No. 02-1697

IN THE UNITED STATES COURT OF APPEALS
FOR THE FIRST CIRCUIT

LORETTA ROLLAND, et al.
Plaintiffs-Appellees

v.

JANE SWIFT, et al.
Defendants-Appellants

ON APPEAL FROM AN ORDER OF THE UNITED STATES DISTRICT COURT
FOR THE DISTRICT OF MASSACHUSETTS

BRIEF OF *AMICI CURIAE* THE ARC OF THE UNITED STATES, NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS, JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW, NATIONAL HEALTH LAW PROGRAM, AND NATIONAL SENIOR CITIZENS LAW CENTER

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(application filed 9/17/02)

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TABLE OF CONTENTS

TABLE OF AUTHORITIES

CASES

STATUTES

OTHER AUTHORITIES

REGULATIONS

CORPORATE DISCLOSURE STATEMENT

Pursuant to Federal Rules of Appellate Procedure 26.1 and 29(c), the undersigned hereby represents that none of the *amici* organizations have parent corporations and that no publicly held company owns 10% or more stock in any *amicus*.

INTERESTS OF AMICI[1]

The Arc of the United States ("The Arc"), through its nearly 1,000 state and local chapters, is the largest national voluntary organization in the United States devoted solely to the welfare of the more than seven million children and adults with mental retardation and other developmental disabilities and their families. Since its inception, The Arc has vigorously challenged attitudes and public policy that have authorized or encouraged segregation of people with mental retardation in virtually all areas of life. The Arc also advocates for appropriate services and supports and for quality assurance mechanisms to ensure that those services and supports meet the needs of the intended beneficiaries. The Arc worked with other advocates to ensure that the Nursing Home Reform Act included the provisions requiring screening and appropriate services to beneficiaries with mental retardation.

The National Association of Protection and Advocacy Systems ("NAPAS") is the membership organization for the nationwide system of protection and advocacy ("P&A") agencies. Located in all 50 states, the District of Columbia, Puerto Rico, and the federal territories, P&As are mandated under various federal statutes to provide legal representation and related advocacy services on behalf of all persons with disabilities in a variety of settings. The P&A system comprises the nation's largest provider of legally based advocacy services for persons with disabilities. NAPAS facilitates coordination of P&A activities and provides training and technical assistance to the P&A network. This case is of particular interest to NAPAS because P&As represent individuals with

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[1] *Amici* are concurrently filing a motion with this Court for leave to file this brief.

mental retardation or other developmental disabilities who are trying to obtain adequate care in nursing facilities.

The Judge David L. Bazelon Center for Mental Health Law ("Bazelon Center") is a national, nonprofit public-interest organization that works to advance the legal rights of people with mental disabilities and ensure their equal access to the services and supports their need for participation in community life. The Bazelon Center has successfully challenged many of the barriers to dignity and choice that confront people with mental illnesses and mental retardation. The Center works to clarify and uphold the rights of people with mental disabilities and to ensure them equal access to health care, insurance coverage, housing and employment. The Bazelon Center has extensive experience with the history of the statutes at issue in this suit, and believes that the Court will benefit from an understanding of the issues considered by Congress in drafting this legislation.

The National Health Law Program is a nonprofit public-interst law firm that works to improve access to health care for people with disabilities, including those with mental disabilities. Its clients include persons who are in nursing homes and in community based settings who depend on the Medicaid program for their treatment services. For over thirty years, the National Health Law Program has provided in depth legal and policy analysis of Medicaid Act provisions, including provisions of the Nursing Home Reform Act. As such, the Program has both practical and scholarly interests in the issues before the Court.

The National Senior Citizens Law Center ("NSCLC"), a nonprofit law firm founded in 1972, defends the interests of seniors through nationwide advocacy, education and policy development. NSCLC has played a pivotal role in the implementation of the Nursing Home Reform Amendments ("NHRA"), representing a state-wide class of nursing facility residents in a case establishing that a state is obligated to implement and enforce the NHRA. *Valdivia v.*

California Department of Health Services, CIV-S-90-1226 (E.D. Cal. 1990). This case raises issues that are critical to NSCLC and its constituency. Nursing home residents are extremely vulnerable, and historically the care provided in nursing homes has been of dubious quality. *See, e.g.*, General Accounting Office, Nursing Homes: Additional Steps Needed to Strengthen Enforcement of Federal Quality Standards, Report No. GAO/HEHS-99-46 (1999), *available at* http://www.ascp.com/public/ga/gao_report.pdf. For the provisions of the Nursing Home Reform Amendment to be meaningful, they must be enforceable. This case raises important issues regarding the rights of residents to obtain the high quality nursing home care promised by the NHRA.

I. INTRODUCTION

This appeal arises out of the refusal of the Commonwealth of Massachusetts to recognize important rights that Congress provided to individuals with mental retardation and other developmental disabilities in the Nursing Home Reform Amendments: rights to receive adequate care in accordance with their determined needs when they are placed in nursing facilities. Congress passed the Nursing Home Reform Amendments ("NHRA") to the Medicaid Act, Pub. L. No. 100-203, § 4211, 101 Stat. 1330 — legislation that dramatically altered nursing facility quality of care standards and enforcement procedures — partly in response to the problem of states "dumping" individuals with mental retardation and other developmental disabilities inappropriately into Medicaid-funded nursing facilities and failing to ensure that they receive adequate care in those facilities. Congress addressed this problem by: (1) imposing requirements on States to ensure that, before being admitted to a nursing facility, individuals with mental retardation and other developmental disabilities are screened to determine whether they need a nursing facility level of care and whether they need "specialized services" to address their mental disabilities; and (2) directing the Secretary of the Department of Health and Human Services to "assure that the requirements which govern the provision of care in nursing facilities . . . and the enforcement of such requirements, are adequate to protect the health, safety, welfare, and rights of residents . . . ." 42 U.S.C. § 1396r(f)(1). The Secretary promulgated regulations consistent with Congress's intent, requiring States to provide specialized services which meet federal "active treatment" standards to all nursing facility residents with mental retardation and other developmental disabilities who are assessed to need those services.

The District Court's decision below, finding that the Commonwealth is indeed responsible for ensuring that individuals with mental retardation and other developmental disabilities receive the services recommended by the congressionally mandated screening process and including active treatment, as required by federal law, is consistent with Congress's intent in the NHRA. *Rolland v. Cellucci*, 52 F. Supp. 2d 231, 234-35 (1999); *Rolland v. Cellucci*, 198 F. Supp. 2d 25, 32-33 (2002). *Amici* urge this Court to affirm the District Court's decision.

II. BACKGROUND

The NHRA applies to all persons with mental retardation and other developmental disabilities (termed "related conditions" by Congress). Mental retardation is the most common developmental disability and ranks first among chronic conditions causing major activity limitations among persons in the United States. The American Association on Mental Retardation currently defines mental retardation as a disability, originating before age 18, characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. *See* AAMR, *Mental Retardation Fact Sheet, available at* http://www.aamr.org/Policies/faq_mental_-retardation.shtml. Developmental disabilities are severe, chronic disabilities attributable to mental and/or physical impairment, which manifest before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency, as well as the continuous need for individually planned and coordinated services. *See* Administration on Developmental Disabilities, *ADD Fact Sheet, available at* http://www.acf.dhhs.gov/programs/add/Factsheet.htm.

Mental retardation and other developmental disabilities are widespread. There are approximately 4.1 million Americans with developmental disabilities, including almost 1.1 million Americans with mental retardation who are also considered individuals with developmental disabilities. Additionally, there are approximately 945,000 Americans with mental retardation who do not have developmental disabilities. *See* S.A. Larson, K.C. Lakin, L. Anderson, N. Kwak, & J.H. Lee, *Prevalence of Mental Retardation and Developmental Disabilities, Estimates from the 1994 and 1995 National Health Interview Survey Disability Supplements*, 106 Amer. J. on Mental Retardation 231-52 (2001).

III. CONGRESS INTENDED THE NURSING HOME REFORM ACT TO REQUIRE STATES TO PROVIDE SPECIALIZED SERVICES TO ALL NURSING FACILITY RESIDENTS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES WHO WERE DETERMINED TO NEED THOSE SERVICES.

The Commonwealth claims that the extent of its obligation regarding specialized services is to provide services to those nursing facility residents with mental retardation and other developmental disabilities determined not to require the level of care provided by a nursing facility.[2] The Commonwealth's contention

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[2] *Amici* note that the Court may not need to reach the arguments they present in this Part and Part V if it accepts the plaintiff class members' arguments that Appellants have an enforceable obligation in the Settlement Agreement to provide specialized services to all nursing facility residents with mental retardation and developmental disabilities. The Commonwealth concedes that it "agreed to provide specialized services to those residents who remain in nursing facilities as part of the overall settlement of the case." App. Br. at 21 n.5. *Amici*, however, strongly disagree with the positions advanced by the Commonwealth on this question, and so provide this Court with their views on the State's arguments to assist the Court should it determine these questions are properly before it.

that, because the plaintiffs "have been determined to require nursing facility care, they do not have an enforceable right to receive specialized services," App. Br. at 20, cannot be squared the statutory scheme, Congressional intent, or common sense. The statutory scheme reflects Congress's intent to require States to provide specialized services to all residents who are determined to require specialized services through the PASARR screening, even if the resident is also determined to require the level of care provided by a nursing facility. This is the intent of Congress, reflected in the statutory language and the legislative history of the NHRA. The Secretary's regulations requiring States to provide specialized services to all nursing facility residents with mental retardation and other developmental disabilities determined to need them are consistent with Congress's intent and authoritatively construe the statute.

A. The legislative history reflects a pattern of States failing to provide adequate care to individuals with mental retardation and other developmental disabilities and Congress's desire to remedy that problem.

Prior to the mid 1970's, there were few federal standards for, and little federal reimbursement of, treatment of those with mental retardation or other developmental disabilities. States provided their own facilities for treating these individuals, and bore the cost of that treatment. This state-provided treatment, however, was grossly inadequate. Inadequate care and abuse were common. *See, e.g., Pennhurst State School & Hosp. v. Halderman*, 451 U.S. 1 (1981) (cataloguing institutional conditions for individuals with mental retardation that were inhumane, unsanitary, and dangerous, including physical abuse and drugging of residents by staff members, and inadequate habilitation that caused the physical, intellectual and emotional skills of residents to deteriorate, but rejecting argument

that federal Developmentally Disabled Assistance and Bill of Rights Act creates substantive rights to appropriate treatment in the least restrictive environment).

Beginning in 1971, Congress gave States the option of obtaining federal Medicaid reimbursement for care provided in "intermediate care facilities" for individuals with mental retardation, known as ICF/MRs. 42 U.S.C. §§ 1396a(a)(31)(A) & 1396d(a)(15). Massachusetts and other States chose to provide ICF/MR services in their Medicaid programs. Federal reimbursement of ICF/MR facilities is offered to promote the provision of professionally adequate care to individuals with mental retardation and other developmental disabilities. As a condition of receiving federal funds, States are required to ensure that adequate care is provided to these individuals in ICF/MRs – specifically including a program of "active treatment." 42 U.S.C. § 1396d(d)(2).

The Secretary of Health and Human Services (the "Secretary")[3] promulgated regulations governing the standard of care at ICF/MRs and defining the meaning of "active treatment." *See* 42 C.F.R. §§ 483.400 – 483.480. "Active treatment" describes an individually tailored series of programs and therapies designed to help an individual with mental retardation or other developmental disability reach an optimal level of independence. The care provided is "directed toward . . . [t]he acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible [and] [t]he prevention or deceleration of regression or loss of current optional functional status." 42 C.F.R. § 482.440(a)(1). An active treatment program can include training and vocational programs, physical, occupational, and speech therapies,

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[3] At that point in time, the Department of Health and Human Services ("HHS") was known as the Department of Heath, Education, and Welfare. Our reference to HHS includes its predecessor department.

and behavioral and interpersonal counseling. The specific contours of any individual's program are based upon that individual's needs.

In order to avoid the burdens of meeting the active treatment standards required in ICF/MRs, many States began inappropriately transferring individuals with mental retardation and other developmental disabilities from ICF/MRs to *nursing facilities*. Nursing facility services also are a covered Medicaid service for which States receive federal reimbursement. 42 U.S.C. § 1396d(a)(4)(A). Before Congress enacted the NHRA, however, active treatment standards did not apply to nursing facilities. Because active treatment was not required in nursing facilities, the condition of individuals with mental retardation and other developmental disabilities placed in those facilities deteriorated. As a consequence, Congress found itself subsidizing the nursing facility care of individuals with mental retardation and other developmental disabilities that did not meet professional standards — precisely the situation it sought to rectify when it made compliance with active treatment standards a condition for receipt of federal funding for the care of persons with mental retardation and other developmental disabilities.

In 1985, the Senate convened hearings to investigate the effects of improper institutionalization of individuals with mental disabilities, including the inappropriate care provided to those individuals in nursing facilities. *Care of Institutionalized Mentally Disabled Persons: Joint Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Human Resources and the Subcomm. on Labor, Health and Human Services, Educ., and Related Agencies of the Senate Comm. on Appropriations*, 99th Cong., S. Hrg. 99-50 (1985) at 352. The Senate heard testimony about the warehousing of individuals with mental retardation in nursing facilities as well as other institutions and the failure to provide proper care in those settings:

> Unless there is a specific medical need, no retarded person should live in any institution. There is no justification for it. . . . If someone has a medical need, put them in a hospital or in a nursing home. If they do not have a medical need, put them in a community residence where they have a home like setting that is caring and as normal like as possible. . . . What gets slipped by the wayside and which is not going to be attended to is the day-to-day neglect that occurs on behalf of retarded people, the languishing around, the lack of programming, [and] the lack of interest. . . .

Id. at 365 (testimony of Bruce Goldstein). The Senate further heard that the proper placement and care of individuals with mental retardation could change a life: one individual with mental retardation made "a complete turnaround" after spending 44 years in an institution, beginning to speak and dress himself after a short period of time in an appropriate community residence. *Id.* at 361, 364-65 (testimony of Elena Rose).

The widespread practice of dumping individuals with mental retardation and other developmental disabilities into nursing facilities was also documented by the General Accounting Office in a 1987 report. *See Medicaid: Addressing the Needs of Mentally Retarded Nursing Home Residents*, GAO/HRD-87-77 (1987). This report surveyed residents of nursing facilities with mental retardation in Massachusetts and two other states. It found that, because nursing facilities are not part of the State mental retardation service network in these States (unlike ICF/MRs), the State retardation agencies are generally not aware of the admission of individuals with mental retardation into a nursing facility. *Id.* at 18. As a consequence, about 66% of the residents surveyed were admitted without an assessment of their active treatment needs by the State — an assessment that would not have been missed if the individuals had been admitted to an ICF/MR. *Id.* A full two-thirds of the residents evaluated by GAO were determined to require active treatment. *Id.* at 23. However, not a *single one* of these residents was

receiving this necessary active treatment. *Id.* Among the causes of the States' failure to provide active treatment to residents of nursing facilities with mental retardation was the lack of a requirement that nursing facilities provide a plan of care to address the active treatment needs of residents with mental retardation and the lack of state inspection of nursing facilities to determine whether residents with mental retardation are receiving the active treatment they need. *Id.* at 20-22.

B. The statutory scheme of the Nursing Home Reform Act reflects Congress's intent to ensure that individuals with mental retardation and other developmental disabilities who are admitted to nursing facilities receive appropriate care.

Congress responded to the problem exposed by the GAO report by removing the financial incentive for States to place individuals with mental retardation and other developmental disabilities in nursing facilities without minimally adequate treatment, by imposing affirmative obligations on States: (1) to screen residents with mental retardation and other developmental disabilities for their active treatment needs, a process known as pre-admission screening and resident review ("PASARR");[4] and (2) to ensure a program of active treatment to all persons with mental retardation and other developmental disabilities who are determined to need it as a result of the screen. Congress enacted these changes in 1987 as the Nursing Home Reform Amendments ("NHRA"), which was part of the Omnibus Budget Reconciliation Act of 1987 ("OBRA '87"). *See* Pub. L. No. 100-203 § 4211, 101 Stat. 1330, *codified at* 42 U.S.C. § 1396r.

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[4] The NHRA initially contained a requirement that an annual review be conducted for each nursing facility resident to determine whether the individual needed a nursing facility level of care. In 1996, the NHRA was amended to eliminate the requirement of an annual resident review on the ground that such reviews were duplicative of other annual assessments that were required. *See* Pub. L. No. 104-315 (1996).

The mandatory screening was imposed as "a two-step approach [i.e., the preadmission screening and the resident review] to end the inappropriate placement of mentally ill or mentally retarded individuals in nursing facilities." H. Rept. 100-391(I) at 459, *reprinted in* 1987 U.S.C.C.A.N. 2313-1, 2313-279 (1987). It was also designed to stop the provision of professionally inadequate care, by determining whether an individual needs a nursing facility level of care and whether he needs specialized services. Specifically, the statute forbids nursing facilities from admitting any new individual with mental retardation or other developmental disability unless the State has determined that "because of the physical and mental condition of the individual the individual requires the level of care of services provided by a nursing facility. . . ." 42 U.S.C. § 1396r(b)(3)(F)(ii) & (e)(7)(A)(i). The State is also required to undertake a similar resident review for current nursing facility residents. *Id.* § 1396r(e)(7)(B)(ii). If the resident review determines that the resident is inappropriately placed in the nursing facility, the State must arrange for the discharge of the resident and prepare the resident for discharge. *Id.* § 1396r(e)(7)(C)(ii)(I), (ii)(II), (iii)(I), & (iii)(II). Congress intended the number of nursing facility residents with mental retardation and other developmental disabilities to decline dramatically as a result of the PASARR screening.

The second major change, the mandatory provision of specialized services (formerly called "active treatment"),[5] was imposed to ensure that individuals with mental retardation and other developmental disabilities obtain the care they needed *regardless* of whether they reside in a nursing facility because they also

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[5] See Part IV, *infra*, for a discussion of why "specialized services" is synonymous with "active treatment" in the context of treating individuals with mental retardation and other developmental disabilities.

require the level of care provided there. Specifically, as part of the PASARR screening, Congress imposed an obligation on States to determine whether nursing facility residents with mental retardation and other developmental disabilities require "specialized services." *Id.* § 1396r(e)(7)(B)(ii). Congress intended to ensure that if the resident requires specialized services, the State must provide those services. *See id.* § 1396r(e)(7)(C)(i)(IV) & (ii)(III) (requiring the State to "provide for (or arrange for the provision of) such specialized services for the [resident's] mental illness or mental retardation").

This statutory scheme reflects Congress's intent to place the obligation to provide specialized services on the States. The review process mandated by the statute requires screening of *all* residents with mental retardation and other developmental disabilities — not just those residents determined to be ineligible for nursing facility services — to assess their need for specialized services. In fact, Congress has explicitly stated that the intent of this statute was to obligate States to provide specialized services for *all* residents with mental retardation and other developmental disabilities who require them. The House Committee on Energy and Commerce, in introducing the bill enacted as NHRA, plainly stated that "[i]n the Committee's view, the responsibility for providing, or paying for the provision of, active treatment *lies with the States*." H. Rept. 100-391(I) at 462, *reprinted in* 1987 U.S.C.C.A.N. 2313-282 (emphasis added). The Senate Budget Committee — speaking two years after enactment of OBRA '87 — confirmed that the NHRA was intended to require the States to provide active treatment while also recognizing that this requirement is inferred from the statute:

> If a resident is found to be mentally ill or mentally retarded and does not require nursing facility care, the individual may not reside in a facility, except under very limited circumstances. If a resident is found to be mentally ill or mentally retarded and requires nursing facility care, the individual may reside in a facility, but *the State is*

> *required to provide active treatment if the individual is found to need it.* . . . The law implies, but does not explicitly indicate, that it is the obligation of a State to furnish "active treatment" to an individual who needs it.

135 Cong. Rec. S13057, S13238 (leg. day 9/12/89) (emphasis added).

Contrary to the Commonwealth's argument, then, the statutory scheme created by the PASARR provisions of NHRA reflects Congress's intent to impose an obligation on the States to provide specialized services to all residents who need them. Congress intended to prevent the inappropriate placement of individuals with mental retardation and other developmental disabilities in nursing facilities, a problem noted by the 1987 GAO report, and chose this method to do so. Congress's own explanations of the statute, and its intent in enacting the NHRA, demonstrate the existence of this obligation, as does the background against which Congress implemented the statute.

C. The Secretary authoritatively interpreted the statute to require States to provide specialized services to nursing facility residents who require them.

The regulations promulgated by the Secretary of HHS also reflect and reemphasize the States' obligation to provide specialized services imposed on the States. Congress specifically delegated to the Secretary the "duty and responsibility . . . to assure that requirements which govern the provision of care in nursing facilities . . . are adequate to protect the health, safety, welfare, and rights of residents. . . ." 42 U.S.C. § 1396r(f)(1). Congress further instructed the Secretary to issue regulations defining the criteria for conducting and implementing the PASARR process. *Id.* § 1396r(f)(8). In promulgating regulations to implement the NHRA, the Secretary acted consistently with Congress's intent. With regard to the States' obligation to offer specialized

services to all nursing facility residents who need them, the Secretary required that:

> The State must provide or arrange for the provision of specialized services . . . to *all NF residents with MI or MR* whose needs are such that continuous supervision, treatment and training by qualified mental health or mental retardation personnel is necessary, as identified by the [PASARR] screening. . . .

42 C.F.R. § 483.120(b) (emphasis added). In short, "specialized services are a State — and not a NF — responsibility." 57 Fed. Reg. 56,472 (1992).

In promulgating this regulation, the Secretary specifically considered, and *rejected*, the argument made here by the Commonwealth that the States are not required by the statute to provide these services:

> *Comment:* A couple of States objected to the requirement that States must provide specialized services to those who need both NF services and specialized services. They noted that section 1919(e)(7)(C) explicitly requires the State to provide specialized services only to those residents who do not need NF services but do need specialized services. They argued that, since the Act does not explicitly require provision of specialized services in dual need cases, we are exceeding our statutory authority. . . .
>
> *Response:* We do not agree with the commenters. In our view, the law does require that the States provide specialized services to persons in NFs who have been determined through their PASARR programs to require both NF services and specialized services. While the statute contains no explicit reference to provision of specialized services to those residents with dual needs, *we are, in placing this requirement on States, relying on the central theme of all the OBRA '87 nursing home reform provisions which is that all of a resident's needs must be identified and served.* ***Congress could not possibly have intended that the specialized services needs of those residents who also need NF services, and are therefore approved for NF residence, should be ignored or go unmet.*** Since the description of specialized services at section 1919(e)(7)(G) clearly indicates that specialized services is beyond the scope of NF services, the NF

> cannot be required to provide it. Both the statute and the legislative history indicate that the provision of specialized services is solely a State responsibility (see the House Committee Report language quoted in the preamble to the proposed rule on p. 10962). The logical corollary is that the State must provide specialized services to residents with dual needs.
>
> *It is also clearly the intent of Congress to assure that NF placements are appropriate and that the States supply the specialized services needed for persons who are residents of NFs.*

57 Fed. Reg. 56,477 (1992) (emphasis added). The Secretary's authoritative interpretation of the statute, especially given the explicit consideration and rejection of the argument made here by the Commonwealth, should be given controlling weight by this Court. *See Chevron U.S.A., Inc. v. Natural Resources Defense Council, Inc.*, 467 U.S. 837, 843-44 (1984); *Duckworth v. Pratt & Whitney, Inc.*, 152 F.3d 1 (1st Cir. 1998).

D. Appellants' arguments are particularly troubling given that the Commonwealth's nursing facility admission criteria are so broad.

Appellants' arguments that Congress intended to obligate States to provide specialized services only to nursing facility residents who do not need a nursing facility level of care are of particular concern given how broadly the Commonwealth has defined the criteria for nursing facility admission. Congress gave each State the ability to define the criteria for admission to nursing facilities. *See* 42 U.S.C. § 1396r(e)(7). Massachusetts has created a sufficiently low threshold for admission to nursing facilities[6] that any person with moderate or severe mental retardation would likely meet that standard. Thus, even with the NHRA in place, it is rare for these individuals to be determined not to need a

[6] For instance, anyone who needs even one nursing service may be admitted. *See* Mass. Regs. Code tit. 130, § 456.209.

nursing facility level of care. Once an individual with mental retardation or other developmental disability is admitted to a nursing facility, the Commonwealth contends in this appeal that it has no responsibility to provide *any* specialized services or the active treatment required by these individuals. In effect, the Commonwealth can admit any person with mental retardation to a nursing facility, receive federal funding and then abdicate its duty to comply with federal standards of care concerning active treatment. This reading of the NHRA and this ability to circumvent the requirements of federal law for persons with mental retardation and other developmental disabilities is directly contrary to Congress's intent in enacting the NHRA fifteen years ago. This backdrop demonstrates why it is important to give effect to Congress's intent to ensure that States provide specialized services to all nursing facility residents determined to need them.

IV. CONGRESS INTENDED THAT INDIVIDUALS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES RECEIVE ACTIVE TREATMENT IN NURSING FACILITIES.

The Commonwealth additionally argues that, even if it is required to provide "specialized services" to residents of nursing facilities with mental retardation and other developmental disabilities, this level of care is not the same as the "active treatment" level of care required in ICF/MRs. Once again, the Commonwealth's claim cannot be squared with the statutory and regulatory scheme created by the NHRA — for residents with mental retardation and other developmental disabilities, "specialized services" and "active treatment" are synonymous.

The NHRA, as originally enacted by OBRA '87, required screening of both individuals with mental illness and individuals with mental retardation and other developmental disabilities to determine whether they required "active treatment."

See Pub. L. No. 100-203, 101 Stat. 1330, § 4211. Congress specifically authorized the Secretary to define this term. *See* 42 U.S.C. § 1396r(e)(7)(G)(iii) . As noted above, the "active treatment" standard of care, developed through years of regulation in the ICF/MR context, has a specific meaning to professionals who treat individuals with mental retardation and other developmental disabilities. However, "active treatment" does not have a similar, or even any well understood, meaning in the context of treating individuals with mental illness.

Because OBRA '87 required individuals with mental illness, as well as individuals with mental retardation and other developmental disabilities, to be provided with "active treatment," this lack of a definition in the context of mental illness caused considerable confusion. The Secretary of HHS, in fact, received comments from mental illness treatment professionals which noted this confusion:

> A mental health professional organization expressed support for the separation of the definitions of specialized services for MI and MR. . . . [T]he organization recognized that the old statutory term "active treatment" had created problems in implementing these PASARR provisions. The commenter indicated that his organization, like a number of others, favored a statutory change in the term to "specialized and intensive treatment" with separate applications to persons with MI and MR instead of the term active treatment.

57 Fed. Reg. 56,472 (1992).

To alleviate the confusion, and in response to lobbying by groups such as the organization commenting on the Secretary's regulations, Congress replaced the term "active treatment" in the PASARR provisions of NHRA with the current term, "specialized services." *See* Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, 104 Stat. 1388, § 4801(b)(8) ("OBRA '90"). The Senate Finance Committee clearly noted the reason for the term change:

> The Committee bill would make a technical change to substitute the term "specialized services" for the term "active treatment." ***The***

Committee intends that specialized services include active treatment where appropriate.

136 Cong. Rec. S15629, S15661 (legs. day 10/2/90) (emphasis added). Notably, Congress did not change the statutory provision requiring the Secretary to define the term, and did not give any additional guidance to the Secretary as how to define the term.

Therefore, Congress's adoption of a new term did not, as the Commonwealth argues, demonstrate that Congress intended "specialized services" to have a different meaning than "active treatment" for individuals with mental retardation and other developmental disabilities. Rather, Congress merely changed the statute's terminology to eliminate the confusion concerning the "active treatment" terminology for individuals with mental illness. Congress explicitly intended for "specialized services" to include active treatment "where appropriate."

Consistent with Congress's intent, the Secretary, who is specifically charged by Congress with the duty to define the term "specialized services," 42 U.S.C. § 1396r(e)(7)(G)(iii), defined it for individuals with mental retardation and other developmental disabilities as equivalent to the active treatment standard of ICF/MRs. *See* 42 C.F.R. § 483.120(a)(2), *referencing id.* § 483.440(a)(1); *see also* 57 Fed. Reg. 56,474 ("In § 483.120(a)(2), we proposed to define specialized services (formerly active treatment) for mental retardation as treatment that meets the requirements of § 483.440(a)(1). That section defines active treatment for residents of intermediate care facilities for the mentally retarded (ICFs/MR)."). The Secretary noted that, "by exchanging the term 'specialized services' for 'active treatment,' *we are substituting terms and not concepts.*" 57 Fed. Reg. 56,472 (emphasis added). Therefore, the active treatment standard is the measure

of what the Commonwealth must provide to the residents of nursing facilities with mental retardation and other developmental disabilities.

Indeed, the Commonwealth concedes as much. App. Br. at 39 ("The state, the nursing facility, and 'other service providers' are charged with meeting only the general standard set forth in subsection (a)(1)."). The Commonwealth's further protestation that it need not comply with every obligation imposed upon ICF/MRs under § 483.440 misses the point — no one contends that the statute and the regulations turn nursing facilities into ICF/MRs.[7] They do, however, obligate the Commonwealth to provide an active treatment level of care to those individuals with mental retardation and other developmental disabilities who require it — whether those individuals are in a nursing facility, ICF/MR, or elsewhere.

V. CONGRESS INTENDED TO PERMIT PERSONS WITH MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES WHO ARE NOT GETTING THE SPECIALIZED SERVICES THEY NEED TO SUE IN FEDERAL COURT TO PROTECT THEIR RIGHTS

The Commonwealth also claims that nursing facility residents with mental retardation and other developmental disabilities have no right to sue in federal court to obtain the specialized services that they need, and that the NHRA and the Secretary's regulations guarantee to them. As the Commonwealth concedes, however, whether residents have a judicially-enforceable right to specialized services "is a question of Congressional intent." App. Br. at 24. The threshold

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[7] Indeed, the active treatment regulations impose certain requirements upon ICF/MRs that would make no sense if imposed on nursing facilities. *See, e.g.*, 42 C.F.R. § 483.440(b)(1) ("Clients who are admitted by the facility must be in need of and receiving active treatment services.").

inquiry into whether plaintiffs have a right to sue under § 1983 for a federal statutory violation is whether Congress intended in the statute to create a federal right. *Gonzaga University v. Doe*, 122 S. Ct. 2268, 2275 (2002); *see also Wilder v. Virginia Hospital Ass'n*, 496 U.S. 498, 509 (1990) (plaintiff must be an "intended beneficiary" of the statute); *Blessing v. Freestone*, 520 U.S. 329, 340 (1997).[8] Likewise, determining whether plaintiffs have a private right of action for violations of federal regulations hinges on Congressional intent: when Congress "intends the statute to be enforced through a private cause of action," it "intends the authoritative interpretation of the statute to be so enforced as well." *Alexander v. Sandoval*, 532 U.S. 275, 284 (2001).

The language and structure of the NHRA, Congress's purpose in enacting it, and the Secretary's regulations all demonstrate conclusively that Congress intended to require the States to provide specialized services for all nursing facility residents determined to need them *and* that Congress intended to give individuals a right to sue in federal court if the States ignore that statutory and regulatory mandate.

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[8] In addition, the plaintiffs' asserted interests must be specific and "not so vague and amorphous" as to be "beyond the competence of the judiciary to enforce," and the statute must impose a binding obligation on the state. *Wilder*, 496 U.S. at 509; *Blessing*, 520 U.S. at 340. *Amici* address here only Congress's intent to create a federal right to specialized services. Plaintiffs-Appellees convincingly demonstrate in their brief that the NHRA and regulations under it impose a detailed and clearly defined set of requirements for the provision of specialized services. Resp. Br. at Part III. Plaintiffs-Appellees also dispose of the Commonwealth's argument that the right to specialized services is amorphous because a court cannot distinguish specialized services that the States are required to provide from services that nursing facilities must provide, explaining that "maintaining an obligation on nursing facilities to provide ordinary nursing services and establishing a new obligation on States to provide special mental retardation services" is "neither confusing nor ambiguous." *Id.* at 54.

As *amici* explain above, when it enacted the NHRA, Congress sought to ensure that individuals with mental retardation are not inappropriately placed in nursing facilities, and that they receive treatment appropriate for their needs once they are there. *See supra* at 9. Congress's goal was to protect those individuals from the State practice of transferring people with mental retardation and other developmental disabilities from state ICF/MRs and then warehousing them in nursing facilities, where they are not given adequate care. In Massachusetts alone, thousands of persons with disabilities were found to be languishing in nursing facilities without receiving the level of care that Congress proscribed as a condition for federal funding. *See supra* at 7. Accordingly, in the NHRA Congress acted with an "unmistakable focus on the benefited class" — persons with mental retardation and other developmental disabilities in nursing facilities — and imposed mandatory, affirmative requirements on the States to take action to benefit these individuals. *See* 42 U.S.C. § 1396r(b)(3)(F)(ii) & (e)(7)(B) (mandating screening of all individuals with mental retardation prior to admission and on a periodic basis); *id.* § 1396r(e)(7)(C) (directing states to provide specialized services). This is precisely the kind of classic "rights-creating" language that the *Gonzaga* Court recognized as creating a federal right giving rise to a claim under § 1983. *Gonzaga*, 122 S.Ct. at 2275.

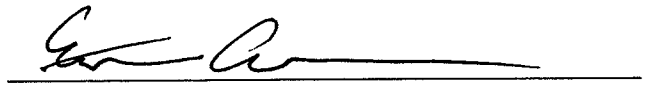
As *amici* also demonstrate above, the regulations that Congress directed the Secretary to promulgate to assure the "health, safety, welfare, and rights" of nursing facility residents with mental retardation, 42 U.S.C. § 1396r(f)(1), impose an equally unambiguous requirement for States to ensure that all nursing facility residents with mental retardation get the specialized services they need. *See* 42 C.F.R. §§ 483.116(b) & 483.120(a)(2). The Secretary's regulations effectuate Congress's purpose, and they define, clarify, and amplify the obligations that Congress created in the statute. *See id* § 483.120(a)(2) & (b) (defining

"specialized services" as "active treatment," and requiring the State to provide such services to those who are determined to need them). The Secretary definitively rejected the States' comments that her regulations go beyond Congress's intent, noting that Congress "could not possibly" have meant for any nursing facility resident who needs specialized services to go unserved. 57 Fed. Reg. 56,477 (1992). That interpretation is "valid and reasonable," and it "authoritatively construe[s]" the NHRA. *Sandoval*, 532 U.S. at 284. In such a circumstance, it is "meaningless to talk about a separate cause of action to enforce the regulations apart from the statute," for Congress's intent to create a federal right in the statute extends to the regulations under it as well. *Id.*

VI. CONCLUSION

For the foregoing reasons, *amici* respectfully request this Court to affirm the decision of the District Court determining that the Commonwealth is obligated to provide class members with active treatment.

Respectfully submitted,



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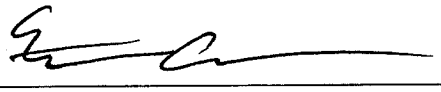
CERTIFICATE OF COMPLIANCE

Pursuant to Federal Rules of Appellate Procedure 29(c)(5) and 32(a)(7)(B), I hereby certify that this brief uses proportional type, 14 point Times New Roman. The brief was prepared using Microsoft Word 97, and contains 6,426 words, including headings and footnotes, according to that systems' word count function.



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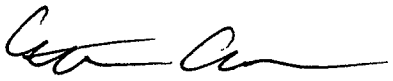

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