

Kathleen L. Wilde - OSB#97105
Disability Rights Oregon
620 SW Fifth Ave - 5th floor
Portland, OR 97204
(503) 243-2081
(503) 243-1738 (FAX)
kwilde@disabilityrightsoregon.org

Peter James - OSB#892691
Oregon Law Center
1655 State St - Suite B
Salem OR 97301
(503) 485-0696
(503) 586-0037 (FAX)
peterjamesolc@yahoo.com

Stephen Gold
125 S. Ninth Street, Suite 700
Philadelphia, PA 19107
(215) 627-7100
(919) 627-3183 (FAX)
SteveGoldADA@cs.com

ATTORNEYS FOR PLAINTIFF

IN THE UNITED STATES DISTRICT COURT
FOR THE DISTRICT OF OREGON

Clay Freeman,

Plaintiff,

vs.

CASE NO. 08-6168-TC

Dr. Bruce Goldberg, in his official capacity
as Director of the Oregon Department of
Human Services, James D. Toews, in his
official capacity as Assistant Director of the
Oregon Department of Human Services,
Seniors and People with Disabilities, the
Oregon Department Human Services,
Cheryl Sanders, in her official capacity as
Executive Director of the Oregon Home

AMENDED COMPLAINT
(Civil Rights - Title II of the Americans with
Disabilities Act and Section 504 of the
Rehabilitation Act)

Care Commission and the Oregon Home
Care Commission,

Defendants.

COMES NOW the Plaintiff, by and through counsel, and pursuant to Rule 15(a)(2), F.R.Civ.P., files this his Amended Complaint, adding as parties defendant the Oregon Home Care Commission and Cheryl Sanders, its Executive Director, in her official capacity, having first obtained the written consent of the opposing parties:

PRELIMINARY STATEMENT

1. This is an action under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. §12132 and Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794(a)(Section 504), enjoining Defendants from denying, as a reasonable accommodation pursuant to the ADA and Section 504, adequately trained personal attendants to enable Plaintiff to remain in his home, rather than being forced unnecessarily into a nursing facility – a more costly, more restrictive setting and more dangerous setting than his current placement.

2. Plaintiff Freeman is a 34 year old man who has quadriplegia and must use a ventilator to assist him to breathe. He is kept alive by 11 machines, including a ventilator, a humidifier, a concentrator (that provides oxygen), a cough assist machine, an oximeter, a kangaroo pump (for tube feeding), a suction device, a special wheelchair and a hoist lift. He requires around the clock care, and the proper operation of his ventilator and other machines must be checked regularly to ensure their proper functioning.

3. Since 1999, Mr. Freeman has been fully integrated into the community and has successfully lived in his own apartment, attended college, and participated in life throughout the

community.

4. Mr. Freeman requires total assistance with all functions of daily living, including breathing, eating, and toileting, which he receives from his five (5) personal attendants.

5. Presently, he is without three of the five personal attendants. One of his personal attendants has been working from 8 a.m. on Saturdays til 4 p.m. on Mondays, with only a few hours break to sleep, to cover the weekend shifts, a schedule that cannot safely continue. Since the third personal attendant quit on June 2, 2008, the remaining two personal attendants are alternating 24 hour shifts. This schedule significantly increases the likelihood that Mr. Freeman will lose yet another personal attendant to burnout, and places Mr. Freeman's safety in jeopardy.

6. Mr. Freeman seeks injunctive relief to enjoin Defendants from denying him adequately trained personal attendants to avoid institutionalization.

JURISDICTION

7. Jurisdiction is conferred on this Court by 28 U.S.C. §1331.

VENUE

8. Venue is proper in this judicial district because Plaintiff resides in the District of Oregon and the violations have taken place and continue to take place there.

PARTIES

9. Clay Freeman is 34 year old man who lives by himself in a rented apartment. He is a person with a disability, as Congress has defined that term in the ADA and Section 504. Mr. Freeman is eligible for, and receives benefits under, Oregon's Home and Community Based Services Waiver (HCBSW).

10. Dr. Bruce Goldberg is the Director of the Oregon Department of Human Services

(DHS). He is sued in his official capacity.

11. James D. Toews is the Assistant Director of DHS, Seniors and People with Disabilities (SPD), a subdivision of DHS. He is sued in his official capacity.

12. Defendant Oregon Department of Human Services is the department of the State of Oregon that administers Medicaid and, through the Seniors and People with Disabilities program within DHS, is responsible for overseeing the administration of the HCBSW.

13. Cheryl Sanders is the Executive Director of the Oregon Home Care Commission (OHCC). She is sued in her official capacity.

14. The Oregon Home Care Commission is a public entity charged, *inter alia*, with ensuring the quality of home care services under the HCBSW.

15. DHS, SPD and OHCC are recipients of federal funds.

FACTS

Medicaid and the Home and Community Based Waiver

16. The Medicaid program is a joint federal and state funded program enacted to provide necessary medical assistance to needy persons who are elderly or disabled, and for families with dependent 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. §1396n.

17. States have the option under Medicaid to cover home and community based services, including in-home care provided by personal attendants, for persons who would otherwise require institutional care. 42 U.S.C. §1396n(c)(1). The federal Department of Health and Human Services (HHS) authorizes states to provide home and community based services through

“waivers.” Under HHS’ waiver authority, the Secretary of HHS may allow states to waive specified Medicaid requirements, such as service limitations, that are otherwise applicable to services covered under the State’s Medicaid Plan. 42 U.S.C. §1396n(c)(3). Waiver programs must, in the aggregate, be cost-neutral in that the total average cost of covering care for program participants in the home and community based setting must not exceed the estimated total average cost of providing care in the institutional setting that they would require. 42 U.S.C. §1396n(c)(2)(D), 42 C.F.R. §441/302(e).

18. The Secretary of HHS has approved a HCBS waiver in Oregon for people who would otherwise require care in a nursing facility. This is the program through which Mr. Freeman currently receives his home and community-based services. It includes in-home personal attendant services as one of the components of service delivery.

19. HCBSW services are administered by DHS, Oregon’s single state Medicaid agency, through its SPD program.

20. A state must apply for permission to operate a HCBSW. The state must make certain assurances, including that necessary safeguards, including standards for provider participation, have been taken to protect the health and welfare of individuals provided services under the waiver. 42 U.S.C. §1396n(c)(2)(A).

21. In its Application for a HCBSW, Oregon agreed that it would ensure that, to assure participant health and welfare, “Provider Capacity and Capabilities: There are sufficient HCBS providers and they possess and demonstrate the capability to effectively serve participants.” (Waiver Application:1).

22. In addition, under the terms of the Oregon HCBS waiver, the Oregon Medicaid agency (DHS) and Local, Non-State Entity (county SPD offices) have responsibility for recruiting providers (Waiver Application: Appendix A: 5) and local SPD case managers are responsible for assisting the participant with referrals of Homecare Workers, also known as personal attendants (Waiver Application, Appendix E-2:6).

23. Furthermore, under the terms of the Oregon Waiver, Backup Care Providers are to be made available to participants:

Back-Up Care Providers: SPD has alternate service providers such as Medicaid contracted in-home care agencies in some regions that an individual can employ on short notice if they cannot locate a Homecare Worker who meets their needs...

(emphasis added).

24. The waiver further requires that:

For individuals with significant personal care needs, such as those with quadriplegia, case managers often assist with identifying a regularly-scheduled relief care provider as part of the service plan or have identified back-up providers or care setting alternatives as part of the plan of care in case the participant's primary provider becomes ill or is suddenly no longer available...

(Waiver Application Appendix D-1:7)(emphasis added).

25. While participants are required to "orient and instruct staff in duties," the waiver does not make them responsible for training an in-home care provider (Waiver Application Appendix E-2:9).

The Duties and Powers of the Oregon Home Care Commission

26. The Oregon Home Care Commission is responsible for providing the following services for HCBS Waiver participants:

- (1) establishing and maintaining a registry of qualified home care workers;
- (2) providing training opportunities for home care workers; and
- (3) providing routine, emergency and respite referrals of home care workers.

ORS §410.604.

27. The OHCC is required to enter into an interagency agreement with DHS for carrying out the duties or functions of the commission. ORS §410.604(2)(b).

28. The OHCC is the employer of record of home care workers for purposes of collective bargaining. It enters into a collective bargaining agreement with the union representing home care workers, which sets the wage rates for home care workers. DHS is a party to those negotiations. ORS §410.612.

29. The OHCC may provide non-employee compensation for home care workers who attend training sessions approved or sponsored by the commission. ORS §410.625(1)(b).

CLAY FREEMAN'S FACTS

30. Mr. Freeman's medical condition resulted from a diving accident in 1996, when he was 21 years old, in which he sustained a fracture of his vertebrae and became both a quadriplegic and a ventilator user. Like most quadriplegics who use a ventilator, he has a tracheotomy and must regularly ensure it does not become blocked or malfunctions. In addition, he regularly must check for and attempt to prevent chronic bedsores on his coccyx and buttocks. He also has pneumonias secondary to aspiration, and urinary tract infections from his public catheter. Mr. Freeman has a bowel program with chronic impaction.

31. Unlike virtually all other participants in Defendants' waiver program, Mr. Freeman has exceptional and complex needs. His ventilator must be monitored and adjusted day and

night; he uses oxygen as needed requiring adjusting the levels of oxygen according to his needs; he requires manual breathing during the periods when there are ventilator or power failures as well as during periods when he must be detached from the ventilator for bathing; he receives tube feedings on an ongoing basis; irrigation of his catheter must be done several times per day; suctioning of his trachea must be done every 10 minutes; chest percussions must be performed three times daily for 20 minutes; and he requires frequent transfers with a hydraulic hoist lift, as well as continual repositioning. Unlike with other participants in Defendants' waiver program, Mr. Freeman's personal attendants must be specially trained in, or knowledgeable about, performing all these necessary functions.

32. Mr. Freeman is dependent upon 11 different machines to survive. His personal attendants must be trained in, or knowledgeable about, the proper functioning of all of these machines.

33. Defendants have approved Mr. Freeman for 24 hours of care per day, 7 days per week. His personal attendants, despite the exceptional level of care that Mr. Freeman requires, are paid \$9.90 per hour, the same rate paid under bargaining agreement that the DHS and OHCC has entered into with the union to all personal attendant caretakers, regardless of the functions they perform and regardless of the severity of the person with a disability.

34. Until recently, for a period of several years, Mr. Freeman was granted an hourly rate that exceeds the standard hourly rate paid for other personal attendants by a few dollars per hour. In addition, he was provided a higher rate (then \$12.50 per hour) for his "lead" worker, who was responsible for monitoring and ordering supplies and prescriptions, managing his medical condition, scheduling doctor and home health visits, providing routine care of the medical

equipment and scheduling regular maintenance, and having a pager with him at all times for emergency situations, as he was required to be available to Mr. Freeman at all times.

35. With this previous system in place, Mr. Freeman was able to obtain the personal attendants he required who would perform all the exceptional tasks he required. As a result, his medical condition was significantly stabilized, requiring less hospitalization for him.

36. According to his case manager,

[Mr. Freeman] has adjusted extremely well to living in his own home; it is his wish to remain there with his care plan as it has been. He is beginning to access the community more frequently and has taken a very important step in beginning to work with VRD [Oregon Department of Vocational Rehabilitation] and attend college. A change in his living situation would prevent him from continuing what has been the goal he has focused on throughout his recovery and rehabilitation process. I believe that the current care

plan affords [him] the maximum independence and dignity, which could not be achieved in any other setting.

Request for Exception, February 3, 2005, p. 6.

37. In the July 2007 Exceptions Request, the case manager further noted:

[Mr. Freeman] continues to work with a Vocational Rehabilitation counselor and has just graduated from Chemeketa Community College earlier this month. He plans to begin classes at Western Oregon University in September and work towards a Bachelor's Degree in Sociology. His VR counselor feels that his potential to meet this goal is very good with adequate supports in place.

38. By contrast, an institutional hospital or nursing home setting, according to his case manager, "would most likely not be in this area, which would then restrict his ability to maintain his connection with his support system that has been so much a part of his life...[Mr. Freeman] does not believe (and I agree) that any other setting would be as appropriate for a young person...with the interests of a young person such as he is and has." Id., p. 6.

39. Mr. Freeman's current personal attendants are no longer paid a higher rate for his care, and there is no additional compensation for a "lead" caregiver. As a result, he has been having difficulty finding personal attendants willing to work for him. He is currently without two of his five personal attendants, and is in extreme crisis. One of his personal attendants has been working from 8 a.m. on Saturday until 4 p.m. on Monday, with a few hours of sleep made possible by Mr. Freeman's mother taking over her duties each weekend. Now that the third personal attendant left, his two remaining providers are alternating 24 hour shifts.

40. Mr. Freeman requested from Defendants a list of personal attendants who might agree to work for him at the standard rate. He has used the list provided by his SPD caseworker to attempt to hire personal attendants to replace those two who left him due to burn out, but to no avail. He called 142 people on Defendants' lists, none of whom was willing to work for him given his complex needs and at the hourly rate authorized by Defendants.

41. Also, since he was provided access to the OHCC's data base, he has called all persons listed in the data base as having some of the skills he requires, but has been unable to hire a personal attendant from this data base. His job posting on Craig's list, an internet-based classified advertising service, provided no applicants.

42. Mr. Freeman has contacted the in-home care agencies in his area. They all refuse to provide a personal attendant because of the complexity of his needs.

43. In addition, there is no respite care available to Mr. Freeman's personal attendants. If one of his personal attendants becomes sick or does not show up for a shift, there is no one to provide coverage other than his existing personal attendants. Very few facilities which provide respite care are even equipped to provide the level of care that he requires. For example, one

facility is staffed to provide suctioning of the trachea 1-2 times per shift while Mr. Freeman requires suctioning more often. Gresham Rehabilitation Facility no longer provides care to ventilator-dependent people with quadriplegia. Salem Hospital has refused to care for him on an emergency basis, unless he is in a medical crisis. In short, there are no resources available to Mr. Freeman if he is without a personal attendant.

MR. FREEMAN'S REASONABLE ACCOMMODATION REQUESTS

44. Mr. Freeman has repeatedly asked Defendants for assistance in locating personal attendants, including respite providers. He has asked Defendants, as a reasonable accommodation pursuant to the ADA and Section 504, due to his severe disability, to find two personal attendants who are able to care for his needs. In the alternative, Mr. Freeman has asked that he be authorized to pay his personal attendants a higher rate, as he was previously permitted to do, to perform his complex level of care. Based on his prior experience when Defendants had authorized him to pay a higher rate for his personal attendants, his chances of being able to hire a personal attendant were greatly increased.

45. Defendants Goldberg, Toews and DHS have refused to grant either of these two reasonable accommodation requests, instead referring Mr. Freeman to the OHCC

46. Mr. Freeman, along with two other individuals with quadriplegia who are ventilator dependent and receive HCBWS, went before the OHCC on April 3, 2008 and requested that they be provided with trained caregivers or, in the alternative, that they receive payment for training hours so that their personal attendants could train new personal attendants. They also requested a higher rate of pay for their personal attendants. Further, by letter of the same date, they requested:

(1) a registry of qualified home care workers who will serve clients with quadriplegia who are ventilator dependent;

(2) training opportunities for home care workers in the care of clients with quadriplegia who are ventilator dependent; and

(3) respite referrals for home care workers who are trained and willing to serve clients with quadriplegia who are ventilator dependent.

47. The response of OHCC was to provide Mr. Freeman with instructions on how to access the Registry and Referral System, which does not screen for qualifications to serve people using ventilators and trach tubes. Mr. Freeman contacted all of the people on the list with some of the qualifications that he requires, and was unable to hire a single personal attendant. OHCC was unable to meet his needs for either personal attendants or respite providers.

48. In addition, Defendants have provided no training to any of the personal attendants that Mr. Freeman has been able to hire regarding proper use and maintenance of a ventilator or with the other machines Mr. Freeman uses. As a result, he has been forced to train his own providers. For a time, his case manager authorized a sufficient number of additional hours to pay an existing personal attendant to train a new personal attendant. This abruptly ceased a number of months ago, and Mr. Freeman must now find a personal attendant willing to work for free during the time the new person is being trained.

49. None of the Defendants offer training on how to care for someone on a ventilator, or with a trach tube, nor do they maintain a list of providers who are trained to perform those services.

50. Mr. Freeman has requested Defendants, as a reasonable accommodation pursuant to the ADA and Section 504 due to his severe disability, alternatively to provide him with trained personal attendants, or to permit payments for both the existing attendant and the new one, during the time the existing personal attendant trains a new one. Defendants have refused these requests for a reasonable accommodation.

51. If Mr. Freeman does not obtain the two caregivers he so desperately needs within a very short time, he will be required to move to a nursing home, despite the Defendants' acknowledgment and finding that he can, as he has for a number of years, be well cared for in a community setting.

52. Mr. Freeman has no complete and adequate remedy at law and will suffer irreparable injury if forced to leave his home.

CAUSES OF ACTION

Violation of Title II of the Americans with Disabilities Act

And Section 504 of the Rehabilitation Act

53. Plaintiff realleges each of the paragraphs above as though set forth again here.

54. Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. §12132, prohibits public entities from discriminating against people with disabilities in the delivery of services.

55. Section 504 of the Rehabilitation Act prohibits recipients of federal funds from discriminating against people with disabilities in the administration of their programs and services. 29 U.S.C. §794(a).

56. Mr. Freeman is a "qualified individual with a disability" within the meaning of both statutes. A "qualified individual with a disability means an individual who, with or without

reasonable modifications to rules, policies or practices...meets the essential eligibility requirements for the receipt of services or the participation in the programs or activities provided by a public entity.” 28 C.F.R. § 104 and 45 C.F.R. §8.3.

57. Defendant DHS and the SPD program, a part of DHS, along with OHCC are public entities and recipients of federal funds within the meaning of Title II of the ADA and Section 504 of the Rehabilitation Act. Defendants are the Director and Assistant Director of DHS, along with the Executive Director of the OHCC.

A. Defendants Have a Duty to Provide The Requested Reasonable Modifications to Its Practices

58. The ADA requires that “a public entity shall make reasonable modifications in policies, practices or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate the making the modifications would fundamentally alter the nature of the service, program or activity.” 28 C.F.R. §35.130(b)(7).

59. Mr. Freeman has asked that Defendants immediately provide him with trained personal attendants who can meet his complex needs. In the alternative, Mr. Freeman has requested a higher rate of pay for his caregivers, given the complexity of his needs, a reasonable accommodation that has been provided him in the past. Neither modification would result in a fundamental alteration to Defendants’ program.

60. Under the terms of the waiver, DHS and the local SPD office are responsible for recruiting in-home personal attendant service providers. The SPD casemanager is also responsible to assist with identifying personal attendants and assist with identifying a regularly-scheduled relief personal attendant as part of the service plan or having identified back-up

providers or care setting alternatives as part of the plan of care in case the participant's primary provider becomes ill or is suddenly no longer available. Further, OHCC is responsible for "establishing and maintaining a registry of qualified home care workers and providing routine, emergency and respite referrals of home care workers." The reasonable accommodation that Mr. Freeman requests falls squarely within the existing duties already assigned to DHS under the HCBS Waiver and to OHCC by statute.

61. Nor would the request for a higher rate of pay for his personal attendants result in a fundamental alteration. Mr. Freeman's care needs are so complex that there are very few people in Oregon who would have equivalent needs so as to claim the same rate. On information and belief, there are only seven (7) persons with quadriplegia who are dependent on ventilators in the state. Further, this accommodation was previously provided to Mr. Freeman to allow him to retain personal attendants and have a "lead" care provider who would be available to provide services in the event of an emergency, and was continued even after the union contract was signed, by agreement of the union, DHS and OHCC.

62. Mr. Freeman's request that Defendants train in-home workers so they are able to meet his needs, or that in the alternative, that Defendants pay one of Mr. Freeman's care providers to train a new worker, would not result in a fundamental alteration of the HCBS Waiver program or the program run by Defendant Sanders and OHCC.

63. Under the requirements of the Medicaid waiver, Defendants Goldberg, Toews and DHS must "assure participant health and welfare" by ensuring that "[t]here are sufficient HCBS providers and they possess and demonstrate the capability to effectively serve participants." (Waiver Application:1).

64. Further, OHCC is charged by statute with the responsibility for “providing training opportunities for home care workers.” ORS §410.604.

65. Finally, Defendants have, in the past, provided funding so that a trained care provider could train a new in-home worker to competently care for Mr. Freeman.

66. Accordingly, Defendants’ failure to grant Mr. Freeman’s request for reasonable modification constitutes discrimination on the basis of disability, in violation of Title II of the ADA and Section 504 of the Rehabilitation Act.

2. Defendants Have a Duty to Maintain Mr. Freeman In the Most Integrated Setting

67. 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).

68. Defendants DHS, SPD and OHCC are public entities within the meaning of Title II of the ADA and are recipients of federal funds under the Rehabilitation Act.

69. Mr. Freeman is a qualified individual with a disability within the meaning of Title II of the ADA and under Section 504 of the Rehabilitation Act.

70. The state’s professionals have found that treatment in the community is appropriate. Mr. Freeman actively seeks to remain in his home and continued placement in the community can be reasonably accommodated, taking into account the state’s resources and the needs of others with similar disabilities.

71. If Defendants fail to grant the requested reasonable accommodations, Mr. Freeman will be forced into a nursing home, which is precisely the type of “unjustified institutional

isolation” that the Supreme Court in Olmstead v. L.C. described as a form of discrimination prohibited by the ADA and Section 504 of the Rehabilitation Act.

PRAYER FOR RELIEF

Plaintiff respectfully requests the following relief of this Honorable Court:

(1) an emergency injunction requiring Defendants to immediately provide him with sufficient trained personal attendants to safely maintain his care in his home;

(2) in the alternative, an emergency and permanent injunction requiring Defendants to authorize a higher rate of pay for Mr. Freeman’s personal attendants, so that he can find and retain in home care providers;

(3) an emergency and permanent injunction requiring Defendants to train personal attendants so that they can provide the level of services needed by Plaintiff, or in the alternative that Defendants authorize the payment of funds to an existing personal attendant to provide needed training to a new care provider;

(4) a permanent injunction requiring Defendants to provide Mr. Freeman with a sufficient number of trained personal attendants to safely maintain his care in his home, including respite and emergency care;

(5) award Plaintiff his reasonable attorneys fees and costs;

(6) all such other and further relief as this Honorable Court deems just and proper.

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THIS 9th day of July, 2008.

Respectfully submitted,

/s/ Kathleen L. Wilde
Kathleen L. Wilde - OSB#97105
(503) 243-2081

ATTORNEYS FOR PLAINTIFF