

CLASS ACTION COMPLAINT

I. PRELIMINARY STATEMENT

1. This is a Civil Rights class action against Tennessee state officials. The case is brought on behalf of the more than half million children throughout Tennessee who depend on TennCare for essential medical and mental health services. They seek injunctive relief, and the appointment of a Special Master, to remedy systemic violations of federal and state laws which result in the widespread denial of essential diagnostic and treatment services. The unlawful

deprivation of medically necessary care results in the needless infliction of pain, the endangerment of young lives, and the stunting of children's chances to achieve their full potential.

- 2. Specifically, this action seeks to enjoin state officials from:
- a. Depriving children of early and periodic screening, diagnosis and treatment (EPSDT) services in violation of Title XIX of the Social Security Act, 42 U.S.C. §§1396 *et seq*. (hereinafter referred to as the "Medicaid Act"), the terms and conditions of Tennessee's Medicaid managed care demonstration project called "TennCare," and the terms and conditions of risk agreements between the State of Tennessee d/b/a TennCare and managed care organizations (MCOs) and behavioral health organizations (BHOs);
- b. Depriving TennCare eligible children who are in state custody, or who are at risk of entering state custody, of needed health and mental services, in violation of the Medicaid Act; Title IV of the Social Security Act, 42 U.S.C. §§620-629a and 670-679, also known as the Adoption Assistance and Child Welfare Act (hereafter the "Adoption Assistance Act"); and the Due Process Clause of the United States Constitution.

II. JURISDICTION AND VENUE

- 3. 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;
- b. 28 U.S.C. §1343(a)(3) and (4), which provides for original jurisdiction of this court to hear all claims asserted under 42 U.S.C. §1983 to redress deprivation under color of state law of any rights, privileges and immunities guaranteed by the Constitution of the United States or the acts of Congress; and,
- c. 28 U.S.C. §1367(a), which provides for supplemental jurisdiction concerning claims arising under state law.
 - 4. Venue is proper pursuant to 28 U.S.C. §1391(b).
 - 5. Plaintiffs' request for declaratory and injunctive relief, and for other appropriate

equitable relief, is authorized by 28 U.S.C. §§2201 and 2202(1988), 42 U.S.C. §1983, and Fed. R. Civ. P. 57 and 65.

III. PARTIES

A. Plaintiffs

- 6. John B. is ten years old. He has cerebral palsy. He has been in state custody for eight years. He resides in a foster home in Castilian Springs, Tennessee. John B. is eligible for TennCare. John appears in this action by his next friend, L.A., his foster mother.
- 7. Carrie G. is eleven years old. She has cerebral palsy. She has been in state custody since she was seven weeks old. She resides in a foster home in Castilian Springs, Tennessee. Carrie G. is eligible for TennCare. She appears in this action by her next friend and foster mother, L.A.
- 8. Joshua M. is four years old. He has cerebral palsy. He has been in state custody for his entire life. He resides in a foster home in Castilian Springs, Tennessee. Joshua M. is eligible for TennCare. Joshua appears in this action by his next friend and foster mother, L.A.
- 9. Meagan A. is ten years old. She has cerebral palsy. She spent many years in state custody. She now resides with her adoptive family in Castilian Springs, Tennessee. Meagan A. is eligible for TennCare. Meagan appears in this action by her next friend and mother, L.A.
- 10. Erica A. is eight years old. She has cerebral palsy. She spent many years in state custody. She now resides with her adoptive family in Castilian Springs, Tennessee. Erica A. is eligible for TennCare. Erica appears in this action by her next friend and mother, L.A.
- 11. Dustin P. is a eleven year old boy who is severely emotionally disturbed. He currently resides in a state institution and is in the custody of the state. He appears in this action by his next friend and grandmother, Linda C.
- 12. Bayli S. is eleven years old. She has severe physical and cognitive disabilities. Bayli lives with her family in Leoma, Tennessee, and is eligible for TennCare. She appears in this action by her next friend and mother, C.W.

- 13. James D. is twelve years old. He is mentally ill and mildly mentally retarded. He came into state custody when he was nine years old due to extreme neglect and physical abuse with likely sexual abuse. He remains in state custody and resides in a foster home in Nashville, Tennessee. James D. is eligible for TennCare. James appears in this action by his next friend, Susan H., his former teacher and current foster mother.
- 14. Elsie H. is eleven years old. She is mentally ill. She has been in state custody most of her life. She currently resides in a psychiatric hospital in Chattanooga, Tennessee. Elsie H. is eligible for TennCare. Elsie appears in this action by her next friend, Stacy Miller, who serves as her guardian *ad litem* in Juvenile Court.
- 15. Julian C. is a four year old boy who, as a result of serious congenital illness and a stroke suffered in infancy, is developmentally delayed and unable to walk. Julian C. is eligible for TennCare. He lives in Nashville, Tennessee, with his mother, Shawn C., who brings this action as his next friend.
- 16. Troy D. is eleven years old. He is seriously emotionally disturbed. He lives with his mother and two stepbrothers in Kingston, Tennessee, and is eligible for TennCare. Troy appears in this action by his next friend and mother, T.W.
- 17. Ray M. is nineteen years old. He is hearing impaired. He lives with his family in Lafayette, Tennessee. Ray M. is eligible for TennCare. He appears in this action by his next friend and grandmother, P.D.
- 18. Roscoe W. is nine years old. He is hearing impaired. He lives with his family in Jamestown, Tennessee. Roscoe W. is eligible for TennCare. Roscoe appears in this action by his next friend and mother, B.W.
- 19. William B. is a six year-old boy who is a seriously emotionally disturbed child. He is also moderately retarded and autistic. William B. is eligible for TennCare. William appears in this action by his next friend and mother, K.B.
 - 20. Jacob R. is a eleven year old TennCare-eligible boy with cerebral palsy, mental

retardation and epilepsy. He lives with his family in Antioch, Tennessee. He brings this action through his mother, Kim R., acting on his behalf as next friend.

- Justin S. is a nine year old boy who is severely emotionally disturbed. He currently resides with his mother in Memphis. Justin appears in this action by his next friend and mother, D. P.
- 22. Estel W. is fifteen years old. He is an insulin dependent diabetic. He lives with his mother in Oneida, Tennessee, and was formerly a Medicaid Spend Down eligible whose eligibility ended and who is seeking reinstatement. Estel appears in this action by his next friend and mother, E.D.

B. <u>Defendants</u>

- 23. Nancy Menke is the Commissioner of the Tennessee Department of Health (TDH). TDH is designated as the single state agency responsible for the administration and supervision of Tennessee's Medicaid Program under the Medicaid Act. In January 1997, by Executive Order of Tennessee's Governor, TDH reassumed all functions related to the administration and supervision of Tennessee's Medicaid Demonstration Project Number 11-W-00002/4, called "TennCare."
- 24. Theresa Clarke is the Assistant Commissioner for the Bureau of TennCare (Bureau). She supervises the day-to-day operations of the Medicaid program and TennCare.
- 25. George Hattaway is the Commissioner of the Tennessee Department of Children's Services (DCS). He is responsible for the care of children in state custody and the provision of certain health services to those children at risk of entering state custody.
- 26. At all times relevant to these proceedings, defendants have acted, and continue to act, under color, custom and usage of state law.

C. <u>Plaintiff Class - Definition</u>

27. Plaintiffs seek declaratory and injunctive relief in this action pursuant to Fed. R. Civ. P. 23(a) and (b)(2) on behalf of present and future TennCare beneficiaries who are under the age of 21 years (hereinafter referred to as "TennCare children"). This class includes a subclass

referred hereafter as the State Custody Subclass. - TennCare children who are or will be in the custody of the State of Tennessee, or who are or will be at risk of entering the custody of the State of Tennessee.

D. <u>Numerosity</u>

- About one-third of all persons residing in Tennessee who are under 21 years old are TennCare beneficiaries. According to the 1994 Current Population Survey, Tennessee's population under 21 years of age totaled 1,509,356. Of that number, approximately 500,000 are currently enrolled in TennCare, according to state figures.
- 29. The Tennessee Commission on Children and Youth (TCCY) reports that approximately 12,000 children were in state custody in the fiscal year 1997, an increase of nearly 500 children from 1996. Over ninety percent of these children are enrolled in TennCare, and hence are members of the State Custody Subclass.
- 30. The requirements of Fed. R. Civ. P. 23(a) are met in that the class and subclass are so numerous that joining all members is impractical.

E. <u>Common Issues of Law and Fact</u>

- 31. 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 defendants for provision of critical EPSDT and services necessary to address children's health needs. Plaintiffs are subject to systemic deficiencies in TennCare, which impair access to such services.
 - 32. Questions of fact common to the entire class or subclass include, whether:
- a. Defendants fail to ensure that the families of children enrolled in TennCare are adequately informed of their children's right to receive EPSDT services, or how they might obtain such services;
- b. Defendants fail to provide, or require MCOs and BHOs to provide, appropriate screening and diagnosis services for TennCare children, including, but not limited to,

medical, vision, hearing, dental, mental health and developmental screening at appropriate intervals that meet reasonable standards of medical practice;

- c. Defendants fail to provide, or require MCOs and BHOs to provide, treatment to alleviate or treat conditions consistent with the broad definition of medically necessary care in the Medicaid Act;
- d. Defendants fail or refuse to develop and implement a coordinated system of care that provides for the mental health and developmental needs of class members;
- e. Defendants fail to provide an adequate array of mental health or developmental services, including residential and nonresidential treatment;
- f. Defendants fail to provide or require MCOs and BHOs to provide nonresidential mental health or developmental services or to provide such services on a timely basis;
- g. Defendants fail to identify the mental health and developmental needs of children by allowing unlawful limitations and restrictions on screening and diagnostic services;
- h. Defendants fail to inform responsible parties of the right to EPSDT services when a child enters the foster care system and fails to provide information needed to access these services;
- i. Defendants fail to provide foster children who have mental disabilities with timely placements and services appropriate to their particular needs;
- j. Defendants fail to provide foster children with legally required health services necessary to prevent them from deteriorating physically and psychologically while in state custody;
- k. Defendants fail to develop and implement on a timely basis individual care plans for short and long term treatment for children in its custody; and
- l. Defendants fail to monitor individual case plans as they affect treatment and adjust them to meet the needs of the class members.

- 33. Questions of law common to the entire class or subclass include whether:
- a. Defendants' acts and omissions deprive plaintiffs of EPSDT services in violation of the Medicaid Act, 42 U.S.C. §§1396a, 1396d(a) and (r) and regulations promulgated pursuant thereto.
- b. Defendants' acts or omissions deprive members of the State Custody

 Subclass of services necessary to address children's health needs, in violation of the Adoption

 Assistance Act and the Due Process Clause of the Fourteenth Amendment to the Constitution

F. Adequate Representation of Class

34. The named plaintiffs will fairly and adequately protect the interests of the class. They are represented by attorneys employed by the Tennessee Justice Center, the Bazelon Mental Health Law Center, the National Health Law Program, and the Southern Poverty Law Center, all of which are non-profit, charitable organizations. Counsel have experience in complex class action litigation involving health care and civil rights law. Counsel have the resources, expertise and experience to prosecute this action. Counsel knows of no conflict among members of the class or subclass.

G. Appropriateness of Declaratory and Injunctive Relief

35. Defendants have failed or refused to act on grounds generally applicable to the class, making declaratory and injunctive relief with respect to the class as a whole appropriate and necessary, as more fully set forth in Section V, infra. The nature of the violations complained of here is such that, absent broad systemic relief for all TennCare children, it is impossible to adequately protect the rights of any single plaintiff.

IV. FACTUAL ALLEGATIONS

A. Overview of the Programs and Services at Issue

Medicaid/TennCare -

36. 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.

- 37. Tennessee has participated in Medicaid since shortly after the program's inception in the 1960s. Until 1994, the program operated much like a commercial fee-for-service insurance plan, paying claims submitted directly to the state by health care providers who served eligible individuals. In 1993, Tennessee obtained from the Secretary of Health and Human Services a five year waiver under Section 1115 of the Social Security Act, 42 U.S.C. §1315, to permit the state to replace its conventional Medicaid program with a demonstration program called TennCare. The new program was implemented in January, 1994. The state has applied for a three year extension of the waiver, pursuant to 42 USC § 1396n.
- 38. TennCare has two major features which distinguish it from standard Medicaid programs. First, each TennCare beneficiary is assigned to one of 11 managed care organizations (MCO). The MCO is paid a fixed amount per beneficiary, referred to as a capitation payment, to provide covered medical services as medically necessary. (Nursing facilities and other long term care services are still reimbursed directly by the state.) The MCO is at financial risk, meaning that it must absorb any losses which result if it cannot keep its beneficiaries' medical costs within the total amount of TennCare capitation revenues. Conversely, to the extent that the managed care company reduces costs below the level of its TennCare receipts, it gets to keep the difference (within certain limits) as profit. The MCO is responsible for affirmatively managing the care of its enrollees. The MCOs have assigned each of their enrollees to primary care providers (PCP) who act as "gatekeepers" and control their access to specialists or other medical care.

- 39. The other major change effected by the conversion to TennCare was a significant expansion in eligibility. The TennCare waiver allows Tennessee to cover, in addition to those who are eligible under federal Medicaid rules, state residents who lack access to group health insurance. The waiver also authorizes coverage for those who are deemed commercially "uninsurable" because they have preexisting health conditions which make commercial insurers unwilling to sell them coverage. These so-called "waiver eligibles" receive the same medical benefits as those who are Medicaid eligible. If they have incomes below the federal poverty level, their coverage is free. Otherwise, they pay premiums, co-payments and deductibles on a sliding scale adjusted for ability to pay. Currently, a total of more than 1.2 million Tennesseans, approximately half of whom are under the age of 21, are enrolled in TennCare. The program's total budget is more than \$3.5 billion, of which the federal government provides approximately two thirds.
- 40. Since 1967, the Medicaid Act has included a mandate that states provide to all children covered by their Medicaid programs early and periodic screening, diagnosis and treatment (EPSDT) services. In 1989, the law was expanded to require that the states provide to each covered child any recognized medical service which he needs, regardless of whether the needed service is otherwise covered by the state. EPSDT thus stands as a broad directive that states which accept federal Medicaid subsidies must actively screen eligible children for medical conditions on an ongoing basis, and must provide comprehensive health services to treat any conditions detected. The TennCare Partners Program -
- 41. In July, 1996, Tennessee implemented a major amendment to the TennCare waiver. The federally approved revision established within TennCare a new managed care program for behavioral health services, i.e., services for the treatment of mental illness and chemical addiction. The new initiative is known as the TennCare Partners Program. The program folded into the TennCare budget almost all state and federal block grant funding for behavioral health services in Tennessee. These funds, combined with TennCare's existing budget for behavioral health services, were disbursed to a new set of behavioral health organizations (BHO). TennCare's

managed care organizations ceased to have any responsibility for behavioral health care, and the BHOs assumed responsibility for providing such services to TennCare's entire enrollment.

- 42. The Partners Program designates as a priority population for service approximately 6,000 TennCare children who are deemed to be severely emotionally disturbed (SED). The program originally paid BHOs a single capitation rate for all TennCare children, regardless of whether they were members of the priority population classified as SED. When the Partners Program began, information distributed to beneficiaries and the public indicated that the scope of the benefits package available to each child turned on the SED designation. According to such information, non-SED children were only entitled to in-patient psychiatric hospitalization and a limited number of outpatient mental health visits. SED children, on the other hand, were eligible for an "enhanced benefits package" of mental health services as needed.
- Assessment Functioning" (GAF) test. GAF scores fluctuate with treatment. Scoring above fifty means that a child does not fall into the SED population, and therefore is not entitled to the "enhanced benefits" although such services may be necessary to correct or ameliorate that child's illness and condition. The definition for SED excluded 55% of the children served by Tennessee Department Mental Health Mental Retardation (DMHMR) prior to implementation of the Partners Program. Because BHOs received no more money for serving SED children, but were required to provide them with enhanced services, there were strong incentives for the BHOs and their contractors to delay the GAF testing required for a child to receive the SED designation.
- 44. The waiver amendment approved by the Health Care Financing Administration, and the contracts signed by the BHOs, contained stock language that the behavioral health plans were to provide children all services required by the federal EPSDT mandate. But such assurances were inconsistent with the program's emphasis, in communications with BHOs and the public, on children's classification as SED or non-SED. In practice, the BHOs and providers have treated the designation as determinative of a child's access to services. As a result, many medically necessary

behavioral health services have been unavailable to children who did not meet the GAF score criteria for SED designation.

45. In mid-1997, after HCFA had criticized the Partners Program's failure to adequately serve SED children, TennCare restructured the capitation payments for BHOs, so that SED enrollees now earn the BHOs markedly higher capitation payments than do non-SED children. This reimbursement differential has reinforced the BHOs' perception that they need not provide the full array of mental health services which a severely disturbed child needs, unless the child has the required GAF score. For example, as recently as December 17, 1997, the Clinical Director for Premier Behavioral Health (Premier), the larger of the two TennCare BHOs, testified that only children whose GAF scores qualify them as SED have access to those medically necessary services which are covered as part of the "enhanced benefits package"; this individual directs the Premier personnel who manage care for TennCare children.

EPSDT Services for Children in State Custody -

- 46. There are about 12,000 children in state custody at any given time. These include children who have been abused, are dependent and neglected, are orphaned or who have been voluntarily placed by their parents in custody because the parents believe that they cannot meet the children's needs. Only a small percentage of the children in custody are not covered by TennCare due to their confinement in correctional facilities for delinquent youth, or for other technical reasons.
- 47. In July, 1996, coincident with the implementation of the Partners Program, Tennessee created the Department of Children's Services as the agency responsible for all children committed to state custody. This department was established in order to consolidate a variety of services and programs which had previously been divided among several different agencies.
- 48. TennCare allocates to DCS \$129 million earmarked for EPSDT services for children who are in state custody, or at risk of coming into custody. Taking advantage of the broad EPSDT definition of covered services in order to obtain federal Medicaid funding, DCS purports to use this allocation to pay for a range of "therapeutic interventions" which complement the health and

behavioral health services covered by the managed care plans. The TennCare allocation, two thirds of which is drawn from federal Medicaid appropriations, represents the largest single source of revenues in the new department's budget. DCS administers the EPSDT funds outside of the TennCare MCO/BHO care delivery system. The department also purports to coordinates those therapeutic services with the various educational, social and custodial services needed by children entrusted to its care.

- 49. TennCare's MCOs are supposed to meet these children's medical/surgical needs. At the same time, DCS shares responsibility with the TennCare BHOs for the funding and management of behavioral health services for children in custody. The effective sharing of these duties is important, because over half of all children in state custody have a mental health diagnosis, and nearly a third are SED. In fact, slightly over half of all SED children in Tennessee are in state custody.
- 50. The responsibilities of DCS and the BHOs are divided along the boundary separating SED and non-SED children. The BHOs must provide the basic benefits package to all children in custody, whether SED or not. But the behavioral health plans' obligation to provide enhanced services for severely disturbed children ends when those children enter state custody, at which point the enhanced benefits become the responsibility of DCS.
- 51. This design feature of the Partners Program creates a strong inducement for a BHO to steer children into custody. The bifurcation of responsibility also leads the BHOs to take a cribbed view of their obligations to children in custody. The result has been that the plans' approach to case management has consisted primarily of pressing for prompt discharge from psychiatric hospital, with little attention to aftercare services, which they see as the responsibility of the custodial agency. There has been little coordination between DCS and the behavioral health care plans. For months following establishment of the Partners Program and the new Department of Children's Services, written protocols were lacking which would clearly delineate responsibilities and make possible the coordination of care between the BHOs and DCS.

Related Health Services for Children in State Custody -

- 52. Independently of its participation in Medicaid, Tennessee accepts federal funds under the Adoption Assistance Act. Attached to receipt of those funds are a number of federal statutory conditions relating to the state's administration of services for children in custody, or at risk of coming into custody. Most of those conditions are not at issue in this case; they govern the provision of social and custodial services to such children, or are designed to achieve permanent placements for them.
- 53. At issue in these proceedings is the Adoption Assistance Act's requirement of provision of necessary health services for children in custody, or at risk of coming into state custody. The Act also requires that health services for a child in custody, or at risk of entering custody, be coordinated with the other educational, social and custodial services which the child needs.

B. <u>Injury to the Named Plaintiffs</u>

The A. Family

- The A.s are a family who live in rural Sumner County, Tennessee. Ms. A is a registered nurse, and Mr. A is a respiratory therapist. They have almost thirty years experience apiece in their respective professions. They have adopted two children with cerebral palsy, Meagan A. and Erica A., and provided foster care for four other children with severe cerebral palsy, Joe E., Joshua M., John B. and Carrie G. All of the children needed wheelchair repairs or replacements, but systemic barriers to care for children on TennCare or in state custody delayed their receipt of such equipment, in some instances for more than two years. Throughout that period, Mr. and Ms. A. phoned the children's TennCare MCO at least once a month, and the MCO's supplier of durable medical equipment (ME) at least every two weeks.
- 55. They called every one they knew to call to get their children what they needed, including the TennCare Consumer Advocacy Line, the Tennessee Attorney General's office, a television station, and an attorney. At one point they used social connections to bring their children's plight to the personal attention of the defendant Commissioner of Children's Services. Nothing

worked. In October, 1996, an investigative reporter on consumer issues did a story on their case that aired on the television nightly news, and their attorney contacted the state's counsel. It was only after those interventions that some of the needed adaptations were made. Only in the last few months have these children's longstanding medical needs been met.

- 56. It is a testament to the defendants' refusal or inability to comply with the laws cited herein that parents with the professional health backgrounds, persistence and social connections of Mr. and Ms. A. could not access prescribed medical services which their children indisputably needed. Their children's suffering occurred in spite of the state's awareness of their problems, and the fact that, since the children involved were in state custody or were receiving adoption assistance, both TennCare and DCS had independent responsibilities to assure delivery of the needed care.
- 57. One of the children for whom Mr. and Ms. A. waged their struggle was their foster son, Joe E. Joe was six years old at the time of his death on February 9, 1997. He was blind, with hydrocephalus and cerebral palsy. He could not walk or talk and required suctioning and breathing treatments frequently. He lived with his foster parents from shortly after his first birthday until his death.
- July of 1995. The wheelchair was so unstable it actually tipped over when Joe got into it. It took half a year of efforts by Mr. and Ms. A just to get the ME provider to measure him for the proper adaptations on the chair. After that, it was another two months of calling to get the supplier to come back to make the actual modifications, whereupon they took the chair away for another two months. When the chair was returned the seat was only attached with Velcro. The seat belt was strapped to the frame of the chair. If the seat slid forward, Joe would suffer internal injury as a result of the insecurity of the seat and the positioning of the belt. The foot plate was improperly positioned so his feet could be trapped and badly bruised.
- 59. For the better part of two years, Joe was forced to spend the entire school day in his car seat. Joe had scoliosis, and the car seat, which was not designed to replace a wheelchair for long

term use, lacked the proper support for his back. As a result, he was in great discomfort for much of the day. On October 31, 1996, his leg was broken on the bus ride home, due to the lack of a properly adapted wheelchair. It was only after that injury, and following the television news report exposing the MCO's neglect, that Joe's MCO finally provided him a wheelchair with appropriate adaptations.

John B.

- 60. John B. is a ten year old with severe cerebral palsy, blindness, arthritis, two dislocated hips, kyphosis and a severe seizure disorder. He cannot walk or talk and must be given liquids through a feeding tube. He weighs about sixty pounds. He has been in foster care since he was eighteen months old.
- discussion at that time of replacing the chair because it was so unsteady that he could not ride on the school bus safely. However, it took another year of persistent calls just to obtain adaptations to the existing chair. The supplier finally acknowledged that, even with the adaptations, the chair was so unstable that it was not safe. Nonetheless, it took three more months to obtain TennCare approval of a replacement. He was forced to rely on his old unsafe wheelchair until July, 1997.

Carrie G.

- 62. Carrie G. is a eleven year old girl with severe cerebral palsy. She has been in foster care since her father beat her into a coma when she was seven weeks old. She was placed with Mr. and Ms. A. in September of 1993.
- 63. Carrie was measured for a wheelchair in October 1995. The chair was delivered in April of 1996. However, several critical adaptations needed to be made. For example, the back of her chair needed to be fixed to compensate for her scoliosis.
- 64. Despite the fact that no one disputed her needs, none of the required adjustments were made until October 18, 1996. Those changes still left major modifications to be done, but they have never been fully completed. Carrie is still waiting for her chair to meet all of her needs.

Joshua M.

65. Joshua M. is a three year old boy with severe cerebral palsy. He has been with the A.s since he was three weeks old. Joshua's doctor ordered a wheelchair for him in May 1996. The ME supplier took his measurements and promised to deliver the chair to Joshua in time for the start of school in August. But the wheelchair never arrived, forcing Joshua to spend his school days in a car seat. Joshua also has scoliosis so that sitting in a car seat all day denied him the support necessary to keep his back straight. His disabilities made it impossible for him to change positions so that he could relieve his discomfort and pain. Joshua finally received the wheelchair in October, 1996, after the interventions described in paragraphs 100-101, above.

<u>Meagan A.</u>

66. Meagan A. is a ten year old girl with moderately severe cerebral palsy. She is in regular fourth grade at her local elementary school. She cannot walk, but is outgoing and bright. She needed a new wheelchair and was measured for one in July, 1994. Delivery was promised by September, but did not occur until more than a year later, on December 22, 1995. However, it was missing several adaptations which were critical to her safety. There was not enough support to keep her upright and she lacked ability to hold herself up. Meagan was humiliated at school when the inadequacies of her chair meant she would fall over in front of her classmates. The ME provider and MCO were notified of the safety hazards immediately after the chair's delivery, but refused to make the necessary adaptations until October, 1996, after the interventions described in paragraphs 100-101, above.

Erica A.

- 67. Erica A. is an eight year old girl with severe cerebral palsy. She cannot walk or talk, is nourished through a feeding tube and suffers from a seizure disorder. Erica was first placed with her parents when she was five months old. Erica had been a "boarder baby" at the public hospital in Nashville, where she was abandoned by her mother, who was addicted to cocaine. Mr. and Ms. A have since adopted Erica.
 - 68. Erica needed a new wheelchair and was measured on October 26, 1995. The chair was

not delivered until April 22, 1996, and, even then, it lacked the adaptations necessary to keep her safe and comfortable. There was no support to keep her upright, and the shoulder straps continuously cut into the side of her neck. Because the chair did not properly fit Erica, she almost choked herself when her head got hung in the headrest during the period when she was waiting for the proper adaptations. It was not until after the October, 1996, television news report on the family's plight that the needed modifications were made.

Dustin P.

- 69. Dustin P. is an eleven year old boy who is severely emotionally disturbed. He has a little brother who is nine and a little sister who is seven. His brother suffers from mental illness and leukemia. His sister suffers from achondroplasia (dwarfism). Dustin began living with his grandparents when he was eight years old. Dustin's life before then was chaotic, and he is believed to have been severely sexually abused.
- 70. Dustin was first admitted to a psychiatric hospital when he was eight. Though only a small child, he displayed repeated, chillingly violent aggression, including sexual aggression, against his siblings.
- 71. Beginning in April, 1996, the clinicians who worked with Dustin consistently recommended the same treatment: residential care. When Dustin was first referred for such treatment, his grandmother, Linda C., contacted a residential treatment facility, Youth Villages, which participated in the provider network of Dustin's TennCare MCO. Facility staff explained to her that there was a quota on the number of TennCare children whom they could serve. They informed her that, despite the urgency of his need, Dustin would have to go onto a waiting list, and only when his name approached the top of the list would Youth Villages start the process to see if TennCare would pay for the services.
- 72. In September 1996, after waiting vainly for five months to receive residential treatment as prescribed, Dustin again became a danger to himself and his siblings and was readmitted to a psychiatric hospital on an emergency basis. By this time, responsibility for his TennCare mental

health coverage had shifted from the MCO to a BHO. The BHO, Premier Behavioral Health, agreed to cover only five days of hospitalization. Hospital staff again informed the family that Dustin could not safely return home, and should be discharged to a residential care facility. The hospital staff communicated their finding to the BHO and to a residential care provider, Camelot Care Centers, Inc. The provider instructed the family to drive Dustin directly to their facility in Kingston, TN. The family and hospital staff believed Dustin would be admitted immediately, and he was discharged from the hospital.

- 73. That afternoon Dustin's grandmother drove him nearly 150 miles to Camelot. When they arrived, the Camelot staff informed the family that they had not received permission from Dustin's TennCare BHO to admit him for treatment. They explained that getting approval from TennCare could be a long process. Although she feared for the lives of all three of her grandchildren, Linda C. had no choice but to take Dustin home.
- 74. He stayed in his grandparents home for twenty-four days before Premier decided to deny the residential treatment which had been requested on October 5, 1996. His brother received intensive in-home counseling from Camelot for his severe emotional problems, but Linda C. was told that Dustin could not receive similar services because he was on a wait list for TennCare coverage of other services, and because TennCare will not pay for counseling of this sort for more than one family member. As a result of these policies, Dustin received neither residential care nor counseling services in his own home.
- 75. On November 19, 1996, despite the recommendations of every clinician who had actually treated Dustin, the TennCare Partners Program internal review unit upheld Premier's denial of residential treatment.
- 76. In December, 1996, his suicidal and homicidal behaviors becoming more frequent, Dustin was admitted to another Nashville psychiatric hospital. After a short stay, he was placed in a partial hospitalization program. Later that month, some eight months after residential treatment was first prescribed for him, Dustin finally reached the top of the waiting list at the Youth Villages facility

in Memphis, Tennessee. His mother, apprehensive about sending the ten year old boy so far from his family, hesitated. The slot was lost, and he went back to the bottom of the waiting list. The opportunity had been illusory in any event, for on January 29, 1997, the family received notice that Premier had once again refused coverage for residential treatment.

- 77. Throughout their long, futile battle to obtain residential treatment for him, Dustin's grandparents were told repeatedly by DCS staff, Dustin's clinicians, and others familiar with the TennCare system that the only way for the child to get the mental health care that he needed was for the family to place him in state custody. Concerned about his more severe symptoms and the safety of the other children, and convinced by Premier's latest refusal of care that he would never receive treatment otherwise, the family finally placed Dustin in state custody on January 30, 1997.
- 78. Ironically, that same day, his family finally received approval from the BHO for Dustin's residential placement at Youth Villages. However, since TennCare relieves a BHO of responsibility for such care as soon as a child enters state custody, the BHO's belated approval was moot, and Dustin again missed the opportunity for admission to Youth Villages. Instead, DCS put him in a Nashville facility, called Crockett Academy, which is operated by DMHMR. Crockett Academy is not a residential treatment facility of the type prescribed for Dustin, and he was, in effect, warehoused there. Dustin waited for the DCS bureaucratic process to arrange for his placement at Youth Villages, as recommended nearly a year before. While awaiting that placement, a bed became available at a residential sexual offender program where Dustin would be the youngest child. DCS made the decision, ignoring the only clinician involved with the case, to place Dustin there. His mother's and grandmother's fears were ignored.
- 79. First, Dustin's TennCare MCO, and then his BHO, ignored his individual medical needs and denied him medically necessary service for ten months for bureaucratic and fiscal reasons. DCS then ignored those same individual needs for similar reasons.
- 80. Dustin's family, like many others throughout the state, were forced to choose between retaining custody of their child or obtaining needed treatment. When defendants accept Federal

Medicaid and Adoption Assistance Act funds they promise not to predicate the receipt of these services on any criteria except the child's individual needs.

<u>Bayli S.</u>

- Bayli S., who is eleven years old, has severe scoliosis with contractures of all major joints and limited mobility. She is blind, unable to communicate, and requires constant care to meet all of her needs. Bayli's health has been deteriorating for some time with increasing inability to swallow and handle secretions so that she requires constant observation and suctioning to maintain her airway, sometimes as frequently as every fifteen minutes. She is medically fragile with suppressed immunities so that she has constant upper respiratory and urinary tract infections. She has three to five seizures per day. Unless she is kept well hydrated, her secretion becomes thick and increases congestion. She receives no fluid or food by mouth and is dependant on formula and pureed food, which she ingests through a gastrostomy tube. Feedings must be small and frequent, and must be monitored carefully to prevent aspiration, which could easily prove fatal.
- 82. During this time, Bayli's father worked two jobs in order to support the family and Bayli's mother stayed at home in order to provide her continuous care. Given Bayli's medical fragility and the care she needs, someone had to be listening constantly to make sure that Bayli was safe and not aspirating.
- 83. Bayli's physician prescribed extensive home nursing services for her, which were not only medically necessary, but urgently so. However, her TennCare MCO, HealthNet, refused to provide the services, simply stating that it would not cover more than 28 hours of such care per week, without regard to a child's need. Lacking such care, Bayli had repeated emergency hospitalizations due to life-threatening respiratory distress. When Bayli's mother was in the hospital delivering her third child, the MCO provided a temporary increase in home nursing hours. But it quickly cut the hours back, without notice or an opportunity to be heard, despite the fact that Bayli's medical needs had not changed. It was suggested to Bayli's parents that they place her in a state institution, where the MCO would no longer be responsible for her care.

- 84. The family contacted counsel. Finally, the state responded to legal pressure and, in recognition of the medical necessity of the care which the MCO had refused to provide, started covering the prescribed amount of home nursing care itself. Rather than enforce the MCO's EPSDT obligations, however, state officials are paying directly for the services through a special Medicaid-funded program, known as the Model Waiver. The waiver, which operates outside of TennCare, is available to only a fraction of the children who need care.
- 85. Upon information and belief, there are substantial numbers of other medically fragile TennCare children across the state who, like Bayli, urgently need home nursing care. Because of the defendants' failure to enforce the EPSDT mandate, these children continue to go without such care as Bayli did, at risk to their lives. And Bayli herself continues to be at risk of being denied medically necessary care, based on arbitrary, financially motivated decisions of the MCO, so long as there continues to be systemic noncompliance with EPSDT.
- 86. Bayli's problems obtaining EPSDT-covered services are not, unfortunately, limited to home nursing care, and even apparently stable treatment regimens can quickly fall prey to the whim and caprice of her MCO. The managed care entity to which she had been assigned was recently taken over by another company, Phoenix Health care. On January 22, 1998, Bayli was rushed to Vanderbilt Hospital, 90 miles from her home, with a life-threatening respiratory infection and a fever of 105°. On January 23, 1998, Phoenix refused to cover the second phase of her treatment with special injectable antibiotic prescribed by her physician to combat the infection. The MCO conceded that the drug was appropriate, but invoked an arbitrary corporate policy providing that the drug would only be covered if Bayli - a blind, critically ill little girl -- could self-inject it. When Bayli's mother pointed out that the home health nurse could administer the antibiotic, Phoenix still refused. Mrs. W. received no notice of the reasons for the denial, or of her right to appeal on Bayli's behalf.
- 87. On January 28, 1998, Mrs. W. took a urine sample from Bayli to the hospital in Lawrenceburg, Tennessee, to have a urinalysis and culture ordered by Bayli's physician to diagnose a suspected urinary infection. When Mrs. W. arrived at the hospital, she was informed that the hospital

would not provide the prescribed lab service, because Phoenix had a record of nonpayment. The lab work would only be done if Mrs. W. agreed to pay the bill, which would be approximately \$300, an amount which she does not have. Mrs. W. received no notice of her right to appeal the denial on Bayli's behalf, or to receive the care without regard to her ability to pay.

88. On January 30, 1998, Bayli's medical supplier called Mrs. W. and told her that, effective February 1, the supplier was cutting Bayli's already insufficient quota of incontinence supplies and eliminating altogether the supplies needed to maintain the sterility of Bayli's feeding tube. This change was not based on any apparent consideration of Bayli's medical needs, but on an arbitrary directive from the MCO. There was, of course, no notice of Bayli's right to challenge the denial.

James D.

- 89. James D. is twelve years old. He has been on Tennessee Medicaid/TennCare all of his life. When he was eighteen months old, his mother died from a cocaine overdose. He was left with the body for three days before being found. Thereafter, he was shuffled between relatives until he was about three, when his father, who is addicted to alcohol and cocaine, took custody of him.
- 90. When James was six, the Department of Human Services (DHS) [the predecessor agency of the Department of Children's Services] started receiving reports that James was being seen around his Nashville neighborhood begging for food and was unsupervised for long periods of time. At the same time, neighbors reported that James was frequently locked out of the house, and that he told of being beaten by his father when his father was drunk. Similar reports were made to the state over the next two years. On one occasion, he was whipped across the face with a belt and had beer bottles thrown at him. He continued to go hungry and occasionally homeless. Each time DHS investigated the complaints, it was clear that James had experienced serious trauma and neglect and was at risk of going into state custody. It was also known that he was on Medicaid and therefore should be receiving regular EPSDT screenings. Yet the state failed to arrange a screening to comprehensively assess the child's medical and developmental needs.
 - 91. When James was eight years old, he was placed with his paternal aunt. At that point,

DHS promised the aunt to pay for before and after school care for him, but failed to do so. The aunt relied on James's father to provide such care. While with his aunt, James continued to receive severe beatings. At age nine, a school counselor noted that James exhibited symptoms of being sexually abused. As is common for victims of such abuse, he became sexually aggressive himself, and attempted to sexually abuse one of his classmates. Finally, after finding severe linear bruises on James's back in September 1995, DHS picked James up and took him into their legal custody. James was ten years old at that time. When taken into DHS custody, James sat crying in the back of a police car with his caseworker, and asked if she would find him a mother. Since he had never had one before, he thought that was what he needed.

- 92. The unanimous recommendation in the custodial agency's plan for James was to find him a therapeutic foster family, and one without other children whom he might endanger. A week after placement, James tried to kill himself at school. After a few days of being moved among different temporary foster care homes, James was placed in the M.'s home, where there were five other young children. The foster mother, who was trying to address James's severe needs as well as care for the other children in her home, called after a couple of months to tell DHS that she could not handle him anymore. DHS explained to her that they had no other place to put him, but that they might find her some respite care. DHS never arranged the respite care, and Ms. M. found herself increasingly overwhelmed by the seriousness of James' problems.
- 93. In April of 1996, he was admitted to Vanderbilt Children's Psychiatric Hospital. When he was admitted to the facility, he had threatened to physically harm a little girl next door and had been threatening suicide for several months. James was hearing voices. He was also having visual hallucinations in which he saw a man speaking to him in the middle of the night, telling him to kill other people. After James had been at Vanderbilt for a week, he was discharged with a diagnosis of psychosis, with borderline mental retardation. There was again a consensus that he needed placement in a therapeutic foster care setting without other children.
 - 94. Despite the unanimity of contrary professional opinion, DHS again asked the M.

family if James could return there, but they declined. On April 16, 1996 DCS contracted for placement of James in Cumberland House, a Level IV residential program for children operated by DMHMR. Less than a month after he was placed there, he was reported to have acted out sexually against other children in the facility, yet he received no treatment focused on the effects of the sexual abuse he had himself experienced.

- 95. By early July, James was ready to be discharged from Cumberland House. (The Child Protective functions of the Department of Human Services merged into the Department of Children's Services on July 1, but it had no practical impact on James or his treatment.) His doctor again prescribed therapeutic foster care, but none was available. At that time the state contracted with three different agencies to provide therapeutic foster care for children. Each of them has a waiting list that is so long that James could have literally waited years before being placed. (DCS indicated that as of July 1997, he remained on the waiting list because a home had still not been found for him through these agencies.) From early July until mid-September DCS paid over \$300 a day for James to be warehoused at Cumberland House while their contractor's waiting list for foster care remained full.
- 96. In September, as a result of the involvement of counsel, the Juvenile Court in Nashville ordered DCS to find a home for James. At that point, the agency proposed to place him back in the aunt's home where he had previously been abused. Only the threat of contempt of court against DCS and the compassion of a former schoolteacher of James' averted that placement. His teacher (who had formerly been a therapeutic foster care parent) learned what was about to happen and offered to provide foster care herself. Under pressure from the Juvenile Court, DCS paid for James' therapeutic foster care without making him wait to be placed through one of the agency's three contractors. He started receiving therapeutic foster care two days shy of a full year after such care was first prescribed for him.
- 97. Upon information and belief, the defendants certify to federal Medicaid officials that the TennCare funds allocated to DCS are used to provide EPSDT services to children in the agency's custody, or at risk of entering state custody, in accordance with federal law. In fact, during the five

years since he was first identified as at risk of entering custody, and even while he was in the physical custody of the state, he did not receive the screenings which should have been provided. His severe emotional needs therefore went undetected until after he had injured other children and attempted to kill himself. Then, once therapeutic foster care was unanimously identified as the treatment James' mental health needs required, it was not provided for nearly a year. During that time, James first experienced official neglect, then more than two months of inappropriate institutionalization.

98. As a TennCare child and ward of the Department of Children's Services, James continues to be utterly dependent on the defendants for the medical care required to treat his serious, complex emotional disorders. Like many other children, he remains at risk in a system which rations therapeutic services on the basis of contractual quotas, rather than providing medical care as necessary to meet children's individualized needs.

Elsie H.

- 99. Elsie H. was born February 22, 1986. Her mother is severely mentally ill and Elsie's first years, when she lived in Nashville, were chaotic and abusive. Elsie experienced sexual abuse as a pre-schooler, and had been diagnosed as both mentally ill and mentally retarded by the time she entered first grade. She entered state custody at age 6, as a dependent and neglected child. She became a difficult "case" in a harried social worker's caseload, shuffled by the Department of Human Services among a number of different hospital and residential settings over the ensuing years. Elsie was an extremely unstable little girl, given to destructive and violent outbursts. In reaction to her own sexual victimization, she acted out sexually with other children and adults.
- 100. In 1993, after years of abuse and neglect, Elsie had her first experience of nurturing, unconditional love. She was placed in the Chattanooga home of Mr. and Ms. K., who were trained as therapeutic foster parents. The couple had the support of regular ongoing mental health care for Elsie, and backup from a local 24-hour mental health intervention team to assist during the little girl's frequent psychiatric crises. With this professional psychiatric support, Mr. and Ms. K. devoted themselves to Elsie unstintingly.

- 101. And Elsie responded, dramatically. Over the thirty month period during which she lived with the K family, Elsie blossomed. She was still severely disturbed and emotionally volatile. But in a loving environment, it soon became evident that much of her developmental delay had been a function of her environment, and she began to develop intellectually. She was no longer only the self-hating, enraged and violent little "monster" previously described by one witness. Elsie became a child who was, as the Juvenile Court subsequently found, "bright, sweet... [with] the ability and possibility to [become] stabilized enough to ... live successfully in a family setting".
- 102. Throughout that period, the ongoing intensive psychiatric services essential to Elsie's progress were reimbursed by the state custodial agency, outside of Elsie's TennCare MCO. Funding came from TennCare funds earmarked by Tennessee for meeting the special needs of children in state custody. Those funds were ostensibly budgeted for the purchase of unique medical and behavioral health services. But oversight of their expenditure was ineffective, and little was done to define TennCare MCOs' EPSDT obligations to children in state custody, much less hold the plans accountable for meeting those obligations. As a result, the special pool of TennCare funds was often used to buy for a second time services which had already been purchased once from the MCOs, but which they had not provided.
- 103. For these reasons, financial pressures on the special TennCare fund mounted. The state responded by rationing the children's care, rather than rationalizing the arrangements for their treatment. In October, 1995, the custodial agency came up with a new contract for purchasing the TennCare-funded "therapeutic intervention" services needed by children in its care. The former contractor which served the Chattanooga area was no longer willing to provide Elsie the ongoing psychiatric care she needed, and those services were withdrawn.
- 104. The reduction of mental health care was predictably disastrous. Mr. and Ms. K. were unable to manage Elsie's mental illness without professional psychiatric support, and her mental status deteriorated almost immediately. She became destructive, defected in a neighbor's front yard, and the police were called. Though only a little girl, she attacked the officer with such violence that

she was handcuffed and taken into police custody. From there she was placed in a locked unit of a psychiatric hospital.

- 105. This initial separation from the K.'s was the beginning of a downward spiral. Over a six month period, she required emergency psychiatric hospitalization on three separate occasions. While in the hospital, she was the financial responsibility of the TennCare managed care plan, but primary responsibility shifted to the custodial agency when she left the hospital. Without clear delineation of responsibility, and lacking effective state oversight of the MCOs, these arrangements fairly guaranteed fragmentation of children's care. The TennCare plans and state agencies shoved children back and forth in a constant effort to avoid costs, rather than meet medical needs.
- herself or others resulted in another emergency psychiatric hospitalization. The MCO's focus was on discharging her at the earliest possible date, without regard to her ongoing mental health needs. During each hospitalization, she would be medicated to reduce her most violent behaviors, but not really stabilize her severe mental illness, then discharged back to the K. household. As the Juvenile Court for Davidson County later found, "... From October, 1995 when she was first hospitalized until March, the state failed to provide Elsie with planned, coordinated or adequate treatment for her serious mental health needs..." Her records were replete with recommendations that she receive the comprehensive and consistent mental health services needed to enable her to live with Mr. and Ms. K., for it was evident that they were the center of her life, her one source of love and stability.
- TennCare plan to provide the mental health rehabilitative services needed, nor was it willing to spend for that purpose any of the EPSDT funding set aside for children in state custody. Instead, the custodial agency just kept moving her from one placement to another, and her ties to Mr. and Ms. K. became more and more attenuated. The favorite toys and clothing, brought to her by Ms. K. during a visit, were lost almost immediately when the state moved Elsie yet again. It became more and more difficult for Ms. K. to visit. Finally, in March, the state placed Elsie in a residential treatment program

in Memphis, despite the fact that both state agency staff and the treatment program's administrator warned that the program was unequipped to meet her needs.

- 108. In Memphis, 400 miles from the K. household, Elsie was beyond any possibility of contact with the only people she loved, and who loved her. Her nightmarish hallucinations intensified, and she became fixated on trying to destroy herself or others. The facility locked her in a room and assigned staff to guard her, one-on-one, around the clock. Meanwhile, the program's administrator tried frantically to arrange a transfer to a psychiatric hospital in Chattanooga, so that Elsie could eventually return to her therapeutic foster home. Throughout this grave psychiatric crisis, her TennCare plan provided no mental health services.
- 109. The Juvenile Court for Davidson County, which still had jurisdiction over Elsie, became aware of the crisis and held a series of emergency hearings in late May, 1996. The hearings were attended by representatives from the custodial agency, the state Department of Mental Health and Mental Retardation and the state diagnostic and care planning team annexed to the court. Testimony established the unanimity of professional opinion regarding the severity of Elsie's emotional disorder, her acute need for treatment, and the crucial importance of maintaining and supporting the relationship between Elsie and the K.'s. But none of the various state agencies knew how to implement the agreed upon treatment plan. The officials were unaware of EPSDT, by that name or any other. They had not asked Elsie's TennCare plan to meet her treatment needs, because, they said, they had learned from experience with other children that it would do no good: the plans simply refused to provide care, and the state would not compel them to do otherwise.
- 110. As for using those EPSDT funds which were allocated for the special needs of children in state custody, they could only be used for children with "unique needs". Elsie's needs were not unique, according to the custodial agency. That was why she had been assigned, like most other children in state custody with severe behavioral needs, to one of several state contractors which purported to provide a continuum of care spanning different types of mental illness. As Elsie's experience demonstrated, these contract agencies often amount to "one-size-fits-all" default

placements in lieu of the individually tailored care which children actually need, and which federal and state law prescribe.

- 111. As a result of the Juvenile Court's persistent intervention and the involvement of counsel, Elsie was finally moved to a psychiatric hospital in Chattanooga, where she has been hospitalized on a locked unit since May, 1996, and is receiving regular visits from Ms. K. But Elsie has still not recovered to the point where she was before the withdrawal of the community psychiatric services which had enabled her to function in the K. home, and it is doubtful that she ever will. Ironically, the financially motivated termination of those services proved to be not only cruelly destructive for this little girl, but a false economy, as well. Elsie's hospitalization alone has far exceeded in cost whatever was initially saved by refusing to meet her medical needs. It is unclear when she will ever be well enough to return to the home of those who love her, and whom she so loves.
- of all children in state custody to receive the medical and mental health services which they need. Elsie's neglect did not occur as a result of individual incompetence or indifference. Instead the organization of medical and mental health services for children in custody is so dysfunctional that even competent, well-informed state officials often find themselves unable to obtain medically necessary care for the children in their charge -- even though such care has already been paid for by TennCare.
- order dated May 23, 1996, the Juvenile Court contrasted the unanimity of professional opinion regarding the mental health services which Elsie needed, with the persistent failure of the state to meet those needs. The court summarized her treatment as "neglectful" and "shocking" and ordered the state to provide and pay for the competent psychiatric management of her care, without regard to the "bureaucratic rules and policies" which had confounded previous attempts to meet her need. The custodial agency's response was telling: in a remarkably candid motion to reconsider, the agency

stated flatly that, "The Department has *no* ability to comply with the Court's Order." [emphasis in the original]

Julian C.

- 114. Julian C. is a four year old boy born with a diaphragmatic hernia. As a result of this condition his lungs did not develop properly. During a medical procedure to correct his inability to produce oxygen, Julian suffered a stroke, further limiting his ability to swallow, speak, use his right arm and right leg, and delaying his cognitive development. When he was less than a year old he was diagnosed with a life-threatening heart condition. He cannot walk and eats only a small portion of his meals by mouth, receiving most of his nutrition through a gastrointestinal tube.
- 115. Julian's oxygen level has been unpredictable since birth. During the first year of life, his TennCare MCO refused to provide medially necessary home nursing care prescribed by Julian's doctors. As a result, he was constantly in and out of the hospital because his oxygen level would drop and his mother could not stabilize him. During these frequent spells, sometimes caused by agitation, sometimes caused by nothing at all, Julian would become breathless and clammy, would turn blue and appear to be strangling. It required Julian's participation in other proceedings in this court [see *Daniels v. Wadley*, No. 79-CV-3107, Motion To Modify Second Consent Decree and for Further Relief (R. 323), filed December, 1994] and a state administrative law judge's ruling that the MCO's denial violated Julian's right to EPSDT services, in order to obtain the home nursing services he required. Only then did frequent hospitalizations abate.
- 116. Julian is an extremely happy and personable toddler. He speaks a few words and knows around twenty words in sign language. He seems to understand much more than he can verbalize. His doctors prescribed speech therapy twice a month, occupational therapy four times a month, and physical therapy four times a month in order meet Julian's medical needs and enable him to reach his best possible functional level. He received these TennCare services until shortly after his third birthday.
 - 117. On January 21, 1997, the Nashville school system convened his first multidisciplinary

team (M-Team) meeting to formulate an individual educational plan to address his special education needs. At that time school administrators explained to his mother that the schools are only required under federal and state education laws to provide Julian such occupational and physical therapy services as are minimally needed to enable him to derive "some" educational benefit from school. [This special education standard is, very different from, and much lower than the medical needs standard set by EPSDT, specifically the rehabilitation definition at 42 C.F.R. 440.130(d).] School officials offered Julian two speech therapy visits per month during an initial six week period of educational evaluation, and one session per month thereafter. They offered a physical therapy and occupational therapy evaluation during the first six weeks to determine the exact need for these services.

- 118. Three days later, when Julian was supposed to receive physical therapy, Ms. C. received a call from Julian's therapist informing her that his therapy had been discontinued by the TennCare MCO, effective that day, because Julian would now be receiving services from the school system. Ms. C., who was aware because of her earlier legal struggles to obtain care for Julian that this was illegal, protested the MCO's failure to afford Julian any prior notice or opportunity to appeal the termination of treatment. When she referred to the law, the MCO temporarily reinstated Julian's physical therapy.
- 119. A little over a week later, Julian's pediatrician received a letter from the same MCO stating that TennCare coverage for Julian's treatments should be discontinued, since the school system would be providing for his care. Meanwhile, the MCO continued to accept monthly TennCare capitation payments for Julian's treatment. The MCO instructed the doctor to discontinue his prescription for home care for Julian. The letter misled the doctor to in two ways. First, it implied that the EPSDT medical necessity standard and special education standards are identical. Second, it implied that the services provided by the TennCare MCO and the school system are identical. Both implications were false.
 - 120. The same letter was copied to Julian's mother with no explanation of her right to

appeal. Julian's mother immediately contacted counsel. Julian's pediatric physician contacted counsel on February 4, 1997, and confirmed that there had been no clinical decision to discontinue services, and that the MCO had terminated the treatment without regard to Julian's medical needs. Counsel for Julian requested continuation of benefits pending appeal on February 4, 1997, but it was not until two weeks later, after a motion for a temporary restraining order was filed in this court [see *Daniels v. Wadley*, No. 79-CV-3107, Motion for Temporary Restraining Order and for Leave to Investigate Contempt, filed February, 18 1997] that services were finally reinstated.

- 121. In April 1997, the school officials and Julian's pediatrician gathered to develop an educational plan for Julian to go to school in the community (he had been receiving educational services at home). The school system asked that Julian's counsel to obtain assurances from his TennCare MCO that private duty nursing would continue so that Julian could attend school and be safe. The TennCare MCO said that it would not continue to provide private duty nursing because under the MCO's policies, such care could only be provided in the home. Only after an appeal was filed, did Julian's MCO agree to continue the services he had been receiving for two years, thereby enabling him to start school.
- 122. Until systemic deficiencies with the TennCare system are corrected, Julian's health care services and life are constantly at risk.

Trov D.

- 123. Troy D. is eleven years old. He lives with his mother and his two step-brothers. At the age of four years, Troy D. began exhibiting emotional problems. Troy's primary care doctor referred him to Ridgeview Psychiatric Hospital in Oak Ridge. Troy was diagnosed as having Attention-Deficit Hyperactivity Disorder (ADHD) and Oppositional Defiant Disorder. Medication was prescribed and outpatient therapy was initiated.
- 124. In 1993, Troy D., was certified as "seriously emotionally disturbed" (SED) and eligible for special education services. He was hospitalized at Children's Hospital in Knoxville during the spring of 1995 due to the danger he posed to himself and his step-brothers. After discharge, Troy

- D. continued in outpatient therapy with medication through the fall of 1995 from Ridgeview. From 1990 through 1995, Troy's global assessment of functioning (GAF) level ranged between 25 and 55. The Ridgeview therapist informed T.W. that the only way she could get the services Troy needed was to place him in state custody. T.W. rejected this option.
- September 24, T.W. sought more effective treatment for Troy. Troy's therapist, who is on contract with his TennCare BHO, recommended "Home Ties," an intensive in-home mental health treatment service, covered by EPSDT. T.W. was told that, despite Troy's obvious and immediate need for this service, he could not receive the service at that time. T.W. was told he would be put on a waiting list. It was unclear whether DCS or Troy's BHO would pay for the services. However, T.W. was told that the only way to move up on the waiting list was to have a Juvenile Court petition filed.
- 126. By the middle of November 1996, Troy was becoming more dangerous-- frequently physically attacking his younger stepbrother and kicking T.W. in the stomach-- and refused to attend school. Disciplinary actions were initiated at school. T.W. filed an unruly petition against her son in attempt to get him the services needed to address his needs. Troy's therapist now believed that he was evidencing features of bi-polar disorder.
- 127. In December, Troy's mother sought hospitalization, because Troy was depressed and hearing voices that told him to "choke people." Troy was again entertaining thoughts of hurting himself. Troy's BHO, Tennessee Behavioral Health, approved hospitalization for a short period, then moved him into "partial hospitalization" based on a diagnosis of depression with psychotic features. "Partial hospitalization" consisted of all-day intensive therapy with educational services at Peninsula Lighthouse in Knoxville. Peninsula confirmed Troy's diagnosis of bi-polar disorder. Home Ties completed its evaluation and services while Troy was hospitalized at Peninsula.
- 128. Around the middle of January, Troy's therapist at Peninsula Lighthouse told Troy's mother that he could not continue in the all-day therapy treatment. Peninsula Lighthouse agreed to allow Troy to attend all-day therapy while its workers tried to obtain approval from Tennessee

Behavioral Health (TBH). On January 16, 1997, Troy's mother filed a grievance. Despite the filing of a grievance, Troy's treatment was stepped down to intensive outpatient therapy.

- 129. For several days following discharge, Troy was bused to his local school where he remained for 1 1/2 hours. Then he was bused to Peninsula Lighthouse for 3 or 4 hours of "outpatient therapy." He was then taken home. Troy became unstable and was admitted for inpatient treatment at Peninsula Hospital on or about January 20. On January 23, 1997, TBH wrote to Troy's mother confirming the hospitalization and informing her that her grievance was "resolved."
- outpatient intensive therapy was continued or reinstated. Troy's mother requested reinstatement of all-day therapy pending a hearing decision on her grievance. In response, the Tennessee Department of Mental Health and Mental Retardation (DMHMR) informed Troy's mother that Troy's BHO was "aggressively pursuing" appropriate treatment for Troy. However, DMHMR refused or failed to require the BHO to restore all-day therapy and continue such therapy pending a hearing decision.
- of 30 days. Therefore, it was unwilling to reinstate partial hospitalization during his mother's appeal. Troy's mother sought assistance from counsel. On February 11, 1997, TBH reinstated partial hospitalization services for Troy -- almost a month after his mother's appeal and request for reinstatement. TBH's proposed termination of partial hospitalization services was eventually reversed by DMHMR. Troy finished out the school year in the partial hospitalization program. An independent psychologist evaluated Troy and concluded:

[T]he parents, the schools, and the Peninsula Lighthouse program are hereby warned that such threats [of homicidal attacks and suicidal gestures] as may be made against other persons and, most particularly, threats made against himself should be taken most seriously. He is unlikely to be able to resist such impulses. If he clearly identifies a targeted person as being one whom he is likely to attack, or if he reports a wish to do away with himself by some means or other, the three parties mentioned, and other interested persons, should take immediate action to seek emergency assistance and probable commitment. It is my expectation that . . . residential treatment is very likely in the near to intermediate future.

By July, Troy was admitted to a residential treatment facility due to aggressive behavior. In mid-

November, 1977, he was discharged without notice. The BHO had not coordinated its actions with the school district, leaving Troy without an individual educational program appropriate to his mental health needs.

132. Defendants have refused or failed to assist Troy and his mother to access and coordinate the continuum of services and treatment from Child and Family Services, Home Ties, the school system, and Peninsula. The bases for the BHO's decisions to approve or deny care are unclear, other than that the BHO appears oblivious to Troy's individual needs.

Ray M.

- 133. Ray M. is a nineteen year old boy who has lived his entire life with his grandmother, Ms. D.. Ray has a fifty percent hearing loss in each of his ears. He also has a seizure disorder. Since he was in kindergarten, Ray has been going to an audiologist at Cookeville Hearing Center, the only provider in the region capable of providing comprehensive speech and hearing therapy services.
- him, as prescribed by a hearing specialist, so that he could function adequately in school and interact with other people. Ray presently has one hearing aid that echoes as if he were in a barrel. The other hearing aid works only intermittently. When he recently went to the Cookeville Hearing Center for audiology services, the Center told his grandmother, Ms. D., that TennCare would not pay for the Center to treat and screen Ray or service his hearing aids. Ms. D. called Ray's TennCare MCO, Blue Cross Blue Shield of Tennessee. Blue Cross referred her to an ear, nose and throat doctor. When Ms. D. called this doctor, he explained that he could not test nor service hearing aids. She again called Blue Cross Blue Shield and was told to see a provider in Brentwood, Tennessee, nearly one hundred miles distant.
- 135. In order for Ms. D. and Ray to get to Brentwood, she had to hire someone to drive them there. Reimbursement for the screening that occurred at the Brentwood hearing center was denied by Blue Cross Blue Shield as "non preventive care/non primary". Upon information and belief, based on reports from regional speech and hearing therapy centers, Ray's experience is typical

of that of members of the plaintiff class, in that TennCare MCOs routinely refuse to provide medically necessary speech and hearing services, and EPSDT-mandated screenings for TennCare children.

- 136. Ray has been on Medicaid since he was twelve years old but has never received the comprehensive EPSDT screenings required by federal Medicaid law. Ms. D. describes Ray as behaving like a four or five year old, even though he recently graduated from high school. Because of the failure to receive appropriate EPSDT screening, likely developmental problems have not been assessed. He left high school May, 1997. The mixture of inadequately treated hearing loss and probable unaddressed developmental needs leaves him unprepared for independent living. *Roscoe W.*
- 137. Roscoe W. is a nine year old boy who lives in Jamestown, Tennessee. He has been on Medicaid since birth. He was given a physical by a pediatrician soon after he was born, but was never referred for a hearing test. When he was three years old and still not speaking, his parents took him for a hearing test. It was discovered that he has a 35% hearing loss in both ears.
- 138. Since that time, he has gone to the Cookeville Speech and Hearing Center once a year for intensive tests to determine how much he is hearing, and whether his hearing aids are working effectively. When Ms. W. took Roscoe to the audiologist in August, 1996, before school began, she was told that the Cookeville Speech and Hearing Center could not screen Roscoe because her TennCare plan was not covering the service. The Center explained that the TennCare plan was not contracting with audiologists. When the Center had served children as an out-of-plan provider, because the MCO had no other providers who could provide such services to children in that region, the TennCare MCO had denied coverage in every instance.
- 139. Mrs W. called Blue Cross Blue Shield, Roscoe's TennCare MCO. Blue Cross referred her to a doctor in Knoxville, more than a hundred miles away. Anxious to have her son screened before school started so that he would be able to function in school, she again contacted the local Center, which served Roscoe for the small amount of money she was able to scrape together. She was informed that his hearing aids are almost worn out and will soon need to be replaced. Her

MCO does not contract with anyone in a hundred mile radius to provide hearing aid services for children, however. On information and belief, Blue Cross typically denies coverage for such services in any event, without regard to their medical necessity.

- 140. Ms. W. cannot recall ever being informed of the availability and importance of EPSDT screenings, and Roscoe has not received a visual screening within her memory. It was not until last August, when his mother suspected that he was visually impaired, that Roscoe's vision was tested, and it was discovered that he needed glasses.
- 141. Roscoe has a significant speech impairment. His parents run a business out of their home and have found that many people who come into the house cannot understand Roscoe without the assistance of his parents interpreting for him. In spite of the boy's obvious need, and although the audiologist has told his mother that he needs speech therapy, he has never received such care from Medicaid, and cannot obtain it now from his TennCare MCO. In August, 1996, at the urging of her child's audiologist, Ms. W. filed a formal grievance with Blue Cross seeking speech and hearing services for her son. She never received a response, and Roscoe has still not received the services which he needs.

William B.

- 142. William B. is a six year-old seriously emotionally disturbed child who lives in Murfreesboro. He is also moderately retarded and autistic. William was sexually abused as a toddler. When William was four years old, he still would not talk, and he was constantly aggressive. He frequently tried to hurt himself or others. He bit himself, banged his head against the wall, and pinched himself.
- 143. K.B., William's mother, took William to the local community mental health center. The clinicians there thought he needed therapeutic nursery services. William began therapeutic nursery services when he was four. The progress he made in three or four months was remarkable. His violent behavior decreased. In July of 1996, the TennCare Partners program began and William's therapeutic nursery services were reduced, although William's needs remained the same. The

clinicians said that TennCare would only pay enough for two days of treatment a week instead of five.

- Many weeks, he did not even get his allotted two days a week, because Quality Transportation ("Quality") which was the transportation company with which TBH contracted, did not show up to take him to the therapeutic nursery. K.B. did not own a car and could not get him to therapy. Other days Quality would not pick him up and he would be stuck at the mental health center waiting to get home. Quality had a rule that children could only get a ride if parents would agree to ride with the children. Quality said that if William wanted to ride, K.B. needed to ride with him. However, they would not allow Jerry, K.B.'s two year old brother, to ride with them. As a result, William could only obtain care when his mother managed to find a baby sitter for Jerry, so that she could escort William on the van.
- 145. Recently, William's thirteen month old sister drowned in the bathtub. William found her body floating in the bathtub. The entire family was traumatized by the tragedy.
- that could treat William. The name of the clinician TBH gave her would not see any children under eight years old. The only other clinician they gave was the Guidance Center, a local mental health center. Until her baby daughter died, K.B. worked at a program affiliated with the Guidance Center, called the Regional Intervention Program (R.I.P.). R.I.P. is an intervention program which works with parents of children with behavior problems and teaches parenting skills. Due to her close connection with the Guidance Center, she did not think it would be appropriate to take William to the Center's therapists. When K.B. called TBH back to get clinicians who could address symptoms resulting from William's trauma, she was told that the closest clinicians were in Nashville. K.B. has no means of transportation to enable her to travel to Nashville.
- 147. It is only through the kindness of strangers that William was able to receive any therapy at all for many months. A doctor in Nashville agreed to see William for five dollars a session

and also has agreed to be flexible so that if at the last minute a friend could lend K.B. a car, she can call the clinician in the morning and come in the afternoon. This is completely unpredictable and unacceptable for long term treatment of her child, but it was William's only option until November, 1997.

- 148. In November, TBH denied a request for intensive in-home therapy, but finally agreed to pay William's clinician for twice a week sessions. Since November, nearly half of the appointments have been missed due to TBH's transportation contractor not showing up.
- 149. William's critical mental health needs must be addressed early before it is too late. The current system allows his individual needs to be ignored.

Jacob R.

- 150. Jacob R. is an eleven year old with cerebral palsy, mental retardation and epilepsy. He requires braces in order to be able to take food by mouth. His orthodontist has prescribed the immediate provision of braces because Jacob is medically fragile, and delay would necessitate more invasive and complex procedures in the future.
- dental claims. Delta Dental explained to the provider and the family that they do not cover orthodontic treatment or functional treatment regardless of the child's individual needs unless a child is over twelve years old. They denied the treatment as a non-covered service. After an attorney became involved on the child's behalf, TennCare overturned the MCO denial. However, on information and belief based on discussions with dental and orthodontic providers, TennCare MCOs routinely impose arbitrary limits on the coverage of medically necessary dental services for children, and the state has not intervened on a systemic basis to prevent such denials of care. Jacob will continue to require dental and other TennCare covered services in the future, but, given the defendants' failure to implement EPSDT, he has no assurance that those services will be available.

Justin S.

152. Justin S. was born on September 25, 1988. Shortly after birth, Justin began

exhibiting abnormal behavior. It started with frequent and prolonged periods of uncontrollable screaming and the appearance of extreme discomfort when being held or touched. Bouts of head banging soon followed. Justin's mother, Diane P., was concerned about these symptoms, but she was repeatedly assured by Justin's pediatrician that his behavior was well within the normal range. With no help, Justin's mother continued to cope as best she could, even though the behavior worsened over time.

- When Justin was two, Ms. P. attempted to go back to work. She enrolled Justin in day care but within a short time was asked to take him out, because the child care workers could not control him. He was then enrolled in another day care center, but again he was asked to leave. Justin's mother voluntarily took him out of a third day care center because of constant complaints by the workers. By this time Justin was very agitated all of the time. He had frequent tantrums (screaming, fighting and uncontrollable body movements) and had become very aggressive toward other children, including biting, kicking, hitting and pinching. At night Justin was experiencing serious sleep disorders. He often could not fall asleep until well after midnight, but by 4:00 a.m. he was awake and agitated.
- 154. After a series of referrals to different therapists and programs, and following an unsuccessful course of medication for severe depression, Justin was admitted to Charter Lakeside psychiatric facility in Memphis. Special provisions had to be made because Justin was so young, but physicians were adamant that the seriousness of his condition warranted inpatient treatment. Once admitted, Justin was hospitalized for two and one half months. His treatment included very intensive behavior modification, daily working visits with the parents and medication. This treatment proved to be very effective and Justin experienced dramatic improvement. He was discharged in September, 1991, and follow-up care was recommended to help Justin maintain his higher level of functioning. Unfortunately, Justin did not receive this badly needed follow up care because the state would not cover the services. Consequently Justin's condition began to deteriorate.
 - 155. In an effort to maintain a consistent level of services, Justin's mother took Justin to the

Child Development Center at the University of Tennessee. He was given an intensive screening and received outpatient behavior modification and medication. This treatment, while helpful, did not bring Justin back to his peak level of functioning.

- 156. Treatment lasted a year but ended when Justin became eligible for early intervention services through the Memphis school system. A series of unsuccessful school placements ensued, until Justin's mother tried to provide home schooling. Although the home schooling was more effective academically, his mother could not handle the behavior problems, because she was unable to get Medicaid to provide coverage for the ongoing services which Justin needed.
- 157. At four years old, Justin was again admitted to Charter Lakeside for two and one half months. He was discharged because Medicaid would not pay for further treatment. As before, Justin received no follow-up treatment. Day treatment was recommended, but staff members from Charter told Justin's mother that their day treatment was not covered by Medicaid.
- 158. Thwarted in her efforts to find consistent and appropriate treatment for her child, Justin's mother sent Justin to stay with his grandparents in Louisiana. There, Justin received what the family believed to be appropriate services through the state of Louisiana. However, Justin and his family missed each other and his care was difficult for his aging grandparents. Justin therefore returned to Tennessee, where the family resumed its struggle to obtain needed medical services.
- 159. At six years old, Justin began to hallucinate. He began seeing demons and hearing voices. His TennCare provider told his parents to take him to Midtown Mental Health Center for crisis screening. The crisis team sent him directly to St. Joseph Hospital, were he was admitted for a few days and then transferred to the day treatment facility at St. Joseph for two weeks. However, he received little more than observation, the St. Joseph staff explaining to Justin's mother that his TennCare MCO, Access Med Plus, would not pay for the treatment he needed. She pled with the MCO to provide care for Justin, but in vain. For several months, he simply went without treatment, while his symptoms escalated.
 - 160. In late 1995, Justin was readmitted to St. Joseph. The treatment plan was to take

Justin off medication and monitor him. But when the MCO would not cover the services, Justin's mother was told to pick him up the next day. Justin was once more without treatment.

- 161. In July, 1996, the state began the TennCare Partners Program, and Justin's mental health coverage under TennCare was shifted from his MCO to one of the new BHOs, Tennessee Behavioral Health (TBH). That same month, Justin was admitted to Charter Lakeside Hospital again. He received residential treatment until September, when Justin's hospital therapist, a BHO subcontractor, informed Ms. P. that Justin needed longer and more intensive treatment than would be covered. State custody was suggested as an option for treatment. She received no information about her right to contest the possible BHO's termination of his treatment. Ms. P., who was unwilling to give custody to the state, took Justin out of the hospital. For weeks thereafter, she tried without success to find outpatient care for her son.
- 162. Finally, in November, 1996, Ms. P. took Justin to Professional Counseling Services, the Partners Program care coordinator to which she was assigned by TBH, where he was seen by the crisis team. While the team acknowledged that Justin needed residential treatment, they suggested that he try outpatient care first. When the outpatient services failed to produce results, the caseworker told Justin's mother that TennCare would not pay for additional hospitalization and that Justin could only receive the long term care he needed through state custody.
- deteriorating behavior: hitting, kicking, biting, throwing objects, fire starting, extremely aggressive behavior towards siblings, parents and pets and sexually acting out toward siblings. The caseworker recommended intensive, long term residential treatment. Home Ties was also called in by the crisis team to work with the family. After four weeks, the Home Ties worker also recommended residential care because Justin was a danger to himself and the other children. Justin's mother was advised that if Justin were to hurt one of the children, DCS would take her other children. Thinking that it was her only alternative, Justin's mother decided to agree to custodial care, but when she called DCS she was told that Justin was not eligible for custodial care.

- escalating to the point that Justin's parents were calling the crisis team every night. A safety plan, put in place earlier, to have the two siblings sleep with the parents every night and to restrict Justin's contact with the children during the day, was not working. It got to the point that Justin's mother could no longer guarantee the safety of his siblings or anyone else in the house. Finally, on January 31, 1996, the crisis team sent someone to the house to take Justin and his mother to the center. They stayed at the center all day until arrangements could be made to take Justin to St. Joseph where he was admitted. Initially Justin was certified, by TBH, until February 2. Thereafter, Justin was recertified at five day intervals. On February 12, TBH began recertifying Justin at one day intervals.
- about a more permanent placement. She was told by the TBH representative that Justin could get residential treatment or other services, if he qualified as Severely Emotionally Disturbed (SED). Justin's mother called the Crisis team to ask if he met the SED requirements. She was advised that he did. However, when she called TBH back, she was told that it is up to the doctors to order a more permanent placement. However, the doctors continue to advise Justin's mother that TBH will not allow a longer term certification. Thus, Justin and his family remained in limbo, not knowing from day to day whether he will receive care the next day.
- 166. Finally, Justin received residential services for five months. Upon discharge, he received some outpatient counseling. Justin was doing well when TBH terminated his counseling services. Justin began to hear voices and hurt his siblings. Neither TBH nor DCS could obtain outpatient therapy for almost three months. After this, Justin's TBH case manager told his mother that he still needed long term residential treatment, but there were "no beds" available for Justin.
- 167. Throughout this long ordeal, Justin was unable to receive consistent or appropriate services. As a result, Justin's condition dramatically deteriorated over time and he and his family suffered needlessly. The irony of this situation is that, had Justin received suitable services at the outset, his mother could have continued working, resumed her education, and possibly obtained

private insurance. More importantly, Justin would not have been so tormented, and his prospects for functioning at his full potential would not have been so cruelly compromised.

Estel W.

- 168. Estel W. is a fifteen year old boy who lives with his mother, E.D. In November, 1993, doctors told E.D. that Estel had diabetes and will have to take daily insulin shots the rest of his life. Ms. D. signed her family up for TennCare when the program began in January, 1994, and was assigned to Blue Cross Blue Shield as their MCO. Estel started seeing a diabetic specialist in Knoxville, and was also referred to a Knoxville opthamologist for yearly eye examinations which were required because of his diabetes. Knoxville is over an hour away from the family's home in Oneida, Tennessee, and Ms. D. had no way to get her son to those appointments except by spending money from her meager resources to pay a friend to take him. Neither TennCare nor Blue Cross informed her that transportation was available to Estel, if he needed to access these EPSDT-required services.
- 169. After the family had been on the program for several months, TennCare increased their premiums to over \$400, due to an erroneous calculation of their income. Estel's mother tried to correct the premium mistake, but could never get TennCare to straighten out the problem, and the family lost coverage because of their inability to pay the incorrect premium. When TennCare was stopped, Estel's mother attempted to pay for his insulin and visits to specialists. However, she soon incurred medical expenses that she could not pay. Ms. D. was finally able to reestablish Estel's TennCare in 1996, based on his Medicaid eligibility. She enrolled Estel in BlueCare, as Blue Cross now called its TennCare MCO.
- 170. BlueCare assigned Estel to a primary care doctor in Oneida, who will act as his "gatekeeper", controlling his access to specialty care. However, when Ms. D. tries to make appointments for Estel to be seen by that physician, none are available in the afternoon, when he is out of school and she has gotten off of work. Unable to access the primary care provider, Ms. D. went ahead and took Estel to the diabetes specialist in Knoxville for his regular appointment, as she

was supposed to do. This was the same specialist to whom Estel had been referred when he was previously on Blue Cross TennCare. On January 24, 1997, BlueCare sent an "Explanation of Benefits" (EOB) form stating that Estel must pay for that visit to his diabetes specialist, since a "referral for services was not obtained" from the primary care doctor. The EOB contained no information regarding the child's right to appeal the denial of coverage, or how to pursue such an appeal.

- 171. A packet of TennCare information which BlueCare sent to Ms. D. when Estel first enrolled indicated that children could get dental checkups every six months and "other routine children's dental care can be given as needed". The packet referred enrollees to the list of dentists in a provider directory. Estel's mother called dentists in the county and could not find any that accepted BlueCare or any other TennCare plan. Many of Estel's teeth are decayed, because the family could not afford regular dental care or treatment. Because Estel was in pain and because of his diabetes, E.D. decided that Estel needed immediate dental treatment and paid a local dentist \$205 to repair two teeth. The dentist told E.D. that Estel needed restoration treatment on seven more teeth. E.D. could not afford the additional treatment.
- 172. E.D. filed a grievance with BlueCare regarding the lack of available dental care for her child. After counsel became involved, BlueCare offered to cover restoration of the decayed teeth which were at issue in the grievance, but still does not provide Estel or other children in his community reasonable access to ongoing preventive and therapeutic dental services.

C. <u>Systemic Deficiencies in Services for TennCare Children</u>

173. Upon information and belief, the injuries and suffering experienced by the named plaintiffs are caused by systemic deficiencies in services for children covered by TennCare. Those deficiencies, caused by the acts and omissions of the defendant state officials and their agents, subject the members of the plaintiff class to widespread deprivations of necessary medical and related services, thereby imperiling their health and resulting in needless suffering.

Outreach, Screening and Diagnosis

- 174. There is a nearly complete failure to provide outreach and screening of TennCare eligible children. This failure extends to children who are in the state's custody, and whose access to care is directly controlled by state officials.
- 175. The state relies on "encounter data", comprised of electronically formatted reports of clinical encounters between TennCare enrollees and providers, to track the MCOs' and BHOs' compliance with their obligations under EPSDT. There are significant incentives for providers, MCOs and BHOs to over report encounters. The defendants compiled such encounter data in the state's annual report to HCFA, known as the HCFA 416 Report. The data in that report is unaudited and is, by the state's own admission, suspect.
- 176. Although, for the reasons just identified, the 416 Report almost certainly overstates the extent of Tennessee's compliance with the screening mandate of EPSDT, the most recent reported figures themselves are damning enough: for the period from January 1, 1994 through September 30, 1994, only 8% of children who were entitled to at least four screens (medical, dental, vision and developmental) received one. For the period October 1, 1994 through September 30, 1995, only 15% of TennCare children received even one of the screenings required by EPSDT.
- 177. Even the relatively small number of children who receive some form of screening do not have a reasonable assurance of receiving an adequate assessment of their medical needs. The defendants have not informed, or required the MCOs/BHOs to inform, providers of the required elements of an EPSDT screen. When initial screening by a primary care provider identifies a need for further diagnosis, such diagnostic services are often denied, due to managed care companies' refusal to cover such services. It is commonplace for plans to create a "Catch 22" requirement that referrals for further diagnosis (e.g., of developmental problems) be supported by a demonstration of medical necessity, something which is of course impossible to demonstrate until such services are provided. Denial of Medically Necessary Services

178. The state permits TennCare MCOs, BHOs and (with regard to children in state custody) DCS to deny children medically necessary services as a matter of course under a number of

circumstances. In part, such denials result from the state's failure to impose and enforce consistent definitions of medical necessity to guide the care management decisions of its agents. See *Hinds v. Blue Cross Blue Shield of Tennessee*, No. 3:95- 0508, Memorandum Opinion (M.D. Tenn. January 3, 1996). Widespread denials occur because some managed care contractors impose explicit arbitrary limits on treatment unrelated to individual children's medical needs. For example, children often must try and fail on an extended course of treatment with older, cheaper types of drugs (e.g., an antibiotic or psychopharmacological agent) before they are able to access newer, more effective medications, even if their medical records amply document previous failures of the cheaper drugs to meet their clinical needs. Plans have also imposed arbitrary coverage exclusions unrelated to a child's medical need (e.g., refusal to cover audiology services except those required for treatment of traumatic injury).

- 179. Needed care is withheld because the state's division of responsibilities among different entities (MCOs, BHOs and DCS), combined with the defendants' ineffectual enforcement of those entities' legal and contractual obligations, fosters shifting of costs and the consequent distortion of patient care. (An example is the BHOs' encouragement of children's placement in state custody in order to make DCS liable for the provision of services which the BHO is obligated to provide.)
- 180. The managed care companies' arbitrary denials of medically necessary care become institutionalized through the conditioning of providers in the MCOs/BHOs networks. As providers prescribe needed treatment, only to see the TennCare plans repeatedly bar their patients access to such care, the providers learn the futility of ordering treatment which they know will be denied. The doctors therefore modify their own treatment practices to conform to the TennCare contractors' arbitrary limits. MCOs/BHOs achieve the same result by imposing arbitrary and time-consuming requirements for providers to obtain prior approval to prescribe certain treatments. While prior approval can be a legitimate utilization and quality control tool, it is often abused by TennCare contractors for purely financial reasons, resulting in denials of medically necessary care for children. The defendants have made these systemic denials of medically necessary care possible, by their

failure to hold their agents accountable for their EPSDT compliance, and by the state's failure to educate health care providers, beneficiaries and the agencies which serve them regarding the scope of services available under the law.

MCOs/BHOs fail to recruit and maintain adequate networks of providers. Many providers only take a certain quota of TennCare patients, although they may be counted as a provider months after they have reached their quota. Major gaps in access are especially pronounced in the specialty areas of orthopaedics and dentistry. In the East Tennessee Region, for example, a recent health department study found "that there are gaps and inadequacies in the TennCare provider network for eligible TennCare recipients to receive basic dental care such as preventive and restorative services." The study concluded that, in that region alone, about 20,000 individuals, most of whom were children, enrolled in the two largest MCOs had no or inadequate access to dental care.

Behavioral Health Services

- 182. Medically necessary behavioral health services are denied because BHOs withhold "enhanced benefits" from children who do not qualify as SED. As described at paragraph 48, above, the definition of SED encompasses only children who score below 50 on the "Global Assessment of Functioning" (GAF) test. GAF scores are volatile, fluctuating with a child's treatment, and rising or dropping as children move in or out of crises. Many TennCare children scoring above 50 are, in fact, severely emotionally disturbed and in need of a broad array of behavioral health services. But the state's arbitrary classification system renders the children ineligible in practice for the mental health services necessary to correct or ameliorate their illness or condition due to the reality that they fall in the "enhanced benefits" category. The definition for SED eliminates access to enhanced benefits for 55% of the severely disturbed children who were known to DMHMR to be receiving such services in the year before the Partners Program began.
- 183. For SED and non-SED children alike, such care as they receive is fragmented, crisisdriven and episodic. Rather than actually managing children's care across a spectrum of needs and

services, the BHOs' focus on simply restricting utilization of those services, especially hospitalization, for which they are financially responsible. For children who are not in state custody, and who must rely on the BHOs for the full range of needed behavioral health services, this translates into a failure to develop or implement a comprehensive plan of care. This failure extends even to the BHOs' disregard of their responsibility for ensuring appropriate discharge planning for acutely ill children leaving hospitals. In the cases of children in state custody, the BHOs are preoccupied with moving them out of the hospital and back to DCS, but with little or no coordination of the children's care as they move from one setting to another.

Failure to Coordinate EPSDT with other services

184. Neither the defendants nor their agents ensure the coordination of EPSDT services among the different entities (MCOs, BHOs and DCS) responsible for the delivery of such services. And there is almost no coordination of EPSDT with the other educational, nutritional, health and social services which TennCare children need.

Children in, or at risk of entering, state custody

They also face additional barriers to care which are unique to their circumstances as wards of the state. Prior to the creation of DCS, independent Assessment and Care Coordination Teams (ACCT) under regional community health agencies evaluated children at risk of or in state custody. These teams assisted families and caseworker to assess their needs for treatment and to find and contract for necessary treatment for these children. Between July and October, 1996, the ACCT teams responsibilities were changed. Presently, children who are at risk of going into state custody or who are in state custody are screened pursuant to DCS protocol. There is no independent assessment of their needs. As for TennCare children generally, there is no mechanism for ensuring the coordination of their care among the various entities (MCOs, BHOs and DCS) responsible for meeting their EPSDT needs, or for coordinating EPSDT with the broad array of other educational, social and custodial services which these children need. DCS does not even inform foster parents of children's

right to EPSDT screening and treatment services.

- 186. As a result of the lack of adequate screenings for children coming into state custody and the lack of necessary treatment for the children's illnesses and conditions, defendants commonly fail to provide either adequate assessments of each child's needs, or clear plans for meeting those needs. When there is a plan, it often fails for lack of implementation.
- DCS delivers those services through "continuum of care" contractors. Children are assigned to those contractors even when the contractors lack the capacity to meet their medical needs. DCS imposes arbitrary limits on the number of "slots" or placements available to children with special needs, e.g., for therapeutic foster care. Therefore, even when a child's needs are consistent with DCS's provider contracts, a child may be put on a waiting list. This may result in a child being kept in an inappropriate placement, some times at a greater cost. And DCS fails or refuses to hold its contractors, or the MCOs/BHOs, responsible for serving the children in the agency's custody.
- 188. The Tennessee Commission on Children and Youth (TCCY) evaluates services for children in state custody. According to its report for 1996, the most recent year for which data is publicly available, TCCY found that in 29% of the cases sampled, plans of care were inadequate. In a full third of the cases, plans were not implemented. Among the evaluation's other findings were the following:
- a. There were problems of delayed or nonexistent access to dental and medical specialty care, due to inadequate TennCare provider networks;
- b. Among children in custody who were found to be doing poorly, they were most often found to have serious mental health needs related to abandonment, attachment problems, separation and loss, and sexual or physical abuse. Yet many of these children were not receiving needed treatment for their problems due to barriers posed by the TennCare Partners program, or obstacles created by poor coordination between with DCS and the managed care organizations.
 - c. Some children and their families had never even been seen by the case managers

responsible for planning and coordinating their care while in state custody.

V. CLAIMS FOR RELIEF

A. Denial of EPSDT Information and Outreach (42 U.S.C. §1396a(a)(43)

- 189. The Medicaid Act, 42 U.S.C. § 1396a(a)(43), federal regulations, 42 C.F.R. part 441.56, and policy directives judicially recognized as having the force of law, including HCFA State Medicaid Manual §5010, require defendants to:
 - a. Effectively inform recipients of the existence of the EPSDT program; and,
 - b. Inform recipients about the availability of specific EPSDT services.
- c. Inform plaintiffs and adults responsible for them, of health resources, the benefit of preventative care through both oral and written activities that are aggressive and effective;
- d. Provide plaintiffs information in clear and nontechnical terms, so that their caretakers -- foster, adoptive and biological parents and others -- are informed of what services are available under the EPSDT program, where these services are available and how to obtain them;
- e. Provide plaintiffs and their adult caretakers information concerning the necessary transportation to EPSDT services;
- f. Provide plaintiffs and their adult caretakers scheduling services for EPSDT services; and,
- g. Conduct outreach to plaintiffs and their caretakers within 60 days of the initial determination of Tenncare eligibility and at least annually thereafter.
- 190. In violation of 42 U.S.C. §1396a(a)(43), defendants refuse or fail to inform or to require its contractors to effectively inform plaintiffs and their caretakers of the existence of the EPSDT program and about the availability of specific EPSDT services.
- 191. Defendants' violation of 42 U.S.C. §1396a(a)(43) has caused and will cause plaintiffs to suffer irreparable injury in that they have been or will be denied information about and access to EPSDT services.

- 192. Defendants' violation of 42 U.S.C. §1396a(a)(43) provides a cause of action to plaintiffs under 42 U.S.C. §1983, inasmuch as defendants, under color of state law, custom or usage, have deprived, are depriving and will continue to deprive plaintiffs of their clearly established rights under 42 U.S.C. §1396a(a)(43).
- 193. Plaintiffs have no adequate remedy at law to prevent the continuing wrong and irreparable injury caused by defendants acts and omissions.

B. Denial of EPSDT Screenings (42 U.S.C. §§1396a(a)(43), 1396d(r)(1)(A) and (B))

- 194. The Medicaid Act, 42 U.S.C. §§1396a(a)(43) and 1396d(r)(1)(A) and (B), federal regulations, 42 C.F.R. pt. 441.57 and policy directives, judicially recognized as having the force of law, including HCFA State Medicaid Manual § 5123.2 A-D, require defendants to:
 - a. provide or arrange medical (mental and physical) screenings for plaintiffs.
- b. Include and cover lead blood level assessments as a mandatory laboratory screening test for plaintiffs;
- c. Include Hib (meningitis) vaccine for very young infants as a required immunization for plaintiffs;
- d. Include substance abuse counseling as part of "anticipatory guidance" during screenings of plaintiffs;
- e. Provide plaintiffs separate periodicity schedules for medical, vision, dental and hearing screens as recommended by HCFA;
 - f. Provide older plaintiffs dental screens more frequently than physical screens;
 - g. Cover "interperiodic" and partial screens;
- h. Allow health, developmental, or educational professionals who come in contact with plaintiffs outside the health care system to determine that an interperiodic screen is needed;
 - i. Prohibit prior authorization for screens, including interperiodic screens, of

plaintiffs; and,

- j. Submit annual reports that provide accurate information of the numbers of children receiving EPSDT services.
- 195. In violation of 42 U.S.C. §§1396a(a)(43) and 1396d(r)(1)(A) and (B), defendants refuse or fail to provide or to require its contractors to provide plaintiffs timely, adequate and appropriate screens.
- 196. Defendants' violation of 42 U.S.C. §§1396a(a)(43) and 1396d(r)(1)(A) and (B) has caused and will cause plaintiffs to suffer irreparable injury in that they have been or will be denied EPSDT screening services.
- 197. Defendants' violation of 42 U.S.C. §§1396a(a)(43) and 1396d(r)(1)(A) and (B) provides a cause of action to plaintiffs under 42 U.S.C. §1983, inasmuch as defendants, under color of state law, custom or usage, have deprived, are depriving and will continue to deprive plaintiffs of their clearly established rights under 42 U.S.C. §§1396a(a)(43) and 1396d(r)(1)(A) and (B).
- 198. Plaintiffs have no adequate remedy at law to prevent the continuing wrong and irreparable injury caused by defendants acts and omissions.

C. Denial of EPSDT Treatment (42 U.S.C. §1396d(r)(5))

- 199. The Medicaid Act, 42 U.S.C. §1396d(r)(5), federal regulations, 42 C.F.R. pt. requires defendants to:
- a. provide or arrange necessary health care, diagnosis services, treatment, and other measures to correct or ameliorate plaintiffs' defects and physical and mental illnesses and conditions discovered by screening services.
 - b. Arrange for plaintiffs' needed treatment directly or through a referral;
- c. Include treatment for plaintiffs' preexisting conditions identified during the screen;
 - d. Provide necessary health care, diagnosis services, treatment, and other

measures, whether or not such services are covered under the Tennessee Medicaid Plan as it existed in fiscal year 1993-94;

- e. Assure that any prior authorization of necessary services is consistent with preventive care for plaintiffs;
 - f. Cover necessary orthodontics and dental sealants for plaintiffs; and,
- g. Require that managed care organizations provide continuity of care and necessary referrals of plaintiffs.
- 200. In violation of 42 U.S.C. §1396d(r)(5), defendants refuse or fail to provide or to require its contractors to provide plaintiffs necessary health care, diagnosis services, treatment, and other measures to correct or ameliorate their defects and physical and mental illnesses and conditions discovered by screening services.
- 201. Defendants' violation of 42 U.S.C. §1396d(r)(5) has caused and will cause plaintiffs to suffer irreparable injury in that they have been or will be denied necessary health care, diagnosis services, treatment, and other measures to correct or ameliorate their defects and physical and mental illnesses and conditions discovered by screening services.
- 202. Defendants' violation of 42 U.S.C. §1396d(r)(5) provides a cause of action to plaintiffs under 42 U.S.C. §1983, inasmuch as defendants, under color of state law, custom or usage, have deprived, are depriving and will continue to deprive plaintiffs of their clearly established rights under 42 U.S.C. §1396d(r)(5).
- 203. Plaintiffs have no adequate remedy at law to prevent the continuing wrong and irreparable injury caused by defendants acts and omissions.
- D. <u>Denial of Adoption Assistance health services (42 U.S.C. §§620-40 and 670-79)</u>
- 204. The Adoption Assistance Act, 42 U.S.C. §622(b)(2) and 42 U.S.C. §629b(a)(3), requires defendants to coordinate the provision of child welfare services with other services in a manner that promotes the welfare of children and their families, including:

- a. Mental health, physical health and developmental services that protect and promote the welfare of all children, including handicapped children, 42 U.S.C. §625(a)(1)(A);
- b. Mental and physical health services that will prevent the breakup of families or restore children to their families, 42 U.S.C. §§625(a)(1)(C) and (D), 629a(B) and 675(1)(B);
- c. Adequate health care of children, especially children with special mental or physical health needs, so that children need not be put into state custody, and so that permanency of placement can be achieved, either through returning a child home or by placement in an adoptive home, 42 U.S.C. §§625(a)(1)(F), 675(1)(B) and 673(c);
- d. Follow-up care to families to address a child's mental and physical disabilities when the child has been returned after a foster care placement, 42 U.S.C. §629a(a)(1)(C);
- 205. In violation of the Adoption Assistance Act, defendants have engaged in policies and practices that deprive plaintiffs in state custody, or at risk of entering state custody, of health services that ensure their preventive, and rehabilitative health care needs are met and that they receive appropriate and effective behavioral and mental health treatment.
- 206. Defendants' violation of the Adoption Assistance Act has caused and will cause plaintiffs in state custody or at risk of entering state custody to suffer irreparable injury in that they have been and will be denied treatment and preventive health services that meet their preventive, and rehabilitative health care needs and that constitute appropriate and effective behavioral and mental health treatment.
- 207. Defendants' violation of the Adoption Assistance Act provides to plaintiffs in state custody or at risk of entering state custody a cause of action under 42 U.S.C. § 1983, inasmuch as defendants, under color of state law, custom or usage, have deprived, are depriving and will continue to deprive plaintiffs in state custody of their clearly established federal rights under the Adoption Assistance Act.
 - 208. Plaintiffs in state custody or at risk of entering state custody have no adequate remedy

at law to prevent the continuing wrong and irreparable injury caused by defendants' policies and practices.

E. <u>Denial of Substantive Due Process</u>

- 209. In violation of the Fourteenth Amendment to the United States Constitution, the defendants refuse or fail to:
 - a. Protect plaintiffs in state custody from harm:
 - b. Ensure plaintiffs in state custody safe and secure custody;
- c. Provide plaintiffs in state custody with adequate appropriate screenings, assessments and mental health or developmental services while they are in custody;
- d. Provide plaintiffs in state custody with minimally adequate care and treatment for their mental health, physical health and developmental service needs;
- e. Not unreasonably restrain plaintiffs' liberty by keeping them in state custody while at the same time denying them appropriate and adequate screenings, assessments, and mental health or developmental services, both nonresidential and residential.
- 210. Defendants' violation of the Fourteenth Amendment to the United States

 Constitution has caused and will continue to cause disabled plaintiffs to suffer irreparable injury in that members of the class have been and will be denied their liberty while at the same time denying them appropriate and adequate screenings, assessments, and mental health or developmental services, both nonresidential and residential.
- 211. Plaintiffs have no adequate remedy at law to prevent the continuing wrong and irreparable injury caused by defendants' policies and practices.

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 and the plaintiff class the health services to which they are entitled under the laws cited herein.

4. Issue injunctive relief pursuant to Rule 65, Federal Rules of Civil Procedure, 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.

5. Pursuant to Rule 53, Federal Rules of Civil Procedure, appoint a Special Master to oversee the defendants' compliance with the Court's orders.

 Award the plaintiffs reasonable attorneys fees and costs, as authorized by 42 U.S.C. §1988 and 28 U.S.C. §1920.

7. Grant such other and further relief as the court deems just and proper.

Respectfully submitted,

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