UNITED STATES DISTRICT COURT
FOR THE EASTERN DISTRICT OF NORTH CAROLINA
WESTERN DIVISION
Case No.: 5:11-cv-273-BO

HENRY PASHBY, *et al*, individually and on behalf of all others similarly situated, Plaintiffs v. LANIER CANSLER, Secretary, North Carolina Department of Health and Human Services, in his official capacity, Defendant.	**PLAINTIFFS' REPLY BRIEF IN SUPPORT OF MOTION FOR PRELIMINARY INJUNCTION**

Plaintiffs have filed Motions for Preliminary Injunction and Class Certification and, on July 11, 2011, filed an Amended Complaint adding two additional named plaintiffs. Plaintiffs file this Reply to respond to new issues and evidence raised by Defendant's Response and to provide information to the Court about the new plaintiffs. Contrary to Defendant's assertions, Plaintiffs do not seek to dismantle an established program, but only to preserve the status quo, and ask the Court to order Defendant to continue to cover medically necessary personal care services (PCS) for which federal reimbursement is available.[1]

I. THREE NAMED PLAINTIFFS AND HUNDREDS OF OTHERS CONTINUE TO BE THREATENED WITH IRREPABABLE HARM.

Pursuant to the policy challenged in this suit, 2,405 elderly, blind, or disabled North Carolina citizens have been notified that their PCS will be terminated. Def. Resp. at 7. Eleven named plaintiffs have had their PCS reinstated since this suit was filed,[2] but preliminary relief

[1] Plaintiffs filed their motion before ICHA Policy 3E took effect. Thus, contrary to Defendant's assertions, the injunction would not be mandatory because "the status quo has been consistently defined as the last uncontroverted status preceding the pending litigation." *Fed. Leasing, Inc. v. Underwriters at Lloyd's,* 487 F. Supp. 1248, 1259 (D. Md. 1980), *aff'd* 650 F.2d 495.

[2] Defendant has reversed his decisions to terminate PCS for eleven named plaintiffs in a thinly disguised effort to moot out their claims. Each of those plaintiffs remains threatened, however, with termination of their PCS the next time they are reassessed under Defendant's new policy.

continues to be needed for Named Plaintiffs Robert Jones, Rebecca Pettigrew, and Ayleah Phillips, all of whom have lost or are threatened with the loss of essential PCS. *See* Decls. of Phillips, Pettigrew, Ruth Percer, Joseph Percer, Melton. In addition, hundreds of unnamed class members need immediate relief. Defendant concedes this Court may grant preliminary relief to those persons without first certifying a class if class relief is warranted. Def. Resp. at 15.

The availability of administrative hearings does not remove the irreparable harm. According to Defendant, 1,322 of the 2,405 persons terminated from PCS effective June 1, 2011 did not file an administrative appeal. Def. Resp. at 7. Plaintiffs' evidence shows that those 1,322 persons are at substantial risk each day they remain without PCS and therefore need immediate preliminary relief reinstating their PCS. *See* Decls. of Smith, Webb, Annarino. And, though they continue to receive PCS pending the outcome of their administrative appeals, the 1,083 class members who did file administrative appeals also need preliminary relief. Medicaid services continue only through a final administrative appeal decision, which will be ultimately made *by Defendant*. N.C.G.S. §§ 108A-70.9A(f).[3] Though Defendant claims that 78% of Medicaid administrative appeals are resolved at mediation, he does not say *how* they are resolved. Def. Resp. at 8. For example, Plaintiff Robert Jones dismissed his appeal after Defendant's representatives stated at mediation that he could not win his appeal if he did not meet the new clinical policy and that ICHA could not be given to persons with mental impairments. Decl. of Faye Lewis. Given Defendant's clearly stated position that his policy is legal and his authority to decide all administrative appeals, there is no reason to believe that any class member can successfully challenge ICHA Clinical Policy 3E in an administrative appeal.

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[3] The N.C. Office of Adminstrative Hearings has issued a stay of all administrative appeals by Plaintiff class members pending a decision by this Court on the preliminary injunction.

Defendant nonetheless argues that this case is not ripe until Plaintiffs lose administrative appeals and PCS is then terminated. Def. Resp. at 12, 18. This argument fails for three reasons. First, administrative remedies need not be exhausted prior to seeking relief under 42 U.S.C. §1983. *Patsy v. Bd. of Regents*, 457 U.S. 496 (1982); *McCartney v. Cansler*, 608 F.Supp.2d 694 (E.D.N.C. 2009). Second, Plaintiff Jones and hundreds of others have no pending appeal so are currently being harmed. Third, this argument contradicts Defendant's assertion that Plaintiffs should have filed their lawsuit sooner. Def. Resp. at 1-2. In fact, Plaintiffs filed suit neither too soon nor too late, after notices of termination were sent but before those notices took effect.

Defendant has not rebutted Plaintiffs' evidence that the 2,405 persons terminated from PCS are threatened with irreparable harm because they will have to choose between risking their health and safety or being institutionalized in an ACH. See, Decls. of Smith at ¶¶33-37, Webb at ¶¶16-18 (listing risks to Plaintiff class including failure to take medications, isolation without ability to obtain necessities, and injury or illness resulting in hospitalization). Defendant also ignores the numerous cases cited by Plaintiffs holding that loss of Medicaid services constitutes irreparable harm. Pla. Memo at 15. Instead, Defendant attacks Plaintiffs' declarants as not disinterested even though the same is true of each affiant for Defendant, who all work for Defendant. Defendant even cynically suggests that because Plaintiffs have managed to remain in their homes with part-time PCS, they must be able to remain at home with no help at all. Def. Resp. at 14. This ignores Plaintiffs' evidence showing how critical part-time PCS is for its recipients and that many PCS recipients get some help from family members when PCS workers are not there. *See* Decls. of Smith, Webb, J. Percer, R. Percer, Melton, Pettigrew, Phillips.

Defendant correctly states that the in-home PCS program is for those whose needs can be met at home but this means their needs can be met *with* PCS, not *without* it. Feasal Aff. ¶8.

Similarly, Defendant argues that in-home PCS is for persons who are "medically stable" and do not require "continuous monitoring by a licensed nurse." Feasal Aff. ¶8. But this proves nothing because the same is true of those institutionalized in ACHs, all of whom receive PCS . N.C.G.S. §131D-2.2(a)(2). Dr. Feasal, Dr. Best, and Ms. Botto all state that those being terminated from in-home PCS will be able to qualify for in-home PCS again as soon as their health deteriorates. Feasal Aff. ¶ 24; Best Aff. ¶25; Botto Aff. ¶7. But this amounts to a concession that the plaintiff class is threatened with deterioration of their health unless they go into an ACH. Defendant also suggests that PCS providers can request a new assessment as soon as a class member's condition worsens. Feasal Aff. ¶26; Botto Aff. ¶10; Best Aff. ¶7. But without relief from this Court, Plaintiff class members *will have no PCS providers* to monitor their conditions unless they go into an ACH institution. Dr. Best disputes the importance of meal preparation, housekeeping and other home management tasks in allowing PCS recipients to remain in their homes, but is contradicted by Ms. Botto. *Compare* Botto Aff. ¶ ¶8, 9 with Best Aff. ¶¶19, 20, 22, 23. Ms. Botto suggests that plaintiffs can receive adult day care as a Medicaid- reimbursed service, Botto Aff. ¶14, but in fact Defendant does not cover that service for the Plaintiff class. *See* N.C. Medicaid Clinical Policies 3A-3J, *available at* www.ncdhhs.gov/dma/mp/index.htm.[4]

II. PLAINTIFFS ARE LIKELY TO PREVAIL ON THE MERITS.

Defendant fails to refute the three central facts proven by Plaintiffs: (1) Defendant provides PCS in two different settings under two different sets of rules-- restrictive rules

[4] Dr. Best also repeatedly claims that the risk of harm from mental impairments is immaterial because PCS aides cannot assist with that diagnosis. Best Aff. ¶¶ 9, 10, 11, 14, 16. If so, Dr. Best needs to explain to the Court why Plaintiffs Jones, Hutter, Ford, and Moore were initially approved by Defendant for in-home PCS for their mental impairments, why Defendant has reversed its PCS terminations for all but one of those Plaintiffs, and why Defendant routinely approves PCS for residents of ACH's with only mental impairments. *See* Pollitt Aff. Exh A.

governing coverage of PCS in the home but much more liberal rules for covering PCS in large, institutional ACHs; (2) ACHs are institutional in nature; and (3) Defendant's own study demonstrates that the needs of those receiving PCS in ACHs are no greater than the needs of those whose in-home PCS is being terminated. Barat Aff. Exh. I. Defendant's failure to dispute these three critical facts shows that Plaintiffs are likely to succeed on the merits.

A. Plaintiffs are Likely to Prevail on their Comparability Claim.

Defendant never directly denies that his policies for the provision of PCS at home and in ACHs are not comparable and thus violate the federal Medicaid Act. Instead, Defendant relies almost entirely upon CMS's approval of his state plan amendment (SPA), but fails to rebut the reasons in Plaintiffs' brief why the Court should not defer to the CMS approval.

First, no deference is due because CMS did not approve what Defendant has done. The SPA imposes new limits on PCS provided in the home *and* in ACHs. But, Defendant does not dispute he has made none of the changes to the criteria for obtaining PCS in an ACH that CMS required, nor does he claim that CMS is aware of his failure to do so. Thus, *Ark. Dep't of Human Servs. v. Ahlborn,* 547 U.S. 268 (2006) is directly on point because, like here, the policy approved by the federal agency was not the same as the challenged policy. *See also Neb. Pharm. Ass'n, Inc. v. Neb. Dep't of Social Services*, 863 F. Supp. 1037 (D. Neb. 1994) (no deference to CMS approval of Medicaid state plan because it did not describe specific practice at issue).

Second, to the extent CMS did approve different standards for PCS in the two settings, this approval is inconsistent with the repeatedly-stated position of CMS over the last four years that Defendant's differing PCS coverage policies violate comparability. *See* Pla. Memo at 18, 19. Indeed, Defendant concedes CMS has recently instructed him to correct the continuing comparability violation with a new SPA to replace the one Defendant relies upon and to make

the requirements for PCS the same in all settings. Larson Aff. ¶12. If the court is to defer to CMS's interpretation of the statute, it must consider all CMS statements on the subject.

Third, Defendant has misstated the law, incorrectly claiming that the SPA approval by CMS should receive *Chevron* deference. Def. Resp. at 25. Unlike published regulations, subregulatory decisions such as the state plan approval here receive only "some deference." *U.S. v. Mead Corporation* 533 U.S. 218, 234 (2001). The Supreme Court has since cited *Mead* in a Medicaid case to give only "respectful consideration" to a *consistent* agency interpretation contained in a State Medicaid Letter and proposed regulation. *Blumer v. Wisconsin Dep't of Health and Social Services*, 122 U.S. 962 (2001). *See also Rehab. Assn. v. Kozlowski*, 42 F.3d 1444 (4th Cir. 1994). Defendant also claims it gave no incorrect information to CMS but never explains the misstatements it made to CMS about the needs of the two populations. *See* Pl. Memo at 18-19. And, while it is true that Plaintiffs' attorneys sent a letter to CMS describing the comparability violation in October 2010, that letter could not correct all of Defendant's misstatements, which included ongoing communications through the present. Def. Resp. at 9.

B. Plaintiffs Are Likely to Succeed on the Merits on their ADA/504 Claim.

Contrary to Defendant's assertions, Plaintiffs meet the definition of "qualified individuals with disabilities" because they, "with or without reasonable accommodations to rules, policies, or practices, . . . meet[ ] the essential eligibility requirements for receipt of services or participation in programs or activities provided by a public entity." *See* 42 U.S.C. § 12131(2); *see also Townsend v. Quasim,* 328 F.3d 511, 516 (9th Cir. 2003) (holding plaintiffs are qualified individuals with disabilities because they meet the eligibility requirements for the relevant Medicaid programs). It is undisputed that Plaintiffs are eligible for Medicaid. Moreover,

Defendant's agent, CCME, has already determined that Plaintiffs were qualified for the amount of PCS that they were receiving prior to the cuts. Pla. Memo at 4-5.

Plaintiffs have also shown that they are at imminent risk of institutionalization. Numerous courts have held that individuals need not actually submit to institutionalization in order to show a violation of the ADA's integration mandate. *See* Pla. Memo at 22, fn. 6 . And, Plaintiffs have shown that, without coverage of PCS, they will not be able to safely remain in their homes. *See* Decls. of Smith, Webb, J. Pender, R. Pender, Melton, Phillips. Plaintiffs risk not only stays in hospitals or nursing homes but more likely the untenable choice of risking injury and deterioration without PCS at home or, in order to get the PCS that they need, moving into institutional ACHs. *See* Pla. Memo at 13-14, Decls. of Smith, Webb, Annarino. Named Plaintiffs and hundreds of class members meet the qualifications for PCS in ACHs, but no longer meet them for In-Home PCS. Defendant does not dispute Plaintiffs' characterization of ACHs as institutions, nor could he. As Plaintiffs have shown, ACHs are large institutions with an average of 60.6 beds in each facility, have regimented routines, restrict visitors, look and feel like institutions, and are often isolated from the rest of the community.[5] Pla. Memo at 8-9.

C. The Relief Requested Would Not Be a Fundamental Alteration.

[5] Defendant cites an ADA regulation which he claims does not require public entities to provide services of a personal nature as a reasonable accommodation. Def. Resp. at 22. The U.S. Department of Justice has, however, made it clear that this regulation does not apply where a program already provides personal services. U.S. Dep't of Justice, ADA Title II Technical Assistance Manual, § II-3.6200, http://www.ada.gov/taman2.html#I-1.200 ("Of course, if personal services or devices are customarily provided to the individuals served by a public entity, such as a hospital or nursing home, then these personal services should also be provided to individuals with disabilities"). Other courts have required coverage of Medicaid personal care under the ADA. *Haddad v. Arnold,* No. 3:10-cv-414-J-99-MMH-TEM, 2010 WL 6650335 (M.D. Fla. July 9, 2010); *V.L. v. Wagner,* 669 F. Supp. 2d 1106 (N.D. Cal. 2009) (on appeal).

The burden is upon Defendant to show that the accommodation Plaintiffs request would be a fundamental alteration. Defendant's conclusory and unsupported assertions fall short of meeting this burden. The sole evidentiary support is Tara Larson's unexplained assertion that any significant change to the PCS policy will fundamentally alter the state's plan to establish the 1915(i) option. Def. Resp. at 16. Larson Decl. ¶ 14. In fact, nothing in the relief requested would prevent Defendant from pursuing a 1915(i) SPA. Ms. Larson also claims that the relief sought would cause the State to lose federal financial participation. Larson Decl. ¶ 15. This is simply not true; federal regulations provide that federal funds are available to pay "for services provided within the scope of the *Federal* Medicaid program and made under a court order." 42 C.F.R. § 431.250(b)(2) (emphasis added).

All accommodations involve modifications to programs. The only alterations that are considered fundamental are those that would be "inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with . . . disabilities." *Olmstead,* 527 U.S. at 603-604. Defendant's assertion that the state will be unable to pay for services for others with disabilities is completely unsupported. Def. Memo at 17. "[S]tates cannot sustain a fundamental alteration defense solely on the conclusory invocation of vaguely-defined fiscal constraints." *Frederick L. v. Dep't of Public Welf.*, 364 F.3d 487, 496 (3d Cir. 2005).[6]

D. Plaintiffs' Due Process Claims are Likely to Succeed.

[6] Defendants contend that Plaintiffs cannot enforce the Medicaid "reasonable standards provision. The court need not reach this issue, because Plaintiffs have shown a strong likelihood of success on their other claims. *See generally Multi-Channel TV Cable Co. v. Charlottesvillle Quality Cable Operating Co.,* 22 F.3d 546, 553 n. 5 (4th Cir. 1994) But, Defendants are incorrect because this provision is enforceable through the Supremacy Clause, which is how Plaintiffs have pleaded their claim. *Lankford v. Sherman,* 451 F.3d 496, 510 (8th Cir. 2006); Complaint, ¶194.

Defendant does not discuss any of the due process cases cited in Plaintiffs' brief and cites no case approving a boilerplate notice of the sort at issue here. In *Goldberg v. Kelly*, the Supreme Court held that due process requires notice "*detailing* the reasons for a proposed termination." 397 U.S. at 267-68 (emphasis added). Indeed, in *Baker v. State*, 191 P.3d 1005 (Alaska 2008), the court rejected notices on facts very similar to this case because they did not contain factual information about the individual Medicaid PCS recipient. Defendant suggests his notice must have been adequate because about half of class members filed an appeal. Def. Resp. at 7. But this is of little comfort to the half who did not appeal. Nor did the notice give those who did appeal adequate information to prepare for their hearing.

Defendant also asserts that his confusing technical notice is adequate because no plaintiff alleged mental limitations, Def. Resp. at 30, but this is not correct. *See* e.g. Decls. Of Gabijan (dementia and traumatic brain injury); Hutter (borderline personality disorder); L. Moore (bipolar disorder); J. Percer, R. Percer, Melton (Plaintiff Jones has mental retardation and schizophrenia). Finally, Defendant says that on June 1, 2011 he posted, on the website listed in the notice, the clinical policy containing the legal authority for his decision. Feasel Aff. ¶25. But this ignores that those receiving the notice had to decide whether to appeal before June 1 in order to receive uninterrupted benefits. *See* Plaskie Aff. Exh. A at 2.[7]

III. THE BALANCE OF EQUITIES AND PUBLIC INTEREST FAVOR PLAINTIFFS.

[7] Defendant asserts incorrectly that the PCS termination notices mailed to Plaintiffs complied with a settlement in another class action. That agreement required that notices include a "reasonable explanation" for Defendant's decision and "a citation to the appropriate clinical coverage policy for the service requested and the correct webpage where that policy may be found ." *DTM v. Cansler*, Civ. No. 7:08-CV-57-H (E.D.N.C.) Settlement Agreement, Exh. B at VIII. Also, that settlement did not address the requirements for notices in PCS cases. *Id.* at p. 3.

As noted above, Defendant will not lose federal funds if the court grants the requested relief. Defendant's lengthy discussion of fraud in the PCS program, the need for independent assessments, and of previous litigation by PCS providers are all irrelevant. Plaintiffs do not challenge independent assessments or any other efforts to combat fraud. Rather, Plaintiffs object to the *lack* of such protections for the provision of PCS in ACHs. Moreover, Defendant fails to rebut Plaintiffs' evidence that in-home services reduce Medicaid spending *and* prevent institutionalization. Though Dr. Feasal lists minor differences between PCS in N.C. and the study provided by Plaintiffs, she does not explain why those differences are significant and cites no evidence to the contrary. *See also* Kaye, LaPlante, Harrington, *Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending* (Jan/Feb 2009)(attached). Defendant also argues that cases cited by Plaintiff on the balancing of equities have been overruled. This is incorrect. The Fourth Circuit held that under the Supreme Court's decision in *Winter v. Nat. Res. Defense Council*, the *Blackwelder* overall balance of hardships test may no longer be used, but *Winter* did not abolish the balancing of equities as one of four factors. *Real Truth About Obama v. F.E.C.*, 575 F.3d 342, 346 (4th Cir. 2009). The cases cited in Plaintiffs' brief relate to the balance of equities factor, not to the use of the *Blackwelder* standard. *See* Pla. Memo at 28.

CONCLUSION

For all the foregoing reasons and those stated in Plaintiff's initial brief and evidence, Plaintiffs renew their request that this Court issue a preliminary injunction prohibiting Defendant from implementing IHCA Policy 3E.

Dated: July 11, 2011 Respectfully Submitted,

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CERTIFICATE OF SERVICE

This is to certify that I have served a copy of the foregoing PLAINTIFFS' REPLY TO IN SUPPORT OF MOTION FOR PRELIMINARY INJUNCTION, DECLARATION OF FAYE B. LEWIS, DECLARATION OF RUTH DENISE PERCER, DECLARATION OF JOSEPH PERCER, DECLARATION OF VERNESTINE MELTON, and DECLARATION OF REBECCA PETTIGREW upon the attorneys for the Defendant in this matter by electronically filing same with the Clerk of Court using the CM/ECF system.

This the 11th day of July, 2011.

/s/Douglas Stuart Sea
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Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?

Home and community-based services help people with disabilities stay in their homes while reducing long-term care spending.

by H. Stephen Kaye, Mitchell P. LaPlante, and Charlene Harrington

ABSTRACT: Medicaid spending on home and community-based services (HCBS) has grown dramatically in recent years, but little is known about what effect these alternatives to institutional services have on overall long-term care costs. An analysis of state spending data from 1995 to 2005 shows that for two distinct population groups receiving long-term care services, spending growth was greater for states offering limited noninstitutional services than for states with large, well-established noninstitutional programs. Expansion of HCBS appears to entail a short-term increase in spending, followed by a reduction in institutional spending and long-term cost savings. [*Health Affairs* 28, no. 1 (2009): 262–272; 10.1377/hlthaff.28.1.262]

ENACTED IN 1965 TO PROVIDE HEALTH COVERAGE for impoverished Americans, the Medicaid program quickly became a major source of payment for long-term care (LTC) services for elderly and nonelderly people with disabilities. During the program's first two decades, these services were offered almost exclusively in institutional settings, such as nursing homes and facilities for people with intellectual disabilities. In the mid-1980s, however, states began to offer LTC services to people living outside of institutions, through what are known as Home and Community-Based Services Waiver programs and Personal Care Services (PCS) Optional Benefit programs. These two programs, plus the smaller Medicaid Home Health Benefit, are collectively referred to as Medicaid home and community-based services (HCBS); all such programs may offer personal assistance that enables people who need help in performing daily activities to continue to live and thrive in the community, instead of being forced to relinquish their independence and move into an institution.

Pressured by advocates for people with disabilities and the elderly, and com-

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pelled by the Supreme Court's 1999 *Olmstead* decision to offer services in "the most integrated setting" appropriate to the person's needs, many states have created or expanded HCBS programs, offering an alternative to institutionalization for millions of poor or near-poor Americans.[1] As a result, HCBS spending has constituted a steadily increasing share of Medicaid LTC costs, rising at a much more rapid rate than spending on institutional services.[2] The estimated $35.2 billion spent on HCBS in 2005 amounts to 37.2 percent of the $94.5 billion national Medicaid LTC expenditure, or 11.7 percent of the $300.3 billion total Medicaid expenditure.[3] A decade earlier, HCBS spending accounted for only 19.2 percent of Medicaid LTC spending and 6.3 percent of all Medicaid spending.[4]

Although states still spend much more on institutional than noninstitutional LTC, the expansion of HCBS programs has nonetheless been blamed for the overall growth in LTC spending. Opponents of further expansion in HCBS have recently used the continued growth in overall LTC spending to argue that noninstitutional LTC services are not cost-effective, in the sense that they increase rather than reduce overall expenditures.[5]

This paper explores the question of whether states that offer extensive HCBS programs experience greater or lesser growth in Medicaid LTC spending than states in which institutional LTC continues to predominate. We are aware of no similar analyses, although one study compared LTC spending in three states that were offering extensive HCBS with projections of spending in the absence of such programs, and concluded that those states had greatly reduced their spending.[6]

The main issue is not the cost of services per person served. A recent study found that the average total public expenditure on a recipient of HCBS waiver services (who must meet the eligibility criteria for institutionalization) was about $44,000 less per year than for a person receiving institutional services.[7] Indeed, waiver programs are required to demonstrate cost-neutrality, in that the per participant spending under the waiver cannot exceed the state's estimate of the costs for the same people had they entered institutions.

Instead, the concern is with the aggregate cost, which may grow if increasing numbers of eligible people are served. There is a fear that the introduction of HCBS programs would create a "woodwork effect," in which large numbers of people who previously received help from family members and did not seek institutional services might sign up for the more desirable noninstitutional services, thus increasing the overall costs. The impact of HCBS programs on aggregate Medicaid spending has been studied in several demonstration projects, but results have been inconclusive.[8]

Data Sources And Methods

■ **Sources.** State data on Medicaid LTC spending for fiscal years 1995–2005 were obtained from reports submitted by state Medicaid agencies to the Centers for Medicare and Medicaid Services (CMS). States report both institutional spending,

for services provided in either nursing homes or so-called intermediate care facilities for people with mental retardation (ICF/MR), and noninstitutional spending, for services provided through waiver, personal care, and home health programs. Data on nursing home, ICF/MR, personal care, and home health spending were obtained from CMS 64 reports, as compiled annually by the Medstat Group.[9] Data on HCBS waiver spending, by type of waiver, were obtained from CMS 64 reports on individual waiver programs, occasionally corrected with data obtained from CMS 372 reports.[10]

Because spending patterns, including the proportion devoted to HCBS, differ markedly according to the targeted population, we analyzed spending explicitly directed toward people with mental retardation and other developmental disabilities (MR/DD) separately from those primarily directed toward people with other types of disabilities. ICF/MR spending and MR/DD waiver spending are classified as MR/DD spending, while nursing home, non-MR/DD waiver, personal care, and home health spending is classified as non-MR/DD spending.

■ **Data limitations.** Limitations in these data include occasional incomplete or inaccurate reporting and expenditures reported according to the date of payment rather than the date of service provision, causing year-to-year fluctuations when states delay payment and shift expenditures to the next fiscal year. Furthermore, a limited amount of spending on services provided under capitated managed care programs is not reported; this limitation is mostly an issue for Arizona, which we excluded from the analysis because the bulk of its expenditures are not listed. A few states (most notably Texas) have or had relatively small "frail elderly" programs distinct from the noninstitutional services already mentioned; because data for these programs are available from the Medstat compilations for some years but not others, we omitted these programs from the analysis, too.

In a few cases of missing or incomplete waiver data for particular waivers or states, we interpolated or extrapolated to estimate expenditures. In one case of a suspiciously large expenditure followed by a negative reported expenditure in the subsequent year, we replaced both numbers with their average.

■ **Facilitating comparisons.** To facilitate comparison across states, we obtained per capita (not per recipient) expenditures for each state by dividing the reported spending by the Census Bureau's population estimate for the state for the given year.[11] To further facilitate comparison across years, we adjusted the per capita spending for inflation in medical care costs, using the Consumer Price Index (CPI) for medical care services; amounts shown are in 1995 medical care dollars.[12]

■ **Classification process.** We then classified states according to their level and pattern of HCBS spending. First, we divided the states into two groups according to the proportion of their total 2005 LTC spending devoted to HCBS. States that spent less than the median proportion on HCBS were classified as low-HCBS states; the remaining states were classified as high-HCBS states. The latter were further divided into two categories according to whether their HCBS spending remained rela-

tively stable or increased markedly during the decade of interest: states whose per capita, inflation-adjusted HCBS spending more than doubled during 1995–2005 were classified as expanding-HCBS states; the remaining states, as established-HCBS states. States that were pioneers in offering extensive noninstitutional services fell into this latter group.

The classification process was done twice, once for non-MR/DD spending and once for MR/DD spending. Thus, two separate groupings of states were obtained (Exhibit 1).

Study Findings

■ **Non-MR/DD spending.** The high- and low-HCBS states (as differentiated according to their 2005 expenditures) differed markedly in the types and amounts of spending on the non-MR/DD population (Exhibit 1). Low-HCBS states spent only about $14 per capita on HCBS in 1995, compared to more than $24 for the high-HCBS states. Both groups of states increased their HCBS spending over the decade much faster than the rate of inflation, with the low-HCBS states increasing by 56.7 percent and the high-HCBS states growing still faster, by 110.0 percent.

HCBS spending data reveal vastly different rates of growth for the established- and expanding-HCBS states (Exhibit 2). Established states increased their HCBS spending relatively modestly during the period (21.2 percent), while expanding states increased their spending by 276.2 percent. Especially rapid HCBS growth is apparent among the expanding states during 2000–2005, mostly because of program growth but also because California shifted a state-only program to a Medicaid personal care plan in 2001.

Nursing home spending grew by 3.4 percent in the low-HCBS states over the period, after adjusting for inflation, but declined by 15.3 percent in the high-HCBS states (Exhibit 3). A pattern of substantial growth is apparent in the low-HCBS states between 1997 and 2002 (followed by a sharp one-year decline, which we hypothesize is attributable to state budget shortfalls), and a steady decline is apparent for the high-HCBS states beginning in 2002.

Total LTC spending on the non-MR/DD population grew by similar amounts in the low- and high-HCBS states (Exhibit 4). But when we compared established and expanding HCBS states, we found that LTC spending actually declined by 7.9 percent in the established-HCBS states, but increased markedly in the expanding-HCBS states (24.2 percent). Spending increased greatly in both the low- and expanding-HCBS states during 1997–2002, when the established-HCBS states were able to hold their LTC spending relatively constant. The established-HCBS states also experienced a large decline in spending between 2003 and 2005, which is not seen in the data from the other states.

■ **MR/DD spending.** Also shown in Exhibit 1 is HCBS and institutional spending targeted to the MR/DD population. The practice of deinstitutionalizing this population, or avoiding institutionalization entirely, is much better established than

EXHIBIT 1
Mean Per Capita, Inflation-Adjusted Medicaid Long-Term Care (LTC) Spending In States With High And Low Home And Community-Based Services (HCBS), By Type Of Expenditure, And Percentage Change, Fiscal Years 1995 And 2005

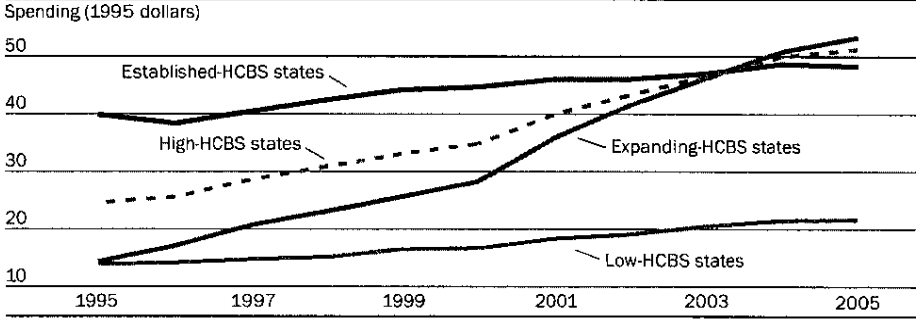
Non-MR/DD spending	Low-HCBS states[a]	High-HCBS states		
		All	Established[b]	Expanding[c]
HCBS spending				
FY 1995	$13.69	$24.35	$39.67	$14.12
FY 2005 (1995 $)	$21.46	$51.10	$48.09	$53.12
Change	56.7%	110.0%	21.2%	276.3%
Institutional spending (nursing homes)				
FY 1995	$122.64	$110.83	$138.54	$92.35
FY 2005 (1995 $)	$126.85	$93.88	$116.03	$79.12
Change	3.4%	−15.3%	−16.3%	−14.3%
Total LTC spending				
FY 1995	$136.34	$135.17	$178.21	$106.47
FY 2005 (1995 $)	$148.31	$144.99	$164.12	$132.24
Change	8.8%	7.3%	−7.9%	24.2%
HCBS proportion of total				
FY 1995	10.0%	18.0%	22.3%	13.3%
FY 2005	14.5	35.2	29.3	40.2

MR/DD spending	Low-HCBS states[d]	High-HCBS states		
		All	Established[e]	Expanding[f]
HCBS spending (MR/DD waivers)				
FY 1995	$14.21	$28.89	$47.82	$18.24
FY 2005 (1995 $)	$36.31	$59.49	$71.04	$52.99
Change	155.6%	105.9%	48.6%	190.4%
Institutional spending (ICF/MR)				
FY 1995	$42.44	$24.81	$26.73	$23.72
FY 2005 (1995 $)	$36.33	$11.93	$10.30	$12.86
Change	−14.4%	−51.9%	−61.5%	−45.8%
Total LTC spending				
FY 1995	$56.65	$53.70	$74.55	$41.97
FY 2005 (1995 $)	$72.64	$71.42	$81.34	$65.84
Change	28.2%	33.0%	9.1%	56.9%
HCBS proportion of total				
FY 1995	25.1%	53.8%	64.1%	43.5%
FY 2005	50.0	83.3	87.3	80.5

SOURCE: Authors' calculations based on data from Centers for Medicare and Medicaid Services 64 and 372 reports.
NOTES: MR/DD is mental retardation/developmental disability. ICF/MR is intermediate care facility for mental retardation.
[a] AL, CT, DE, FL, GA, HI, IN, IA, KY, LA, MD, MI, MS, NE, NH, NJ, ND, OH, PA, RI, SC, SD, TN, UT.
[b] AR, CO, ME, MA, MT, NY, OR, VA, WV, WI.
[c] AK, CA, ID, IL, KS, MN, MO, NV, NM, NC, OK, TX, VT, WA, WY.
[d] AK, CA, CT, ID, IL, IN, IA, KY, LA, MI, MO, NV, NJ, NY, NC, ND, OH, OK, PA, SC, TN, TX, UT, VA.
[e] CO, MA, NH, OR, RI, SD, VT, WA, WY.
[f] AL, AK, DE, FL, GA, HI, KS, ME, MD, MI, MN, MT, NE, NM, WV, WI.

for people with other types of disabilities, and even the low-HCBS states devoted, on average, half of their 2005 MR/DD LTC spending to noninstitutional services. Both the low- and high-HCBS states more than doubled their HCBS spending over the period; this spending nearly tripled among the expanding-HCBS states. Institu-

EXHIBIT 2
Mean Per Capita, Inflation-Adjusted Spending On Home And Community-Based Services (HCBS), Excluding Mental Retardation/Developmental Disability (MR/DD) Programs, In States With Low And High HCBS, Fiscal Years 1995–2005

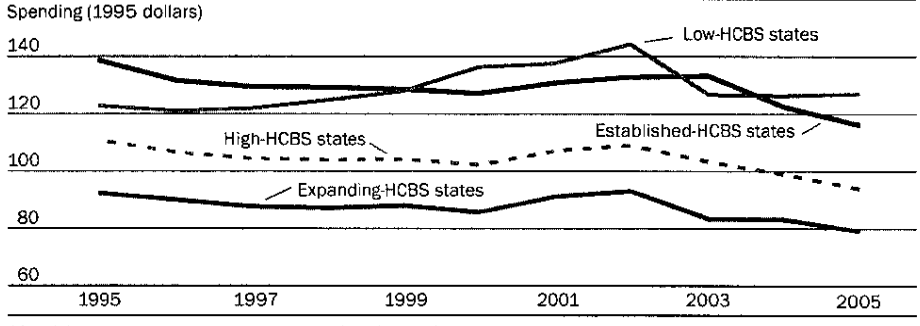


SOURCE: Authors' calculations based on data from Centers for Medicare and Medicaid Services (CMS) 64 and 372 reports.
NOTE: For explanation of types of HCBS states, see text.

tional spending dropped for both low- and high-HCBS states, after adjusting for inflation, but the drop was much more dramatic for the high-HCBS states, where ICF/MR spending declined by more than half, compared to a 14.5 percent drop among the low-HCBS states. Particularly impressive is the 61.5 percent drop in ICF/MR spending among established-HCBS states.

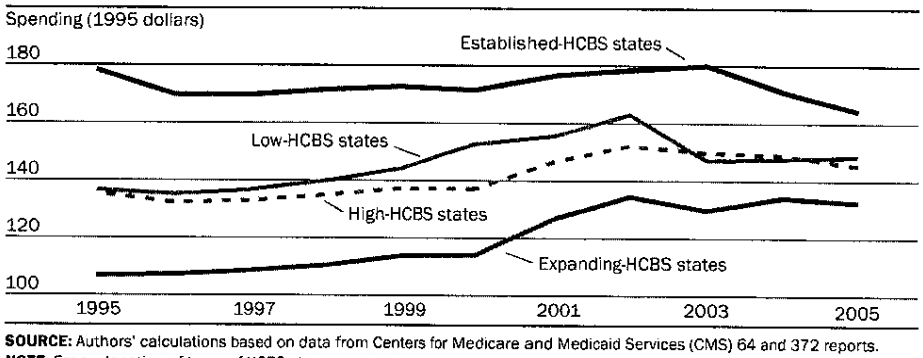
Total LTC spending for the MR/DD population increased for all types of states, with a 28.2 percent increase among low-HCBS states and a 33.0 percent increase among high-HCBS states (Exhibit 5). Established-HCBS states, however, experienced by far the lowest rate of growth (9.1 percent), with hardly any growth in inflation-adjusted spending between 1998 and 2005. Expanding-HCBS states had the highest rate of spending growth, at 56.9 percent.

EXHIBIT 3
Mean Per Capita, Inflation-Adjusted Nursing Home Spending In States With Low And High Home And Community-Based Services (HCBS), Fiscal Years 1995–2005



SOURCE: Authors' calculations based on data from Centers for Medicare and Medicaid Services (CMS) 64 and 372 reports.
NOTE: For explanation of types of HCBS states, see text.

EXHIBIT 4
Mean Per Capita, Inflation-Adjusted Long-Term Care (LTC) Spending, Excluding Mental Retardation/Developmental Disability (MR/DD) Programs, In States With Low And High Home And Community-Based Services (HCBS), Fiscal Years 1995–2005

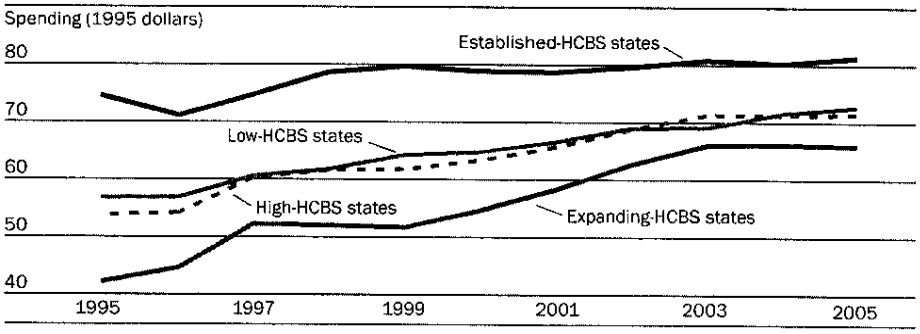


SOURCE: Authors' calculations based on data from Centers for Medicare and Medicaid Services (CMS) 64 and 372 reports.
NOTE: For explanation of types of HCBS states, see text.

■ **Expenditures following HCBS expansion.** Having observed that for both non-MR/DD and MR/DD programs, established-HCBS states controlled spending better than low-HCBS states and much better than expanding-HCBS states did, we hypothesized that HCBS programs incur an initial cost and have the eventual, but not immediate, effect of reducing institutional spending and limiting the growth of overall LTC spending. To explore this possibility, we examined LTC spending before, during, and after expansion of HCBS programs in several states.

Nine states rapidly expanded their non-MR/DD HCBS spending during the latter part of the 1990s and then held that (inflation-adjusted) spending relatively steady until at least 2005. One state created a new PCS program and another ex-

EXHIBIT 5
Mean Per Capita, Inflation-Adjusted Long-Term Care (LTC) Spending On Mental Retardation/Developmental Disability (MR/DD) Programs, In States With Low And High Home And Community-Based Services (HCBS), Fiscal Years 1995–2005



SOURCE: Authors' calculations based on data from Centers for Medicare and Medicaid Services (CMS) 64 and 372 reports.
NOTE: For explanation of types of HCBS states, see text.

panded an existing program, two states created new waiver programs and four expanded existing waivers, and one state expanded both a PCS and a waiver program. The growth in HCBS spending typically occurred over two years and then leveled off.

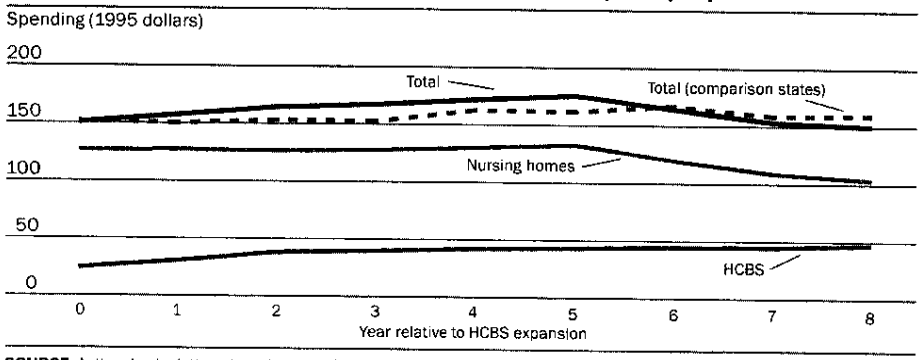
Exhibit 6 presents the mean spending on non-MR/DD HCBS, nursing homes, and total non-MR/DD LTC for the nine states; data for the states are combined not according to the fiscal year of expenditure but instead according to the year relative to the expansion. The states had not yet begun to increase spending during Year 0 (1995 for three states, 1996 for two, and 1997 for four); the expansion was essentially complete by Year 2; and HCBS spending remained relatively steady for the six subsequent years (ending in 2003, 2004, or 2005).

For these states, HCBS spending increased on average by 57.3 percent during the two years of rapid growth, and then much more slowly during subsequent years. Nursing home spending remained fairly stable for the three years following full expansion and then declined in each subsequent year. Total non-MR/DD spending rose especially rapidly during the period of HCBS expansion and then rose more slowly for the next three years. During subsequent years, however, total inflation-adjusted spending fell substantially, returning to just below its pre-expansion level in the final year.

For comparison, we identified fifteen states that held their non-MR/DD HCBS spending stable over the entire period (Exhibit 6). With flat HCBS spending and increasing nursing home spending, the comparison states saw a 4.6 percent increase in overall spending over the period. Initial levels were roughly equal in the comparison and expansionary states; following a temporary increase, the expan-

EXHIBIT 6

Mean Per Capita, Inflation-Adjusted Long-Term Care (LTC) Spending, Excluding Mental Retardation/Developmental Disability (MR/DD) Programs, In Nine States, Before, During, And After Home And Community-Based Services (HCBS) Expansion



SOURCE: Authors' calculations based on data from Centers for Medicare and Medicaid Services (CMS) 64 and 372 reports.
NOTES: Expansion states are CO, CT, KS, MN, NC, NE, TX, WA, WI. Comparison states are AL, AR, DE, FL, GA, IN, KY, MI, NJ, NY, ND, RI, TN, VA, WV.

sionary states were able to reduce their overall non-MR/DD LTC spending to approximate that of the comparison states in Year 6, and then further reduce it in subsequent years to below the comparison levels.

A similar analysis of states that expanded their MR/DD spending in the late 1990s (not shown) also suggests a lag between an increase in HCBS spending and a reduction in institutional spending, but the lag period appears to be shorter than for the non-MR/DD population.

Discussion

An analysis of state-by-state Medicaid LTC spending for 1995–2005 reveals that states offering extensive noninstitutional services experienced growth in overall spending comparable to that in states offering lower levels of such services. This finding holds true for spending on services both for people with nondevelopmental physical or cognitive disabilities, on the one hand, and for people with intellectual and other developmental disabilities, on the other.

For both types of spending, states with extensive, well-established noninstitutional programs saw much less spending growth than states with minimal noninstitutional services. In the case of non-MR/DD spending, states with well-established noninstitutional programs actually reduced their overall, inflation-adjusted LTC spending, in contrast with growing expenditures among states with minimal noninstitutional services. States that greatly expanded their HCBS programs during the period, however, saw greater increases in overall spending than other states did; the bulk of this expansion occurred after 2000, and its long-term effects are not yet observable.

■ **Negligible impact of other factors.** In comparing LTC spending patterns across states, it is worth exploring whether economic or population factors might account for the observed differences. Published models of state variations in total LTC spending have identified the most important predictors as average income and proportion of the population likely to need LTC, based either on a disability measure or on the proportion of residents who are very elderly.[13] We obtained state-by-state data from the 2000 census on median household income and on the proportion of residents with self-care difficulties; we found no significant correlation between either of these variables and the proportional change in LTC spending. It is therefore unlikely that such factors could explain the different spending trends observed among the states.

■ **Lag between HCBS expansion and lower LTC spending.** An examination of a group of states that expanded HCBS programs in the late 1990s suggests that there is a lag between the expansion of noninstitutional services and a subsequent, compensatory reduction in institutional spending, resulting after several years in lower total LTC spending than in states that did not expand HCBS programs. Because HCBS programs tend to serve people at risk of needing institutional services, with the goal of deferring or obviating their eventual institutionalization, and not merely

people gradually moving out of institutions, a lag between the introduction of an HCBS program and a reduction in the institutional population might be expected. Furthermore, real savings in institutional costs occur only when the number of Medicaid-financed nursing home residents is reduced, a process that can take years.

It seems apparent that states offering noninstitutional LTC services as an alternative to institutionalization are not only complying with the *Olmstead* decision and meeting the demands of their citizens with disabilities, but are also potentially saving money. One caveat, however, is that an initial outlay is required to launch a new HCBS program, followed several years later by a reduction in institutional spending and the possibility of overall cost savings. Additionally, our results do not necessarily imply that institutional savings occur automatically, but instead may result from parallel policy initiatives such as certificate-of-need programs or moratoria on new nursing home beds.[14]

It is clear, in any case, that states offering noninstitutional alternatives do not generally suffer any long-term financial penalty as a result. Such states have been able to contain and even reduce costs, largely avoiding a feared "woodwork effect" in which the demand for services was predicted to grow tremendously once HCBS programs became available.

■ **Pending legislation and its costs.** Legislation pending before Congress would require states not already doing so to offer noninstitutional alternatives to anyone eligible for institutional services. The Community Choice Act, successor to the Medicaid Community-Based Attendant Services and Supports Act (MiCASSA), was once estimated by the Congressional Budget Office to require additional Medicaid expenditures of $10–$20 billion or more annually, but a recent study calculates that the cost would be much lower, $1.4–$3.7 billion.[15] Neither analysis attempted to estimate cost savings through a commensurate reduction in institutional spending, however. Our study suggests that if experience is any guide, such legislation would likely entail no additional long-term spending and might in fact save money over the long run by providing less costly services to people who could then avoid or defer entering a nursing home or an ICF/MR.

FRAIL ELDERLY PEOPLE, and especially nonelderly people with various types of disabilities, need services that allow them to remain in their homes and retain their independence, and avoid entering an institution, possibly to remain there for the rest of their lives. In some states, those who cannot afford to purchase their own services have no alternatives to institutionalization. Justifications based on financial constraints can no longer be credibly offered as reasons for forcing such people into nursing homes and other institutions. HCBS programs may be one instance in which offering people greater choice also helps reduce costs.

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