IN THE UNITED STATES DISTRICT COURT
FOR THE MIDDLE DISTRICT OF TENNESSEE
AT NASHVILLE

STEPHEN TOD NEWBERRY,	)	
CAROLYN JONES,	)	
CAROL SMITH,	)	
MARY ANN WILSON,	)	
MARVIN RAY BERRY,	)	
CHRISTOPHER JACKSON, by his mother,	)	
Wanda Jackson, acting as next friend,	)	
individually and on behalf of all others	)	
similarly situated,	)	Civil Action No._________
	)	
Plaintiffs,	)	Class Action
	)	
- vs. -	)	
	)	
NANCY MENKE, in her official capacity as the	)	
Tennessee Commissioner of Health; and the	)	
TENNESSEE DEPARTMENT OF HEALTH,	)	
	)	
Defendants.	)	

CLASS ACTION COMPLAINT

I. PRELIMINARY STATEMENT

1. This class action challenges Tennessee state policies and practices which condemn people with disabilities to lives of wasteful, inhumane and needless institutionalization. The case is brought on behalf of thousands of individuals throughout Tennessee who depend on TennCare for essential medical services. TennCare routinely refuses to provide medically necessary care in the home, even though such care is mandated by law and ostensibly covered by the program. Instead, Tennessee effectively requires that disabled individuals be institutionalized in nursing homes in order to receive care, despite the fact that care in an institutional setting is typically more costly to the state.

2. The state is in violation of federal Medicaid requirements that states provide home health services to individuals for whom such care is medically necessary. Tennessee's policies also violate specific federal mandates that guarantee access to home health care for children, as well as for individuals who are eligible for nursing home care and who request home care in lieu of institutionalization. 42 U.S.C. §§1396a(a)(43)(C), 1396d(r)(5) and 1396a(a)(10)(D); 42 C.F.R. §440.70.

3. The state's policies violate the Americans with Disabilities Act (A.D.A.) requirement that public services and programs be provided in the most integrated setting appropriate to the needs of individuals with disabilities. The unlawful relegation of people with disabilities to the isolation, loneliness and despair of nursing homes results in the needless infliction of pain and the squandering of human potential.

4. The plaintiffs seek declaratory and injunctive relief for themselves and the class and subclass members whom they represent. Specifically, the plaintiffs seek to enjoin the state from continuing to deny medically necessary home health care to eligible TennCare beneficiaries. The plaintiffs also request an injunction barring the defendants from continuing to wrongfully segregate disabled TennCare beneficiaries in nursing homes, when such patients' medical needs could be met through the provision of home health services in the community.

II. JURISDICTION AND VENUE

5. This court has subject matter jurisdiction over this action pursuant to:

   a. 28 U.S.C. §1331, which confers original jurisdiction over all civil suits arising under the Constitution and laws of the United States; and

   b. 28 U.S.C. §1343(a)(3) and (4), which provides for original jurisdiction of this court to hear all claims to redress deprivation under color of state law of any rights, privileges and immunities guaranteed by the acts of Congress;

6. This action is authorized by 42 U.S.C. §§1983, 12133 and by 28 U.S.C. §§2201 and 2202.

7. Venue is proper pursuant to 28 U.S.C. §1391(b), because a substantial part of the events or omissions giving rise to the claims occurred in this District.

III. PARTIES

A. Plaintiffs

8. Stephen Tod Newberry is a 37 year-old resident of Rutherford County, Tennessee. He has been diagnosed with spinal muscular atrophy, a degenerative neurological disorder. He needs assistance with all activities of daily living. Mr. Newberry is enrolled in the TennCare program, upon which he must depend for access to needed home health services.

9. Carolyn Jones is a 49 year-old resident of Brownsville, Haywood County, Tennessee. The effects of rheumatoid arthritis have left her blind, bedfast and dependent on others for assistance with all activities of daily living. She is enrolled in the TennCare program, upon which she relies for the provision of necessary home health services.

10. Carol Smith is a 22 year-old resident of Knoxville, Knox County, Tennessee. She has major disabilities resulting from severe cerebral palsy, and she must rely upon the TennCare program for necessary medical care.

11. Mary Ann Wilson is a 63 year-old resident of Old Hickory, Davidson County, Tennessee. She has severe chronic obstructive pulmonary disease (COPD), which leaves her incapable of caring for herself. She is enrolled in the TennCare program, upon which she relies for the provision of necessary home health services.

12. Marvin Ray Berry is a 26 year-old resident of Madison, Davidson County, Tennessee. He is quadriplegic as a result of a childhood traumatic injury. He relies upon TennCare for medically necessary medical care.

13. Christopher Jackson is a 6 year-old child who brings this action by and through his mother, Wanda Jackson, who acts as his next friend. Christopher Jackson and his mother live in Hermitage, Davidson County, Tennessee. He has multiple disabilities and relies on TennCare for medically necessary health care.

B. Defendants

14. Nancy Menke is the Tennessee Commissioner of Health. As Commissioner, she is the chief executive officer of the defendant Tennessee Department of Health. Pursuant to T.C.A. §71-5-134, the Commissioner is responsible for promulgating rules for the administration of Tennessee's Medicaid program and the TennCare waiver. The defendant is sued in her official capacity.

15. The Tennessee Department of Health (TDH) is designated as the single state agency responsible for the administration and supervision of Tennessee's Medicaid Program under Title XIX of the Social Security Act. T.C.A. § 71-5-104. In January 1997, by Executive Order of Tennessee's Governor, TDH was assigned all functions related to the administration and supervision of Tennessee's Medicaid Demonstration Project Number 11-W-00002/4, called "TennCare." TDH is the parent agency of the TennCare Bureau, which has direct responsibility for the TennCare program's implementation and administration. TDH is a public entity within the meaning of Title II of the Americans with Disabilities Act. 42 U.S.C. §§ 12131-12134.

C. Plaintiff Class

Definition

16. Plaintiffs seek declaratory and injunctive relief in this action pursuant to Fed. R. Civ. P. 23(a) and (b)(2) on behalf of all present and future TennCare beneficiaries for whom home health services are, or will be, medically necessary. In addition,

a. the named plaintiffs represent a subclass ("The Disability Subclass") consisting of beneficiaries with disabilities; and

b. plaintiff Christopher Jackson represents a subclass ("The Children's Subclass") consisting of those plaintiff class members who are under the age of 21.

Numerosity

17. As of October 23, 1998, the TennCare Bureau reported that 1,291,539 individuals were enrolled in the TennCare program statewide. In 1993, the last year for which such published figures are available, the state reported that 14,243 Medicaid patients received home health care.

Coverage has since expanded by a net increase of 375,000 beneficiaries, and the level of need for home health care has increased accordingly.

a. The Disability Subclass - In 1993, the last year for which such published figures are available, the state reported that 7,666 of the Medicaid patients who received home health care were formally classified as disabled for purposes of determining their eligibility. A substantial number of other recipients of home health care were also disabled, although they were classified as falling in another eligibility category. With the subsequent increase in enrollment, the number of beneficiaries with disabilities who are in need of home health care has also increased.

b. The Children's Subclass – In 1993, the last year for which such published figures are available, the state reported that 3,110 of the Medicaid patients who received home health care were under the age of 21. Net enrollment in Medicaid (or, as it is now called, TennCare) has risen since then, from 426,031 children in 1993, to a present enrollment of approximately 550,000 children. The number of enrolled children in need of home health care has also increased.

18. Based on these statistics, the numbers of individuals in the plaintiff class and each subclass can be conservatively estimated to be in the thousands. The requirements of Fed. R. Civ. P. 23(a) are met in that the class and subclasses are so numerous that joining all members is impractical.

Common Issues of Law and Fact

19. The named plaintiffs raise claims based on questions of law and fact that are common to, and typical of, the putative class members. Plaintiffs and the proposed class must rely on TennCare for the provision of vital long term care services, but face state policies and practices which effectively deny them such services.

20. Questions of fact common to the entire class include, whether:

a. The TennCare program has a policy or practice of denying home health care (or permitting its contractors to deny home health care) because individuals require the service on a long term basis;

b. The TennCare program has a policy or practice of denying home health care (or permitting its contractors to deny home health care) to individuals because they are not homebound;

c. The TennCare program has a policy or practice of denying home health care (or permitting its contractors to deny home health care) when such care is needed to assist a person with activities of daily living.

d. The TennCare program has a policy or practice of denying home health care (or permitting its contractors to deny home health care) to individuals who are eligible for nursing home care.

e. The TennCare program has a policy that long term medical care is to be rendered in a nursing home setting, whether or not such care could more appropriately be rendered in a less segregated setting.

21. Questions of law common to the entire class or subclass include whether:

a. The TennCare program is in violation of those Medicaid Act provisions and regulations that require states to provide medically necessary home health services to eligible individuals;

b. With regard to the Disability Subclass, the TennCare program is in violation of the Americans with Disabilities Act requirement that services to persons with disabilities be provided in the most integrated setting appropriate to their needs and conditions;

c. In the case of the Children's Subclass, whether the TennCare program is in violation of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) provisions of the Medicaid Act, which govern the provision of medically necessary services to enrollees under the age of 21.

d. Injunctive and declaratory relief are appropriate and, if so, what the terms of such relief should be.

Typicality of Claims and Defenses

22. The claims of the named plaintiffs are typical of those asserted on behalf of the plaintiff class and subclasses. Because they challenge a common set of state policies and practices, it is anticipated that the defendants will assert similar defenses as to all of the individual plaintiffs and class members.

Adequate Representation of Class

23. The named plaintiffs will fairly and adequately protect the interests of the class. They are represented by attorneys from the Tennessee Justice Center who have experience in complex class action litigation involving health care, disability and civil rights law. Counsel have the resources, expertise and experience to prosecute this action. Counsel know of no conflict among members of the class or subclass.

Appropriateness of Declaratory and Injunctive Relief

24. Defendants have failed or refused to act on grounds generally applicable to the class and each subclass, making declaratory and injunctive relief with respect to each such class/subclass as a whole appropriate and necessary. The nature of the violations complained of here is such that, absent systemic relief for all class members, it is impossible to adequately protect the rights of any single plaintiff.

IV. FACTUAL ALLEGATIONS

A. Overview of the Medicaid Program

25. Title XIX of the Social Security Act, sometimes referred to as the Medicaid Act, provides medical assistance to individuals who lack the financial means to obtain needed health care on their own. 42 U.S.C. §1396. Medicaid is partially administered by the federal government, under

the aegis of the Health Care Financing Administration (HCFA) of the Department of Health and Human Services (HHS). Each state is at liberty to decide whether to participate in the Medicaid program, and all states do. The state and federal governments share responsibility for funding Medicaid. States administer the program, subject to federal requirements imposed by the Medicaid Act and HCFA regulations and policy directives. Once a state opts to participate in the program and accept federal funding for its operation, the state must comply with the conditions and requirements imposed by the Medicaid Act and related regulations.

26. Tennessee has participated in Medicaid since shortly after the program's inception in the 1960s. Under the Tennessee Medical Assistance Act of 1968, the program is to provide

> "payment of the cost of care, services and supplies necessary to prevent, diagnose, correct or cure conditions in the person that cause acute suffering, endanger life, result in illness or infirmity, interfere with the person's capacity for normal activity, or threaten some significant handicap and which are furnished an eligible person in accordance with the provisions of this part and the rules and regulations of [TDH]. Such care, services and supplies includes [sic] services of qualified practitioners licensed under the laws of this state…" [T.C.A. §71-5-103]

The defendant Commissioner is required to administer the TennCare program in conformity with federal law and the terms of any federal waiver granted the state. T.C.A. §§ 71-5-102, 104.

27. In accordance with federal and state law, Tennessee's Medicaid program covered recipients of public assistance, such as Supplemental Security Income (SSI) and Aid to Families with Dependent Children (AFDC). Additional groups of medically indigent individuals were added over the years in response to changes in federal or state law.

28. Until 1994, the program operated on a fee-for-service basis, paying claims submitted directly to the state by health care providers who served eligible individuals. Tennessee's Medicaid program covered an array of services, including doctor, hospital, prescription drug and other services. Federal law required the state to provide enhanced benefits to children under the

age of 21, under what is known as the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate. See *John B. v. Menke,* No. 3-98-0168 (M.D. Tenn. 1998).

29. Among the services covered by Tennessee's Medicaid program were home health services. See Tennessee Department Health Rule 1200-13-1-.03(1)(i). Consistent with federal law, Medicaid home health services are part-time or intermittent services provided by a licensed home health agency (HHA), under a plan of care prescribed by a physician, and include:

a. skilled nursing services rendered by licensed personnel;
b. home health aide services provided by the HHA;
c. medical supplies, equipment, and appliances suitable for use in the home; and
d. therapy services provided by the HHA or by a facility licensed by the state to provide medical rehabilitation services.

42 C.F.R. §440.70(b)

30. The state HHA licensure requirements referred to in the federal Medicaid regulation are codified as Tennessee Department of Health Rules, Chapter 1200-8-8. The licensure requirements mandate that home health aides meet certain specified regulatory standards pertaining to their selection, training, supervision and duties. State regulations define their duties to include:

> "the performance of simple procedures as an extension of therapy services, personal care, ambulation and exercises, household services essential to health care at home, assistance with medications that are ordinarily self-administered, reporting changes in the patient's condition and needs, and completing appropriate records."

Tennessee Department of Health Rule 1200-8-8-.03(16)(a)

31. Prior to 1994, Tennessee's Medicaid rules limited the scope of covered home health services to 60 visits per beneficiary per fiscal year, and required that the patient be homebound.

B. The TennCare Program

The Federal Waiver

32. In 1993, Tennessee obtained from the Secretary of Health and Human Services a Medicaid demonstration waiver under Section 1115 of the Social Security Act, 42 U.S.C. §1315.

The waiver permitted the state to replace its conventional Medicaid program with a demonstration program called TennCare. The five-year waiver was implemented in January, 1994, and recently renewed for an additional three years, pursuant to 42 USC § 1396n. Federal Medicaid funds account for approximately two thirds of the TennCare program's budget.

33. The federal waiver exempted the demonstration program from compliance with only a few selected federal Medicaid statutes and rules. All laws and rules not explicitly waived remain fully applicable to TennCare. Among the terms and conditions of the waiver are an enumeration of the amount, duration and scope of services to be provided to TennCare beneficiaries. Tennessee may not alter those services without approval of the Secretary. No such approval that would be pertinent to this case has been sought or received.

Expansion of Eligibility and Benefits

34. Under the terms and conditions of the waiver, TennCare substantially broadened coverage by making eligible many uninsured Tennesseans who would not meet traditional Medicaid criteria. The TennCare waiver also made significant changes in the amount, duration and scope of some covered services. Among the affected services was home health care. By the terms of the waiver, the state agreed to remove the 60 visit annual limit on home health services. The waiver also deleted the requirement that a patient be homebound in order to receive home health care. Under the waiver, home health services were to be provided, "as medically necessary", without any further limitation. The waiver provided that, for these purposes,

> Medically Necessary shall mean services or supplies provided by an institution, physician, or other provider that are required to identify or treat a TennCare Enrollee's illness or injury and which are:
>
> a. Consistent with the symptoms or diagnosis and treatment of the Enrollee's condition, disease, ailment or injury; and
> b. Appropriate with regard to standards of good medical practice, and
> c. Not solely for the convenience of an Enrollee, physician, institution or other provider; and
> d. The most appropriate supply or level of services which can be safely provided to the Enrollee.

As required by state law, the TennCare Bureau promulgated legally binding rules which incorporated these changes in the scope of the home health benefit. Tennessee Department of Health Rules §§1200-13-12-.01(4) and 1200-13-12-.04(n); T.C.A. §§ 4-5-216 and 71-5-134.

Conversion to Managed Care

35. The TennCare waiver also permitted the state to convert its Medicaid program from a traditional fee-for-service model to a new financing and delivery system, known as capitated managed care. Under the new delivery model, the state assigns each beneficiary to one of nine managed care organizations (MCO), or health plans. The largest of these MCOs is Blue Cross Blue Shield of Tennessee, which participates in TennCare under the name "BlueCare", covering approximately half of the TennCare beneficiary population statewide. Because of its dominant role in the program, BlueCare policies and practices influence the behavior of the other MCOs as well.

36. Each MCO is paid a fixed amount per beneficiary, referred to as a capitation payment, to provide covered medical services as medically necessary. The MCOs' responsibilities include the provision of the home health services described above. The benefits and other contract terms are identical for each of the different MCOs.

37. Each MCO is at financial risk, meaning that it must absorb any losses which result if beneficiaries' medical costs exceed the total amount of TennCare capitation revenues. (For this reason, the TennCare contract between the state and the MCOs is referred to as a "risk agreement".) Conversely, to the extent that the managed care company reduces costs below the level of its aggregate TennCare receipts, it gets to keep the difference (within certain limits) as profit. As in the case of conventional health insurance, the profits made on healthy beneficiaries offset the higher costs of caring for sicker beneficiaries who require extended, or very intensive, care. According to their reports to the state, the largest TennCare MCOs, including Blue Cross, are profitable.

38. Each MCO is responsible for affirmatively managing the care of its enrollees. Unlike the state's former Medicaid program, TennCare is exempt from the federal requirement that

beneficiaries be given free choice of health care providers. Instead, each MCO has an exclusive network of selected providers, with whom it contracts for the care of its enrollees. The MCOs assign each of their enrollees to designated primary care providers (PCP) within their network. The PCPs act as "gatekeepers", controlling the enrollees' access to specialists or other medical care.

The "Carve-out" of Nursing Facility Services

39. Nursing facility services are excluded (or, in managed care terminology, "carved out") from TennCare's managed care arrangements. Nursing facility services are still reimbursed directly by the state, on a fee-for-service basis. The state continues to refer to the program which subsidizes nursing facilities as "Medicaid". However, Medicaid and the "TennCare" managed acute care program are a single administrative entity in Tennessee, funded under the common federal statutory authority of Title XIX of the Social Security Act, 42 U.S.C. §§ 1396 et seq. Tennessee Medicaid currently pays nursing homes rates of approximately $33,000 per year for so-called Level 1 nursing facility care, or $54,341 for more skilled Level 2 care. Medicaid is the principal source of revenues for Tennessee's nursing home industry: 75% of all nursing home care rendered in the state is subsidized in whole or in part by the program, at a total current cost of more than $700 million annually.

40. In order for an individual to obtain Medicaid coverage for her nursing home care, she must do more than demonstrate that her income and savings are below Medicaid's prescribed standards of indigency. The individual must also satisfy certain medical and social criteria, referred to in Tennessee as Pre-Admission Evaluation (PAE) requirements. The PAE rules are intended to ensure that Medicaid covers nursing home care only for those for whom such care is medically necessary. The PAE process includes an assessment of whether the person needs ongoing assistance with activities of daily living. Tennessee Department of Health Rules, Chapter 1200-13-1-.10.

C. The State's Policy of Denying Home Health Services

41. Under the TennCare risk agreements which the state has signed with each MCO, an MCO's profits are reduced by the provision of covered medical services, thereby creating in the MCOs a "pecuniary interest in denying beneficiaries medical care". *Daniels v. Wadley*, 926 F.Supp. 1305 (M.D.Tenn. 1996) An MCO can further that interest by refusing care outright. A plan can also further its financial interests by contriving to shift the financial burden of a beneficiary's care to another party, a practice known as "cost-shifting". Or, the MCO can combine the strategies by denying care for which it is responsible, while encouraging or requiring the beneficiary to seek the needed care from another source.

42. An MCO's incentive to deny medically necessary care is especially strong in the case of individuals whose chronic conditions require extended care, since avoidance of their care will realize continuing savings. And, by carving nursing facility services out of the TennCare contracts and continuing to pay for those services directly, Tennessee has created a specific incentive, and opportunity, for the MCOs to steer such beneficiaries into nursing facilities. If a beneficiary with disabilities needs home health services or equipment to assist with activities of daily living, an MCO can, by denying such services, compel the beneficiary to accept nursing home placement in order to obtain them. The MCO thereby shifts the cost of such care to the state's Medicaid nursing facility budget.

43. Because of these inherent incentives, the only way for the state to protect disabled TennCare beneficiaries from wrongful denials of care and unwanted institutionalization is to rigorously enforce regulations and laws which guarantee beneficiaries medically necessary care. However, rather than do so, the state has, over the past two years, developed a policy and practice of ratifying MCOs' denials of care to people with disabilities, and has supported the health plans' practice of steering such beneficiaries into nursing homes.

44. In February, 1997, Blue Cross sent the TennCare Bureau a request to expand the list of authorized "exclusions", i.e., services which the MCO would **not** be required to provide to its TennCare beneficiaries. The TennCare risk agreement, the description of covered benefits in the

federal waiver and the state's formally promulgated regulations already excluded services which were "not medically necessary". Blue Cross sought an "additional exclusion" for "custodial services". In April, 1997 the TennCare Bureau granted the MCO's request.

45. However, the state did not seek or obtain federal approval to modify the waiver, nor did it alter the risk agreement and state regulations to conform to the new agreement with Blue Cross.

46. Blue Cross has interpreted the new custodial care exclusion as authorizing the denial of a great deal of home health care that has been explicitly covered by the TennCare waiver and regulations since the program's inception. Blue Cross applies a set of coverage limits published in the Milliman and Robertson *Healthcare Management Guidelines*, a multi-volume commercial insurance publication developed by an actuarial firm without any reference to federal or state Medicaid law or the terms of the TennCare risk agreement. The *Guidelines* authorize home health services, including assistance by home health aides with activities of daily living, for only a few diagnoses, and only for brief periods. Blue Cross supplements the *Guidelines* with an internally developed *Utilization Review Manual* which restricts the coverage of home health care still further.

47. The combined effect of these policies is to permit coverage of home health aides only for those TennCare beneficiaries whose need for such services is of brief duration and not based on long term disability. Blue Cross excludes as "custodial care" any home health service, whether provided by home health aides or skilled nursing personnel, which provides assistance with activities of daily living.

48. It is also the practice of Blue Cross to deny home health coverage to any beneficiary who does not meet the MCO's requirement that they be "homebound". The TennCare beneficiaries most likely to satisfy this requirement are those who suffer from serious chronic illness. However, it is precisely the same group of chronically ill patients who are denied home health services on the grounds that they need care on a long term basis.

49. The state has endorsed the Blue Cross exclusions. The TennCare Bureau's Appeals Unit, which processes beneficiary appeals of coverage denials by the MCOs, applies the same

exclusions to home health cases which it reviews. And, although only Blue Cross obtained the Bureau's formal written approval to deny "custodial care", the Bureau extends the same *de facto* authority to the other TennCare MCOs, as well.

50. Because of the inconsistencies between the terms of the waiver and legally binding regulations, on the one hand, and this informal private agreement between TennCare and the MCOs on the other, a few beneficiaries have been successful in administratively contesting MCO denials of home health care. To strengthen its legal position in individual administrative appeals, Blue Cross demanded that the state formally alter the TennCare home health benefit to match the MCOs' policies and state practice.

51. In June, 1998, Blue Cross injected the issue into private negotiations with the state regarding the plan's acceptance of certain contract amendments sought by the TennCare Bureau. The MCO demanded that the state change its formally promulgated rules as soon as possible to conform to Blue Cross' policies. In letters which the defendant Commissioner faxed to Blue Cross on June 30 and July 1, 1998, the state agreed to meet the contractor's demands. The letters promised that TDH would "move through the process as quickly as possible a Rule change" which would impose a homebound requirement for home health benefits. The defendants also agreed to other steps to respond to the MCO's "concerns relative to long term care issues generally, and your particular concerns about the role of the MCOs in the provision of custodial care". With these assurances, Blue Cross signed the new contract amendments in early July.

52. In the July 15, 1998 *Tennessee Administrative Register*, the TennCare Bureau accordingly published a proposed amendment to Rule No. 1200-13-12-.04(n). The amendment would restrict access to home health care, which now is legally limited only by the requirement that such care be medically necessary, by adding an additional requirement that the beneficiary be homebound. In the face of adverse public reaction to the proposal, the Bureau announced at the August 16, 1998 rulemaking hearing that homebound status would not be an absolute requirement. Instead, the state purported to soften the amendment so that MCOs could consider homebound status in deciding whether home health care is medically necessary, as long as

homebound status is not treated as the sole criteria. However, since the amendment will still allow MCOs to deny home health care as medically unnecessary when the patient is not homebound, the rewording of the amendment is merely semantic.

53. At legislative hearings on August 18 -19, 1998, the defendant Commissioner testified concerning the state's home health policy. She made it clear that the "homebound" requirement is merely part of a broader set of *de facto* TennCare policies limiting access to medically necessary home health care. The defendant stated candidly that, notwithstanding regulations to the contrary, the TennCare Bureau had in fact been denying, and permitting its contractors to deny, home health services for those beneficiaries who require long term care. She explained that the purpose of the proposed rule amendment was merely to bring the law into conformity with actual practice. TennCare's policies regarding home health services are in line with an underlying state policy, she said, that TennCare beneficiaries who need long term care may not obtain such care from an MCO, but must seek such care from other sources.

54. Tennessee's Medicaid nursing facility program is the only other state source of long term medical assistance with activities of daily living or ongoing medical services. The implications of state policy are, therefore, inescapable: TennCare beneficiaries with functional disabilities requiring assistance with activities of daily living, or requiring *any* form of home health services for more than a brief period, must resign themselves to nursing home placement as a prerequisite to obtaining such assistance. Only in that institutional setting will TennCare afford them the nursing care which they need.

D. Injury to the Named Plaintiffs

Stephen Tod Newberry

55. Plaintiff Stephen "Tod" Newberry is thirty-seven years old. He lives with his mother in Murfreesboro, Tennessee. Mr. Newberry has been enrolled in the Tennessee Medicaid program (or, as it has been known since 1994, the TennCare program) since approximately 1982, when he was determined to be eligible for Supplemental Security Income (SSI) on the basis of disability.

56. At age twenty-two, Tod Newberry began to show symptoms of a neurological disorder which was ultimately diagnosed as spinal muscular atrophy (SMA). Spinal muscular atrophy is a degenerative neurological disease, characterized by loss of motor skills and wasting of muscles. There is no cure. Mr. Newberry has been treated by a number of doctors, including neurological specialists at Johns Hopkins University and Vanderbilt Medical Center, but to no avail.

57. The plaintiff uses an electric wheelchair because he has no use of his legs. He can move his upper extremities to a limited extent. However, his muscles are so weak that he is unable to perform any tasks which require even minimal strength or dexterity. It is an effort for Mr. Newberry to feed himself, and he is increasingly unable to shave or brush his teeth. He cannot transfer between his motorized wheelchair and the bed. He requires assistance with all activities of daily living. Both of his parents provide help, but neither is physically capable of meeting his needs without assistance.

58. In addition to these disabilities, Mr. Newberry's disease causes severe, constant pain. Even limited exertion is taxing, and he is easily exhausted. He suffers from chronic, intermittent urinary infections and has been hospitalized on a number of occasions with such disorders. Because of his condition, the plaintiff is also at risk of skin breakdown and respiratory infections. In fact, he begins to show signs of skin breakdown if home health services are unavailable for even a few days. Mr. Newberry's prognosis is grim. He will continue to decline at a rate which can neither be predicted nor controlled, and the disease may ultimately take his life.

59. In the face of SMA's relentless progression, Tod Newberry struggles to maintain, and even enhance, his personal autonomy. He attends Middle Tennessee State University in pursuit of a college degree which will enable him to work in spite of his disabilities.

60. The plaintiff's physicians started prescribing home health care for him while he was enrolled in the Medicaid program. The doctors continued to do so after TennCare was established and Mr. Newberry was assigned to Blue Cross. He intermittently received skilled nurse visits during health crises, such as following surgery. In addition, throughout the period

since home health services began, Mr. Newberry has received ongoing home health aide visits. These have fluctuated in frequency, from several visits per week to every day.

61. For several years, home health aides have come to Mr. Newberry's home early each weekday morning. A home health aide helps him transfer from his bed to a wheelchair, then assists him in using the toilet, bathing, shaving, brushing his teeth, dressing, transferring back into his wheelchair, and eating. During each visit, the home health aide takes Mr. Newberry's vital signs and reports to a nurse any indications of infection or other health problems. The home health nurse then reports those symptoms to Mr. Newberry's primary care physician, who prescribes such further care as he deems appropriate.

62. Neither Medicaid, nor Blue Cross nor the TennCare Bureau challenged the medical necessity of Mr. Newberry's home health services until this year. Throughout the first four years of his enrollment in TennCare, Blue Cross routinely reviewed and approved the renewal of his doctors' prescriptions for those services. In order to comply with HCFA regulatory conditions for federal funding, every 60 days the MCO certified that such care continued to be medically necessary. [See 42 C.F.R. §§440.70(a)(2) and 440.230(d)] Over the course of that period, Mr. Newberry's disease continued to progress, and his need for care increased correspondingly. None of his treating physicians has ever questioned his need for continued home health care.

63. In January, 1998, Blue Cross again reviewed Mr. Newberry's home health care. Coverage was questioned on the grounds that it was "custodial". However, another 60 days of care was authorized because the plaintiff was a student. Therefore, it was noted that he "will not be on Medicaid forever" and, by implication, Blue Cross would not have to provide care much longer.

64. On March 3,1998, the plaintiff's home health care came up for review again. Blue Cross personnel followed their standard review process, referring to the Milliman and Robertson *Healthcare Management Guidelines: Home Health Care* and the Blue Cross *Utilization Review Manual.* Dr. Futrell, a Blue Cross assistant medical director, reviewed the case. He did so without examining the plaintiff, reading any of his medical records, consulting with his treating

physicians or considering any actual medical evidence, other than the prescribing physician's request for continuation of home health care. Dr. Futrell denied TennCare coverage of the plaintiff's home health care, noting in the Blue Cross computer record that:

> "…this request appears to be for the provision of custodial care which is not covered under BlueCare policy and its associated risk agreement with the State of Tennessee, therefore the current request is denied. Family members are available to assist and it seems reasonable that they arrange their schedules and recruit additional family, friends, neighbors, etc. or even hire someone to come assist this pt. with transfers and condom catheter placement…."

65. Another Blue Cross Assistant Medical Director, Dr. Snell, reviewed the case the same day and affirmed the denial "because APPEARS TO BE CUSTODIAL." A Blue Cross representative suggested to Mr. Newberry that he go into a nursing home. This advice was followed by a letter dated March 26, 1998, in which Blue Cross informed him that,

> "Blue Care[sm] listens to your concerns. Our Regional Medical Director has reviewed your case, and the information sent to us by Willowbrook Home Health. Bathing, assistance with dressing and personal care does not require skilled personnel. Medical necessity for the aides five times a week is not established. The denial of the aides five times a week is upheld."

66. Following BlueCare's reaffirmance of its denial, the TennCare Appeals Unit reviewed the plaintiff's appeal. On April 2, 1998, the state's medical consultant upheld the termination of home health care. In the appeal record, the TennCare official marked through the phrase "medically necessary?" and wrote, "…has been receiving HHA support (9-7-97 to 3-7-98 [139 visits]) no doubt assistance required but pt. is MTSU student (? Homebound) …" Another TennCare Bureau representative testified at a subsequent administrative hearing on Mr. Newberry's appeal that the state's denial of care had been "based on home bound status permanently [sic]".

67. In June, 1998, confronted with the termination of their patient's home health care, Mr. Newberry's doctor and home health agency submitted a P.A.E. application to the TennCare

Bureau, requesting approval of nursing home care. The Bureau determined that Mr. Newberry's medical condition makes it medically necessary that he receive "nursing care daily", including assistance with activities of daily living. The agency promptly approved the P.A.E. request, thus certifying that Mr. Newberry's medical condition qualifies him for nursing home care.

68. At an administrative hearing on the plaintiff's appeal of the termination of his home health care, Blue Cross justified the termination as consistent with the company's standard policy regarding services for TennCare patients who have permanent disabilities. Blue Cross witnesses explained that the company does provide home health care, including the services of home health aides, to TennCare patients. But, they said, the MCO does *not* provide home health aide services to those patients, such as Mr. Newberry, who require them for assistance with activities of daily living. Since the primary, if not exclusive, function of home health aides is to assist with activities of daily living, the practical effect of the Blue Cross policy is to make such services unavailable to most TennCare enrollees who need them. Blue Cross considers the care of such patients to be "custodial care", which is excluded under its agreement with TennCare.

69. Further explaining his company's denial of care to Mr. Newberry, a Blue Cross representative testified that the MCO borrows the regulatory definition of "custodial care" as used to determine who qualifies for Medi*care* Skilled Nursing Facility (SNF) coverage. The effect of the Blue Cross policy is that only patients who meet the Medicare SNF coverage standard can qualify for TennCare coverage of home health care.

70. Medicare's SNF benefit is not meant to cover ordinary nursing facility care. The benefit is limited to a maximum of only 100 days. Medicare's medical requirements for SNF coverage are so much more stringent than Medicaid nursing facility criteria that, in Tennessee, less than 20% of Medicaid nursing home patients meet SNF standards. Thus, like the great majority of

other TennCare patients who qualify for nursing home placement, Mr. Newberry's care is classified as "custodial" by Blue Cross, and is excluded from TennCare coverage. The fact that the state has approved his P.A.E. application is, Blue Cross insists, irrelevant to whether he should receive home health care.

71. During the course of the plaintiff's administrative appeal, TennCare aggressively supported the position of its contractor, Blue Cross. TennCare's representative approved the home health coverage guidelines contained in the Blue Cross *Utilization Review Manual*. That manual establishes homebound status as an eligibility criterion for BlueCare patients other than those covered by EPSDT (i.e., patients under age 21). The manual also precludes coverage for "routine long term medical care which can be accomplished by a trained caregiver". Another state official, who is in charge of policy for the TennCare Bureau, confirmed as agency policy that a patient who, like Mr. Newberry, is approved for Medicaid nursing home care does not thereby qualify for home health coverage.

72. Mr. Newberry's administrative appeal of the termination of his home health care is still pending. However, the secret agreement between the defendant Commissioner and Blue Cross dooms that appeal. Even if he succeeds, and the administrative law judge rules in the plaintiff's favor, the ultimate decision will be made by the Commissioner, who is bound by her agreement with Blue Cross to uphold the termination of his care. In any event, as part of the agreement, the Commissioner is moving to revise TennCare's rules in a manner which will make him ineligible for further care in the future, and force his placement in a nursing home.

73. The present cost to Blue Cross of Tod Newberry's home health care is approximately $6,000 per year. Under the terms of its risk agreement with Blue Cross, the cost to the state of the plaintiff's TennCare coverage is the same -- $1,080 per year -- whether or not he receives

home health care. By refusing home health coverage to Mr. Newberry and requiring him to obtain medically necessary care in a nursing facility, the state will relieve Blue Cross of financial responsibility for his home health care. The state will simultaneously increase the cost to TennCare by a total of approximately $33,000 per year.

Carolyn Jones

74. Carolyn Jones is a 49 year old woman who suffers from rheumatoid arthritis and panic disorder. She is blind, totally bedridden and unable to turn herself in the bed. Ms. Jones lives alone in her home, which is next door to her sister's home in Brownsville, Tennessee. Daily care from a home health agency, supplemented by the devoted support of her sister and daughter, has enabled her to remain in her home. Ms. Jones is articulate and bright, completely competent and aware, and maintains strong social relationships with her neighbors and other visitors and, via telephone, with the broader community.

75. Ms. Jones' treating physician and primary care provider, Dr. James G. Pettigrew, has issued orders for home health aide services consistently since August 11, 1988. For six years under Medicaid, and for the first four years after her Medicaid coverage was converted to TennCare, those orders were carried out without question. The appropriateness of the care was reviewed every 60 days for nearly a decade; Medicaid and (after TennCare was established) Blue Cross routinely found the care to be medically necessary.

76. During that period of time, Ms. Jones' medication needs have changed, and her arthritis has worsened. But she has never required in-patient hospitalization for bed sores, dehydration, bowel impaction, or any other of the complications that are often associated with a person with her medical condition, and which frequently afflict patients in nursing home. Her physician

attributes her relative stability to the excellent care provided by the home health agency and her family, working as a team.

77. In October, 1997, Ms. Jones' TennCare MCO, Blue Cross, again reviewed her home health plan of care. For the first time, Blue Cross refused to approve any further home health care. Ms. Jones requested an appeal, which Blue Cross denied. The MCO wrote to assure her that, "Blue Care[sm] listens to your concerns", then informed her that home health care was still denied as "custodial care-not medically indicated."

78. In a notice dated December 17, 1997, the TennCare Bureau affirmed Blue Cross' termination of home health care for Ms. Jones. Acting on behalf of the Bureau, an Associate Medical Director explained that, "my understanding is that these [home health] aides are helping you with activities of daily living. It is my determination that they are not medically necessary, although I appreciate that they are important."

79. Dr. Pettigrew, who had long treated Ms. Jones and had been designated by Blue Cross as her primary care physician, wrote a letter in February, 1998 to the TennCare Bureau. He stated that he was "amazed and appalled" to learn that her services were denied. He predicted that "multiple complications and probable hospitalization … would occur" if the services were terminated. The TennCare Bureau, without reviewing Ms. Jones medical records, or even the administrative records relating to the Blue Cross denial, dismissed her doctor's warnings and reaffirmed the termination of home health care.

80. Had the TennCare Bureau reviewed Blue Cross' records, the Bureau would have found that Dr. Pettigrew's fears for his patient's safety were shared fully by Blue Cross itself. The MCO staff had noted in Ms. Jones' case file on November 19, 1997, "[F]rom the information received from the patient, she will be in danger of starving herself to death and many other

complications that will occur secondary to poor diet and hygiene." Blue Cross personnel suggested that she go into nursing home. The MCO's staff were so convinced that termination of home health would endanger her health that, when she refused their urging to go to a nursing home, the company reported the patient's situation to the state Division of Adult Protective Services (APS). APS investigates the gross neglect, abuse or endangerment of frail adults pursuant to T.C.A. §§ 71-6-101 *et seq*. Based on the company's assessment of Ms. Jones' grim prognosis without home health care, Blue Cross suggested that the state agency institutionalize her against her will. (APS has no such authority, since Ms. Jones is mentally competent.)

81. The conviction of its staff that withdrawal of home health care would endanger Ms. Jones' life did not deter Blue Cross from aggressively pursuing the termination of that care. At the administrative hearing on her appeal, Blue Cross presented witnesses who described the company's policies in the same terms used at the hearing of Tod Newberry. Under those policies, Ms. Jones can no longer receive home health care, because Blue Cross does not provide such care when it is needed to assist with activities of daily living.

82. Consistent with the deal which it struck with Blue Cross, the TennCare Bureau has fully supported its contractor's position during Ms. Jones' appeal, dutifully arguing for the termination of her care.

83. Upon information and belief, the present cost to Blue Cross of Carolyn Jones' home health care is approximately $9,125 per year. Under the terms of its risk agreement with Blue Cross, the cost to the state of the plaintiff's TennCare coverage is the same -- $3,542.76 per year -- whether or not she receives home health care. By refusing home health coverage to Ms. Jones and requiring her to obtain medically necessary care in a nursing facility, the state will relieve Blue Cross of financial responsibility for her home health care. The state will simultaneously

increase the total cost of her care, and will increase TennCare's net cost by approximately $33,000 per year.

Carol Smith

84. Carol Smith is a 22-year-old TennCare beneficiary enrolled in the Blue Cross MCO, which is marketed in the Knoxville area under the name, Tennessee Health Partnership/BlueCare. She lives with her parents, who have provided care for her all of her life. Her diagnoses include severe cerebral palsy, spastic quadriplegia, neurogenic scoliosis and posterior spinal fusion. Due to her inability to use her extremities, Ms. Smith requires assistance with all activities of daily living, including feeding, bathing and using the toilet. In order to communicate, Ms. Smith must use an augmentative communication device (ACD), known as a Liberator, which she operates with a head switch. She is currently studying for the G.E.D. exam and testified earlier this year before a U.S. Senate committee regarding federal disability policy.

85. Ms. Smith began receiving Supplemental Security Income (SSI) at age 16, on the basis of her disability. Under federal and state policies linking SSI and Medicaid eligibility, she automatically qualified for Tennessee Medicaid coverage at the same time, and has been continuously covered since then. In January 1994, when the TennCare demonstration project began, she enrolled in the Blue Cross MCO.

86. Both of Ms. Smith's parents are physically disabled. Her father, Billy J. Smith, receives Social Security disability benefits based on a severe back injury. Her mother, Jean Smith, suffers from Charcot-Marie-Tooth disease, a degenerative neurological condition. The disease, which is a form of muscular dystrophy, causes progressive loss of strength in her extremities. Because of their own impairments, neither of Carol's parents is able to lift or push heavy objects.

87. As Carol grew to maturity, her parents' physical ability to lift, push or turn her declined, to the point where they could no longer meet her care needs without assistance. A Guldman lift was prescribed for her, at an installed cost of $5,325. The Guldman lift is an overhead motorized lifting system which runs along a track installed in the ceiling of the house. The patient sits in a sling and is moved along the track by use of a remote control device. The lift, which can be operated by either of Carol's parents, makes it possible for them to transfer her between her wheelchair and the bed, shower or toilet.

88. In March, 1997, the plaintiff's parents filed a request with Blue Cross to cover the purchase and installation of a Guldman lift as a home health service. The company which supplies the lift was so moved by the urgency of the family's plight, that it installed the lift while the request for TennCare coverage was still pending. With the aid of the lift, plus daily home health aide services covered by Medicare, Mr. and Ms. Smith have been able to continue caring for Carol in the home.

89. Blue Cross denied TennCare coverage of the Guldman lift. The MCO conceded the need for a lift, but contended that a hydraulic wheeled seat, known as a Hoyer lift, which cost $1,124, would suffice. However, Mr. and Ms. Smith had already tried to use a Hoyer lift, without success. The cheaper lift required them to push their daughter's weight across the floor, something which they were physically incapable of doing.

90. Carol's parents appealed the denial. The case then proceeded to an administrative hearing, which was conducted by phone on March 9, 1998. During the administrative hearing, in the face of compelling evidence of the medical necessity of the Guldman lift, the TennCare Bureau changed tack. Consistent with its new agreement with Blue Cross, TennCare argued for Carol's institutionalization, as a basis for denying medically necessary home health services. Dr.

Lewis Moore, Associate Medical Director of TennCare, testified that the prescribed home health equipment need not be provided, because the plaintiff qualified for nursing home placement.

91. On June 22, 1998, the administrative law judge ruled that the Guldman lift is a medically necessary home health service which is covered under state regulations which implement the TennCare waiver:

> Carol's medical condition would seriously deteriorate without the Guldman lift. The lift is necessary for Carol to perform very basic physical functions. The effects on her medical condition should this necessary assistance be denied are apparent. Carol herself, her treating physician and her parents have all testified that placing Carol in a residential nursing facility, away from her parents and home, would have a negative effect on her physical and emotional condition. Changing Carol's placement to an institutional setting in order to provide transfer assistance around the clock without the mechanical hoist would be a far more expensive option and one which was detrimental to her medical condition.

92. On June 26, 1998, Blue Cross sent Ms. Smith a letter assuring her that, "THP/Blue Care[sm] listens to your concerns", but still withholding payment for the lift. On July 6, 1998, the administrative decision became final, but Blue Cross has still refused to pay for the lift, and TennCare has acquiesced to the MCO's refusal.

93. At the same time Mr. and Ms. Smith sought TennCare coverage for the Guldman lift, they requested that Carol's TennCare MCO cover home health aide services which had been prescribed for her by her doctor. Those services are required daily to assist Carol with tasks which, even with the assistance of the lift, her parents cannot perform unaided. Blue Cross refused coverage on the grounds that such services were not medically necessary.

94. The plaintiff's parents subsequently obtained Medi*care* coverage for the required home health aide services, which Medicare covered as ancillary to skilled therapy services. However, Carol is no longer receiving physical therapy, and the home health aide services will soon end

unless another source of coverage can be arranged. Without TennCare coverage, Carol and her parents cannot afford her home health care, which costs an estimated $10,140 per year.

95. The current cost of the plaintiff's care to the defendants is $1,080 per year, regardless of the amount of home health equipment and services which she receives. If the defendants continue to acquiesce to Blue Cross' refusal of coverage of such services, thereby compelling her institutionalization, the state's cost will increase by approximately $33,000 per year, for the rest of her life.

Mary Ann Wilson

96. Mary Ann Wilson is a 64 year-old widow. She lives alone in Old Hickory, Tennessee, in a federally subsidized apartment building. Mrs. Wilson worked for many years as a country music artist and performed on the Grand Ole Opry. However, she became disabled as a result of chronic obstructive pulmonary disease (COPD), and has received Social Security disability insurance and Medicare coverage for more than a decade. Mrs. Wilson qualifies for TennCare because she receives SSI and is therefore eligible for Medicaid. She has had TennCare coverage since March 1995, and has been assigned to the Blue Cross MCO throughout her tenure on the program.

97. In addition to severe end stage COPD, Mrs. Wilson suffers from osteoporosis, emphysema and muscular atrophy. One of her legs is paralyzed as a result of an injury she received while living in a nursing home. She is homebound as a result of these medical conditions. Even the most trivial exertion results in extreme shortness of breath, and she requires oxygen 24 hours a day. Mrs. Wilson needs assistance with all activities of daily living. Incontinence places her at great risk of skin breakdown.

98. Mrs. Wilson has received home health services for approximately four years. Her prescribed plan of care provides for approximately one hour and a half of home health care daily, seven days a week. Home health aides help maintain her oxygen concentrator and nebulizer, without which she cannot breathe. They assist her with activities of daily living, check her vital signs, examine her for skin breakdown and help Mrs. Wilson perform range of motion exercises.

99. Medicare covered Mrs. Wilson's home health care until July, 1998. Medicare coverage stopped then, because she no longer received a skilled nursing service, and Medicare's limited home health benefit covers home health aides only as an adjunct to skilled services. Dr. William Harding, Mrs. Wilson's primary care physician, renewed his order for home health care and asked that TennCare provide it. Blue Cross refused to do so. Citing the urgency of her medical need, Dr. Harding asked for expedited review, and the denial was reversed.

100. Soon thereafter, a Blue Cross case manager contacted Mrs. Wilson's home health agency, Willowbrook Home Health. The Blue Cross representative informed the agency that it would have to come up with an alternative plan for Mrs. Wilson, because Blue Cross does not cover home health care for TennCare patients for more than a short period of time. Willowbrook advised Blue Cross that, because of her medical condition, no community alternatives to home health care are available. The Blue Cross case manager said that the MCO cannot indefinitely provide home health care to its TennCare patients. Therefore, the only option, if those services are discontinued, is placement in a nursing home. Mrs. Wilson had the experience of living in nursing homes from 1988 to 1994, and has resolved that she will face death rather than return to a nursing home.

101. On October 27, 1998, Blue Cross sent Mrs. Wilson a letter notifying her that home health services were terminated as of October 23. The stated reason for termination was: "service is not

medically necessary and custodial". Mrs. Wilson appealed the termination and, with the assistance of the Legal Aid Society, managed to get coverage restored pending the appeal.

102. Dr. Harding wrote a letter reaffirming the medical necessity of Mrs. Wilson's continued care, but to no avail. On November 18, 1998, Blue Cross sent Mrs. Wilson a letter affirming the termination. The letter stated,

> "Blue Care[sm] listens to your concerns. Our Medical Director has reviewed your case…The request for home health aide services was denied due to lack of medical necessity. The denial is upheld…

103. Under the terms of its risk agreement with Blue Cross, the cost to the state of the Mrs. Wilson's TennCare coverage is the same -- $1,080 per year -- whether or not she receives home health care. By refusing home health coverage to Mrs. Wilson and requiring her to obtain medically necessary care in a nursing facility, the state will relieve Blue Cross of financial responsibility for her home health care. The state will simultaneously increase the cost to TennCare by a total of approximately $33,000 per year.

Marvin Berry

104. Marvin Berry is 26 years old. He has been quadriplegic since he was 7 years old, as a result of a traumatic spinal cord injury. He has received SSI benefits since childhood on the basis of his disability, and has been covered by Medicaid as a consequence of his SSI eligibility. He has been enrolled in the Blue Cross MCO since TennCare began in January 1994.

105. Mr. Berry requires ongoing assistance with all activities of daily living. He needs help transferring from his wheelchair to and from the bed, toilet and shower. Because of his quadriplegia, he is at risk of skin breakdown, urinary infections, bowel impaction and respiratory infections, and has, in fact, experienced recurrent life-threatening infections.

106. Mr. Berry's doctor has prescribed home health services for him. Mr. Berry previously attended school with assistance from the federal-state Vocational Rehabilitation program, and that program paid for the prescribed home health services while he was enrolled. During that period, home health aides assisted him with activities of daily living and monitored his health status. He still wants to complete his education, but health problems have prevented him from attending school since 1996, and home health care stopped when his education was interrupted.

107. Mr. Berry lived with his mother until September, 1998, but she has been unable for some time to lift him. Without home health care, and because of his mother's limited ability to assist him, Mr. Berry's health deteriorated. On August 13, 1998, he called Blue Cross and spoke to his case manager. He explained his circumstances and asked for help. The Blue Cross representative explained that Blue Cross does not provide home health aide services for TennCare enrollees, and that she therefore could not help him.

108. Mr. Berry's skin breakdown developed into a serious bedsore. In September, he contracted pneumonia and was admitted to the hospital in respiratory distress.

109. Mr. Berry's physician, Dr. David Edwards, ordered home health aide services for him upon his discharge from the hospital. Blue Cross denied the request. A simple piece of home health equipment, a shower chair, was also prescribed, so that Mr. Berry could be bathed. Despite the fact that the chair cost less than $50, and was essential to combat recurrence of skin breakdown and bedsores, Blue Cross refused that request, as well. Blue Cross took the position that Mr. Berry should go into a nursing home. Dr. Edwards wrote to Blue Cross on October 6, stating that nursing home placement would be inappropriate and that it would deprive Mr. Berry of his desire to lead a productive life. Blue Cross was unmoved.

110. Mr. Berry has lived with a couple of young friends since September. He still needs assistance with all activities of daily living, but has no reliable, consistent source of such help. His friends help as they are able to do so, but several days a week he is forced to stay in bed all day because there is no one to help him get up, even to use the toilet. When friends are not around at night to help him use the toilet and get into bed, he has to sit up until the next day, until someone shows up. He is forced to go for a week or more without being bathed. Because of the lack of prescribed home health care, the bedsore which he had when he was last hospitalized in September, 1998, has still not completely healed.

111. In late November, 1998, Dr. Edwards' office tried to persuade a home health agency to visit Mr. Berry, with the goal of further documenting the urgency of his medical need. However, the agency, a large firm with extensive experience trying to obtain coverage for TennCare patients, refused to visit Mr. Berry as soon as they heard that he was not homebound. The agency said that it would be pointless, since, as a practical matter, TennCare will not provide coverage unless the patient is homebound.

112. Mr. Berry's reliance on his friends for daily incontinence care and constant assistance with activities of daily living is straining what fragile social support he now has. It is therefore uncertain how much longer even the current inadequate care arrangements will last. Without medically necessary home health care, Mr. Berry's health remains in jeopardy.

113. Under the terms of its risk agreement with Blue Cross, the cost to the state of Mr. Berry's TennCare coverage is the same -- $3,542.76 per year -- whether or not he receives home health care. By refusing home health coverage and requiring him to obtain medically necessary care in a nursing facility, TennCare will increase its net cost by approximately $33,000 per year.

Christopher Jackson

114. Christopher Jackson, who is six years old, has been enrolled in the Tennessee Medicaid program since his birth. In January, 1994, when TennCare was established, he was enrolled in the Blue Cross MCO. Christopher receives Supplemental Security Income (SSI) based on disability, and therefore automatically meets Medicaid eligibility criteria.

115. Christopher suffers from severe and permanent complications of extreme preterm birth. He has asthma and bronchopulmonary dysplasia, which is the childhood equivalent of adult emphysema. Christopher requires frequent breathing treatments and medication throughout the day. He is blind and has cerebral palsy. Christopher suffers from hydrocephalus; as a result, he has two ventriculoperitoneal shunts that drain the fluid from his brain, and those must be monitored throughout the day. He is incontinent. In addition to these physical disabilities, Christopher is developmentally delayed, and currently has the cognitive ability of an 18 month-old child.

116. Due to Christopher's combination of conditions, long term home health services are medically necessary to prevent pain, avoid a worsening of his impairments, and guard his fragile health. He needs occupational therapy so that he can learn such essential skills as how to feed himself; speech therapy to learn to communicate; and physical therapy to help him walk, and prevent muscle contractures.

117. During his first five years of life, Christopher received 6 – 8 hours each weekday at a pediatric nursery called Kids and Nurses. The staff at Kids and Nurses provided physical therapy, speech therapy, occupational therapy, and skilled nursing care, all pursuant to his physician's order. Under the care of Kids and Nurses, Christopher was trying to walk and eat by himself.

118. Near the end of December, 1997, Christopher's mother, Wanda Jackson, went to Kids and Nurses to drop Christopher off. The staff told her that they had received a letter from Blue Cross saying that Christopher's coverage for nursing services, physical therapy, speech therapy and occupational

therapy was terminated. Blue Cross would no longer pay for his services. Ms. Jackson never got notice from Blue Cross that it was terminating his services. All she could do was take him back home and try to find some substitute for the care he was receiving.

119. Ms. Jackson appealed in December, 1997. On February 13, 1998, the TennCare Appeals Unit overturned the decision to terminate Christopher's services. Blue Cross was directed to reinstate his home health services. However, Christopher has not received any of these services to date. Disregarding the plan of care prescribed by its own gatekeeper physician, Blue Cross insisted that it would only provide care contingent upon new assessments by speech, occupational and physical therapists. Only a physical therapy assessment was ever provided, and the MCO has not provided the therapy which that assessment confirmed as medically necessary. His attorney has repeatedly contacted the TennCare Bureau by phone and letter to request enforcement of the appeal decision, but to no avail.

120. During the school year, Christopher was going to school half of the day. When the summer started and he was out of school, his mother had no choice but to leave him with a babysitter while she was at work. The babysitter had none of the training or skills needed to provide the home health care Christopher needed. After a few weeks of this makeshift arrangement, the babysitter refused to take Christopher anymore. Ms. Jackson was forced to take him with her to her job cleaning hotel rooms. After months without the prescribed therapy, he experienced painful muscle spasms and cried in pain with increasing frequency. When counsel again called the Appeals Unit to try to obtain the needed care for Christopher, the Appeals Unit staff said there was nothing they could do to require the MCO to provide care, because the case had been taken out of their hands.

121. Christopher has not had any therapy since December, and his condition has steadily worsened. His legs are so stiff that his mother cannot put on his braces. In December, he was trying to walk, but is not even trying now. Even though Ms. Jackson tries to do exercises with him, she feels at a loss without

skilled professionals showing her how to respond to her son's critical therapy needs. In December, he was also trying to feed himself, but has since given up such attempts.

122. Blue Cross and TennCare continue to ignore Christopher's need, documented by his physician, for ongoing home health care. Under the policies and practices of the defendants and their contractors, his needs for long term home health services will remain unmet. His health will continue to be imperiled, and the denial of needed therapies will rob him of the opportunity to realize his potential.

123. The cost to the state of Christopher's TennCare coverage is the same -- $3,542.76 per year -- whether or not he receives home health care. By refusing home health coverage to Christopher, TennCare presents his mother with the cruel prospect of continuing to watch her son suffer, and her hopes for him wither. Her equally wrenching alternative is to consign her six-year old to a Level 2 nursing home, at an annual cost to Medicaid of approximately $54,000. Or, TennCare's wrongful denial of care offers Ms. Jackson the equally poignant choice of surrendering Christopher into state custody as a neglected and dependent child, in the hope that the Department of Children's Services (DCS) will be able to give him the services he needs. The average cost to the state of each DCS residential placement is approximately $24,000 per year. The human cost to Christopher and his mother will be incalculable.

V. CLAIMS FOR RELIEF

A. The Medicaid Act

124. The Medicaid Act requires all state programs which receive federal funding under the Act to cover home health services for any individual who is entitled to nursing facility services. 42 U.S.C. §1396a(a)(10)(D). These services must include part-time and intermittent nursing, home health aides, medical supplies and equipment, as needed.42 C.F.R. §§440.70 and 441.1. In addition, Tennessee has elected to cover the same home health services for all other enrollees for whom such services are

medically necessary. 42 U.S.C. §1396d(a)(7). Under the terms of the TennCare waiver and formally promulgated state rules, the defendants represent that they meet those requirements.

125. The actual policy and practice of the defendant Commissioner, as described above, differs sharply from the legally defined parameters of the program. On the one hand, TennCare and the MCOs apply a *de facto* rule that, in order to receive services, a beneficiary has to be medically homebound, a requirement which can only be met by someone who needs assistance with activities of daily living. At the same time, TennCare refuses home health services to assist with activities of daily living, and refuses to provide *any* home health care for more than a brief period. The combined effect of these policies is that the only TennCare beneficiaries who can obtain home health care are the small number who are so seriously ill or injured as to be homebound, but who, despite the seriousness of their condition, only need care for a brief period. For most TennCare beneficiaries, including those with the greatest medical needs, home health services simply do not exist.

126. By arbitrarily denying medically necessary home health care to individuals, including many individuals who qualify for nursing facility services, the state agency which the defendant Commissioner directs has systematically violated, and continues to violate, the rights of the plaintiff class under the following provisions of the Medicaid Act and regulations:

a. 42 U.S.C. §1396a(a)(10)(D) and 42 C.F.R. §440.70, which require the state to provide medically necessary home health services, including home health aide services and equipment, to any beneficiary who is eligible to receive nursing facility services.

b. 42 C.F.R.§440.230(c), which makes it unlawful for a state to "arbitrarily deny or reduce the amount, duration, or scope of such services to an otherwise eligible individual solely because of the diagnosis, type of illness, or condition".

c. 42 C.F.R. 440.230(b), which mandates that home health services, like other covered Medicaid services, be provided in sufficient amount, duration and scope to reasonably achieve their purpose.

127. The Medicaid Act requires the defendant Commissioner to administer the TennCare program "in the best interests of [the program's] recipients". 42 U.S.C. §1396a(a)(19). At the behest of its managed care contractors, the state has adopted policies and procedures which, as described above, are manifestly harmful to TennCare recipients. By administering the TennCare program in the best interests of the managed care organizations, at the expense of the program's intended beneficiaries, the defendant has violated, and continues to violate, the rights of the plaintiffs under 42 U.S.C. §1396a(a)(19).

128. The Medicaid Act, 42 U.S.C. §§1396a(a)(43)(C) and 1396d(r)(5) requires the defendant Commissioner to provide children (defined for purposes of the TennCare program as extending up to the age of 21) any health care, including home health services, to the full extent medically necessary to correct or ameliorate their defects, conditions and physical and mental illnesses. By arbitrarily denying medically necessary home health care to children who require such care on an intensive and/or long term basis, the defendant has violated, and continues to violate, the rights of members of the Children's Subclass under these cited provisions of the Medicaid Act.

A. The Americans with Disabilities Act

129. The Americans with Disabilities Act (A.D.A.) was enacted to help serve "...the Nation's proper goals regarding individuals with disabilities, [which goals] are to assure equality of opportunity , full participation, independent living, and economic self-sufficiency for each individual." 42 U.S.C. § 12101(a)(8). The law defines disabilities, with respect to an individual, to include "a physical or mental impairment that substantially limits one or more of the major life

activities of such individual… such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." 28 C.F.R. §§ 35.104. Title II of the Act applies to public entities, including TDH, and the programs which they operate, including TennCare. 42 U.S.C. §§12131-12134. The defendants have violated, and continue to violate, the rights of members of the Disability Subclass under Title II of the Act, in the following ways.

130. The A.D.A. requires TDH to comply with implementing regulations promulgated by the United States Department of Justice. 42 U.S.C.§§12132 and 12134(a). Those regulations include the requirement that public entities subject to the A.D.A. "... 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). By denying plaintiffs access to covered medical services which can be most appropriately provided in a home or community setting, and by forcing the plaintiffs into nursing homes, where they are segregated with an exclusively disabled population, TDH has violated, and continues to violate, the rights of the plaintiff class under Title II of the Americans with Disabilities Act.

131. Under state rules regulating home health services and nursing facilities, and in actual medical practice, the services provided by home health aides are the same as those provided in nursing facilities by nurse aides. TennCare's provision of home health aide services to people without disabilities, while requiring that people with disabilities obtain the same services from nursing facilities, violates 28 C.F.R. § 35.130 (b)(1)(iv) and (2). Those regulations prohibit a public entity from denying a qualified individual with a disability the opportunity to participate in services that are not separate or different from those afforded the non-disabled population.

Unlawful Methods of Administration

132. The A.D.A.'s implementing regulations prohibit, not just explicit discrimination on the basis of disability, but also methods of administration or contractual arrangements which, though neutral on their face, are discriminatory in their effect. 28 C.F.R. § 35.130 (b)(3) provides:

> A public entity may not, directly or through contractual or other arrangements, utilize criteria or methods of administration:
>
> (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability;
>
> (ii) That have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities; or
>
> (iii) That perpetuate the discrimination of another public entity if both public entities are subject to common administrative control or are agencies of the same State.

133. The TennCare program employs the following methods of administration and/or contractual arrangements which, in their collective effect, discriminate on the basis of disability:

a. Execution of risk agreements which provide MCOs strong financial incentives to deny medically necessary care;

b. Establishment, through the TennCare risk agreement, of an incentive for MCOs to shun the care of costly beneficiaries with disabilities or handicapping conditions;

c. The contractual carve-out of nursing facility services from the TennCare benefits package, thereby creating an opportunity for TennCare MCOs to shift costs by denying necessary care to patients with disabilities or handicapping conditions, thus necessitating their nursing home placement; and

d. A policy and practice of aiding, legitimating and enforcing MCO actions, when the MCOs, in response to the foregoing incentives and opportunities created by the risk

agreement, improperly deny medically necessary care to people with disabilities or handicapping conditions, and force them into nursing homes.

VI. REQUEST FOR RELIEF

Plaintiffs respectfully request that this court:

1. Assert jurisdiction over this action.
2. Order that plaintiffs may maintain this action as a class action pursuant to Rule 23, Federal Rules of Civil Procedure, on behalf of the class and subclass defined above.
3. Grant declaratory relief, pursuant to Rule 57, Federal Rules of Civil Procedure, declaring unlawful defendants' policy and practice of denying plaintiffs the health services to which they are entitled by law in the most integrated setting appropriate to their needs.
4. Issue injunctive relief prohibiting the defendants from violating the rights of the plaintiff class as complained of herein, and requiring them to take such actions as are necessary to remedy their past violations. Remedial action should include notice to class members of their right to individual relief, including notice to all Medicaid nursing home residents of their potential eligibility for home health care as an alternative to institutionalization.
5. Award the plaintiffs such other and further relief as is just and proper, including reasonable attorneys fees and costs, as authorized by 42 U.S.C. §§1988 and 12205.

DATED this _____ day of December, 1998.

Respectfully submitted,

____

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