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 ARTHUR CONGDON, SEAN BENISON, and IN SPIRIT

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

JERRY THOMAS, by and through his )	CASE NO. 14-CV-08013-FMO(AGR <sub>x</sub> )
<i>guardian ad litem</i> BEVERLY )	
THOMAS, ARTHUR CONGDON, )	<b>FIRST AMENDED COMPLAINT</b>
SEAN BENISON, and IN SPIRIT )	<b>FOR INJUNCTIVE AND</b>
)	<b>DECLARATORY RELIEF</b>
Plaintiffs, )	
v. )	
)	
JENNIFER KENT, Director of the )	
Department of Health Care Services, )	
State of California DEPARTMENT OF )	
HEALTH CARE SERVICES, )	
)	
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, Arthur Congdon and Sean Benison. Failure to receive these  
7 services will result in severe harm and potential institutionalization of these  
8 individuals with disabilities. Due to their fragile medical conditions, placement in  
9 an institution is likely to result in dire health consequences and even death.  
10 Institutional care for Plaintiffs would also cost the State significantly more than it  
11 would to keep them safely in their own homes.

12 2. Plaintiffs have severe disabilities and chronic medical conditions:  
13 Plaintiff Jerry Thomas is diagnosed with Progressive Supranuclear Palsy and Post-  
14 Polio Syndrome. Plaintiffs Arthur Congdon and Sean Benison have advanced  
15 hereditary progressive Muscular Dystrophy. Due to their illnesses, Plaintiffs are  
16 quadriplegic and cannot breathe or move on their own. They have tracheal tubes  
17 connected to ventilators to help them breathe. Plaintiffs Thomas and Congdon  
18 receive nutrition and hydration via Gastrostomy feeding tubes.

19 3. All three Plaintiffs live in their own homes, with round-the-clock care  
20 provided by a combination of licensed nurses, and unlicensed paid and unpaid  
21 attendants. However, pursuant to their doctors' orders, Plaintiffs Thomas and  
22 Congdon need 24 hour nursing care, and Plaintiff Benison needs additional nursing  
23 care, to assess and address their complex and unpredictable needs, including  
24 monitoring their ventilators and oxygen levels, preparing and administering  
25 medications, and clearing fluids from their lungs and tracheotomy tubes.

26 4. While this kind of intensive nursing care is often provided in a hospital  
27 or Subacute medical care facility, Plaintiffs have been able to remain in their  
28 communities and close to their families because of nursing care available to them in

1 their homes under the Medi-Cal Home and Community-Based Services Nursing  
2 Facility/Acute Hospital Waiver (“NF/AH Waiver”), administered by Defendants.

3 5. Plaintiffs have all requested additional licensed nursing care services  
4 from Defendants, so that they can continue living safely in their homes and  
5 communities. Defendants have denied these requests.

6 6. Plaintiff Benison, who lives alone, also requires Case Management and  
7 Habilitation services, which are available under the NF/AH Waiver. However, Mr.  
8 Benison is not able to access these needed NF/AH Waiver services that would help  
9 him live more independently and successfully in his home and community.

10 7. The sole reason Plaintiffs are not able to get these critically needed  
11 services is because Defendants have placed arbitrary cost limitations on services  
12 available under the NF/AH Waiver. For individuals like Plaintiffs who have been  
13 determined to meet the Subacute level of care, Medi-Cal would pay \$271,697 per  
14 year for institutional placement in a Subacute facility; however, Defendants have  
15 capped the budget for comparable in-home services funded through the NF/AH  
16 Waiver at \$180,219 per year, which is at least \$90,000 below the actual cost of  
17 equivalent care in a Subacute facility. The cost of the additional nursing and other  
18 NF/AH Waiver services requested by Plaintiffs would still cost less than placement  
19 in a Subacute facility.

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

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

26 10. Defendants’ actions violate the Americans with Disabilities Act of  
27 1990 (“ADA”), (42 U.S.C. §§ 12101-12213 (2008)), Section 504 of the  
28 Rehabilitation Act of 1973 (“Section 504”), (29 U.S.C. §§ 794-794a (2014)), and

1 California Government Code section 11135 (Cal. Gov't. Code § 11135 (2011)).

2 11. Under the ADA and Section 504, a public agency such as DHCS has a  
3 duty to provide services to people with disabilities in the “most integrated setting  
4 appropriate to their needs” and to prevent unnecessary institutionalization. The  
5 most integrated setting for the individual Plaintiffs is to continue living in their  
6 homes in the community, with adequate NF/AH Waiver services to meet their  
7 significant needs. Placing Plaintiffs at risk of unnecessary institutionalization in  
8 order to receive the care they need violates the ADA.

9 12. Under the ADA, Defendants also have an obligation to use methods of  
10 administration that do not discriminate against individuals with disabilities such as  
11 Plaintiffs. Defendants’ failure to ensure that Plaintiffs are provided with adequate  
12 NF/AH Waiver services to continue living safely in their homes, and their decision  
13 to set funding levels for services that are biased in favor of institutional care results  
14 in discrimination against Plaintiffs in the administration of the Medi-Cal program.

15 **II. JURISDICTION**

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

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

23 15. The Court has Supplemental Jurisdiction over Plaintiffs’ state claim  
24 pursuant to 28 U.S.C. § 1367 (1990) and California Government Code section  
25 11139 (2001).

26 **III. VENUE**

27 16. Venue is proper in the Central District of California pursuant to 28  
28 U.S.C. § 1391(b) (2011), because the Defendants operate and perform their official

1 duties therein and thus reside therein for purposes of venue, and because a  
2 substantial part of the events or omissions giving rise to the claims herein occurred  
3 in the Central District of California. Plaintiff Jerry Thomas lives and receives Medi-  
4 Cal services in Orange County, which is in the Central District of California.  
5 Plaintiff Arthur Congdon lives and receives Medi-Cal services in Los Angeles  
6 County, which is in the Central District of California. Plaintiff Sean Benison lives  
7 and receives Medi-Cal services in Ventura County, which is in the Central District  
8 of California. Defendant DHCS operates the Medi-Cal program, conducts business  
9 and provides Medi-Cal services to Plaintiffs in Orange County, Los County and  
10 Ventura County, all in the Central District of California.

11 **IV. PARTIES**

12 **Organizational Plaintiff**

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

28 //

1 **Individual Plaintiffs**

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

6 19. Plaintiff Jerry Thomas is 73 years old and has Progressive Supranuclear  
7 Palsy (“PSP”), a degenerative brain disorder that causes serious and progressive  
8 problems with gait and balance, eye movement, cognitive difficulties, and muscle  
9 weakness. His disease is progressive and thus symptoms will worsen over time. In  
10 addition to PSP, Mr. Thomas has Post-Polio Syndrome, quadriplegia, chronic pain  
11 syndrome, dysphagia (difficulty swallowing), chronic respiratory failure, recurrent  
12 pneumonia and/or bronchitis, chronic constipation, chronic atelectasis (a complete  
13 or partial collapse of the lung), recurrent episodes of urinary tract infections  
14 (“UTIs”), and hypothyroidism, among other conditions. After 14 years of  
15 institutional placement, Mr. Thomas now resides at home with his wife of over 30  
16 years, Beverly Thomas, who brought him home from a Subacute facility in 2013.  
17 She serves as his Guardian ad Litem in this litigation.

18 20. Plaintiff Arthur Congdon is 36 years old and has advanced hereditary  
19 progressive Duchenne Muscular Dystrophy, chronic respiratory failure, congestive  
20 heart failure, cardiomyopathy, is quadriplegic and legally blind. Mr. Congdon also  
21 suffers from insomnia, chronic back pain, gastric problems and severe contracture of  
22 his joints. He resides at home with his mother, who is his primary caregiver.

23 21. Plaintiff Sean Benison is 43 years old and has advanced hereditary  
24 progressive Becker Muscular Dystrophy; is quadriplegic; and has chronic  
25 respiratory failure, chronic obstructive pulmonary disease, chronic pain disorder,  
26 anxiety disorder, DVT (thromboembolism) prophylaxis and reflux esophagitis. He  
27 lives on his own in his apartment, where he moved in October 2013 after living for  
28 two years in a Subacute facility.

1           22.       All three individual Plaintiffs have a tracheal tube that is connected to  
2 a ventilator to help them breathe. Due to Plaintiffs' mucous secretions and their  
3 inability to swallow due to the tracheotomy and loss of muscle function, Plaintiffs  
4 must be suctioned as needed, sometimes as frequently as four to five times an hour,  
5 when saliva builds up in the mouth, nose, and throat to avoid pooling of mucous or  
6 any fluid in the lungs. If fluid does go into the lungs, it could impair oxygen  
7 exchange, resulting in lack of oxygen and permanent damage to organs (including  
8 brain injury), pneumonia, and infection. Plaintiffs Congdon and Benison use a  
9 cuffed tracheotomy which is uncuffed during the day and allows for the possibility  
10 of communication/speech, but also allows fluid to go into the lungs if not timely  
11 suctioned. Plaintiff Thomas uses a cuffed trach at all times. During the night,  
12 Plaintiffs Congdon and Benison also use a cuffed tracheotomy so they are not able  
13 to speak – which can be more dangerous since they are not able to communicate if  
14 they are in distress. Further, air leaks out of the cuff, and a nurse is required to keep  
15 adding air to the cuff and to monitor the ventilator settings to ensure Plaintiffs are  
16 properly ventilated: too much air puts pressure on the lungs and too little air can  
17 make them unconscious.

18           23.       Plaintiffs are completely dependent on medical technologies for  
19 survival. Plaintiffs Thomas and Congdon have Gastrostomy tubes (“G-tubes”) for  
20 feeding and medication administration. Plaintiffs are dependent on wheelchairs for  
21 mobility at all times. Plaintiffs cannot move, turn, feed, dress, bathe or take care of  
22 themselves. They need total care for every daily activity.

23           24.       Plaintiffs' in-home nursing care is provided by licensed vocational  
24 nurses (“LVNs” or “nurses”). LVNs are licensed to provide skilled nursing care in  
25 many settings including hospitals. 42 C.F.R. § 409.31 (a) (2005); 22 Cal. Code  
26 Regs. §§ 70055(a)(16), §70055(a)(16) & 70217 (a) (2013). These one-on-one  
27 skilled nursing services have been ordered by Plaintiffs' physicians because their  
28 care requires the exercise of judgment informed by experience and expertise in

1 addressing the care needs of persons with severe disabilities and chronic illnesses.  
2 The services Plaintiffs require cannot safely be provided by untrained or unskilled  
3 individuals and are medically necessary.

4 **Defendant Department of Health Care Services**

5 25. 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 26. 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 27. 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 28. 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 29. 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 The remaining funding for the Medi-Cal program comes from the State and from



1 counties.

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

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

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

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

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

20 34. HCBS Waivers in California include the Nursing Facility/Acute  
21 Hospital (“NF/AH”) Waiver. The purpose of the NF/AH Waiver is to provide  
22 Medi-Cal beneficiaries with long-term medical conditions who meet one of the  
23 designated "levels of care" described below, the option of returning to and/or  
24 remaining in their homes or home-like community settings in lieu of  
25 institutionalization. State of California Dep’t of Health Care Servs., Application for  
26 § 1915(c) HCBS Waiver Nursing Facility/Acute Hospital (NF/AH) Waiver,  
27 (12/1/2012-12/31/2016)  
28 <http://www.dhcs.ca.gov/services/ltc/Documents/NFAH%20Transition%20and%20D>

1 version%20Waiver%2012-1-2012.pdf ("NF/AH Waiver") at 7-8.

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

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

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

18 38. California offers various services under the NH/AH Waiver, including  
19 Private Duty Nursing, Case Management and Habilitation services, that Plaintiffs  
20 are seeking. NF/AH Waiver at 59.

21 39. "Private duty nursing" services means individual and continuous care  
22 (in contrast to part-time or intermittent care) provided by a licensed nurse or a  
23 certified home health aide employed by a home health agency within the scope of  
24 state law. Private duty nursing services are provided in a recipient's home, home-  
25 like environment or an approved out-of-home setting. 42 U.S.C. § 1396d(a)(9)  
26 (2012); 42 C.F.R. § 440.80 (1987); NF/AH Waiver at 196.

27 40. "Case Management" services are designed to assess the participant and  
28 determine the need for medical, psycho-social, social and other services and to assist

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

11 41. "Habilitation Services" are provided in a participant's home or an out-  
12 of-home non-facility setting and are designed to assist the participant in acquiring,  
13 retaining, and improving self-help, socialization, and adaptive skills necessary to  
14 reside successfully in the person's natural environment. Habilitation services  
15 include training on: the use of public transportation; personal skills development in  
16 conflict resolution; community participation; developing and maintaining  
17 interpersonal relationships; personal habits; daily living skills (cooking, cleaning,  
18 shopping, money management) and community resource awareness to support  
19 independence in the community. It also includes assistance with: selecting and  
20 moving into a home; locating and choosing suitable housemates; locating household  
21 furnishings; settling disputes with landlords; managing personal financial affairs;  
22 recruiting, screening, hiring, training, supervising, and dismissing personal  
23 attendants; dealing with and responding appropriately to governmental agencies and  
24 personnel; asserting civil and statutory rights through self-advocacy, and building  
25 and maintaining interpersonal relationships. NF/AH Waiver at 72-84.

26 42. In order to meet federal cost-neutrality requirements, the NF/AH  
27 Waiver contains assurances that, in the aggregate for the entire NF/AH Waiver  
28 population, services provided in the community pursuant to the NF/AH Waiver will

1 not exceed the cost of services in the institution designated for comparable care.  
 2 NF/AH Waiver at 10. Defendants, however, have chosen to use an individual  
 3 maximum benefit level, rather than an aggregate cost-cap. *Id.* at 26-27. Thus, the  
 4 three Waivers within the NF/AH HCBS Waiver correspond to an institutional level  
 5 of care and have individual “cost-caps” depending on the Medi-Cal rate for their  
 6 corresponding facility. These cost-caps allow a qualifying individual to choose  
 7 from a menu of available home and community-based services but only up to the  
 8 cost-cap for his or her level of care set by DHCS in the applicable HCBS Waiver.  
 9 NF/AH Waiver at 26-27.

10 43. Defendants have set NF/AH Waiver cost-caps at all levels of care  
 11 significantly below the annual rate Medi-Cal pays to institutions of the same level of  
 12 care, as set forth below<sup>1</sup>:

Institutional Level of Care	Annual Institutional Rate (Based on 2007 NF/AH Waiver)	Annual Waiver Cost-Cap (Current in 2012 NF/AH Waiver)
Nursing Facility (NF)-A	\$34,388	\$29,548
Nursing Facility (NF)-B	\$56,074	\$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

23 44. For individuals such as Mr. Thomas, Mr. Congdon and Mr. Benison  
 24 who meet the institutional criteria and would otherwise be placed in a Subacute  
 25

26 <sup>1</sup> The current NF/AH Waiver contains only the Waiver cost-cap, but not the  
 27 corresponding institutional rate. NF/AH Waiver at 27-28. The annual institutional  
 28 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.

1 nursing facility, Defendants have arbitrarily set the cost-cap for NF/AH Waiver  
2 services at the adult Subacute level of care at \$180,219, which is more than \$90,000  
3 below the rate for a Subacute facility. NF/AH Waiver at 27.

4 45. Defendants will not authorize a level of HCBS waiver funding for  
5 home-based services which is comparable to the level of funding Medi-Cal would  
6 otherwise pay for institutional care. However, federal cost-neutrality requirements  
7 do not prohibit Defendants from using an aggregate cost-cap, setting the Waiver  
8 cost-caps at or just below the rate paid to equivalent level of care facilities, or even  
9 exceeding the amount paid to those facilities so long as in the aggregate, the State's  
10 overall Medi-Cal spending remains cost-neutral.

11 **In-Home Supportive Services**

12 46. The In-Home Supportive Services ("IHSS") program is the State's  
13 personal attendant care program pursuant to Cal. Welf. & Inst. Code §§ 12300 *et*  
14 *seq.* (2004) and Welf. & Inst. Code §§ 14132.95 (2004), 14132.951 (2009),  
15 14132.952 (2009). The IHSS program pays for certain services so eligible  
16 recipients can remain safely in their homes. To be eligible, an individual must be  
17 over 65 years of age, or disabled, or blind. IHSS services include: housecleaning,  
18 meal preparation, laundry, grocery shopping, personal care services (such as bowel  
19 and bladder care, bathing, grooming and paramedical services), accompaniment to  
20 medical appointments, and protective supervision for the mentally impaired.  
21 Recipients may choose their IHSS workers, who must meet minimal requirements  
22 for approval, such as a background check, but who are not required to be licensed or  
23 skilled medical practitioners.

24 **B. ANTI-DISCRIMINATION LAWS**

25 47. Qualifying individuals with disabilities are protected from disability  
26 discrimination, including segregation in institutions, by the ADA and Section 504.

27 48. In enacting the ADA, Congress found that "[i]ndividuals with  
28 disabilities continually encounter various forms of discrimination,

1 including...segregation...” 42 U.S.C. § 12101(a) (5) (2008). Title II of the ADA  
2 provides that “no qualified individual with a disability shall, by reason of disability,  
3 be excluded from participation in or be denied the benefits of services, programs, or  
4 activities of a public entity or be subjected to discrimination by such entity.” 42  
5 U.S.C. § 12132 (1990).

6 49. Regulations implementing Title II of the ADA provide: “[a] public  
7 entity shall administer services, programs, and activities in the most integrated  
8 setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R.  
9 § 35.130(d) (2010); *see also* Section 504, 29 U.S.C. §§ 794-794a (2014); 28 C.F.R.  
10 § 41.51(d) (1982). Further, “[t]he most integrated setting appropriate to the needs of  
11 a qualified individual with a disability means a setting that enables individuals with  
12 disabilities to interact with non-disabled persons to the fullest extent possible.” 28  
13 C.F.R. pt. 35, App. A, (2010).

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

22 51. Regulations implementing Title II of the ADA and Section 504 also  
23 provide: “A public entity may not, directly or through contractual or other  
24 arrangements, utilize criteria or other methods of administration: (i) that have the  
25 effect of subjecting qualified individuals with disabilities to discrimination on the  
26 basis of disability; [or] (ii) that have the purpose or effect of defeating or  
27 substantially impairing accomplishment of the objectives of the entity’s program  
28 with respect to individuals with disabilities...” 28 C.F.R. § 35.130(b)(3) (2010); 28

1 C.F.R. § 41.51(b)(3)(I) (1982); 45 C.F.R. § 84.4(b)(4) (2005).

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

9 53. As set forth in federal regulations: “[a] public entity shall make  
10 reasonable modifications in policies, practices, or procedures when the  
11 modifications are necessary to avoid discrimination on the basis of disability, unless  
12 the public entity can demonstrate that making the modifications would  
13 fundamentally alter the nature of the service, program, or activity.” 28 C.F.R.  
14 § 35.130(b)(7) (2010).

15 54. Similar to the ADA, California’s anti-discrimination statute prohibits  
16 discriminatory actions by the state and state-funded agencies or departments, and  
17 provides civil enforcement rights for violations. Cal. Gov’t. Code §§ 11135-11139  
18 (2011).

## 19 **VI. FACTS RELATED TO INDIVIDUAL PLAINTIFFS**

### 20 **JERRY THOMAS**

21 55. Jerry Thomas was diagnosed with Progressive Supranuclear Palsy in  
22 2007 at 66 years of age. Progressive Supranuclear Palsy is a degenerative brain  
23 disorder that involves a loss of muscle control impacting gait and balance, eye  
24 movement, and thought processes.

25 56. Mr. Thomas’s in-home nursing services have been funded entirely by  
26 Medi-Cal.

27 57. Mr. Thomas lives at home with wife of over thirty years, Beverly  
28 Thomas. Mr. Thomas’s wife is his primary care giver and his Guardian ad Litem.

1           58. Before Mr. Thomas became ill, he worked as a road manager for his  
2 brother, singer B.J. Thomas. When he was not spending time with his wife or  
3 working, most weekends Mr. Thomas was hunting with his dogs and family  
4 members.

5           59. Mr. and Mrs. Thomas desire that he continue living at home with  
6 appropriate nursing services.

7           60. Mr. Thomas is medically fragile and technology dependent. Mr.  
8 Thomas requires oxygen 24 hours a day and is connected to a ventilator at least 18  
9 hours a day, and more when needed. He receives nutrition, hydration and  
10 medication through his G-tube. Mr. Thomas is non-ambulatory and cannot bear  
11 weight. He uses a wheelchair and requires assistance with all activities of daily  
12 living (“ADLs”).

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

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

18           63. In order to control his symptoms and severe pain, he takes over 40  
19 medications, including several narcotics and 7 medications that are provided pro re  
20 nata (“PRN” as needed).

21           64. In addition to PSP, Mr. Thomas has been diagnosed with Post Polio  
22 Syndrome, among other conditions.

23           65. Mr. Thomas lived in a nursing facility for fourteen years, until his wife  
24 was able to bring him home with services under the NF/AH Waiver. Since moving  
25 home on April 1, 2013, Mr. Thomas has been in the hospital or hospitalized several  
26 times including most recently in January 2015, as well as seen by his doctors on  
27 numerous occasions. Mr. Thomas is regularly seen by his pulmonologist and  
28 primary care physician, as well as a neurologist.



1           66.    Since Mr. Thomas moved home, his condition has worsened due to the  
2 natural progression of his diseases. He now requires more time connected to the  
3 ventilator and takes additional medications to assist with his digestive and  
4 tracheotomy suctioning needs. In July 2014, Dr. Kayaleh, Mr. Thomas's treating  
5 physician, ordered for him to be provided with 24 hour nursing care.

6           67.    Mrs. Thomas is not a licensed vocational nurse and is not capable of  
7 providing the additional nursing care that Mr. Thomas requires.

8    **Mr. Thomas' Nursing Care Needs**

9           68.    As set forth in his Plan of Treatment approved by his physician, Mr.  
10 Thomas has frequent, ongoing, and unpredictable skilled care needs that must be  
11 addressed by a licensed nurse. These include, e.g.,: monitoring Mr. Thomas'  
12 oxygen saturation levels and providing skilled interventions when his oxygen levels  
13 drop below 92%, including breathing with ambu-bag, CPR, and calling 911;  
14 determining when Mr. Thomas must be placed on the ventilator during sprinting  
15 hours; monitoring and administering his medications including over 40 daily  
16 medications and 7 medications to be taken PRN as needed for proper dosage,  
17 effectiveness, interactions, and side effects; monitoring the amount, sound, and color  
18 of Mr. Thomas' secretions for signs of infection; monitoring the sound of Mr.  
19 Thomas' lungs to assess for a respiratory infection or blockage; monitoring and  
20 performing deep tracheal suctioning; monitoring the color, consistency, odor, and  
21 frequency of Mr. Thomas' urine and bowels for signs and symptoms of infections;  
22 administering and checking all equipment to ensure proper functioning and replace  
23 equipment or intervene as needed; monitoring feeding tolerance and knowing when  
24 Mr. Thomas' G-tube feeding should be stopped when he presents signs of  
25 abdominal pain and discomfort; monitoring, caring for, and replacing his trach  
26 stoma when necessary; taking and interpreting vital signs and knowing when they  
27 indicate a possible infection or when CPR is required; monitoring Mr. Thomas'  
28 entire system for signs of infection, change, or emergency; assessing and monitoring

1 Mr. Thomas' skin for signs of infection, breakdown, or ulcers; and identifying and  
2 responding to emergencies.

3 **In-Home Nursing Authorization**

4 69. Before moving home from Chapman Subacute facility on April 1,  
5 2013, Mr. Thomas was approved to receive 450 LVN hours under the NF/AH  
6 waiver at the Subacute level of care, along with 240.04 hours of IHSS, and 2 hours  
7 of RN case management. He and his wife accepted this combination of skilled and  
8 unskilled care because Mr. Thomas unquestionably required round-the-clock  
9 coverage, and they understood that, due to the Subacute Waiver cost-cap, he would  
10 not be able to receive the 24-hour nursing he needed.

11 70. On October 16, 2013, DHCS conducted a home visit to reassess Mr.  
12 Thomas' level of care. Based on the assessment, DHCS determined that Mr.  
13 Thomas remained eligible for the NF/AH waiver at the Subacute level of care.  
14 However, DHCS determined that the expenditures for the services he was receiving  
15 exceeded the NF/AH waiver cost-cap at the Subacute level of care, which is  
16 \$180,219.00.

17 71. Even though Mr. Thomas' needs had increased due to the progression  
18 of his disease since his move home in 2013, DHCS issued a Notice of Action  
19 ("NOA") on January 9, 2014 reducing his in-home LVN nursing authorization to  
20 430 hours per month. The NOA provided that the decrease in services was solely  
21 due to the cost-cap under the NF/AH waiver, not a change or improvement in Mr.  
22 Thomas' condition.

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

27 73. On September 23, 2014, a Medi-Cal fair hearing was held, where Mr.  
28 Thomas presented his medical need for 24 hour nursing care, consistent with his

1 doctor's July 2014 orders. The administrative law judge has not yet issued a ruling;  
2 thus Mr. Thomas has not yet experienced a reduction in his nursing care. However,  
3 because DHCS has the ability to "alternate", or overturn, the decision, even a  
4 favorable ruling does not offer Mr. Thomas protection from this cut. Moreover, at  
5 the hearing, Defendants argued that the hearing issues should be limited to the 20-  
6 hour per month reduction, and not whether Mr. Thomas was entitled to receive 24-  
7 hour per day nursing care. Thus, even a favorable decision may not provide Mr.  
8 Thomas with permanent or adequate relief.

9 **ARTHUR CONGDON**

10 74. Arthur Congdon is 36 years old. He was diagnosed with Duchenne  
11 Muscular Dystrophy as a child. Muscular Dystrophy is a degenerative disease  
12 involving advancing muscle weakness, loss of muscle tissue, and atrophy. As a  
13 result of Muscular Dystrophy, Mr. Congdon is quadriplegic and uses a wheelchair.  
14 Mr. Congdon also has congestive heart failure, cardiomyopathy, chronic respiratory  
15 failure and is legally blind. In addition, Mr. Congdon suffers from chronic  
16 insomnia, chronic back pain, gastric problems, urinary incontinence and severe  
17 contracture of his joints.

18 75. Mr. Congdon lives at home with his mother, Jennifer Knight. Ms.  
19 Knight is also legally blind. Ms. Knight is Mr. Congdon's primary caregiver, and is  
20 involved in planning for and providing his care. Mr. Congdon's father lives in  
21 Pennsylvania.

22 76. Mr. Congdon has a Ph.D. in Astrophysics. In October 2008, he began  
23 an assignment at the prestigious Jet Propulsion Laboratory (JPL) at the California  
24 Institute of Technology in Pasadena, California. He was a participant in NASA's  
25 Postdoctoral Program administered by Oak Ridge Associated Universities.  
26 However, due to his advancing Muscular Dystrophy, Mr. Congdon is no longer able  
27 to work at JPL. Mr. Congdon now remains exclusively at home and is working on  
28 an astrophysics textbook.

1           77. In March 2002, Mr. Congdon was named one of five winners nationally  
2 of the Recording for the Blind and Dyslexic academic awards. To recognize his  
3 accomplishment, Mr. Congdon was invited to the White House in Washington, DC,  
4 where he met with then First Lady Laura Bush.

5           78. Mr. Congdon and his mother desire that he continue living at home  
6 with appropriate nursing services.

7           79. Mr. Congdon's in-home nursing care has been funded entirely by  
8 Medi-Cal.

9           80. Mr. Congdon is medically fragile and technology dependent. Eleven  
10 years ago, Mr. Congdon could no longer breathe on his own due to muscle  
11 weakness, and he had a tracheotomy. Since that time, Mr. Congdon has been  
12 dependent on a ventilator 24 hours a day.

13           81. Mr. Congdon receives nutrition, hydration and medication through his  
14 G-tube. He is given water three times a day, and medicines four times a day, via his  
15 G-tube. His G-tube needs to be cleaned every day and flushed every time he gets  
16 hydration.

17           82. Mr. Congdon needs total care for every daily activity. Mr. Congdon is  
18 non-ambulatory and cannot bear weight. He uses a wheelchair. He cannot walk,  
19 cannot move himself or even turn over in bed. He cannot feed himself and has  
20 limited use of his hands.

21           83. Mr. Congdon had spinal fusion surgery in 1993. He was hospitalized at  
22 Cedars Sinai for aspiration pneumonia in May 2013.

23 **Mr. Congdon's Nursing Care Needs**

24           84. As set forth in his Plan of Treatment approved by his physician, Mr.  
25 Congdon has frequent, ongoing, and unpredictable skilled care needs that must be  
26 addressed by a licensed nurse. These include: monitoring vital signs for signs or  
27 symptoms of a change in condition and ensuring his vital signs remain within  
28 parameters listed in the physician's orders, with more frequent checks if he is

1 running a fever; monitoring Mr. Congdon's respiratory function through regular  
2 interventions of deep and oral suctioning; providing trach care including  
3 mobilization of lung secretions; monitoring and providing ventilator support and  
4 responding to signs and symptoms of respiratory distress; ensuring adequate  
5 nutrition, hydration and medication is provided for Mr. Congdon via his G-tube,  
6 through close monitoring; assessing the G-tube site for any problems or infection;  
7 monitoring for signs and symptoms of weight change, altered bowel function and  
8 dehydration; assessing and changing Mr. Congdon's tracheotomy and addressing  
9 problems or infections; preparing and administering medications as prescribed;  
10 monitoring Mr. Congdon's pain level and re-positioning him and administering  
11 analgesics as needed; ensuring Mr. Congdon remains infection free at his trach and  
12 G-tube sites and keeping sites clean and dry at all times; ensuring no skin  
13 impairment develops by repositioning Mr. Congdon frequently and by providing  
14 skin care every shift to ensure no skin breakdown; reporting any change in Mr.  
15 Congdon's condition to the physician, the RN, or others as appropriate.

16 **In-Home Nursing Authorization**

17 85. Mr. Congdon has been receiving NF/AH Waiver services since October  
18 2008. He is authorized for up to 500 hours per month of licensed vocational  
19 nursing, and two hours per month of RN case management. This provides him with  
20 16 hours nursing coverage daily. He does not receive any IHSS attendant care.

21 86. Mr. Congdon's mother, Ms. Knight, has been trained in his care needs  
22 and provides the remainder of his care each day. She also provides backup care  
23 during times when Mr. Congdon's needs are so intense that two caregivers are  
24 required or when the home health agency fails to staff a shift and a nurse is not  
25 available.

26 87. However, Ms. Knight is unable to provide additional care for Mr.  
27 Congdon. Mr. Congdon's father lives on the East Coast and is unavailable to  
28 provide any caregiver duties. Moreover, since Mr. Congdon is over the age of 18,

1 neither parent has a legal obligation to provide for his care.

2 88. In June 2013, Mr. Congdon’s physician ordered one-to-one nursing  
3 care for him for twenty four hours per day. Accordingly, Mr. Congdon asked  
4 Defendants for an additional 240 hours per month of private duty nursing to be  
5 provided by a licensed vocational nurse. Defendants denied the request and, in lieu  
6 of the 240 hours per month, only authorized Mr. Congdon an additional 20 hours per  
7 month of nursing care, up to the Subacute Waiver cost-cap. Mr. Congdon did not  
8 appeal the denial because he believed that doing so would be futile.

9 **SEAN BENISON**

10 89. Mr. Benison was diagnosed with progressive hereditary Becker  
11 Muscular Dystrophy when he was 9 years old. Mr. Benison started using a manual  
12 wheelchair when he was 13 year old and a power wheel chair at age 21. Mr.  
13 Benison is quadriplegic. In addition to Muscular Dystrophy, Mr. Benison has  
14 chronic respiratory failure, chronic obstructive pulmonary disease, chronic pain  
15 disorder, anxiety disorder, DVT (thromboembolism) prophylaxis and reflux  
16 esophagitis. Mr. Benison takes 19 different medications.

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

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

23 92. Mr. Benison and his family desire that he continue living at home with  
24 appropriate nursing services.

25 93. Mr. Benison’s nursing care has been funded entirely by Medi-Cal.

26 94. While a student at UCSB, Mr. Benison was living in campus housing  
27 and had an IHSS care worker assisting with his needs. Mr. Benison also had close  
28 friends who helped with his care needs, which enabled Mr. Benison to enroll in and

1 pursue graduate studies.

2 95. In November 2011, while a student at UCSB, Mr. Benison's health  
3 took a turn for the worse. Mr. Benison had a severe attack of pneumonia and was  
4 hospitalized at the Goleta Valley Cottage Hospital in Santa Barbara. He remained in  
5 the Subacute unit of the acute care hospital for two years before he moved out to his  
6 current apartment. While in the hospital, Mr. Benison could no longer breathe on  
7 his own. Mr. Benison had to undergo a tracheostomy due to the pneumonia and  
8 neuromuscular and lung weakness caused by the Muscular Dystrophy. Mr. Benison  
9 is now dependent on a ventilator 24 hours a day.

10 96. Mr. Benison is medically fragile and technology dependent. Until a  
11 few months ago, he had a G-tube for feeding and medication. Mr. Benison cannot  
12 walk, cannot move himself or even turn over in bed. Mr. Benison is non-  
13 ambulatory and cannot bear weight. He uses a wheelchair for mobility. He cannot  
14 feed himself and has limited use of his hands. He requires assistance with all  
15 activities of daily living.

16 97. Mr. Benison has been on the NF/AH Waiver since October 2013 when  
17 he moved out of the Subacute facility and into his own apartment in the community.  
18 At that time, DHCS authorized 416 hours per month of Medi-Cal funded one-to-one  
19 in-home, private duty nursing care through the NF/AH Waiver, based on its  
20 determination that Mr. Benison met the Subacute level of care. In order to remain  
21 within the cost-cap limitation at the Subacute level of care, he is authorized for 16  
22 hours nursing coverage daily from Monday through Friday, and 8 hours of nursing  
23 coverage each on Saturdays and Sundays. Mr. Benison requires 24-hour care, and  
24 because he lives alone, Mr. Benison supplements his nursing care with 260 hours of  
25 unlicensed IHSS personal care aide hours per month. However, on weekends he  
26 does not have any nursing coverage for 16 hours each day, which leaves him at risk.  
27 Hence, a minimum of 8 hours more of private duty nursing each on Saturday and  
28 Sunday is necessary to keep Mr. Benison safely in his home.

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

2 98. As set forth in his Plan of Treatment approved by his physician, Mr.  
3 Benison has frequent, ongoing, and unpredictable skilled care needs that must be  
4 addressed by a licensed nurse. These include: monitoring Mr. Benison's vital signs  
5 to ensure they remain within parameters listed in the physician's orders, and  
6 instructing caregivers in proper vital sign monitoring; monitoring cardiac status and  
7 assessing for signs and symptoms of tachycardia (resting heart rate faster than  
8 normal); assessing Mr. Benison for signs and symptoms of pain; assessing for signs  
9 and symptoms of skin breakdown, rash and perfusion; instructing caregivers in  
10 measures to protect skin integrity; assessing for medication compliance,  
11 effectiveness and complications and instructing caregivers in medication dosages,  
12 schedules, effects and side effects, and any food and drug interactions; assessing  
13 Mr. Benison's level of consciousness, motor and sensory reflexes, and for  
14 progression of his muscular dystrophy; ensuring adequate respiratory function  
15 through trach care including mobilization of lung secretions; monitoring and  
16 providing ventilator support and responding to signs and symptoms of respiratory  
17 distress; checking ventilator settings as per the physician orders; assessing Mr.  
18 Benison's lung fields for clear, crackles, wheezing or the absence of these in his  
19 breathing patterns; monitoring Mr. Benison's trach stoma for signs and symptoms of  
20 infection; monitoring Mr. Benison's abdomen for signs and symptoms of abdomen  
21 distention and constipation; monitoring Mr. Benison for signs and symptoms of  
22 urinary tract infections; and reporting significant findings and changes in Mr.  
23 Benison's condition as appropriate.

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

25 99. As of September 2014, the cost to the Medi-Cal program for Mr.  
26 Benison's home care, including 416 hours per month of private duty nursing, 260  
27 hours of unlicensed IHSS aides and his medical equipment and supplies, was  
28 approximately \$180,219.00 per year. This is his maximum budget for NF/AH



1 Waiver services because of the cost-cap imposed by DHCS.

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

16 101. Additionally, Mr. Benison needs Case Management Services and  
17 Habilitation services to help him organize his nurses and IHSS workers' schedules,  
18 enroll back in graduate studies, enable him to avail of social activities and  
19 community services, and gain an overall better quality of life. These services are  
20 available through the NF/AH Waiver, but are not available to Mr. Benison because  
21 of the Subacute Waiver cost-cap.

22 **DEFENDANTS' ACTIONS PLACE INDIVIDUAL PLAINTIFFS AT RISK**  
23 **OF INSTITUTIONALIZATION AND VIOLATE THE LAW**

24 102. Defendants have placed an arbitrary cost-cap on home and community-  
25 based services provided under the NF/AH Waiver, which is far less than the actual  
26 rate for institutional facilities.

27 103. Defendants have great flexibility and discretion in their administration  
28 of the NF/AH waiver. They have the authority to make modifications to ensure that

1 Medi-Cal recipients such as individual Plaintiffs receive sufficient and medically  
2 necessary NF/AH Waiver services to avoid institutional placement and receive the  
3 necessary services as their medical conditions require.

4 104. According to Plaintiffs Thomas, Congdon, and Benison's medical  
5 professionals, home is the safest place for them to maximize their health condition  
6 and prolong their lives. Placement in an institution, however, will almost certainly  
7 cause health deterioration and possible death within a short period of time.

8 105. Defendants are refusing to provide additional NF/AH Waiver services  
9 for individual Plaintiffs solely due to the fact that DHCS has imposed a cost-cap on  
10 NF/AH Waiver services, which is lower than the equivalent institutional rate, and  
11 which is without medical justification, nor is it required by federal law.

12 106. Defendants' administration and imposition of the NF/AH Waiver cost-  
13 cap directly injures organizational Plaintiff IN SPIRIT. As a result of Defendants'  
14 illegal administration of the NF/AH waiver, IN SPIRIT's mission to enable clients  
15 to live safely at home is frustrated and its limited resources are diverted from other  
16 clients in order to serve NF/AH Waiver recipients whose at-home care needs would  
17 be met, but for the NF/AH Waiver cost-cap.

18 107. Plaintiffs' needs can be reasonably accommodated by Defendants  
19 providing NF/AH Waiver services up to the rate that Defendants would actually pay  
20 if Plaintiffs were to be admitted to an institutional facility; and/or modifying any of  
21 their Home and Community-Based Services Waivers to permit Plaintiffs to receive  
22 the NF/AH Waiver services that they require and that their physicians have ordered.

23 108. Defendants have the option to administer the NF/AH waiver so as not  
24 to create a bias towards institutional placement. Defendants could increase the  
25 NF/AH Waiver cost-caps to levels that are equal to the amount actually paid to  
26 institutional facilities, or utilize an aggregate cost-cap. Instead, Defendants have  
27 chosen to administer the NF/AH Waiver in such a way as to discriminate against  
28 Plaintiffs and to place them at risk of institutional placement, with life threatening

1 consequences.

2 109. Without the appropriate level of NF/AH Waiver services to remain in  
3 their homes, individual Plaintiffs will have no choice but institutional placement,  
4 which will separate them from their families and communities and also poses  
5 significant risks to their health.

6 **VII. LEGAL CLAIMS**

7 **FIRST CLAIM FOR RELIEF**

8 **(Defendant Director Jennifer Kent)**

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

10 110. Plaintiffs reallege and incorporate herein by reference each and every  
11 allegation and paragraph set forth previously.

12 111. Individual Plaintiffs are “qualified individuals with a disability”  
13 within the meaning of the ADA in that they have physical and/or mental  
14 impairments that substantially limit one or more major life activities, including their  
15 ability to live independently without support.

16 112. Individual Plaintiffs meet the essential eligibility requirements for  
17 Medi-Cal services, including services necessary to maintain them in their homes in  
18 the community.

19 113. Organizational Plaintiff IN SPIRIT represents the interests of  
20 individual Plaintiffs in that it provides assistance to individuals with disabilities to  
21 enable them to live in their own homes. IN SPIRIT’s mission is thwarted by  
22 Defendant’s actions, which hinder its ability to provide assistance and divert its  
23 resources from serving clients who would otherwise be served by the organization.

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

28 115. Defendant is obligated under the ADA to administer its programs in a

1 manner that enables qualified individuals with disabilities to live in the most  
2 integrated setting appropriate to their needs. Defendant's denial and reduction of  
3 adequate and medically necessary in-home nursing, and failure to provide Plaintiffs  
4 with medically necessary NF/AH Waiver services, has denied Plaintiffs the services  
5 they need to remain safely in the community, thereby placing them at risk of  
6 institutionalization in violation of the ADA's integration mandate.

7 116. Defendant has discriminated against Plaintiffs in ways that include  
8 arbitrarily setting cost-caps for the NF/AH Waiver far below the actual rate paid for  
9 institutional services in equivalent facilities, thus denying Plaintiffs funds for home  
10 and community-based services that would otherwise be available for institutional  
11 services.

12 117. Defendant has discriminated against Plaintiffs by failing to provide  
13 reasonable modifications to programs and services in ways that include: failing to  
14 increase the NF/AH Waiver cost-caps within federal cost neutrality limitations to  
15 enable Plaintiffs to receive adequate and medically necessary NF/AH Waiver  
16 services; and failing to offer an exception to the NF/AH Waiver cost-cap that would  
17 enable Plaintiffs to receive NF/AH Waiver services at a level adequate to meet their  
18 needs.

19 118. By denying Plaintiffs adequate and necessary NF/AH Waiver services  
20 commensurate with their actual need, as opposed to arbitrary service limitations,  
21 Defendant has imposed eligibility requirements which unlawfully screen Plaintiffs  
22 out from fully and equally enjoying NF/AH Waiver services, and from receiving  
23 adequate care to remain safely at home.

24 119. Defendant has utilized criteria and methods of administration that  
25 subject Plaintiffs to discrimination on the basis of disability, including risk of  
26 unnecessary institutionalization, in ways that include: (1) designing and  
27 implementing Home and Community-Based Services Waivers which set arbitrarily  
28 low cost-caps for NF/AH Waiver services, while paying significantly higher rates

1 for the institutional alternative; and (2) imposing eligibility criteria, cost limitations  
2 and other criteria not required by federal limitations, which restrict in-home care in  
3 favor of institutional care.

4 120. Defendant's actions are in violation of Title II of the ADA.

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

8 **SECOND CLAIM FOR RELIEF**

9 **(Defendant DHCS)**

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

11 122. Plaintiffs reallege and incorporate herein by reference each and every  
12 allegation and paragraph set forth previously.

13 123. Individual Plaintiffs are "qualified individuals with a disability" under  
14 Section 504 of the Rehabilitation Act of 1973, as amended – 29 U.S.C. § 794 and  
15 implementing regulations – in that they have physical and/or mental impairments  
16 that substantially limit one or more major life activities, including their ability to  
17 live independently without support.

18 124. Individual Plaintiffs meet the essential eligibility requirements for  
19 Medi-Cal services, including services necessary to maintain them in their homes in  
20 the community.

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

26 126. Defendant DHCS is a recipient of federal monies that provides Medi-  
27 Cal home and community-based and institutional services and other Medi-Cal  
28 services and is therefore a government entity subject to Section 504. 29 U.S.C. §

1 794(b) (2014).

2 127. Defendant’s denial and reduction of adequate and necessary in-home  
3 nursing and refusal to provide NF/AH Waiver services has barred individual  
4 Plaintiffs from receiving the services they need to continue to live in the community,  
5 thereby placing them at imminent risk of institutionalization in violation of Section  
6 504’s integration mandate.

7 128. Defendant has discriminated against Plaintiffs in ways that include  
8 arbitrarily setting cost-caps for the NF/AH Waiver far below the actual rate paid for  
9 institutional services in equivalent nursing facilities, thus denying Plaintiffs funds  
10 for home and community-based services that would otherwise be available for  
11 institutional services.

12 129. By denying Plaintiffs adequate and necessary NF/AH Waiver services  
13 commensurate with their actual need, as opposed to arbitrary service limitations,  
14 Defendant has imposed eligibility requirements which unlawfully screen Plaintiffs  
15 out from fully and equally enjoying NF/AH Waiver services, and from receiving  
16 adequate care to remain safely at home.

17 130. Defendant has utilized criteria and methods of administration that  
18 subject Plaintiffs to discrimination on the basis of disability, including risk of  
19 unnecessary institutionalization, by, including but not limited to the following: (1)  
20 designing and implementing Home and Community-Based Services Waivers which  
21 set arbitrarily low cost-caps for NF/AH Waiver services, while paying significantly  
22 higher rates for the institutional alternative; and (2) imposing eligibility criteria, cost  
23 limitations and other criteria not required by federal limitations, which restrict in-  
24 home care in favor of institutional care.

25 131. Defendant’s actions violate Section 504.

26 //

27 //

28 //

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

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

1  
2  
3  
4       132. Plaintiffs reallege and incorporate herein by reference each and every  
5 allegation and paragraph set forth previously.

6       133. Individual Plaintiffs are persons with disabilities within the meaning  
7 of California Government Code section 11135(c) *et seq.* (2011) and its  
8 implementing regulations.

9       134. Individual Plaintiffs meet the essential eligibility requirements for  
10 Medi-Cal services, including services necessary to maintain them in their homes in  
11 the community.

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

17       136. Defendants DHCS and Director Kent conduct, operate or administer  
18 the state Medicaid program, entitled Medi-Cal, which is directly funded, in part, by  
19 state financial assistance within the meaning of California Government Code section  
20 11135(a) and implementing regulations.

21       137. Defendants are obligated to administer their programs in a manner  
22 that enables qualified individuals with disabilities to live in the most integrated  
23 setting appropriate to their needs. Defendants' denial and reduction of adequate and  
24 medically necessary in-home nursing, and failure to provide Plaintiffs with  
25 medically necessary NF/AH Waiver services, has denied Plaintiffs the services they  
26 need to remain safely in the community, thereby placing them at risk of  
27 institutionalization in violation of the integration mandate of Government Code  
28 section 11135.

1           138. By administering its programs in ways that deny Plaintiffs NF/AH  
2 Waiver services commensurate with their actual need, and instead imposing  
3 arbitrary cost limitations on the services they may receive, Defendants have  
4 discriminated against Plaintiffs, thereby excluding them from participation in,  
5 denying them the benefits of, and otherwise subjecting them to discrimination in  
6 violation of California Government Code section 11135 *et seq.* and implementing  
7 regulations.

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

12 **VIII. ALLEGATIONS CONCERNING INJUNCTIVE AND DECLARATORY**  
13 **RELIEF**

14           140. Defendants' actions, as alleged herein, have resulted in and will  
15 continue to result in irreparable injury to Plaintiffs caused by the refusal to cover  
16 medically necessary services under the NF/AH waiver, which they need to remain in  
17 their homes and avoid unnecessary institutional placement. Plaintiffs have no plain,  
18 speedy or adequate remedy at law.

19           141. IN SPIRIT is also subject to irreparable injury as a result of the  
20 NF/AH Waiver cost-cap, for it provides financial aid to NF/AH Waiver recipients to  
21 supplement at-home care which would otherwise be covered by the NF/AH Waiver,  
22 but for imposition of the cost-cap. IN SPIRIT's mission is thereby impeded, where  
23 funds are put toward assisting NF/AH Waiver recipients with home care needs,  
24 rather than funding non-Waiver recipients.

25           142. An actual controversy exists between Plaintiffs and Defendants, in  
26 that Plaintiffs claim that Defendants have failed to provide services in the most  
27 integrated setting appropriate to meet Plaintiffs' needs, in violation of federal and  
28 state law and Defendants deny all such contentions.



1           143. Defendant Kent can either adopt or “alternate” (reject in whole or  
2 part) any administrative decision arising out of claims against DHCS. California  
3 Manual of Policies and Procedures, Sections 22-061 and 22-062. Therefore, the  
4 administrative appeal process offers no remedy or protection to Plaintiffs, as the  
5 Defendants in this action are the very entity which will make a determination of  
6 what NF/AH Waiver services will be provided to Plaintiffs.

7 **IX. REQUEST FOR RELIEF**

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

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

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

- 16           i. The Americans with Disabilities Act (“ADA”), (42 U.S.C. §§  
17 12101-12213 (2008)) and implementing regulations.
- 18           ii. Section 504 of the Rehabilitation Act (“Section 504”), (29  
19 U.S.C. §§ 794-794a (2014)) and implementing regulations; 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, 2 hours per month  
27 of RN care and 240.04 hours per month of IHSS personal care services until such  
28 time as the matter before this Court may be finally decided.

1           144. 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 Plaintiffs, including placing  
4 them at risk of unnecessary institutionalization, by:

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

18           145. Issue an order requiring Defendants to:

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

1                                    assessed needs, and as identified by their treating physicians,  
2                                    consistent with federal cost neutrality requirements.

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

6            147.    Award Plaintiffs the costs of this action and reasonable attorneys’  
7 fees pursuant to 20 U.S.C. § 794a (2014); 42 U.S.C. §§ 12133 (1990), 12205  
8 (1990); Cal. Civ. Proc. Code § 1021.5 (1993); and as otherwise may be allowed by  
9 law.

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

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Respectfully submitted:

Date: January 29, 2015

/s/

Elissa Gershon  
Disability Rights California  
Attorneys for Plaintiffs