiff S.J. is 18 years old and is a Medicaid beneficiary. She lives with her parents and sibling in Sunset Hills, Missouri. As a result of her complex medical conditions, Defendants have determined that S.J. needs 81 hours of private duty nursing each week. S.J. does not receive this amount of private duty nursing services. S.J. brings this action through her mother, S.S.

13. Plaintiff C.T. is 18 years old and is a Medicaid beneficiary. She lives with her father and sibling in Ferguson, Missouri. As a result of her complex medical conditions, Defendants have determined that C.T. needs 16 hours per day of private duty nursing services. C.T. does not receive this amount of private duty nursing services.

14. Plaintiff P.W. is 16 years old and is a Medicaid beneficiary. She lives with her parents and sibling in Highlandville, Missouri. As a result of her complex medical

conditions, Defendants have determined that P.W. needs 16 hours per day of private duty nursing services. P.W. does not receive this amount of private duty nursing services. P.W. brings this action through her mother, C.W.

15. Plaintiff S.E.S. is eight years old and is a Medicaid beneficiary. She lives in Wildwood, Missouri with her parents and siblings. As a result of her complex medical conditions, Defendants have determined that S.E.S. needs eight hours a day of private duty nursing services when she is in school and 16 hours of private duty nursing services per day at all other times. S.E.S. does not receive this amount of private duty nursing services. S.E.S. brings this action through her mother, J.L-S.

16. Plaintiff T.S. is four years old and is a Medicaid beneficiary. He lives with his grandparents in Lynchburg, Missouri. As a result of his complex medical conditions, Defendants have determined that T.S. needs 16 hours per day of private duty nursing services. T.S. does not receive this amount of private duty nursing services. T.S. brings this action through his grandmother and legal guardian, M.S.

17. Plaintiff S.A. is three years old and is a Medicaid beneficiary. She lives with her parents in Maryland Heights, Missouri. As a result of her complex medical conditions, Defendants have determined that S.A. needs 14 hours per day of private duty nursing services. S.A. does not receive this amount of private duty nursing services. S.A. brings this action through her mother M.A.

18. Plaintiff R.R. is three years old and is a Medicaid beneficiary. He lives with his grandparents and sibling in Park Hills, Missouri. As a result of his complex medical conditions, Defendants have determined that R.R. needs 16 hours per day of private duty nursing services. R.R. does not receive this amount of private duty nursing services. R.R.

brings this action through his grandmother, M.D.

19. Plaintiff B.B. is one year old and is a Medicaid beneficiary. She lives with her parents and siblings in Union, Missouri. As a result of her complex medical conditions, Defendants have determined that B.B. needs 16 hours per day of private duty nursing services. B.B. does not receive this amount of private duty nursing services. B.B. brings this action through her mother, C.B.

20. Plaintiff I.B. is one year old and is a Medicaid beneficiary. She lives with her parents and siblings in Florissant, Missouri. As a result of her complex medical conditions, Defendants have determined that I.B. needs 16 hours per day of private duty nursing services. I.B. does not receive this amount of private duty nursing services. I.B. brings this action through her mother, A.B.

21. Caring for Complex Kids Coalition (CCKC) is an unincorporated association of parents and caregivers of medically complex children who live in Missouri. The group's goals are to share information about caring for medically complex children, to enable each other to better advocate for their own children, and to advocate for policies and practices that will improve the lives of medically complex children in Missouri, including access to Medicaid-covered private duty nursing services. Families with a child who has special medical needs may become members by participating in one or more telephone meetings of the group. Decisions are made by majority vote, so long as the decision is on the agenda distributed in advance of the meeting, and at least three members participate in the vote. A majority of CCKC's members have children who are enrolled in Missouri's Medicaid program and have been determined by DSS to need in-home private duty nursing services. None of CCKC's members have consistently received the private

duty nursing services that have been authorized for their children by DSS. Plaintiff T.S.'s grandmother and legal guardian, M.S., is a member of CCKC and its President.

22. Defendant Jennifer Tidball is the Acting Director of the Missouri Department of Social Services (DSS) and, as such, is responsible for the administration and implementation of laws concerning the social welfare of the people of the State of Missouri, including the Medicaid program. Defendant Tidball is the chief administrative officer of DSS and is responsible for administration of the single state agency for the Missouri Medicaid program. Defendant Tidball is charged with the ultimate control and administration of DSS, including the duty to administer the Missouri Medicaid program in compliance with the Medicaid Act. She is sued in her official capacity. Her principal office is located in Jefferson City, Missouri.

23. Defendant Missouri Department of Social Services is the single state agency responsible for administering Missouri's Medicaid program.

## **LEGAL FRAMEWORK**

### **A. Medicaid and Early and Periodic Screening, Diagnostic and Treatment**

24. The Medicaid Act, Title XIX of the Social Security Act, 42 U.S.C. §§ 1396-1396w-5, establishes a medical assistance program cooperatively funded by federal and state governments. The purpose of the Medicaid program is to enable states to “furnish, as far as practicable . . . medical assistance” on behalf of individuals whose income and resources are insufficient to meet the costs of necessary medical services and “to help such families and individuals to attain or retain capability for independence or self-care. . . .” 42 U.S.C. § 1396-1.

25. Participation by states in Medicaid is voluntary; however, once a state elects

to participate, it must comply with all requirements of the federal Medicaid Act and its implementing regulations and mandatory guidelines.

26. Missouri has elected to participate in, and receive federal matching funding through, the Medicaid program. The federal matching rate for Missouri is currently set at 65.65%. *See* Federal Matching Shares for Medicaid and CHIP for Oct. 1, 2019 through Sept. 30, 2020, 83 Fed. Reg. 61157, 55385 (Nov. 28, 2018).

27. States participating in the Medicaid program must designate a single state agency to administer the Medicaid program and ensure the program complies with all relevant laws and regulations. *See* 42 U.S.C. § 1396a(a)(5); 42 C.F.R. § 431.10. The duties of the single state agency are non-delegable. *Id.*

28. DSS is the single state agency that administers Medicaid in Missouri.

29. The Medicaid program does not provide Medicaid beneficiaries with money to purchase health care services directly. Rather, Medicaid is a vendor payment program that reimburses participating providers—including in-home private duty nursing providers—for the services they provide to Medicaid recipients.

30. States must ensure that medical assistance will be provided consistent with the best interests of recipients. *See* 42 U.S.C. § 1396a(a)(19).

31. Federal law requires states participating in Medicaid to operate their program pursuant to a state Medicaid plan that has been approved by the Secretary of the U.S. Department of Health and Human Services.

32. States must cover certain mandatory services in their state Medicaid plans. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a)(1)-(5), (17), (21), and (28)-(29). One mandatory service is Early and Periodic Screening, Diagnostic and Treatment (EPSDT) for children

under age 21. *Id.* §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).

33. EPSDT requires that the services listed in the Medicaid Act at 42 U.S.C. § 1396d(a) must be provided to a child if they are “necessary . . . to correct or ameliorate defects and physical and mental illnesses and conditions . . . regardless of whether or not such services are covered” for adults. 42 U.S.C. § 1396d(r)(5). Services must be covered if they correct, compensate for, improve a condition, or prevent a condition from worsening, even if the condition cannot be prevented or cured. U.S. Dep’t of Health & Human Servs., Ctrs. for Medicare & Medicaid Servs. (CMS), *EPSDT: A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*, 10 (June 2014), [https://www.medicaid.gov/medicaid/benefits/downloads/epsdt\\_coverage\\_guide.pdf](https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf).

34. Private duty nursing is a service listed at Section 1396d(a). *See* 42 U.S.C. § 1396d(a)(8). Accordingly, the EPSDT benefit includes private duty nursing care when necessary to ameliorate, correct, or maintain a child’s condition.

35. Private duty nursing is defined as “nursing services for beneficiaries who require more individual and continuous care than is available from a visiting nurse or routinely provided by the nursing staff of the hospital or skilled nursing facility. . . .” 42 C.F.R. § 440.80.

36. Private duty nursing must be provided by a registered nurse (RN) or a licensed practical nurse (LPN). *Id.* § 440.80(a). RNs and LPNs are licensed to provide skilled nursing care in many settings including homes and hospitals. *Id.* § 409.31(a).

37. Case management services are also listed at Section 1396d(a). *See* 42 U.S.C. § 1396d(a)(19). Accordingly, the EPSDT benefit includes case management when necessary to ameliorate, correct, or maintain a child’s condition.



38. Case management is defined as, *inter alia*, the development of a specific plan of care, referral to services, scheduling appointments, and monitoring and follow-up. *See* 42 C.F.R. § 440.169(d)(1)-(4). Monitoring and follow-up activities are meant to ensure that the plan of care is implemented and that services are furnished in accordance with the care plan. *Id.* § 440.169(d)(4).

39. The EPSDT mandate requires Defendants to “provide for . . . arranging for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment the need for which is disclosed by such child health screening services.” 42 U.S.C. § 1396a(a)(43)(C).

40. Defendants “must set standards for the timely provision of EPSDT services which meet reasonable standards of medical and dental practice . . . and must employ processes to ensure timely initiation of treatment, if required, generally within an outer limit of 6 months after the request for screening services.” 42 C.F.R. § 441.56(e).

41. Defendants are obligated to “design and employ methods to assure that children receive . . . treatment for all conditions identified as a result of examination or diagnosis.” CMS, *State Medicaid Manual* § 5310.

42. Defendants must “make available a variety of individual and group providers qualified and willing to provide EPSDT services.” 42 C.F.R. § 441.61(b).

43. The Medicaid Act requires Defendants to have agreements with every person or institution providing services under the state Medicaid plan, including private duty nursing services, under which such persons or entities “keep such records as are necessary fully to disclose the extent of the services provided to individuals receiving assistance under the State plan.” 42 U.S.C. § 1396a(a)(27)(A).

## **B. Anti-Discrimination Laws**

44. Qualified individuals with disabilities are protected from disability discrimination, including segregation in institutions, by the Americans with Disabilities Act of 1990 (ADA), 42 U.S.C. §§ 12101-12213; and by Section 504 of the Rehabilitation Act of 1973 (Section 504), 29 U.S.C. §794.

45. In enacting the ADA, Congress found that, “[i]ndividuals with disabilities continually encounter various forms of discrimination, including . . . segregation. . . .” 42 U.S.C. § 12101(a)(5).

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

47. Section 504 imposes the same prohibition on programs or activities that receive federal funds. 29 U.S.C. §§ 794-794a.

48. Regulations implementing Title II of the ADA provide 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); *see also* 29 U.S.C. §§ 794-794a; 28 C.F.R. § 41.51(d). The most integrated setting appropriate to the needs of a qualified individual with a disability means “a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.” 28 C.F.R. pt. 35, App. B.

49. The United States Supreme Court in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), held that the unnecessary institutionalization of individuals with

disabilities is a form of discrimination under Title II of the ADA. The Court interpreted the ADA's "integration mandate" as requiring persons with disabilities to be served in the community when: (1) the state determines that community-based treatment is appropriate; (2) the individual does not oppose community placement; and (3) community placement can be reasonably accommodated. *Id.* at 607.

50. Regulations implementing Title II of the ADA and Section 504 provide: "A public entity may not, directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; [or] (ii) That have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the entity's program with respect to individuals with disabilities. . . ." 28 C.F.R. § 35.130(b)(3); *see also* 28 C.F.R. § 41.51(b)(3); 45 C.F.R. § 84.4(b)(4).

51. ADA regulations further provide: "A public entity shall not impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered." 28 C.F.R. § 35.130(b)(8); *see also* 45 C.F.R. § 84.4(b)(1)(iv).

52. As set forth in federal regulations: "A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity." 28 C.F.R. § 35.130(b)(7).

## FACTUAL ALLEGATIONS

### A. DSS's Methods of Administering Private Duty Nursing for Children

53. Oversight and responsibility for administering the EPSDT benefit in Missouri, including private duty nursing services, rests with Defendants. These are non-delegable duties.

54. The Missouri Medicaid program provides health coverage to beneficiaries either on a fee-for-service basis or through managed care organizations (MCOs).

55. Under fee-for-service Medicaid, the beneficiary seeks care from any provider who is participating in the Medicaid program, willing to treat the particular beneficiary, and willing to accept reimbursement at the amount set by DSS for the medical services provided.

56. Under managed care Medicaid, DSS contracts with managed care organizations (MCOs) that agree to provide a designated set of health care services to Medicaid enrollees when they are needed and, in return, is prepaid for that care, receiving a per member per month payment.

57. School-based private duty nursing services for children with medically complex conditions are always provided on a fee-for-service basis by DSS, even if the child is enrolled in a managed care plan. *See* State of Missouri, Private Duty Nursing Manual, 172, § 13.8, [http://manuals.momed.com/collections/collection\\_pdn/print.pdf](http://manuals.momed.com/collections/collection_pdn/print.pdf) (hereinafter "Private Duty Nursing Manual").

58. DSS refers to EPSDT benefits as the "Healthy Children and Youth (HCY) Program."

59. Prior authorization determines the amount, duration and scope of the

requested service. Private duty nursing services are authorized only after a finding, with the support of a treating physician, that the services are medically necessary. The amount, duration, and scope of services are documented in a plan of care for each child. Medicaid-eligible children must receive prior authorization for private duty nursing, regardless of whether they receive Medicaid on a fee-for-service basis or through an MCO.

60. DSS has entered into a cooperative agreement with the Bureau of Special Health Care Needs (BSHCN) to conduct prior authorization and provide case management services to children receiving services through the fee-for-service system, including children with medically complex conditions.

61. BSHCN assesses the child to determine whether private duty nursing services should be authorized. BSHCN determines the frequency, amount, and duration of private duty nursing services that are then documented in the child's plan of care. Private Duty Nursing Manual at 163, § 13.10. In addition, when a Medicaid-enrolled child is being discharged from a hospital or other institution, the facility contacts BSHCN so that BSHCN staff can participate in discharge planning. *Id.* at 161, § 13.8.

62. Private duty nursing services are only authorized when a child requires at least four hours of skilled nursing care per day. 13 C.S.R. 70-95.010(2).

63. According to DSS, "It is the policy of MO HealthNet and the BSHCN that 64 units (16 hours) per day is the maximum amount of private duty nursing services that may be authorized. Exceptions to the policy can be made on a short term basis not to exceed 21 consecutive days or with the notification of the BSHCN Regional Office Coordinator and approval of the HCY Program Manager when there is documentation to

support this need.” MO HealthNet Private Duty Nursing Manual at 164, § 13.10, *see also Id.* at 153, § 12.2.A.

64. Once approved, private duty nursing services are provided by a home health agency enrolled with Medicaid and licensed by the State of Missouri to provide nursing services.

65. A home health agency is a private organization that recruits, hires, and trains health professionals to provide services such as private duty nursing; arranges scheduling of nurses; and ensures that staff is in compliance with licensing and certification requirements. Home health agencies also develop plans of care for review and approval by patients’ physicians, and provide services in accordance with approved plans of care.

66. A home health agency cannot be reimbursed for providing private duty nursing services without first receiving prior authorization from Defendants to do so.

67. DSS has also contracted with BSHCN to review requests for service coordination for children receiving services through the fee-for-service delivery system and assigns a “Service Coordinator” to each child. The responsibilities of Service Coordinators include developing a service plan, identifying funding options for needed services, completing activities necessary to obtain services, and advocating for services. *See* State of Missouri, HCY Program Guidebook Part 1, at 7, *available at* <https://health.mo.gov/shcn-secure/HCYGuidebook.htm>.

68. In addition, case management services are available under the HCY program through BSHCN. Case management services ensure that children receive medically necessary services and include making and following up on referrals to providers.

69. BSHCN does not assign a Service Coordinator to children enrolled through MCOs.

70. For children enrolled in MCOs, the State has delegated the initial responsibility for obtaining an assessment and plan of care. For these children, the home health agency requests the authorization directly from the MCO and the MCO approves or denies the request. For children in managed care, a home health agency cannot be reimbursed for providing private duty nursing services without first receiving prior authorization from an MCO to do so.

71. Medicaid beneficiaries enrolled in an MCO receive care coordination services from the MCO. Care coordination should ensure each individual has an ongoing source of care appropriate to their needs. 42 C.F.R. § 438.208(b). MCOs are required to perform an assessment for care management for “individuals who without services such as private duty nursing, home health, durable medical equipment/supplies, and/or care management may require hospitalization or institutionalization.” MO HealthNet Managed Care Contract, at 70, § 2.11.1, <https://dss.mo.gov/business-processes/managed-care/docs/ManagedCareContractFY20.docx>.

72. Care coordination services through the MCOs are meant to coordinate the services the MCO provides between settings of care and with services provided outside the MCO, such as from community and social support providers. Care coordination services incorporate and identify appropriate methods of assessment and referral.

**B. DSS’s Failure to Arrange for Private Duty Nursing**

73. Although the Plaintiffs have been authorized to receive private duty nursing services as medically necessary, Defendants have failed to arrange for these services by

failing to establish and implement meaningful and effective policies, practices, and procedures to administer this benefit.

74. Home health agencies regularly request that family members assist in recruiting nurses.

75. On information and belief, even nurses who participate in the Medicaid program often leave these positions for jobs at hospitals or other health care provider organizations.

76. Unlike other services offered through Missouri Medicaid, such as personal care services, Plaintiffs are unable to self-direct their private duty nursing services. This means that even if Plaintiffs are able to find nurses independently, Defendants require that they be employed by a licensed home health agency prior to issuing reimbursement for services.

77. Defendants fail at a systemic level to provide effective case management and otherwise arrange for the medically necessary private duty nursing services they have approved, thereby placing the burden on families to find medically necessary private duty nursing services and navigate a complex system with little to no support in obtaining necessary services for their children.

78. Plaintiffs have repeatedly informed the Defendants that they are not receiving the private duty nursing services that the Defendants have found them to need. The Defendants' agent, BSHCN, routinely directs families to continue contacting home health agencies on their own. As a result, Plaintiffs have had to take extraordinary measures to try to locate Medicaid providers, such as making repeated calls to home health agencies, contacting nursing schools, and making their children's circumstances public through



social media forums such as Facebook.

79. Upon information and belief, Defendants do not train BSHCN Service Coordinators on what steps to take when a Medicaid enrollee is not receiving the private duty nursing services that Defendants have determined are medically necessary.

80. Upon information and belief, Defendants do not authorize overtime payment or higher wages when there is no provider available to provide private duty nursing that a child needs.

81. Upon information and belief, Defendants do not authorize higher rates for hard to fill shifts, such as weekends or overnight.

82. Upon information and belief, Defendants do not permit nurses with licenses from neighboring states to provide private duty nursing services.

83. Upon information and belief, Defendants do not permit nurses who have graduated from a nursing program to be employed by home health agencies pending the outcome of their nurse licensure examination.

84. Upon information and belief, Defendants do not permit parents who are licensed RNs or LPNs to serve as paid providers for their medically fragile children.

85. Defendants require fee-for-service Plaintiffs to obtain prior authorization of private duty nursing services from BSHCN. As a result, Defendants have actual knowledge of the number of weekly hours of private duty nursing services they have found to be medically necessary for each fee-for-service Plaintiff.

86. Defendants have knowledge of the monthly billing for each fee-for-service Plaintiff's private duty nursing services. Therefore, Defendants are or should be aware of their failure to arrange medically necessary private duty nursing services when Defendants

are not billed for the full amount of approved care.

87. Defendants also receive “HCY Provider Monitoring Logs” for children enrolled in fee-for-service Medicaid. The HCY Provider Monitoring Logs describe the authorized services and the actual services provided. Private Duty Nursing Manual at 165, § 13.12. Therefore, Defendants are, or should be, aware of their failure to arrange medically necessary private duty nursing services when the logs show actual services used are less than services authorized.

88. On information and belief, Defendants do not monitor whether Medicaid eligible children enrolled with managed care companies are receiving all of the private duty nursing services that are authorized, although those records are or should be available from the managed care companies.

89. Defendants fail at a systemic level to identify and assist children who are in need of private duty nursing services but are not receiving those services.

90. Defendants fail at a systemic level to effectively track and monitor children who are institutionalized because a lack of available nursing in the community or who have a shortfall between authorized and staffed nursing hours.

91. The Medicaid payment rate for private duty nursing is \$535 per 16-hour day. Sixteen hours is the maximum number of hours Missouri Medicaid will authorize, subject to narrow limitations. MO HealthNet Division Provider Manual, § 13.10, available at: [http://manuals.momed.com/collections/collection\\_pdn/print.pdf](http://manuals.momed.com/collections/collection_pdn/print.pdf). On information and belief, the Medicaid payment rate for the inpatient hospital care of a medically-complex child is roughly \$4,000 per day, and the Medicaid payment rate for inpatient step down care at a facility such as Ranken Jordan Pediatric Bridge Hospital is \$2,235 per day.

92. On information and belief, Defendants have no policy to address crisis situations where a nurse is suddenly unavailable.

### **C. The Plight of the Plaintiffs**

#### Plaintiff S.J.

93. Eighteen-year-old S.J. lives with her parents and brother in Sunset Hills, Missouri.

94. S.J. has had numerous medical challenges over her lifetime, including respiratory conditions, infections, and fractures. She also has a rare, severe, and lifelong form of epilepsy known as “Dravet syndrome.” One symptom of Dravet syndrome is seizures. Before the age of three, S.J. had already had 23 severe seizures and hundreds of shorter seizures (less than 20 minutes long).

95. When three years old, S.J. had a five-hour-long seizure during which she sustained severe brain injury. Although she was given only a 20 percent chance of survival, S.J. lived. A baclofen pump was surgically implanted to deliver medicine to her spinal column and treat the spasticity (continuous muscle contractions) that resulted from the brain injury. S.J. also had a procedure called “Nissen surgery” to treat gastrointestinal disease and prevent her from refluxing or vomiting into her lungs. At that time, she was considered “neurologically devastated.” She had no facial expression, was totally blind, and could not hold up her head. Except for her left wrist, S.J. could not move her body. Her doctors believed she would be tube-fed, non-verbal, and non-ambulatory from that point on.

96. S.J. is now 18 years old. She is a sweet, loving child who laughs, smiles, vocalizes, loves music, and enjoys having people read to her.

97. S.J. participates in weekly occupational, physical, and speech therapy and recently began music therapy. In May 2019, S.J. graduated from the Special School District, from which she received homebound instruction.

98. S.J.'s seizures now come less frequently but she is regularly administered three anti-seizure medications. S.J. also has a seizure protocol. For example, at the start of any convulsive seizure, S.J. must immediately receive Diastat, a rectally administered "rescue medication" and, depending on the nature of the seizure, additional emergency medications. If she has myoclonic seizures (brief, shock-like muscle jerking that causes her to look startled), S.J. must immediately receive Clorazepate through a gastric tube. Someone who is trained to know when and how to administer these medications must always be with S.J.

99. S.J. receives medicine through a button on her "G-J" (gastro-jejunal) tube which allows her nurse or, more often her mother, to put medicine into her stomach. She was previously on parenteral nutrition (IV nutrition) because she could not absorb enough nutrients through her tube feedings, but she was transferred fully to tube feeding in January 2019.

100. S.J. has scoliosis and is non-ambulatory. She uses a "molded chair" to support the curvature in her spine, and this also helps her to breathe. She needs medical equipment to lift and move.

101. S.J. uses a Bi-PAP (Bilevel Positive Airway Pressure) machine to ensure that she receives enough oxygen, particularly at night while she sleeps. S.J. must use additional machinery, such as an oxygen concentrator, when she is sick, including any time she has a respiratory illness. She uses an airway clearance vest to clear her lungs and

prevent pneumonia. She takes nebulizer medications to help maintain her lungs so she does not get sick. Because S.J. can choke, she must use a suctioning machine two to three times a day to keep her airway clear.

102. S.J. relies on adult diapers but sometimes has to be catheterized if she does not urinate for twelve hours or when she has urinary tract infection or respiratory illness.

103. S.J. is privately insured through Anthem and is also enrolled in the Missouri Medicaid program, which is her “secondary payer.”

104. Due to her medical conditions, Defendants have determined that S.J. needs 81 hours of in-home private duty nursing services per week. Her mother tries to schedule these hours as follows: 13 hours daily Monday through Friday (an 8:00 a.m. to 4:00 p.m. day shift and a 4:00 p.m. to 9:00 p.m. evening shift), and eight hours daily on Saturday and Sunday.

105. When S.J. was younger, she received her approved nursing hours more consistently, but it has gotten harder to find nurses as she ages. For most of 2019, S.J. was not receiving any of her approved nursing services on Tuesday, Wednesday or Thursday evenings.

106. S.J.’s mother, S.S., has cared for S.J. all her life. In recent years, S.S. has tried to use multiple part-time nurses and coordinate nursing through a Google calendar just to keep minimal coverage. She has worked most closely with Craig Home Care, a Medicaid-participating home health agency, for scheduling, supervisory visits, and occasional paperwork. She has recently spoken with other agencies, including Team Select and Bayada, but was told they do not have Medicaid-participating nurses available for S.J.

107. Case managers at the Bureau of Special Health Care Needs have merely provided S.S. with a list of home care agencies, encouraged her to contact nursing schools, and to take it on herself to find her own nursing, but she has already been doing that for many years.

108. In October 2019, S.S. was diagnosed with breast cancer. She has been in chemotherapy every other week. People are trying to help. Beginning the week of November 11, S.S. found a nurse through her church and another through a parents' Facebook group run through the school district. S.J.'s regular nurses have also provided extra help out of the goodness of their hearts. S.J. still is not receiving the full amount of private duty nursing that the Medicaid agency has determined that she needs.

109. The lack of private duty nursing coverage is stressful for the family. S.S. has only limited ability to leave the house because she is caring for S.J. She cannot exercise, go to her own doctor appointments, or sometimes even take a shower. She cannot be employed full time outside the home and, thus, has not paid into Social Security as she would have hoped. S.S. has never visited her step-son and her young step-grandchildren in Wisconsin. S.J.'s father is 70 years old, has his own health issues, and cannot care for S.J. for more than an hour at a time. The lack of nursing coverage for S.J. affects S.S.'s ability to help her husband with his health needs. S.J.'s brother cannot participate fully in school activities, and his parents often miss his activities because nursing is unavailable. Currently, S.J.'s brother is not participating in any sports, clubs or activities because S.S. cannot reliably get him there. The family rarely does anything together as a family because S.J.'s weekend nursing shifts often are not covered.

110. S.S. worries about S.J. and what will happen to her. S.J. needs the Medicaid-approved private duty nursing to avoid hospitalization or some other form of institutionalization. S.S. is concerned that she cannot provide the care S.J. needs. She worries that, if she gets sicker, there will be no one to take care of S.J. The weekly chemotherapy has caused S.S. to feel ill, extremely exhausted, sleepy, sick to her stomach, and dizzy. Her ability to care for S.J. at home is more precarious than ever.

Plaintiff C.T.

111. C.T. lives with her family in Ferguson, Missouri. She is 18 years old. When she was 12 years old, a brain infection put her in a coma for a month. She was placed on an ECMO (extracorporeal membrane oxygenation) machine, which circulated her blood and breathed for her.

112. After she came out of the coma, it was clear that the brain infection changed C.T.'s life. She has feeling in her entire body and is alert mentally, but she cannot walk, breathe, eat, or urinate on her own. She uses a ventilator 24/7, is fed through a tube, and has a catheter. She needs enemas, suppositories, and medicine to keep everything moving through her gut. She can lift one arm, but cannot hold or lift anything with that hand. C.T. takes about 16 medications daily.

113. Despite her condition, C.T.'s father, G.T., describes her as a "sassy girl." She is about to graduate from high school. Her favorite subjects are history, art, and science. She likes to listen to Whitney Houston and Drake. She loves cartoons, all the Madea movies, and all kinds of "girly stuff." She has good relationships with her twin brother and G.T.'s girlfriend's two daughters.

114. After coming out of the coma, C.T. lived at the hospital and then at Ranken Jordan Pediatric Bridge Hospital for over five years. Depending on her condition, she would go back and forth between the two facilities. C.T. missed her family and had to be prescribed medication for depression. She was clinically ready to go home approximately one year ago; however, she needed in-home nursing care.

115. C.T. has health coverage through Missouri Medicaid. DSS determined that C.T. needed to receive 24-hour care for the first three weeks she was home, and 16 hours per day of private duty nursing thereafter. Defendants did not arrange that care. C.T. remained in the hospital.

116. On December 23, 2019, a Medicaid-participating home health agency had been lined up, and C.T. went home. She was supposed to get 24 hours a day for the first three weeks. She did not get that for even one week. G.T. did his best to care for her. G.T. is not trained as a private duty nurse.

117. C.T. made it at home for less than a month. Her bowels got backed up, and she had stomach problems. She was admitted to St. Louis Children's Hospital on January 17, 2020. G.T. thinks this happened because he does not know enough about nursing and because C.T. did not have the private duty nursing that she was supposed to get.

118. On January 29, C.T. was discharged home. Although she was approved for 16 hours a day (112 hours per week) of private duty nursing services, she was getting only about 30 hours per week. On February 11, C.T. again had to return to the hospital. In the time leading up to her admission, she had no nursing coverage and was struggling to breathe. At the hospital, G.T. learned that C.T.'s tracheostomy had dried saliva built up inside it, constricting her airway. G.T. believes that a trained nurse would have been able



to suction the tracheostomy properly, and C.T. would not have had to go back to the hospital.

119. C.T. was discharged home on February 17. She currently has private duty nursing services during the day on weekdays. G.T. is providing care for her himself in the evenings and overnight.

120. C.T.'s condition has caused family stress. Before C.T.'s hospitalization, G.T. had a permanent, full-time job as maintenance technician. He then took a job as an on-call maintenance technician so that he could be there when C.T. needed him. When C.T. came home in December 2019, G.T. was not able to respond to emergency repair calls because Defendants failed to arrange private duty nursing services for C.T. G.T. has now been fired because he could not be predictably available for repair calls. He is the family's breadwinner and is now very worried about how his family will manage financially.

121. C.T. and her family want her to live at home around her own people who know and love her.

Plaintiff P.W.

122. P.W. is 16 years old. She lives in Highlandville, Missouri with her mother, C.W.; her father, A.W.; and her 17-year-old brother.

123. When P.W. was five years old, she was in a car accident. As a result, she has quadriplegia and depends on a ventilator to breathe. Other than these significant physical challenges, P.W. is completely cognitively intact. She loves the teenaged Disney shows, music, YouTube videos, and the trends young teens follow. "My Little Ponies" is one of her favorite shows, and she can give a detailed history of that series. She also loves watching cooking shows; especially "Chopped." Movies are a family pastime, and P.W.

collects movie figurines. Her favorite movies are “The Nightmare Before Christmas” and “Coraline.”

124. Despite the fact that she cannot move anything from her neck down, P.W. is great at being her own advocate. She is strong-willed. Her mother jokes that she is going to be a lead FBI negotiator one day.

125. P.W. needs private duty nursing because she depends on a ventilator to breathe. Someone must be available 24 hours a day because she has a critical airway need. If P.W. were somehow disconnected from her ventilator, she would be without oxygen until she was reconnected. She effectively would be suffocating. P.W. is a teenager, so she does spend time in her room alone. C.W. and A.W. have a video monitor, so that they can see and hear if P.W.’s vent disconnects. They can respond immediately.

126. P.W. has health coverage through the Missouri Medicaid program. Defendants have consistently approved P.W. to receive 16 hours of private duty nursing each day.

127. The family has struggled for years to get the private duty nursing services that Medicaid has approved. It has gotten much worse in the last three years when there have always been gaps in coverage, particularly at night. As a result, one of her parents must stay up at night to monitor her ventilator. The other parent will then get up and get P.W. ready for school. The parents cannot focus on P.W.’s brother as they would like, and this is hard on him.

128. P.W. was admitted to St. Louis Children’s Hospital in May 2019 for back surgery. She had developed scoliosis and needed surgery to fuse her vertebrae. She got an infection and spent most of the summer in the hospital. P.W. was medically ready for

discharge in early September. However, she remained in the hospital until November 8, 2019. The only reason she was stuck in the hospital and could not come home, was because Defendants did not arrange for the private duty nursing services they had approved for P.W.

129. It was hard on the family while P.W. was at Children's Hospital. The hospital is in St. Louis, 230 miles away from their home. P.W. missed her family and friends. She missed most of the first half of her freshman year of high school. C.W. missed a good portion of her son's senior year because she was staying in St. Louis with P.W.

130. The Bureau of Special Health Care Needs was in touch with Children's Hospital discharge planners to arrange nursing services for P.W, but P.W. came home without all the nursing services she needs. She has a day nurse who comes nine hours a day, from 7:00 a.m. to 4:00 p.m., Monday through Friday. In December of last year, P.W. got some overnight nursing because another nurse's usual patient was in the hospital. The family thinks that will be temporary.

131. At least three or four home care agencies are working to find nurses. P.W. had the same BSHCN caseworker for three or four years, but he has been on leave for a while. He was good about giving the family information but the necessary nursing hours were never covered. The new case worker knows that P.W. is not receiving the amount of private duty nursing that she needs. She gave C.W. the list of the five nursing agencies in the area, which C.W. already has.

132. If P.W.'s approved private duty nursing services were actually provided, C.W. and A.W. could both have jobs. Previously, C.W. was a restaurant manager, and A.W. the manager of a retail store. For several years after the accident, A.W. stayed home

while C.W. worked. A few years ago, they swapped and C.W. now stays home. They tried to both work outside the home, but with the inconsistent nursing coverage it was impossible for both of them to keep jobs. It has been a financial struggle for the family.

133. If P.W. had the nursing services she needs, the family could spend time together as a family. P.W.'s parents would have enough energy and attention for both children. They could sleep like a normal adult couple who sleeps at the same time in the same bed. They could enjoy leaving the house together as a couple.

134. The shortage of private duty nursing is hard because the family feels pressured to take any nurse they can get. Without the necessary private duty nursing hours, P.W. faces a serious risk of going back into the hospital and being far away from her family and friends.

Plaintiff S.E.S.

135. S.E.S. is the youngest of J.L-S and E.S.'s nine children—six adopted special needs children and three biological children (ages 19, 18, 17, 16, 15, 15, 12, 10, and nine-year-old S.S.). The family lives in St. Louis, Missouri.

136. J.L-S. and E.S. adopted S.E.S. shortly after her traumatic birth in 2011. S.E.S. was considered to be a “stillbirth resuscitation” and has been fighting for her life ever since. When she was placed in J.L-S. and E.S.'s home for adoption two months after her birth, her prognosis was poor, and she was not expected to make it through her first year. S.E.S.'s medical diagnoses include severe spastic cerebral palsy, severe scoliosis, torticollis (problems with her neck muscles), and uncontrolled severe epilepsy.

137. Since the fall of 2011, S.E.S. has been dependent on technology for breathing and eating. She is ventilator- and oxygen-dependent, has a feeding tube, and

requires a wheelchair for movement. She uses a Continuous Positive Airway Pressure (C-PAP) machine by day, and a Bi-level Positive Airway Pressure (Bi-PAP) machine nightly. S.E.S. needs to stretch three to four times a day. She wears leg braces. She needs positional changes every 90 minutes. To communicate, S.E.S. controls a specialized computer tablet with her eyes. She relies on an implanted baclofen pump to deliver medications directly to her spinal cord and nervous system. These medications quiet her spastic movements. Without those uncontrolled movements, S.E.S. can breathe and eat better. She can also move the switches on her wheelchair. S.E.S. has even started learning how to hold and make marks with a marker. S.E.S. is dependent other people for everything, including eating, bathing, dressing, all personal care, and moving.

138. S.E.S. requires constant care from a trained care provider because she has a complex medication regimen and requires specialized care. As a child on a ventilator, S.E.S. must be monitored by a nurse who is ventilator-trained and able to suction S.E.S. Her airways must be clear at all times. Any time S.E.S.'s secretions build up, a nurse or a trained caregiver has to use a bulb syringe to suction her orally and through her tracheostomy tube. This can happen between 12 and 50 times a day.

139. S.E.S.'s pain pump requires constant monitoring because she gets medications delivered on a schedule. She currently takes four medications daily and has a variety of over 15 other medications that need to be administered on an as-needed basis. S.E.S. has one to two seizures per day and also has other neurological incidents that are not considered seizures. She needs to be monitored during these events to ensure her oxygen levels are appropriate and have someone administer oxygen if they are not. S.E.S.

sometimes needs emergency medication during a seizure. This happens once or twice a month.

140. S.E.S. sees numerous specialists at Mercy Hospital, Ranken Jordan Pediatric Bridge Hospital, and Cardinal Glennon Children's Hospital.

141. From when she was just a few months old to three years, S.E.S. received therapy through Early Childhood Intervention services and then she began attending school in the Rockwood School District. She is currently served by the Special School District and Rockwood at Blevins Elementary, where she attends third grade. Her school provides her with care while she is at school. That is usually when her mother sleeps or catches up on the other things needed to keep S.E.S. and the entire household going.

142. S.E.S. is an amazing young lady. She is notable for many things, including that she is still alive and fighting. She loves dinosaurs, dancing, swimming, playing games with friends, and swinging with her peers on the playground at school. S.E.S. is a Girl Scout and a "Big Buddy" at her school (where older kids are partnered with younger kids). She participates with her mainstreamed class as well as in her special education class. S.E.S. has friends and people who love her.

143. S.E.S. is insured through the Medicaid program. Initially, in 2011, she was enrolled in a Medicaid managed care plan. The plan determined that S.E.S. only needed "custodial care" and did not approve her for any private duty nursing services. After much effort by her parents, the plan approved S.E.S. for four hours per week of private duty nursing. In 2013 or 2014, S.E.S.'s parents moved her out of managed care into fee-for-service Medicaid after learning that her doctors would accept fee-for-service and because

other families with medically complex children were getting approvals for private duty nursing services through the HCY program.

144. Defendants have currently determined that S.E.S. needs 16 hours of private duty nursing per day when she is not in school, and eight hours a day when she is in school. She receives a prorated number of hours if she is in school for a partial day.

145. Medicaid has arranged no services for S.E.S., and she currently is getting no private duty nursing services at home. Since May 15, 2019, S.E.S. has had a total of two nursing shifts covered. As a result, S.E.S.'s family has been providing 24/7 care for S.E.S. when she is not in school.

146. Over the course of S.E.S.'s life, DSS has arranged and paid for only about 75% of the private duty nursing hours that they have authorized for S.E.S. She has never had full coverage of the authorized care. E.S. works full-time, so J.L-S. meets S.E.S.'s care needs when there is no nursing coverage. J.L-S. is not a trained medical professional.

147. S.E.S. is registered with three home health agencies that are Medicaid-approved providers. Each of these agencies is looking for licensed nursing staff to provide nursing services for S.E.S. J.L-S. speaks with them at least once a month, but usually calls every week about finding nursing for S.E.S.

148. About once or twice a month, J.L-S. calls the case manager at the Bureau of Special Health Care Needs for help. The case manager tells her to "keep calling" other home care agencies or that two agencies together can provide the care. So far, nothing has come of her calls to the Bureau.

149. J.L-S. does everything she can to find nurses who will provide private duty nursing for S.E.S. She made a flyer for job boards that she sends to every nursing school

and college in the region just before the fall, winter, and spring graduations. She makes public Facebook posts about once a week, asking for nurses to work for S.E.S. J.L-S. feels conflicted about invading S.E.S.'s privacy by posting her photo and saying she has medical needs so publicly, but she is doing what she has to do to find nurses.

150. The lack of private duty nursing services is stressful for the family. J.L-S. is often pulled away from the other children (e.g., while sitting at a high school play or some other event) and has to tend to S.E.S. This has caused the older children to have hurt feelings.

151. In about December 2016, J.L-S. had to go to the emergency room for a gallbladder attack and was ordered to go directly into surgery. There was no nursing coverage for S.E.S. so, against the doctor's wishes, she left the ER and returned home. She made an appointment to have surgery two days later. J.L-S. left the hospital hours after surgery because she had to go home to care for S.E.S.

152. In the summer of 2016, S.E.S. had recently had surgery on her leg to remove a pin from a prior surgery, J.L-S. was home alone and had to transfer her to address her breathing issues. When she moved S.E.S.—as she had done many other times—the location in her leg from which the pin had been removed cracked. She had to go into the hospital, have another surgery, and get an external fixator placed on her leg. J.L-S. believes this incident would never have happened if a qualified nurse were with S.E.S.

153. S.E.S. sleeps beside J.L-S. in a hospital crib. J.L-S. gets up five to 10 times a night to adjust S.E.S.'s sleeping position, change her oxygen settings, and adjust her vent settings. S.E.S.'s parents also monitor for seizures and give medicine. J.L-S. and E.S. have not slept a complete eight hours since S.E.S. received her tracheostomy in the Fall of 2011.



154. J.L-S. fears that at some point without nursing support, she will no longer be able to care for S.E.S., and S.E.S. will have to go back into the hospital.

155. The family learned in late 2019 that S.E.S. needed to have her gallbladder taken out. Before that surgery, the doctors needed to wean her off some medications. Because S.E.S. had no private duty nursing coverage, she was hospitalized from December 4 to December 31 so that she could be weaned. S.E.S. could have been weaned at home if she had private duty nursing care. Happily, her surgery went well and she came home shortly afterwards. J.L-S. fears that, without sufficient private duty nursing services, sooner or later, S.E.S. is going to be back in the hospital again.

Plaintiff T.S.

156. T.S. lives with his grandmother and legal guardian, M.S., and his grandfather, in Lynchburg, Missouri. Before T.S. came home with them, both grandparents worked full-time—his grandfather as a licensed practical nurse and M.S. as a certified medication technician. T.S. is five years old.

157. T.S. was born with congenital central hypoventilation syndrome (CCHS), a rare, lifelong, and life-threatening disorder that affects the central and autonomic nervous system (ANS). The ANS controls many of the body's automatic functions like heart rate, blood pressure, body temperature, bowel and bladder control, and sensing of oxygen and carbon dioxide levels in the blood. A child with CCHS does not sense lack of oxygen or shortness of breath, so the child's body does not automatically change behavior when it needs to work harder to breathe. Someone must constantly monitor the child's oxygenation (oxygen levels) and ventilation (breathing).

158. T.S. was flown from Oklahoma (where he was born) to St. Louis Children's Hospital in early August 2016. His grandparents spent several weeks undergoing training at the hospital so that they could help care for T.S. at home. By September, they had completed the training, and T.S. was stable and ready for discharge home with private duty nursing services. DSS did not arrange for the private duty nursing services that T.S. needed. Children's Hospital transferred T.S. to Ranken Jordan Pediatric Bridge Hospital, where he stayed for about six weeks. T.S. went home with his grandparents on November 15.

159. Because of his CCHS, T.S. relies on a ventilator to breathe and a pulse oximeter to constantly monitor the oxygen level in his blood. On average, T.S. is off the ventilator two-to-four hours a day. T.S. is quite susceptible to viruses and illnesses, so he is often on a vent. Even when the vent is operating properly and oxygen is going into his body, a caregiver must make sure that carbon dioxide is exiting his body.

160. T.S. needs a ventilator to breathe for him at night. Someone must be present to ensure his ventilator is functioning. If the alarm goes off, a nurse or someone trained in ventilator-patient care must act immediately. This usually means T.S. must be repositioned and/or be suctioned to ensure his airways are functioning. Failure to immediately respond would mean that T.S. would go without oxygen, which could cause brain damage or even death. His vent alarm goes off often at night. Some nights he has extra trouble—for example when there is change of weather or when he has a virus—and requires suctioning as often as every 15 minutes. Monitoring T.S. is a serious duty that requires vigilance and skilled attention.

161. T.S. has health coverage through Missouri Medicaid. Defendants have authorized him to receive 16 hours of private duty nursing per day, or 112 hours per week.

T.S. has almost never actually received all the nursing services prescribed and approved for him. As a long-term average over the past few years, he has received approximately 75-80 hours of private duty nursing per week. There was a three-month period when T.S. had no private duty nursing. Currently, T.S. is receiving 70-86 hours per week. This level of nursing care is not stable. One of T.S.'s nurses is pregnant and will stop working with him. Another nurse is planning to leave to go work at a hospital.

162. M.S. is constantly looking for private duty nurses to work with T.S. For example, in late 2019, she had new tires put on the car. While visiting with folks at the car shop, she talked about T.S. One of mechanics said his daughter was a nurse. M.S. immediately got her name and number and called her that same night. This nurse is considering doing training so she can care for T.S. On another occasion, M.S. met a woman who worked at the school lunchroom. She talked about T.S. and learned that the woman is a nurse. That woman now provides nursing care for T.S. two to three nights per week. T.S.'s grandfather supervises nursing students and will recruit nurses at work. One of T.S.'s nurses is a former student recruited by T.S.'s grandfather. The family is constantly looking because, even when T.S.'s hours are covered, it is not clear how long that will last.

163. T.S.'s family has been assigned a Bureau of Special Health Care Needs caseworker. When T.S. first came home, the caseworker visited the home every 60 days. However, since late 2017 or early 2018, the family has received a visit every 120 days and every other visit takes place by phone. At the initial visit, the caseworker gave M.S. a folder with resources but left it to the family to figure out which resources would be helpful for T.S. and how to access them. The caseworker has helped M.S. in discussions about how to manage the nurses who working are in the home, for example to discuss whether something

a nurse has done is acceptable. Otherwise, the family feels that BSHCN does not have time for them. As a result, securing nursing services has fallen to M.S. She updates BSHCN on a monthly basis, but BSHCN has not been involved in arranging for the nursing services that T.S. needs.

164. M.S. has spoken with many nurses about providing care for T.S. Nurses tell her that the home care agencies do not provide the same level of pay, health insurance, and benefits that nurses can get working in other places. Similarly, T.S.'s grandfather is a nurse who could provide professional and appropriate care for T.S., but Medicaid will not pay him for T.S.'s care.

165. The lack of private duty nursing is stressful for the family. M.S. cannot work a regular job because she never knows when there will be no nursing coverage. If a nurse quits or calls in sick, it takes the family a long time to find a replacement. M.S. takes per diem shifts at long-term care facilities. In December 2019, she started working for a credit card vending company in sales, which allows her to make her own schedule.

166. Despite the dire predictions and the daunting challenges T.S. has faced, he is a thriving, joyful boy. He walks, and talks, and laughs. He is in preschool learning to recognize letters. However, without the private duty nursing services that are medically necessary for him, T.S. is at serious risk for hospitalization, further complications of his medical conditions, and even death.

Plaintiff S.A.

167. S.A. lives with her parents in Maryland Heights, Missouri. She is three years old.

168. Born prematurely in 2016, S.A. weighed one pound, nine ounces. When she was four months old, she had brain surgery to place a shunt to drain fluid from her brain. Right after that, S.A. had eye surgery; she had opened her eyes too early and they were damaged. She had a hard time coming back from these surgeries and coded five or six times. Hospital staff told S.A.'s mother M.A., that S.A. could die at any time and suggested removing her oxygen. M.A. refused. S.A. was later discharged after one year and nine months in the hospital.

169. S.A. lived at home with her parents for more than two years. She continued to grow and learn. She loves music, Dave and Ava baby songs are some of her favorites. She also likes movies. Moana and Sing are two that she really likes. S.A. enjoys her therapy time and getting into her stander is fun for her. She also knows when her dad comes home. She wants to be in the living room to greet him. Even though she eats through a G-J tube, the family has dinner together every evening. Being at the table interacting with her parents is an important part of S.A.'s day.

170. S.A. qualified for Medicaid, and because the doctors who cared for her in the hospital did not accept fee-for-service Medicaid, M.A. kept S.A. in a Medicaid managed care organization, Home State Health Plan (Home State). Home State authorized S.A. to receive 20 hours per day of private duty nursing services. However, she never got this level of services. During the first two years after she was discharged, there were two months with no night nursing, six months with no day nursing, and a four-month period where S.A. had no private duty nursing services at all. S.A. remained home and healthy because her family did everything they could to care for her themselves. It was difficult and stressful, financially and emotionally.

171. At the end of 2019, S.A. somehow lost Medicaid coverage and thus lost private duty nursing services. For some 10 days, M.A. cared for S.A. around the clock. At one point, M.A. left S.A. for a brief time only to wash her hands. When she returned, S.A. was having a seizure, something that had not happened before. S.A. was admitted to the hospital, where they were able to stabilize her.

172. S.A.'s Medicaid coverage was subsequently reinstated, and she was placed in the fee-for-service program. The Bureau of Special Health Care Needs authorized S.A. for 14 hours per day (98 hours per week) of private duty nursing services. The Bureau informed M.A. that all S.A.'s hours must be provided by a single nursing agency, though Home State had allowed multiple agencies to provide services to S.A.

173. The hospital refused to discharge S.A. until private duty nursing services were in place. M.A. understood that it would be dangerous for S.A. to be entirely without private duty nursing services. Although S.A. was approved for 98 hours per week of private duty nursing services, Defendants only arranged for 56 hours per week. The hospital staff and M.A. believed this amount would temporarily be sufficient while additional nursing hours were arranged. S.A. was thus discharged home on February 14, 2020. On that date, M.A. understood that S.A. would have one nurse who provided four 10-hour day shifts on Monday, Tuesday, Wednesday, and Friday; and a second nurse who would provide eight-hour shifts on Saturday and Sunday. However, since being discharged, S.A. has only had one 10-hour shift of private duty nursing services. The weekday nurse has not returned after her first day, and the weekend nurse is only able to work on alternate weekends starting as of February 29.

174. After 10 days of providing round the clock care for S.A. at home in December 2019, M.A. was worn down. She is now very worried about her ability to provide care for S.A. She is able to sleep for four hours a night while her husband monitors S.A. M.A. then wakes to allow her husband four hours of sleep before he must go to work. M.A. and her husband worry about how long they can properly care for S.A. with no nursing services.

175. S.A. has doctor's appointments and needs someone who is trained to watch her while M.A. is driving. It is a risk to S.A.'s health for her to miss doctor's appointments, but it is also a risk for her to travel without two adults in the car. M.A. has not been able to work because S.A. has not had private duty nursing services. The family's finances are strained. Even worse, M.A. is worried because she knows there is a strong chance S.A. will go back to the hospital or even something worse if she does not have the private duty nursing services that she needs.

Plaintiff R.R.

176. R.R. lives with his grandparents and seven-year-old brother in Park Hills, Missouri. He is three years old.

177. R.R. was diagnosed at birth with Escobar Syndrome, a form of arthrogyrosis, which causes abnormalities in the muscle tissue and contractions in the joints. R.R. has a very severe form of Escobar Syndrome, and almost every joint in his body is affected, especially his shoulders, hips, and back. R.R. has severe scoliosis, which will likely need surgery at some point. He cannot breathe on his own or digest foods easily. He relies on a ventilator to breathe. He is fed and receives medication through his j-tube. He uses a g-tube to vent gas from his stomach.

178. R.R. also has an auto-immune disorder, which requires an infusion of Hizentra every week to boost his autoimmune system.

179. R.R. was born at St. John's Mercy Hospital and transferred to Ranken Jordan Pediatric Bridge Hospital in December 2018. Although he was clinically ready for discharge by the summer of 2019, he was stuck in Ranken Jordan for several more months because Ranken Jordan could not locate Medicaid-participating private duty nurses. In November 2019, R.R. was discharged and went home with his grandmother, M.D.

180. R.R. receives his health coverage through the Missouri Medicaid program. Defendants have determined that R.R. needs 16 hours per day of private duty nursing (112 hours of nursing care per week).

181. When he first came home, R.R. was getting 40 hours per week of nursing services from one nurse who worked eight hours per day on weekdays. A night nurse worked one shift but left, leaving R.R. with no night and weekend coverage. Two weeks after R.R. came home, the home health agency, Craig Home Care, added a nurse who works eight hours a night Monday through Friday. R.R.'s grandparents have struggled on weekends to provide all of R.R.'s care. A weekend nurse was added in December 2019; she works eight hours during the day on Saturday and Sunday.

182. Even with this coverage, R.R. has never received the amount of private duty nursing that the Defendants determined is needed. R.R.'s weekday day nurse is now pregnant and taking off for doctor's appointments and other reasons. Like any other workers, R.R.'s nurses take vacations or have their own appointments. When the nurses take off, R.R.'s grandparents do not get a substitute nurse. His grandmother M.D. cares for him.



183. R.R.'s grandparents feel lucky for the nursing that they have; nevertheless, it is hard for them to manage. Being responsible for all of R.R.'s care for eight hours during weekdays and for 16 hours each day of the weekend is demanding and stressful. R.R. needs constant, skilled attention. For example, R.R. needs a CoughAssist treatment every four hours. This requires the nurse, or his grandmother, to hook a machine to his vent so that it can simulate coughing and clear secretions. Every four hours during the day and once at night R.R. needs to be fitted with a SmartVest, also called a "shaker vest," to shake things from his lungs. R.R. needs to be suctioned. There are days when R.R.'s grandmother suctions him 15 times in an eight-hour period. R.R. must also receive medications daily and as needed. His nurse or caregiver must decide when as needed medications should be administered.

184. Caring for R.R. is stressful for the family, and the family is living on the edge. His grandparents cannot go out together to a movie, dinner, or to see friends. His grandmother can no longer go to church—something that is a very important part of her life and that she did every Sunday. Because R.R. is not receiving all of the necessary weekend hours, his grandmother asked DSS if she could add hours during the week. She was told that this was not allowed.

185. R.R.'s grandmother used to work as a nursing assistant in hospice care. She had to quit her job after R.R. returned from the hospital. This situation is causing financial strain. Besides the loss of income, she lost her health insurance and all benefits. She has gotten an application for food stamps. She will pick up hospice shifts as she is able, but this is only for a few hours—far less than the full-time job she used to be able to do. R.R.'s grandfather works the night shift in a mail room and sleeps during the day. The

grandparents take turns caring for R.R. and sleeping. The situation is challenging for R.R.'s seven-year-old bother who for many years got all of his grandparents' attention. Now, he gets mad and has fits because it feels unfair to him. He has anxiety and difficulty sleeping.

186. The Bureau of Special Health Care Needs has assigned R.R.'s family a case worker. When informed that R.R. is not getting all the private duty nursing hours that Medicaid has authorized as needed, the case worker provided M.D. with a list of home health care agencies and told her to call them. The case worker said that more than one agency could provide nurses for R.R. While there were many home health agencies on this list, M.D. has learned that not all of them employ licensed nurses and, thus, offer only home health aide and not nursing care. To date, M.D. has not been able to locate additional private duty nursing using the Bureau's list.

187. M.D. does not want R.R. to go back into the hospital. He was in a crib there all the time. At home, R.R. has made big improvements. He is playful. He stacks blocks, does puzzles, is learning his colors, and builds towers with Legos. He loves music and likes to watch parades and Elmo. He is learning to use a communication board to say things like, "I hurt," "I want to do music," or "I want blocks." At home, R.R. only goes into a crib to sleep.

188. R.R. is also being weaned from his vent. Going off the vent while awake will allow him mobility. M.D. has set up a meeting with the school district to see if he can go to school.

189. R.R.'s grandparents are doing everything possible to prevent him from going back into the hospital. Their anxiety level is very high. They worry that if he does not get the private duty nursing care that he needs, they are going to wear down. They are

afraid of something happening if they were to doze off and miss the vent alarm.

Plaintiff B.B.

190. B.B. lives with her parents and siblings in Union, Missouri. B.B.'s father, J.B., is in the National Guard. He was deployed to Afghanistan in June 2019. Before B.B. was born, her mother, C.B., worked part time as a gas station cashier. B.B. is one year old.

191. B.B. was born in 2018 with three holes in her heart. Doctors said two of the holes would close on their own, but B.B. would need surgery for the third. Early one morning in August 2018, B.B. began to cry inconsolably. The doctor told C.B. to take B.B. to Children's Hospital in St. Louis, which is about an hour away from their home. On the way to the hospital, C.B. saw B.B. "lock up" and begin sweating. J.B. pulled the car over and called 911. C.B. began CPR. Emergency personnel arrived and took B.B. to Mercy Hospital in Washington, Missouri and, from there, she was transferred to Children's Hospital.

192. B.B. had suffered cardiac arrest. Doctors performed surgery to repair her aorta. The surgery was successful. However, B.B. was without sufficient oxygen for approximately 45 minutes after the cardiac arrest and suffered hypoxic-ischemic encephalopathy (HIE) as a result. In December 2019, B.B. was diagnosed with spastic quadriplegia cerebral palsy, caused by oxygen deprivation and resulting brain injury.

193. B.B. was discharged from the hospital in September 2018. Since that time, she has been hospitalized at St. Louis Children's Hospital numerous times. For example, in October 2018, she was hospitalized for two days because she had a fever, was not gaining weight, and had yellow secretions. In January 2019, she was hospitalized for 16 days with upper respiratory tract infection and an infection of her trachea. In June 2019, she was

hospitalized for seven days because her lungs were in distress due to pseudomonas, a bacteria caused by aspiration. In January 2020, B.B. was hospitalized for three days because of a high fever and elevated heart rate. Children's Hospital is about an hour away from Union.

194. After J.B. was deployed, C.B.'s mother and stepfather moved closer to Union in order to help C.B. When B.B. was in Children's Hospital in January, C.B.'s mom stayed with C.B.'s older children so they could have their normal routine. It was hard for the children to visit B.B.

195. B.B. now weighs 17 lbs. She has limited facial expressions but can now smile a full-blown, gummy smile. She now has three teeth. She often sleeps with her eyes open, because her brain does not tell her to close them or blink. B.B. can hear sounds, but the quality and clarity of her hearing are not yet known.

196. B.B. can roll over front to back and back to front, but that is the only mobility she has. She has equipment to help: a feeding seat so she can sit up, a gait trainer, and a rolling stander. She has ankle foot orthosis (AFO) leg braces, which provide leg support and keep her feet in a standing position. B.B.'s toes and feet will point downward because the muscles are so tense. C.B. stretches her toes out and gives her little massages throughout the day to try to keep the muscles as loose as possible.

197. B.B. has an upper airway obstruction, and because of the brain damage, does not know when to swallow. She has a tracheostomy (trach) and needs to be suctioned. On a bad day, B.B. may need suctioning as much as two times every minute. She can also go longer periods without any suctioning at all: when she is sleeping, she frequently does not need to be suctioned for hours at a time. B.B. recently got a special device called a

Passy-Muir valve, which allows her to breathe in through the trach and out through her nose. This enables her to vocalize more, and hear her own voice. B.B. needs to have her trach changed once a week. She does not like trach changes; she gags, coughs, and sometimes throws up.

198. B.B. does not swallow on her own. She is fed through a G-button that has been placed in her stomach. The G-button must be cleaned daily.

199. B.B. has many needs during the night. She may need to be suctioned, have medicine administered, or be treated with the oxygen concentrator.

200. B.B. takes numerous medications, including for seizures, muscle tone (to relax her muscles), heart rate, acid reflux, and dry eyes.

201. B.B. receives in-home therapy through Missouri First Steps—speech therapy biweekly and occupational and physical therapy weekly. During speech therapy, B.B. works with picture boards; the goal is for her to use a device like a tablet or eye gaze. During physical and occupational therapy, she works on mobility: using the gait trainer, but also tummy time and trying to sit upright.

202. B.B. communicates through picture boards with Velcro pictures—Core Vocabulary (go, stop, more, all done), Descriptors (fast, slow, up, down, big, little), and Common Choices (bubbles, ball, book, music, eat, drink, hug). She especially likes the board with animals on it. Her favorite song is Itsy Bitsy Spider. She likes to watch shows on Disney Junior, especially T.O.T.S., Muppet Babies, and Mickey Mouse.

203. B.B.'s family celebrates all of her milestones, even “small” ones like transferring an object from one hand to another at midline (which occurred on July 13, 2019), walking in her gait trainer, and rolling from belly to back (August 20, 2019). They

also celebrate medical milestones, like being discharged home (September 25, 2018), being freed from a corrective helmet used to address a flat spot because she was on her back so much in the hospitals (August 8, 2019), and being released for only annual cardiology follow-up appointments.

204. B.B. was most recently hospitalized on January 11, 2020. Prior to this admission, B.B. had been home for six months—her longest stretch of time at home without an inpatient stay. B.B. had a norovirus (for most, a common cold) that caused her to develop a high fever and elevated heart rate. She was able to come home on Tuesday, January 14.

205. B.B. is insured through Missouri Medicaid. She is enrolled in Missouri Care, a managed care company that contracts with Missouri Medicaid. Since January 17, 2019, Missouri Care has approved B.B. to receive eight hours of daytime in-home private duty nursing care, seven days a week (56 hours weekly) and eight hours of nighttime private duty nursing, seven days a week (56 hours weekly).

206. The process of finding in-home nursing was confusing for her family from the start. It was up to C.B. to start calling companies to get the shifts covered. She googled to find companies. She created a Facebook page. Once she located a home care agency, Craig Home Care, the agency took over to see what it could get covered. C.B. does not remember getting any information from Missouri Care, not even a list of companies to call.

207. As soon as B.B. was approved for nursing, C.B. began approaching friends and acquaintances who have graduated from nursing school. She posted about it on Facebook and also made a job posting on Craigslist. On January 25, 2019, C.B. posted on the Facebook page “Praying these nursing positions are filled ASAP. I’m 100% drained.”

One year later, B.B. is still receiving less than half of the private duty nursing services that Defendants have determined she needs.

208. Currently, B.B. is receiving eight hours a day of daytime nursing care, Monday-Friday five days a week plus every other Saturday. The day nurse works for Team Select and has been with B.B. since February 2019. The nurse lives a half hour away.

209. The family has struggled to find a night nurse and has only found one, who started at the end of October 2019 and only lasted one week. C.B. had to let her go because she was falling asleep on the job. C.B. has three home health agencies looking for a night nurse for B.B.: Team Select, Craig Home Care, and Phoenix Home Care.

210. The lack of private duty nursing is causing stress for the family. B.B.'s life can easily be in danger. For example, on January 5, 2019, C.B. was warming up a bottle. J.B. noticed her breathing did not look right, and they called 911. An ambulance came and B.B. was taken to Washington Hospital and then to Children's Hospital. B.B. had aspirated on vomit. In June 2019, B.B. was hospitalized for five days because of pseudomonas, bacteria that grew in her lungs because of aspiration. This is a constant risk for B.B. C.B. worries about falling asleep and having B.B. choke on her vomit. If B.B. had a good night nurse, C.B. would be able to sleep more. She could be more involved with the other kids helping with homework and taking them to evening activities. Currently, her oldest child, age 9, helps out a lot at home. C.B. worries this is taking a toll on her.

211. C.B. has not received any help from DSS or the Medicaid managed care company Missouri Care to fill B.B.'s night nursing hours. At first, a care manager who would sometimes call periodically to check in on things. She did not help C.B. get nursing hours filled. C.B. was recently assigned a new care manager. She made a house visit and

suggested things C.B. could do to keep B.B. from getting a high temperature and going to the hospital—things that C.B. does already. C.B. also pointed out that she always contacts her pediatrician first to get his opinion as to whether B.B. needs to go to the hospital. The case manager was not helpful and did not do anything to address Blake’s continued need for night nurses.

Plaintiff I.B.

212. I.B. lives with her parents and four siblings (ranging in age from one to eight years old) in Florissant, Missouri. The family is expecting a sixth child this month.

213. I.B. was born in 2018. She was diagnosed with congenital central hypoventilation syndrome (CCHS), which is a rare genetic disorder that affects her central and autonomic nervous system. Most seriously, her brain does not tell her to breathe. I.B. tends to remember to breathe when she is awake, but not when she is sleeping. She recently started having seizures which her doctors think are triggered by lack of oxygen. She requires 24-hour care to monitor her breathing.

214. I.B. had surgery to place a tracheotomy tube when she was about seven weeks old. She relies on a ventilator to help her breathe.

215. I.B. has health coverage through Missouri Medicaid. In early 2019, Defendants approved her for 24 hours per day of private duty nursing for her first few weeks home from the hospital, and approved her to receive 16 hours per day of private duty nursing after that. I.B. has never received the hours of nursing that the State has found are medically necessary for her.

216. I.B.’s mother, A.B., began looking for nurses to cover her plan of care in February 2019 when I.B. was close to being ready to come home. The discharge planners



at St. Louis Children's Hospital also started looking. The hospital staff contacted the Bureau of Special Health Care Needs. The Bureau only sent a list of home care agencies. I.B.'s mother reached out to at least eight different home care agencies trying to find a nurse. I.B. was completely ready for discharge and medically able to come home on March 26, 2019. She remained in the hospital for over four months because the family could not find a nurse who would accept Medicaid for I.B.'s care. I.B. finally went home on August 7, 2019.

217. Three days later, she was re-hospitalized through the E.R. because her oxygen level was low, and she had a fever. Her CO2 monitor had also quit working. I.B.'s parents were new to taking care of her at home. The day she was readmitted she had not had a night nurse. I.B. went home again on October 16, 2019. She did not have all of the private duty nursing services in place that were prescribed for her.

218. The lack of nighttime nursing coverage has been a repeated problem for I.B. She has never had any night nursing coverage on the weekends. I.B.'s parents are caring for her. I.B.'s grandmother also moved into the home to help.

219. Other than giving A.B. a list of home health agencies, the Bureau of Special Health Care Needs has not helped the family arrange private duty nursing. The Bureau told A.B. to call home health agencies every day to see if they have a nurse. She calls two or three agencies every week, but I.B. is still without night coverage.

220. I.B.'s night nurse left to take a hospital job on October 31, 2019. While the family was able to find weekday help, I.B. did not have a night nurse on Fridays and Saturdays.

221. In December 2019, I.B. had her first seizure at home on a Friday night. There was no nurse with I.B. when she had the seizure. She was admitted to St. Louis Children's Hospital through the E.R. and spent two days in the hospital. Doctors told A.B. that the seizure was from a lack of oxygen to the brain.

222. In January 2020, I.B. lost her night nurse again. She has not had any night nursing services since January 14, 2020.

223. A.B. is worried that I.B. will have to go back to the hospital. I.B.'s father works at the General Motors plant most weekends until 11:30 pm. His schedule is unpredictable, and there are long parts of the month that he is not able to help at all. A.B. is afraid that she will be too tired to properly care for I.B. She is afraid the entire family is going to suffer if dependable night nursing from a trained and licensed nurse is not located.

224. If Defendants fail to arrange for the in-home private duty nursing services at the levels they have approved each Plaintiff as needing, then each Plaintiff may be forced to go into an institution. Defendants' failure to arrange for medically necessary nursing services puts each Plaintiff at serious risk of institutionalization.

**FIRST CLAIM FOR RELIEF**  
(Against Defendant Acting Director Jennifer Tidball)  
Violation of Federal Medicaid EPSDT

225. Plaintiffs re-allege and incorporate herein by reference each and every allegation and paragraph set forth previously.

226. Defendant Tidball, while acting under the color of law, has failed to provide individual Plaintiffs and CCKC's members, with private duty nursing services necessary to correct or ameliorate their conditions in violation of the EPSDT provisions of the

Medicaid Act, 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a)(4)(B), 1396d(r)(5), and 1396a(a)(43)(C).

227. Defendant Tidball, while acting under the color of law, has failed to “arrang[e] for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment [in-home private duty nursing services]” to Plaintiffs and Class members in violation of the EPSDT provisions of the Medicaid Act, 42 U.S.C. § 1396a(a)(43)(C).

228. Defendant Tidball’s violations have been repeated and knowing and are ongoing, and entitle Plaintiffs to relief under 42 U.S.C. § 1983.

**SECOND CLAIM FOR RELIEF**  
(Against Defendant Acting Director Jennifer Tidball)  
Violation of Americans with Disabilities Act

229. Plaintiffs re-allege and incorporate herein by reference each and every allegation and paragraph set forth previously.

230. Title II of the ADA provides that no qualified person with a disability shall be subjected to discrimination by a public entity. 42 U.S.C. §§ 12131-32. It requires 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).

231. Plaintiffs are “qualified individuals with a disability” within the meaning of the ADA in that they have physical and mental impairments that substantially limit one or more major life activities, including their ability to live independently without support.

232. Plaintiffs meet the essential eligibility requirements for Missouri Medicaid, including by requiring services necessary to maintain them in their homes in the community.

233. Defendant DSS is responsible for administering Missouri's Medicaid program in accordance with state and federal law, and is therefore a government entity subject to Title II of the ADA. 42 U.S.C. §§ 12131(1)(A)-(B). Defendant Tidball is the Acting Director of Defendant DSS.

234. Defendants are obligated under the ADA to administer DSS's programs in a manner that enables qualified individuals with disabilities to live in the most integrated setting appropriate to their needs. Defendants failure to arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment (in-home private duty nursing services) for qualified individuals with disabilities such as Plaintiffs has placed them at risk of institutionalization in violation of the ADA's integration mandate.

235. Defendants have discriminated against Plaintiffs by failing to provide reasonable modifications to programs and services in order to arrange for medically necessary in-home private duty nursing.

236. Defendants have utilized criteria and methods of administration that subject Plaintiffs to discrimination on the basis of disability, including risk of unnecessary institutionalization, in ways that include failing to take the necessary steps to arrange for medically necessary in-home private duty nursing.

237. Defendants' actions are in violation of Title II of the ADA.

238. Plaintiffs are entitled to declaratory and injunctive relief to remedy Defendants' violations of the ADA.

**THIRD CLAIM FOR RELIEF**  
(Against Defendants DSS and Acting Director Jennifer Tidball)  
Violation of Section 504 of the Rehabilitation Act

239. Plaintiffs re-allege and incorporate herein by reference each and every allegation and paragraph set forth previously.

240. Section 504 of the Rehabilitation Act prohibits public entities and recipients of federal funds from discriminating against any individual by reason of disability. Public and federally-funded entities must provide programs and activities “in the most integrated setting appropriate to the needs of the qualified individual with a disability.” *See* 28 C.F.R. § 41.51(d). Policies, practices, and procedures that have the effects of unjustifiably segregating persons with disabilities in institutions constitute prohibited discrimination under Section 504.

241. Plaintiffs are “qualified individuals with a disability” under Section 504 of the Rehabilitation Act of 1973 in that they have physical and/or mental impairments that substantially limit one or more major life activities, including their ability to live independently without support.

242. Plaintiffs meet the essential eligibility requirements for Medicaid services, including services necessary to maintain them in their homes in the community.

243. DSS is a recipient of federal funds under the Rehabilitation Act and is therefore a government entity subject to Section 504. 29 U.S.C. § 794(b).

244. Defendants’ failure to arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment (in-home private duty nursing services) to Plaintiffs places them at risk of institutionalization in violation of Section 504’s integration mandate.

245. Defendants have utilized criteria and methods of administration that subject Plaintiffs to discrimination on the basis of disability, including risk of unnecessary

institutionalization, by Defendants' failure to arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment (in-home private duty nursing services) to Plaintiffs.

246. Plaintiffs are entitled to declaratory and injunctive relief to remedy Defendants' violations of Section 504.

### **REQUEST FOR RELIEF**

WHEREFORE, Plaintiffs request that the Court order the following relief and remedies:

- a. Declare that the Defendants' policies and practices related to making in-home private duty nursing available to Medicaid-enrolled children violate the EPSDT mandate of Title XIX of the Social Security Act, the ADA, and Section 504 of the Rehabilitation Act;
- b. Permanently enjoin the Defendants from maintaining an inadequate number of nurses in their private duty nursing program;
- c. Permanently enjoin the Defendants from failing to make available assistance to Plaintiffs, Medicaid-eligible children under age 21, by maintaining an inadequate network of nurses;
- d. Declare that Defendants' failure to arrange directly or through referral to appropriate agencies, organizations, or individuals, corrective treatment (in-home private duty nursing services) to Plaintiffs is unlawful;
- e. Issue preliminary and permanent injunctive relief enjoining Defendants from subjecting Plaintiffs to practices that violate their rights under the Medicaid Act, ADA, and Section 504;

- f. Issue preliminary and permanent injunctive relief requiring Defendants to arrange directly or through referral to appropriate agencies, organizations, or individuals, corrective treatment (in-home private duty nursing services) to Plaintiffs;
- g. Retain jurisdiction over the Defendants until such time as the Court is satisfied that Defendants' unlawful policies, practices, and acts complained of herein cannot recur;
- h. Award Plaintiffs their costs and reasonable attorneys' fees pursuant to 42 U.S.C. §§ 1988, 12133, and 12205 and any other applicable law or regulation; and
- i. Grant such other and further relief as the Court deems to be just and equitable.

Date: March 3, 2020

Respectfully submitted,

/s/ Joel Ferber

Joel Ferber # 35165

Lisa J. D'Souza # 65515

Lucas Caldwell-McMillan # 61345

Jamie Rodriguez # 64323

Legal Services of Eastern Missouri

4232 Forest Park Avenue

St. Louis, Missouri 63108

(314) 534-4200

[jdferber@lsem.org](mailto:jdferber@lsem.org)

[ljsouza@lsem.org](mailto:ljsouza@lsem.org)

[lfcaldwell-mcmillan@lsem.org](mailto:lfcaldwell-mcmillan@lsem.org)

[jlrodriguez@lsem.org](mailto:jlrodriguez@lsem.org)

/s/ Jane Perkins

Jane Perkins

Sarah Grusin

National Health Law Program

200 N. Greensboro St., Ste. D-13

Carrboro, NC 27510

(919) 968-6308  
[perkins@healthlaw.org](mailto:perkins@healthlaw.org)  
[grusin@healthlaw.org](mailto:grusin@healthlaw.org)  
*Pro hac vice to be submitted*

Counsel for the Plaintiffs