

IN THE UNITED STATES DISTRICT COURT
FOR THE NORTHERN DISTRICT OF ILLINOIS
EASTERN DIVISION

DAVID GROOMS,

Plaintiff

v.

BARRY S. MARAM,
Director, Illinois Department of
Healthcare and Family Services
Defendant.

FILED
APR 20 2006
MICHAEL W. DOBINSKI
CLERK, U.S. DISTRICT COURT

06CV2211
JUDGE PALLMEYER
MAG. JUDGE ASHMAN

COMPLAINT

I. PRELIMINARY STATEMENT

1. Plaintiff David Grooms (David) reached the age of 21 years old on October 8, 2005. David has Type II Glycogen Storage Disease (GSD Type II). David's condition was diagnosed when he was about 12 years old. GSD Type II is a muscle disease that progressively affects skeletal muscle and muscles involved in respiration. David's condition has resulted in quadriplegia. David is eligible for assistance under the Medicaid Program.

2. Although David's cognitive ability is unimpaired, all of his body functions have been compromised and his medical needs are very complex. David relies on others for virtually all care and mobility. He does have some use of his hands, and is therefore able to drink from a straw without assistance, to feed himself certain foods, and to use a computer. Aside from these limited activities, David has no control of his limbs.

3. During 2005, the Illinois Department of Healthcare and Family Services (HFS) approved and paid for monthly benefits that allowed David to obtain services in his own home and avoid institutionalization. Payment for the care was through a Medicaid waiver program for children who have exceptional medical needs who would be institutionalized at state expense if

not given care at home. HFS approved the extensive nursing services plan for David based on its determination that the services were medically necessary and that the cost of the care David needed to remain at home was less than the cost of the care in a hospital or other institutional setting.

4. At the end of 2005, HFS significantly cut funding for David's in-home nursing services. The reduction was based solely on the fact that David reached the age of 21 years on October 8, 2005; it was not due to a change in his medical needs or in the cost to HFS for the care he would require in an institutional setting. Due to the reduction in funding by HFS, David faces an impossible choice in the coming months: remaining at home with severely reduced services or moving to an institution. The latter choice would require that he be removed from family and community in order to receive the care that he needs. The former places him in danger of a lethal medical crisis.

5. David seeks declaratory relief that the actions of HFS and its director constitute illegal discrimination under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. § 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. § 794(a). David also seeks injunctive relief to require HFS and its director to provide nursing and other home services to him at the level that he received prior to turning 21.

II. JURISDICTION

6. Jurisdiction is conferred on this Court by 28 U.S.C. § 1331. Declaratory relief is authorized under 28 U.S.C. § 2201.

7. David's discrimination claims are brought pursuant to 42 U.S.C. § 12133 and 29 U.S.C. § 794.

III. PARTIES

8. David resides in LaSalle County, Illinois.

9. Defendant Barry S. Maram is the Director of the Illinois Department of Healthcare and Family Services (HFS).

IV. FACTS

10. David is 21 years old. His date of birth is October 8, 1984.

11. David is an individual with a disability and is eligible for Medicaid.

12. The Medicaid program is a joint federal and state funded program enacted to provide necessary medical assistance to needy aged or disabled persons and families with dependant children, whose income and resources are insufficient to meet the cost of care. 42 U.S.C. § 1396. States choosing to participate in the Medicaid program must operate the program in conformity with federal statutory and regulatory requirements. 42 U.S.C. § 1396a.

13. Each State participating in the Medicaid program must submit a Medicaid Plan to the Secretary of Health and Human Services (HHS) for approval. 42 U.S.C. § 1396.

14. Each State that participates in the Medicaid program must also designate a single state agency to administer and/or supervise the administration of that state's Medicaid Plan. 42 U.S.C. § 1396a(a)(5).

15. In Illinois, HFS is the single state agency responsible for administering the Medicaid program.

16. States have the option under Medicaid of providing home and community based services to persons who would otherwise require institutional care. 42 U.S.C. Sec 1396n(c)(1). Home and community based services are provided through HHS-approved "waiver" programs. Under HHS' waiver authority, the Secretary of HHS may grant waivers of specified

requirements, such as service limitations, that are otherwise applicable to the state's Medicaid Plan. 42 U.S.C. § 1396n(c)(3). Waiver programs must be cost-neutral in that the average cost of providing care for program participants in the home or community based setting must not exceed the estimated average cost of providing care in the institutional setting they would require. 42 U.S.C. § 1396n(c)(2)(D), 42 C.F.R. § 441.302(E).

17. The Secretary of HHS has approved waivers in Illinois for Medically Fragile and Technology Dependent Children (Medically Fragile Children's Waiver) and for Home Services for Adults with Disabilities (Adult Home Services Waiver).

18. Under the Medically Fragile Children's Waiver, HFS pays for home based care for children under age 21 who have exceptional medical needs. HFS administers this waiver program with participation of the University of Illinois Division of Specialized Services for Children (DSSC) under an agreement with HFS.

19. Under the Adult Home Services Waiver, HFS provides funds to enable disabled adults to remain in their homes or in a community setting. HFS administers the HSP program with the participation of the Department of Rehabilitative Services (DRS) of the Illinois Department of Human Services under an agreement with HFS.

20. David's condition, known as GSD Type II, was diagnosed in or about 1996 when he was about 12 years old.

21. David's physical condition has progressively worsened since the condition was diagnosed. David currently has quadriplegia and is 100% ventilator dependent.

22. David has complex medical needs and requires constant monitoring. His medical condition must be assessed constantly. David requires the service of a registered nurse or a

licensed practical nurse to care for certain of his medical needs, such as those associated with his ventilator.

23. David's mother, Kathy Grooms, has diabetes. She was hospitalized on several occasions during 2005 and 2006 due to complications from diabetes, with the most recent hospitalization occurring in or about March of 2006.

24. David's father, David Grooms, Sr., works full time to support his family.

25. HFS approved David's care plan as a medically necessary and cost effective alternative to the care in the institutional setting it determined David would otherwise require.

26. HFS paid for David's skilled nursing care under the Medically Fragile Children's Waiver.

27. During 2005, HFS approved and paid for approximately \$16,000.00 for monthly medical services provided by a registered nurse and a licensed practical nurse. The monthly benefits allowed David to meet the costs of salaries and benefits for the medical care that his condition requires. In addition to nursing services, the benefits allowed David to receive approximately \$1,000.00 per month for respite care. His mother and father provided the balance of David's care. In the year before David reached the age of 21 years, the cost of the services he received amounted to approximately \$221,760.00.

28. As David's 21st birthday approached, DSSC staff began informing David and his parents that David would "age out" of the Medically Fragile Children's Waiver and that he would thereafter be required to transition into the Adult Home Services Waiver.

29. In May of 2005, David and his family participated in a conference concerning David's care. Representatives of DRS and DSSC also attended. At the meeting, DRS informed David that funding for pediatric patients is decreased once a child reaches the age of 21 because

there are only 11 pediatric nursing facilities in the state, as compared with over 700 adult facilities.

30. In late 2005, HFS approved a new care plan that reduced David's monthly funding to approximately \$8,620.00. This amount translates into approximately \$103,440.00 per year, less than half of the previous funding level. The amount is not sufficient to meet the costs of the nursing services that David requires, nor is the amount sufficient to allow for respite care.

31. David's parents are not able to increase the level of care that they provided prior to David turning 21, due to their own health concerns and work demands.

32. The reduction in services by HFS is based solely on the fact that David reached the age of 21 years on October 8, 2005. The reduction in funding is not due to a change in David's medical needs. David wants to remain in his home and not be isolated in an institution. He has greatly benefited from the love and support of his mother and father, as well as of his extended family, all of whom are actively involved in David's life.

33. David's physicians have determined that David can be cared for at home safely and appropriately.

34. Under the laws governing the Adult Home Services Waiver, HFS has discretion to set funding for services for ventilator dependent persons and others whose needs cannot be met by otherwise applicable caps, provided that the waiver program is cost-neutral.

35. With no modification in its regulations, and little modification in its practices, HFS could continue to fund the level of nursing care that David requires in order to remain at home at a cost less than would be required to serve him in a hospital or other specialized institution for the care he needs.

36. The current reduction in funding for nursing care will ultimately force David into an institutional setting, isolating him from home and community.

37. Title II of the Americans with Disabilities Act, 42 U.S.C. § 12132, prohibits public entities from discriminating against persons with disabilities in the delivery of services. Section 504 of the Rehabilitation Act, 29 U.S.C. § 794(a), prohibits recipients of federal funds from discriminating against qualified persons with disabilities. Policies and practices that have the effects of unjustifiably segregating persons with disabilities in institutions constitute prohibited discrimination under both Acts.

38. Under 28 C.F.R. § 35.130(d), implementing Title II of the ADA, public entities must administer services in the most integrated setting appropriate to the needs of qualified individuals with disabilities. This same requirement applies to recipients of federal funds under the regulations implementing the Rehabilitation Act. 28 C.F.R. § 41.51(d).

39. HFS is a public entity within the meaning of Title II of the ADA and is a recipient of federal funds under the Rehabilitation Act.

40. David is a qualified individual with a disability within the meaning of Title II of the ADA and under Section 504 of the Rehabilitation Act,

41. The actions by taken by HFS with respect to David's services constitute unlawful discrimination under 42 U.S.C. § 12321 and 29 U.S.C. § 794(a) and violate the integration mandate of the regulations implementing these statutory prohibitions. 28 C.F.R. § 130.51(d) and 41.51(d).

42. Defendant's actions have caused and will continue to cause David irreparable injury for which there is no adequate remedy of law.

V. **CLAIMS**

43. David's sole income is the funding that he receives through HFS.

44. Defendant's reduction of funding for the home nursing and other services David needs in order to avoid institutionalization violates 42 U.S.C. § 12321 and 29 U.S.C. § 794(a) and their implementing regulations, 28 C.F.R. § 130.51(d), 41.51(d).

VI. **PRAYER FOR RELIEF**

45. Plaintiff prays for the following relief:

A. That this Court enter a declaratory judgment that Defendant's reduction in funding violates U.S.C. § 12132 and 29 U.S.C. § 794(a), and their implementing regulations, 28 C.F.R. § 130.51(d), and 41.51(d).

B. That this Court restore David's pre-age 21 levels of funding for home nursing services.

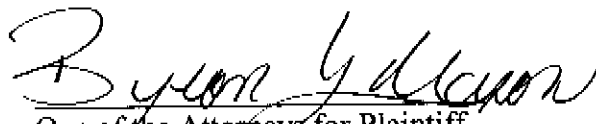
C. That this Court preliminarily and permanently enjoin Defendant's reduction in services for David's home nursing services.

D. That the Court award plaintiff costs and fees.

E. That the Court grant such additional relief that it deems equitable and just.

Respectfully Submitted,

BYRON L. MASON


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