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(continued on following page)

8 **UNITED STATES DISTRICT COURT**
9 **FOR THE EASTERN DISTRICT OF CALIFORNIA**

10 PABLO CARRANZA,) **Case No.:**
11)
12 Plaintiff,)
13 v.)
14 TOBY DOUGLAS, Director of the) **COMPLAINT FOR INJUNCTIVE AND**
15 Department of Health Care Services, State of) **DECLARATORY RELIEF**
16 California DEPARTMENT OF HEALTH)
17 CARE SERVICES,)
18 Defendants.)
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I. INTRODUCTION

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2 1. This civil rights action seeks declaratory and injunctive relief to prevent the
3 devastating reduction in Medi-Cal funded in-home nursing care to Plaintiff Pablo Carranza. This
4 young man has Muscular Dystrophy, a severe and progressive disease that has left him unable even
5 to breathe or swallow on his own. Pursuant to his doctor’s orders, he needs constant skilled
6 nursing care to monitor his ventilator, feeding tube and oxygen levels, to clear fluids from his lungs
7 and tracheotomy tube, to transfer him from bed to wheelchair and back, and to bathe and reposition
8 him. While this kind of twenty-four hour care is often provided in a hospital or Subacute medical
9 care facility, Pablo has been able to remain at home with his family. If the Medi-Cal program
10 reduces Pablo’s in-home nursing care as planned, he will be placed at risk of unnecessary
11 institutionalization, and separated from his family and community. Due to his fragile medical
12 condition, placement in an institution is also likely to result in dire health consequences and even
13 death.

14 2. Until he turned age 21, Pablo was authorized to receive, and did receive, 615 hours
15 per month of Medi-Cal funded, one-to-one nursing care in his home. This was based on Medi-
16 Cal’s determination that he would otherwise be placed in a Pediatric Subacute medical facility.
17 The cost of his care was \$230,000 per year, which is far less than the amount Medi-Cal would
18 actually pay for institutional placement for an individual with Pablo’s care needs. On Pablo’s 21st
19 birthday - September 17, 2012 - Defendant Department of Health Care Services and its Director,
20 Toby Douglas (collectively “DHCS” or “Defendants”), reduced the authorization for his in-home
21 nursing by more than 200 hours per month, even though his condition has not improved. The sole
22 reason for this drastic and life-threatening reduction in Plaintiff’s in-home nursing care is that
23 Defendants have placed arbitrary cost limitations on the home care services available to adults
24 versus those for children. Specifically, Defendants capped the cost of in-home nursing care for
25 adults such as Pablo at \$180,000 per year, which is at least \$90,000 below the actual cost of
26 equivalent care in an Adult Subacute facility, and also significantly below the cost that Medi-Cal
27 provided for his care prior to his 21st birthday.

28 3. Defendants have the discretion and the ability to modify State Medi-Cal rules to

1 increase the arbitrary cap on Plaintiff's in-home nursing care to enable him to receive the skilled
2 nursing care he needs, and that is ordered by his doctors. They have refused to do so.

3 4. So far, Defendants have not cut Plaintiff's in-home nursing care but may do so at
4 any time after December 16, 2012, when his current authorization from Medi-Cal expires. Plaintiff
5 obtained a delay in the planned reduction in his nursing via an administrative appeal, but because
6 Defendant Douglas has the authority to set aside any administrative decision and substitute his own
7 decision, this process offers Plaintiff no protection after December 16, 2012, when his current
8 Medi-Cal authorization for in-home nursing services ends.

9 5. Defendants' actions violate the Americans with Disabilities Act of 1990, 42 U.S.C.
10 § 12312 ("ADA") and Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 ("Section
11 504"). Under the ADA and Section 504, a public agency such as DHCS has a duty to provide
12 services to people with disabilities in the "most integrated setting appropriate to their needs" and
13 avoid unnecessary institutionalization. The most integrated setting for Pablo is to live in the
14 community with his family, as he has for the past 21 years of his life, with adequate in-home
15 nursing to meet his significant needs. Placing him at risk of unnecessary institutionalization in
16 order to receive the care he needs violates the ADA.

17 6. Under the ADA, Defendants also have an obligation to use methods of
18 administration that do not discriminate against individuals with disabilities such as Pablo.
19 Defendants' failure to ensure a smooth transition to adult services for Pablo and their decision to
20 set funding levels for home care services that are biased in favor of institutional care result in
21 discrimination against Plaintiff in the administration of the Medi-Cal program.

22 7. Defendants' failure to provide Pablo adequate notice and opportunity for hearing
23 prior to the reduction in his nursing hours also violates the federal constitutional guarantee of
24 procedural due process.

25 II. JURISDICTION

26 8. This is an action for declaratory and injunctive relief for violations of Title II of the
27 Americans With Disabilities Act, 42 U.S.C. § 12132; Section 504 of the Rehabilitation Act of
28 1973, 29 U.S.C. § 794; and the Due Process Clause of the Fourteenth Amendment to the U.S.

1 Constitution, 42 U.S.C. § 1983.

2 9. Jurisdiction is based on 28 U.S.C. §§ 1331 and 1343. Plaintiff's claims for
3 declaratory and injunctive relief are authorized under 28 U.S.C. §§ 2201 and 2202. At all times
4 relevant to this action, Defendants have acted under color of state law.

5 **III. VENUE**

6 10. Venue is proper in the Eastern District of California pursuant to 28 U.S.C.
7 § 1391(b), because the Defendants operate and perform their official duties therein and thus reside
8 therein for purposes of venue.

9 **IV. PARTIES**

10 11. Plaintiff Pablo Carranza is a "qualified person with a disability" within the meaning
11 of all applicable statutes, including 42 U.S.C. §12131(2) and 29 U.S.C. §705(20)(B). Plaintiff is
12 21 years old and has been and continues to be a Medi-Cal beneficiary.

13 12. At a young age, Pablo was diagnosed with Muscular Dystrophy, a disease which
14 causes the muscles of the body to atrophy and which worsens over the lifespan of the individual.
15 Pablo is an intelligent and self-aware young man, but he needs total care for every daily activity.
16 He cannot walk, and cannot move himself or even turn over in bed. He cannot feed himself and
17 has limited use of his hands. He has difficulty speaking.

18 13. Plaintiff is completely dependent on medical technologies for survival. He has a
19 gastrostomy tube ("G-tube") for feeding and medication administration and uses a tracheal tube for
20 breathing. He is dependent on a ventilator to breathe at all times. Pablo requires one-to-one care by
21 a licensed nurse 24 hours per day.

22 14. Pablo lives with his mother and older brother, Raul (who also has Muscular
23 Dystrophy), in San Diego County, California.

24 15. Defendant California Department of Health Care Services ("DHCS") administers
25 the California Medicaid program, called "Medi-Cal." DHCS is the single state agency responsible
26 for supervising the administration of the Medi-Cal program. DHCS' primary place of business is
27 in Sacramento, within Sacramento County, California.

28 16. Defendant Toby Douglas is DHCS' current Director and is sued only in his official

1 capacity. Director Douglas is responsible for directing, organizing, and administering the Medi-
2 Cal program, including Medi-Cal Home and Community Based Services Waivers, in accordance
3 with all applicable laws and regulations. As such, he is responsible for DHCS' compliance with
4 state and federal laws governing the Medi-Cal program. Director Douglas' primary place of
5 business is Sacramento, within Sacramento County, California.

6 **V. STATUTORY AND REGULATORY FRAMEWORK**

7 **A. THE MEDICAID PROGRAM**

8 17. Medicaid is a joint federal and state medical assistance program for certain groups
9 of low-income people, including children. 42 U.S.C. §§ 1396-1396v. California has elected to
10 participate in the Medicaid program, and so must comply with the requirements of the federal
11 Medicaid Act and its implementing regulations. California's Medicaid program is known as
12 "Medi-Cal."

13 18. The purpose of Medicaid is to furnish, as far as practicable, "medical assistance on
14 behalf of . . . aged, blind or disabled individuals, whose income and resources are insufficient to
15 meet the costs of necessary medical services" and "to help such families and individuals to attain or
16 retain capability for independence or self-care" 42 U.S.C. § 1396.

17 19. Participating States are reimbursed by the federal government for a portion of the
18 cost of providing Medicaid benefits. *See* 42 U.S.C. § 1396b. The remaining funding for the Medi-
19 Cal program comes from the State and from counties.

20 20. States participating in Medicaid must designate a "single state agency" to administer
21 or supervise the administration of the Medicaid program. 42 U.S.C. § 1396a(a)(5). DHCS is the
22 single state agency so designated in California.

23 21. The California Medi-Cal program provides an array of medical services, treatments,
24 and therapies that are authorized based on individuals' meeting "medical necessity" criteria. Welf.
25 & Inst. Code §§ 14059, 14059.5, 14133.3; 22 California Code of Regulations ("C.C.R.") §
26 51303(a).

27 22. "Private duty nursing services" means services, which are individual and continuous
28 care (in contrast to part-time or intermittent care) provided by a licensed nurse or a certified home

1 health aide employed by a home health agency within the scope of state law. Private duty nursing
2 services are provided in a recipient's home, home-like environment or an approved out-of-home
3 setting. 42 U.S.C. 1396d(a)(9); 42 CFR 440.90.

4 23. As required by federal Medicaid law, California provides Medi-Cal coverage for
5 private duty nursing for children under age 21 if medically necessary to treat or ameliorate a
6 condition, illness, or defect. 42 U.S.C. § 1396d(r)(5). For adults over age 21, private duty nursing
7 is provided through Medi-Cal Home and Community Based Waivers, described below.

8 **Medi-Cal Home and Community-Based Services Waivers**

9 24. The Centers for Medicare and Medicaid ("CMS") is the federal agency that oversees
10 the administration of the Medicaid programs offered by each state. CMS has the authority to waive
11 certain provisions of federal Medicaid law to allow states to provide home and community-based
12 services ("HCBS") in lieu of institutional care, for targeted groups of individuals who otherwise
13 would require care in a medical facility. 42 U.S.C. § 1396n(c)(1).

14 25. States may receive federal financial participation for such HCBS "waiver" services
15 to the same extent as provided to other Medicaid services offered by the State. CMS approves or
16 denies a state's HCBS waiver application and must approve any amendments to an approved
17 waiver application. *Id.*

18 26. DHCS has been mandated by the Legislature to "seek all necessary waivers . . . in
19 order to provide in-home and community-based care." Welf. & Inst. Code §§ 14132(t), 14137.
20 DHCS routinely seeks and secures approval to renew and amend HCBS Waivers within
21 permissible federal limitations.

22 27. HCBS Waivers in California include the Nursing Facility/Acute Hospital
23 ("NF/AH") Waiver. Under the umbrella of the NF/AH HCBS Waiver, DHCS administers three
24 HCBS waivers which each correspond to an institutional level of care. These levels of care are:
25 Nursing Facility Level A or B ("NF-A/B"), Nursing Facility Subacute ("Subacute"), and Acute
26 Hospital. Each of the three HCBS Waivers contained in the NF/AH Waiver offers an array of
27 home and community-based services, including private duty nursing.

28 28. The level of care criteria for the NF/AH Home and Community Based Services

1 Waivers explicitly describe the type and level (or severity) of functional limitations and/or skilled
2 nursing needs an individual must have to be admitted to an institutional setting. Upon meeting
3 those eligibility criteria, or level of care, an individual may qualify for corresponding NF/AH
4 HCBS Waiver services.

5 29. In order to meet federal cost-neutrality requirements, the NF/AH Waiver contains
6 assurances that services provided in the community pursuant to the NF/AH Waiver will not exceed
7 the cost of services in the institution designated for comparable care. Thus, the three Waivers
8 within the NF/AH HCBS Waiver correspond to an institutional level of care and have individual
9 maximum benefit levels, or cost-caps, depending on the Medi-Cal rate for their corresponding
10 facility. These “cost-caps” allow a qualifying individual to choose from a menu of available home
11 and community-based services up to the cost-cap for his or her level of care set by DHCS in the
12 applicable HCBS Waiver.

13 30. Upon information and belief, the Medi-Cal program pays \$271,697 per year to
14 Subacute facilities for adults over the age of 21 who are placed in those institutions.

15 31. However, Defendants will not provide a comparable level of HCBS waiver funding
16 for home-based services for individuals such as Pablo who meet the Subacute criteria and would
17 otherwise be placed in a Subacute facility. This is because Defendants have arbitrarily set the cost-
18 cap under the NF/AH Waiver services at the adult Subacute level of care at \$180,219, which is
19 more than \$90,000 below the actual cost of the comparable institutional placement.

20 32. Federal cost-neutrality requirements do not prohibit Defendants from setting the
21 Waiver cost-cap at or just below the rate paid to Subacute facilities.

22 **B. FEDERAL ANTI-DISCRIMINATION LAWS**

23 33. Qualifying individuals with disabilities are protected from disability discrimination,
24 including segregation in institutions, by the ADA and Section 504.

25 34. In enacting the ADA, Congress found that “[i]ndividuals with disabilities
26 continually encounter various forms of discrimination, including...segregation...” 42 U.S.C.
27 § 12101(a) (5). Title II of the ADA provides that “no qualified individual with a disability shall, by
28 reason of disability, be excluded from participation in or be denied the benefits of services,

1 programs, or activities of a public entity or be subjected to discrimination by such entity.” 42
2 U.S.C. § 12132.

3 35. Regulations implementing Title II of the ADA provide: “[a] public entity shall
4 administer services, programs, and activities in the most integrated setting appropriate to the needs
5 of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d) (1991); *see also* Section 504, 29
6 U.S.C. §§ 794-794a; 28 C.F.R. § 41.51(d). Further, “[t]he most integrated setting appropriate to
7 the needs of a qualified individual with a disability means a setting that enables individuals with
8 disabilities to interact with non-disabled persons to the fullest extent possible.” 28 C.F.R. pt. 35,
9 App. A, p. 450 (1998).

10 36. The United States Supreme Court in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581
11 (1999) held that the unnecessary institutionalization of individuals with disabilities is a form of
12 discrimination under Title II of the ADA. In doing so, the Court interpreted the ADA’s “integration
13 mandate” as requiring persons with disabilities to be served in the community when: (1) the state
14 determines that community-based treatment is appropriate; (2) the individual does not oppose
15 community placement; and (3) community placement can be reasonably accommodated. *Olmstead*,
16 527 U.S. at 607.

17 37. Regulations implementing Title II of the ADA and Section 504 also provide: “A
18 public entity may not, directly or through contractual or other arrangements, utilize criteria or other
19 methods of administration: (i) that have the effect of subjecting qualified individuals with
20 disabilities to discrimination on the basis of disability; [or] (ii) that have the purpose or effect of
21 defeating or substantially impairing accomplishment of the objectives of the entity’s program with
22 respect to individuals with disabilities...” 28 C.F.R. § 35.130(b)(3); 28 C.F.R. § 41.51(b)(3)(I); 45
23 C.F.R. § 84.4(b)(4).

24 38. ADA regulations further provide: “[a] public entity shall not impose or apply
25 eligibility criteria that screen out or tend to screen out an individual with a disability or any class of
26 individuals with disabilities from fully and equally enjoying any service, program, or activity,
27 unless such criteria can be shown to be necessary for the provision of the service, program, or
28 activity being offered.” 28 C.F.R. § 35.130(b)(8); *see also* parallel Section 504 regulations, 45

1 C.F.R. § 84.4(b)(1)(iv).

2 39. As set forth in federal regulations: “[a] public entity shall make reasonable
3 modifications in policies, practices, or procedures when the modifications are necessary to avoid
4 discrimination on the basis of disability, unless the public entity can demonstrate that making the
5 modifications would fundamentally alter the nature of the service, program, or activity.” 28 C.F.R.
6 § 35.130(b)(7).

7 VI. FACTUAL ALLEGATIONS

8 About Pablo Carranza

9 40. Pablo Carranza was diagnosed with Muscular Dystrophy at two years of age.
10 Muscular Dystrophy is a degenerative disease involving advancing muscle weakness and loss of
11 muscle tissue over time.

12 41. Pablo’s health care has been funded entirely by Medi-Cal.

13 42. Pablo lives at home with his mother, Leticia Martinez, and brother, Raul Carranza,
14 who also has Muscular Dystrophy. Pablo’s father, Raul Carranza, visits on a weekly basis.
15 Pablo’s mother is his primary care giver, but both his mother and father are involved in planning
16 for and providing his care.

17 43. Pablo takes community college courses online and requires assistance with
18 repositioning and equipment when doing his school work.

19 44. Pablo and his family desire that he continue living at home with appropriate nursing
20 services.

21 45. Pablo is medically fragile and technology dependent. He had a G-tube placed at age
22 12 and receives nutrition, hydration and medication through his G-tube. Pablo is non-ambulatory
23 and cannot bear weight. He uses a wheelchair and requires assistance with all activities of daily
24 living (“ADLs”).

25 46. At 14 years of age, Pablo could no longer breathe on his own due to muscle
26 weakness and he had a tracheotomy. Since that time, Pablo has been dependent on a ventilator 24
27 hours per day. Unlike many ventilator patients, Pablo is alert and oriented. Pablo has an uncuffed
28 tracheotomy, which allows for the possibility of communication/speech, but also allows fluid to go

1 into the lungs if not timely suctioned. This is one of the reasons that Pablo requires constant
2 skilled monitoring. In addition, when Pablo is able to communicate, it is by whisper, and
3 individuals need training to understand him.

4 47. Due to Pablo's mucous secretions and his inability to swallow due to the
5 tracheotomy, he must be orally suctioned approximately every 10-15 minutes when saliva or
6 mucus builds up in his mouth, nose and throat. Pablo also requires deep suctioning through his
7 tracheotomy tube into his lungs up to nine times per day to clear mucous that has flowed down into
8 the tracheotomy. The oral suctioning and deep suctioning help keep fluid from going into his
9 lungs. If fluid does go into his lungs, it could impair oxygen exchange, resulting in lack of oxygen
10 and permanent damage to organs (including brain injury), pneumonia, and infection.

11 48. In addition to Muscular Dystrophy, Pablo has been diagnosed with scoliosis and had
12 spinal fusion surgery in 2010.

13 49. Pablo is regularly seen by the following doctors and specialists at the University of
14 California San Diego and other hospitals: a primary care physician, neurologists, a pulmonologist,
15 a pediatric otolaryngologist, an orthopedist, a cardiologist, a pain management specialist, and a
16 gastroenterologist. In the past two years, Pablo has been in the hospital or hospitalized several
17 times, as well as seen by his doctors on numerous occasions.

18 50. For the past seven years, Pablo's physician has ordered one-to-one nursing care 24
19 hours per day. His in-home skilled care is provided by licensed vocational nurses ("LVNs" or
20 "nurses"). LVNs are licensed to provide skilled nursing care in many settings including hospitals.
21 42 C.F.R. Sec. 409.31 (a); 22 C.C.R. §§ 70055(a)(16), §70055(a)(16) & 70217 (a). Pablo also is
22 authorized to receive two hours per month of case management by a Registered Nurse.

23 51. Upon information and belief, in 2005, DHCS authorized 720 hours per month of
24 Medi-Cal funded one-to-one in-home, or "private duty" nursing care, based on its determination
25 that he met the Pediatric Subacute level of care at all times. This provided him with 24 hour
26 coverage. On information and belief, between 2005 and 2012, DHCS reduced Pablo in-home
27 nursing hours by approximately 4 hours per day, leaving him with 615 hours of nursing care per
28 month, which is the number of monthly hours he currently receives.

1 52. Pablo's mother, Leticia has been trained in his care needs and provided the
2 remainder of his 24-hour per day care, with limited assistance from his father. She has also
3 provided backup care during times when Pablo's needs are so intense that two caregivers are
4 required or when the home health agency fails to staff a shift and a nurse is not available.

5 53. Neither Pablo's mother nor his father is available to provide additional care for
6 Pablo. His mother is a full-time caregiver for Pablo's older brother, Raul, who also lives at home.
7 In addition, Pablo's mother's own health is deteriorating and could potentially affect her ability to
8 provide caregiver duties. Pablo's father works full-time and is unavailable to provide additional
9 caregiver duties. Moreover, since Pablo is over the age of 18, neither parent has a legal obligation
10 to provide for his care.

11 **Pablo's Nursing Care Needs**

12 54. The following are Pablo's medical care needs as set forth and approved by his
13 physician in the Plan of Treatment document created by the Home Health Agency and approved by
14 DHCS and funded by Medi-Cal prior to Pablo's 21st birthday:

- 15 A. Generally, skilled nurses perform/assist with personal care, Activities of
16 Daily Living ("ADLs"), incontinent care, skin care, dressing, tracheotomy
17 care, G-tube care and feedings every shift and as needed at other times.
- 18 B. Skilled nurses provide passive range of motion ("PROM") exercises as
19 tolerated every shift and PRN since Pablo cannot move any part of his body
20 or use his muscles, with the exception of minimal movement of his eyes,
21 tongue, mouth and one finger.
- 22 C. Skilled nurses monitor his skin condition every shift and PRN to look for
23 change in status. They also reposition his body every 2 hours and PRN to
24 prevent skin breakdown and bed sores.
- 25 D. Skilled nurses administer medications per doctor's order and take vital
26 signs every shift and PRN change in status. Nurses also must count
27 controlled substances on each shift. Pablo has a lengthy list of prescribed
28 and PRN medications that are administered on a daily basis.

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- E. Skilled nurses check all equipment, including the ventilator settings and suctioning machine, every shift and PRN. Ventilator settings must be checked and kept constant, and can only be changed by licensed personnel. Nurses may increase certain settings one point at a time every day until Pablo is comfortable and able to speak, and change settings as requested and as tolerated by Pablo and at his request.
- F. Skilled nurses must monitor oxygen settings and keep his oxygen saturation level greater than 93%, and utilize a heated circuit via the ventilator as needed to keep oxygen saturation greater than 93%.
- G. If the tracheotomy comes out (i.e., decannulation occurs), skilled nurses must check client, replace tracheotomy (which requires two people), administer oxygen, suction as necessary and use an ambu-bag, a hand-held device used to manually pump air into the lungs of the individual when not connected to the ventilator (which also takes two people), as necessary.
- H. Skilled nurses or Respiratory Therapist must change tracheotomy 1 to 2 times each month and as needed.
- I. Skilled nurses monitor the tracheotomy stoma every shift and as needed for change in status, including changing the tracheotomy ties if they come lose or as needed, and clean around the tracheotomy stoma with normal saline every shift and as needed. Skilled nurses must suction as needed increased secretions both orally and deep/tracheotomy suctioning. They monitor and observe secretions/sputum for symptoms of infection and notify doctor.
- J. Skilled nurses perform tracheal suctioning on average 1 to 3 times during each shift, and oral suctioning 5 to 10 times per hour during each shift every day.
- K. Skilled nurses must ambu-bag Pablo as needed for shortness of breath. Skilled nurses must contact the doctor or RN for any significant changes in status.

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- L. Skilled nurses need to ensure that G-tube balloon remains inflated with 5-6 milliliters (“ml”) water each day. Skilled nurses change the G-tube every 4-5 months and as needed if it is dislodged or if it malfunctions. Skilled nurses monitor the G-tube site every shift and as needed for change in status. Also, G-tube must be cleansed with normal saline each shift and as needed.
- M. For nutrition, skilled nurses prepare and administer G-tube feedings of a specialized formula that is made with water and is administered via pump at 75 ml per hr continuously. Pablo may have 120 ml of water 4 times per day via G-tube in addition to current feeding regimen and as needed, as well as 20ml of Pedialite via G-tube for extra fluids.
- N. Skilled nurses flush the G-tube with 10-60ml of water both before and after medications are given. Nurses may increase water consumption above 500 ml per day, may mix more with feedings, or give small doses of 100 ml via G-tube throughout day as tolerated and as needed per Pablo’s request.
- O. Skilled nurses assist Pablo to cough with an inxsuflator machine as needed to clear the mucous, followed by suction. Settings for the inxsuflator machine are very specific. Skilled nurses give nebulizer (breathing) treatments as needed and at client’s request.
- P. Skilled nurses apply stockings up to thighs as needed for restless leg syndrome, as needed, or at client’s request, and use Transcutaneous Electrical Nerve Stimulation (“TENS”) Unit as needed at specified frequencies. This unit must be turned off for 1 hour two times daily to let the skin breath.
- Q. Skilled nurses use a straight catheterization method (this is a method that requires one time insertion to relieve the bladder, as opposed to a catheter that is left in the site over time) as needed for bladder distention and may use urinary straight catheter every 8 hours as needed if client is not

1 urinating spontaneously; they notify the doctor or RN if there is a foul odor
2 or change in color of urine; they notify the doctor if client has no bowel
3 movement for 5 days, or sooner if there is abdominal pain or distress.

4 R. Skilled nurses to observe and monitor for symptoms of complications to
5 pulmonary status and gastrointestinal status. Skilled nurses monitor
6 musculoskeletal and neurological systems every shift and PRN. Skilled
7 nurses report to the doctor any abnormal findings and contact the registered
8 nurse or doctor if there are any unusual occurrences and/or any significant
9 changes in client's status. Safety measures practiced by skilled nurses
10 include aspiration precaution and universal precaution/infection control.

11 S. Skilled nurses monitor Pablo's back pain related to past spinal fusion
12 surgery and provide pain medication every 4 hours, as well as other over
13 the counter pain medications as needed.

14 T. Pablo's mother has to assume all care for Pablo when skilled nurses are not
15 present, which under the Plan of Care was for a total of 2 hours per day
16 between LVN shifts.

17 55. The skilled nursing services Pablo currently receives cannot safely be provided by
18 untrained or unskilled individuals. One-on-one skilled nursing services are ordered by Pablo's
19 physician 24 hours per day, and have been found to be medically necessary by DHCS since at least
20 2005.

21 **In-Home Nursing Authorization**

22 56. At and before Pablo's 21st birthday, the cost to the Medi-Cal program for Pablo's
23 home care, including 615 hours per month of private duty nursing and his medical equipment and
24 supplies, was approximately \$230,000 per year.

25 57. On July 24, 2012, DHCS conducted a home visit to reassess Pablo to determine the
26 appropriate amount of care needed upon reaching his 21st birthday. The DHCS reviewer told Pablo
27 and his mother that a notice would be forthcoming with DHCS' decision. However, Pablo and
28 family did not receive a written notice. Pablo's mother called the DHCS reviewer on several

1 occasions, but no one returned her calls.

2 58. On August 29, 2012, a high-level DHCS employee called Pablo's mother on the
3 telephone. This DHCS employee informed his mother that, upon turning age 21, Pablo's nursing
4 care would be authorized through the NF/AH Home and Community Based Services Waiver at the
5 Subacute level of care. The DHCS employee stated that because the cost-cap for the Subacute
6 level of care under the NF/AH Waiver is \$180,219, Pablo would no longer be authorized for 615
7 hours per month of private duty nursing, and that his nursing hours would be reduced. DHCS did
8 not offer any exception to the cost-cap to Pablo.

9 59. During the conversation with DHCS on August 29th, 2012, Pablo's mother asked
10 whether she could appeal that decision, and how to do so. On August 30, 2012, DHCS sent her
11 information on how to ask for state hearing, along with a number of different combinations of care,
12 called a Menu of Health Services ("MOHS"), up to the cost-cap of \$180,219. Included in the cost-
13 cap in these various combinations are: private duty nursing (including shared nursing with his
14 brother), two hours per month of case management by a Registered Nurse, payment for Pablo's
15 county-authorized unskilled personal care services. Yet each of these combinations offered by
16 DHCS would require Pablo to accept far fewer hours of nursing care (between 100 and 225 fewer
17 hours per month). Most scenarios would require him to share nursing care with his brother, which
18 his doctors and the home health agency that employs his nurses reject as dangerous to both
19 brothers. All scenarios would leave him without any care for five to 10 hours per day.

20 60. On September 6, 2012, Pablo appealed DHCS' verbal decision to reduce nursing
21 services by certified receipt mail and requested "aid paid pending" or, continuation of 615 hours
22 per month of in-home nursing pending his hearing decision.

23 61. DHCS refused to authorize aid paid pending.

24 62. On October 22, 2012, an administrative law judge issued an order for aid paid
25 pending. As of this date, Pablo continues to receive 615 hours of private duty nursing. DHCS has,
26 however, challenged the aid paid pending order, which may be reversed at any time.

27 **Defendants' Actions Place Pablo at Risk of Institutionalization**

28 63. According to Pablo's medical professionals, home is the safest place for Pablo to

1 maximize his health condition and prolong his life. Placement in an institution, however, will
2 almost certainly cause health deterioration and possible death within a short period of time.

3 64. Defendants have cut Pablo's nursing hours solely due to the fact that Pablo turned
4 21 years of age and are without medical justification. Pablo's medical condition has not improved;
5 his need for in-home nursing has not decreased.

6 65. Defendants have placed an arbitrary cost-cap on home and community based
7 services at the Subacute level of care under the NF/AH Waiver, which is far less than the actual
8 institutional rate for a Subacute facility.

9 66. Defendants have great flexibility and discretion in their administration of the
10 NF/AH waiver. They have the authority to make modifications to ensure that Medi-Cal recipients
11 such as Pablo receive sufficient and medically necessary in-home care to avoid institutional
12 placement and are not subjected to abrupt reductions in their home care services.

13 67. Pablo's needs can be reasonably accommodated by Defendants continuing to
14 provide Pablo with in-home nursing up to the rate that Defendants would actually pay if Pablo
15 were to be admitted to a Subacute facility; and/or modifying any of its Home and Community
16 Based Waivers to permit Pablo to receive the nursing care hours that he requires and that are
17 physician ordered.

18 68. Defendants have many options to administer the NF/AH waiver so as not to create a
19 bias towards institutional placements. One option would be to increase the cost-cap for the
20 Subacute level of care of the NF/AH Waiver to a level that is equal to amount actually paid to
21 Subacute facilities. Alternatively, Defendants could also create a provision in the waiver to allow
22 youth such as Pablo who turn age 21 to continue with the same number of nursing hours, Instead,
23 Defendants have chosen to administer the waiver in such a way as to discriminate against Pablo
24 and to place him at risk of institutional placement, with life threatening consequences.

25 69. Without the appropriate level of in-home nursing hours to remain in his home, Pablo
26 will have no choice but institutional placement, which will separate him from his family and
27 community and also poses significant risks to his health.

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1 **VII. LEGAL CLAIMS**

2 **FIRST CLAIM FOR RELIEF**

3 **(Defendant Director Toby Douglas)**

4 **Americans with Disabilities Act, 42 U.S.C. § 12134-35 et seq.**

5 70. Plaintiff realleges and incorporates herein by reference each and every allegation
6 and paragraph set forth previously.

7 71. Plaintiff is a “qualified individual with a disability” within the meaning of the ADA
8 in that he (1) has a physical impairment that substantially limits one or more major life activities;
9 and (2) meets the essential eligibility requirements for community-based long-term care under
10 California’s Medicaid program.

11 72. Defendant Toby Douglas is the Director of Defendant DHCS, which has
12 responsibility for providing Medi-Cal and state-funded home and community based and
13 institutional services, and is therefore a government entity subject to Title II of the ADA. 42 USC
14 §12131(1)(A) and (B).

15 73. Defendant’s reduction in adequate and necessary in-home nursing, and failure to
16 provide Plaintiff with sufficient medically necessary in-home nursing, has denied Plaintiff the
17 services he needs to remain safely in the community, thereby placing him at risk of
18 institutionalization in violation of the ADA’s integration mandate.

19 74. Defendant has discriminated against Plaintiff in ways that include arbitrarily setting
20 a cost-cap for the Subacute level of care of the NF/AH Waiver far below the actual rate paid for
21 institutional services in a Subacute facility, thus denying Plaintiff funds for home and community-
22 based services that would otherwise be available for institutional services.

23 75. Defendant has discriminated against Plaintiff by failing to provide reasonable
24 modifications to programs and services in ways that include: failing to increase the Subacute level
25 of care cost-cap, within federal cost neutrality limitations, to enable Plaintiff to fund necessary in-
26 home nursing, and failing to offer an exception to the Subacute level of care cost-cap that would
27 enable Plaintiff to fund in-home nursing at a level adequate to meet his undisputed need.

28 76. By denying Plaintiff adequate and necessary in-home nursing commensurate with

1 his actual need, as opposed to arbitrary service limitations, Defendant has imposed eligibility
2 requirements which unlawfully screen him out from fully and equally enjoying in-home nursing
3 services, and from receiving adequate care to remain safely at home.

4 77. Defendant has utilized criteria and methods of administration that subject Plaintiff
5 to discrimination on the basis of disability, including risk of unnecessary institutionalization, in
6 ways that include: (1) designing and implementing Home and Community Based Waivers which
7 set arbitrarily low cost-caps for in-home nursing services, while paying significantly higher rates
8 for the institutional Subacute facility alternative; and (2) imposing eligibility criteria, cost
9 limitations and other criteria not required by federal limitations, which restrict in-home care in
10 favor of institutional care, and (3) refusing to continue Plaintiff's current hours of nursing care
11 during his transition to the NF/AH Home and Community Based Services Waiver so that his
12 appropriate level of care can be determined and the risk of institutionalization minimized.

13 78. Defendant's actions are in violation of Title II of the ADA.

14 79. Pursuant to 42 U.S.C. § 12133, Plaintiff is entitled to declaratory and injunctive
15 relief, as well as reasonable attorneys' fees and costs incurred in bringing this action.

16 **SECOND CLAIM FOR RELIEF**

17 **(Defendant DHCS)**

18 **Section 504 of the Rehabilitation Act, 29 U.S.C. § 794 *et seq.***

19 80. Plaintiff realleges and incorporates herein by reference each and every allegation
20 and paragraph set forth previously.

21 81. Plaintiff is a "qualified individual with a disability" within the meaning of Section
22 504 in that his physical impairments substantially limits one or more major life activities; and he
23 meets the essential eligibility requirements in that he is capable of living independently in his
24 family home and/or in the most integrated community setting possible, with assistance.

25 82. Defendant DHCS is a recipient of federal monies that provide Medi-Cal home and
26 community-based and institutional services and other Medi-Cal services and is therefore a
27 government entity subject to Section 504. 29 USC 794(b).

28 83. Defendant's reduction in adequate and necessary in-home nursing has denied

1 Plaintiff the services he needs to continue to live in the community, thereby placing him at
2 imminent risk of institutionalization in violation of Section 504's integration mandate.

3 84. Defendant DHCS discriminates against Plaintiff in ways that include setting a cost-
4 cap for the Subacute level of care of the NF/AH Waiver far below the actual rate paid for
5 institutional services in a Subacute facility, thus denying Plaintiff funds for home and community-
6 based services that would otherwise be available for institutional services.

7 85. Defendant has discriminated against Plaintiff by failing to provide reasonable
8 modifications to programs and services in ways that include: failing to increase the Subacute level
9 of care cost-cap, within federal cost neutrality limitations, to enable Plaintiff to fund necessary in-
10 home nursing, and failing to offer an exception to the Subacute level of care cost-cap that would
11 enable Plaintiff to fund in-home nursing at a level adequate to meet his undisputed need.

12 86. By denying Plaintiff adequate and necessary in-home nursing commensurate with
13 his actual need, as opposed to arbitrary service limitations, Defendant has imposed eligibility
14 requirements which unlawfully screen him out from fully and equally enjoying in-home nursing
15 services, and from receiving adequate care to remain safely at home.

16 87. Defendant has utilized criteria and methods of administration that subject Plaintiff
17 to discrimination on the basis of disability, including risk of unnecessary institutionalization, by,
18 including but not limited to the following: (1) designing and implementing Home and Community
19 Based Waivers which set arbitrarily low cost-caps for in-home nursing services, while paying
20 significantly higher rates for the institutional Subacute facility alternative; and (2) imposing
21 eligibility criteria, cost limitations and other criteria not required by federal limitations, which
22 restrict in-home care in favor of institutional care; and (3) refusing to continue Plaintiff's current
23 hours of nursing care during his transition to the NF/AH Home and Community Based Services
24 Waiver so that his appropriate level of care can be determined and the risk of institutionalization
25 minimized.

26 88. Defendant's actions violate Section 504.

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1 **THIRD CLAIM FOR RELIEF**

2 **(Defendant Director Toby Douglas)**

3 **Claim Under 42 U.S.C. §1983, Deprivation of Federal Constitutional Rights -**

4 **Violation of Procedural Due Process**

5 89. Plaintiff realleges and incorporates herein by reference each and every allegation
6 and paragraph set forth previously.

7 90. Under the due process clause of United States Constitution, when recipients of
8 needs-based public benefits such as Medicaid are facing a reduction or termination of benefits, they
9 are entitled to advance written notice explaining the basis for the adverse government action and an
10 opportunity for a hearing prior to reduction or termination of their benefits. U.S. Const. Amend.
11 XIV.

12 91. Defendant has a policy and practice of failing to provide written notice of the
13 proposed reduction of shift nursing hours to Medi-Cal recipients such as Pablo when they turn age
14 21. Defendant fails to provide notice that explains their right to a hearing, and if a hearing is
15 requested, refuses to continue benefits pending the hearing.

16 92. Defendant's practices and procedures alleged herein violate the Due Process clause
17 of the Fourteenth Amendment to the U.S. Constitution by, among other things, denying Plaintiff
18 adequate notice and the opportunity for a hearing prior to reduction, suspension or termination of
19 essential health care benefits. .

20 93. In all of the above-mentioned actions, Defendant has, acting under color of state
21 law, deprived Plaintiff of rights, privileges or immunities secured to him by the Constitution of the
22 United States, in violation of 42 U.S.C. § 1983.

23 **VIII. ALLEGATIONS CONCERNING INJUNCTIVE AND DECLARATORY RELIEF**

24 94. Defendants' actions, as alleged herein, have resulted in, and will continue to result
25 in irreparable injury to Plaintiff caused by the denial of necessary in-home nursing to which he is
26 entitled and which he needs to remain at home with his family and avoid unnecessary institutional
27 placement. Plaintiff has no plain, speedy or adequate remedy at law.

28 95. An actual controversy exists between Plaintiff and Defendants, in that Plaintiff

1 claims that Defendants have violated his rights under the ADA, other federal anti-discrimination
2 laws, and the Federal Constitution, and Defendants deny all such contentions.

3 96. Defendant Douglas can either adopt or “alternate” (reject in whole or part) any
4 administrative decision arising out of claims against DHCS. California Manual of Policies and
5 Procedures, Sections 22-061 and 22-062. Therefore, the administrative appeal process offers no
6 remedy or protection to Pablo, as the Defendant in this action is the very person who will make a
7 determination of what level of care under DHCS’ NF/AH Waiver will be provided to Pablo.

8 **IX. REQUEST FOR RELIEF**

9 WHEREFORE, Plaintiff prays that the Court order the following relief and remedies on
10 behalf of themselves and all others similarly situated:

11 A. Assume jurisdiction over this action and maintain continuing jurisdiction until
12 Defendants are in full compliance with every order of this Court;

13 B. Declare that Defendants' failure to provide Plaintiff with sufficient Medi-Cal
14 funded in-home nursing hours to meet his undisputed need for 24-hour per day nursing care and
15 Defendants’ policies, practices, acts and omissions as set forth above violate the American with
16 Disabilities Act, and Section 504 of the Rehabilitation Act.

17 C. Declare that Defendants' failure to continue Plaintiff’s current nursing hours during
18 his transition to adult services, and prior to a determination of his current needs and level of care
19 and the provision of written notice of the basis of the reduction in his nursing hours and an
20 opportunity for a hearing, prior to any reduction, and Defendants’ policies, practices, acts and
21 omissions as set forth above violate the American with Disabilities Act, the Due Process Clause of
22 the United States Constitution and 42 U.S.C. § 1983.

23 D. Grant a temporary restraining order and preliminary injunction enjoining
24 Defendants, their officers, agents, employees, attorneys, and all persons who are in active concert
25 or participation with them from reducing medically necessary Medi-Cal funded in-home nursing
26 below his current level of 615 hours per month until such time as this matter may be finally
27 decided.

28 E. Grant a permanent injunction enjoining Defendants, their officers, agents,

1 employees, attorneys, and all persons who are in active concert or participation with them from
2 discriminating against Plaintiff and thereby placing him at risk of unnecessary institutionalization
3 by:

- 4 i. Failing to offer reasonable modifications to their programs and policies to
5 enable Plaintiff to receive medically necessary in-home nursing as ordered
6 by his physicians;
- 7 ii. Imposing eligibility requirements which unlawfully screen Plaintiff out of
8 the NF/AH Waiver program and prevent him from fully and equally
9 enjoying in-home nursing services, and from receiving adequate care to
10 remain safely at home;
- 11 iii. Utilizing criteria and methods of administration that subject Plaintiff to
12 discrimination on the basis of disability, including placing him at risk of
13 unnecessary institutionalization.

14 F. Grant a temporary restraining order, preliminary and permanent injunction
15 enjoining Defendants, their officers, agents, employees, attorneys, and all persons who are in active
16 concert or participation with them from reducing medically necessary Medi-Cal funded in-home
17 nursing below his current level of 615 hours per month to Plaintiff without first providing adequate
18 and effective written notice of the proposed termination and reduction of Medi-Cal funded health
19 services, notice of the right to appeal these actions and of the right to continued benefits pending an
20 appeal hearing.

21 G. Issue an order requiring Defendants to provide Plaintiff with Medi-Cal funded in-
22 home nursing through the Nursing Facility/Acute Hospital Waiver or other appropriate Home and
23 Community Based Waivers, subject to federal cost neutrality requirements, to enable him to
24 receive in-home nursing commensurate with his needs identified by his treating physicians, and as
25 medically necessary.

26 H. Retain jurisdiction over the Defendants until such time as the Court is satisfied that
27 defendants' unlawful policies, practices, and acts complained of herein cannot recur;

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I. Award the Plaintiff the costs of this action and reasonable attorneys' fees pursuant to 20 U.S.C. § 794a; 42 U.S.C. §§ 1988, 12133, 12205; and as otherwise may be allowed by law.

J. Grant such other and further relief as the Court deems to be just and equitable.

Dated: 12/4/2012

Respectfully Submitted,
DISABILITY RIGHTS CALIFORNIA
WESTERN CENTER ON LAW & POVERTY

By: /s/ Debra Marley
Debra Marley

Attorneys for Plaintiff