

# Addressing Home and Community-based Waiver Waiting Lists Through the Medicaid Program

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## Introduction

Many states have reduced institutional placements by shifting public funding to home and community settings. They have done so, in part, through the use of Medicaid home and community-based waivers. States have used these waivers delicately, however, concerned that people who are being cared for in institutions or by family members will “come out of the woodwork” and place heavy demands on limited Medicaid budgets. As a result, states offer only limited numbers of waiver slots, for example 200 slots per year. And, beneficiaries who would otherwise qualify for community-based care have been placed on waiting lists when these slots become full.

Moreover, states have assumed that they have nearly unchecked flexibility in how they will administer these waiver programs – so long as the federal government does not find them to be too expensive. States have caused waiting lists to grow by decreasing the number of slots allocated to their waiver programs and by keeping allocated slots unfilled. States have not provided children and nursing-home eligible adults with Medicaid-covered home care services while they are on waiting lists. Individuals are not being informed of their rights to complain when services are delayed or denied. States are allowing home care facilities to operate with inadequate direct care staff, and waiver participants cannot find home care providers.<sup>1</sup> Growing increasingly frustrated with long waits and the lack of care, Medicaid beneficiaries and advocates are asking whether the Medicaid Act might be violated.

Until recently, litigation regarding home and community-based services waivers has focused on cases which look at whether an individual claimant has met the state’s cost effectiveness test for program eligibility.<sup>2</sup> However, litigation efforts increasingly seek to ensure that home and community-based services are available and accessible to beneficiaries.

The need to clarify the role of Medicaid in providing home and community-based services has been made all the more pressing by the U.S. Supreme Court’s *Olmstead v. L.C. ex rel. Zimring* decision, which holds the Americans with Disabilities Act to prohibit states in their

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<sup>1</sup> This and other provider participation issues will be the focus of a future issue brief.

<sup>2</sup> See, e.g., *Ash v. Ohio Dep’t of Human Serv.*, 126 Ohio App.3d 211, 709 N.E.2d 1257 (Ohio App. 4 Dist. 1998); *Leach v. Comm’r*, 1995 WL 495907 (Va. App., Aug. 22, 1995); *Madsen v. Dep’t of Health & Welf.*, 114 Idaho 182, 755 P.2d 479 (Idaho App. 1988).

public programs from unnecessarily institutionalizing persons with disabilities.<sup>3</sup> Among other things, this case discussed the need for states to have a “comprehensive, effectively working plan” for placing qualified individuals in less restrictive settings and waiting lists that move at a “reasonable pace.”<sup>4</sup> As states develop comprehensive plans, Medicaid must play a central role. Not only does Medicaid provide major funding for home and community-based services, but those who qualify for Medicaid have a legal entitlement to receive services as required by the Act.

This issue brief discusses legal strategies for improving service delivery and highlights recent and ongoing cases. While the limitations of the issue brief format prohibit an extensive discussion of the interplay between the ADA and Medicaid, this paper will discuss Medicaid provisions that states must comply with and that should be acknowledged in every state where integration plans are being developed.

### **Overview of the Medicaid waivers<sup>5</sup>**

The Medicaid Act allows states to request waivers of certain federal laws in order to provide services to persons at home or in the community.<sup>6</sup> These waivers are notable for the comprehensive services package they can provide beneficiaries, including services that may not otherwise be available to beneficiaries such as case management, home modification, personal care, adult day health, and respite care.<sup>7</sup>

A number of different types of home and community-based waivers are authorized.<sup>8</sup> For example, waivers can be used to provide services to individuals who, but for the waiver services, would be institutionalized in a hospital, nursing facility, or intermediate care facility for the mentally retarded<sup>9</sup> or to children under age five who are infected with AIDS or who are drug

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<sup>3</sup> 527 U.S. 581 (1999).

<sup>4</sup> *Id.* at 605-06.

<sup>5</sup> For a further introduction to Medicaid home and community-based waivers, *see* Kulkarni, Fact Sheet: Accessing Medicaid Home and Community-Based Services (Mar. 2000) (available at <<http://www.healthlaw.org>>).

<sup>6</sup> *See* 42 U.S.C. § 1396n(c) (listing various home and community-based waiver options); 42 C.F.R. § 440.180.

<sup>7</sup> 42 C.F.R. § 440.180.

<sup>8</sup> 42 U.S.C. § 1396n.

<sup>9</sup> 42 U.S.C. § 1396n(c); 42 C.F.R. §§ 441.300 *et seq.*, 440.180.

dependent at birth.<sup>10</sup>

To obtain and maintain a waiver program, a state must provide assurances to the federal government that: (1) necessary safeguards have been taken to protect the health and welfare of beneficiaries and to assure financial accountability for funds expended; (2) the state will evaluate a beneficiary's need for institutional services and inform individuals determined to be likely to need institutional services of the alternatives under the waiver; (4) the state will spend less per capita under the waiver than without the waiver; and (5) the state will annually provide information to the Secretary of Health and Human Services (HHS) on the impact of the waiver.<sup>11</sup>

There are currently 240 home and community-based waiver programs. All states except Arizona have a least one program.<sup>12</sup>

### **Budgetary constraints: the ADA and Medicaid**

Congress' authority to enact Medicaid and the Americans with Disabilities Act (ADA) derives from different constitutional powers. While seemingly rarefied, this distinction directly affects implementation of home and community-based services at the state level.

The ADA is a piece of civil rights legislation enacted pursuant to the Fourteenth Amendment.<sup>13</sup> Enforcement of the ADA extends only to "reasonable modifications" to avoid discrimination, not the fundamental alteration of a program in view of the resources available to the state.<sup>14</sup> Justice Kennedy has said that nothing about the ADA requires a state to create a community treatment program where none exists. Rather, decisions regarding the use and shifting of government funds are political decisions not within reach of the ADA.<sup>15</sup> As case law and state activities to develop integration plans evolve, there are sure to be disputes regarding

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<sup>10</sup> 42 U.S.C. § 1396n(e).

<sup>11</sup> *Id.* § 1396n(c)(2).

<sup>12</sup> NATIONAL CONFERENCE OF STATE LEGISLATORS, DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL ASSISTANCE REPORT FOR LEGISLATORS at 5 (2000) (available at <[www.ncsl.org/programs/health/Forum/pub6683.htm](http://www.ncsl.org/programs/health/Forum/pub6683.htm)>). Arizona is a technical exception because its home and community-based waivers fall within its section 1115 demonstration waiver.

<sup>13</sup> The Supreme Court has accepted review in an employment case to determine whether Congress had authority to abrogate the 11<sup>th</sup> Amendment and apply the ADA to the states. *See* *Garrett v. Univ. of Alabama at Birmingham, Bd. of Trustees*, 193 F.3d 1214 (11<sup>th</sup> Cir. 1999), *cert. granted*, 120 S.Ct. 1669 (U.S. Apr. 17, 2000) (No. 99-1240).

<sup>14</sup> 42 U.S.C. § 12132; 28 C.F.R. § 35.130(b). *See L.C.*, 527 U.S. at 603-04.

<sup>15</sup> 527 U.S. at 612-13.

how much cost a state should bear, and it is too early to know how courts will treat this question.

By contrast, the role of budgetary constraints is more settled in the Medicaid context. Congress enacted the Medicaid Act pursuant to the spending clause. As such, Congress has offered federal financial assistance to states to provide medical care to the needy, but it has made that federal funding available with strings attached. Once a state elects to participate in Medicaid, it “must comply with the requirements imposed both by the Act itself and by the Secretary of Health and Human Services.”<sup>16</sup> Courts have repeatedly noted that “inadequate state appropriations do not excuse noncompliance [with the Medicaid Act].”<sup>17</sup>

In *Benjamin H. v. Ohl*, the state recently cited the ADA to argue that the court could not require it to expand the availability of community-based services through the Medicaid program. The court, however, noted that the authority for the ADA differs from the Medicaid Act.<sup>18</sup> Ordering relief to address Medicaid waiver waiting lists, the court put it this way: “Medicaid provides entitlements.... Budgetary constraints are no defense for the failure to provide Medicaid entitlements.... The reason is simple. States could easily renege on their part of the Medicaid bargain by simply failing to appropriate sufficient funds.”<sup>19</sup> Thus, while states may be able to cite budgetary constraints to limit their accommodations to achieve integration under the ADA, budgetary constraints alone should not excuse a state from complying with the Medicaid Act.

### **Assuring reasonable promptness and free choice in the delivery of services**

One of the most common legal claims in Medicaid waiver waiting list cases concerns the requirement that “assistance shall be furnished with reasonable promptness to all eligible individuals.”<sup>20</sup> Interestingly, the “reasonable promptness” provision was originally enacted to address the hardship caused when needy individuals were placed on waiting lists or otherwise

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<sup>16</sup> *Schweiker v. Gray Panthers*, 453 U.S. 34, 36-37 (1981). *See also* *Wilder et al. v. Virginia Hosp. Ass’n*, 496 U.S. 498, 500 (1990).

<sup>17</sup> *See, e.g. Doe v. Chiles*, 136 F.3d. 709, 722 (11<sup>th</sup> Cir. 1998); *Alabama Nursing Home Ass’n v. Harris*, 617 F. 2d 388, 396 (5<sup>th</sup> Cir. 1980).

<sup>18</sup> No. 3:99-0338 (S.D.W.Va.) (June 30, 1999, Preliminary injunction transcript).

<sup>19</sup> *Benjamin H v. Ohl*, No. 3:99-0338, slip op. at 25-26 (S.D.W.Va.) (July 15, 1999, Memorandum Opinion and Order on Preliminary Injunction).

<sup>20</sup> 42 U.S.C. § 1396a(a)(8). *See also* 42 C.F.R. § 435.930 (“agency must: (a) furnish Medicaid promptly to recipients without any delay caused by the agency’s administrative procedures; [and] (b) continue to furnish Medicaid regularly to all eligible individuals until they are found to be ineligible....”); *Id.* § 435.911 (“agency must establish time standards for determining eligibility and inform the applicant of what they are.”).

denied public assistance, despite the fact that they had been found eligible for that assistance.<sup>21</sup> Over the years, courts have consistently held the reasonable promptness provision to prohibit states from responding to administrative constraints by making beneficiaries wait for services.<sup>22</sup> In *Doe v. Chiles*,<sup>23</sup> for example, individuals with developmental disabilities were being placed on long waiting lists for intermediate care facilities (ICFs). The court found a violation of the reasonable promptness requirement and ordered the state to establish a reasonable waiting period for ICF services not to exceed 90 days.<sup>24</sup>

In conjunction with the reasonable promptness provision, some plaintiffs are also citing the “free choice” provision. When a state covers both institutional and waiver program services, it must inform eligible individuals about feasible alternatives, if available under the waiver, and allow individuals to choose whether they will receive care under the waiver program or in an institutional setting.<sup>25</sup> In *Cramer v. Chiles*,<sup>26</sup> the court found that the state had violated the free choice rights of developmentally disabled Medicaid beneficiaries. At issue was a new state legislative plan that would have eliminated most ICF/DD placements. The court held that the

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<sup>21</sup> See Conf. Rep. No. 2271, 81<sup>st</sup> Cong., 2d Sess. (1950), *reprinted in* 1950 U.S.C.C.A.N. 3287, 3482, 3507; H.R. Rep. No. 1300, 81<sup>st</sup> Cong., 1<sup>st</sup> Sess. 48 (1949) (decision by states “not to take more applications or to keep eligible families on waiting lists until enough recipients could be removed from the assistance rolls to make a place for them ... results in undue hardship on needy persons and is inappropriate in a program financed from federal funds”). See *Jackson v. Hackney*, 406 U.S. 535, 545 (1972).

<sup>22</sup> *E.g.* *Sobky v. Smoley*, 855 F. Supp. 1123, 1149 (E.D. Cal. 1994) (“insufficient funding by the State and counties of methadone maintenance treatment slots has caused providers . . . to place eligible individuals on waiting lists for treatment . . . precisely the sort of state procedure the reasonable promptness provision is designed to prevent”); *Linton v. Carney*, 779 F. Supp. 925, 936 (M.D. Tenn. 1990) (policy of limiting the number of nursing homes beds that could be used for Medicaid patients violated the reasonable promptness provision by causing those patients “to experience extended delays and waiting lists in attempting to gain access to long term nursing home care”); *Clark v. Kizer*, 758 F. Supp. 572, 580 (E.D. Cal. 1990), *aff’d in part and vacated in part on other grounds sub nom.*, *Clark v. Coye*, 967 F.2d 585 (9th Cir. 1992) (granting summary judgment on reasonable promptness claim where declarations of county public health officials indicated that a shortage of Medicaid-participating dentists caused frequent “delays in obtaining appointments for regular and emergency dental care[.]”); *Morgan v. Cohen*, 665 F. Supp. 1164, 1177 (E.D. Pa. 1987) (Medicaid-covered transportation services “must be furnished with reasonable promptness”).

<sup>23</sup> 136 F.3d 709 (11<sup>th</sup> Cir. 1998).

<sup>24</sup> *Id.* at 720.

<sup>25</sup> 42 U.S.C. § 1396n(c)(2); 42 C.F.R. § 441.302(d).

<sup>26</sup> 33 F. Supp. 2d 1342 (S.D. Fla. 1999).

plan violated free choice because

it gives beneficiaries no real choice. The beneficiary must choose between (1) a Home and Community-Based Waiver option which gives no assurance that the supports and services will meet individuals needs, and (2) a hope for a future ICF/DD placement. The defendants have admitted that selecting an ICF/DD placement means going on a waiting list for decades unless new facilities are found.<sup>27</sup>

While *Cramer* dealt with free choice and availability of ICF services, there are a couple of subsequent court decisions that focus on reasonable promptness, free choice, and availability of home and community-based waiver services. The experiences of the plaintiffs in two cases illustrate the disparate conclusions that courts can reach.

The first case, *Benjamin H.*, challenged the failure of the state to make intermediate care level services adequately available to needy beneficiaries. The situation in West Virginia was unusual. First, some years ago, the state legislature had officially declared a moratorium on any new ICF-MR/DD beds, in favor of the expansion of these services in the community. The state did, in fact, expand community offerings, in part through a Medicaid home and community-based waiver program. However, in April 1999, the state abruptly limited the waiver program only to “emergency” placements and submitted a waiver re-application to HHS that sought only 25 slots a year for the next five years.

Medicaid beneficiaries argued that this turn of events meant that ICF-level services were simply not operating in the state in either institutional or community-based settings – even though the state included ICF-level services in its state plan. They alleged violations of Medicaid provisions requiring beneficiaries to be given a free choice of waiver or institutional placement, the right to obtain services with reasonable promptness, and the right to due process when services are delayed or denied.<sup>28</sup>

Entering a preliminary injunction for the plaintiffs, the court was persuaded that, in this situation, the plaintiffs “are not confined to a limited choice. They have no choice at all, except to languish on a waiting list for one unavailable service or another.”<sup>29</sup> The court rejected the state’s claim that the Medicaid Act was not violated because the waiver alternative was not available due to the fact that the demand for slots exceed the budget for the program. Citing *Martinez v. Ibarra*,<sup>30</sup> it held that feasible alternatives should be determined by the beneficiary’s

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<sup>27</sup> *Id.* at 1352.

<sup>28</sup> Although EPSDT and ADA claims were included in the complaint, preliminary injunctive relief was not granted on these claims, and they did not receive focus.

<sup>29</sup> No. 3:99-0338, slip op. at 26 (S.D.W.Va. July 15, 1999).

<sup>30</sup> 759 F. Supp. 664, 669 (D.Colo. 1991).

needs and treatment plan, and not solely by the funds available to service that plan.<sup>31</sup> In a March 15, 2000 order, both the free choice and reasonable promptness provisions were found to have been violated. The Court ordered the state to allow individuals to apply for waiver services without delay and to make eligibility determinations within 90 days. It also ordered waiting lists for waiver services to move at a reasonable pace, defined as 90 days from the date eligibility is determined.<sup>32</sup> In addition, West Virginia increased the number of waiver slots that it was seeking from HHS.

By contrast, in *Makin v. Cayetano*,<sup>33</sup> a federal judge in Hawaii dismissed most of the plaintiffs' claims based on the free choice and reasonable promptness provisions. The court cited Medicaid provisions which discuss limits on the size of the waiver program,<sup>34</sup> and held that, once these "population limits" are reached, there is no entitlement to waiver services and the program is no longer an available alternative.<sup>35</sup> The plaintiffs could obtain the services in ICFs if they chose.<sup>36</sup> The court distinguished *Benjamin H.*, finding that those plaintiffs had no feasible alternatives at all since services were available in neither institutional nor home-based settings.

Not all of *Makin* was dismissed, however. Medicaid provisions require the agency to assure financial accountability for funds expended under the waiver.<sup>37</sup> The record revealed

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<sup>31</sup> *Id.* See also *Lewis v. Dep't of Health*, Civ. No. 99-0021 MV/RLP, 2000 U.S. Dist. LEXIS 6025 (D.N.M., Apr. 24, 2000) (rejecting the state's argument that neither the constitution nor statute creates a right to participate in the waiver program because, in the case, plaintiffs did not claim an absolute right to the waiver program but rather the right to have their applications processed with reasonable promptness).

<sup>32</sup> Civ. Action No. 3:99-0338 (S.D.W.Va) (Mar. 15, 2000, Order) (July 15, 1999, Memorandum Opinion and Order Re: Preliminary Injunction). See also *Lewis v. Dep't of Health*, No. Civ. 99-0021 MV/RLP, 2000 U.S. Dist. LEXIS 6025 (D.N.M., Apr. 24, 2000) (holding that plaintiffs have a private right of action to enforce reasonable promptness requirement in a case seeking expansion of home and community-based waiver services); *Roland v. Celluci*, 52 F. Supp.2d 231 (D. Mass. 1999) (interpreting the reasonable promptness requirement); *McMillan v McCrimon*, 807 F. Supp. 475 (C.D. Ill. 1992) (granting preliminary injunction on plaintiffs' claim that § 1396a(a)(8) required Medicaid agency to accept applications for home and community-based waiver program).

<sup>33</sup> No. 98-0097 DAE (D. Haw., Nov. 26, 1999).

<sup>34</sup> See 42 U.S.C. § 1396n(c); 42 C.F.R. § 441.303.

<sup>35</sup> No. 98-0097 DAE, slip op. at 22, 28.

<sup>36</sup> There was apparently some dispute on this point, but the court found ICF placements to be available.

<sup>37</sup> See 42 C.F.R. § 441.302(b).

questions of fact concerning the state's allocation of waiver funds since there were some remaining unfilled slots available at the end of a previous year when the state had allowed unspent waiver appropriations to lapse without an explanation.<sup>38</sup> The court also agreed to hear further testimony on whether discrimination under the ADA has occurred and, if so, the extent to which the state must modify its program to remedy the situation. The plaintiffs claim that the state could force individuals into institutions in violation of the ADA's non-discrimination policy since its Medicaid program fails to offer all qualified disabled people services in the most integrated setting possible.<sup>39</sup>

### **Obtaining home-based services for children on waiver waiting lists**

Early and Periodic Screening, Diagnosis and Treatment (EPSDT) is a mandatory Medicaid service for children under age 21 that emphasizes early screening for illness and continuous and comprehensive care.<sup>40</sup> As part of EPSDT, states must provide eligible children with health care, diagnostic services, treatment, and other measures "to correct or ameliorate defects and physical and mental illnesses and conditions[.]"<sup>41</sup> Moreover, the state must "arrang[e] for ... corrective treatment" for children's identified needs.<sup>42</sup> Thus, while the state generally is required only to pay for Medicaid-covered services when medically necessary, a state must arrange for EPSDT for needy children.<sup>43</sup> In addition, the agency must ensure timely initiation of treatment, generally within an outer limit of six months after the request for screening services.<sup>44</sup>

Child health advocates have used the EPSDT provisions to obtain services for children while they sit on home and community-based waiver waiting lists. Rather than attack the waiting lists directly, these cases seek to fill health care gaps with the fairly comprehensive range of services that EPSDT can provide. A major advantage of the EPSDT statute is that it is clearly

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<sup>38</sup> No. 98-0097 DAE, slip op. at 31 (D. Haw., Nov. 26, 1999).

<sup>39</sup> *Id.*, slip op. at 37-39.

<sup>40</sup> *See* 42 U.S.C. §§ 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).

<sup>41</sup> 42 U.S.C. § 1396d(r)(5).

<sup>42</sup> *Id.* § 1396a(a)(43).

<sup>43</sup> GEORGE ANNAS, ET AL., AMERICAN HEALTH LAW 186-87 (1990). *See also, e.g., Doe v. Pickett*, 480 F. Supp. 1218, 1221 (S.D.W.Va. 1979) (EPSDT "imposes on the states an affirmative obligation to see that minors actually receive necessary treatment and medical services").

<sup>44</sup> 42 C.F.R. § 441.56(e).

written and has been enforced in a number of court decisions and settlements.<sup>45</sup> The disadvantage is that, on its face, the provision extends only to children under age 21.<sup>46</sup>

In a Louisiana case, *Chisholm v. Hood*,<sup>47</sup> a recent settlement promises a number of positive changes to enhance availability of case management services for children with mental retardation and developmental disabilities.<sup>48</sup> Among other things, the state will mail notices of the availability of these services to Medicaid-eligible families. It will assure that case managers possess minimum qualifications, will only handle a caseload of 35 clients, and will be trained on Medicaid and EPSDT services. This case is not over, however. The plaintiffs have recently filed a second motion for partial summary judgment, arguing that the failure of the state to arrange for needed personal care<sup>49</sup> and physical therapy services<sup>50</sup> for children on waiting lists violates EPSDT.<sup>51</sup>

Plaintiffs in *French v. Concannon*, suing on behalf of Medicaid-eligible children with severe mental impairments, also have used the EPSDT provisions to challenge long waits for

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<sup>45</sup> See National Health Law Program, EPSDT Case Docket (Oct. 4, 1999) (posted at <<http://www.healthlaw.org>>). *But see* Charlie and Nadine H v. Whitman, 83 F. Supp. 2d 476 (D.N.J. 2000).

<sup>46</sup> *But see, e.g.*, Salgado v. Kirschner, 878 P.2d 659 (Ariz. 1994) (discussion of EPSDT in case involving transplant for an adult). See also 42 U.S.C. §1396a(a)(10)(D) (requiring states to provide for the “inclusion of home health services for any individual who, under the State plan, is entitled to nursing facility services”); 42 U.S.C. § 1396a(a)(21) (“[I]f the State plan includes medical assistance in behalf of individuals 65 years of age or older who are patients in public institutions for mental diseases, [a State plan for medical assistance must] show that the State is making satisfactory progress toward developing and implementing a comprehensive mental health program, including provision for utilization of community mental health centers, nursing facilities, and other alternatives to care in public institutions for mental diseases.”)

<sup>47</sup> Civ. Action No. 97-3274 (E.D.La.) (Feb. 16, 2000, Stipulation and Order of Partial Dismissal).

<sup>48</sup> For provisions authorizing case management services, see 42 U.S.C. §§ 1396d(a)(19), 1396n(g)(2).

<sup>49</sup> For provisions authorizing personal care services, see 42 U.S.C. § 1396d(a)(24); 42 C.F.R. §§ 440.167, 440.170(f).

<sup>50</sup> For provisions authorizing physical therapy and related services, see 42 U.S.C. § 1396d(a)(11); 42 C.F.R. § 440.110.

<sup>51</sup> *Chisholm v. Hood*, Civ. Action No. 97-3274 (E.D.La.) (Apr. 24, 2000, Second Motion for Partial Summary Judgment).

needed services.<sup>52</sup> A settlement was reached between the parties, achieving a number of positive results, including: (1) creation of a position within the Maine Department of Mental Health to identify children who are waiting for services and to ensure that treatment is being implemented; (2) revision of the EPSDT brochure and the EPSDT provider screening forms, (3) hiring of additional case managers, (4) streamlining of the prior authorization process, and (5) creation of a new provider category “behavioral health specialist,” to increase availability of home care providers.<sup>53</sup>

### **Assuring due process**

The constitution and Medicaid Act require states to grant an opportunity for a fair hearing “to any individual whose claim for medical assistance under the plan is denied or is not acted upon with reasonable promptness.”<sup>54</sup> Medicaid regulations require written notice when services are denied, reduced, terminated, or suspended, and clearly specify the content of the notice and the requirements for the fair hearing.<sup>55</sup>

Advocates repeatedly express frustration that waiver waiting list problems come to light only after a patient’s situation reaches a crisis. At that point, the advocate is contacted and learns of the long waiting period. The beneficiary, meanwhile, has received no notice from the Medicaid agency that discusses the reason for the delay or how to complain about it. Given the clarity of the law, it is not surprising that courts are increasingly enjoining state Medicaid agencies’ failures to meet the due process standards when home and community-based services are delayed or denied.<sup>56</sup>

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<sup>52</sup> No. 97-CV-24-B-C (D. Me.) (July 1998, Order of dismissal and agreement).

<sup>53</sup> For provisions authorizing home health services, *see* 42 U.S.C. § 1396d(a)(7); 42 C.F.R. § 440.70.

<sup>54</sup> *See* *Goldberg v. Kelly*, 397 U.S. 245 (1970); 42 U.S.C. § 1396a(a)(3).

<sup>55</sup> *See* 42 C.F.R. § 431.200 *et seq.*

<sup>56</sup> *See* *Benjamin H v. Ohl*, No. 3:99-0338 (S.D.W.Va.) (July 15, 1999, Memorandum Opinion and Order) (Mar. 15, 2000, Settlement of Due Process Claim, including agreed-upon template notices); *Cramer v. Chiles*, 33 F. Supp. 2d 1342, 1352 (S.D. Fla. 1999) (individualized due process notices required when a state statutory change denied beneficiaries a choice between an ICF/MR facility or a home and community-based waiver program); *Catanzano v. Dowling*, 60 F.3d 113 (2d Cir. 1995) (certified home health agencies are state actors which must adhere to due process requirements); *King v. Fallon*, 801 F. Supp. 925 (D.R.I. 1992) (Medicaid agency must provide notice regarding level-of-care assessments governing eligibility for home and community-based waiver services). *See also* *Parry v. Crawford*, 990 F. Supp. 1250 (D.Nev. 1998) (beneficiaries required to be notified of fair hearing rights when applications for placement at ICF/MR facility rejected); *J.K. v. Dillenberg*, 836 F. Supp. 694, 699 (D. Ariz. 1993) (regional behavioral health authorities are state actors which must adhere to due process requirements).

## Conclusion

The statutory protections, coupled with recent case law developments, mean that advocates should focus attention on home and community-based services. In addition to working on *L.C.* plan development, advocates can be involved in Medicaid home and community-based waiver applications, re-applications, and implementation. In this role, advocates can urge states to review the services of all residents in Medicaid-funded institutions and to assess home-based needs of the population to determine whether the waiver is consistent with the Medicaid Act provisions discussed above. Advocates must constantly monitor states' efforts to provide home and community care at a reasonable pace. To the extent that the state is not satisfying the Medicaid Act, carefully tailored litigation should be considered. The National Health Law Program is available to provide assistance with these cases.