

1 Elissa Gershon, State Bar No. 169741
2 Elissa.Gershon@disabilityrightsca.org
3 Anne Hadreas, State Bar No. 253377
4 Anne.hadreas@disabilityrightsca.org
5 Deborah Gettleman, State Bar No. 267309
6 Deborah.gettleman@disabilityrightsca.org
7 DISABILITY RIGHTS CALIFORNIA
8 1330 Broadway, Suite 500
9 Oakland, CA 94612
10 Telephone: (510) 267-1200
11 Facsimile: (510) 267-1201

12 Marilyn Holle, State Bar No. 61530
13 Marilyn.Holle@disabilityrightsca.org
14 Betsy Havens, State Bar No. 296842
15 Betsy.Havens@disabilityrightsca.org
16 DISABILITY RIGHTS CALIFORNIA
17 350 South Bixel Street, Suite 290
18 Los Angeles, California 90017
19 Telephone: (213) 213-8000
20 Fax: (213) 213-8001

21 Attorneys for Plaintiffs JERRY THOMAS,
22 SEAN BENISON, JUAN PALOMARES and IN SPIRIT

23 **UNITED STATES DISTRICT COURT**
24 **CENTRAL DISTRICT OF CALIFORNIA**

25 JERRY THOMAS, by and through his) CASE NO. 14-CV-08013-FMO (AGR_x)
26 *guardian ad litem* BEVERLY THOMAS,)
27 SEAN BENISON, JUAN PALOMARES) **SECOND AMENDED COMPLAINT**
28 and IN SPIRIT) **FOR INJUNCTIVE AND**
) **DECLARATORY RELIEF**
)
29 Plaintiffs,)
30 v.) Courtroom: 22, 5th Floor
31) Judge: Hon. Fernando M. Olguin
32 JENNIFER KENT, Director of the) Action Filed: 10/25/2014
33 Department of Health Care Services, State) Trial Date: 04/26/2016
34 of California DEPARTMENT OF)
35 HEALTH CARE SERVICES,)
36)
37 Defendants.)

1 **I. INTRODUCTION**

2 1. This civil rights action seeks declaratory and injunctive relief to stop
3 Defendants Department of Health Care Services and its Director, Jennifer Kent
4 ("DHCS" or "Defendants") from continuing their illegal practices which result in
5 denial of critically needed Medi-Cal funded in-home services to individuals such as
6 Plaintiffs Jerry Thomas, Sean Benison, and Juan Palomares, and the clients of
7 organizational Plaintiff IN SPIRIT. Failure to receive these services will result in
8 severe harm and potential institutionalization of these individuals with disabilities.
9 Due to their fragile medical conditions, placement in an institution is likely to result
10 in dire health consequences and even death. Institutional care for Plaintiffs would
11 also cost the State significantly more than it would to keep them safely in their own
12 homes.

13 2. Individual Plaintiffs have severe disabilities and chronic medical
14 conditions: Plaintiff Jerry Thomas is diagnosed with Progressive Supranuclear Palsy
15 and Post-Polio Syndrome. Plaintiff Sean Benison has advanced hereditary
16 progressive Muscular Dystrophy. Plaintiff Juan Palomares has a complete spinal
17 cord injury at the 4th vertebrae in the cervical area (C-4); the spinal cord injury also
18 caused autonomic dysreflexia, which is instability in his nervous system that can
19 cause unpredictable and potentially life-threatening blood pressure changes. Due to
20 their health conditions, Plaintiffs are quadriplegic and cannot move on their own.
21 Plaintiffs Thomas and Benison have tracheal tubes connected to ventilators to help
22 them breathe. Plaintiff Thomas receives nutrition and hydration via a Gastrostomy
23 feeding tube.

24 3. Although Plaintiffs meet the criteria for placement in nursing
25 institutions, Plaintiffs have been able to remain in their communities and close to
26 their families because of in-home care available to them in their homes under the
27 Medi-Cal Home and Community-Based Services Nursing Facility/Acute Hospital
28 Waiver ("NF/AH Waiver"), administered by Defendants.

1 4. All three Plaintiffs live in their own homes, with round-the-clock care
2 provided by licensed nurses, and unlicensed paid and/or unpaid attendants.
3 However, Plaintiffs also have unmet care needs. Pursuant to their doctors' orders,
4 Plaintiff Thomas needs 24 hour nursing care, and Plaintiff Benison needs additional
5 nursing care, to assess and address their complex and unpredictable needs, including
6 monitoring their ventilators and oxygen levels, preparing and administering
7 medications, and clearing fluids from their lungs and tracheotomy tubes. Plaintiff
8 Palomares needs, among other things, nursing care to manage his complicated
9 catheter care, and monitor and assess his unstable and unpredictable health
10 conditions; additional attendant hours so that he can be repositioned and cared for
11 more frequently to prevent health crises; and reinstatement of RN case management.
12 Plaintiff Benison, who lives alone, also requires Case Management and Habilitation
13 services, which are available under the NF/AH Waiver.

14 5. Plaintiffs have all requested additional in-home care services from
15 Defendants, so that they can continue living safely in their homes and communities.
16 Defendants have denied these requests. The sole reason Plaintiffs are not able to get
17 these critically needed services is because Defendants have placed arbitrary cost
18 limitations on services available under the NF/AH Waiver.

19 6. For Waiver participants like Plaintiffs Thomas and Benison, who have
20 been determined to meet the Subacute level of care, Medi-Cal would pay \$271,697
21 per year for institutional placement in a Subacute facility; however, Defendants have
22 capped the budget for comparable in-home services funded through the NF/AH
23 Waiver at \$180,219 per year, which is at least \$90,000 below the actual cost of
24 equivalent care in a Subacute facility. The cost of the additional nursing and other
25 NF/AH Waiver services requested by Plaintiffs Thomas and Benison would cost
26 less than placement in a Subacute facility.

27 7. Similarly, for Waiver participants like Plaintiff Palomares, who have
28 been determined to meet the Nursing Facility Level B ("NF-B") Level of Care,

1 Medi-Cal would pay approximately \$70,000 per year for institutional placement in a
2 Nursing Facility; however, Defendants have capped the budget for in-home services
3 funded through the NF/AH Waiver at \$48,180.00 per year, which is more than
4 \$21,000 below the actual cost of equivalent care in a Nursing Facility. The cost of
5 the additional nursing and other NF/AH Waiver services requested by Plaintiff
6 Palomares would cost less than placement in a Nursing Facility.

7 8. The NF/AH Waiver cost-caps at all levels of care are significantly
8 below the rate Medi-Cal pays to institutions at the equivalent level of care.

9 9. Defendants have the discretion and the ability to modify the NF/AH
10 Waiver to enable Plaintiffs to receive the skilled nursing care and other services they
11 need to remain safely at home. But, they have refused to provide these essential
12 services on the grounds that it exceeds their arbitrary cost-caps.

13 10. Defendants' actions violate the Americans with Disabilities Act of
14 1990 ("ADA"), (42 U.S.C. §§ 12101-12213 (2008)), Section 504 of the
15 Rehabilitation Act of 1973 ("Section 504"), (29 U.S.C. §§ 794-794a (2014)), and
16 California Government Code section 11135 (Cal. Gov't. Code § 11135 (2011)).

17 11. Under the ADA and Section 504, a public agency such as DHCS has a
18 duty to provide services to people with disabilities in the "most integrated setting
19 appropriate to their needs" and to prevent unnecessary institutionalization. The
20 most integrated setting for the individual Plaintiffs and clients of IN SPIRIT is to
21 continue living in their homes in the community, with adequate NF/AH Waiver
22 services to meet their significant needs. Placing individuals with disabilities such as
23 Plaintiffs at risk of unnecessary institutionalization in order to receive the care they
24 need violates the ADA.

25 12. Under the ADA, Defendants also have an obligation to use methods of
26 administration that do not discriminate against individuals with disabilities such as
27 Plaintiffs. Defendants' failure to ensure that individuals with disabilities like
28 Plaintiffs are provided with adequate NF/AH Waiver services to continue living

1 safely in their homes, and their decision to set funding levels for services that are
2 biased in favor of institutional care results in discrimination against Plaintiffs in the
3 administration of the Medi-Cal program.

4 **II. JURISDICTION**

5 13. This is an action for declaratory and injunctive relief for violations of
6 Title II of the Americans with Disabilities Act, 42 U.S.C. § 12132 (2008) and
7 Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (2014).

8 14. Jurisdiction is based on 28 U.S.C. §§ 1331 (1980) and 1343 (1979).
9 Plaintiffs' claims for declaratory and injunctive relief are authorized under
10 28 U.S.C. §§ 2201 (2010) and 2202 (1948). At all times relevant to this action,
11 Defendants have acted under color of state law.

12 15. The Court has Supplemental Jurisdiction over Plaintiffs' state claim
13 pursuant to 28 U.S.C. § 1367 (1990) and California Government Code section
14 11139 (2001).

15 **III. VENUE**

16 16. Venue is proper in the Central District of California pursuant to
17 28 U.S.C. § 1391(b) (2011), because the Defendants operate and perform their
18 official duties therein and thus reside therein for purposes of venue, and because a
19 substantial part of the events or omissions giving rise to the claims herein occurred in
20 the Central District of California. Plaintiff Jerry Thomas lives and receives Medi-
21 Cal services in Orange County, which is in the Central District of California.
22 Plaintiff Juan Palomares lives and receives Medi-Cal services in Los Angeles
23 County, which is in the Central District of California. Plaintiff Sean Benison lives
24 and receives Medi-Cal services in Ventura County, which is in the Central District
25 of California. Defendant DHCS operates the Medi-Cal program, conducts business
26 and provides Medi-Cal services to Plaintiffs in Orange County, Los Angeles County
27 and Ventura County, all in the Central District of California.

28

1 **IV. PARTIES**

2 **Organizational Plaintiff**

3 17. Organizational Plaintiff IN SPIRIT is a non-profit organization which
4 provides financial aid to people with disabilities to help them pay for personal care
5 attendants to enable them to live in their own homes. IN SPIRIT’s mission is to
6 empower individuals with disabilities to sustain their health, continue their
7 participation in their families and communities, and avoid nursing facility
8 placement. IN SPIRIT has been directly injured by Defendants’ actions, which
9 impede its ability to carry out its mission to assist people with disabilities in
10 accessing community support services. IN SPIRIT has provided and currently
11 provides financial assistance to individuals on the NF/AH Waiver, in order to
12 supplement their limited at-home care services covered by the Waiver. Because of
13 its commitment to provide financial support for attendant care for needy, high-level
14 quadriplegics, IN SPIRIT will serve clients on the NF/AH Waiver in the future. IN
15 SPIRIT has had to divert scarce resources from other potential clients to NF/AH
16 Waiver recipients to pay for services that, but for the cost-caps, would be funded by
17 the NF/AH waiver.

18 **Individual Plaintiffs**

19 18. Each individual Plaintiff is a “qualified person with a disability” within
20 the meaning of all applicable statutes, including 42 U.S.C. §12131(2) (1990) and 29
21 U.S.C. § 705(20)(B) (2014). Plaintiffs have been and continue to be Medi-Cal
22 beneficiaries and are on the NF/AH Waiver.

23 19. Plaintiff Jerry Thomas is 73 years old and has Progressive Supranuclear
24 Palsy (“PSP”), a degenerative brain disorder that causes serious and progressive
25 problems with gait and balance, eye movement, cognitive difficulties, and muscle
26 weakness. His disease is progressive and thus symptoms will worsen over time. In
27 addition to PSP, Mr. Thomas has Post-Polio Syndrome, quadriplegia, chronic pain
28 syndrome, dysphagia (difficulty swallowing), chronic respiratory failure, recurrent

1 pneumonia and/or bronchitis, chronic constipation, chronic atelectasis (a complete
2 or partial collapse of the lung), recurrent episodes of urinary tract infections
3 (“UTIs”), and hypothyroidism, among other conditions. After 14 years of
4 institutional placement, Mr. Thomas now resides at home with his wife of over 30
5 years, Beverly Thomas, who brought him home from a Subacute facility in 2013.
6 She serves as his *Guardian ad Litem* in this litigation.

7 20. Plaintiff Sean Benison is 43 years old and has advanced hereditary
8 progressive Becker Muscular Dystrophy; is quadriplegic; and has chronic
9 respiratory failure, chronic pain disorder, anxiety disorder, DVT
10 (thromboembolism) prophylaxis and reflux esophagitis. He lives on his own in his
11 apartment, where he moved in October 2013 after living for two years in a Subacute
12 facility.

13 21. Plaintiff Juan Palomares is 38 years old and had a complete spinal cord
14 injury at the 4th vertebrae in the cervical (neck) part of his spine in 2005. He has
15 quadriplegia and is dependent on others for all of his daily care needs. He is
16 susceptible to recurring urinary tract infections and has recurring difficulties with
17 his suprapubic catheter tube clogging. He has chronic pain, which must be managed
18 with medications, including narcotics, on an as-needed basis. Mr. Palomares is
19 subject to frequent (currently 5-6 episodes a week) and life threatening autonomic
20 dysreflexia, which is an episode of acute, uncontrolled hypertension for which he
21 requires frequent and skilled preventative care. Mr. Palomares lives with his father
22 who is his primary caregiver.

23 22. Plaintiffs Thomas and Benison have a tracheal tube that is connected to
24 a ventilator to help them breathe. Due to their mucous secretions and their inability
25 to swallow due to the tracheotomy and loss of muscle function, Plaintiffs Thomas
26 and Benison must be suctioned as needed, sometimes as frequently as four to five
27 times an hour, when saliva builds up in the mouth, nose, and throat to avoid pooling
28 of mucous or any fluid in the lungs. If fluid does go into the lungs, it could impair

1 oxygen exchange, resulting in lack of oxygen and permanent damage to organs
2 (including brain injury), pneumonia, and infection. Plaintiff Benison uses a cuffed
3 tracheotomy which is uncuffed during the day and allows for the possibility of
4 communication/speech, but also allows fluid to go into the lungs if not timely
5 suctioned. Plaintiff Thomas uses a cuffed trach at all times. During the night,
6 Plaintiff Benison also uses a cuffed tracheotomy so he is not able to speak – which
7 can be more dangerous since he is not able to communicate if they are in distress.
8 Further, air leaks out of the cuff, and a nurse is required to keep adding air to the
9 cuff and to monitor the ventilator settings to ensure Plaintiffs are properly
10 ventilated: too much air puts pressure on the lungs and too little air can make them
11 unconscious. Plaintiff Thomas has a Gastrostomy tube (“G-tube”) for feeding and
12 medication administration.

13 23. Plaintiffs are completely dependent on medical technologies for
14 survival. Plaintiffs use wheelchairs for mobility at all times. Plaintiffs cannot
15 move, turn, feed, dress, bathe or take care of themselves. They need total care for
16 every daily activity.

17 24. Plaintiffs Thomas and Benison's in-home nursing care is provided by
18 licensed vocational nurses (“LVNs” or “nurses”). LVNs are licensed to provide
19 skilled nursing care in many settings including hospitals. 42 C.F.R. § 409.31(a)
20 (2005); 22 Cal. Code Regs. §§ 70055(a)(16), 70055(a)(16) and 70217(a) (2013).
21 These one-on-one skilled nursing services have been ordered by Plaintiffs Thomas
22 and Benison’s physicians because their care requires the exercise of judgment
23 informed by experience and expertise in addressing the care needs of persons with
24 severe disabilities and chronic illnesses. The services Plaintiffs Thomas and
25 Benison require cannot safely be provided by untrained or unskilled individuals and
26 are medically necessary.

27 25. Plaintiff Palomares’ in-home care includes In-Home Supportive
28 Services and Waiver Personal Care Services. Because of the severity of his

1 disability, his constant risk of autonomic dysreflexia and complications related to his
2 catheter, Plaintiff Palomares requires, but does not receive, additional in-home
3 attendant care, nursing care by licensed nurses, and nursing case management.

4 **Defendant Department of Health Care Services**

5 26. Defendant California Department of Health Care Services (“DHCS”)
6 administers the California Medicaid program, called “Medi-Cal.” DHCS is the
7 single state agency responsible for the administration of the Medi-Cal program.

8 27. Defendant Jennifer Kent is DHCS’ current Director and is sued only in
9 her official capacity. Director Kent is responsible for directing, organizing, and
10 administering the Medi-Cal program, including Medi-Cal Home and Community-
11 Based Services Waivers, in accordance with all applicable laws and regulations. As
12 such, she is responsible for DHCS’ compliance with state and federal laws
13 governing the Medi-Cal program.

14 **V. STATUTORY AND REGULATORY FRAMEWORK**

15 **A. THE MEDICAID PROGRAM**

16 28. Medicaid is a joint federal and state medical assistance program for
17 certain groups of low-income people, including children. 42 U.S.C. §§ 1396-1396v
18 (2014). California has elected to participate in the Medicaid program, and so must
19 comply with the requirements of the federal Medicaid Act and its implementing
20 regulations.

21 29. The purpose of Medicaid is to furnish, as far as practicable, “medical
22 assistance on behalf of . . . aged, blind or disabled individuals, whose income and
23 resources are insufficient to meet the costs of necessary medical services” and “to
24 help such families and individuals to attain or retain capability for independence or
25 self-care” 42 U.S.C. § 1396 (2014).

26 30. Participating States are reimbursed by the federal government for a
27 portion of the cost of providing Medicaid benefits. *See* 42 U.S.C. § 1396b (2010).

28

1 The remaining funding for the Medi-Cal program comes from the State and from
2 counties.

3 31. States participating in Medicaid must designate a “single state agency”
4 to administer or supervise the administration of the Medicaid program. 42 U.S.C.
5 § 1396a(a)(5) (2014). DHCS is the single state agency so designated in California.

6 32. The California Medi-Cal program provides an array of medical
7 services, treatments, and therapies that are authorized based on individuals’ meeting
8 “medical necessity” criteria. Welf. & Inst. Code §§ 14059 (1969), 14059.5 (1985),
9 and 14133.3 (2004); 22 Cal. Code Regs. § 51303(a) (2013).

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

11 33. The Centers for Medicare and Medicaid (“CMS”) is the federal agency
12 that oversees the administration of the Medicaid programs offered by each state.
13 CMS has the authority to waive certain provisions of federal Medicaid law to allow
14 states to provide home and community-based services (“HCBS”) in lieu of
15 institutional care, for targeted groups of individuals who otherwise would require
16 care in a medical facility. 42 U.S.C. § 1396n(c)(1) (2010).

17 34. DHCS has been mandated by the Legislature to “seek all necessary
18 waivers . . . in order to provide in-home and community-based care.” Welf. & Inst.
19 Code §§ 14132(t) (2014), 14137 (1986). DHCS routinely seeks and secures federal
20 approval to renew and amend HCBS Waivers within permissible federal limitations.

21 35. HCBS Waivers in California include the Nursing Facility/Acute
22 Hospital (“NF/AH”) Waiver. The purpose of the NF/AH Waiver is to provide
23 Medi-Cal beneficiaries with long-term medical conditions who meet one of the
24 designated "levels of care" described below, the option of returning to and/or
25 remaining in their homes or home-like community settings in lieu of
26 institutionalization. The NF/AH Waiver application, which is submitted and
27 approved by CMS, governs DHCS’ administration of NF/AH Waiver services. The
28 current version of the Waiver is State of California Department of Health Care

1 Services, Application for § 1915(c) HCBS Waiver Nursing Facility/Acute Hospital
2 (NF/AH) Waiver, (12/1/2012 - 12/31/2016),
3

5 36. In seeking federal approval for the NF/AH Waiver, DHCS gave
6 assurances to CMS, including that: (a) Necessary safeguards have been taken to
7 protect the health and welfare of participants receiving services under the NF/AH
8 Waiver; and, (b) Plans of Care are responsive to NF/AH Waiver participants' needs.
9 NF/AH Waiver at 9-10.

10 37. Under the umbrella of the NF/AH HCBS Waiver, DHCS administers
11 several HCBS waivers which each correspond to an institutional level of care. The
12 relevant levels of care for adults are: Nursing Facility Level A or B ("NF-A" and"
13 NF-B"), Nursing Facility Subacute ("Subacute"), and Acute Hospital. Each of the
14 HCBS Waivers contained in the NF/AH Waiver offers an array of home and
15 community-based services, discussed below.

16 38. The level of care criteria for the NF/AH Home and Community-Based
17 Services Waivers explicitly describe the type and level (or severity) of functional
18 limitations and/or skilled nursing needs an individual must have to be admitted to an
19 institutional setting. Upon meeting those eligibility criteria, or level of care, an
20 individual may qualify for corresponding NF/AH HCBS Waiver services.

21 39. California offers various services under the NH/AH Waiver, including
22 Private Duty Nursing, Waiver Personal Care Services, Case Management and
23 Habilitation services that Plaintiffs are seeking. NF/AH Waiver at 59.

24 40. "Private duty nursing" services means individual and continuous care
25 (in contrast to part-time or intermittent care) provided by a licensed nurse or a
26 certified home health aide employed by a home health agency within the scope of
27 state law. Private duty nursing services are provided in a recipient's home, home-
28

1 like environment or an approved out-of-home setting. 42 U.S.C. § 1396d(a)(9)
2 (2012); 42 C.F.R. § 440.80 (1987); NF/AH Waiver at 196.

3 41. “Case Management” services are designed to assess the participant and
4 determine the need for medical, psycho-social, social and other services and to assist
5 participants in gaining access to those needed services, regardless of the funding
6 source, to ensure the participant’s health and safety and support of his/her home and
7 community-based program. Case Managers also assist in securing personal care
8 providers, work with the participant and his/her physician in developing goals and
9 identifying a course of action to respond to the assessed needs of the individual, as
10 well as oversee the implementation of the services described in the Plan of
11 Treatment. Case Management responsibilities include assessing, care planning,
12 locating, coordinating, and monitoring services for community-based participants on
13 the waiver. Case Management may be provided by an array of provider types.
14 NF/AH Waiver at 59-72.

15 42. “Habilitation Services” are provided in a participant’s home or an out-
16 of-home non-facility setting and are designed to assist the participant in acquiring,
17 retaining, and improving self-help, socialization, and adaptive skills necessary to
18 reside successfully in the person’s natural environment. Habilitation services
19 include training on: the use of public transportation; personal skills development in
20 conflict resolution; community participation; developing and maintaining
21 interpersonal relationships; personal habits; daily living skills (cooking, cleaning,
22 shopping, money management) and community resource awareness to support
23 independence in the community. It also includes assistance with: selecting and
24 moving into a home; locating and choosing suitable housemates; locating household
25 furnishings; settling disputes with landlords; managing personal financial affairs;
26 recruiting, screening, hiring, training, supervising, and dismissing personal
27 attendants; dealing with and responding appropriately to governmental agencies and
28

1 personnel; asserting civil and statutory rights through self-advocacy, and building
2 and maintaining interpersonal relationships. NF/AH Waiver at 72-84.

3 43. “Waiver Personal Care services” (“WPCS”) are services designed to
4 assist Waiver participants in gaining independence in their activities of daily living
5 and preventing social isolation, and assisting Waiver participants in remaining in
6 their homes and being part of their communities. WPCS includes, *inter alia*,
7 assistance with activities of daily living, adult companionship, housekeeping, food
8 shopping, and other assistance to promote the participant’s highest level of
9 independence in self-care. NF/AH Waiver at 99-100. In order to meet federal cost-
10 neutrality requirements, the NF/AH Waiver contains assurances that, in the
11 aggregate for the entire NF/AH Waiver population, services provided in the
12 community pursuant to the NF/AH Waiver will not exceed the cost of services in the
13 institution designated for comparable care. NF/AH Waiver at 10. Defendants,
14 however, have chosen to use an individual maximum benefit level, rather than an
15 aggregate cost-cap. *Id.* at 26-27. Thus, each of the Waivers within the NF/AH
16 HCBS Waiver correspond to an institutional level of care and have individual “cost-
17 caps” depending on the Medi-Cal rate for their corresponding facility. These cost-
18 caps allow a qualifying individual to choose from a menu of available home and
19 community-based services but only up to the cost-cap for his or her level of care set
20 by DHCS in the applicable HCBS Waiver. NF/AH Waiver at 26-27.

21 44. Defendants have set NF/AH Waiver cost-caps at all levels of care
22 significantly below the annual rate Medi-Cal pays to institutions of the same level of
23 care, as set forth below¹:

24
25
26
27 ¹ The current NF/AH Waiver contains only the Waiver cost-caps, but not the corresponding
28 institutional rates. NF/AH Waiver at 27-28. The annual institutional rate is contained in the
previous version of the NF/AH Waiver and is calculated using the weighted daily average rate for
each facility type for 365 days a year.

Institutional Level of Care	Annual Institutional Rate (Based on 2007 NF/AH Waiver)	Annual Waiver Cost-Caps (Current in 2012 NF/AH Waiver)
Nursing Facility (NF)-A	\$34,388	\$29,548
Nursing Facility (NF)-B	\$56,074 ²	\$48,180
NF-B Pediatric	\$110,280	\$101,882
NF-Distinct Part	\$124,342	\$77,600
NF-Subacute, Adult	\$271,697	\$180,219
NF-Subacute, Pediatric	\$282,574	\$240,211
Acute Hospital	\$437,757	\$305,283

45. For individuals such as Mr. Thomas and Mr. Benison, who meet the institutional criteria and would otherwise be placed in a Subacute nursing facility, Defendants have arbitrarily set the cost-cap for NF/AH Waiver services at the adult Subacute level of care at \$180,219, which is more than \$90,000 below the rate for a Subacute facility. NF/AH Waiver at 27.

46. For individuals such as Plaintiff Palomares, who meet the institutional criteria for and would otherwise be placed in a Nursing Facility Level B, Defendants have arbitrarily set the cost-cap for NF/AH Waiver services at the Nursing Facility-B level of care at \$48,180, which is more than \$21,000 below the current rate of \$70,000 for a Nursing Facility-B facility. NF/AH Waiver at 27. Moreover, the NF/AH Waiver cost-cap at the Nursing Facility-B level of care has remained flat at the 2007 level, while Nursing Facility level B facilities have received substantial rate increases each year.

47. Defendants will not authorize a level of HCBS waiver funding for home-based services which is comparable to the level of funding Medi-Cal would otherwise pay for institutional care. However, federal cost-neutrality requirements

² According to recent State analyses, the current rate paid by Medi-Cal to Nursing Facility Level B facilities is at least \$70,000 annually.

1 do not prohibit Defendants from using an aggregate cost-cap, setting the Waiver
2 cost-caps at or just below the rate paid to equivalent level of care facilities, or even
3 exceeding the amount paid to those facilities so long as in the aggregate, the State's
4 overall Medi-Cal spending remains cost-neutral.

5 48. CMS permits Defendants the option of authorizing NF/AH Waiver
6 services to individual participants in excess of their individual cost limitation, but
7 Defendants have not done so. NF/AH Waiver at 29. Defendants have declined to
8 develop an exception process as a safeguard to enable participants to remain on the
9 Waiver, but rather, have indicated to CMS that if a Waiver participant's service
10 costs exceed the cost-cap set by Defendants, they will instead: 1) refer the
11 individual to another Waiver; 2) assist the participant to identify lower cost services
12 within the cost-cap; or 3) refer the individual for institutional placement. *Id.*

13 **In-Home Supportive Services**

14 49. The In-Home Supportive Services ("IHSS") program is the State's
15 personal attendant care program pursuant to California Welfare and Institutions
16 Code sections 12300 *et seq.* (2004), 4132.95 (2004), 14132.951 (2009), and
17 14132.952 (2009). The IHSS program pays for certain services so eligible
18 recipients can remain safely in their homes. IHSS hourly wages are set county-wide
19 throughout the State and vary by county.

20 50. To be eligible for IHSS, an individual must be over 65 years of age, or
21 disabled, or blind. IHSS services include: housecleaning, meal preparation,
22 laundry, grocery shopping, personal care services (such as bowel and bladder care,
23 bathing, grooming and paramedical services), accompaniment to medical
24 appointments, and protective supervision for the mentally impaired. Recipients may
25 choose their IHSS workers, who must meet minimal requirements for approval, such
26 as a background check, but who are not required to be licensed or skilled medical
27 practitioners. The cost of IHSS services is factored into an individual's NF/AH
28

1 Waiver budget, thereby reducing the amount of Waiver services that can be
2 provided.

3 **B. ANTI-DISCRIMINATION LAWS**

4 51. Qualifying individuals with disabilities are protected from disability
5 discrimination, including segregation in institutions, by the ADA and Section 504.

6 52. In enacting the ADA, Congress found that “[i]ndividuals with
7 disabilities continually encounter various forms of discrimination,
8 including...segregation...” 42 U.S.C. § 12101(a)(5) (2008). Title II of the ADA
9 provides that “no qualified individual with a disability shall, by reason of disability,
10 be excluded from participation in or be denied the benefits of services, programs, or
11 activities of a public entity or be subjected to discrimination by such entity.”
12 42 U.S.C. § 12132 (1990).

13 53. Regulations implementing Title II of the ADA provide: “[a] public
14 entity shall administer services, programs, and activities in the most integrated
15 setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R.
16 § 35.130(d) (2010); *see also* Section 504, 29 U.S.C. §§ 794-794a (2014); 28 C.F.R.
17 § 41.51(d) (1982). Further, “[t]he most integrated setting appropriate to the needs of
18 a qualified individual with a disability means a setting that enables individuals with
19 disabilities to interact with non-disabled persons to the fullest extent possible.”
20 28 C.F.R. pt. 35, App. A, (2010).

21 54. The United States Supreme Court in *Olmstead v. L.C. ex rel. Zimring*,
22 527 U.S. 581 (1999) held that the unnecessary institutionalization of individuals
23 with disabilities is a form of discrimination under Title II of the ADA. In doing so,
24 the Court interpreted the ADA’s “integration mandate” as requiring persons with
25 disabilities to be served in the community when: (1) the state determines that
26 community-based treatment is appropriate; (2) the individual does not oppose
27 community placement; and (3) community placement can be reasonably
28 accommodated. *Olmstead*, 527 U.S. at 607.

1 55. Regulations implementing Title II of the ADA and Section 504 also
2 provide: “A public entity may not, directly or through contractual or other
3 arrangements, utilize criteria or other methods of administration: (i) that have the
4 effect of subjecting qualified individuals with disabilities to discrimination on the
5 basis of disability; [or] (ii) that have the purpose or effect of defeating or
6 substantially impairing accomplishment of the objectives of the entity’s program
7 with respect to individuals with disabilities...” 28 C.F.R. § 35.130(b)(3) (2010);
8 28 C.F.R. § 41.51(b)(3)(I) (1982); 45 C.F.R. § 84.4(b)(4) (2005).

9 56. ADA regulations further provide: “[a] public entity shall not impose or
10 apply eligibility criteria that screen out or tend to screen out an individual with a
11 disability or any class of individuals with disabilities from fully and equally
12 enjoying any service, program, or activity, unless such criteria can be shown to be
13 necessary for the provision of the service, program, or activity being offered.”
14 28 C.F.R. § 35.130(b)(8) (2010); *see also* parallel Section 504 regulations, 45 C.F.R.
15 § 84.4(b)(1)(iv) (2005).

16 57. As set forth in federal regulations: “[a] public entity shall make
17 reasonable modifications in policies, practices, or procedures when the
18 modifications are necessary to avoid discrimination on the basis of disability, unless
19 the public entity can demonstrate that making the modifications would
20 fundamentally alter the nature of the service, program, or activity.” 28 C.F.R.
21 § 35.130(b)(7) (2010).

22 58. Similar to the ADA, California’s anti-discrimination statute prohibits
23 discriminatory actions by the state and state-funded agencies or departments, and
24 provides civil enforcement rights for violations. Cal. Gov’t. Code §§ 11135-11139
25 (2011).

26 ///

27 ///

28 ///

1 **VI. FACTS RELATED TO INDIVIDUAL PLAINTIFFS**

2 **JERRY THOMAS**

3 59. Jerry Thomas was diagnosed with Progressive Supranuclear Palsy in
4 2007 at 66 years of age. Progressive Supranuclear Palsy is a degenerative brain
5 disorder that involves a loss of muscle control impacting gait and balance, eye
6 movement, and thought processes.

7 60. Mr. Thomas' in-home nursing services have been funded entirely by
8 Medi-Cal.

9 61. Mr. Thomas lives at home with wife of over thirty years, Beverly
10 Thomas. Mr. Thomas's wife is his primary care giver and his *Guardian ad Litem*.

11 62. Before Mr. Thomas became ill, he worked as a road manager for his
12 brother, singer B.J. Thomas. When he was not spending time with his wife or
13 working, most weekends Mr. Thomas was hunting with his dogs and family
14 members.

15 63. Mr. and Mrs. Thomas desire that he continue living at home with
16 appropriate nursing services.

17 64. Mr. Thomas is medically fragile and technology dependent. Mr.
18 Thomas requires oxygen 24 hours a day and is connected to a ventilator at least 18
19 hours a day, and more when needed. He receives nutrition, hydration and
20 medication through his G-tube. Mr. Thomas is non-ambulatory and cannot bear
21 weight. He uses a wheelchair and requires assistance with all activities of daily
22 living ("ADLs").

23 65. Mr. Thomas can no longer speak and is only able to communicate by
24 blinking his eyes. Individuals need training to understand his body language for
25 signs and symptoms of changes in his condition, need, and medical emergencies.

26 66. At age 66, when Mr. Thomas could no longer breathe on his own due
27 to muscle weakness, he had a tracheotomy.

28

1 67. In order to control his symptoms and severe pain, he takes over 40
2 medications, including several narcotics and seven medications that are provided
3 *pro re nata* (“PRN” as needed).

4 68. In addition to Progressive Supranuclear Palsy, Mr. Thomas has been
5 diagnosed with Post-Polio Syndrome, among other conditions.

6 69. Mr. Thomas lived in a nursing facility for 14 years, until his wife was
7 able to bring him home with services under the NF/AH Waiver. Since moving
8 home on April 1, 2013, Mr. Thomas has been in the hospital or hospitalized several
9 times including most recently in January 2015, as well as seen by his doctors on
10 numerous occasions. Mr. Thomas is regularly seen by his pulmonologist and
11 primary care physician, as well as a neurologist.

12 70. Since Mr. Thomas moved home, his condition has worsened due to the
13 natural progression of his diseases. He now requires more time connected to the
14 ventilator and takes additional medications to assist with his digestive and
15 tracheotomy suctioning needs. In July 2014, Dr. Kayaleh, Mr. Thomas’s treating
16 physician, ordered for him to be provided with 24 hour nursing care.

17 71. Mrs. Thomas is not a licensed vocational nurse and is not capable of
18 providing the additional nursing care that Mr. Thomas requires.

19 **Mr. Thomas’ Nursing Care Needs**

20 72. As set forth in his Plan of Treatment approved by his physician, Mr.
21 Thomas has frequent, ongoing, and unpredictable skilled care needs that must be
22 addressed by a licensed nurse. These include, *e.g.*,: monitoring Mr. Thomas’
23 oxygen saturation levels and providing skilled interventions when his oxygen levels
24 drop below 92%, including breathing with ambu-bag, CPR, and calling 911;
25 determining when Mr. Thomas must be placed on the ventilator during sprinting
26 hours; monitoring and administering his medications including over 40 daily
27 medications and seven medications to be taken PRN as needed for proper dosage,
28 effectiveness, interactions, and side effects; monitoring the amount, sound, and color

1 of Mr. Thomas' secretions for signs of infection; monitoring the sound of Mr.
2 Thomas' lungs to assess for a respiratory infection or blockage; monitoring and
3 performing deep tracheal suctioning; monitoring the color, consistency, odor, and
4 frequency of Mr. Thomas' urine and bowels for signs and symptoms of infections;
5 administering and checking all equipment to ensure proper functioning and replace
6 equipment or intervene as needed; monitoring feeding tolerance and knowing when
7 Mr. Thomas' G-tube feeding should be stopped when he presents signs of
8 abdominal pain and discomfort; monitoring, caring for, and replacing his trach
9 stoma when necessary; taking and interpreting vital signs and knowing when they
10 indicate a possible infection or when CPR is required; monitoring Mr. Thomas'
11 entire system for signs of infection, change, or emergency; assessing and monitoring
12 Mr. Thomas' skin for signs of infection, breakdown, or ulcers; and identifying and
13 responding to emergencies.

14 **In-Home Nursing Authorization**

15 73. Before moving home from Chapman Subacute facility on April 1,
16 2013, Mr. Thomas was approved to receive 450 LVN hours under the NF/AH
17 waiver at the Subacute level of care, along with 240.04 hours of IHSS, and 2 hours
18 of RN case management. He and his wife accepted this combination of skilled and
19 unskilled care because Mr. Thomas unquestionably required round-the-clock
20 coverage, and they understood that, due to the Subacute Waiver cost-cap, he would
21 not be able to receive the 24-hour nursing he needed.

22 74. On October 16, 2013, DHCS conducted a home visit to reassess Mr.
23 Thomas' level of care. Based on the assessment, DHCS determined that Mr.
24 Thomas remained eligible for the NF/AH waiver at the Subacute level of care.
25 However, DHCS determined that the expenditures for the services he was receiving
26 exceeded the NF/AH waiver cost-cap at the Subacute level of care, which is
27 \$180,219.00.

28

1 75. Even though Mr. Thomas’ needs had increased due to the progression
2 of his disease since his move home in 2013, DHCS issued a Notice of Action
3 (“NOA”) on January 9, 2014 reducing his in-home LVN nursing authorization to
4 430 hours per month. The NOA provided that the decrease in services was solely
5 due to the cost-cap under the NF/AH waiver, not a change or improvement in Mr.
6 Thomas’ condition.

7 76. On February 10, 2014, Mrs. Thomas, on behalf of her husband, timely
8 appealed DHCS’ 20-hour per month nursing reduction by mail and requested aid-
9 paid-pending. At Plaintiffs’ request, DHCS reassessed Mr. Thomas in August 2014
10 but refused to authorize increased nursing hours for him.

11 77. On September 23, 2014, a Medi-Cal fair hearing was held, where Mr.
12 Thomas presented his medical need for 24 hour nursing care, consistent with his
13 doctor’s July 2014 orders. On February 4, 2015, the Administrative Law Judge
14 ordered DHCS to reassess Mr. Thomas’ level of care in order to determine whether
15 his health condition qualified him for the Acute Hospital level of care. DHCS has
16 not yet performed a reassessment of Mr. Thomas and thus Mr. Thomas has not
17 experienced a reduction or increase in his nursing care.

18 78. Because DHCS has the ability to “alternate”, or overturn, the decision,
19 or reassess him at a lower level of care at any time, even a favorable decision does
20 not provide Mr. Thomas with permanent or adequate relief.

21 **SEAN BENISON**

22 79. Mr. Benison was diagnosed with progressive hereditary Becker
23 Muscular Dystrophy when he was nine years old. Mr. Benison started using a
24 manual wheelchair when he was 13 years old and a power wheel chair at age 21.
25 Mr. Benison is quadriplegic. In addition to Muscular Dystrophy, Mr. Benison has
26 chronic respiratory failure, chronic pain disorder, anxiety disorder, DVT
27 (thromboembolism) prophylaxis and reflux esophagitis. Mr. Benison takes 19
28 different medications.

1 80. Mr. Benison is working towards a Ph.D. in Geography at the University
2 of California, Santa Barbara (“UCSB”). He has a B.A. from California State
3 University Northridge. He has a Master’s degree in Geography from UCSB.

4 81. Mr. Benison lives in an apartment in Ventura, California with a live-in
5 IHSS personal care worker. Mr. Benison’s father, Edward Benison, does not
6 provide any daily care but is involved in planning for and providing his care.

7 82. Mr. Benison and his family desire that he continue living at home with
8 appropriate nursing services.

9 83. Mr. Benison’s nursing care has been funded entirely by Medi-Cal.

10 84. While a student at UCSB, Mr. Benison was living in campus housing
11 and had an IHSS care worker assisting with his needs. Mr. Benison also had close
12 friends who helped with his care needs, which enabled Mr. Benison to enroll in and
13 pursue graduate studies.

14 85. In November 2011, while a student at UCSB, Mr. Benison’s health
15 took a turn for the worse. Mr. Benison had a severe attack of pneumonia and was
16 hospitalized at the Goleta Valley Cottage Hospital in Santa Barbara. He remained in
17 the Subacute unit of the acute care hospital for two years before he moved out to his
18 current apartment. While in the hospital, Mr. Benison could no longer breathe on
19 his own. Mr. Benison had to undergo a tracheostomy due to the pneumonia and
20 neuromuscular and lung weakness caused by the Muscular Dystrophy. Mr. Benison
21 is now dependent on a ventilator 24 hours a day.

22 86. Mr. Benison is medically fragile and technology dependent. Until a
23 few months ago, he had a G-tube for feeding and medication. Mr. Benison cannot
24 walk, cannot move himself or even turn over in bed. Mr. Benison is non-
25 ambulatory and cannot bear weight. He uses a wheelchair for mobility. He cannot
26 feed himself and has limited use of his hands. He requires assistance with all
27 activities of daily living.

28

1 87. Mr. Benison has been on the NF/AH Waiver since October 2013 when
2 he moved out of the Subacute facility and into his own apartment in the community.
3 At that time, DHCS authorized 416 hours per month of Medi-Cal funded one-to-one
4 in-home, private duty nursing care through the NF/AH Waiver, based on its
5 determination that Mr. Benison met the Subacute level of care. In order to remain
6 within the cost-cap limitation at the Subacute level of care, he is authorized for 16
7 hours nursing coverage daily from Monday through Friday, and 8 hours of nursing
8 coverage each on Saturdays and Sundays. Mr. Benison requires 24-hour care, and
9 because he lives alone, Mr. Benison supplements his nursing care with 283 hours of
10 unlicensed IHSS personal care aide hours per month. However, on weekends he
11 does not have any nursing coverage for 16 hours each day, which leaves him at risk.
12 Hence, a minimum of 8 hours more of private duty nursing each on Saturday and
13 Sunday is necessary to keep Mr. Benison safely in his home.

14 **Mr. Benison's Nursing Care Needs**

15 88. As set forth in his Plan of Treatment approved by his physician, Mr.
16 Benison has frequent, ongoing, and unpredictable skilled care needs that must be
17 addressed by a licensed nurse. These include: monitoring Mr. Benison's vital signs
18 to ensure they remain within parameters listed in the physician's orders, and
19 instructing caregivers in proper vital sign monitoring; monitoring cardiac status and
20 assessing for signs and symptoms of tachycardia (resting heart rate faster than
21 normal); assessing Mr. Benison for signs and symptoms of pain; assessing for signs
22 and symptoms of skin breakdown, rash and perfusion; instructing caregivers in
23 measures to protect skin integrity; assessing for medication compliance,
24 effectiveness and complications and instructing caregivers in medication dosages,
25 schedules, effects and side effects, and any food and drug interactions; assessing
26 Mr. Benison's level of consciousness, motor and sensory reflexes, and for
27 progression of his muscular dystrophy; ensuring adequate respiratory function
28 through trach care including mobilization of lung secretions; monitoring and

1 providing ventilator support and responding to signs and symptoms of respiratory
2 distress; checking ventilator settings as per the physician orders; assessing Mr.
3 Benison's lung fields for clear, crackles, wheezing or the absence of these in his
4 breathing patterns; monitoring Mr. Benison's trach stoma for signs and symptoms of
5 infection; monitoring Mr. Benison's abdomen for signs and symptoms of abdomen
6 distention and constipation; monitoring Mr. Benison for signs and symptoms of
7 urinary tract infections; and reporting significant findings and changes in Mr.
8 Benison's condition as appropriate.

9 **In-Home Nursing Authorization; Case Management and Habilitation Services**

10 89. Currently, the cost to the Medi-Cal program for Mr. Benison's home
11 care, including 416 hours per month of private duty nursing, 283 hours of
12 unlicensed IHSS aides and his medical equipment and supplies, was approximately
13 \$180,219.00 per year. This is his maximum budget for NF/AH Waiver services
14 because of the cost-cap imposed by DHCS.

15 90. Since January 2014, Mr. Benison's physician has ordered one-to-one
16 private duty nursing care for him so that he can receive the 24-hour care that he
17 needs to remain safely at home. Mr. Benison requested 24-hour nursing from
18 Defendants in February 2014. Defendants deferred his request for 24-hour nursing
19 and have not provided him with a written notice of action as to their decision.
20 However, because Mr. Benison lives on his own, he relies on an unlicensed live-in
21 IHSS aide as a backup care provider. In addition to the NF/AH Waiver cost-cap
22 which would prevent Mr. Benison from receiving authorization for 24-hour nursing,
23 DHCS will also not authorize direct care services, or any combination of direct care
24 services, exceeding 24 hours of care per day under the NF/AH Waiver. NF/AH
25 Waiver at 196. Therefore, Plaintiff Benison needs 24 hours of nursing care per day,
26 but he also cannot give up his live-in backup caregiver. Thus, given the limitations
27 of the existing NF/AH Waiver rules, he is requesting additional hours per month of
28 nursing care to ensure that he can receive round-the-clock care.

1 91. Additionally, Mr. Benison needs Case Management Services and
2 Habilitation services to help him organize his nurses and IHSS workers' schedules,
3 enroll back in graduate studies, enable him to avail of social activities and
4 community services, and gain an overall better quality of life. These services are
5 available through the NF/AH Waiver, but are not available to Mr. Benison because
6 of the Subacute Waiver cost-cap.

7 **JUAN PALOMARES**

8 92. Juan Palomares had a complete C-4 spinal cord injury in 2005 at age 28
9 due to a motor vehicle accident in which he was a passenger. As a result of the
10 injury, he has quadriplegia and uses a power wheelchair. He is in constant pain,
11 uses a suprapubic catheter, and is prone to autonomic dysreflexia episodes which is
12 imbalanced reflex sympathetic discharge and leads to potentially life-threatening
13 hypertension. Mr. Palomares experiences autonomic dysreflexia episodes
14 approximately 5-6 times per week.

15 93. Mr. Palomares lives at home with his father, Manuel Palomares, who is
16 also his primary caregiver.

17 94. Mr. Palomares' home care is provided through In-Home Supportive
18 Services and Waiver Personal Care Services. Mr. Palomares' in-home services are
19 funded entirely by Medi-Cal.

20 95. Mr. Palomares and his father desire that he continue living at home
21 with appropriate in-home services.

22 96. Prior to Mr. Palomares' accident, Mr. Palomares had recently obtained
23 his certification as a laboratory technician. His injury occurred when he was
24 returning from a family funeral in San Diego to interview for a job as a lab
25 technician.

26 97. Following Mr. Palomares' accident, he received care at the University
27 of California San Diego hospital, where he was placed on a ventilator and had a
28 tracheostomy. After approximately two months, he was taken off the ventilator, his

1 tracheostomy was closed, and he was transferred to the Rancho Los Amigos
2 Rehabilitation Center in Los Angeles for acute rehabilitation.

3 98. After his discharge from Rancho Los Amigos, Mr. Palomares moved in
4 with his sister for approximately two and a half months, where he received support
5 only from In-Home Supportive Services. He then moved to the Palomares
6 Rehabilitation and Nursing Center³ in Pomona.

7 99. At the Pomona nursing facility, Mr. Palomares was admitted into the
8 Subacute unit but was soon discharged to the Nursing Facility unit. During that
9 time, he was experiencing episodes of autonomic dysreflexia 9-10 times per week.
10 While at the Nursing Facility unit, Mr. Palomares also experienced recurring urinary
11 tract infections, requiring intravenous (“IV”) antibiotics. However, due to the high
12 ratio of patients to nurses, the nurses were not able to quickly attend to his needs,
13 and he had no method or alarm to alert them when he was having an emergency. As
14 a result, Mr. Palomares was consistently in fear for his life while at the facility. Mr.
15 Palomares stayed at the nursing facility for approximately one year.

16 100. In 2006, because of the difficulty the Pomona nursing facility had in
17 meeting Mr. Palomares’ intensive care needs, Mr. Palomares’ father moved into an
18 apartment that had room for Juan Palomares. Although Mr. Palomares’ father had
19 been in training to become a licensed contractor, he abandoned this career path in
20 order to care for his son Juan around-the-clock. Plaintiff Palomares was not offered
21 NF/AH Waiver services when he first came home. He applied for and began to
22 receive NF/AH Waiver services in 2007.

23 101. Since moving home in 2006, Mr. Palomares has been hospitalized
24 several times. In 2014, he went to the emergency room approximately 9-10 times
25 when he was experiencing side effects from his pain medications or autonomic
26

27
28 ³ Although the nursing facility’s name was the same as Mr. Palomares’ last name, there is no
relationship. The nursing facility is now called the Inland Valley Care Rehabilitation Center.

1 dysreflexia episodes. Mr. Palomares is regularly seen by a primary care physician,
2 urologist, a podiatrist and a pulmonologist.

3 **Mr. Palomares' In-Home Care Needs**

4 102. As a result of his C-4 spinal cord injury, Mr. Palomares is quadriplegic,
5 incontinent of bowel and bladder, unable to feed himself, and dependent for all of
6 his Activities of Daily Living. He uses a power wheelchair for ambulation, which
7 he operates by his chin and head and which has a recline feature that he uses every
8 hour. He requires assistance to administer his medications. He also requires
9 frequent repositioning due to his physical limitations, in order to assist with
10 circulation and to prevent skin ulcers. Because of his health conditions and severe
11 pain, Mr. Palomares takes numerous medications, including narcotics administered
12 as needed due to his constant pain in his neck and shoulder.

13 103. The spinal cord injury has resulted in impairment of Mr. Palomares'
14 sympathetic nervous system (autonomic dysreflexia), which has caused problems
15 modulating body temperature and therefore hypothermia and hyperthermia episodes.

16 104. Mr. Palomares currently experiences about five to six autonomic
17 dysreflexia episodes a week. A majority of the episodes happen at night or in the
18 early morning hours. Such episodes may be triggered by, *e.g.*, a need for
19 repositioning, excessive heat or cold, having something tight on his body (*e.g.*, shoe
20 laces, a shirt), the position of his catheter tube, urinary or bowel obstruction, and
21 inflammation of the stomach. He is at constant risk of having an autonomic
22 dysreflexia episode. During an episode, his heart rate and blood pressure elevate to
23 dangerous levels. If not treated immediately, by removing the triggering stimuli
24 and (when necessary) administering anti-hypertensive medication, autonomic
25 dysreflexia can lead to death.

26 105. Mr. Palomares undergoes treatments through an oscillating vest twice a
27 day to keep fluids and mucus from pooling in his lungs including mobilization of
28

1 mucus. This treatment helps to prevent lung infections such as pneumonia and
2 prevent the need for a ventilator.

3 106. Mr. Palomares has a system in place where he can voice activate 911 so
4 he can be brought to an emergency room. He had approximately ten such
5 emergency room visits last year, many because of difficult-to-control autonomic
6 dysreflexia episodes.

7 107. Mr. Palomares sleeps on a special mattress with air chambers that
8 fluctuate to reduce the risk of decubiti ulcers. His father wakes up every two hours
9 at night to reposition him. During the evening when he is in his wheelchair which
10 he operates with his chin and head, he reclines with his legs brought up at least once
11 an hour to prevent pressure sores and autonomic dysreflexia episodes.

12 108. Mr. Palomares needs to be repositioned and cared for more frequently
13 than he is currently, in order to reduce the incidence of autonomic dysreflexia
14 episodes and prevent decubitus ulcers, but that is not possible without an increase in
15 his NF/AH Waiver budget.

16 109. This past year Mr. Palomares was switched from a Foley catheter to a
17 suprapubic catheter (which is inserted directly into his bladder) in order to reduce
18 the incidence of urinary tract infections (UTIs) and the incidence of autonomic
19 dysreflexia episodes related to Foley catheter erosion and UTIs. However, he has
20 had chronic problems with the suprapubic catheter because the tubing clogs,
21 triggering his autonomic dysreflexia episodes. In addition, the suprapubic catheter
22 must be changed monthly, by a trained provider with experience in order to avoid
23 obstructing.

24 **In-Home Services Authorization; IHSS and Waiver Personal Care Services**

25 110. As of January 1, 2015, the cost to the Medi-Cal program for Mr.
26 Palomares' home care, including In-Home Supportive Services and Waiver Personal
27 Care Services per month, and his medical equipment and supplies, was
28

1 approximately \$48,180 per year. This is his maximum budget for NF/AH Waiver
2 services because of the cost-cap imposed by DHCS.

3 111. Mr. Palomares receives daytime care from a paid attendant six days per
4 week. His father provides all of his nighttime care, seven nights per week, and all
5 day on Sundays.

6 112. Between 2007 and present, Mr. Palomares' medically necessary
7 NF/AH Waiver in-home care services have been reduced at least twice, including
8 once in 2013. This reduction was not because Mr. Palomares' care needs decreased.
9 The Nursing Facility-B level of care cost-cap has remained at \$48,180.00, but the
10 hourly rate for attendant care services in his county has increased twice. Therefore,
11 to maintain cost neutrality, DHCS reduced the number of in-home care service
12 hours authorized under the Waiver. Mr. Palomares no longer receives any nursing
13 services because of the last reduction in his Waiver budget, which forced him to
14 accept only unlicensed attendant care in order to have as many hours of coverage
15 each day that his Waiver budget would allow.

16 113. To address one of the reductions in NF/AH Waiver services, Mr.
17 Palomares appealed DHCS' reduction of his Waiver Personal Care Services from
18 207 hours to 143 hours, which was effective March 22, 2013. The final
19 administrative decision issued by DHCS concluded that DHCS correctly determined
20 that Mr. Palomares' skilled care needs are consistent with the HCBS NF/AH Waiver
21 Nursing Facility-B level of care and that the reduction of hours was proper in order
22 to adhere to the annual Nursing Facility-B cost-cap of \$48,180.

23 114. However, Mr. Palomares needs additional in-home care services in
24 order to meet his round-the-clock needs, which include nursing care and nursing
25 case management, and to enable him to hire additional care providers. Mr.
26 Palomares needs a care provider to monitor him throughout the night and reposition
27 him more frequently in order to reduce his recurrent episodes of autonomic
28 dysreflexia. Additional attendant care would also enable him to bathe more

1 frequently, as this is a task that is very taxing to do as frequently as needed, given
2 Mr. Palomares height of 6 feet and weight of 180 pounds.

3 115. With more attendant care hours, his father could have some additional
4 relief, as he is providing paid and unpaid care and has difficulty managing both day
5 and night care with the limited hours of in-home care covered under the Waiver.

6 116. In addition, Plaintiff Palomares requires reinstatement of case
7 management by a Registered Nurse to supervise and assess his care. Mr. Palomares
8 also requires a Licensed Vocational Nurse with experience in urology to change his
9 suprapubic catheter, flush his port, and assess and monitor any changes to his
10 condition, among other things.

11 117. In-home care services, including IHSS, skilled nursing, and Waiver
12 Personal Care Services are available through the NF/AH Waiver, but are not
13 available to Mr. Palomares because of the Nursing Facility-B Waiver cost-cap.

14 **DEFENDANTS' ACTIONS PLACE INDIVIDUALS WITH DISABILITIES**
15 **LIKE PLAINTIFFS AT RISK OF INSTITUTIONALIZATION AND**
16 **VIOLATE THE LAW**

17 118. Defendants have placed arbitrary cost-caps on home and community-
18 based services provided under the NF/AH Waiver, which are far less than the actual
19 rates for institutional facilities.

20 119. Defendants have great flexibility and discretion in their administration
21 of the NF/AH waiver. They have the authority to make modifications to ensure that
22 Medi-Cal recipients such as individual Plaintiffs receive sufficient and medically
23 necessary NF/AH Waiver services to avoid institutional placement and receive the
24 necessary services as their medical conditions require.

25 120. According to Plaintiffs Thomas, Benison, and Palomares' medical
26 professionals, home is the safest place for them to maximize their health condition
27 and prolong their lives. Placement in an institution, however, will almost certainly
28 cause health deterioration and possible death within a short period of time.

1 121. Defendants are refusing to provide additional NF/AH Waiver services
2 for individual Plaintiffs solely due to the fact that DHCS has imposed cost-caps on
3 NF/AH Waiver services, which are lower than the equivalent institutional rates, and
4 which are without medical justification, nor are they required by federal law.

5 122. Defendants' administration and imposition of the NF/AH Waiver cost-
6 caps directly injures organizational Plaintiff IN SPIRIT. As a result of Defendants'
7 illegal administration of the NF/AH waiver, IN SPIRIT's mission to enable clients
8 to live safely at home is frustrated and its limited resources are diverted from other
9 clients in order to serve NF/AH Waiver recipients whose at-home care needs would
10 be met, but for the NF/AH Waiver cost-caps.

11 123. Without the appropriate level of NF/AH Waiver services to remain in
12 their homes, qualified individuals with disabilities such as Plaintiffs will have no
13 choice but institutional placement, which will separate them from their families and
14 communities and also poses significant risks to their health.

15 **VII. LEGAL CLAIMS**

16 **FIRST CLAIM FOR RELIEF**

17 **(Defendant Director Jennifer Kent)**

18 **Americans with Disabilities Act, 42 U.S.C. § 12131 *et seq.***

19 124. Plaintiffs reallege and incorporate herein by reference each and every
20 allegation and paragraph set forth previously.

21 125. Individual Plaintiffs are "qualified individuals with a disability" within
22 the meaning of the ADA in that they have physical and/or mental impairments that
23 substantially limit one or more major life activities, including their ability to live
24 independently without support.

25 126. Individual Plaintiffs meet the essential eligibility requirements for
26 Medi-Cal services, including services necessary to maintain them in their homes in
27 the community.

28

1 127. Organizational Plaintiff IN SPIRIT represents the interests of
2 individual Plaintiffs in that it provides assistance to individuals with disabilities to
3 enable them to live in their own homes. IN SPIRIT's mission is thwarted by
4 Defendant's actions, which hinder its ability to provide assistance and divert its
5 resources from serving clients who would otherwise be served by the organization.

6 128. Defendant Jennifer Kent is the Director of Defendant DHCS, which has
7 responsibility for providing Medi-Cal and state-funded home and community-based
8 and institutional services, and is therefore a government entity subject to Title II of
9 the ADA. 42 USC §§ 12131(1)(A) and (B) (1990).

10 129. Defendant is obligated under the ADA to administer its programs in a
11 manner that enables qualified individuals with disabilities to live in the most
12 integrated setting appropriate to their needs. Defendant's denial and reduction of
13 adequate and medically necessary in-home services, and failure to provide qualified
14 individuals with disabilities such as Plaintiffs with medically necessary NF/AH
15 Waiver services, has denied them the services they need to remain safely in the
16 community, thereby placing them at risk of institutionalization in violation of the
17 ADA's integration mandate.

18 130. Defendant has discriminated against qualified individuals with
19 disabilities such as Plaintiffs in ways that include arbitrarily setting cost-caps for the
20 NF/AH Waiver far below the actual rate paid for institutional services in equivalent
21 facilities, thus denying them funds for home and community-based services that
22 would otherwise be available for institutional services.

23 131. Defendant has discriminated against qualified individuals with
24 disabilities such as Plaintiffs by failing to provide reasonable modifications to
25 programs and services in ways that include: failing to increase or eliminate the
26 individual NF/AH Waiver cost-caps within federal cost neutrality limitations to
27 enable them to receive adequate and medically necessary NF/AH Waiver services;
28 and failing to create and implement an exception process for the NF/AH Waiver

1 cost-caps by which they could receive NF/AH Waiver services at a level adequate to
2 meet their needs.

3 132. By denying Plaintiffs and other qualified individuals with disabilities
4 adequate and necessary NF/AH Waiver services commensurate with their actual
5 need, as opposed to arbitrary service limitations, Defendant has imposed eligibility
6 requirements which unlawfully screen Plaintiffs out from fully and equally enjoying
7 NF/AH Waiver services, and from receiving adequate care to remain safely at home.

8 133. Defendant has utilized criteria and methods of administration that
9 subject Plaintiffs and other qualified individuals with disabilities to discrimination
10 on the basis of disability, including risk of unnecessary institutionalization, in ways
11 that include: (1) designing and implementing Home and Community-Based
12 Services Waivers which set arbitrarily low cost-caps for NF/AH Waiver services,
13 while paying significantly higher rates for the institutional alternative; and
14 (2) imposing eligibility criteria, cost limitations and other criteria not required by
15 federal limitations, which restrict in-home care in favor of institutional care.

16 134. Defendant's actions are in violation of Title II of the ADA.

17 135. Pursuant to 42 U.S.C. § 12133 (1990), Plaintiffs are entitled to
18 declaratory and injunctive relief, as well as reasonable attorneys' fees and costs
19 incurred in bringing this action.

20 **SECOND CLAIM FOR RELIEF**

21 **(Defendant DHCS)**

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

23 136. Plaintiffs reallege and incorporate herein by reference each and every
24 allegation and paragraph set forth previously.

25 137. Individual Plaintiffs are "qualified individuals with a disability" under
26 Section 504 of the Rehabilitation Act of 1973, as amended – 29 U.S.C. § 794 and
27 implementing regulations – in that they have physical and/or mental impairments
28

1 that substantially limit one or more major life activities, including their ability to
2 live independently without support.

3 138. Individual Plaintiffs meet the essential eligibility requirements for
4 Medi-Cal services, including services necessary to maintain them in their homes in
5 the community.

6 139. Organizational Plaintiff IN SPIRIT represents the interests of
7 individual Plaintiffs in that it provides assistance to individuals with disabilities to
8 enable them to live in their own homes. IN SPIRIT's mission is thwarted by
9 Defendant's actions, which hinder its ability to provide assistance and divert its
10 resources from serving clients who would otherwise be served by the organization.

11 140. Defendant DHCS is a recipient of federal monies that provides Medi-
12 Cal home and community-based and institutional services and other Medi-Cal
13 services and is therefore a government entity subject to Section 504. 29 U.S.C.
14 § 794(b) (2014).

15 141. Defendant's denial and reduction of adequate and necessary in-home
16 nursing and refusal to provide NF/AH Waiver services has barred individual
17 Plaintiffs from receiving the services they need to continue to live in the community,
18 thereby placing them at imminent risk of institutionalization in violation of Section
19 504's integration mandate.

20 142. Defendant has discriminated against Plaintiffs in ways that include
21 arbitrarily setting cost-caps for the NF/AH Waiver far below the actual rate paid for
22 institutional services in equivalent nursing facilities, thus denying qualified
23 individuals with disabilities such as Plaintiffs funds for home and community-based
24 services that would otherwise be available for institutional services.

25 143. By denying qualified individuals with disabilities such as Plaintiffs
26 adequate and necessary NF/AH Waiver services commensurate with their actual
27 need, as opposed to arbitrary service limitations, Defendant has imposed eligibility
28

1 requirements which unlawfully screen them out from fully and equally enjoying
2 NF/AH Waiver services, and from receiving adequate care to remain safely at home.

3 144. Defendant has utilized criteria and methods of administration that
4 subject qualified individuals with disabilities such as Plaintiffs to discrimination on
5 the basis of disability, including risk of unnecessary institutionalization, by,
6 including but not limited to the following: (1) designing and implementing Home
7 and Community-Based Services Waivers which set arbitrarily low cost-caps for
8 NF/AH Waiver services, while paying significantly higher rates for the institutional
9 alternative; and (2) imposing eligibility criteria, cost limitations and other criteria
10 not required by federal limitations, which restrict in-home care in favor of
11 institutional care.

12 145. Defendant's actions violate Section 504.

13 **THIRD CLAIM FOR RELIEF**
14 **(Defendants DHCS and Director Kent)**

15 **Violation of Government Code Sections 11135 and 11139**

16 146. Plaintiffs reallege and incorporate herein by reference each and every
17 allegation and paragraph set forth previously.

18 147. Individual Plaintiffs are persons with disabilities within the meaning of
19 California Government Code section 11135(c) *et seq.* (2011) and its implementing
20 regulations.

21 148. Individual Plaintiffs meet the essential eligibility requirements for
22 Medi-Cal services, including services necessary to maintain them in their homes in
23 the community.

24 149. Organizational Plaintiff IN SPIRIT represents the interests of
25 individual Plaintiffs in that it provides assistance to individuals with disabilities to
26 enable them to live in their own homes. IN SPIRIT's mission is thwarted by
27 Defendants' actions, which hinder its ability to provide assistance and divert its
28 resources from serving clients who would otherwise be served by the organization.

1 150. Defendants DHCS and Director Kent conduct, operate or administer
2 the state Medicaid program, entitled Medi-Cal, which is directly funded, in part, by
3 state financial assistance within the meaning of California Government Code section
4 11135(a) and implementing regulations.

5 151. Defendants are obligated to administer their programs in a manner that
6 enables qualified individuals with disabilities to live in the most integrated setting
7 appropriate to their needs. Defendants' denial and reduction of adequate and
8 medically necessary in-home nursing, and failure to provide qualified individuals
9 with disabilities such as Plaintiffs with medically necessary NF/AH Waiver
10 services, has denied them the services they need to remain safely in the community,
11 thereby placing them at risk of institutionalization in violation of the integration
12 mandate of California Government Code section 11135.

13 152. By administering its programs in ways that deny qualified individuals
14 with disabilities such as Plaintiffs NF/AH Waiver services commensurate with their
15 actual need, and instead imposing arbitrary cost limitations on the services they may
16 receive, Defendants have discriminated against them , thereby excluding them from
17 participation in, denying them the benefits of, and otherwise subjecting them to
18 discrimination in violation of California Government Code section 11135 *et seq.* and
19 implementing regulations.

20 153. Plaintiffs further allege that violations of their rights under the
21 Americans with Disabilities Act and implementing regulations contained in the First
22 Claim for Relief are incorporated herein and constitute a violation of California
23 Government Code section 11135 *et seq.* as well, as set forth in section 11135(b).

24 **VIII. ALLEGATIONS CONCERNING INJUNCTIVE AND DECLARATORY**
25 **RELIEF**

26 154. Defendants' actions, as alleged herein, have resulted in and will
27 continue to result in irreparable injury to Plaintiffs and other qualified individuals
28 with disabilities caused by the refusal to cover medically necessary services under

1 the NF/AH waiver, which they need to remain in their homes and avoid unnecessary
2 institutional placement. Plaintiffs have no plain, speedy or adequate remedy at law.

3 155. IN SPIRIT is also subject to irreparable injury as a result of the NF/AH
4 Waiver cost-caps, for it provides financial aid to NF/AH Waiver recipients to
5 supplement at-home care which would otherwise be covered by the NF/AH Waiver,
6 but for imposition of the cost-caps. IN SPIRIT's mission is thereby impeded, where
7 funds are put toward assisting NF/AH Waiver recipients with home care needs,
8 rather than funding non-Waiver recipients.

9 156. An actual controversy exists between Plaintiffs and Defendants, in that
10 Plaintiffs claim that Defendants have failed to provide services in the most
11 integrated setting appropriate to meet the needs of qualified individuals with
12 disabilities such as Plaintiffs in violation of federal and state law and Defendants
13 deny all such contentions.

14 157. Defendant Kent can either adopt or "alternate" (reject in whole or part)
15 any administrative decision arising out of claims against DHCS. California Manual
16 of Policies and Procedures, Sections 22-061 and 22-062. Therefore, the
17 administrative appeal process offers no remedy or protection to Plaintiffs, as the
18 Defendants in this action are the very entity which will make a determination of
19 what NF/AH Waiver services will be provided to Plaintiffs.

20 158. The needs of qualified individuals with disabilities such as Plaintiffs
21 can be reasonably accommodated by Defendants in a number of ways such as:
22 increasing the individual NF/AH Waiver cost-caps commensurate with institutional
23 costs; replacing individual NF/AH Waiver cost-caps with an aggregate cost-cap;
24 establishing an exception process for requesting additional services and/or
25 preventing reductions in service; and/or modifying any of their Home and
26 Community-Based Services Waivers to permit these individuals to receive the
27 services that they require and that their physicians have ordered.
28

1 159. Defendants have the option to administer the NF/AH Waiver so as not
2 to create a bias towards institutional placement. Instead, Defendants have chosen to
3 administer the NF/AH Waiver in such a way as to discriminate against qualified
4 individuals with disabilities such as Plaintiffs, and to place them at risk of
5 institutional placement, with life threatening consequences.

6 **IX. REQUEST FOR RELIEF**

7 WHEREFORE, Plaintiffs pray that the Court order the following relief and
8 remedies on behalf of themselves and all others similarly situated:

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

11 B. Declare that Defendants' imposition of arbitrary NF/AH Waiver cost-
12 caps, which deny qualified individuals with disabilities such as Plaintiffs sufficient
13 NF/AH Waiver services to meet their undisputed needs, and Defendants' policies,
14 practices, acts and omissions as set forth above violate:

- 15 i. The Americans with Disabilities Act ("ADA"), (42 U.S.C.
16 §§ 12101-12213 (2008)) and implementing regulations.
17 ii. Section 504 of the Rehabilitation Act ("Section 504"),
18 (29 U.S.C. §§ 794-794a (2014)) and implementing regulations;
19 and,
20 iii. California Government Code section 11135. (Cal. Gov't. Code
21 § 11135 (2011)) and implementing regulations.

22 C. Grant a temporary restraining order and preliminary injunction
23 enjoining Defendants, their officers, agents, employees, attorneys, successors, and
24 all persons who are in active concert or participation with them from reducing
25 medically necessary Medi-Cal funded in-home care below Mr. Thomas' current
26 level of 450 hours per month of licensed vocational nursing care, two hours per
27 month of RN care and 240.04 hours per month of IHSS personal care services until
28 such time as the matter before this Court may be finally decided.

1 D. Grant a permanent injunction enjoining Defendants, their officers,
2 agents, employees, attorneys, successors, and all persons who are in active concert
3 or participation with them from discriminating against qualified individuals with
4 disabilities such as Plaintiffs including placing them at risk of unnecessary
5 institutionalization, by:

- 6 i. Failing to offer reasonable modifications to their programs and
7 policies to enable them to receive medically necessary in-home
8 nursing as ordered by their physicians;
- 9 ii. Failing to offer reasonable modifications to their programs and
10 policies to enable them to receive other NF/AH Waiver services
11 like Case Management, Habilitation services, and Waiver
12 Personal Care Services;
- 13 iii. Imposing eligibility requirements which unlawfully screen them
14 out of the NF/AH Waiver program and prevent them from fully
15 and equally enjoying NF/AH Waiver services, and from
16 receiving adequate care to remain safely at home;
- 17 iv. Utilizing criteria and methods of administration that subject them
18 to discrimination on the basis of disability, including placing
19 them at risk of unnecessary institutionalization.

20 E. Issue an order requiring Defendants to:

- 21 i. Authorize Medi-Cal funded services for Plaintiffs through the
22 Nursing Facility/Acute Hospital Waiver or other appropriate
23 Home and Community-Based Services Waivers, subject to
24 federal cost neutrality requirements, to enable them to receive
25 medically necessary services commensurate with their needs;
- 26 ii. Amend their policies and procedures consistent with the
27 injunction above, and to require that Nursing Facility/Acute
28 Hospital Waiver participants be provided with medically

1 necessary Medi-Cal in-home services, commensurate with their
2 assessed needs, and as identified by their treating physicians,
3 consistent with federal cost neutrality requirements.

4 F. Retain jurisdiction over the Defendants until such time as the Court is
5 satisfied that Defendants' unlawful policies, practices, and acts complained of herein
6 cannot recur.

7 G. Award Plaintiffs the costs of this action and reasonable attorneys' fees
8 pursuant to 20 U.S.C. § 794a (2014); 42 U.S.C. §§ 12133 (1990), 12205 (1990);
9 California Code of Civil Procedure section 1021.5 (1993); and as otherwise may be
10 allowed by law.

11 H. Grant such other and further relief as the Court deems to be just and
12 equitable.

13
14 Respectfully submitted: DISABILITY RIGHTS CALIFORNIA

15
16 Date: July 7, 2015 /s/ _____
17 Elissa Gershon
18 Attorneys for Plaintiffs
19
20
21
22
23
24
25
26
27
28