

**UNITED STATES DISTRICT COURT
DISTRICT OF MASSACHUSETTS
Western Division**

Catherine Hutchinson, by her guardian,
Sandy Julien; Raymond Puchalski,
by his guardian Nickie Chandler;
Glen Jones, by his guardian Steven Jones;
Jason Cate, by his next friend and father, Addison
Cate, and Nathaniel Wilson,
on behalf of themselves and all others
similarly situated; and

The Brain Injury Association of
Massachusetts and the Stavros Center for
Independent Living

Plaintiffs,

v.

Deval L. Patrick, Governor;
JudyAnn Bigby, Secretary of the Executive Office
of Health and Human Services,
Leslie Kirwan, Secretary of the Executive Office
of Administration and Finance;
Thomas Dehner, Acting Director of Mass Health,
Elmer C. Bartels, Commissioner of Massachusetts
Rehabilitation Commission

Defendants.

Civil Action No. 07-CV-30084-MAP

AMENDED CLASS ACTION COMPLAINT

I. INTRODUCTION

1. Catherine Hutchinson, Raymond Puchalski, Glen Jones, Nathaniel Wilson, and Jason Cate (hereafter “the individual plaintiffs”) have serious brain injuries that substantially impair basic life skills and require ongoing rehabilitation and support. Each of these individuals is qualified for the defendants’ system of long term care services for persons with disabilities, including Medicaid services. Each is unnecessarily institutionalized in a nursing or rehabilitation

facility because of the defendant's failure to provide these services and support in appropriate, integrated community settings. Instead, the defendants require these individuals, and hundreds of other individuals with brain injuries, to live in facilities segregated from the community as a condition of receiving care and assistance.

2. More than 8000 individuals with brain injuries currently live in nursing and rehabilitation facilities in Massachusetts. At least a quarter of these individuals are able to, and prefer to, reside in integrated community settings with appropriate supports. In the absence of these services, they remain unnecessarily institutionalized, sacrificing their personal liberty, autonomy and freedom of association, as well as meaningful access to community life, in order to receive care and treatment for their disability. Hundreds more individuals with brain injuries are at risk of admission to such facilities just to receive the limited rehabilitative services that the defendants do provide.

3. Despite their ability to benefit from community-based supports, all of these individuals, and others similarly-situated, are experiencing or will experience unnecessary and prolonged institutionalization in violation of the Americans with Disabilities Act (ADA). 42 U.S.C. § 12132 *et seq.*; 28 C.F.R. § 35.130(d) *et seq.*, and Section 504 of the Rehabilitation Act of 1973 ("Rehabilitation Act"). 29 U.S.C. § 794(a) *et seq.*

4. The brain injuries experienced by these individuals are profound and life changing, but they need not result in a lifetime of institutional care. Like persons without disabilities, these individuals need "family relations, social contacts, work options, economic, independence, educational advancement and cultural enrichment." *Olmstead v. L.C.*, 527 U.S.581, 600 (1999). Their medical and rehabilitative needs can best be met in community settings, which have been demonstrated to improve skills, promote rehabilitative goals, and

facilitate independence for persons with brain injuries and other severe disabilities. These individuals are entitled to receive services in the most integrated setting appropriate for their needs and should not continue to suffer the isolation and indignity of institutional care because of the defendants' ineffective reliance on institutions like nursing and other long term care facilities.

5. The defendants' excessive use of institutions to care for persons with brain injuries is longstanding. Many individuals with brain injuries have been determined by their treatment professionals to be ready for placement into a community setting, but these professional recommendations have not been implemented for many years due to the lack of appropriate alternatives. Despite knowledge of these recommendations, of the professional consensus about the benefits of community living, of the cost-effectiveness of non-institutional alternatives, and of the mandates of federal law, the defendants have not made reasonable efforts to develop community alternatives to institutional confinement for persons with brain injuries.

6. Instead, the number of persons with brain injuries who remain needlessly institutionalized in nursing and rehabilitation facilities in Massachusetts has *increased* over the past decade. There has been no meaningful effort by the defendants, through the Executive Office of Health and Human Services (EOHHS) and other state agencies, to create community alternatives for these individuals. Moreover, the defendants have failed to develop and implement a comprehensive and effectively working plan to move individuals with brain injuries into the community at a reasonable pace.

7. In fact, defendants have effectively denied nursing and rehabilitation facility residents access to their two, small community services programs for individuals with traumatic brain injuries. The defendants fail to inform nursing and rehabilitation facility residents of these programs, fail to assess them for these programs, and fail to afford them equal access to these

programs. Moreover, the defendants administer these programs in a discriminatory manner, purposefully excluding individuals with acquired brain injuries or who, because of the severity of their disability, find themselves with no option but to be admitted to a nursing or rehabilitation facility for long term care.

8. By requiring these individuals, and others similarly situated, to submit to institutionalization as a condition for receiving long term care, the defendants cause the plaintiffs to experience unnecessary regression, deterioration, isolation, and segregation. This segregation “perpetuates unwarranted assumptions” that these individuals are “incapable or unworthy of participating in community life.” *Olmstead*, 527 U.S. at 600.

9. As Medicaid-eligible individuals, the plaintiffs are entitled to a choice of institutional and community settings, 42 U.S.C. § 1396n(c) *et seq*, including reasonable access to the defendants’ federally-funded Home and Community-Based Services (HCBS) waiver program. Instead, the defendants have failed to administer this Medicaid program in an efficient and effective manner, providing inadequate notice of, and access to, the HCBS program.

10. Even within nursing facilities, the defendants provide these individuals, and others like them, limited access to rehabilitative services such as speech, occupational and physical therapies. The provision of nursing and related services is often based on a person’s needs in the institutional setting, as opposed to the rehabilitative services necessary for successful community integration. The denial of these medically necessary therapies, all of which are Medicaid- covered services and which must be provided promptly and as long as medically necessary under the law, further impedes the plaintiffs’ prospects for recovery and for independent community living. Over time, this failure to provide necessary services has resulted in significant deterioration of the plaintiff’s basic functioning, abilities, and medical condition.

11. The defendants' failure to provide community-based support services has caused, and will continue to cause, serious, long-term, and potentially irreversible harm to the individual plaintiffs and the class that they represent. The plaintiffs, therefore, seek prospective injunctive relief ordering the defendants to provide the rehabilitative services they need, and the integrated, community-based support services to which they are entitled, in accordance with federal law.

II. JURISDICTION AND VENUE

12. This is a civil action authorized by 42 U.S.C. § 1983 to redress the deprivation of rights, privileges, and immunities guaranteed by federal law. This Court has subject matter jurisdiction pursuant to 28 U.S.C. § 1331, 1343(a)(3), and 1343(a)(4).

13. This Court has jurisdiction over this action for declaratory relief pursuant to 28 U.S.C. § 2201 and Rule 57 of the Federal Rules of Civil Procedure. Injunctive relief is authorized by 28 U.S.C. § 2202, 42 U.S.C. § 1983, and Rule 65 of the Federal Rules of Civil Procedure.

14. Venue is proper in the District of Massachusetts pursuant to 28 U.S.C. § 1391(b)(2), as a substantial part of the events or omissions giving rise to these claims occurred within the Commonwealth of Massachusetts. The majority of the plaintiffs reside in western Massachusetts.

III. THE PARTIES

A. *The Individual Plaintiffs*

1. Catherine Hutchinson

15. Catherine Hutchinson is a 54 year-old woman and mother who resides in Bristol County, Attleboro, but who currently is institutionalized at the Middleboro Skilled Care Center (MSCC) in Middleboro, Massachusetts. She brings this action through her guardian, Sandy Julien, who lives at 405 Willett Avenue in Riverside, Rhode Island.

16. Ten years ago, Ms. Hutchinson suffered a stroke that caused bleeding in her brain stem. As a result of this acquired brain injury, she has very little movement in her arms and legs. She operates an electric wheelchair using a button and directional arrows she can manipulate with her head. Although Ms. Hutchinson is unable to speak, she can effectively communicate her thoughts and wishes. With her eyes, she can answer basic questions, utilize a letter board and operate e-mail via the internet. She has re-learned many basic skills since her injury, including how to swallow on her own and how to use a straw for drinking.

17. Ms. Hutchinson receives no ongoing, rehabilitative services, despite a medical need for these services in order to maintain her physical well-being and prevent further deterioration of her medical condition. What restorative treatment she does receive is limited in nature.

18. Ms. Hutchinson has been a resident of the nursing facility for more than nine years. She has long expressed her desire and intention to return home with community support services, and to be closer to her family and friends. Her social worker and treatment professionals agree that she could live in a less restrictive setting with the appropriate services in place. Ms. Hutchinson describes herself as trapped, a prisoner of her disability and of the nursing facility that leaves her isolated from the life she used to know.

19. Because Ms. Hutchinson's disability resulted from a medical event, rather than an accident, she is considered to have an "acquired" brain injury, rather than a traumatic brain injury. As a result of this arbitrary distinction she, and many class members like her, are denied access to the only brain injury services offered by the defendants. Ms. Hutchinson is a remarkable and intelligent woman who uses her time and energy to advocate on behalf of people with similar disabilities. She would benefit from access to community-based services, but is

forced to remain in an overly restrictive nursing facility due to the defendants' discriminatory administration of their long term care system.

2. Raymond Puchalski

20. Raymond Puchalski, ("Ray") is a 58 year-old man who resides in Millers Falls in Franklin County, but who currently is institutionalized in Kindred/Goddard Hospital's neurobehavioral unit in Stoughton, Massachusetts. Mr. Puchalski brings this action through his guardian, Nickie Chandler, who resides at 165 Old Bay Road in Belchertown, MA.

21. Four years ago, Mr. Puchalski's car was struck by a driver who fell asleep at the wheel. Mr. Puchalski was in a coma for four weeks following the accident and was not expected to survive. Following the acute phase of his treatment, he spent eighteen months in a nursing facility with little specialized treatment. In order to secure more appropriate care, his partner and guardian was again forced to place him in an institutional setting, one far from his home in western Massachusetts.

22. In the two years since his admission, Mr. Puchalski has made significant progress. He can ambulate and feed himself independently. He has also learned to shower on his own with cues. Although he has had significant difficulty with both expressive and receptive language communication, his communication skills are also showing signs of improvement.

23. Social work staff and Mr. Puchalski's treatment professionals agree that he could be discharged to a small, supervised community residence with appropriate support, but there is no community setting available for him. He longs to have more freedom, to spend time outdoors and with family, and to return to his home in Millers Falls, the only place he ever wanted to live. These goals seem remote, however, and his unnecessary institutionalization likely to continue, given the lack of appropriate community support services made available by the defendants.

3. Glen Jones

24. Glen Jones is a 57 year-old man who resides in Essex County, but who currently is institutionalized at the Worcester Skilled Care Center (WSCC) in Worcester, Massachusetts. He brings this action through his guardian, Steven Jones, who resides at 51 Kent Street in Haverhill, Massachusetts.

25. Mr. Jones worked as an auto mechanic and owned his own business prior to the accident that changed his life. In 1986, he sustained an open head injury following a motor vehicle crash and spent three weeks in a coma. After receiving rehabilitative treatment in two area facilities, he was discharged to WSCC in 1990.

26. Mr. Jones has spent the past 21 years of his life in institutional settings. He has chafed against the limitations of these environments, longing for a return to meaningful employment and the life of independence he used to know. Following his injury, his family applied to the one state-funded program for persons with traumatic brain injury, but never received the services necessary to facilitate his discharge to the community. Efforts to identify existing residential programs were unsuccessful.

27. Mr. Jones is articulate, mobile and motivated to resume his former life. He has the continuing support of family, and intends to return to the Haverhill area where his brother and mother reside. Mr. Jones' treatment professionals agree that he could benefit from more integrated community support services, if those services existed. In their absence, he has been forced to spend decades of his adult life isolated from the community, living apart from family and friends, and unnecessarily confined in an institutional setting.

4. Nathaniel Wilson

28. Nathaniel Wilson is a 54 year old man who resides in Springfield in Hampden

County and who currently is institutionalized at the Wingate of Wilbraham skilled nursing facility in Wilbraham, Massachusetts. He brings this action on his own behalf.

29. A former machinist, Mr. Wilson began experiencing physical limitations approximately ten years ago that affected his ability to work. He struggled to secure section 8 housing and to survive on disability benefits. In April of 2006, he experienced a stroke that damaged the right side of his brain. This acquired brain injury primarily impacted the left side of his body, affecting his speech, mobility, facial muscles and hand.

30. Despite significant progress in the early phase of his rehabilitation, Mr. Wilson still suffers from chronic and debilitating pain in the left side of his body. However, he can ambulate with a walker and is able to communicate clearly.

31. Mr. Wilson has limited opportunities to leave the nursing facility. A brother provides his only regular access to the community, transporting him to volunteer at an area church each week. Otherwise, a chair outside the nursing facility entrance is his only exposure to the outside world.

32. Mr. Wilson has little in common with the facility's older residents, and he longs for the autonomy and privacy of his former life. He is able to independently perform most activities of daily living and has no hands-on nursing needs. He has received only short-term rehabilitative services at Wingate. He would benefit from the opportunity to live in an integrated community setting and to participate in more community-based programs. He needs ongoing physical therapy to support these community integration goals.

33. Mr. Wilson wishes to leave the facility and intends to return to the Springfield area to be near his daughter. He wants to live as independently as possible in the community. His social worker and treatment professionals agree that he could function in the community

with supervision and support, and believe he would be happier living in a less restrictive setting with people his own age. However, a lack of appropriate community-based services has prevented his discharge.

34. Since Mr. Wilson's disability resulted from a medical event, rather than an external accident, he is considered to have an "acquired" brain injury. As a result of this arbitrary distinction, Mr. Wilson, and many class members like him, are denied access to the only brain injury services offered by the defendants. Mr. Wilson would benefit from access to integrated, community-based services, but is forced to remain in an overly restrictive nursing home setting due to the discriminatory nature of the defendants' service system.

5. Jason Cate

35. Jason Cate is a forty year old man who resides in Westfield in Hampden County, but is currently institutionalized at the Heritage Hall West nursing facility in Agawam, Massachusetts. He brings this action through his father and next friend, Addison Cate, who lives at 40 Huckleberry Lane in Easthampton, Massachusetts.

36. In the late 1990's, Mr. Cate required several surgeries for metastasized testicular cancer, including surgeries to remove tumors from his abdomen and brain. Despite the serious and complex nature of these procedures, he continued to live independently in his own home. In 2004 and 2005, Mr. Cate experienced two seizures, the second leaving him incapacitated on the floor for three days. He was hospitalized and spent several weeks in an acute treatment center. When he was discharged from the hospital, his father, Addison Cate, had little choice but to transfer his son to Heritage Hall West's nursing facility because of the lack of appropriate community alternatives.

37. As a result of his injuries, Jason Cate experiences diminished cognitive abilities and vision loss. He requires assistance with walking and coordinating his physical movements. Despite his mobility, Mr. Cate spends most of his time in a wheel chair. His only access to the community is provided by a companion who is privately funded by his family.

38. Mr. Cate has spent almost two years living in a nursing facility. He has very little in common with the older residents and requires little, if any, skilled nursing. Despite ongoing needs for physical therapy to maintain and improve his coordination, Mr. Cate has received only brief and sporadic access to this service.

39. In 2006, Mr. Cate was evaluated by a private service provider who found he was able to live in the community with appropriate supports. However, the lack of an accessible residential site, and the absence of residential supports in western Massachusetts have forced him to remain institutionalized at Heritage Hall.

40. Since Mr. Cate's acquired brain injury occurred as a result of internal medical conditions, he is denied access to the only brain injury services offered by the defendants. As a result, Mr. Cate is forced to remain in an overly restrictive nursing facility due to the discriminatory nature of the defendants' service system.

41. Mr. Cate longs to return to his community. He is frustrated by the confining nature of life in the nursing facility. He intends to return to the Hamden County area to be closer to his family and friends. Mr. Cate's treatment professionals agree that he could benefit from more integrated community supports. Unless appropriate services are made available, Mr. Cate will remain unnecessarily segregated in an institutional setting, and without any hope for a better future.

B. The Organizational Plaintiffs

42. The Brain Injury Association of Massachusetts (“BIAMA”) is a statewide, nonprofit advocacy organization comprised of, and operated by, persons with brain injuries, their families and friends, and other medical professionals.

43. BIAMA is dedicated to ensuring that all citizens with brain injuries in the Commonwealth are afforded appropriate services and supports in the most integrated, home-like setting possible, and that these individuals and their families have meaningful choices about the nature and location of those services. Over the course of its 25-year history, BIAMA has listened to, and sought to magnify the voices of, those living with brain injury, particularly those who, because of a lack of appropriate services, find themselves segregated in institutional settings or at risk of institutional placement. As an organization, BIAMA has advocated for enhancement of government services for persons with brain injuries, and particularly for the expansion of community support services. It also has monitored the actions of the defendants in order to ensure that such services are made available. It has expended considerable organizational resources attempting to expand community services and supports for persons with brain injuries. Despite these committed efforts, BIAMA has been unable to achieve the improvements necessary to redress the ongoing civil rights violations experienced by its members and alleged within this Complaint.

44. BIAMA is a membership organization that includes individuals with both acquired and traumatic brain injury who reside in nursing facilities. In addition to its organizational interest in expanding community settings and supports, BIAMA has many members who are also members of the plaintiff class and who are directly harmed by the actions and inactions of the defendants.

45. The Stavros Center for Independent Living (hereafter "Stavros") is a private, non-profit corporation and is one of the oldest independent living programs in the country. It serves Franklin, Hampshire, and Hampden counties of western Massachusetts. State and federal funds support Stavros' independent living programs. Each year Stavros provides individual advocacy, peer counseling, skills training, information, and referrals to more than five thousand individuals with significant disabilities, including persons with brain injuries who live in nursing facilities in western Massachusetts. Stavros also administers the PCA program for the counties that it serves. Additionally, Stavros offers lift-equipped van transportation, independent living services to individuals who are deaf or hard of hearing, an equipment loan program, and assistive technology services. Directed, managed, and staffed by people with disabilities, Stavros is mandated to provide a full range of disability services to members of the plaintiff class, subject to available resources. The defendants' actions impede Stavros' ability to effectively provide Personal Care Attendant services to individuals with brain injuries and limit its ability to offer these services in integrated community settings.

46. Stavros is required to file annual reports with the Rehabilitation Services Administration (RSA), the federal agency responsible for setting and enforcing the standards for independent living centers, and with the Massachusetts Rehabilitation Commission (MRC), concerning the number of persons whom it assists to transition from an institution to the community. RSA may use this information to determine the level of funding which Stavros will receive. The defendants' actions compromise Stavros' ability to carry out its federal responsibilities and jeopardize its funding.

C. The Plaintiff Class

47. Pursuant to Rule 23(a) and (b)(2) of the Federal Rules of Civil Procedure, the individual plaintiffs bring this matter as a class action on behalf of Massachusetts residents who now, or at any time during this litigation: (1) are Medicaid eligible; (2) have suffered a brain injury; (3) reside in a nursing or rehabilitation facility or are eligible for admission to such a facility; and (4) would benefit from community support services. The proposed class excludes nursing facility residents who are class members in a related case, *Rolland v. Cellucci*, 191 F.R.D. 3 (D. Mass. 2000).

48. The plaintiff class is so numerous and geographically diverse that joinder of all members is impracticable. It is estimated that, at any given time, the plaintiff class exceeds at least several thousand individuals.

49. There are questions of law and fact common to the plaintiff class including, *inter alia*:

(1) whether defendants are violating the ADA and Section 504 by: i) failing to provide community support services to nursing or rehabilitation facility residents who have brain injuries in the most integrated setting appropriate to their needs; ii) failing to develop a comprehensive and effectively working plan for achieving this goal; iii) utilizing methods of administration that do not allow for community placements to occur at a reasonable pace; iv) requiring persons with brain injuries to be admitted to and remain in nursing and rehabilitation facilities due to a lack of appropriate community support services; v) unlawfully discriminating against persons with acquired brain injuries; and vi) unlawfully discriminating against persons with brain injuries based on the severity of their disabilities; and

(2) whether defendants are in violation of the federal Medicaid program by: i) failing to provide necessary rehabilitative services with reasonable promptness; ii) failing to provide nursing or rehabilitation facility residents with brain injuries with adequate notice of, assessment for, and access to community support services; and iii) denying persons with brain injuries a choice between an institutionalized nursing or rehabilitation facility and integrated community waiver services by failing to inform them of these alternatives, failing to provide them with relevant information necessary to exercise this choice, and failing to afford them meaningful access to community waiver services.

50. As a result of the defendants' actions and inactions, the individual plaintiffs have been denied access to the rehabilitative and community support services needed to avoid unnecessary segregation and the devastating effects of prolonged institutionalization. These claims are typical of the plaintiff class, allowing the individual plaintiffs to adequately and fairly represent the federal rights and interests of class members. The individual plaintiffs will fully and vigorously prosecute this action, understanding that many class members are unable to pursue their individual rights, or to remedy these systemic violations, on their own. The plaintiffs seek certification of a class pursuant to Fed. R. Civ. P. 23(b)(2) on the grounds that the defendants' policies, practices, and procedures are unlawful, discriminatory, and perpetuate an ongoing harm against similarly situated individuals with serious brain injuries, thereby making injunctive and declaratory relief appropriate with respect to the entire plaintiff class.

51. The individual plaintiffs seek relief that will inure to the benefit of the plaintiff class as a whole. The plaintiffs are represented by attorneys experienced in federal class action litigation, disability law and public assistance benefits, including the Massachusetts Medicaid program.

D. The Defendants

52. Deval L. Patrick, Governor of Massachusetts, is the Chief Executive Officer of the Commonwealth. He oversees the various executive departments of state government including the multiple secretariats and agencies responsible for the care and treatment of individuals with disabilities and specifically persons with brain injuries, including the Executive Office of Health and Human Services (EOHHS) and the Executive Office of Administration and Finance (EOAF). He appoints the heads of these secretariats and approves the appointment of Commissioners responsible for the operation of state departments and agencies that manage and fund health and disability services, including the director of the Office of Medicaid (MassHealth) and the Commissioner of the Massachusetts Rehabilitative Commission (MRC). He also is responsible for seeking funds from the legislature to implement the Medicaid program. He is sued in his official capacity.

53. JudyAnn Bigby, Secretary of EOHHS, is responsible for the oversight, supervision, and control of the health and human services departments within the Executive Office, which includes the agencies responsible for providing, funding, or arranging community-based services for individuals with disabilities, and specifically MassHealth and MRC. Secretary Bigby is responsible for ensuring that persons with disabilities are cared for, treated, and supported as required by law, and for coordinating and monitoring the agencies within EOHHS that are assigned to fulfill this duty. EOHHS is also the single state Medicaid agency for the Commonwealth pursuant to 42 U.S.C. § 1396a(a)(5). As such, Secretary Bigby is responsible for ensuring that the defendants' Medicaid programs, including their long-term care program, their nursing facility program, and their Home and Community-Based Services waiver program are operated in a manner consistent with federal requirements. She is sued in her official capacity.

54. Leslie Kirwan, Secretary of EOAF, is responsible for seeking and approving the expenditure of adequate funds from the legislature to comply with the requirements of the Medicaid program and the provision of integrated community services consistent with federal law. She is sued in her official capacity.

55. Thomas Denher, Acting Director of MassHealth and the Office of Medicaid, is responsible for the day-to-day operations of the Massachusetts Medicaid program. He oversees the development and execution of the defendants' Medicaid plan, all Medicaid policies, procedures, contracts, and practices, including those regarding services for persons with brain injuries. He is sued in his official capacity.

56. Elmer C. Bartels, Commissioner of the Massachusetts Rehabilitation Commission ("MRC"), is responsible for directing his agency's efforts to promote employment and independent living for persons with disabilities. Commissioner Bartels oversees MRC's Vocational Rehabilitation Services, Community Services, and Federal Eligibility Determinations divisions. The Brain Injury and Statewide Specialized Community Services Program (BISSCS) is part of the Community Services Division of MRC. Formerly identified as the Statewide Head Injury Program (SHIP), BISSCS is the only state program devoted to serving persons with traumatic brain injury. MassHealth has designated BISSCS as the entity responsible for applications to and screening of candidates for the defendants' Traumatic Brain Injury Waiver. Commissioner Bartels is sued in his official capacity.

57. In light of the duties of all state defendants as set forth above, the Governor, the Secretaries of EOHHS and EOAF, the Commissioner of MRC and the Director of MassHealth are necessary for effective relief in this case.

IV. FACTUAL ALLEGATIONS

A. Individuals with Brain Injuries

58. Brain injuries vary in origin and effect. When brain injuries are caused by internal medical events such as stroke, loss of oxygen (anoxia), poisoning (toxemia) or brain tumors, they are referred to as acquired brain injuries (ABI). If they are caused by external events, like falls, auto accidents or other head wounds, they are part of a subset of acquired brain injuries called traumatic brain injuries (TBI). Both types of brain injuries can result in a similar disabling conditions that severely limit functioning, basic skills, and cognitive processing. These injuries also necessitate very similar community-based supports for affected individuals.

59. Brain injury can cause a wide range of functional changes that negatively affect an individual's basic life skills including movement, memory, thinking, learning, sensation, communication, and behavior. It can also increase a person's risk for a variety of medical conditions and other brain disorders including Alzheimer's and Parkinson's diseases.

60. The Center for Disease Control estimates that there are currently 5.3 million individuals -- or more than two percent of the U.S. population -- living with a long-term disability resulting from traumatic brain injury. When considering an individual's family and circles of support, brain injury touches the lives of approximately one in ten persons in the United States. Of the 1.4 million traumatic brain injuries every year, 50,000 result in deaths, 235,000 in hospitalization, and 1.1 million in emergency room visits.

61. Acquired brain injuries occur with equally staggering prevalence. For example, approximately 700,000 Americans each year suffer a new or recurrent stroke, resulting in the death of 157,000 citizens annually.

62. Massachusetts' experience with brain injury mirrors that of the Nation. In 2004, there were 486 traumatic brain injury-related deaths among Massachusetts residents. In fiscal year 2004, there were 4,994 inpatient hospitalizations associated with non-fatal traumatic brain injuries. Approximately 1,750 individuals with brain injuries – more than thirty-five percent of those hospitalized – were discharged to a nursing or rehabilitation facility in 2004.

63. Individuals who survive serious brain injuries are likely to need hospitalization and intensive rehabilitation during the initial phase of their care and treatment. However, many individuals can subsequently reside in more integrated community settings with appropriate supports. Of the estimated 8,200 individuals with brain injuries currently in nursing and rehabilitation facilities across the Commonwealth, at least a quarter could transition to integrated community settings if appropriate services were available. Hundreds more who currently live in the community are eligible for, and at risk of, institutionalization because of the lack of adequate community services.

64. While individual needs may vary widely, most persons recovering from serious brain injuries require some level of assistance with personal care and activities of daily living, ongoing speech, occupational and physical therapies, medical and nursing services, vocational training or day habilitation programs, durable medical equipment, transportation, and integrated social and recreational activities. Many also require accessible living arrangements.

65. All these services are available to some degree in the community, and most are covered by Medicaid. However, there is simply an insufficient capacity and intensity of supports to meet the needs of nursing facility residents and others who no longer require institutional care for their brain injuries. For these individuals, the denial of access to community-based support services has profound consequences. The majority of individuals who sustain moderate or

severe brain injuries experience significant medical, physical, behavioral, and cognitive problems. These conditions are exacerbated by prolonged and unnecessary institutionalization, leading to deterioration in individuals' functional independence and daily living skills, severe limitations on their community access, and negative outcomes for their social/vocational development and emotional well-being.

B. The Requirements of the Americans with Disabilities Act and Section 504 of The Rehabilitation Act

1. Nondiscrimination and the Integration Mandate

66. In 1990, Congress enacted the ADA, 42 U.S.C. §§ 12101 – 12181, to advance the civil rights of people with disabilities. The ADA's purpose and goal is "the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101(b)(1). In enacting the ADA, Congress stated that, "Historically, society has tended to isolate and segregate individuals with disabilities" and that such forms of discrimination "continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2). Congress further determined that "The Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic sufficiency for such individuals." 42 U.S.C. § 12101(a)(8).

67. Title II of the ADA provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. Title II prohibits unnecessary segregation and institutionalization. 28 C.F.R. § 35.130(d) ("A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of the qualified individual with disabilities"). As the Supreme Court stated in *Olmstead*, "unjustified institutional isolation of persons with

disabilities is a form of discrimination” because “[i]n order to receive needed medical services, persons with mental disabilities, because of those disabilities, relinquish participation in community life....” 527 U.S. at 600-601.

68. Discrimination on the basis of disability is also prohibited by Section 504 of the Rehabilitation Act. 29 U.S.C. § 794(a) *et seq.* Section 504’s accompanying regulations provide that recipients of federal funds “shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.” 28 C.F.R. § 41.51(d).

2. Methods of Administration

69. Both the ADA and Section 504 of the Rehabilitation Act prohibit public entities from utilizing “criteria or methods of administration” that have the effect of subjecting qualified individuals with disabilities to discrimination, including unnecessary institutionalization. 28 C.F.R. § 35.130(b)(3); § 41.51(b)(3); 45 C.F.R. § 84.4(b)(4).

70. Section 504 regulations specifically prohibit recipients of federal financial assistance from “utiliz[ing] criteria or methods of administration ... (i) [t]hat have the effect of subjecting handicapped persons to discrimination on the basis of handicap; [or] (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient’s program with respect to handicapped persons.” 28 C.F.R. § 41.51(b)(3).

C. *The Mandates of the Medicaid Program*

1. The Federal Medicaid program

71. The Medicaid program, authorized and regulated pursuant to Title XIX of the Social Security Act, is a joint federal-state medical assistance program for low-income persons. *See* 42 U.S.C. § 1396a *et seq.* One of the purposes of the Medicaid program is to provide “services to help such families and individuals attain or retain capability for independence or

self-care.” *Id.* At the federal level, the Medicaid program is administered by the U.S. Department of Health and Human Services’ Center for Medicaid and Medicare Services (“CMS”).

72. States are not required to participate in Medicaid, but once a State agrees to participate, it must comply with the requirements imposed by the Act and the regulations promulgated by the Secretary of Health and Human Services. The services that the State must provide, as well as the services they elect to provide, are described in the State plan, which is approved by the Secretary.

73. States are reimbursed by the federal government for a portion of the cost of providing Medicaid benefits. Massachusetts receives approximately fifty cents in federal reimbursement for every dollar it spends on Medicaid services.

74. Pursuant to Section 1915 of the Social Security Act, the Secretary may waive certain requirements of the Act and provide that an approved State plan include as medical assistance payment for the cost of Home and Community-Based Services (HCBS). 42 U.S.C. § 1396n. Although States must apply for a specific number of persons to be served by a HCBS waiver, there is no limit to how many persons may be included on a waiver. Historically, States have routinely requested, and the federal government has regularly approved, incremental increases in the number of persons included in a waiver. In fact, the federal government has informed States that a limit on the number of persons served by a waiver, or the lack of sufficient waiver capacity, does not excuse States from complying with other federal laws, including the ADA’s integration mandate.

75. HCBS are provided to individuals pursuant to a written plan of care, following a determination that, but for the provision of such services, the individual would require the level

of care provided in a nursing facility. 42 U.S.C. § 1396n(c)(1). If a State chooses to offer a HCBS waiver program, it must inform eligible individuals about any feasible alternatives available under the waiver, and give those individuals the choice of either institutional or home and community-based services. 42 U.S.C. § 1396n(c)(2)(C); 42 C.F.R. § 441.302(d).

76. A State's HCBS waiver program must also assess whether potential home and community-based service recipients need inpatient hospital services, nursing facility services or services in an intermediate care facility. 42 U.S.C. § 1396n(c)(2)(B).

77. A core provision of the Medicaid Act requires that States provide Medicaid benefits to all eligible individuals with reasonable promptness and for as long as medically necessary. 42 U.S.C. § 1396a(a)(8); 42 U.S.C. § 1396a(a)(10)(A); 42 C.F.R. § 435.930(a).

2. The Massachusetts Medicaid program

78. Massachusetts has chosen to participate in the Medicaid program. EOHHS is the single state agency that administers the Massachusetts Medicaid program. M.G.L. c. 118E §1.

79. As required by the Medicaid Act, Massachusetts has prepared a State plan that the Department of Health and Human Services has approved. That plan, along with relevant federal law and regulations, form the foundation for the Massachusetts Medicaid program and establish the defendants' obligations and responsibilities to Medicaid recipients. The plan includes all treatment, services, and supports required by the Medicaid Act (mandatory services), numerous services and treatment permitted by the Act (optional services), and several HCBS waiver programs. Specifically, the plan includes care and treatment in nursing facilities, physician and nursing services, a range of rehabilitative services like physical and occupational therapy, personal care assistance, durable medical equipment like wheelchairs and assistive technology,

and certain home-based services like residential supports, vocational training and respite services.

3. Massachusetts' Waiver Programs

80. In 2001, CMS approved a Section 1915 HCBS waiver to provide a wide range of community services and supports solely to persons with traumatic brain injuries.

81. In 2006, MassHealth submitted a demonstration waiver to CMS under Section 1115 of the Social Security Act to provide community alternatives for persons currently residing in, or at risk of being admitted to, nursing facilities. The demonstration waiver, if approved by CMS, would incorporate the HCBS waiver for persons with traumatic brain injury, as well as other existing waiver programs for elders. Because it does not focus on persons with brain injuries or even persons with disabilities, the demonstration waiver is not likely to address the longstanding needs of the plaintiffs for integrated community services.

D. The Segregation and Discrimination of Persons with Serious Brain Injuries

1. The effects of unnecessary institutionalization on persons with brain injuries

82. The individual plaintiffs, and the majority of persons with serious brain injuries, have spent weeks or months in acute care hospitals and rehabilitative facilities. Once their acute treatment needs end, there are few community-based options for continued rehabilitative care. As a result, individuals with serious brain injuries have little choice but to be admitted to nursing and rehabilitation facilities in order to have their basic needs met.

83. Nursing facilities are not homelike environments. Most are large, self-contained facilities, where available recreation, social activities, and medical care are provided in the same building where residents live, sleep, and eat. Residents share bedrooms and bathrooms. Living areas lack privacy, are sparsely furnished, and do not provide space for

the personal items or belongings one would normally associate with a home.

84. The congregate nature of these facilities limits residents' personal choices, individual expression, relationships, and freedom of association. Residents are often under-occupied and socially isolated, with limited exposure to the community or to age-appropriate peer groups. Opportunities to be outdoors or to participate in life outside the facility are limited or non-existent, except to the extent that family members can provide these opportunities for integration.

85. Because they are usually large, segregated, and isolated from the rest of society, nursing and rehabilitation facilities inhibit meaningful community involvement by depriving residents of the opportunity to interact with non-disabled people in non-custodial relationships in the community. Residents often are not able to express basic human preferences, such as what to eat and where to go, or to exercise basic human rights, such as voting, working, intimacy and privacy. Residents often are denied the experiences of observing and interacting with others, enjoying the dignity and freedom of living in the community, and participating in the rhythm and activities of community life.

86. Active speech, occupational and physical therapies generally are not provided on an ongoing basis in nursing facilities. The plaintiffs' inability to access medically necessary, ongoing rehabilitative services has limited their potential for continued recovery, while jeopardizing the maintenance of their physical and independent living skills.

87. Perhaps most devastating for the individual plaintiffs, and the class that they represent, is the reality that these nursing and rehabilitation facility placements are indefinite, with little prospect for accessing the kinds of community support services needed to live in a less restrictive setting.

88. This lack of appropriate community support services, and the dependency on institutional care that results, forces the plaintiffs to reside in segregated settings, away from their children and families, away from their homes and communities. This isolation places an additional burden and strain on their families, who are sometimes forced to travel considerable distances to spend time with their loved ones and to monitor their care.

2. Limitations on the state service system for individuals with brain injuries

89. There is no state agency specifically devoted to serving persons with brain injuries. In the absence of an agency with a mandate and mission to serve persons with brain injuries, the MRC has been arbitrarily assigned the duty to administer the Brain Injury Waiver. In addition to its focus on vocational training and related community services, MRC now also administers the small state program called BISSCS, formerly SHIP. This is the only state program that coordinates services for persons with traumatic brain injuries. It explicitly excludes those with other types of brain injuries.

90. Despite the size and scope of this obligation, BISSCS's resources are limited and its network is wholly inadequate to meet the need for community-based services among persons with brain injuries in Massachusetts. Applicants to BISSCS usually wait for years without receiving necessary services. Those residing in nursing and rehabilitation facilities usually never receive such services, and are arbitrarily excluded from the services they need to leave the institution. BISSCS' limited array of service options is insufficient to meet the needs of individuals seeking to transition from institutional settings to the community, effectively denying community access to nursing facility residents based on the severity of their disabilities.

91. Although Massachusetts' section 1915 waiver was originally approved to serve 200 individuals per year, two years later, the defendants reduced the capacity of their only

waiver program for persons with brain injury 100. They formally renewed the program in 2004 at this reduced level, which remains in effect today. This reduction is not only unprecedented, since most States, including Massachusetts, usually seek increases in the capacity of their waivers, but also unjustified, since there were clearly more, rather than less, individuals with brain injuries who needed waiver services. The federal government approved this request in 2004. This HCBS waiver is now, and has always been, limited to persons with *traumatic* brain injuries, expressly excluding individuals whose injuries occurred as a result of an internal medical condition, disease or stroke.

92. BISSCS' and the Massachusetts' HCBS traumatic brain injury waiver's categorical exclusion of persons with acquired brain injuries, leaves these individuals without any access to state or federally-funded, community-based supports, solely because of the nature and origin of their disability.

E. The Defendant's Responsibility for the Unnecessary Institutionalization of Persons with Brain Injuries

93. The defendants have failed to provide adequate community support services to individuals with brain injuries. Indeed, they have categorically excluded individuals with acquired brain injuries from accessing the only state and federally-funded programs delivering integrated community services.

94. Furthermore, the defendants have failed to develop and implement a comprehensive plan for placing qualified persons with brain injuries in the community and avoiding their prolonged, unnecessary institutionalization. Instead, with full knowledge of the need and numbers of persons with brain injuries who are unnecessarily institutionalized in nursing facilities, the defendants have administered the limited community programs that do exist in a manner which effectively excludes persons with serious brain injuries in nursing

facilities. As a result, there have been few persons with brain injuries who have been able to leave nursing and rehabilitation facilities over the past decade. Instead, there is an increasing number of such individuals who are now needlessly segregated and even more who are at imminent risk of such segregation.

95. Moreover, by failing to provide a sufficient array of community settings and supports for persons with brain injuries, the defendants have effectively required such individuals to become institutionalized as a condition of obtaining long-term care.

96. The defendants have administered the state Medicaid system and its programs in a manner that perpetuates the segregation of persons with brain injuries. These methods of administration arbitrarily limit access to integrated, community support services by persons with brain injuries in nursing facilities. Specifically, limitations on the availability of Medicaid-funded, community support services result from:

- (1) the lack of information provided to individuals with brain injuries and their families about community-based services and the HCBS waiver specifically;
- (2) inadequate assessments to determine an individual's ability to benefit from community support services;
- (3) the failure to provide nursing and rehabilitation facility residents and their guardians with a meaningful choice of community as well as institutional services;
- (4) the failure to offer meaningful access to the community services that are available, and the discriminatory exclusion of persons with severe brain injuries and/or acquired brain injuries from the few community services that do exist;

- (5) decisions and actions that intentionally limit the number and availability of community services, including federal funding for such services;
- (6) policies, procedures, restrictions and program definitions which unreasonably limit access to ongoing rehabilitative services for individuals with brain injuries; and
- (7) inadequacies in the funding of community support services, including the unreasonable refusal to seek available federal funding for such services, that the defendants are authorized to provide for Medicaid-eligible, individuals with brain injuries.

V. LEGAL CLAIMS

97. In their capacities as state officials, and under color of law, the defendants have subjected the plaintiffs to prolonged and unnecessary institutionalization, resulting in violations of the ADA, Rehabilitation Act, and Medicaid Act.

Count I: The Americans with Disabilities Act

98. The plaintiffs re-allege paragraphs 1 through 97 as though fully set forth herein.

A. Violation of the ADA's Integration Mandate

99. The plaintiffs and the members of the plaintiff class are qualified individuals with disabilities within the meaning of the ADA. 42 U.S.C. § 12131(2).

100. Title II of the ADA requires that "a public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).

101. The individual plaintiffs and plaintiff class members qualify for the defendants' program of long-term rehabilitative services, and would benefit from community support

services. Although community programs are the most integrated setting appropriate to meet their needs, the plaintiffs remain institutionalized in nursing or rehabilitation facilities, or at imminent risk of such institutionalization. By denying them access to existing community programs, and by requiring that plaintiffs to be confined in the segregated institutional settings in order to receive rehabilitative services, defendants violate the ADA's integration mandate.

102. It would not fundamentally alter the defendants' programs, services, or activities to provide plaintiffs with the supports necessary to reside in the community. The defendants do not have a comprehensive, effectively working plan for serving people with brain injuries in the most integrated setting appropriate for their needs.

B. Methods of Administration

103. Regulations implementing Title II of the ADA provide that "a public entity may not, directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) that have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; [or] (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the entity's program with respect to individuals with disabilities" 28 C.F.R. § 35.130(b)(3).

104. The defendants' criteria and methods of administering Massachusetts' long-term care system for persons with brain injuries have subjected the plaintiffs to unnecessary and unjustified segregation. The defendants administer the only joint state and federally-funded programs for persons with brain injuries in a manner that fails to inform nursing and rehabilitation facility residents of the programs, fails to assess them for the programs, fails to offer them a choice of the waiver program, and fails to afford them equal access to these programs.

C. Discrimination Based on Nature and Severity of Disability

105. The ADA prohibits discrimination on the basis of disability. 42 U.S.C. § 12132 *et seq.* The defendants illegally discriminate against qualified persons with disabilities who reside in nursing and rehabilitation facilities based upon the nature and severity of their disability. Both the defendants' state and federally-funded community programs totally exclude persons with acquired brain injuries and effectively exclude those with the most serious brain injuries.

106. The exclusion of individuals with acquired brain injuries constitutes discrimination on the basis of disability and results in their continued, unnecessary segregation in violation of the ADA. The few community supports and services that are available in the Commonwealth are not of sufficient duration and intensity to allow those with serious brain injuries to transition from nursing and rehabilitation facilities to the community, thus discriminating against the plaintiff class based on the severity of their disabilities.

Count II: Section 504 of the Rehabilitation Act

107. The plaintiffs re-allege paragraphs 1 through 106 as though fully set forth herein.

108. The plaintiffs are qualified individuals with disabilities under Section 504 of the Rehabilitation Act. 29 U.S.C. § 794(a).

109. EOHHS and its state agencies receive federal financial assistance.

110. The regulations accompanying Section 504 provide that: “[r]ecipients shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.” 28 C.F.R. § 41.51(d).

111. These regulations further prohibit recipients of federal financial assistance from “utiliz[ing] criteria or methods of administration ... (i) [t]hat have the effect of subjecting handicapped persons to discrimination on the basis of handicap; [or] (ii) that have the purpose

or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program with respect to handicapped persons." 28 C.F.R. § 41.51(b)(3); 45 C.F.R. § 84.4(b).

112. The individual plaintiffs and plaintiff class members qualify for the defendants' program of long-term rehabilitative services, and would benefit from community support services. Although the community is the most integrated setting appropriate to meet their needs, the plaintiffs remain institutionalized in nursing and rehabilitation facilities, or at risk of such institutionalization. By denying them access to existing community programs, and by requiring that plaintiffs and class members be confined in the segregated institutional settings in order to receive needed rehabilitative services, the defendants violate § 504.

113. The defendants' criteria and methods of administering their system of long-term services for people with serious brain injuries subject plaintiffs to illegal discrimination and unnecessary segregation.

114. It would not fundamentally alter the defendants' programs, services, or activities to provide the plaintiffs with the services necessary to allow them to live in the community.

Count III: Title XIX of the Social Security Act

115. The plaintiffs re-allege paragraphs 1 through 114 as though fully set forth herein.

116. Title XIX requires states to provide Medicaid benefits to all eligible persons with reasonable promptness and for as long as medically necessary. 42 U.S.C. §§ 1396a(a)(8); 1396a(a)(10)(A). Medicaid waiver programs must be administered in a fair and efficient manner, must inform persons about the program, and must afford qualified persons a choice of program services. 42 U.S.C. § 1396n(c). Provision of services must not be delayed by the agencies' administrative procedures. 42 C.F.R § 435.930(a).

117. The defendants have failed to provide medically necessary, specialized therapies to eligible nursing home residents with reasonable promptness, in violation of 42 U.S.C. §§ 1396a(a)(8); 1396a(a)(10)(A).

118. The defendants also have failed to provide residents of nursing and rehabilitation facilities with brain injuries: 1) notice of, and equal opportunities to apply for, waiver services; 2) an assessment of their eligibility for such services; and 3) meaningful choice between institutional and HCB waiver services, in violation of 42 U.S.C. § 1396n(c).

VI. PRAYERS FOR RELIEF

WHEREFORE, the plaintiffs respectfully request that this Court:

1. Certify this case a class action pursuant to Fed. R. Civ. P. 23;
2. Grant preliminary and permanent injunctive relief requiring the defendants to:
 - (1) inform residents of nursing and rehabilitation facilities, their guardians, families, and all members of the plaintiff class of all state and federally-funded programs that provide community services to persons with brain injuries; assess all qualified residents of nursing and rehabilitation facilities for such programs; offer eligible residents a choice of such programs; and administer such programs in a manner that ensures equal access for such residents, regardless of the type or severity of their brain injuries;
 - (2) develop and implement a comprehensive, effectively working plan that provides integrated, community settings and supports to residents of nursing and rehabilitation facilities with brain injuries and all members of the plaintiff class, regardless of the type or severity of their brain injuries;
 - (3) implement such plan in a manner that ensures that any wait list for community settings and supports moves at a reasonable pace, so that all current

nursing and rehabilitation facility residents with brain injuries and all members of the plaintiff class who would benefit from community placement are actually placed within five years; and

(4) promptly provide Medicaid-covered rehabilitative services to residents with brain injuries in nursing and rehabilitation facilities for as long as medically necessary, in order to promote their rehabilitation and opportunities for community living and/or prevent the deterioration of their basic functioning.

3. Issue a declaratory judgment stating that the defendants have violated the Americans with Disabilities Act, the Rehabilitation Act, and the Social Security Act in their failure to prevent the unnecessary segregation and institutionalization of persons with brain injuries and their failure to provide community-based services to Medicaid-eligible individuals with brain injuries in nursing and rehabilitation facilities and other members of the plaintiff class;

4. Award the plaintiffs costs of this litigation and their reasonable attorneys' fees; and,

5. Grant such further and other relief as may be just and proper.

RESPECTFULLY SUBMITTED,
THE PLAINTIFFS,
BY THEIR ATTORNEYS,

/s/ Steven J. Schwartz
Steven J. Schwartz (BBO# 448440)
Kathryn Rucker (BBO# 644697)
Center for Public Representation
22 Green Street
Northampton, MA 01060
(413) 586-6024

/s/ Richard A. Johnston

Richard A. Johnston (BBO# 253420)

Michael R. Dube (BBO# 654748)

Miranda Hooker (BBO# 661569)

Anne McLaughlin (BBO# 666081)

Wilmer Cutler Pickering Hale and Dorr, LLP

60 State Street

Boston, MA 02109

(617) 526-6000

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