

UNITED STATES DISTRICT COURT
WESTERN DISTRICT OF MISSOURI
CENTRAL DIVISION

STEVEN HILTIBRAN, by and through his)
mother and guardian, Debra Burkhart;)
NICHOLAS TATUM, by and through his)
mother and next friend, Stacy Tatum;)
RONALD COONTZ, by and through his)
mother and guardian, Patricia Coontz; and)
NENA HAMMOND,)

Plaintiffs,)

v.)

Case No. 10-4185-CV-C

RONALD J. LEVY, in his official capacity)
as Director of the Missouri Department of)
Social Services; and)
IAN McCASLIN, M.D., in his official)
capacity as Director of the MO HealthNet)
Division,)

Defendants.)

COMPLAINT

I. PRELIMINARY STATEMENT

1. Plaintiffs bring this action to compel the Missouri Department of Social Services to cover medically necessary incontinence briefs for them through the Medicaid program. Plaintiffs suffer from a range of disabilities, including cerebral palsy, multiple sclerosis, liver disease, and brain damage and, as a result of their disabilities, are completely incontinent. Plaintiffs' physicians have prescribed incontinence briefs as medically necessary to prevent skin breakdowns and infections and to maintain their ability to live in the community. Plaintiffs are low-income Missouri residents who

receive their health services through Missouri's Medicaid program, also known as MO HealthNet. Defendants' policy is to cover incontinence briefs for individuals age 21 and over only when they live in institutions.

2. Defendants have also promulgated a regulation, 13 C.S.R. § 70-60.010, and policy that restrict Medicaid coverage of incontinence briefs to those recipients who are over age 20. As a result, several Plaintiffs lost coverage upon turning 21 and will be left without coverage unless they go into an institutional setting. Plaintiffs face a high likelihood of hospitalizations to address infections and may be forced into institutional settings, such as hospitals, nursing homes, or rehabilitation centers in order to receive the necessary care. Such choices should not have to be made because the state rules violate federal Medicaid and disability discrimination laws.

3. Plaintiffs seek declaratory and injunctive relief to enjoin Defendants from implementing the invalid state regulation and policy, and thereby violating federal Medicaid and disability discrimination mandates.

II. JURISDICTION AND VENUE

4. This action arises under Title XIX of the Social Security Act, Title II of the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act. The Court has jurisdiction pursuant to 28 U.S.C. § 1331 which gives district courts original jurisdiction over all civil actions arising under the Constitution, laws, or treaties of the United States and 28 U.S.C. §§ 1343(a)(3) and (4) which give district courts original jurisdiction over suits to redress the deprivation under color of state law of any rights, privileges, or immunities guaranteed by the Constitution or acts of Congress. Plaintiffs'

action for declaratory, injunctive, and other appropriate relief is authorized by 28 U.S.C. §§ 2201 and 2202.

5. Venue is proper under 28 U.S.C. § 1391(b).

III. PARTIES

Plaintiffs

6. Plaintiff Steven Hiltibran is a 22-year-old Missouri Medicaid recipient living with his mother and guardian Debra Burkhart in Springfield, Missouri. He suffers from a variety of medical conditions, including cerebral palsy, psychosis, multiple sclerosis and scoliosis. As a result of his disability, Steven is substantially limited in his physical and cognitive abilities and requires assistance with activities of daily living, including dressing, feeding, mobility and bowel and bladder care.

7. Plaintiff Ronald Coontz is a 30-year-old MO HealthNet recipient living with his mother and guardian Patricia Coontz in St. Louis, Missouri. He suffers from a variety of medical conditions, including anoxia, static encephalopathy (permanent brain damage), and a seizure disorder. As a result of his disability, Ronald is substantially limited in his life activities and requires assistance with activities of daily living, including feeding, dressing, bathing, walking, and bowel and bladder care.

8. Plaintiff Nicholas Tatum is a 22-year-old MO HealthNet recipient living with his mother Stacy Tatum in St. Louis, Missouri. He suffers from a variety of medical conditions, including Alagille Syndrome, liver disease, and mental disabilities. As a result of his disability, Nicholas is substantially limited in his life activities and requires assistance with activities of daily living, including eating, dressing, bathing, and bowel and bladder care.

9. Plaintiff Nena Hammond is a 49-year-old Missouri Medicaid recipient living by herself in O'Fallon, Missouri. She suffers from a variety of medical conditions, including a spinal cord injury, cysts in her kidneys and liver, and occasional spasticity in her limbs and body. As a result of her disability, Nena is substantially limited in her life activities but is able to care for herself in her own home.

Defendants

10. Defendant Ronald J. Levy is the Director of the Missouri Department of Social Services (hereinafter, "DSS") and, as such, is responsible for the general administration and implementation of laws concerning the social welfare of the people of the State of Missouri, including the Medicaid program. Defendant Levy is the chief administrative officer of DSS and is responsible for administration of the single state agency for the Missouri Medicaid program. Defendant Levy 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, the ADA, and Section 504 of the Rehabilitation Act. He is sued in his official capacity. His principal office is located in Jefferson City, Missouri.

11. Defendant Ian McCaslin, M.D., is the Director of MO HealthNet, a division of DSS, and, as such, is responsible for the administration of the Missouri Medicaid program, with the exception of determination of eligibility for the program. Defendant McCaslin holds ultimate administrative power within the MO HealthNet Division subject to the supervision of Defendant Levy. He is sued in his official capacity. His principal office is located in Jefferson City, Missouri.

IV. STATUTORY AND REGULATORY FRAMEWORK

Medicaid

12. Title XIX of the Social Security Act, codified at 42 U.S.C. §§ 1396–1396w-2 (hereinafter, “Medicaid Act”), establishes the Medicaid program. The objective of the Medicaid Act is to enable each State to furnish medical assistance to families with children and to aged, blind, or disabled individuals whose incomes and resources are insufficient to meet the costs of necessary medical services and to furnish “rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care.” 42 U.S.C. § 1396.

13. The Medicaid program typically does not directly provide health care services to eligible individuals, nor does it provide beneficiaries with money to purchase health care directly. Rather, Medicaid is a vendor payment program, wherein Medicaid-participating providers are reimbursed by the program for the services they provide to recipients.

14. Medicaid is a cooperative federal-state program designed to cover necessary medical services for poor people. Participation in the Medicaid program is not mandatory for the states, but once they choose to participate, they must operate their programs in conformity with federal statutory and regulatory requirements. 42 U.S.C. § 1396a.

15. Each state choosing to participate in the Medicaid program must designate a single state agency which is responsible for administering the program. 42 U.S.C. § 1396a(a)(5).

16. The Medicaid Act includes mandatory and optional eligibility groups and mandatory and optional service coverage requirements. 42 U.S.C. §§ 1396a(a)(10), 1396d(a).

17. The Act requires states to cover individuals who are “categorically needy.” 42 U.S.C. § 1396a(a)(10)(A). The categorically needy include persons who are aged, blind, or disabled, working disabled individuals, and certain children and pregnant women who meet federal poverty level standards, and families and children who meet the eligibility standards of the now-repealed AFDC program. 42 U.S.C. § 1396a(a)(10)(A)(i).

18. States, like Missouri, that have elected to provide Medicaid using more restrictive definitions of blindness or disability or more restrictive financial eligibility standards than are currently used by the federal Supplemental Security Income (hereinafter “SSI”) program, must also cover aged, blind, and disabled individuals with incomes exceeding the categorical income eligibility levels when those individuals incur sufficient medical expenses to “spend down” to Medicaid eligibility levels. 42 U.S.C. § 1396a(f). These individuals are also “categorically needy.” Id.

19. Under the State plan, categorically needy individuals are entitled to nursing facility services. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a); 42 C.F.R. §§ 440.70, 440.210(a)(1), 441.15(b)(1). States must “provide ... for the inclusion of home health services for any individual who, under the State plan, is entitled to nursing facility services....” 42 U.S.C. § 1396a(a)(10)(D).

20. Home health services are provided to the Medicaid recipient at his place of residence, and include “medical supplies, equipment, and appliances suitable for use in the home.” 42 C.F.R. § 440.70(a)(1), (b)(3); 42 C.F.R. § 441.15(a)(3).

21. Incontinence briefs are medical supplies and, thus, a home health service. Defendants recognize that incontinence briefs are a medical supply. Missouri Department of Social Services, Provider Bulletin Vo. 31, No. 52, March 6, 2009.

22. A participating state must establish reasonable standards, consistent with the objectives of the Medicaid Act, for determining the extent of coverage of home health services and other medical assistance. 42 U.S.C. § 1396a(a)(17) (the “reasonable standards” requirements).

23. A participating state must ensure that the amount, duration, and scope of coverage are reasonably sufficient to achieve the purpose of the service. 42 C.F.R. § 440.230(b). Furthermore, a State may not impose arbitrary limitations on mandatory services, such as home health services, based solely on diagnosis, type of illness, or condition. 42 C.F.R. § 440.230(c).

24. Controlling precedent requires the State to cover all non-experimental, medically necessary services within a covered Medicaid category. Lankford v. Sherman, 451 F.3d 496 (8th Cir. 2006); Weaver v. Reagen, 886 F.2d 194, 198 (8th Cir. 1989). “[A] state’s failure to cover non-experimental, medically necessary services within a covered Medicaid category is both per se unreasonable and inconsistent with the stated goals of Medicaid.” Lankford, 451 F.3d at 511.

Americans with Disabilities Act

25. The Americans with Disabilities Act, codified at 42 U.S.C. §§ 12101 – 12181 (hereinafter “ADA”) was enacted with the “elimination of discrimination against individuals with disabilities” as its purpose and objective. 42 U.S.C. § 12101(b)(1).

26. Title II of the ADA prohibits discrimination against individuals with disabilities by public entities, including state and local governments, their departments and agencies. 42 U.S.C. §§ 12131, 12132. “[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” 42 U.S.C. § 12132; 28 C.F.R. §§ 35.130(b)(1)(iv), 35.130(b)(7), 35.130(b)(8), 35.130(d).

27. The ADA prohibits segregation of people with disabilities into institutions and requires services, programs and activities of state and local governments to be administered in “the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d).

28. The ADA requires state governments and agencies to make reasonable modifications to policies, practices and procedures to avoid discrimination on the basis of disability. 28 C.F.R. § 35.130 (b)(7).

Section 504 of the Rehabilitation Act

29. Section 504 of the Rehabilitation Act, 29 U.S.C. § 794 (hereinafter, “Section 504”), prohibits discrimination against individuals with disabilities by any program or activity, including any department or agency of a State government, receiving Federal financial assistance. 29 U.S.C. § 794(a),(b). “No otherwise qualified individual with a disability ... shall, solely by reason of her or his disability, be excluded from

participation in, be denied the benefits of , or be subjected to discrimination under any program or activity receiving Federal financial assistance....” 29 U.S.C. § 794; 45 C.F.R. §§ 84.4(a), 84.4(b)(1)(i), (iv), & (vii); 84.4(b)(2); 84.52(a)(1), (4) & (5).

30. Section 504 prohibits segregation of people with disabilities into institutions and requires services, programs and activities of state and local governments to be administered in “the most integrated setting appropriate to the needs of qualified individuals with disabilities.” § 28 C.F.R. § 45.51 (d).

31. Section 504 requires federally funded state governments and agencies to make reasonable modifications to policies, practices and procedures to avoid discrimination on the basis of disability. 29 U.S.C. § 794(a).

V. STATEMENT OF FACTS

32. The State of Missouri has elected to participate in the Medicaid program and has designated DSS as the single state Medicaid agency. DSS is a department of state government.

33. The federal government shares the cost of the Missouri Medicaid program by providing funding to the State of Missouri. During fiscal year 2010, the State will receive enhanced federal funding as a result of the American Recovery and Reinvestment Act of 2009. During fiscal year 2010 and the first half of fiscal year 2011, the federal government is paying more than 70 cents of each dollar spent on Medicaid services in Missouri, including more than 74 cents of each dollar for the second quarter of fiscal year 2010. 75 Fed. Reg. 22807-08 (April 30, 2010). The federal government would normally pay approximately 64 cents of each dollar spent on Medicaid services in Missouri. Id.

34. All individuals who are Medicaid recipients under the Missouri Medicaid program are “categorically needy.”

35. Missouri’s Medicaid statute requires coverage of prescribed medically necessary durable medical equipment. Mo. Rev. Stat. § 208.152.1(19). The law further requires that an “electronic web-based prior authorization system using best medical evidence and care and treatment guidelines consistent with national standards shall be used to verify medical need.” Mo. Rev. Stat § 208.152.1(19).

36. A state regulation, 13 C.S. R. 70-60.010, promulgated by the MO HealthNet Division of the DSS, excludes “incontinence briefs” as a covered service for non-institutionalized adults in the Missouri Medicaid program. The MO HealthNet Division’s DME Provider Manual and Bulletins “are incorporated by reference and made a part of this rule.” 13 C. S.R. 70-60.010(6) (covered services). “Covered services are limited as specified in the DME provider manual and bulletins.” 13 C.S.R. 70-60.010(2).

37. The MO HealthNet Provider Manual and provider bulletins implement mandatory policies of the MO HealthNet Division. Physicians and other Missouri health care providers must follow these provisions in order to receive Medicaid payment for their services.

38. The Missouri Medicaid Program’s Durable Medical Equipment Provider Manual indicates that incontinence briefs are covered for individuals age four through twenty years. Missouri Durable Medical Equipment Provider Manual, § 31.22.B., at http://manuals.momed.com/collections/collection_dme/Durable_Medical_Equipment_Section13.pdf.

39. For individuals ages 4 through 20, DSS covers incontinence briefs where the items are prescribed and determined to be appropriate when there is presence of a medical condition causing bowel/bladder incontinence. Documentation of the qualifying condition must be maintained in the provider's record. A combination of incontinence products that exceed 186 per month must be prior authorized. Prior authorization "must include documentation of medical need from a physician, indicating a condition causing excessive fecal or urine output." Missouri Durable Medical Equipment Provider Manual, § 31.22.B (emphasis added).

40. On March 6, 2009, Defendants issued a Provider Bulletin entitled "Physician and Durable Medical Equipment" that established policy concerning Medicaid coverage of incontinence briefs. Provider Bulletin Vol. 31, No. 52, March 6, 2009, at http://www.dss.mo.gov/mhd/providers/pdf/bulletin31-52_2009mar06.pdf (hereinafter "DME Provider Bulletin").

41. According to the DME provider bulletin, incontinence briefs are covered for individuals ages 4 through 20. Effective for dates of services on or after March 24, 2009, the Provider Bulletin established new prior authorization criteria for obtaining approval of underpads, diapers/briefs, and protective underwear for individuals aged 4 through 20. The Provider Bulletin states that "[i]n order to be approved, participants must be between ages 4 through 20 and meet the medical criteria established by the MO HealthNet Division (MHD)." Id. (emphasis added).

42. The purpose of the new prior authorization criteria is "[t]o allow a consistent and streamlined process for authorization for diapers, pull-ons and underpads

for participants ages 4 through 20.” The new prior authorization criteria also include the following statement:

Senate Bill 577 passed by the 94th General Assembly directs MO HealthNet ... to authorize Durable Medical Equipment using best medical evidence and care and treatment guidelines, consistent with national standards to verify medical need.

MO HealthNet Division, MO HealthNet PA Criteria, at <http://www.dss.mo.gov/mhd/cs/dmeprecert/pdf/diapers.pdf>; Mo. Rev. Stat. § 208.152.1 (19) (emphasis added).

43 The DME Provider Bulletin also establishes medical necessity criteria for coverage. Medical criteria for coverage of incontinence briefs include the requirement that there be a “medical condition causing bowel/bladder incontinence.” MO HealthNet PA criteria. The criteria include the following question for the physician who prescribes incontinence briefs: “What is the “medically necessary quantity per month? ___ (quantities over 186 require submission of a separate pre-certification and detailed medical justification)” Id.

44. According to the Defendants’ medical prior authorization criteria, one of the “denial criteria” for these incontinence supplies is that “Patient is age 21 or over.” Id.

45. Individuals over age 20 are not allowed to establish “medical necessity” for incontinence briefs nor are they allowed to use the State’s prior authorization process to “verify medical need.” Once an individual turns 21, these medical supplies are deemed to be a “personal hygiene item” as a matter of state policy. Missouri Durable Medical Equipment Provider Manual, § 31.22.B, DME Provider Bulletin, MO HealthNet Prior Authorization Criteria.

46. The Missouri Medicaid program uses an “Exceptions Process” for services that are not normally covered by the Missouri Medicaid program. The Exceptions Process is set forth at 13 C.S.R. 70-2.100. The Exceptions Process is only available for items that the Missouri Medicaid program considers to be essential medical services or items that would otherwise exceed the limitations of the Missouri Medicaid program. 13 C.S.R. 70-2.100. The Exceptions Process allows for exceptions to be made on a “case by case basis to limitations and restrictions” on the receipt of benefits in the Missouri Medicaid program. Id.

47. Defendants do not cover incontinence briefs through Missouri’s Exceptions Process because Defendants consider them to be “personal hygiene items” rather than “essential medical items” for individuals over age 20.

48. On April 28, 2009, Defendant McCaslin stated in an electronic mail communication that adult incontinence supplies are not a covered service for individuals age 21 and older. Defendant McCaslin stated that these items are a covered service for individuals aged 4 through 20 when those services are prior authorized by the MO HealthNet Division.

49. On July 15, 2009, Defendant McCaslin stated that while “the determination of medical necessity is key for participants under age 21,” medical necessity is “not the guiding principle” for determining whether adults can receive a service pursuant to the State’s Medicaid Exception Process.” Defendant McCaslin stated that adults cannot obtain incontinence briefs pursuant to the State’s “Exceptions Process” because “diapers are a personal hygiene item, not an essential medical item, they are not approved by the Exceptions Process.”

50. The Missouri Medicaid Program does not cover adult incontinence briefs for disabled individuals over age 20 who reside in the community. DME Provider Bulletin.

51. Missouri Medicaid recipients over age 20 who reside in the community are not permitted to demonstrate the “medical criteria” that would establish the need for coverage for incontinence supplies prescribed for them by their health care providers.

52. The Missouri Medicaid program covers adult diapers for individuals over age 20 who reside in nursing homes or other institutional settings. Incontinence briefs are a covered supply for individuals receiving long-term care services, including nursing home services, and are included in Missouri’s per diem rate for those services. 13 C.S.R. §§ 70-10.010(5) and 70-10.015(5) (L), Appendix A.

53. On February 23, 2010, Special Counsel for the Missouri Department of Social Services stated as follows:

Incontinence supplies are non-covered for adults through MO HealthNet’s DME program. Diapers are considered a personal hygiene item, not an essential medical item, and have never been a covered service for adults in Missouri . . . Incontinence supplies, other than diapers, may be covered through the exception process on a case by case basis. . . . Incontinence Supplies and diapers for any age participant in an institutional nursing facility or hospital are included in the facility’s per diem rate.

Plaintiff Steven Hiltibran

54. Plaintiff Steven Hiltibran is 22 years old and lives with his mother and guardian Plaintiff Debra Burkhart.

55. Steven suffers from severe cerebral palsy, psychosis, multiple sclerosis, scoliosis, and chronic pain, muscle spasms and contractures. He is completely bed-bound and terminally ill.

56. Because of his disabilities, Steven is unable to work and receives SSI benefits of \$674.00 per month. He also receives Medicaid MO HealthNet benefits from the Missouri Department of Social Services based on his disability. He has been covered by the Missouri Medicaid program since approximately age one.

57. Due to his disabilities, Steven is completely incontinent of both bladder and bowel.

58. Steven lives in the community with his family.

59. According to Steven's treating health care providers, the most appropriate place for Steven to receive care and to live is in his home, where he has lived all his life. Steven's disabilities make him highly susceptible to respiratory and other life-threatening infections, and placement in an institution would expose him to such infections.

60. Steven needs incontinence briefs to prevent skin breakdown and infections. His treating physicians have prescribed incontinence briefs to prevent skin breakdowns and ulcers that result from sitting in wet and soiled undergarments.

61. The Missouri Medicaid program covered incontinence briefs as medically necessary for Steven until he turned 21 years of age. Steven's medical condition did not change or improve when he turned age 21.

62. Steven's treating physicians wrote letters to the MO HealthNet Division on January 6, June 19, and June 24, 2009, documenting his medical need for adult diapers.

63. On March 2, 2009, the MO HealthNet Division denied Steven's physician's prior authorization request for coverage of these medical supplies.

64. On or about April 15, 2009, the MO HealthNet Division denied his physician's request to obtain coverage for the medical supplies through the Exceptions Process. The Division's reason for denying Steven's request was that diapers are a "personal hygiene item" for adults, not a medical item, and "for this reason, diapers are not approved by the Exceptions Unit."

65. Debra Burkhardt appealed this denial and DSS upheld the denial on October 6, 2009. The decision was signed by Defendant Ian McCaslin, the Director of the MO HealthNet Division.

66. Defendant McCaslin found that "disposable diapers are a personal hygiene item, not a medical item" and that Steven "did not meet the burden of proof to show that disposable diapers are an essential medical item." Id.

67. Incontinence briefs are required for the treatment of Steven's multiple medical impairments and conditions consistent with his diagnoses, in accordance with the determinations of his treating physicians.

68. Steven's incontinence briefs will be covered by the MO HealthNet program if he moves into a nursing home.

69. The Missouri Department of Health and Senior Services has already found that Steven meets the "level of care" requirements for coverage in a nursing facility or other such institution.

70. Steven's incontinence supplies cost approximately \$80 per month, while nursing facility care would cost approximately \$4,000 per month.

71. Paying for these supplies out of pocket causes financial and emotional stress for Steven's family who must forego basic necessities in order to pay for adult

diapers. His mother is afraid that she will not be able to continue paying for these diapers.

Plaintiff Ronald Coontz

72. Plaintiff Ronald Coontz is 30 years old and lives with his mother and guardian Plaintiff Patricia Coontz.

73. Ronald suffers from anoxia, static encephalopathy (permanent brain damage) and a seizure disorder. He can no longer walk unassisted and has severe balance problems. He is completely dependent on others for his care.

74. Because of his disabilities, Ronald is unable to work and receives Social Security Disability Insurance benefits of \$562.00 per month and SSI benefits of \$132.00 per month. He also receives Medicaid MO HealthNet benefits from the Missouri Department of Social Services based on his disability. He has been covered by the Missouri Medicaid program since approximately age fifteen.

75. Due to his disabilities, Ronald is completely incontinent of both bladder and bowel.

76. Ronald lives in the community with his family.

77. According to Ronald's treating health care providers, the most appropriate place for Ronald to receive care and to live is in his home, where he has lived all his life. Adult diapers make it possible for him to be cared for at home by his mother.

78. Ronald needs incontinence briefs to prevent skin breakdown and infections. His treating physicians have prescribed incontinence briefs to prevent skin breakdowns and infections.

79. The Missouri Medicaid program covered incontinence briefs as medically necessary for Ronald until he turned 21 years of age. Ronald's medical condition did not improve or change when he turned age 21.

80. Ronald's treating physicians have written letters documenting his continuing medical need for adult diapers.

81. To the best of Ronald's mother's recollection, Ronald's treating physician submitted a letter requesting an "exception" to continue coverage of adult diapers shortly after he reached the age of 21 but the State denied the request.

82. In 2005, Ronald's mother provided to his caseworker a letter from Ronald's treating physician indicating that he was still incontinent and that diapers were still medically necessary. The caseworker told Ms. Coontz that Medicaid would not cover Ronald's incontinent supplies. Ms. Coontz has received the same response from several other caseworkers.

83. Incontinence briefs are required for the treatment of Ronald's multiple medical impairments and conditions consistent with his diagnoses, in accordance with the determinations of his treating physicians.

84. Ronald's incontinence briefs will be covered by the MO HealthNet program if he moves into a nursing home.

85. The Missouri Department of Health and Senior Services has already found that Ronald meets the "level of care" requirements for coverage in a nursing facility or other such institution.

86. Ronald's incontinence supplies cost approximately \$300 per month, while nursing facility care would cost approximately \$4000 per month.

87. Paying for these supplies out of pocket has caused financial hardship and emotional stress for the Coontz family which is struggling to pay for Ronald's adult diapers while meeting other basic needs. Ronald's mother Patricia Coontz fears that Ronald will have to enter a nursing home to continue receiving the incontinent supplies he needs.

Plaintiff Nicholas Tatum

88. Plaintiff Nicholas Tatum is 22 years old and lives with his mother Plaintiff Stacy Tatum.

89. Nicholas suffers from Alagille Syndrome, liver disease and mental disabilities.

90. Because of his disabilities, Nicholas is unable to work and receives SSI benefits of \$547.00 per month. He also receives Medicaid MO HealthNet benefits from the Missouri Department of Social Services based on his disability. He has been covered by the Missouri Medicaid program since approximately age two.

91. Due to his disabilities, Nicholas is completely incontinent of both bladder and bowel. His mother and his teachers have tried to teach Nicholas to use the bathroom without success.

92. Nicholas lives in the community with his family.

93. According to Nicholas' treating health care provider, he can be served appropriately in the community as long as he receives adult diapers.

94. Nicholas needs incontinence briefs to prevent skin breakdown and infections. His treating physicians have prescribed incontinence briefs to prevent skin breakdowns and infections.

95. The Missouri Medicaid program covered incontinence briefs as medically necessary for Nicholas until he turned 21 years of age. Nicholas' medical condition did not change or improve when he turned age 21.

96. Nicholas's mother asked his Medicaid caseworker and his St. Louis Regional Center caseworker if there was a way for him to continue receiving the incontinence supplies. The caseworkers were not able to help Nicholas and referred him to Catholic Charities. Catholic Charities did not provide the requested diapers.

97. Incontinence briefs are required for the treatment of Nicholas' multiple medical impairments and conditions consistent with his diagnoses, in accordance with the determinations of his treating physicians.

98. Nicholas' incontinence briefs will be covered by the MO HealthNet program if he moves into a nursing home.

99. The Missouri Department of Health and Senior Services has already found that Nicholas meets the "level of care" requirements for coverage in a nursing facility or other such institution.

100. Nicholas's incontinence supplies cost approximately \$100 per month, while nursing facility care would cost approximately \$4000 per month.

101. Paying for these supplies out of pocket has caused financial hardship and emotional stress for the Tatum family. Nicholas's mother even has to do without eating some months in order to pay for adult diapers and Nicholas's other medical needs.

Plaintiff Nena Hammond

102. Plaintiff Nena Hammond is 49 years old and lives on her own in O'Fallon, Missouri.

103. Nena suffers from a spinal cord injury, cysts in her kidneys and liver, and occasional spasticity in her limbs and body. She is paralyzed and must use a wheelchair to get around.

104. Because of her disabilities, Nena is unable to work and receives SS I benefits of \$380.00 per month and SSDI benefits of \$314 per month. She receives \$60 per month in Food Stamp benefits. She also receives Medicaid MO HealthNet benefits from the Missouri Department of Social Services based on her disability. She has been covered by the Missouri Medicaid program since September 1998.

105. Due to her disabilities, Nena is incontinent of both bladder and bowel.

106. Nena lives in the community.

107. According to Nena's treating health care providers, the most appropriate place for Nena to receive care and to live is in the community rather than a nursing home or other such institution.

108. Nena needs incontinence briefs to prevent skin breakdown and infections. Her treating physicians have determined that incontinence briefs are medically necessary to prevent skin breakdowns and ulcers that result from sitting in wet and soiled undergarments. She is not always able to purchase all of the diapers she needs and sometimes suffers from skin infections.

109. As a result of multiple skin infections, Nena has become allergic to many of the most common antibiotics and taking antibiotics causes her to experience side effects, including severe vomiting. Nena's physician reports that she has limited treatment options and faces a higher risk of hospitalization with each infection.

110. Nena's adult diapers help prevent skin infections and reduce the need for using antibiotics to treat skin infections as well as the risk of hospitalization and/or institutionalization.

111. The Missouri Medicaid program has never covered incontinence briefs for Nena because she is over the age of 20.

112. Incontinence briefs are required for the treatment of Nena's multiple medical impairments and conditions consistent with her diagnoses, in accordance with the determinations of her treating physicians.

113. Nena's incontinence briefs will be covered by the MO HealthNet program if she moves into a nursing home.

114. In October 2009, Nena asked her Medicaid caseworker for financial assistance for the cost of adult diapers and was told that no help was available.

115. Nena's incontinence supplies cost anywhere from \$18 to \$90 per month depending on her health, while nursing facility care would cost approximately \$4,000 per month.

116. Paying for these supplies out of pocket causes financial and emotional stress for Nena who must forego basic necessities in order to pay for adult diapers. She is afraid that she will not be able to continue paying for these diapers. Nena lives in fear of embarrassment and public humiliation if she is forced to go out of the house without adult diapers as well as fear of hospitalization or other such institutionalization as a result of skin infections related to her incontinence.

117. Institutionalization of Plaintiffs due to incontinence alone is medically inappropriate treatment for this condition.

118. There is no medical basis for covering adult diapers for Plaintiffs if they reside in a nursing home but not if they live in the community.

119. Defendants have failed and refused, after request from Plaintiffs, to cover their doctors' requests for incontinence briefs.

120. Defendants have not taken reasonable actions to ensure that Medicaid services are provided in the most integrated setting appropriate for Plaintiffs.

121. At all times relevant, Defendants have acted under color of state law in failing and refusing to provide coverage of medically necessary incontinence briefs for Plaintiffs.

122. There is no plain, adequate, or complete remedy at law to prevent or redress the harm suffered by Plaintiffs as a result of Defendants' failure and refusal to provide coverage of medically necessary incontinence briefs.

123. Plaintiffs are suffering and will suffer irreparable harm as a result of Defendants' ongoing unlawful failure to cover incontinence briefs.

VI. CLAIMS FOR RELIEF

First Claim for Relief

124. Plaintiffs restate and incorporate by reference paragraphs 1 through 123 above.

125. Defendants' regulation, 13 C. S.R. § 70-60.010, and policy, Missouri Durable Medical Equipment Provider Manual, § 31.22.B, which exclude incontinent supplies for adults who live in their homes and communities, are in conflict with the reasonable standards requirements of federal Medicaid Act, 42 U.S.C. § 1396a(a)(17), its

implementing regulations and interpretive federal guidelines, and are preempted by the Supremacy Clause of the United States Constitution, art. VI.

Second Claim for Relief

126. Plaintiffs restate and incorporate by reference paragraphs 1 through 125 above.

127. Defendants' regulation, 13 C.S.R. § 70-60.010, policy, Missouri Durable Medical Equipment Provider Manual, § 31.2 2.B, and practice of denying Plaintiffs coverage of incontinence briefs violates the Medicaid Act's home health requirement, 42 U.S.C. §§ 1396a(a)(10)(A), 1396a (a)(10)(D), 1396d(a)(4), enforceable by Plaintiffs pursuant to 42 U.S.C. § 1983, in that it eliminates coverage of a mandatory home health service—medical supplies—for the categorically needy Medicaid Plaintiffs.

Third Claim for Relief

128. Plaintiffs restate and incorporate by reference paragraphs 1 through 127 above.

129. Defendants' regulation, 13 C. S.R. 13 C.S.R. § 70-60.010, and policy, Missouri Durable Medical Equipment Provider Manual, § 31.22.B, which eliminate coverage of mandatory home health services, including medical supplies, for categorically needy individuals, including Plaintiffs, is in conflict with the mandatory service coverage requirements of the federal Medicaid Act, 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(10)(D), 1396d(a)(4) and implementing regulations, and is preempted by the Supremacy Clause of the United States Constitution, art. VI.

Fourth Claim for Relief

130. Plaintiffs restate and incorporate by reference paragraphs 1 through 129 above.

131. Each of the Plaintiffs is “a qualified individual with a disability” within the meaning of 42 U.S.C. § 12131(2). Each of the Plaintiffs has multiple disabilities which significantly limit their life activities in profound ways, including mobility, the ability to provide self-care, the ability to communicate, and their bowel and bladder control, among other major life activities.

132. Defendants’ policy of providing incontinence briefs to those living in institutions, such as nursing homes, but not those living in the community, violates the Americans with Disabilities Act, 42 U.S.C. § 12131-12134, and its implementing regulations, which prohibit discrimination on the basis of disability, require that services be made available in the community, rather than in institutions, where to do so meets the needs of qualified individuals with disabilities, and require that reasonable modifications be made to state programs to avoid discrimination on the basis of disability.

133. Defendants have utilized criteria and methods of administering the Missouri Medicaid program that subject the Plaintiffs to discrimination on the basis of disability by (1) arbitrarily refusing to make their Medicaid Exception Process available under *any* circumstances to Plaintiffs; and (2) covering adult diapers for adults residing in nursing homes and other such institutions but not the Plaintiffs who reside in the community.

Fifth Claim for Relief

134. Plaintiffs restate and incorporate by reference paragraphs 1 through 133 above.

135. The Plaintiffs are qualified individuals with disabilities under Section 504 of the Rehabilitation Act, 29 U.S.C. §794(a).

136. The Missouri Department of Social Services receives federal financial assistance.

137. Defendants' policy of providing incontinence briefs to those living in institutional settings, such as nursing homes, but not to those living in the community, violates Section 504 of the Rehabilitation Act, 29 U.S.C. § 794(a) and its implementing regulations, which prohibit discrimination on the basis of disability, require that services be made available in the community, rather than in institutions, where to do so meets the needs of qualified individuals with disabilities, and require that reasonable modifications be made to the Federally funded program to avoid discrimination on the basis of disability.

138. Defendants have utilized criteria and methods of administering the Missouri Medicaid program that subject the Plaintiffs to discrimination on the basis of disability by (1) arbitrarily refusing to make their Prior Authorization Process or their Medicaid Exception Process available under *any* circumstances to Plaintiffs; and (2) covering adult diapers for adults residing in nursing homes and other such institutions but not the Plaintiffs who reside in the community.

REQUEST FOR RELIEF

- A. Assume jurisdiction over this action;
- B. Issue a declaratory judgment holding that: (1) Mo. Rule 13 C.S.R. 13 C.S.R. § 70-60.010 and policy violate the mandatory service coverage requirements of the Medicaid Act, 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(10)(D), 1396d(a)(4), and are

thus invalid; (2) Mo. Rule 13 C.S.R. 13 C.S.R. § 70-60.010 and policy are inconsistent with the reasonable standards and mandatory service coverage requirements of 42 U.S.C. §§ 1396a(a)(10)(A), (B), & (D); 1396a(a)(17); and 1396d(a)(4), their im plementing federal regulations and guidelines, and are thus preempted by the Suprem acy Clause of the United States Cons titution, art. VI; and (3) Mo. Rule 70-60.010 and policy, and Defendants' failure to m ake reasonable modifications in that rule violate the AD A, 42 U.S.C. § 12132, and Section 504, 29 U.S.C. § 794, and are thus invalid;

C. Grant preliminary and perm anent injunctions that prohibit Defendants Levy and McCaslin from im plementing and enforcing Mo. Rule 13 C.S.R. 70-60.010 and from refusing to provide Med icaid coverage of m edically necessary incontinence briefs for Plaintiffs as determined by their physicians;

D. Award Plaintiffs their reasonable attorneys' fees and costs; and

E. Grant such other and further relief as may be just and proper.

Respectf ully submitted,

Daniel
Robert
Legal
4232
St.
(314)
(314)

/s/ Joel Ferber
Joel Ferber # 35165
Claggett # 26982
Swearingen # 33339
Services of Eastern Missouri, Inc.
Forest Park Avenue
Louis, Missouri 63108
534-4200 telephone
534-1028 facsimile
jdferber@lsem.org
declaggett@lsem.org
rlswearingen@lsem.org

John
Saint

/s/ John J. Ammann
J. Ammann # 34308
Louis University Legal Clinic

321
St.
(314)
(314)

N. Spring Street
Louis, Missouri 63108
977-2778 telephone
977-1180 facsimile
ammannjj@slu.edu

Thom

/s/ Thomas E. Kennedy, III
as E. Kennedy, III # 46617
Law Offices of Thomas E.
Kennedy, III, L.C.

230
St.
(314)
(314)

S. Bemiston Avenue
Louis, Missouri 63105
872-9041 telephone
872-9043 facsimile
tkennedy@tkennedylaw.com

National

/s/ Jane Perkins
Jane Perkins
Health Law Program, Inc.
101 East Weaver St., Suite G-7
Carrboro, North Carolina 27510
968-6308 telephone
968-8855 facsimile
perkins@healthlaw.org

(919)
(919)

ATTORNEYS FOR PLAINTIFFS