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PLAYING THE LOTTERY: HCBS LAWSUITS AND OTHER MEDICAID LITIGATION ON BEHALF OF THE DEVELOPMENTALLY DISABLED

Margaret K. Feltz[†]

LITIGATION CONCERNING Medicaid-funded services for individuals with developmental disabilities has dramatically increased in recent decades. Generally speaking, two categories of litigation have emerged. Initially, Medicaid litigation focused on the improvement of institutional services for mentally retarded/developmentally disabled (MR/DD) individuals.¹ However, as the location for care provisions shifted from the institution to the home/community, there has been a parallel shift in the litigation focus. Recent Medicaid litigation has concentrated on the expansion of home and community-based service systems. With the majority of Medicaid-eligible individuals now receiving services outside of the institutional setting, litigation of the past few years has revolved around the prompt provision of appropriate care in home and community environments.

This Note will discuss the maturation of Medicaid-funded care delivery as embodied in home and community-based care modalities. Litigation has been an essential tool and a driving force in carving out home and community-based services for developmentally disabled individuals. But, was litigation the most effective tool to achieve these gains? If so, does it con-

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¹ These lawsuits date back three decades, to the 1970's. For examples of institution-based Medicaid litigation see *infra* Part II.A.

tinue to be the most effective tool? What problems have arisen as a result of employing a litigation approach to securing Medicaid home and community-based services? What alternatives are there to litigation and how effective are they? How might these alternatives be made more effective? Would a combination of approaches produce greater benefit?

By way of providing background, Part I of this Note will supply a primer on the Health Care Financing Administration's² home and community-based services (HCBS) waiver program. Part II will discuss the current litigation climate with regard to Medicaid-funded services for the developmentally disabled and will discuss the relevant law with regard to Medicaid litigation. Part III will discuss a recent Massachusetts case, *Boulet v. Cellucci*, and will use the Massachusetts experience as a case study for dissecting the litigation approach to securing Medicaid services for the developmentally disabled. Part IV will discuss widespread challenges inherent in HCBS waiver programs and will analyze various approaches to securing Medicaid services. In addition, this section will provide recommendations for advocates seeking to protect and provide for the needs of developmentally disabled individuals.

PART I: HOME AND COMMUNITY-BASED SERVICES PRIMER

A. Creation of a Medicaid HCBS Waiver

Under § 1915(c) of the Social Security Act, States are allowed to request waivers of certain federal requirements in order to create alternative care and treatment modalities that are Medicaid-financed.³ "Waivers are intended to provide the flexibility needed to enable States to try new or different approaches to the efficient and cost-effective delivery of health care services, or to adapt their programs to the special needs of particu-

² As of July 1, 2001, the Health Care Financing Administration (HCFA) is the Center for Medicare and Medicaid Services (CMS). CTR. FOR MEDICARE AND MEDI-CAID SERVS., U.S. DEP'T OF HEALTH AND HUMAN SERVS., INTRODUCING CMS (n.d.), *at* http://cms.hhs.gov/about/reorg.asp (last visited Oct. 29, 2001). Much of this Note's source material was cited when the agency was still HCFA and is titled as such. Thus, this Note will still refer to the agency as the Health Care Financing Administration for the purpose of uniformity and a desire to not confuse the reader.

³ 42 U.S.C.A. § 1396n (West Supp. 2001).

lar areas or groups of recipients."⁴ Waiver can be obtained with regard to three different requirements: services need not be provided statewide;⁵ States can use more liberal financial eligibility criteria:⁶ and designated groups can be given benefits that other groups are not eligible to receive.⁷

First authorized in 1981, HCBS waivers have become the primary mechanism for States to provide Medicaid-funded, community-based, long-term care services to the mentally retarded, mentally ill, developmentally disabled, physically disabled, and other target populations.⁸ In allowing for HCBS waivers, the Health Care Financing Administration (HCFA) has afforded States the "flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities, or intermediate care facilities."9 The Social Security Act specifically lists the services that may be provided via HCBS waiver programs as follows:

[C]ase management services, homemaker/home health aide services and personal care services, adult day health services, habilitation services, respite care, and such other services requested by the State as the Secretary may approve and for day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.¹⁰

The rationale behind the waiver program is that by providing these and other HCFA-approved services,¹¹ the goal of preserv-

¹¹ HCFA maintains broad discretion over the approval of additional services in a state waiver proposal. For example, in-home support services or special commu-

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^{4 42} C.F.R. § 430.25(b) (2000).

⁵ See 42 U.S.C.A § 1396a(a)(1) (requiring a state plan for medical assistance to be in effect in all political subdivisions of the State).

⁶ See id. § 1396a(a)(10)(C)(i)(III) (requiring that a State employ a single standard in determining income and resource eligibility).

⁷ See id. § 1396a(a)(10)(B) (relating to comparability of services require-

⁸ STEVEN LUTZKY ET AL., LEWIN GROUP, INC., REVIEW OF THE MEDICAID 1915(C) HOME AND COMMUNITY BASED SERVICES WAIVER PROGRAM LITERATURE AND PROGRAM DATA 1 (June 2000), http://www.hcfa.gov/medicaid/litfinal.pdf.

⁹ HEALTH CARE FINANCING ADMIN., U.S. DEP'T OF HEALTH AND HUMAN SER-VICES, HOME AND COMMUNITY-BASED SERVICES 1915(C) WAIVERS ¶ 1 (n.d.), at http://www.hcfa.gov/medicaid/hpg4.htm (last visited Mar. 18, 2001) [hereinafter HCBS]. ¹⁰ 42 U.S.C.A. § 1396n(c)(4)(B).

ing the independence of developmentally disabled individuals will be achieved. Mentally retarded/developmentally disabled individuals will be allowed to remain in the community, maintaining emotional ties to both family and friends, thereby improving their quality of life.

While a State's HCBS waiver proposal must be HCFAapproved, States retain great latitude in determining the composition and construction of a waiver.¹² Both medical and nonmedical services may be included under an HCBS waiver. Some States have included the following services in their HCBS program applications: adult day care, adult day habilitation services, adult day health services, adaptive equipment, case management, personal care attendant services, habilitation services, homemaker services, home health aide services, nursing care services, personal care services, respite care, family training, day treatment, and vocational services.¹³ Individual States maintain broad discretion as to both the services that are included and the populations that are served under the state waiver. The design of the program and the selection of services under the waiver are state-specific and services can be provided either on a statewide basis or according to specific geographic designa-tions and/or population definitions.¹⁴ Federal regulations provide for HCBS waiver programs to serve target populations such as the elderly,¹⁵ persons with physical disabilities, developmental disabilities, mental retardation, and mental illness.¹⁶ Finally, States can design HCBS waiver proposals according to specific conditions or illnesses, such as limiting services to individuals who are ventilator-dependent or who suffer from acquired immune deficiency syndrome (AIDS).¹⁷

nication services might be provided pursuant to HCFA approval. HCBS, supra note 9, \P 3.

¹² GARY A. SMITH, NAT'L ASS'N ST. DIRECTORS DEVELOPMENTAL DISABILI-TIES SERVS., INC., STATUS REPORT: LITIGATION CONCERNING MEDICAID SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES § II (Apr. 2001), http://www. qualitymall.org/online/litigation.html.

¹³ LUTZKY ET AL., *supra* note 8, at 15-16.

¹⁴ See generally 42 U.S.C.A. § 1396n (governing waiver programs).

¹⁵ See 42 U.S.C.A. § 1396n(d) (providing for home and community-based services for the elderly).

 $^{^{16}}$ HCBS, supra note 9, \P 5; see generally 42 U.S.C.A. § 1396n (governing waiver programs).

¹⁷ See 42 U.S.C.A § 1396n(e) (permitting waiver programs for children who are infected with AIDS or are drug-dependent at birth); see generally 42 U.S.C.A. § 1396n (governing waiver programs).

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States are permitted to determine not only the groups of individuals that are covered under a particular waiver, but are also permitted to determine the maximum number of individuals to whom the State will offer services under the guise of a waiver plan.¹⁸ Commonly known as a waiver "cap," federal mandates require that a HCBS waiver proposal may not be limited to fewer than 200 individuals.¹⁹

Although a State is allowed tremendous flexibility in the creation of an HCBS waiver proposal, the State must assure HCFA that in implementing the waiver, the cost of providing home and community-based services will not exceed the cost of care in an institutional setting on a per capita basis.²⁰ Similarly, once HCFA has approved the State's HCBS waiver proposal, the State is obligated to provide all the listed services in accordance with Federal Medicaid regulations and guidelines.²¹ States must also assure HCFA that there are adequate safe-guards in place to protect the health and welfare of individuals served under the waiver.²²

B. Current Status of HCBS Waiver Programs in the United States

As Gary Smith, Director of Special Projects for the National Association of State Directors of Developmental Disabilities Services, Inc., has reported, the last thirty years have seen a steady trend toward increased Medicaid funding coupled with unprecedented Medicaid enrollment.²³ Discretionary decisionmaking on the part of state legislators and Medicaid directors has resulted in the expanded availability of services and sup-

¹⁸ See 42 U.S.C.A § 1396n(c)(10) (establishing minimum guidelines for waiver caps).

¹⁹ Id.

²⁰ HCBS, supra note 9, \P 6; see 42 U.S.C.A. § 1396n(c)(2)(D) (permitting a waiver provided that "under such waiver the average per capita expenditure estimated by the State in any fiscal year for medical assistance provided with respect to such individuals does not exceed 100 percent of the average per capita expenditure that the State reasonably estimates would have been made in that fiscal year for expenditures under the State plan for such individuals if the waiver had not been granted").

 21 E.g., Tallahassee Mem'l Reg'l Med. Ctr. v. Cook, 109 F.3d 693, 698 (11th Cir. 1997) (per curiam) (holding that "when a state elects to provide an optional service, that service becomes part of the state Medicaid plan and is subject to the requirements of federal law").

22 42 U.S.C.A. § 1396n(c)(2)(A).

²³ SMITH, *supra* note 12, § II (stating that despite increased funding for community services, waiting lists for services have emerged).

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ports, requiring additional appropriations by the State. Looking for creative ways to provide quality care and save (or better allocate) funds, many States have reduced or eliminated institutional placements in favor of home and community-based services programs.

The 1990's saw a "massive infusion" of funding into community service systems, principally via HCFA's HCBS waiver mechanism.²⁴ HCFA's first HCBS waiver program was approved in 1981.²⁵ As of December 2000, there were 240 waiver programs in the United States.²⁶ Indeed, every State was represented in this count except for Arizona, which operates the equivalent of a HCBS waiver program under the Social Security Act's § 1115 "demonstration waiver" program.²⁷ Between 1990 and 1999, the number of individuals receiving services under the auspices of HCBS waivers increased from 45,000 to 262,000.²⁸ At the same time, there was a ten-fold increase in Medicaid spending during this decade, reaching a total of \$8.4 billion in 1999.²⁹

Many States fear that the movement toward HCBS waiver programs may cause a "woodwork effect"—meaning that individuals who are currently being provided services and care by family members will 'come out of the woodwork' and apply for Medicaid community-based services through HCBS waivers.³⁰ Indeed, this prediction may turn out to be true. Many families are experiencing intense frustration as they try to secure muchneeded Medicaid-funded HCBS services for a developmentally disabled family member, while resisting placing that family member in a long-term care institution. Despite States' clear penchants for HCBS care modalities, lengthy waitlists and in-

²⁹ SMITH, supra note 12, § II.

³⁰ KULKARNI, *supra* note 28, § I; JANE PERKINS & MANJU KULKARNI, NAT'L HEALTH LAW PROGRAM, FACT SHEET: ADDRESSING HOME AND COMMUNITY-BASED WAIVER WAITING LISTS THROUGH THE MEDICAID PROGRAM 1 (May 2000) http://www.healthlaw.org/docs/200005FactSheet_hcbw.pdf.

²⁴ *Id.* ²⁵ HCBS, *supra* note 9, ¶ 8.

 $^{^{26}}$ Id

²⁷ Id.

²⁸ SMITH, *supra* note 12, § II; *see also* MANJU KULKARNI, NAT'L HEALTH LAW PROGRAM, FACT SHEET: ACCESSING MEDICAID HOME AND COMMUNITY-BASED SER-VICES § II.A (Mar. 2000) (describing a 200,000 person increase in those persons receiving home and community-based services based on waiver programs between 1990-1998), http://www.healthlaw.org/pubs/2000003FactSheet_hcbw.html.

sufficient caps³¹ leave many otherwise eligible beneficiaries without appropriate Medicaid-funded long-term care services. This dearth of sufficient, timely, and appropriate services has prompted many families to turn to litigation as a means of securing community-based, Medicaid-funded, long-term care services on behalf of a mentally retarded/developmentally disabled family member.

PART II: LITIGATION CLIMATE AND RELEVANT LAW

A. Background

Thirty years ago, litigation concerning Medicaid services focused on reforms within institutions that provided long-term care services to individuals with mental retardation and developmental disabilities.³² The early 1970's saw numerous cases alleging violations of the civil rights of institutionalized individuals with MR/DD.³³ The vast majority of these cases alleged that individuals were being forced to live in inhumane environments where neglect and physical, mental, emotional, and sexual abuse abounded. The 1970's saw the filing of at least twenty-one cases of this type.³⁴ The following decade saw an even greater proliferation of lawsuits, with at least thirty-two such cases being filed.³⁵

Class action lawsuits of a different sort emerged in the early 1990's. While the allegations of mistreatment from the

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³¹ For information on caps, see supra I.A and infra III.C.4.

³² See LUTZKY ET AL., supra note 8, at 4 (listing the most influential cases).

³³ See Halderman v. Pennhurst State Sch. & Hosp., 446 F. Supp. 1295 (E.D. Pa. 1978) (holding the constitutional rights of mentally retarded residents at a stateoperated institution were violated due to inadequate rehabilitation), *aff'd in part*, *rev'd in part en banc*, 612 F.2d 84 (3d Cir. 1979), *rev'd*, 451 U.S. 1 (1981); New York State Ass'n for Retarded Children v. Carey, 466 F. Supp. 479 (E.D.N.Y. 1978) (holding that mentally retarded students who carried hepatitis B were entitled to readmission to special education programs in public schools), *aff'd*, 612 F.2d 644 (2d Cir. 1979); Welsch v. Likins, 373 F. Supp. 487, 502-03 (D. Minn. 1974) (holding involuntary committed patients have a right, grounded in due process or the Eighth Amendment, to a humane and safe living environment), *aff'd*, 525 F.2d 987 (8th Cir. 1975); Wyatt v. Stickney, 325 F. Supp. 781 (M.D. Ala. 1971) (holding involuntarily committed patients have a constitutional right to receive individual treatment that provides a realistic opportunity for improvement of their condition), *aff'd in part*, *reversed in part sub nom.* Wyatt v. Aderholt, 503 F.2d 1305 (5th Cir. 1974).

³⁴ LUTZKY ET AL., *supra* note 8, at 4.

³⁵ Id.

previous twenty years had not been eradicated, a new litigation focus materialized and the lawsuits of the 1990's revolved around the location of care delivery and the promptness of service delivery.³⁶ This paradigm shift was due, in large part, to a deinstitutionalization trend. A strong advocacy movement intent on improving the quality of life of MR/DD individuals by mainstreaming them and striving to maintain their emotional, familial, educational, and residential ties with the community also had a profound impact.

B. Current Lawsuits

With the tremendous influx of federal and State Medicaid funding, a movement away from providing services in the institutional setting, and a concurrent upsurge in the demand for community-based Medicaid services, the Medicaid environment of the 1990's was ripe for litigation. Dual goals emerged as the litigation objective focused on securing prompt access to longterm care services for the MR/DD individual and ensuring that such services were delivered in the most appropriate setting. While some States developed multi-year initiatives to address the needs of MR/DD Medicaid beneficiaries,³⁷ other States failed to answer the call and many individuals in need of Medicaid-funded services fell through the cracks. Disability advocates wielded the tools provided to them in the Federal Medicaid Act, the Americans with Disabilities Act (ADA), the Rehabilitation Services Act of 1973, and the United States Constitution, in attempts to obtain prompt and appropriate services in the most integrated setting. Gary Smith has described the resulting litigation climate as having produced three interrelated categories of lawsuits: waiting list lawsuits, Olmstead lawsuits, and access to benefits lawsuits.³⁸ As Smith notes, these three litigation approaches are far from distinct; frequently a particular lawsuit will include arguments from two or even all three of these categories. Smith's analysis, however, allows a clear framework for dissecting and examining lawsuits aimed at securing Medicaid-funded services for disabled individuals.

³⁶ See id. at 4-5 (describing the Americans with Disabilities Act's requirement that services be provided in the 'most integrated setting appropriate', its implication on the waiver program, and subsequent cases).

³⁷ For example, New York, Pennsylvania and Maryland have done so. SMITH, supra note 12, § II.

³⁸ Id. § I.

Type of Suit	Description					
Waiting List Lawsuits	Allege that a State has failed to pro- vide long-term Medicaid services with 'reasonable promptness' to oth- erwise eligible persons with devel- opmental disabilities.					
"Olmstead Lawsuits"	Allege that institutionalized persons have been improperly denied an op- portunity to receive services in 'the most integrated setting.'					
Access to Benefits Lawsuits	Allege that Medicaid recipients have not been provided with or have been unable to access services that they have been authorized to receive.					

Figure 1: Types of Medicaid-Related Litigation³⁹

1. Waiting List Lawsuits

Waiting list lawsuits typically assert that a State has violated federal law in failing to provide Medicaid-funded, longterm services with reasonable promptness to otherwise eligible individuals with developmental disabilities.⁴⁰ As of March 2001, there were waiting list lawsuits in fifteen states.⁴¹ Settlement agreements had been reached in five lawsuits and litigation was pending in eleven states.⁴²

³⁹ Information adapted from SMITH, supra note 12, § I.

⁴⁰ See generally id. § III (describing arguments and cases falling into the waiting list category). ⁴¹ Id. § III.B; see also fig.2.

 $^{^{42}}$ See fig.2 (indicating settlement agreements with an asterisk).

Lawsuit	Medicaid	ADA	§ 504	14th	Description
	Law			Am.	
Carpenter v. Alaska Dep't of Health and Soc. Servs. (Alaska). Brought in Jan. 2001 by private attorney on behalf of fif- teen named plaintiffs.	x	x	x	x	Filed in the U.S. District Court for the District of Alaska, this suit asserted that the State's waitlisting practice violates the ADA integration mandate and the reasonable promptness provision of Federal Medi- caid law. Additionally, the State's failure to properly process Medicaid applica- tions denies due process.
Mandy R. v. Owens (Colo- rado). Brought in Aug. 2000 by private at- torney and the Arc of Colo- rado as a class action.	x	x	x	x	Filed in U.S. District Court for the District of Colorado, this complaint pertained to the state practice of waitlist- ing individuals for residen- tial services. Approximately 2,700 individuals have been affected by this practice. The State has filed a motion for dismissal.
John/Jane Does v. Bush origi- nally filed as Does v. Chiles) (Florida). Brought in 1992 as a class action.	x				Filed on behalf of individu- als waitlisted for ICF/MR services, this case became the prototype for subsequent waiting list and "reasonable promptness" suits. In March 1998, the Court of Appeals for the Eleventh Circuit upheld the district court ruling that a waitlist for ICF/MR services violated Federal Medicaid law. There has been no final disposition of the case.

Figure 2: Waiting List Lawsuits as of March 2001⁴³

⁴³ Information adapted from SMITH, supra note 12, § III.B.

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		·	 	
Wolf Prado-				A settlement agreement has
Steinman v.				been reached in this case, in
Bush (Flor-				which the State has agreed
ida).*				to serve all individuals who
				were waiting for services on
				July 1, 1999 by 2001. Addi-
				tionally, the State is in the
				process of negotiating a §
				1915(b)/(c) waiver agree-
				ment with HCFA to provide
				expanded access to HCBS
				services for eligible indi-
				viduals.
Makin v. State	x	x		This complaint alleged that
(Hawaii)*				a waitlist for HCBS services
Brought in Dec.				violated Federal Medicaid
1998 by Hawaii				law and ADA mandates. In
Protection and				April 2000, a settlement
Advocacy				agreement was reached
Agency as a				wherein the State agreed to
class action.				increase the number of
				individuals who would be
				served in the HCBS waiver
				program by approximately
				70% over a three-year pe-
				riod. The state legislature
				approved an additional \$4.3
				million in funding to un-
				derwrite initial stage of
				expansion.
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Boudreau v.	X	x	X	X	Filed in the U.S. District
Ryan (Illinois).					Court for the District of
Brought in					Northern Illinois, this suit
Sept. 2000 by					alleged violation of the
five named					reasonable promptness
plaintiffs with					provision. Additionally,
MR/DD.					plaintiffs claimed that the
					State has not allowed eligi-
					ble individuals freedom of
					choice in selecting between
					ICF/MR and HCBS waiver
					services. The State has filed
					a motion to dismiss, which
ļ					has not yet been ruled upon.
Boulet v. Cel-	х	x			Pertaining to residential
lucci (origi-					services, this case asserted a
nally filed as					violation of Medicaid's
Anderson v.					reasonable promptness
Cellucci) (Mas-					provision. Approximately
sachusetts)*					3,000 individuals comprised
Brought in					the proposed plaintiffs'
Mar. 1999 by					class. In July 2000, the
private attor-					District Court issued sum-
neys on behalf					mary judgment in plaintiffs'
of five named					favor. The proposed class
plaintiffs as a					definition was narrowed and
class action.					the State was directed to
clubs detion.					furnish residential services
					to class members within
					ninety days unless able to
					"show cause" why doing so
					was not feasible. In Novem-
					ber 2000, a settlement
					agreement was reached in
					principle, which was final-
					ized on December 19, 2000.

		, <u> </u>			
Travis D. v.	x				This suit alleged that the
Eastmont Hu-				1	State failed to provide
man Servs. Ctr.		[[HCBS waiver services to
(Montana).					approximately 600 wait-
Filed in May					listed individuals in the
1998 by the					community along with resi-
Montana Pro-					dents of the State's two
tection and					public MR/DD institutions.
Advocacy		}			Settlement discussions are
Agency.		1			reportedly underway in this
Agency.					case.
Lewis v. New	x	x			This suit alleged that the
Mexico Dep't					State's failure to provide
of Health (New					Medicaid services in the
Mexico). Filed					community to eligible dis-
in Jan. 1999 by					abled individuals caused
-		1			
the New Mex-					them to either go without
ico Protection					services or to seek those
and Advocacy					services only in an institu-
Agency and the					tional setting. Approxi-
Arc of New]			mately 1,750 individuals
Mexico.		ł			with developmental disabili-
					ties were on the waiting list
					for services in 1999; the
		}			entire class of affected indi-
		Ì			viduals numbers greater
					than 3,000. In April 2000,
	ļ	}			the federal district court
					rejected the State's motion
					to dismiss and upheld the
		ļ			plaintiffs' right to access to
		1			HCBS waiver services with
					"reasonable promptness."
					New Mexico has filed a
	1				motion of intent to appeal
					the district court decision to
					the Court of Appeals for the
]		ļ			Tenth Circuit in Denver, CO
					based on a sovereign immu-
		1		Į	nity claim under the Elev-
					enth Amendment to the U.S.
	1	{	[[Constitution.

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		w			
Martin v. Taft	x	x			This complaint pertained to
(originally filed					the prompt provision of
as Martin v.					residential services to
Voinovich)					Medicaid-eligible individu-
(Ohio). Filed in					als. In 1998, the parties
1989 by the					agreed to motion to stay
Ohio Protection					further district court pro-
and Advocacy					ceedings. However, in July
Agency as a					2000, the Ohio Protection
class action.					and Advocacy Agency filed
					a motion for partial sum-
					mary judgment asking the
					court to find that the State is
					violating Federal Medicaid
}	l	[law because the waiver
					waiting list is not "moving
}					at a reasonable pace." It was
					anticipated that the case
		ļ			would go to trial in 2001.
Staley v. Kitz-	x	x			This complaint alleged a
haber (Ore-					failure to furnish with rea-
gon)* Filed					sonable promptness Medi-
Jan. 2000 as a					caid long-term services to
class action.					otherwise eligible individu-
					als. In September 2000, the
					parties agreed to settle the
					suit, agreeing to implement
					Oregon's "Universal Access
					Plan." Submitted to the
		ļ			
		ļ			Oregon legislature in Feb-
					ruary 2000, the agreement
					provides for a cumulative
					total of \$350 million by
					2007.
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Gross v. Hous-	x			This complaint alleged that
ton (Pennsyl-				the State failed to provide
vania). Filed in				ICF/MR or equivalent resi-
July 1999 as a				dential services, opting
class action.			•	instead to waitlist eligible
				individuals. Court-related
				activity has been suspended
				as a result of the Governor's
				commitment to provide an
				additional \$850 million in
				funding over the course of
				the next five years.
Delong v.				Filed in the U.S. District
Houston (now				Court for the Eastern Dis-
Penn. Protec-				trict of Pennsylvania, this
tion and Advo-				suit pertained to state im-
cacy, Inc. v.				plementation of the Per-
Houston (Penn-				son/Family Directed Sup-
sylvania). Filed				ports waiver program, a
in Aug. 2000				component in the State's
by the Disabil-				waitlist reduction initiative.
ity Law Pro-				The suit contended that the
ject; Pennsyl-				State was required to pro-
vania Protec-				vide services to 3,392 per-
tion and Advo-				sons during 1999-2000, but
cacy Project.				failed to allocate a suffi-
				cient number of slots under
				the cap, thereby denying
l				services to otherwise eligi-
				ble individuals. The State
				filed a motion to dismiss the
				suit, which was denied in
				March 2001.
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Brown v. The Tennessee Dep't of Mental Health and	x		X	This complaint alleged that the State failed to provide ICF/MR or HCBS waiver services with reasonable
Developmental Disabilities and Rukeyser (Ten- nessee). Filed				promptness to approxi- mately 850 otherwise eligi- ble individuals with MR/DD.
in July 2000 by the Tennessee Protection and Advocacy Pro- ject as a class action.				
People First of Tenn. v. Neal (Tennessee). Filed in Mar. 2001 by People First of Ten- nessee as a class action.	X	x	х	Filed in the U.S. District Court for the Middle Dis- trict of Tennessee, this complaint alleged that some 2,000 individuals with MR/DD are currently and improperly waitlisted for HCB services, despite un- der-enrollment based on the state-established cap.
Quibuyen v. Allen (Vir- ginia). Filed in Dec. 2000 by a coalition of attorneys.				Filed in the U.S. District Court for the District of Virginia, this complaint alleged that Virginia has imposed restrictions on furnishing HCBS waiver services, resulting in unrea- sonable wait lists.

The Arc of X X X X This complaint alleged that the waith the waith of long-term care services to individuals (Washington). Filed in Nov. 1999 as a class cla				 	
Lyle Quasim (Washington). Filed in Nov. 1999 as a class action.	The Arc of	х	x		This complaint alleged that
(Washington). Filed in Nov. 1999 as a class action. With MR/DD violates Fed- eral Medicaid law and the ADA. In December 2000, the District Court granted the State's motion for sum- mary judgment to deny the plaintiffs' ADA claims based on a "fundamental alteration" defense. The plaintiffs plan to raise ar- guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in	Wash. State v.				the waitlist for long-term
Filed in Nov. 1999 as a class action. action. He District Court granted the District Court granted the State's motion for sum- mary judgment to deny the plaintiffs' ADA claims based on a "fundamental alteration" defense. The plaintiffs plan to raise ar- guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in	Lyle Quasim				care services to individuals
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action. the District Court granted the State's motion for sum- mary judgment to deny the plaintiffs' ADA claims based on a "fundamental alteration" defense. The plaintiffs plan to raise ar- guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in	Filed in Nov.				eral Medicaid law and the
action. action. the District Court granted the State's motion for sum- mary judgment to deny the plaintiffs' ADA claims based on a "fundamental alteration" defense. The plaintiffs plan to raise ar- guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in	1999 as a class				ADA. In December 2000,
the State's motion for sum- mary judgment to deny the plaintiffs' ADA claims based on a "fundamental alteration" defense. The plaintiffs plan to raise ar- guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in	action.				the District Court granted
plaintiffs' ADA claims based on a "fundamental alteration" defense. The plaintiffs plan to raise ar- guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in					
plaintiffs' ADA claims based on a "fundamental alteration" defense. The plaintiffs plan to raise ar- guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in					mary judgment to deny the
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plaintiffs plan to raise ar- guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in					based on a "fundamental
guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in					alteration" defense. The
guments related to service entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in					plaintiffs plan to raise ar-
entitlement and reasonable promptness. Court proceed- ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in					
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ings have been stayed while the parties explore a settle- ment agreement; if none is reached, a trial date is set in					promptness. Court proceed-
the parties explore a settle- ment agreement; if none is reached, a trial date is set in					
ment agreement; if none is reached, a trial date is set in					
reached, a trial date is set in					
June 2001.					
					June 2001.
		1			

· · · · · ·			
Benjamin H. v.	x	х	Pertaining to long-term care
Ohl (West			services, this suit alleged
Virginia)*			that services were not being
Filed in Apr.			provided with reasonable
1999 as a class			promptness. In July 1999,
action.		l I	the District Court granted
			the plaintiffs' motion for a
			preliminary injunction and
ļ			the defendants were ordered
			to develop a compliance
			plan that would: (1) elimi-
			nate the waiting lists, (2)
			establish reasonable time
			frames for placing persons
			into the waiver program, (3)
			allow for freedom of choice,
			(4) develop written policies
			and procedures, and (5)
			develop a plan for fair hear-
			ings. In March 2000, the
			court approved an agree-
			ment pertaining to this or-
			der.

* Settlement agreements reached by December 2000.

Waiting list lawsuits directly challenge the viability and legality of a State maintaining a waiting list for Medicaid-funded services. Provisions of Title XIX of the Social Security Act (Federal Medicaid law), Title II of the ADA, and § 504 of the Rehabilitation Services Act of 1973 all provide grounds for challenging state-generated waiting lists for Medicaid-funded services. Similarly, advocates have found a litigation vehicle in the 14th Amendment to the United States Constitution.⁴⁴

Generally, waiting list lawsuits rely on Title XIX's requirement that States promptly provide Medicaid services to all eligible individuals. Plaintiffs typically argue that the defen-

⁴⁴ A discussion of 14th Amendment Due Process and Equal Protection Clause arguments relevant to waiting list lawsuits is beyond the scope of this Note. For a discussion of the legal issues concerning reasonable promptness provisions, see NAT'L HEALTH LAW PROGRAM, REASONABLE PROMPTNESS AND THE PROVISION OF SERVICES UNDER MEDICAID (n.d.), http://www.healthlaw.org/pubs/200101prompt ness.htm (last visited Sept. 8, 2001).

dants (usually the state agency that administers Medicaid, the commissioner(s) of the Medicaid Department, and/or the Department of Mental Retardation, the governor, and others) have caused unreasonable delay in the provision of institutional or HCBS waiver services in violation of § 1396a(a)(8) and other federal and state laws.⁴⁵ Section 1396a(a)(8), the so-called "reasonable promptness provision" of the Medicaid Act, specifically requires that "[a] State plan for medical assistance must—provide that all individuals wishing to make application for medical assistance under the plan shall have opportunity to do so, and that such assistance shall be furnished with reasonable promptness to all eligible individuals."⁴⁶

Accompanying regulations promulgated by the Department of Health and Human Services (DHHS) obligate the State to "[f]urnish Medicaid promptly to recipients without any delay caused by the agency's administrative procedures," and "[c]ontinue to furnish Medicaid regularly to all eligible individuals until they are found to be ineligible."⁴⁷ Similarly regulations mandate that "[t]he agency must establish time standards for determining eligibility and inform the applicant of what they are."⁴⁸ The outer limits on such time standards are determined by regulations not to exceed "[n]inety days for applicants who apply for Medicaid on the basis of disability," and "[f]orty-five days for all other applicants."⁴⁹ Regulations also unambiguously establish that an agency "must not use the time standards" as a "waiting period" for Medicaid services.⁵⁰

Courts have consistently held that § 1396a(a)(8) of the Medicaid Act is enforceable under a § 1983 action. ⁵¹ Section 1983 imposes liability on anyone who, acting under the color of state law, deprives a person of "any rights, privileges, or immu-

 45 See generally SMITH, supra note 12, § III.B (describing waiting list litigation).

⁴⁹ Id. § 435.911(a)(1)-(2).

⁵⁰ Id. § 435.911(e)(1).

⁵¹ See, e.g., Doe v. Chiles, 136 F.3d 709, 715-19 (11th Cir. 1998); Lewis v. New Mexico Dep't of Health, 94 F. Supp. 2d 1217, 1232-36 (D.N.M. 2000); Sobky v. Smoley, 855 F. Supp. 1123, 1146-47 (E.D. Cal. 1994); see also Albiston v. Maine Comm'r of Human Servs., 7 F.3d 258, 265 (1st Cir. 1993) (holding that a "reasonable promptness" requirement in the statute governing Aid to Families with Dependent Children creates rights enforceable under § 1983).

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⁴⁶ 42 U.S.C.A § 1396(a)(8) (West Supp. 2001) (emphasis added).

⁴⁷ 42 C.F.R. § 435.930(a)-(b)(2000).

⁴⁸ Id. § 435.911(a).

nities secured by the Constitution and laws."⁵² In *Blessing v. Freestone*⁵³ the court clarified the conditions under which an individual might seek redress through a § 1983 action: "a plain-tiff must assert the violation of a federal *right*, not merely a violation of federal *law*."⁵⁴ The court further expounded:

We have traditionally looked at three factors when determining whether a particular statutory provision gives rise to a federal right. First, Congress must have intended that the provision in question benefit the plaintiff. Second, the plaintiff must demonstrate that the right assertedly protected by the statute is not so "vague and amorphous" that its enforcement would strain judicial competence. Third, the statute must unambiguously impose a binding obligation on the States. In other words, the provision giving rise to the asserted right must be couched in mandatory, rather than precatory, terms.⁵⁵

A seminal case in waitlist litigation was *Doe v. Chiles.*⁵⁶ In this case, pursuant to § 1396 and its accompanying regulations, the Court of Appeals for the Eleventh Circuit held that Federal Medicaid law does not permit a State to indefinitely waitlist individuals for Medicaid-funded services. The *Doe* court ruled that Medicaid institutional services (i.e., services provided in a nursing home or an intermediate care facility for the mentally retarded⁵⁷ ("ICF/MR") were no different than any other non-waiver Medicaid service. The court mandated that Medicaid-funded services—whether they were provided under the guise of a waiver or not—be furnished with reasonable promptness to all Medicaid-eligible individuals. While the *Doe* decision is binding only in the Eleventh Circuit, the ruling has persuasive

56 136 F.3d 709 (11th Cir. 1998).

⁵⁷ The Code of Massachusetts Regulations lists ICF/MR's under the heading of "Alternatives to Institutional Care" and defines them as follows: "Community intermediate care facilities for the mentally retarded (or for persons with related conditions) are small community-based residential programs for 15 or fewer residents." MASS. REGS. CODE tit. 130, § 433.482 (1994).

⁵² 42 U.S.C. § 1983 (Supp. V 1999).

⁵³ 520 U.S. 329 (1997).

⁵⁴ Id. at 340.

⁵⁵ *Id.* at 340-41 (citations omitted); *see also* Wilder v. Va. Hosp. Ass'n, 496 U.S. 498, 509 (1990) (holding the Boren Amendment creates a federal right enforce-able by health care providers under § 1983).

value in other circuits and has become the foundation for much of the subsequent waitlist litigation.

Waiting list lawsuits rely heavily upon the interconnectedness in Federal Medicaid law between institutional services (i.e., services provided in a nursing home or ICF/MR) and HCBS waiver services. Under federal law, a State may offer HCBS waiver plans as an alternative to institutional care.⁵⁸ In order to receive HCBS waiver services, an individual must be found to have been eligible to receive institutional services. When this equivalency criterion is satisfied, States are permitted to offer HCBS waiver services in lieu of institutional services. The covered individual is allowed to elect receipt of services in the institutional setting or the community setting.⁵⁹

In subsequent HCBS waitlist litigation, plaintiffs have built an argument based on the *Doe* framework and have alleged that an individual's eligibility for institutional services should also permit him or her to receive equivalent services via an HCBS mechanism. Other arguments in waitlist lawsuits allege that state-imposed limits on the availability of both institutional and HCBS waiver services have caused otherwise eligible individuals to forego services for which they have been deemed eligible.⁶⁰ In an argument crafted under § 1902(a)(10) of the Social Security Act,⁶¹ plaintiffs have argued that the State has failed to make available comparable long-term services for all Medicaideligible recipients, either by furnishing services to only a subset of the population⁶² or by providing services only in the institutional setting and not in the more inclusive community environment.⁶³

Waiting list lawsuits have similarly challenged state practices with regard to the processing of Medicaid applications. Some plaintiffs have alleged that States have effectively denied disabled individuals the right to apply for Medicaid long-term

⁶⁰ See also infra Part II.B.3 (discussing access to benefits lawsuits).

61 42 U.S.C.A. § 1396a(a)(10).

⁶² See also infra Part II.B.3 (discussing access to benefits lawsuits).

⁶³ See also infra Part II.B.2 (discussing Olmstead lawsuits).

⁵⁸ See 42 U.S.C.A. § 1396n (West Supp. 2001) (governing waiver programs).

⁵⁹ See 42 U.S.C.A. § 1396n(c)(2)(C) (providing that "individuals who are determined to be likely to require the level of care provided in a hospital, nursing facility, or intermediate care facility for the mentally retarded are informed of the feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of inpatient hospital services, nursing facility services, or services in an intermediate care facility for the mentally retarded").

services by not permitting formal applications for HCBS waiver services and/or by not making prompt determinations with regard to such applications.⁶⁴ Plaintiffs assert that in delaying Medicaid applications or agency decisions on such applications, States are effectively violating § 1902(a)(3) of the Social Security Act by denying disabled individuals the right to appeal the denial of Medicaid services.⁶⁵ In a similar vein, advocates are arguing that application processing delays and denials of applications violate a disabled individual's 14th Amendment Due Process and Equal Protection rights under the U.S. Constitution.

2. "Olmstead Lawsuits"

So called "Olmstead Lawsuits" are based upon the integration mandate found in the United States Supreme Court's 1999 holding in *Olmstead v. L.C.*⁶⁶ Generally speaking, the term "Olmstead lawsuits" refers to litigation⁶⁷ alleging that institutionalized individuals "have been improperly denied the opportunity to receive community services in the 'most integrated setting.""68 The Court ruled in Olmstead that unnecessary segregation of disabled individuals in institutional facilities constituted discrimination and thereby violated the Americans with Disabilities Act (ADA). Olmstead's majority opinion, written by Justice Ginsberg, concluded that the ADA requires a State to deinstitutionalize disabled individuals, placing them in less restrictive community settings whenever: (a) treating professionals determine that a community placement is appropriate; (b) the individual does not oppose the transfer from an institution to the community; and (c) the placement can be reasonably accommodated, taking into account factors such as the availability of state resources and the needs of other disabled individuals.⁶⁹

Considerable overlap exists between Olmstead litigation, waiting list litigation, and access to benefits litigation. Many

⁶⁴ See generally SMITH, supra note 12, § III.B (describing waiting list lawsuits).

^{,,.} ⁶⁵ Id.

⁶⁶ 527 U.S. 581 (1999).

⁶⁷ See generally SMITH, supra note 12, § IV (describing arguments and cases falling into the "Olmstead lawsuits" category).

⁶⁸ SMITH, *supra* note 12, § I; *see also* 28 C.F.R. § 35.130(d) (2000) (providing regulation that a "public entity shall administer services . . . in the most integrated setting appropriate to the needs of qualified individuals with disabilities"); *Olmstead*, 527 U.S. at 591-92 (describing the 'integration regulation').

⁶⁹ Olmstead, 527 U.S. at 587; SMITH, supra note 12, § IV.

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lawsuits allege that the delay in access to community services and the insufficient number of community placements effectively restricts a disabled individual's ability to seek care in anything other than a restrictive, institutional setting.

Lawsuit	Medicaid	ADA	§ 504	14th	Description
	Law			Am.	
Brown v. Bush (Florida). Filed as a class ac- tion.	X	x	x	X	Plaintiffs sought declaratory judgment and permanent injunction to prevent the State from unnecessarily institutionalizing individuals with MR/DD. In March 1999, the district court adopted plaintiffs' proposed class definition. Florida appealed the court's class certification to the Court of Appeals for the Eleventh Circuit, which agreed that the class was overly broad. The parties are reportedly now negotiating a reduction in the number of individuals receiving institu- tional services.
Inch v. Hum- phrey (Indi- ana). Filed in July 2000 by the Indiana Civil Liberties Union as a class action.					Filed in Marion County Su- perior Court (rather than federal district court) on behalf of MR/DD individuals who were currently residing in nursing homes and/or who were at risk of nursing home placement, this suit alleged that 2,000 individuals are either on waiting lists for community services or were suffering "unjustified institu- tional isolation."

Figure 3: Olmstead Lawsuits as of March 2001⁷⁰

⁷⁰ Information adapted from SMITH, supra note 12, § IV.

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HEALTH MATRIX

			.		
Doe v. Ken-					This suit alleged that the
tucky Cabinet					State was not properly ad-
for Human					ministering the Medicaid Pre-
Servs. (Ken-					Admission Screening and
tucky). Filed					Resident Review ("PASRR")
by the Ken-					process for MR/DD individu-
tucky Protec-					als, resulting in inappropriate
tion and Advo-					placements and provision of
cacy Agency					services. The litigation
as a class ac-					ceased when the parties
tion.					agreed to employ a consult-
					ant to evaluate the PASRR
					process and make recom-
				1	mendations.
	· · · · · ·	x	v		
Barthelemy v.		•	Х		This complaint alleged that
Louisiana					restriction of available ser-
Dep't of					vices to "unnecessarily seg-
Health and					regated settings" violated §
Hospitals					504 of the Rehabilitation Act.
(Louisiana).					Settlement talks are report-
Filed in Apr.			1		edly underway.
2000 by five					
plaintiffs and			}		
Resources for					
Independent					
Living.					
Rolland v.		x	ľ		Plaintiffs presented both an
Cellucci (Mas-					ADA claim and a claim under
sachusetts).					the 1987 Nursing Home Re-
Filed in Oct.					form Law contained in Om-
1998 by 7			l		nibus Budget Reconciliation
MR/DD indi-					Act of 1987. In October
viduals; class					1999, the State agreed to
action for 858			ļ		offer residential and special-
MR/DD indi-					ized services to MR/DD
viduals.					nursing home residents under
					the terms of mediated settle-
					ment agreement. Addition-
{			l		ally, \$5.6 million was allo-
					cated to fund the placement
					process between FY 2000-FY
1					2001.
L			<u> </u>	L	2001.

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Olesky v.		x		In June 2000, this case was
Haverman				referred to the U.S. District
(Michigan).				Court for Western Michigan.
Filed in Sept.				Plaintiffs' counsel estimates
1999 by				that there are 500 individuals
Michigan				in Michigan who should be
Protection and				deinstitutionalized. Plaintiffs
Advocacy				allege a violation of the
Agency for six		1		Nursing Home Reform Act of
named indi-				1987 and the ADA. The court
viduals with				denied a state motion to dis-
MR/DD and/or				miss based on Eleventh
mental illness.				Amendment grounds and
				settlement discussions are
				reportedly underway.
Bonnie B v.	x	x	x	Persons with neurological
Shumway				disabilities brought suit under
(New Hamp-				the State's Acquired Brain
shire). Filed in				Injury (ABI) HCBS waiver
Dec. 1999 as a				program, alleging that the
class action.				NH Division of Developmen-
				tal Services (DDS) operated
				its long-term services pro-
				gram with "inadequate,
				capped funding" and that the
	(state administration of the
				program failed to provide
				services in a reasonably
				prompt manner.

3. Access to Benefits Lawsuits

Access to benefits lawsuits allege that Medicaid recipients have not been provided services or are unable to access services that they are authorized to receive.⁷¹ For example, an Arizona case, *Ball v. Biedess*,⁷² alleges that Medicaid payment rates for community-based caregivers and professionals are inadequate to enlist a sufficient number of community providers in order to

⁷¹ See generally SMITH, supra note 12, § V (describing arguments and cases associated with the access to benefits category). ⁷² No. CIV 00-67 TUC ACM (D. Ariz. 2000).

ensure that Medicaid services are locally available to all those who are authorized to receive them.⁷³ Similarly, the *Ball* case alleges that a lack of sufficient service providers places disabled individuals at risk of having to return to a more restrictive institutional environment to receive necessary care.⁷⁴ Sanchez v. Johnson,⁷⁵ a California case, argues that differential payment and benefit structures for institutional versus community-based providers have had the effect of subjecting MR/DD individuals to unnecessary institutional placements and have encouraged discrimination on the basis of disability.⁷⁶

Figure	4:	Access	to	Benefits	Lawsuits	as	of	March	
2001 ⁷⁷									

Lawsuit	Medicaid	ADA	§ 504	14th	Description
	Law			Am.	
Ball v. Biedess	x	х	x		Filed in federal district court,
(Arizona).					this suit argued that Medicaid
Filed in Jan.					payment rates for direct ser-
2000 by Ari-					vice and support professionals
zona and Na-]		in the community were insuf-
tive American					ficient to enlist enough pro-
Protection and					viders to ensure Medicaid
Advocacy					services were available to
Agencies.			1		persons with disabilities eligi-
ĺ					ble and authorized to receive
					such services. The suit alleged
					a violation of § 1902(a)(30)(A)
					of the Social Security Act.
					Additional arguments were
					made regarding reasonable
1			1		promptness; amount, duration
					and scope of services; and
					patients' freedom of choice.

73 42 U.S.C.A. § 1396a(30)(A) (West Supp. 2001) requires that payments be "consistent with efficiency, economy, and quality of care."

⁷⁴ See also supra Part II.B.2 (discussing Olmstead lawsuits).

⁷⁵ No. 00-CV-01 593 (CW) (N.D. Cal. 2000).

⁷⁶ 42 U.S.C.A. § 1396a(30)(A) requires that methods and procedures for the utilization of care and services be "consistent with efficiency, economy, and quality of care." ⁷⁷ Information adapted from SMITH, *supra* note 12, § V.B.

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Sanchez v. Johnson (Cali- fornia). Filed in May 2000. Wolf Prado-		x		Filed in U.S. District Court for the Northern District of Cali- fornia, this complaint alleged that differential payment and wage and benefit structures between institutional and community-based providers resulted in "unnecessary insti- tutionalization and segrega- tion," a violation of the ADA. In May 2000, the parties en-
Steinman v. Bush (Florida). Filed by Flor- ida Protection and Advocacy Agency.				tered into an eighteen-point settlement agreement address- ing the provision of a full- range of HCBS waiver ser- vices in addition to addressing quality improvement, work- load ratios, and provider pay- ment rates.
Malen v. Hood (Louisiana). Filed in Dec. 2000.				Filed in the U.S. District Court for the Eastern District of Louisiana, this class action suit filed against the Louisiana Department of Health and Hospitals pertains to the State's implementation of the "Children's Choices" Medi- caid HCBS waiver program for children with MR/DD.

Benjamin H. v.	х	x	1	In addition to waitlist claims,
Ohl (West				
				the plaintiffs in this suit re-
Virginia). Filed				quested that the State increase
in Apr. 1999.				its payment rates for HCBS
				waiver services. The district
				court ruled that the plaintiffs
				did not marshal sufficient
				evidence in support of their
				claim, but expressed strong
				concerns regarding the ade-
				quacy of provider payment
				rates. In part as a result of this
				litigation, West Virginia offi-
				cials have committed to con-
				duct a thorough review of the
				State's payment rates.

PART III: CASE STUDY: BOULET V. CELLUCCI

A. Introduction

In March 1999, private attorneys from the Commonwealth of Massachusetts filed a class action lawsuit in federal district court on behalf of six named plaintiffs⁷⁸ and their families who were dissatisfied with the pace at which the State was reducing the waiting list for HCBS residential services. The plaintiffs' proposed class definition included "all mentally retarded or developmentally disabled individuals in the Commonwealth of Massachusetts who are not receiving or have not received Medicaid services for which they are eligible."⁷⁹ The plaintiffs' complaint alleged that the Commonwealth of Massachusetts had violated Federal Medicaid law and the Americans with Disabilities Act by failing to provide, with reasonable promptness, Medicaid-funded residential services to otherwise eligible individuals and had instead indefinitely waitlisted those individuals

⁷⁸ On May 25, 1999, lead plaintiff Valerie Anderson moved to dismiss her claims without prejudice. Because of a deterioration of her health, she no longer requested that the Commonwealth immediately provide her with residential habilitation services. Boulet v. Cellucci, 107 F. Supp. 2d 61, 63 n.1 (D. Mass. 2000). This left five named plaintiffs.

⁷⁹ Class Action Compl. for Declaratory and Injunctive Relief at 2, *Boulet* (No. 99-10617-DPW); *Boulet*, 107 F. Supp. 2d at 63.

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for approved services. To remedy violations of the Federal Medicaid Act, the United States Constitution, and the Massachusetts Declaration of Rights, plaintiffs sought permanent injunctive relief⁸⁰ on behalf of approximately 3,000 mentally retarded and developmentally disabled individuals who had been waitlisted for approved services by the Commonwealth.⁸¹

B. Facts

The Commonwealth of Massachusetts participates in the Federal Medicaid program and has committed to provide Medicaid services to both categorically needy and medically needy populations. Pursuant to Federal Medicaid law,⁸² the Commonwealth's HCFA-approved Medicaid plan provides for eligible individuals to receive services in an intermediate care facility for the mentally retarded (ICF/MR). Similarly, the Commonwealth's plan provides for HCBS waiver services in lieu of ICF/MR services as detailed in the Commonwealth's waiver application to HCFA. The Federal Medicaid Act permits the inclusion of such services under the auspices of a waiver provision:

The Secretary may by waiver provide that a state plan approved under this subchapter may include as "medical assistance" under such plan payment for part or all of the cost of home or community-based services (other than room and board) approved by the Secretary which are provided pursuant to a written plan of care to individuals with respect to whom there has been a determination that but for the provision of such services the individuals would require the level of care provided in $a[n] \ldots$ intermediate care facility for the mentally retarded the cost of which could be reimbursed under the State plan.⁸³

⁸⁰ Mem. in Supp. of Pl's Mot. for Summ. J. at 1, *Boulet* (No. 99-10617-DPW). According to the plaintiffs' attorneys, "monetary damages [were] inadequate to cure [the] harm, and [were] also unavailable by operation of the Eleventh Amendment." *Id.* at 30.

⁸¹ Id. at 1.

⁸² 42 U.S.C.A §§ 1396d(a)(15) (West Supp. 2001) (defining "medical assistance"), 1396d(d)(3) (defining ICF/MR care as an optional service that may be provided in a State Medicaid plan).

^{83 42} U.S.C.A. § 1396n(c)(1).

Under its waiver plan, Massachusetts provides for residential habilitation services,⁸⁴ day services and supports, supported employment services, transportation, and respite care.⁸⁵ According to the waiver application, eligible individuals under the waiver plan include developmentally disabled individuals under the age of eighteen and mentally retarded individuals age eighteen and older who also meet the financial qualifications for eligibility (i.e., meet the definitions of categorical need).⁸⁶

In accordance with federal requirements, individuals are eligible to receive waiver services, if, but for the provision of these services, they would require the level of care provided in an ICF/MR,⁸⁷ and provided that HCBS services can be provided at the same or lesser cost than that which would have been incurred in an institutional setting, such as an ICF/MR or a nursing home. Massachusetts's waiver plan provides that when an individual "is determined to be likely to require' the level of care provided by an ICF/MR," the individual shall be given the option of receiving services in either an institutional setting or in the community.⁸⁸ Finally, the Massachusetts waiver plan guarantees individuals the opportunity for a fair hearing when they are not given the choice of HCBS services instead of institutional care.⁸⁹

⁸⁴ Massachusetts's waiver plan defines "residential habilitation" as: [A]ssistance with acquisition, retention, or improvement [of] skills related to activities of daily living, such as personal grooming, and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting. Residential habilitation as used herein includes services and supports that assist individuals with mental retardation to gain independence and skills to live in the community, including in their natural/family home. . . . Residential habilitation also includes services and supports to others which enable the individual with mental retardation to remain living with the family in the natural/family home and to prevent institutionalization of the individual

⁸⁷ Boulet, 107 F. Supp. 2d at 65.

Boulet v. Cellucci, 107 F. Supp. 2d 61, 65-66 (D. Mass. 2000) (quoting letter from Mark E. Reynolds, Acting Commissioner, Executive Office of Health and Human Services, to HCFA 12 (May 22, 2000)). ⁸⁵ Mem. in Supp. of Pl's Mot. for Summ. J. at 4, *Boulet* (No. 99-10617-

DPW). ⁸⁶ Id.

⁸⁸ Id.

⁸⁹ Mem. in Supp. of Pl's Mot. for Summ. J. at 5, Boulet (No. 99-10617-DPW).

In the *Boulet* lawsuit, the plaintiffs alleged the Commonwealth failed to provide needed and approved Medicaid-funded services to more than $3,000^{90}$ MR/DD individuals residing in the Commonwealth of Massachusetts. Plaintiffs further alleged that rather than provide necessary Medicaid-funded services, the Commonwealth, through the Department of Mental Retardation (DMR), placed individuals on waiting lists for approved services, frequently keeping an individual on the list for an extended period of time. Indeed, each of the original six named plaintiffs in the *Boulet* lawsuit had been on DMR's waiting list for at least three years at the time the lawsuit was filed, and three of the plaintiffs had been on the waiting list for more than ten years.⁹¹

In fact, the Massachusetts DMR has 'maintain[ed] a waiting list of individuals eligible for and in need of DMR services' since at least 1988.⁹² At the end of fiscal year 1998, 3,014 individuals were on the Commonwealth's waiting list.⁹³ Of those listed, the 'vast majority' were 'in need of a residential service.'⁹⁴ In fiscal year 1998, for example, DMR reported that 72% of waitlisted individuals were waiting for residential services only and an additional 14% were waiting for residential and day services.⁹⁵ As District Judge Woodlock's opinion made clear:

[T]he human side of this waiting list is far more compelling than any statistics can convey. Aging individuals live with elder caregivers. Young individuals remain at home after leaving special education. Families are in

⁹⁰ According to figures released by the Massachusetts Department of Mental Retardation (DMR) at the end of fiscal year 1998 (July), there were 3,014 unserved individuals on DMR's waiting list. MASS. DEP'T OF MENTAL RETARDATION, OFFICE OF HEALTH AND HUMAN SERVICES, REPORT ON THE USE OF FUNDS FOR SERVICES TO INDIVIDUALS ON THE DMR WAIT LIST 2 (Jan. 1999), available at http://www.dmr. state.ma.us/wait.htm.

⁹¹ At the time the complaint was filed, plaintiffs Valerie Anderson, Edmund Boulet, and Richard Byers had each been on the waiting list for more than ten years. Class Action Compl. for Declaratory and Injunctive Relief at 4-7, *Boulet* (No. 99-10617-DPW). Plaintiffs Robert and Bryan Dubord had waited more than nine years and five years, respectively, for Medicaid-funded services. *Id.* at 7-8. Plaintiff Bridget Studley had waited for Medicaid services for more than three years. *Id.* at 8-9.

⁹² Boulet, 107 F. Supp. 2d at 66.

⁹³ Id.

⁹⁴ Id.

⁹⁵ Id.

crisis because they do not have the means or the natural supports needed to care for their sons, daughters, sisters, and brothers. Given the fact that mental retardation is a life-long disability families are seeking services that would create a secure future for their loved ones. Parents who have cared for their children since birth have dedicated their own lives in order to enrich their children's lives. They have added their names to the DMR waiting list, but their futures remain highly uncertain.⁹⁶

As DMR's own literature intimated, each of the named plaintiffs on DMR's waiting list faced the real possibility that her current caregiver would suddenly be unable to provide further support due to incapacity or death. Such an eventuality was not improbable, as DMR itself had estimated that approximately 43% of individuals on the Commonwealth's waiting list had caregivers over the age of sixty.⁹⁷ Furthermore, DMR noted that "among that subset of older primary caregivers, more than half are over 70 years of age, and approximately 16% are 80 years of age or older."98

Having realized the precarious position of many families with mentally retarded/developmentally disabled children /siblings, the Boulet lawsuit was brought on behalf of "all mentally retarded or developmentally disabled individuals in Massachusetts who [were] not receiving Medicaid services for which they [were] eligible."⁹⁹ The plaintiffs' attorneys waged a classic "waitlist lawsuit" attack,¹⁰⁰ arguing that as a participant in the Federal Medicaid program and as a recipient of federal funds, the Commonwealth of Massachusetts was required to comply with provisions in the Medicaid Act. Specifically, the

⁹⁶ Id. at 66-67 (alteration in original).

99 Boulet, 107 F. Supp. 2d at 63.

¹⁰⁰ Indeed, in their May 6, 1999 Memorandum in Support of Plaintiffs' Motion for Summary Judgment, plaintiffs allege that their action was "legally indistinguishable from a class action filed in Florida by developmentally disabled persons, in which the Eleventh Circuit held that Florida officials violated section 1396a(a)(8) by placing eligible individuals on a waiting list." Mem. in Supp. of Pl's Mot. for Summ. J. at 16, Boulet (No. 99-10617-DPW). The case to which these Massachusetts attornevs were referring was Doe v. Chiles, 136 F.3d 709, 712, 717 (11th Cir. 1998) (affirming district court's order requiring state officials to establish a 'reasonable waiting list time period, not to exceed ninety days'); see supra Part II.B.1.

⁹⁷ Mem. in Supp. of Pl's Mot. for Summ. J. at 9, Boulet (No. 99-10617-DPW). ⁹⁸ *Id*.

plaintiffs' attorneys pointed to the "reasonable promptness"¹⁰¹ and "fair hearing"¹⁰² provisions in the Federal Medicaid Act, which require a state agency to allow any individual whose claim for medical assistance under the plan was denied or not acted upon with reasonable promptness, to request an opportunity for a fair hearing. Predictably, in determining reasonable promptness, the attorneys relied on federal regulations that govern the timeliness of agency response to applications and requests for Medicaid assistance.¹⁰³

In their prayer for relief, plaintiffs specifically requested that the court require the defendants, "to offer all plaintiffs the full range of ICF/MR services or home and community-based waiver services and other services for which they are eligible within 90 days or some other specifically-defined, reasonably prompt period."104 The plaintiffs' attorneys argued that the rights guaranteed by § 1396a(a)(8) of the Medicaid Act were enforceable in a § 1983 action.¹⁰⁵ Applying the elements of the § 1983 test established in *Blessing v. Freestone*,¹⁰⁶ plaintiffs' attorneys argued that Congress had intended the reasonable promptness provision of the Medicaid Act to benefit the named class of plaintiffs, that the rights outlined in the reasonable promptness provision were "not so 'vague and amorphous' that [their] enforcement would strain judicial competence," and that the reasonable promptness provision unambiguously imposed an obligation that was binding on the Commonwealth.¹⁰⁷ Furthermore, citing to *Doe v. Chiles*,¹⁰⁸ the plaintiffs asserted that the implementing regulations helped define the meaning of "reasonable promptness"¹⁰⁹ and directed that plaintiffs should

- ¹⁰¹ Mem. in Supp. of Pl's Mot. for Summ. J. at 13, Boulet (No. 99-10617-DPW) (citing 42 U.S.C.A. § 1396a(a)(8) (West Supp. 2001)).
- ¹⁰² Mem. in Supp. of PI's Mot. for Summ. J. at 13-14, Boulet (No. 99-10617-DPW) (citing 42 U.S.C.A. § 1396a(a)(3)).
- ¹⁰³ See Mem. in Supp. of Pl's Mot. for Summ. J. at 14-15, Boulet (No. 99-10617-DPW) (citing 42 C.F.R. §§ 435.911, 425.930(a) (2000)).
- ¹⁰⁴ Class Action Compl. for Declaratory and Injunctive Relief at 21, Boulet (No. 99-10617-DPW).
- ¹⁰⁵ Mem. in Supp. of Pl's Mot. for Summ. J. at 16-19, Boulet (No. 99-10617-DPW). ¹⁰⁶ 520 U.S. 329 (1997).

¹⁰⁷ Mem. in Supp. of Pl's Mot. for Summ. J. at 16, Boulet (No. 99-10617-DPW).

¹⁰⁸ 136 F.3d 709 (11th Cir. 1998).

¹⁰⁹ Mem. in Supp. of Pl's Mot. for Summ. J. at 17, Boulet (No. 99-10617-DPW).

not be forced to endure the "arbitrary and unpredictable lottery for Medicaid services"¹¹⁰ that was the Commonwealth's waiting list, but should instead promptly receive services within the home or community setting.

Finally, the plaintiffs asserted:

[T]he defendants' violation of section 1396a(a)(8) is not excused by the fact that the various services at issue here – ICF/MR care and waiver services – are optional services that a participating state need not provide. Because the Commonwealth has committed to provide these services as part of its Medicaid plan, it must comply with the statutory "reasonable promptness" requirement in its provision of those services.¹¹¹

C. District Court Ruling

1. Summary of Decision

In a July 14, 2000 decision, Judge Douglas P. Woodlock of the United States District Court for the District of Massachusetts certified the plaintiffs' proposed class, but amended the class definition so as to include only MR/DD adults in the State who were eligible to receive Medicaid services under the cap established in the Commonwealth's waiver proposal and who were also currently on the Commonwealth's waiting list for such services. Granting the plaintiffs' motion for summary judgment and finding that that the defendants had not met their obligation under § 1396a(a)(8) to provide residential habilitation services with reasonable promptness, the court granted injunctive relief and ordered the defendants to provide services to the plaintiffs within a ninety-day period. Leaving the door open, Judge Woodlock permitted the defendants an opportunity to show cause why the specified time period might be insufficient to provide these services.

¹¹⁰ *Id.* at 23. ¹¹¹ *Id.* at 28.

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2. Enforceability of a § 1396a(a)(8) Claim Under 42 U.S.C. § 1983

As a preliminary issue, Judge Woodlock determined, in accordance with several courts before him, that § 1396a(a)(8) provides a right that is enforceable under § 1983. Analyzing the *Boulet* case under the framework established by *Blessing v*. *Freestone*,¹¹² Judge Woodlock explained that "in directing that medical assistance 'shall be furnished with reasonable promptness to all eligible individuals,' Congress clearly intended to protect those eligible individuals from undue delays."¹¹³ Pursuant to part one of the *Blessing* test, he found that "the plaintiffs ... [were] intended beneficiaries of the provision."¹¹⁴

Judge Woodlock also found that part two of the *Blessing* test was satisfied, relying on established First Circuit precedent:

A statute is not impermissibly vague simply because it requires judicial inquiry into 'reasonableness.' . . . Rather, the relevant question is whether the action or purpose whose 'reasonableness' is commanded has been clearly delineated and is susceptible of judicial ascertainment." The fact that the state retains considerable discretion in determining the time period in which the medical services will be provided does not render the requirement of "reasonable promptness" unenforceable. "While there may be a range of reasonable [time periods for provision of assistance], there certainly are some [time periods] outside that range that no State could ever find to be reasonable . . . under the [Medicaid] Act.¹¹⁵

Judge Woodlock concluded that "[c]ertain periods of time, like the three to ten or more years plaintiffs have been waiting, are 'far outside the realm of reasonableness'—a conclusion which a court is perfectly capable of reaching."¹¹⁶

¹¹⁴ Id.

¹¹⁶ Id.; But see Suter v. Artist M, 503 U.S. 347, 360-64 (1992) (finding a requirement of "reasonable efforts" to prevent removal of children from their homes and to facilitate reunification of families too vague for judicial enforcement).

¹¹² 520 U.S. 329 (1997).

¹¹³ Boulet v. Cellucci, 107 F. Supp. 2d 61, 72 (D. Mass. 2000) (citation omitted).

¹¹⁵ Id. (alterations in original) (citations omitted).

With regard to *Blessing*'s third and final requirement, Judge Woodlock found that the Medicaid statute unambiguously imposed a binding obligation on the State and its agencies. Judge Woodlock asserted that the requirement was mandatory, rather than precatory,¹¹⁷ and paralleled the 'federally imposed obligation' found in statutory provisions of the Social Security Act, which require States to provide Aid to Families with Dependent Children with reasonable promptness.¹¹⁸ Regarding § 1396a(a)(8), he concluded, "[t]he mandatory language at issue here unambiguously imposes an obligation upon Massachusetts to furnish medical assistance 'with reasonable promptness."¹¹⁹

3. Defendants' Obligations Under Federal Medicaid Law

Having established that the plaintiffs had a right enforceable under § 1983, the court set out to rule upon the plaintiffs' assertions that the defendants had shirked mandatory obligations promulgated under Federal Medicaid law. First the court reiterated statutory underpinnings already addressed elsewhere in this Note.¹²⁰ Namely, the court upheld traditional statutory analysis in holding that "once a state opts to implement a waiver program and sets out eligibility requirements for that program, eligible individuals are entitled to those services and to the associated protections of the Medicaid Act."¹²¹ Citing to the Eleventh Circuit Doe decision, Judge Woodlock opined that "when a state chooses to provide an optional service, the service 'becomes a part of the state Medicaid plan and is therefore subject to the requirements of federal law."122 Also pertinent was the Doe court ruling that "[i]nadequate state appropriations do not excuse noncompliance' with the Medicaid Act."¹²³

The freedom of choice provision states:

[I] ndividuals who are determined to be likely to require the level of care provided in $a[n] \dots$ intermediate care facility for the mentally retarded are informed of the

¹²¹ Boulet, 107 F. Supp. 2d at 76.

¹¹⁷ Boulet, 107 F. Supp. 2d at 73.

¹¹⁸ Id.

¹¹⁹ Id.

¹²⁰ See supra Part II.B.1.

¹²² Id. at 77.

 ¹²³ Id. (alternation in original) (citing Doe v. Chiles 136 F.3d 709, 722 (11 Cir. 1998) (quoting Alabama Nursing Home Ass'n v. Harris, 617 F.2d 388, 396 (5th Cir. 1980))).

feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of \ldots services in an intermediate care facility for the mentally retarded¹²⁴

This provision is clarified by its associated regulation, which provide that recipients must be "[i]nformed of any feasible alternatives available under the waiver" and "[g]iven the choice of either institutional or home and community-based services."¹²⁵ Clearly, this "freedom of choice provision creates binding obligations on any State that elects to provide supports and services in homes pursuant to the Home and Community-Based Waiver."¹²⁶ Indeed, "neither the hope of a future placement after years on a waiting list nor an option which may not meet an individual's needs constitutes a meaningful choice as contemplated by § 1396n(c)(2)."¹²⁷

4. Impact of the Cap

How the cap on waiver services affects a mentally retarded/developmentally disabled individual's ability to access services for which he is eligible is confounding. Judge Woodlock stated that "[t]he cap on waiver services is simply a constraint on eligibility."¹²⁸ He noted that, "on a theoretical level, a cap may be problematic":

[W]hile all eligible individuals are entitled to waiver services, the statutory scheme allows a cap which may prevent some of those eligible individuals from receiving the services they request. This theoretical construct treats a cap as something distinct from the eligibility requirements. As a practical matter, the statute can best be read to mandate that, once a state chooses to implement a waiver program and chooses the eligibility requirements, a cap is simply another eligibility requirement for that program. . . . Individuals who apply after the cap has been reached are not eligible, or alternatively,

¹²⁴ 42 U.S.C.A. § 1396n(c)(2)(C) (West Supp. 2001).

¹²⁵ 42 C.F.R. § 441.302(d)(1)-(2) (2000).

¹²⁶ Cramer v. Chiles, 33 F. Supp. 2d 1342, 1351 (S.D. Fla. 1999).

¹²⁷ Boulet, 107 F. Supp. 2d at 77.

¹²⁸ Id.

the waiver services are not "feasible" for them until the cap has risen to include them.¹²⁹

Judge Woodlock therefore concluded that all of "the eligible individuals under the cap are entitled to waiver services."¹³⁰ Accordingly, because the state plan provides for ICF/MR services under the waiver (as well as for other approved waiver services) individuals under the cap are entitled to such services.¹³¹

The Commonwealth failed, in Judge Woodlock's estimation, to provide in a reasonably prompt fashion the twenty-four hour community-based residential services that plaintiffs had requested and for which they were deemed to be eligible. "[T]he assistance must correspond to the individual's needs, and . . . the state has recognized that those individuals on the waiting list, and the named plaintiffs in particular, need the services for which they are waiting."¹³² Accordingly, the provision of alternative services that did not rise to the level of requested or needed services was simply insufficient. Furthermore, any

choice between institutional and home or communitybased services sanctioned in § 1396n(c)(2)(C) would be rendered essentially meaningless if states which had implemented a waiver program could escape the promptness requirement and other requirements that would force them to make the waiver services available simply by providing some other services or some other choice to eligible individuals.¹³³

5. Feasibility of State-Generated Waiting Lists

Having determined that the reasonable promptness provision applied to all of the services sought by the plaintiffs, and that the provision of alternate services did not satisfy Federal Medicaid requirements, Judge Woodlock then turned to the viability of state-generated waiting lists, holding that "a determination that the waiting list violates the 'reasonable promptness' requirement if settings are available for the services plaintiffs

 $\begin{array}{c} {}^{129} Id. \\ {}^{130} Id. \\ {}^{131} Id. \ {\rm at} \ 78. \\ {}^{132} Id. \ {\rm at} \ 79. \\ {}^{133} Id. \end{array}$

request follows ineluctably."¹³⁴ Judge Woodlock relied, in part, on the United States Supreme Court decision concerning a parallel provision that governed distributions under Aid to Families with Dependent Children:

That section was enacted at a time when persons whom the State had determined to be eligible for the payment of benefits were placed on waiting lists, because of the shortage of state funds. The statute was intended to prevent the States from denying benefits, even temporarily, to a person who has been found fully qualified for aid.¹³⁵

Citing to Sobky v. Smoley, Judge Woodlock similarly relied on Judge Levi's interpretation of this statement as applied to Medicaid law, who had held "[i]t follows from Jefferson that the Medicaid Act's reasonable promptness requirement, set forth at § 1396a(a)(8), prohibits states from responding to budgetary constraints in such a way as to cause otherwise eligible recipients to be placed on waiting lists for treatment."¹³⁶ Noting that some plaintiffs had been waiting for requested services for more than a decade, Judge Woodlock concluded that "defendants have not been reasonably prompt [in providing services] if facilities are available for offering the requested services."¹³⁷ The practice of placing individuals on a waitlist for necessary services violated the intent of the Medicaid statute and its reasonable promptness requirement.

6. Remedy

Judge Woodlock granted the plaintiffs' requested relief by mandating the defendants provide Medicaid-funded services to eligible individuals in a specifically defined, prompt time frame. The judge adopted the ninety-day proposal propounded by the plaintiffs, stating that "Massachusetts should be able to respond to each new request for plan or waiver services by providing those services within 90 days if the applicant is eligible, the services are feasible, and settings are available for the delivery

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¹³⁴ Id.

¹³⁵ Jefferson v. Hackney, 406 U.S. 535, 545 (1972).

¹³⁶ Sobky v. Smoley, 855 F. Supp. 1123, 1148 (E.D. Cal. 1994).

¹³⁷ Boulet, 107 F. Supp. 2d at 80.

of these services."¹³⁸ In making the ninety-day requirement conditional upon the availability of resources, Judge Woodlock left the door open for the defendants to argue that facilities were not available to provide requested services. Indeed, Judge Woodlock stated that "[t]he rulings in this case cannot create new settings but they can and are intended to encourage vendors to be willing to provide both the settings and the services to meet the promise of the Massachusetts waiver plan by assuring reimbursement up to the waiver cap.¹³⁹ In light of deficiencies in the record with regard to the availability of services, particularly in group home settings as requested by the plaintiffs, the judge afforded the defendants an opportunity to "show cause . . . why 90 days [was] not a feasible timetable" for the transitional order.140

D. "Show Cause" Dispute

Defendants did, in fact, submit a memorandum in response to the court's order to show cause. Plaintiffs' attorneys characterized the defendants' submission as asking the court to "give them open-ended discretion to maintain a waiting list indefinitely."¹⁴¹ In a very substantial reply, plaintiffs insisted that "[a] specific, concrete transitional order [was] absolutely necessary"¹⁴² and went on to propose a detailed transitional order with respect to residential habilitation services. Specifically, plaintiffs requested that the court enter an order requiring the defendants, on a transitional basis and within the proposed ninety-day period, to take several specific steps to make these services available:

1. allocate funding for residential habilitation services;

2. issue [Requests for Responses] and initiate other measures for program development;

¹³⁸ Id. at 82. ¹³⁹ Id.

¹⁴⁰ Id.

¹⁴¹ Pl's Reply to Def.'s Mem. in Resp. to the Ct.'s Order to Show Cause at 1, Boulet (No. 99-10617-DPW). ¹⁴² Id.

3. conduct planning meetings with all members of the plaintiff class to identify an appropriate program model for each plaintiff; and

4. provide interim services and supports until the plaintiff actually receives the requested residential habilitation services.¹⁴³

Plaintiffs similarly requested that the court order periodic progress reports from defendants.¹⁴⁴

E. Settlement Agreement

On December 19, 2000, the parties involved in the Boulet litigation reached a settlement agreement.¹⁴⁵ Approved by Judge Woodlock, the agreement provides for a total of \$114 million in additional funding¹⁴⁶ over the course of the next five years: essentially, \$85 million in new money and \$29 million in base funds (i.e., money already in DMR's budget) were appropriated.¹⁴⁷ The settlement agreement provides services for all plaintiffs, meaning each of the five remaining individually named plaintiffs and all individuals with MR/DD who were on the DMR waiting list as of July 14, 2000. As part of the settlement agreement, the parties submitted an Assented-to Motion to Modify the Plaintiff Class Definition, revising the definition established by the district court judge in his July 14, 2000 ruling. Where Judge Woodlock's definition of the plaintiff class included 'all mentally retarded or developmentally disabled adults in Massachusetts who are eligible to receive Medicaid services under the plan's cap and who are currently on a waiting list for such services,' plaintiffs' revised definition specified all of the 2,437 persons who were on the DMR waiting list as of July 14, 2000.¹⁴⁸

¹⁴⁸ Id. at 2 n.1.

¹⁴³ Id. at 3.

¹⁴⁴ Id.

¹⁴⁵ Settlement Agreement, Boulet (No. 99-10617-DPW).

¹⁴⁶ This additional funding is *annualized*. This means that once the funding has been added to the state budget, it remains as an annual item in years to come. Thus, over the course of a decade, for example, the funding will be worth close to \$1 billion.

¹⁴⁷ Settlement Agreement at 4-7, *Boulet* (No. 99-10617-DPW).

Pursuant to the settlement agreement, beginning in fiscal year 2002 and extending through fiscal year 2006, the "Defendants agree[d] to request additional appropriations for the Department of Mental Retardation (DMR) in a total amount of \$85 million . . . to provide, purchase, or arrange for 1,250 new, state-funded out-of-home placements and Interim Services for the Plaintiffs."¹⁴⁹ Additional appropriations were to be structured in the following manner:

Fiscal Year	Appropriations Amount
2002	\$22 million
2003	\$18 million
2004	\$15 million
2005	\$15 million
2006	\$15 million
Total	\$85 million

Figure 5: Additional (New) Appropriations Under the Settlement Agreement¹⁵⁰

According to the settlement agreement, the Governor¹⁵¹ must request the additional appropriations for each fiscal year.¹⁵² If, for any given year, the legislature fails to designate the entire amount of the additional appropriation, that outstanding sum will be cumulatively added to the amount to be requested in the following year.¹⁵³ Pursuant to the agreement, the Governor's obligation to request additional appropriations will not extend beyond fiscal year 2007.¹⁵⁴

DMR, for its part, committed to use the funds appropriated by the Massachusetts Legislature in a manner consistent with the terms of the appropriations by agreeing to "provide, purchase, or arrange for 1,250 new state-funded out-of-home placements"¹⁵⁵ according to the following schedule:

 155 Id. "State-funded out-of-home placement" is defined as "group homes or staffed apartments in the community, and family partnerships in the community." Id.

¹⁴⁹ Id. at 5.

Adapted from Settlement Agreement at 6-7, Boulet (No. 99-10617-DPW).

¹⁵¹ Massachusetts's current governor is Jane Swift.

¹⁵² Settlement Agreement at 6, Boulet (No. 99-10617-DPW).

¹⁵³ Id.

¹⁵⁴ Id.

Fiscal Year	Out-of-Home Placements Based on New Funding	Funding Allocated
2002	250	\$17 million
2003	275	\$18.7 million
2004	250	\$17 million
2005	250	\$17 million
2006	225	\$15.3 million
Total	1,250	\$85 million

Figure 6: New Residential Placements Under the Settlement Agreement¹⁵⁶

DMR likewise agreed to use \$29 million in funds already appropriated for use by the Massachusetts Legislature (i.e., "base funds") in a manner consistent with appropriations, committing to provide 675 out-of-home placements in existing group homes,¹⁵⁷ staffed apartments,¹⁵⁸ shared living arrangements,¹⁵⁹ adult foster care with DMR support,¹⁶⁰ or family partnerships.¹⁶¹ Specifically, DMR committed to provide out-ofhome placements as follows:

at 3. The definition does not include adult foster care or shared living arrangements, nor does it include ICF/MR facilities.

¹⁵⁶ Adapted from Settlement Agreement at 6-7, Boulet (No. 99-10617-DPW).

¹⁵⁷ "Group Home" is defined as "a residence operated by DMR or by a private provider under contract with DMR that has two or more residents who are DMR consumers and that provides services and supports for each resident." *Id.* at 4.

¹⁵⁸ "Staffed Apartment" is defined as "a community-based apartment operated by a private provider under contract with DMR that has one or more residents who are DMR consumers and that provide services and supports for each resident." *Id.*

¹⁵⁹ "Shared Living Arrangement" is defined as "an arrangement where a private provider under contract with DMR arranges for a DMR consumer to live in the home of a family or individual that provides services and supports to the DMR consumer." *Id.*

¹⁶⁰ "Adult Foster Care with DMR Supports" is defined as "the Medicaid State plan service known as Adult Foster Care in which DMR funds are paid to supplement program activities and expenditures." *Id.*

¹⁶¹ "Family Partnership" is defined as "a cooperative arrangement in which a DMR consumer or his or her family provides or contributes toward the cost of a residence in which DMR provides or arranges for services." *Id.*

Fiscal Year	Out-of-Home Placements Based on Existing Money	Funding Allocated
2002	125	\$5,370,370
2003	125	\$5,370,370
2004	125	\$5,370,370
2005	150	\$6,444,444
2006	150	\$6,444,444
Total	675	\$29 million

Figure 7: Residential Placements Based on Existing Funds Under the Settlement Agreement¹⁶²

In addition to the new 1,250 out-of-home placements based on new appropriations¹⁶³ and the 675 out-of-home placements to be provided based on existing monies,¹⁶⁴ DMR agreed to "provide, purchase, or arrange out-of-home placements for 300 Plaintiffs in Fiscal Year 2001 using funds already appropriated by the Massachusetts Legislature for this purpose in Fiscal Year 2001."¹⁶⁵ Furthermore,

[i]f a total of fewer than 2,225 Plaintiffs receive out-ofhome placements during the Term of this Agreement, then DMR shall provide, purchase or arrange for the remainder of the 2,225 out-of-home placements that DMR has agreed to provide, purchase or arrange pursuant to this Agreement to persons who were not on the DMR Waiting List as of July 14, 2000.¹⁶⁶

In addition to the provision of out-of-home/residential services over the course of the next five years, the settlement agreement also provides for the funding of interim services required for qualified individuals as they await placement in an out-of-home setting. The Settlement Agreement mandates that

[b]eginning in Fiscal Year 2002 . . . DMR will provide, purchase or arrange for all of the Interim Services which DMR determines that each individual Plaintiff needs

¹⁶² Adapted from Settlement Agreement at 7, *Boulet* (No. 99-10617-DPW).

¹⁶³ See supra fig.6.

¹⁶⁴ See supra fig.7.

¹⁶⁵ Settlement Agreement at 9, Boulet (No. 99-10617-DPW).

¹⁶⁶ Id.

while he or she waits for an out-of-home placement; provided, however, that for each fiscal year covered by the term of this Agreement, DMR shall not be obligated to spend more money than appropriated [by the Massachusetts Legislature at the behest of the Governor]. DMR will provide, purchase, or arrange for Interim Services for each Plaintiff, as needed, until such time as the individual Plaintiff moves into an out-of-home placement.¹⁶⁷

The timeline and fiscal allocation for the provision of interim services is as follows:

Figure 8: Interim	Services Under	the Settlement
Agreement ¹⁶⁸		

Fiscal Year	# of Individuals Receiving Interim Services	New Funding Allo- cated
2002	1,550	\$5,000,000
2003	1,150	\$4,300,000
2004	775	\$2,300,000
2005	375	\$300,000
2006	0	\$0
Total		\$11,190,000

Approved by Judge Woodlock on January 29, 2001, the settlement agreement affords choice and predictability to MR/DD individuals, provides a mechanism for pursuing residential placement, develops a timeline for staff training, allows for formal notice to individuals in need of services, provides for formal rights of appeal and judicial review of care determinations, and mandates quarterly progress reports¹⁶⁹ from the

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¹⁶⁷ Id. at 8-9.

¹⁶⁸ Adapted from Settlement Agreement at 6 app.A, *Boulet* (No. 99-10617-DPW).

¹⁶⁹ The Settlement Agreement mandates that

DMR shall submit reports to Class Counsel describing its activities under this Agreement beginning on February 15, 2001 and continuing in threemonth intervals thereafter, on the fifteenth day of each third month, through the term of this Agreement. . . . DMR will also conduct meetings every six months with Class Counsel for the purpose of informing Class Counsel about the progress of its compliance with this Agreement.

State.¹⁷⁰ Advocates lauded the outcome as "provid[ing] a positive outcome to a legal battle that began in March 1999."¹⁷¹

PART IV: APPROACHES TO SECURING MEDICAID SERVICES

How positive was the outcome of the Boulet litigation? Clearly, the plaintiffs saw significant gain in that more than 2,000 previously waitlisted individuals would receive desired and necessary residential services within a five-year time frame. But, what costs were attendant to this gain? What concerns arose from the Boulet decision and settlement agreement? What tools, other than litigation, might have either improved the Boulet outcome or enhanced the process and ultimate success of these plaintiffs?

This first half of this section will discuss some of the specific issues that commonly arise in the creation of HCBS waivers. The second half will look to mitigating steps-some of which were employed in the Boulet case-that can be taken to improve outcomes for individuals and advocates that seek Medicaid-funded HCBS waiver services for MR/DD individuals.

A. Some Issues Arising from the Creation of HCBS Waiver Programs

1. Quality of Life and Quality of Care

Quality of life and quality of care are two distinct issues that are not always compatible.¹⁷² "[Q]uality of life addresses the degree to which individuals are satisfied with their lives, [whereas] quality of care refers to the degree to which the appropriate care that is given will improve or maintain the indi-vidual's level of functioning."¹⁷³ Not only are these two concepts distinct, they can potentially be in conflict. For example, factors that presumably promote quality of care, such as strict care delivery regulations and protocols, can actually decrease an

Id. at 16. ¹⁷⁰ Planning and Action Begin on Heels of Waiting List Settlement, ARC MASS. ADVOC. (Arc Massachusetts, Waltham, Mass.), Spring 2001, at 1, 5.

¹⁷¹ Id. at 1.

¹⁷² LUTZKY ET AL., *supra* note 8, at 25.

¹⁷³ Id.

individual's quality of life by allowing less personal freedom or individual autonomy.¹⁷⁴ Conversely, deficits in quality of care can exacerbate and further diminish an individual's quality of life; poor quality of care can lead to diminished quality of life as evidenced by increased morbidity or premature mortality.¹⁷⁵ Herein lies the struggle that dominates the provision of Medicaid-funded services—how do you provide care in the "least restrictive setting," striving to promote autonomy, freedom, and quality of life while still assuring quality of care, sufficiency in the monitoring of care plans, and adequacy of staff training?

Some state administrators fear that equilibrium has not yet been achieved in the HCBS care environment: the autonomous home-care setting, while preferable to an institutional setting, does not promote the active monitoring and assessment that presumably is more readily achieved in a large-scale care environment.¹⁷⁶ Indeed, the holding in *Olmstead* mandated that the integrated, community-based setting that was least restrictive was also the most preferable, but in avoiding the imposing regulations found in institutional settings, guarantees of quality care may be sacrificed.¹⁷⁷

Lutzky and colleagues, in a report prepared for HCFA, reviewed nationwide program literature and data related to Medicaid § 1915(c) HCBS waiver programs.¹⁷⁸ They concluded that concerns about quality of care could be grouped into the following three categories: difficulty in monitoring noninstitutional care, inexperience in monitoring noninstitutional care, and impact of low provider reimbursement rates on quality of care.¹⁷⁹

a. Difficulty in Monitoring Noninstitutional Care

According to Lutzky's 2000 report, it is more difficult to monitor the quality of care provided in group homes or smaller residential settings than it is to monitor care in large institutions

¹⁷⁷ See LUTZKY ET AL., supra note 8, at 4, 25.

¹⁷⁸ LUTZKY ET AL., *supra* note 8. It is important to note that this is a review of HCBS waiver programs across the country and does not specifically or individually address elements of the Commonwealth of Massachusetts's § 1915(c) waiver plan.

¹⁷⁹ Id. at 25-26.

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¹⁷⁴ Id.

¹⁷⁵ Id.

¹⁷⁶ As stated earlier in Part II.A, and as was evidenced in the lawsuits of the 1970's and 1980's, large-scale/institutional environments do not necessarily support quality of care. Instead, reality has shown that monitoring of care provisions in institutional settings were not widely successful.

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because smaller settings receive less "public traffic" and clients/participants are more "dispersed."¹⁸⁰ The number of smaller licensed residential settings serving people with MR/DD has grown dramatically; while there were 14,700 such settings in 1982, the number grew to 104,800 in 1998.¹⁸¹ Currently, MR/DD waiver programs "serve approximately twice as many recipients as [do] institutions."¹⁸² Reports by county auditors not infrequently found gross deficiencies in the quality of care, resulting in recommendations for "improved screening for new adult foster home operators, enhanced monitoring, more consistent imposition of sanctions, and greater coordination with citizens and professionals to identify problem homes."183

b. Inexperience in Monitoring Noninstitutional Care

Lutzky and colleagues similarly point to individual States' inexperience at monitoring quality in the home and community settings. According to these authors, "states have not established regulations or licensing requirements for certain types of residential alternatives."¹⁸⁴ Lutzky and colleagues assert that homes and settings that are not equipped to serve as skilled nursing facilities are increasingly taking on more responsibilities and more complex patients/clients and yet are still subject to minimal regulation, potentially resulting in diminishing returns in terms of the quality of services provided to consumers.¹⁸⁵

To protect against such inexperience, plaintiffs' counsel is to play an active role in monitoring the implementation of the settlement agreement. Specifically, plaintiffs' counsel will review information on the numbers of people who will receive services pursuant to the settlement agreement and has plans to contact individual plaintiffs to ensure that their needs are being met. Thus, the plaintiffs need not rely on state monitoring of the implementation process.¹⁸⁶

¹⁸⁰ Id. at 25.

¹⁸¹ *Id.* at 26 (citation omitted).

¹⁸² Id. at 29.

¹⁸³ Id. at 26.

¹⁸⁴ Id. ¹⁸⁵ Id.

¹⁸⁶ Email from David Friedman, Counsel for *Boulet* Plaintiffs, Hill & Barlow, to Margaret K. Feltz, Associate Attorney, McDermott, Will & Emery (Oct. 23, 2001) (on file with author).

c. Impact of Low Provider Reimbursement Rates on Ouality of Care

Finally, Lutzky and colleagues warn that "[s]tates may see the reduction of rates paid to providers as an easy mechanism for controlling costs; and community-based care organizations may lack the organizational structure and lobbying power to fight rate reductions possessed by the nursing facility industry."¹⁸⁷ Ouoting a provider association representative from Oregon, Lutzky summarized the negative impact of low provider reimbursement rates on quality of care, stating that it seems that the State is 'balancing its budget on the backs of providers.'¹⁸⁸ Challenges surrounding provider reimbursement in the home and community settings have recently moved to the courtroom, with plaintiffs arguing that disparate benefit and salary structures in the institutional versus HCBS markets are forcing disabled individuals to live in more restrictive institutional settings (a potential *Olmstead* violation) and are violating the ADA by discriminating on the basis of disability.¹⁸⁹ The impact of provider reimbursement rates on quality of care (and, potentially, quality of life) simply cannot be underestimated.

Measuring the quality of care also presents challenges, for mechanisms normally used in the acute care realm do not readily translate to the long-term care environment. The fact that goals in the long-term care environment are not always clearly defined and often vary between the different parties involved (i.e., administrators, providers, clients, families) further compli-cates the situation.¹⁹⁰ Similarly, the fact that the condition of many individuals in long-term care does not improve despite oftentimes intensive treatment further complicates these assessments.¹⁹¹

¹⁸⁷ LUTZKY ET AL., supra note 8, at 26.

¹⁸⁸ Id. (quoting L.M.B. ALECXIH ET AL., ESTIMATED COST SAVINGS FROM THE USE OF HOME AND COMMUNITY-BASED ALTERNATIVES TO NURSING FACILITY CARE IN THREE STATES (1996)).

¹⁸⁹ See Interveners' Am. Compl., Ball v. Biedess, No. CIV 00-67 TUC ACM (D. Ariz. 2000) (describing plaintiffs' allegations that they were denied HCBS services because the provider claimed they were unable to find sufficient workers at their wage levels); Compl., Sanchez v. Johnson, No. 00-CV-01 593 (CW) (N.D. Cal. 2000) (challenging the HCBS provider's criteria and methods of administration and payment); Supra Part III.B.3. ¹⁹⁰ LUTZKY ET AL., supra note 8, at 26.

¹⁹¹ Id.

2. Monitoring Mechanisms

Efforts to ensure quality of care include licensing, certification, and regulatory requirements for providers and care sites as well as monitoring of care activities.¹⁹² Because service providers in many waiver programs are unskilled, these sites do not have the built-in quality controls that are often found in skilled nursing facilities, ICF/MR's, and other institutional settings.¹⁹³ Much of the monitoring in the HCBS environments is programmatic monitoring, rather than provider monitoring, resulting in what Lutzky and colleagues refer to as a regulatory 'hole' left with regard to unskilled long-term care workers.¹⁹⁴ States typically have relied on traditional monitoring practices such as credential checks and records reviews, on-site inspections, unannounced inspections, and "public" sanctions, which have provided incentives for improvements in guality of care.¹⁹⁵ With community-based care provisions, however, these monitoring mechanisms come at a significant financial cost because care sites are so dispersed. With 240 individual waiver programs,¹⁹⁶ each with a multitude of care sites, on-site monitoring presents significant logistical challenges.

Case management and care management have been another means of monitoring the quality of care provided. When case managers maintain regular contact with clients and service providers, they can provide valuable input to a patient's quality of care. Large caseloads have impeded this monitoring mechanism, as have the lack of unified procedures to address problems that are identified by a case manager.¹⁹⁷

Relying on client input as a means of monitoring quality care has both benefits and drawbacks. Some States have established hotlines or ombudsman programs to address consumer complaints regarding HCBS providers.¹⁹⁸ As Lutzky and col-

¹⁹² *Id.* at 27. ¹⁹³ *Id.*

¹⁹⁴ Id. at 28 (citing PROGRAM EVALUATION AND METHODOLOGY DIV., U.S. GEN. ACCOUNTING OFFICE, GAO/PEMD-94-19, LONG-TERM CARE: STATUS OF QUAL-ITY ASSURANCE AND MEASUREMENT IN HOME AND COMMUNITY-BASED SERVICES tbl.3 (1994); Elanor D. Kinney et al., Quality Improvement in Community-Based, Long-Term Care: Theory and Reality, 20 AM. J.L. & MED. 60, 63 (1994)).

¹⁹⁵ Id.

¹⁹⁶ HCBS, *supra* note 9, ¶ 8.

¹⁹⁷ LUTZKY ET AL., supra note 8, at 28.

¹⁹⁸ Id.

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leagues point out, however, it is important to realize the very real limitations that exist in soliciting client complaints as a means of monitoring program quality. Lutzky warns that "the most vulnerable populations, such as those with cognitive impairments and those who lack adequate informal support, are unlikely to complain through formal channels. Consumers may also be reluctant to file a complaint against a service provider out of fear of losing services that are essential to them."¹⁹⁹

3. Cost Control Mechanisms

HCFA and the individual States have been cautious about the expansion of HCBS waiver programs. In part, this is a result of fears that individuals would 'come out of the woodwork' looking for Medicaid-funded HCBS services.²⁰⁰ State control mechanisms in the HCBS realm include a limit on program appropriations in state budgets, caps on the spending per recipient under a waiver plan, or caps on the number of individuals served under the waiver.²⁰¹ Other mechanisms employed to help control or limit costs include: capitalizing on funds from other sources to make waiver funds go further, case management, prior authorization requirements, nurse delegation (i.e., the employment of non-licensed caregivers to perform certain medical services, thereby making the provision of services less costly, but also potentially compromising quality of care), estate recovery plans, information tracking to monitor costs and recovery claims, and utilizing alternate residential care environments, such as apartment communities, that operate under economy of scale principles.²⁰²

4. Segregation of the MR/DD Population into Classes

Another real concern that arises as the result of the initiation of class action Medicaid litigation to achieve gains for the mentally retarded and developmentally disabled has been the creation of distinct classes or groups represented by particular lawsuits. In bringing the *Boulet* lawsuit—or any similar lawsuit did the plaintiffs and their attorneys simply succeed in creating

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¹⁹⁹ Id. at 29.

²⁰⁰ KULKARNI, *supra* note 28, § I; PERKINS & KULKARNI, *supra* note 30, at 1.

²⁰¹ LUTZKY ET AL., *supra* note 8, at 29-30; *see supra* Part III (discussing examples of caps within the *Boulet* litigation).

²⁰² LUTZKY ET AL., *supra* note 8, at 30-31.

a class that excluded other MR/DD individuals who were also in need of Medicaid-funded health care services?²⁰³ Concerns over evenhandedness, "line jumping," and the creation of a void as a result of class action litigation can be realities.²⁰⁴ Does class action Medicaid litigation ultimately create a vacuum that leaves some vulnerable and deserving populations without services? Does one lawsuit produce the domino effect, forcing subsequent litigation, as that is the only way for distinct populations of MR/DD individuals to find a voice to advocate for their medical needs?²⁰⁵

B. Recommended Approach to Securing Medicaid-Funded Services for the Mentally Retarded/Developmentally Disabled

A recent article discussing the *Olmstead* decision that appeared in the *Journal of Poverty Law and Policy* recommended that before initiating litigation under *Olmstead*, "advocates [should] focus on policy advocacy for remedying unnecessary institutionalization of individuals with disabilities."²⁰⁶ The authors, Ira Burnim and Jennifer Mathis of the Judge David L. Bazelton Center for Mental Health Law in Washington, D.C., based their recommendation on an assessment that "the time is ripe for political activity in this area."²⁰⁷ While their recommendations applied specifically to litigation involving *Olmstead*'s ADA integration mandate, valuable lessons can be drawn from their advice.

Burnim and Mathis advise that advocates should urge States to expand the provision of services in small community residential programs; advocate that States expand HCBS and demonstration waiver programs; and encourage States to maxi-

²⁰³ Telephone conversation with Gail Grossman, Deputy Assistant Commissioner, Massachusetts Department of Mental Retardation (Mar. 2001); see also Ira Burnim & Jennifer Mathis, After Olmstead v. L.C.: Enforcing the Integration Mandate of the Americans with Disabilities Act, 33 CLEARINGHOUSE REV.: J. POVERTY L. & POL'Y 633 (2000) (recommending that advocates should use the Olmstead decision as a policy tool, but also reviewing litigation elements).
²⁰⁴ See Burnim & Mathis supra note 203, at 646 (discussing evenhandedness)

²⁰⁴ See Burnim & Mathis supra note 203, at 646 (discussing evenhandedness in the context of the Olmstead litigation). ²⁰⁵ Plaintiffs' counsel asserts that their "experience in Boulet has been very

²⁰⁵ Plaintiffs' counsel asserts that their "experience in *Boulet* has been very positive—our settlement agreement results in additional funding for services, above and beyond the funding that would have been dedicated to the Department of Mental Retardation." Email from David Friedman, *supra* note 186.

²⁰⁶ Burnim & Mathis *supra* note 203, at 636.

²⁰⁷ Id.

mize the use of federal block grant money, federal housing assistance programs, federal disability benefits under the Supplemental Security Income (SSI) program, state general fund appropriations for mental disability services, and resources created by downsizing existing state-run institutions.²⁰⁸ Similarly, they state that "[a]dvocates should insist on being involved in formulating and implementing any plan for remedying needless institutionalization."²⁰⁹ In securing a plan, these authors recommend that advocates work through coalitions of disability advocates, for the "[a]dvocates' approach to policy advocacy, as well as its success, will depend on advocates' strength and their relationships with the state."²¹⁰ Generally speaking, only after advocacy efforts are exhausted do these authors suggest turning to litigation as a means of obtaining desired outcomes on behalf of the population with MR/DD.

In all cases—either in Olmstead litigation or in other Medicaid litigation meant to secure resources and services for the mentally retarded and developmentally disabled—cooperative participation of advocates, consumers, state officials, and other interested parties is the best approach and almost certainly "the best course . . . will be to wait rather than rush to the courthouse."²¹¹ In the end, "[e]ven if little or nothing comes of the state's efforts, [to cooperatively address the needs of individuals with MR/DD,] advocates will be in a much better position to litigate later" for "[t]hey will have educated themselves through involvement in the state's planning and can avoid the political costs of being perceived as having 'sued first and asked questions later."²¹²

At the same time, however, Burnim and Mathis suggest that advocates should be wary of what they call a State's 'obfuscate and delay' approach, which may result in long timelines and nonexistent state efforts to address the needs of these vulnerable populations.²¹³ While the adage "timing is everything" might be invoked to suggest a cautionary "wait and see" approach, there is also something to be said for "striking while the iron is hot." Use of genuine threats of litigation, or the actual initiation of

²⁰⁸ Id.
²⁰⁹ Id.
²¹⁰ Id.
²¹¹ Id. at 637.
²¹² Id.
²¹³ Id.

litigation itself, are sometimes enough to prompt a State to address the needs of disabled individuals.

The approach in the Boulet case adopted many of the tactics suggested by Burnim and Mathis and was further enhanced by taking special account of some of the more problematic characteristics of HCBS waiver programs. While the district court opinion does not indicate that the suggested "wait and see" approach was adopted, litigation may have been the most effective means of terminating a potential "obfuscate and delay" tactic contemplated by the Commonwealth.²¹⁴ By engaging in litigation, the plaintiffs' attorneys in Boulet addressed what can only be described as a very real problem with the State's waiting list for residential habilitation services. In bringing a class action lawsuit, they succeeded in securing Medicaid-funded outof-home services for more than 2,000 individuals. Using litigation as a tool to effectively produce change, the plaintiffs' attorneys also avoided some of the potential pitfalls of Medicaid lawsuits through the use of creative negotiating and drafting during the settlement phase of the case.

Litigation, in this case, provided the impetus for change. While the relationship between the defendants and the plaintiffs in this case was, at times, tenuous and seemingly adversarial, together, the two parties successfully achieved a sound result in concluding settlement negotiations. By advocating aggressively on behalf of the class, plaintiffs' attorneys were able to secure several key points in settlement. Plaintiffs were able to earmark some \$29 million in base funds toward the provision of residential services on behalf of their clients and were similarly successful in securing an additional \$85 million in new appropriations for use in the same purpose. They secured interim services on behalf of their clients and, with the agreement and cooperation of defense counsel, structured a realistic timeline for the

Boulet v. Cellucci, 107 F. Supp. 2d 61, 67 n.3 (D. Mass. 2000).

²¹⁴ Undeniably, a waiting period of three to ten years is simply too long to expect an individual to wait for necessary services to which they are entitled. It is important to note that at least part of this delay was outside of the control of the Massachusetts Department of Mental Retardation. As Judge Woodlock wrote:

This passage illustrates an irony presented by this lawsuit. In this and other reports, DMR has shown a clear concern for individuals on its waiting list and a desire to address the problem that the list presents. In large part, the waiting list appears to be the result of resource allocation choices outside of DMR's control, and DMR has urged legislative action to correct the situation.

rectification of the waitlist dilemma. Built into the settlement agreement were some monitoring mechanisms (i.e., quarterly reports, biannual meetings, etc.) and an "escape clause" permitting a return to litigation channels if the settlement agreement is not followed.

Other goals, such as the active involvement of clients and families in the creation of sufficient care plans and the fair and competitive pay of providers, could not be achieved through the *Boulet* litigation. Success on these fronts might depend on advocacy efforts and lobbying efforts, regulation of the HCBS setting or legislation to standardize care provision. This combined approach, which has its roots in litigation, but draws significantly upon legislative, regulatory, and advocacy components, will ultimately produce the best result in the current Medicaid litigation environment.

POST SCRIPT

On November 21, 2001, almost five months after its July 1, 2001 due date, the Massachusetts legislature passed its fiscal year 2002 budget of \$22.6 billion, which resulted in cuts of \$650 million.²¹⁵ These drastic cuts, an attempt to help meet a \$1.4 billion budget deficit,²¹⁶ were dubbed the 'Thanksgiving massacre' by several lobbyists and advocacy groups who rallied to reverse the budget cuts.²¹⁷

Among the hardest hit by the budget cuts was the Department of Mental Retardation, which suffered deletion of \$22 million worth of annualized funding²¹⁸ mandated under the Boulet settlement agreement. Gerald Morrissey, Commissioner of the Department of Mental Retardation assessed the bleak situation following the elimination of settlement funds:

The Department has already committed approximately \$9.8 million of this appropriation to cover approximately one-third of the new placements as well as all of the interim family support services, and does not have \$9.8 million elsewhere in the budget. Eighty-four individuals who have already been placed in FY02 would likely have the residential services provided under the agreement taken away, requiring them in most instances to return home.²¹⁹

Addressing the elimination of settlement funds, Leo V. Sarkissian, Executive Director of the Association of Retarded Citizens of Massachusetts simply said, '[t]here's no way to make this painless. Reversal must be pursued.'220 Plaintiffs' attorney Neil McKittrick promised a return to litigation if funding was not restored: "'To say the least, it's a little frustrating'....

²¹⁵ Rick Klein, Deal Would Restore Some Budget Cuts, BOSTON GLOBE, Dec. 13, 2001, at B4 [hereinafter Budget Cuts].

²¹⁶ Rick Klein, Lawmakers OK \$22.6B Budget at the Wire, BOSTON GLOBE, Nov. 22, 2001, at A1 [hereinafter Budget at the Wire].

²¹⁷ Rick Klein, Advocates Looking to Neutralize 'Massacre' Groups Rally to Restore Elderly, DMR Funding, BOSTON GLOBE, Nov. 24, 2001, at B1 [hereinafter DMR Funding].

²¹⁸ Eileen McNamara, Defenseless to Fight Back, BOSTON GLOBE, Nov. 28, 2001, at B1. ²¹⁹ Id.

²²⁰ DMR Funding, supra note 217.

'If the money's not there, there will be no services. If the services aren't provided, we're going to end up back in court."221

In an attempt to obtain a reversal of the budget cuts other than through litigation, Sarkissian and plaintiffs' attorneys organized a demonstration to protest the multi-million dollar budget cuts effecting the Department of Mental Retardation.²²² After a week's worth of intensive pressure from advocacy groups, legislative leaders decided on December 13, 2001 that they would restore funding to a variety of programs, including the Department of Mental Retardation,²²³ by passing an \$85 million supplemental budget.²²⁴ While the supplemental budget does help to meet the needs of hundred of MR/DD individuals by restoring the \$22 million in annualized funding promised in the Boulet settlement, countless other individuals are less fortunate. ""[The supplemental budget] makes some modest restorations to the most egregious cuts, but we are still just putting Band-Aids on deep and open wounds,' said Stephen E. Collins, Executive Director of the Massachusetts Human Services Coalition."225

The fact that the proposed House and Senate budget allocated no money to satisfy the Boulet settlement raises interesting issues that are beyond the scope of this Note, but merit brief mention. What happens when a court-mandated settlement agreement is ignored? What is the relief available? The Boulet plaintiffs rallied, organizing themselves, demonstrated, and effectively used the press to champion their cause. But what if their efforts had been ineffective? Plaintiffs' attorneys were successful at exerting political pressure, calling on state representatives to enact a change and enforce the settlement mandated by the courts. And, if they were unsuccessful at enacting change through non-litigation channels, plaintiffs' counsel was prepared to go back to court to secure adequate Medicaid services to which their clients were entitled.

²²¹ Budget at the Wire, supra note 216.

²²² DMR Funding, supra note 217.

²²³ The proposed \$85 million supplemental budget included allocations for adult education (\$12.5 million), AIDS (\$2.5 million), the Department of Mental Health (\$16.6 million), the Department of Mental Retardation (\$33.3 million, including \$15 million of the \$22 million mandated under the Boulet settlement), and the Department of Correction (\$14 million). Budget Cuts, supra note 215.

²²⁴ See id. ²²⁵ Id.

One lesson—unfortunate, but true—that the *Boulet* plaintiffs learned as a result of the Massachusetts budget debacle is that even when all obstacles have seemingly been surmounted and the case has been won, there is still the danger that the legislature will ignore—and thereby invalidate—the ruling of the courts. The road ahead for the *Boulet* plaintiffs and their counsel seems long. In addition to monitoring the implementation of the settlement, they must remain alert and ever-ready to return to court to secure the rights to which they and other MR/DD individuals in the Commonwealth are entitled, for it seems that only through vigilance will their rights be upheld.