I. Introduction

The past seven years have seen a flood of lawsuits concerning home and community services for people with disabilities. Many lawsuits challenge state policies that limit access to Medicaid home and community services. Others aim at securing community services in the most integrated setting for institutionalized persons as provided by the Americans with Disabilities Act (ADA). Still others challenge state policies that prevent individuals with disabilities from obtaining the full range of community services.

This periodic report tracks the status of lawsuits that revolve around home and community services for people with disabilities. We caution that the report is not necessarily inclusive of all lawsuits in this arena. The report tracks three broad categories of lawsuits:

- **Access to Medicaid Home and Community Services.** These lawsuits challenge state policies that prevent people with disabilities from promptly obtaining Medicaid home and community services. Most of these lawsuits have involved people with developmental disabilities who are waiting for services. Individuals with other disabilities who want but cannot obtain home and community services also have filed several lawsuits. The plaintiffs in these lawsuits include individuals who are in nursing or other facilities but want to be in the community as well as persons who face institutionalization absent community services.

- **Community Placement of Institutionalized Persons.** These lawsuits principally (but not exclusively) involve persons served in publicly-operated institutions who could be supported in the community.

- **Limitations on Medicaid Home and Community Benefits.** These lawsuits challenge state policies that affect the scope and quality of Medicaid services in the community. Some lawsuits concern the adequacy of state payments for community services. Others challenge state restrictions on services available through the Medicaid program.

In the following sections of this report, the issues that have prompted these lawsuits are discussed and the lawsuits are summarized, including their current status.

II. Access to Medicaid Home and Community Services

A. Medicaid Home and Community Services

The Medicaid program underwrites more than one-half of the costs of long-term services for individuals of all ages. Because the Medicaid program looms so large in the provision of long-term services, it has attracted a high volume of litigation.

In the past and still today, the majority of Medicaid long-term dollars pay for institutional services in nursing facilities, intermediate care facilities for the mentally retarded (ICFs/MR) and other settings. Federal Medicaid law (Title XIX of the Social Security Act) requires that every state include nursing facility services in its Medicaid program. Since 1971, states have had the option to offer ICF/MR services. Initially, ICF/MR services were concentrated in state-operated institutions. Now, the majority of ICF/MR residents are served by non-state providers and the number of public institutions has decreased. (Prouty et al., 2004).

Medicaid home and community services include home health care, personal care/assistance provided as a
Medicaid state plan benefit, and home and community-based services (HCBS) furnished under federal waivers. All states must provide home health in their Medicaid programs. States may elect to provide personal care/assistance and/or operate HCBS waiver programs.

The HCBS waiver program allows a state to offer community services as an alternative to institutional services (e.g., nursing facility and ICF/MR) to persons who meet institutional eligibility criteria. A state may offer services that it could but does not provide under its regular Medicaid program (e.g., personal care) and other services that cannot be offered as regular Medicaid benefits but aid individuals to remain in the community. Federal law (§1915(c) of the Social Security Act) allows a state to select the services that it offers in a waiver program and target waiver services to Medicaid beneficiary target groups (e.g., individuals with developmental disabilities). (ASPE, 2000) A state also can limit the number of persons who participate in an HCBS waiver program.

While institutional spending still dominates Medicaid long-term services, states have substantially boosted spending for home and community services. For more than a decade, spending for Medicaid home and community services has grown more rapidly than institutional services. Between 1990 and 2003, HCBS waiver expenditures increased more than ten-fold, reaching $18.6 billion. The share of Medicaid long-term services expenditures devoted to home and community services was 33% in 2003 compared to a little over 10% in 1990.1 In developmental disabilities services, HCBS waiver spending surpassed ICF/MR institutional spending in 2001.2

Several critical factors have prompted lawsuits to expand access by people with disabilities to Medicaid home and community services. The most important is that growing numbers of individuals with disabilities want to remain in and be supported in their own homes and communities rather than institutions. Despite the expansion of Medicaid home and community services, most states have not kept pace with upward spiraling demand for long-term services. (Smith, 1999) Demographic and other factors lie behind rising demand for community services. Since the supply of community services has not kept pace with demand, the result has been wait listing individuals for services and a backlog of persons in nursing facilities and other institutional settings who cannot return to the community. Mounting frustration over the shortage of community services has boiled over into litigation.

Under Medicaid law, there is an entitlement to the institutional services included in a state’s Medicaid program. The aim of the lawsuits is to establish that Medicaid beneficiaries with disabilities have access to community services on equal footing with “entitled” institutional services. Until seven years ago, there had been relatively little litigation concerning Medicaid home and community services. In the arena of developmental disabilities services, the 1998 11th U.S. Circuit Court of Appeals decision in the Doe v. Chiles lawsuit held that a state cannot simultaneously limit access to entitled ICF/MR services. This decision (described below) triggered lawsuits elsewhere to challenge state authority to restrict access to Medicaid services by people with developmental disabilities. In 1999, the U.S. Supreme Court issued its landmark Olmstead v. L.C., ruling that Title II of the American with Disabilities Act requires states to make diligent efforts to serve individuals in the most integrated setting. The decision sparked lawsuits to secure community services for institutionalized persons as well as others who potentially face institutionalization absent community services. While there are differences among the lawsuits, at heart their common aim is to ensure that individuals with disabilities who need long-term services can obtain them promptly in the community not just institutional settings.

B. Legal Issues

Lawsuits in this category assert that federal Medicaid law obliges a state to furnish home and community services to eligible individuals when needed, challenging the premise that states have the authority to restrict the availability of these services. 3 In many cases, the U.S. Supreme Court’s Olmstead ruling also serves as the grounds for pleadings that the ADA dictates that states must furnish home and community services in the most integrated setting.

In most cases, these lawsuits have been filed in federal court, although a few have been filed in state court when violations of state law also are alleged. Federal Medicaid law does not specifically provide for a beneficiary’s seeking relief through the federal courts for alleged violations of Medicaid law. Federal law

1 For information concerning 2003 Medicaid long-term services spending nationwide and by state, go to: hcms.org/browse.php/topic/35/ofs/10

2 In 2003, HCBS waiver expenditures for persons with developmental disabilities reached $14.1 billion compared to $11.5 billion for ICF/MR services. There were about 402,000 HCBS waiver participants with developmental disabilities compared to 107,000 ICF/MR residents. (Prouty et al., 2004)

3 A thorough discussion of the legal issues is in: Jane Perkins and Manju Kulkani (May 2000) “Fact Sheet: Addressing Home and Community-based Waiver Waiting Lists through the Medicaid Program.” This article is located at healthlaw.org/pubs/200005FactSheet_hcbw.html.
requires that a state operate an administrative appeals process (called Fair Hearing) through which a person may appeal adverse decisions concerning eligibility or services. Otherwise, if a state does not comply with Medicaid law and regulations, the principal federal remedy is to withhold or deny payments to the state.

In order to bring suit in federal court, plaintiffs rely on provisions of the U.S. Constitution and/or federal law in seeking relief. In particular, the Civil Rights Act of 1871 (42 U.S.C. §1983) grants citizens a private right of action to seek relief in federal court when state officials are alleged to violate the Constitution or federal law. Dating back many years, federal courts – including the U.S. Supreme Court – have affirmed that lawsuits involving Medicaid services can be brought in federal court law so long as the plaintiffs seek prospective relief from alleged violations and federal law confers an individually enforceable right. As a result, lawsuits assert that, by not furnishing community services to eligible individuals, a state violates an enforceable right set forth in federal Medicaid law and/or the ADA.

Usually, these lawsuits also seek certification as a class action complaint because, in addition to the named plaintiffs who allege that their rights have been violated, there are other individuals in the same situation. Class action certification is the subject of a separate determination by the courts.

In defense, some states have claimed “sovereign immunity” from these lawsuits under the provisions of the 11th Amendment to the U.S. Constitution. The 11th Amendment bars suits against states in federal court. With rare exceptions, federal courts have rejected this defense in lawsuits involving Medicaid.

More recently, states have challenged the premise that Medicaid law confers individually enforceable rights that fall under the protections of §1983. These challenges are based on the 2002 U.S. Supreme Court Gonzaga University v. Doe decision that spelled out more stringent conditions for bringing §1983 complaints. Relying on this decision, states have argued that federal Medicaid law only governs a state’s overall administration of its Medicaid program but does not grant beneficiaries individually enforceable rights.

Since the Gonzaga decision was handed down, there have been several decisions concerning the question of whether Medicaid law confers individually enforceable rights. In at least three lawsuits concerning home and community services for people with disabilities (the Pennsylvania Sabree et al. v. Houston and Utah D.C. v. Williams “waiting list” lawsuits as well as the California Sanchez v. Johnson lawsuit concerning payments for community services), district courts found that federal Medicaid law does not confer individually enforceable rights, based on the Gonzaga decision. But, other courts have ruled that Medicaid beneficiaries have individually enforceable rights under at least some key provisions of Medicaid law.

Going forward, the fundamental question of whether individuals can seek relief through the federal courts for alleged violations of Medicaid law likely will continue to be litigated.

While claimed violations of federal Medicaid law vary by lawsuit, they often include:

- **Reasonable Promptness.** §1902(a)(8) of the Social Security Act (hereinafter, “the Act”) and associated federal regulations mandate that a state promptly determine the eligibility of persons who apply for services. The regulatory standard for processing Medicaid applications for long-term care is no more than 90-days. Federal courts have ruled that §1902(a)(8) bars a state from wait listing individuals for entitled Medicaid services rather than providing them right away. In Doe v. Chiles, for example, the court held that this provision requires a state to furnish ICF/MR services promptly once an application has been approved and, thereby, wait-listing individuals indefinitely violates the intent of §1902(a)(8).

- **Comparability.** §1902(a)(10) of the Act requires a state to make Medicaid services available on a “comparable” basis to all eligible individuals. In some lawsuits, plaintiffs claim that, by furnishing community services to some but not all eligible persons, a state violates this provision.

- **Freedom of Choice.** §1915(c)(2)(C) of the Act requires that a state afford an individual the freedom to choose between receiving waiver and institutional

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4 See article at healthlaw.org/pubs/courtwatch/200206gonzaga.html

5 In particular, the federal District Court for Massachusetts ruled that the Medicaid Act’s reasonable promptness (§1902(a)(8) of the Social Security Act), comparability (§1902(a)(10)(B)), and reasonable standards (§1902(a)(17)) confer individually enforceable rights. The court rejected the reasoning in the Sabree decision that found that the entire Medicaid Act was unenforceable (healthlaw.org/pubs/courtwatch/200404.masscourt.html). Similarly, the 2nd Circuit held in Connecticut Rabin v. Wilson-Coker – caselaw.lp.findlaw.com/data2/circ2/2nd/037572p.pdf that Medicaid Act provisions are individually enforceable, the Gonzaga decision notwithstanding. The 2nd Circuit based its ruling on provisions of §1123 of the Social Security Act (the so-called “Suter Fix”) that specifically provides that a provision of the Act cannot be found unenforceable solely because it is in a part of the statute that spells out state plan requirements. healthlaw.org/pubs/courtwatch/200404.tn.html.

6 This decision is at laws.findlaw.com/11th/965144man.html.
In some complaints, plaintiffs claim that, under §1915(c)(2)(C) of the Act, a person who meets eligibility requirements for institutional services has the right to select waiver services instead. In other words, a person’s eligibility for entitled institutional services translates into an entitlement for waiver services. But, pursuing this claim has run up against the authority of a state to limit the number of individuals served in HCBS waiver programs.

- **Right to Apply.** §1902(a)(3) of the Act affords individuals the right to apply for services and have a decision rendered concerning their applications. If a person’s application is denied, then the individual has the right to appeal. In some cases, plaintiffs argue that the practice of waiting listing individuals for services instead of determining their eligibility short-circuits this fundamental protection. Often, there is an accompanying claim that a state’s policies violate the Constitution’s due process protections.

Alleged violations of Medicaid law often are accompanied by claimed violations of Title II of the ADA and §504 of the Rehabilitation Services Act of 1973. Title II requires public entities to provide services in the “most integrated setting” appropriate to a person’s needs. Plaintiffs assert that Title II mandates that individuals have access to community services on equal footing with institutional services and, by making institutional but not community services available, a state violates the ADA. Claimed §504 violations are similar except that this statute dictates that recipients of federal funds furnish services in the “least restrictive setting.”

The U.S. Supreme Court’s Olmstead decision directly addressed Title II of the ADA. While the underlying litigation revolved around the denial of community placement of two institutionalized persons, the Court expressed the view that a state would not violate Title II if it had a “comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings” and “a waiting list that moved at a reasonable pace.” But, the Court qualified its decision by stipulating that a state would not be deemed to violate Title II if achieving compliance forced it to make a “fundamental alteration” in its programs. Courts are grappling with the question of what constitutes a fundamental alteration.  

C. **Lawsuits Involving Individuals with Developmental Disabilities**

There has been a high volume of lawsuits that challenge waiting list individuals with developmental disabilities for Medicaid home and community services. States have experienced a substantial increase in the number of individuals seeking community services and have had difficulty keeping pace with this especially strong service demand. In addition, over the past several years, many states have limited or reduced ICF/MR services in favor of expanding waiver services. But, the total supply of ICF/MR “beds” and HCBS waiver “slots” often has not kept up with demand, resulting in individuals queuing up on waiting lists. In some states, waiting lists have grown quite large. States also have limited their expenditures by capping both the number of persons who receive waiver services and the number of ICF/MR beds. The combination of ICF/MR bed limits and HCBS waiver “slot” caps may mean that neither type of service is readily available to individuals. Waiting lists are a very visible problem in nearly all states, thereby explaining the large number of lawsuits to secure services for persons with developmental disabilities.

As noted, in March 1998, the 11th U.S. Circuit Court of Appeals handed down a watershed ruling in the Florida Doe v. Chiles litigation that made it clear that federal Medicaid law does not allow a state to wait list individuals for ICF/MR services indefinitely. Florida had sought to limit the availability of both ICF/MR and HCB waiver services. The Court ruled that ICF/MR services were no different than any other non-waiver Medicaid service and, hence, must be furnished with reasonable promptness to eligible applicants. Also, the court rejected the state’s attempt to justify limiting services due to budget considerations, noting that courts had repeatedly found that “inadequate state appropriations do not excuse noncompliance.” The Doe decision triggered lawsuits elsewhere.

The 11th Circuit decision spoke directly to ICF/MR but not waiver services. Most developmental disabilities waiting list lawsuits have been filed by people who seek HCBS but are wait-listed. In many of these lawsuits, plaintiffs are attempting to establish the principle that a person’s eligibility for ICF/MR services also extends to “equivalent” or “ICF/MR level” services under the HCBS waiver program.

In the West Virginia Benjamin H litigation (described below), the district court confronted a situation where a state had placed a moratorium on the development of new ICF/MR beds, nearly all available HCBS waiver slots were filled and only persons in crisis were offered services. Other individuals had little or no prospect of

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7 This decision is at supct.law.cornell.edu/supct/html/98-536.ZS.html. For more about the decision, go to the Atlanta Legal Aid Society website: atlantalegalaid.org/impact.htm
receiving services in the near term. The court ruled that “Medicaid provides entitlements” and the state’s restrictions on services violated the reasonable promptness requirement. The court rejected the state’s defense that it lacked the funds to provide the services because, in the court’s view, allowing this defense would permit states to “easily renege on their part of the Medicaid bargain by simply failing to appropriate sufficient funds.” In short, the court found that the state could not impose limits on the total number of people who could receive ICF/MR or HCBS waiver services. The court ordered the state to implement a plan to eliminate the waiting list and ensure that individuals could exercise free choice in selecting between institutional and community services.9

The Doe decision held that a state could not waitlist individuals for ICF/MR services and the Benjamin H decision spoke to the situation where a state had cut off access by limiting both ICF/MR and HCBS waiver services. Federal court rulings in some other lawsuits10 have pointed in the same direction as the Benjamin H ruling: namely, a person’s eligibility for entitled ICF/MR services extends to home and community services. But, it is still far from settled that individuals who are not receiving services but qualify for ICF/MR services are entitled to HCBS.

Developmental disabilities waiting list lawsuits vary with respect to the plaintiffs’ situations and the services they seek. In particular:

- In many cases, the lawsuit involves individuals who receive no services at all and are seeking HCBS waiver services (e.g., KY, TN, UT);
- Other lawsuits involve persons who already participate in the waiver program but have been wait listed for or denied some services offered in the program, most often residential services (e.g., CT, MA, WA);
- In a few lawsuits, the plaintiffs seek ICF/MR services in small community group homes as opposed to HCBS (e.g., CO); and,
- In other lawsuits, plaintiffs also include individuals who reside in ICFs/MR or large public institutions who are seeking HCBS instead as well as persons in the community waiting for services (e.g., NM, TX)

Status of Lawsuits

As of March 2005, lawsuits seeking community services for people with developmental disabilities had been filed in twenty-five states. Each lawsuit is summarized below. Presently, waiting list lawsuits in ten states (AL, CO, CT, KY, NE, OH, PA, TX, UT, WA) remain active. Settlements have been reached in twelve lawsuits (AK, DE, FL, HI, IL, ME, MA, MT, OR, TN, VA and WV). Three other cases (AR, NH, NM) have been dismissed.

Settlement agreements spell out steps to resolve the central issues in a fashion satisfactory to each side. The court must approve the agreement after conducting a “fairness hearing.” In the settlements, states typically have agreed to increase the number of individuals who receive Medicaid HCBS over a multi-year period (e.g., three to five years). Depending on the case, the agreement may address other issues. Settlements also specify the circumstances that might void the agreement (e.g., not securing funds to implement the agreement), and how disputes will be resolved, including returning to court if need be.


This complaint (00-CV-918) was filed in July 2000 in U.S. District Court for Middle Alabama on behalf of six plaintiffs with mental retardation. The lawsuit alleges that Alabama has failed to furnish ICF/MR or HCBS waiver services to eligible individuals. The plaintiffs were wait-listed for HCBS waiver services. The plaintiffs argue that Alabama’s limiting the number of persons who receive Medicaid long-term services violates: (a) the requirement that services must be furnished with reasonable promptness per §1902(a)(8) of the Act; (b) the requirement that services be furnished to all eligible individuals on a comparable basis, as provided in §1902(a)(10)(B) of the Act; and, (c) the 14th Amendment to the U.S. Constitution by depriving individuals of their right to apply for services.

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10 E.g., Prado-Steiman et al. v. Bush (see below)
The state moved to dismiss the complaint, arguing that: (a) waiver services differ from other Medicaid services and, thus, are not subject to the same requirements; (b) states have the authority to limit the number of individuals served through an HCBS waiver program; and, (c) the plaintiffs have no enforceable right under federal or state law to the services they seek and, thereby, an action cannot be brought in federal court. This lawsuit was quiet until recently. In June 2004, the court denied the state’s motion to dismiss and ordered the state to answer the plaintiff complaint. The case is slated to go to trial in October 2005 but the parties are engaged in settlement discussions.

2. Alaska: Carpenter et al. v. Alaska Department of Health and Social Services

A private attorney filed this lawsuit on behalf of 15 individuals in January 2001 in the U.S. District Court for Alaska. The lawsuit asserted that Alaska violated federal Medicaid law, the ADA, §504 of the Rehabilitation Act, and the 14th Amendment to the U.S. Constitution by wait listing indefinitely eligible children and adults with developmental disabilities. The complaint argued that Alaska violated the ADA integration mandate as well as Medicaid’s reasonable promptness requirement. The plaintiffs also alleged that Alaska violated federal requirements by improperly processing Medicaid applications and not giving individuals the opportunity to appeal adverse decisions about service authorization or changes in services. The plaintiffs did not seek class certification. In March 2002, the Court accepted a stipulated agreement by the parties to dismiss the suit.


Filed in June 2003 in the U.S. District Court for Eastern Arkansas, this lawsuit (03cv493) challenged Arkansas’ practice of wait listing individuals for its HCBS waiver program for people with disabilities rather than allowing them to submit an application. In Arkansas, the state’s practice had been to place individuals seeking services on a “request list.” The lawsuit was not brought as a class action.

The plaintiff argued that the state violated §1902(a)(8) of the Act by denying her the opportunity to apply for services and have her application acted upon promptly. The plaintiff also alleged violations of: (a) §1915(c)(2) of the Act for short circuiting her freedom to choose between ICF/MR and waiver services; (b) denying her access to the Medicaid Fair Hearing process under §1902(a)(3); and, (c) violating the procedural due process component of the 14th Amendment to the U.S. Constitution

At hearing, the court indicated that it was strongly inclined to order the state to provide an application to all individuals on the request list. The state conceded that federal law required that individuals be allowed to apply and have their applications acted upon promptly. It also agreed to offer waiver services to individuals on the request list up to its CMS approved participant cap. Reportedly, there were 1,000 available “slots” as a result of additional funding approved by the Arkansas legislature in its last session. Based on the state’s willingness to voluntarily comply, the Court dismissed the case in August 2003.


Private attorneys filed this class action complaint (00cv01609) in the U.S. District Court for Colorado in August 2000. The complaint asserts that Colorado has violated federal Medicaid law, the ADA, §504 of Rehabilitation Services Act of 1973, and the U.S. Constitution by failing to provide ICF/MR residential services with reasonable promptness to eligible individuals. The plaintiffs specifically seek ICF/MR small group home services rather than waiver services. In Colorado, only a handful of individuals are served in ICFs/MR. Almost all individuals receive Medicaid residential services through the state’s Comprehensive Services HCBS waiver program. The Arc of Colorado supports this lawsuit.\footnote{11 See statement at thearcfo.co.org/waitinglist.html}

In March 2002, Judge Richard P. Matsch ruled on the accumulated motions in the case. His rulings on four motions were of particular interest. First, he denied the state’s motion to dismiss the claim that Colorado is violating the §1902(a)(8) reasonable promptness requirement, relying on the opinion handed down by the 10th Circuit Court of Appeals in the New Mexico Lewis litigation. Second, Matsch granted a motion by the Colorado Association of Community Centered Boards (CACCB) to intervene. CCBs are non-profit agencies designated in Colorado law to provide or arrange for community services for individuals with developmental disabilities. The CACCB intervened because the outcome of the litigation could have a substantial impact on CCBs. In its motion to intervene, the CACCB introduced a new claim that Colorado violates §1902(a)(30)(A) of the Social Security Act because the state’s payments for community services are inadequate and caused their quality to erode. Under federal judicial rules, an intervenor may raise new claims germane to the litigation. The CACCB also claimed that wait listing individuals violated federal Medicaid law. However, it argued that this violation should be remedied by
expanding waiver services rather than ordering the state to furnish ICF/MR services.

Third, Judge Matsch denied the plaintiffs’ motion to certify the complaint as a class action. Matsch ruled that the plaintiffs (who seek ICF/MR group home services) were not representative of the class as proposed (which would have included individuals who may want different types of services). Matsch also observed that, if the plaintiffs prevail, systemic change would follow, thereby making class certification unnecessary. Last, he denied the plaintiffs’ motion for a preliminary injunction on two grounds. He pointed out that it was unclear that the plaintiffs would prevail on the merits. Second, he pointed out that the relief sought by the plaintiffs would cause major changes in the Colorado Medicaid program and have a major budgetary impact. Matsch decided that he did not have a basis to issue a preliminary injunction given its potential impact.

In July 2002, the state filed a motion to dismiss the plaintiffs’ claims. The state argued that it had no affirmative responsibility to develop ICFs/MR but instead that its role was akin to an “insurer,” limited to paying for services once delivered. In August 2002, the plaintiffs filed a motion for partial summary judgment. In their brief, the plaintiffs attacked the state’s reasoning, arguing that the state’s responsibilities under Medicaid law extend beyond mere claims payment and include assuring that services are furnished to eligible persons. The plaintiffs asked the Court to summarily find the state in violation of §1902(a)(8) and §1902(a)(10) of the Act for failing to furnish ICF/MR services with reasonable promptness and providing them to some but not all eligible persons. The plaintiffs asked the Court to take up their ADA and §504 claims after deciding the ICF/MR entitlement question. Plaintiffs urged the court to apply the ADA and §504 to remedy the alleged Medicaid Act violations by ordering the state to sponsor the development of small ICF/MR group homes that meet the ADA integration standard.

In September 2003, Judge Matsch ruled on the outstanding summary judgment motions. He denied the plaintiffs’ motions for summary judgment. At the same time, he denied the state’s motion to dismiss the plaintiffs’ claims that Colorado has violated §1902(a)(8) and §1902(a)(10) of the Social Security Act. These claims are at the center of the question of whether Colorado’s policies violate Medicaid law. Matsch also denied the state’s motion to dismiss the CACC B claim that Colorado’s payments for community services violate §1902(a)(30).

But, Matsch dismissed the plaintiffs’ ADA Title II and §504 claims, ruling that these claims were not “viable” and rejecting the plaintiffs’ argument that Colorado’s policies run afoul of the Olmstead decision, pointing out that “Olmstead does not stand for the proposition that a state must create, expand, or maintain programs for the purpose of preventing disabled individuals from becoming institutionalized.” He also rejected the plaintiffs’ proposition that he should consider the plaintiffs’ ADA and §504 claims when fashioning remedies for the Medicaid violations, ruling that each claim must stand on its own merits.

Trial took place in early June 2004. Finally, on February 28, 2005, Judge Matsch dismissed the plaintiffs’ and CACC B intervener claims. In the end, Matsch decided that he could not order the relief that the plaintiffs sought because it would amount to mandating that the state provide or actively develop ICF/MR services. Such an order, Matsch reasoned, would have the effect of his ordering an increase in state taxes or appropriations and/or cause the state to withdraw services from its Medicaid program, actions that would be tantamount to “an exercise of federal judicial authority [that] would encroach upon the fundamental powers of the State government” and undermine the “no more fundamental principle of democratic government than that which reserves to the people the power to tax and spend.” He decided that “the court cannot order the State to provide any particular level of ICF/MR services or to continue them in its State Plan.” At this juncture, it is not known whether the plaintiffs will appeal this decision.


This complaint (01-cv-1871) was filed in October 2001 in U.S. District Court for Connecticut by Arc/Connecticut against the Commissioners of the Departments of Mental Retardation (DMR) and Social Services (the state’s Medicaid agency) on behalf of persons with mental retardation wait-listed for Medicaid home and community-based waiver services. The plaintiffs include persons who receive some waiver services but are wait listed for principally residential services and persons who do not receive any waiver services at all.

The lawsuit challenges several state policies. A central issue is plaintiffs’ allegation that Connecticut has restricted waiver services based on available funding. The plaintiffs argue that this practice violates federal policy which requires that waiver participants receive the full range of services offered in a state’s program that are necessary to meet their needs. The state is al-

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2 The decision is located at: thearcofo.org/documents/MandyRvOwensMatschDecision.pdf
leged to have wait listed individuals who receive day and other supports for waiver residential services. In support, the plaintiffs pointed to January 2001 policy guidance contained in the Centers for Medicare and Medicaid Services (CMS) Olmstead Letter #4.\(^\text{13}\) Among its provisions, the CMS letter spelled out the requirement that waiver participants must be furnished any covered service that they require within a reasonable period. The plaintiffs also allege that the state masks the operation of the waiver in a fashion that results in individuals and families not being allowed to apply for the program and thus leaving them unaware of its benefits. Finally, the plaintiffs argue that, unless Connecticut is directed to change how it operates its program, individuals face the prospect of waiting years for services.

In January 2003, the court granted class certification, thereby expanding the lawsuit’s scope to all 1,700 individuals on the state’s waiting list. The class includes all persons eligible for DMR services who have applied for and are eligible for the waiver program or would be eligible if they had the opportunity to apply. In February 2003, the plaintiffs filed a second amended complaint.\(^\text{14}\) The second amended complaint alleges that the state has violated: (a) §1902(a)(10)(B) of the Act by not making Medicaid services available on a comparable basis to all eligible persons; (b) §1902(a)(8) by not furnishing services with reasonable promptness and denying persons the opportunity to apply; (c) §1915(c)(2)(C) by not giving individuals a choice between institutional and waiver services; (d) §1915(c)(1) and §1915(c)(4) for limiting services under the waiver program to those available and funded rather than providing the services needed by each person; (e) the ADA by not permitting ICF/MR residents to apply for the waiver program until they already have been placed in the community and operating its Medicaid program in a way that does not afford equal access to covered benefits; (f) §1902(a)(3) for not giving individuals the opportunity to appeal decisions concerning their services; and, (g) the plaintiffs’ due process protections under the U.S. Constitution.

In August 2004, the state filed a motion to throw out the plaintiffs’ claims. The state contended that the issues in this litigation were no different than those settled in a similar case (Birks v. Lensink) about ten-years ago which established the state’s current priority waiting list system. The state also argued that the Medicaid Act does not confer individually enforceable rights on the plaintiffs, especially with respect to HCBS waiver services. The state also questioned the applicability of the ADA, contending that the ADA cannot serve as the basis for requiring a state to expand services and that the integration mandate only applies to institutionalized persons.

Arc/CT reports that an agreement has been reached to settle the lawsuit. The agreement must be approved by the Connecticut Legislature before it can be submitted to the court for approval. Until the legislature acts, details of the agreement are not available. However, Arc/CT has noted that “… while the additional resources that will be committed by the State will bring relief to a minimum of 1,250 people over the five-year period of implementation, the critical changes in the way the system treats and interacts with individuals and families will be the lasting legacy of the settlement…While we didn’t get everything we had hoped for, the compromises we did achieve will go a long way to improving the lives of many hundreds of individuals and their families who have been waiting far too long.” At last report, approval of the necessary funding was progressing through the legislature.\(^\text{15}\)


In April 2002, nine individuals – joined by The ARC of Delaware, Homes for Life Foundation, and Delaware People First – filed a class action complaint (02-cv-255) against the Delaware Department of Health and Social Services and its Division of Developmental Disability Services (DDDS) in the U.S. District Court for Delaware. The lawsuit charged that Delaware failed to serve more than 1,180 individuals who were eligible for but denied Medicaid HCBS waiver and/or community ICF/MR services. The Public Interest Law Center of Philadelphia and Community Legal Aid Society Disability Law Program (Delaware’s P&A agency) represented the plaintiffs.

The plaintiffs included individuals who live with aging caregivers along with residents of Stockley Center (Delaware’s public institution) assessed as appropriate to return to the community. The complaint alleged that these individuals have waited many years for services but had little prospect of receiving them any time soon. The proposed class included: (a) all individuals on the DDDS’ waiting list for community residential services; (b) all individuals receiving DDDS services eligible for but not receiving HCBS waiver or ICF/MR services; and, (c) all institutionalized persons who qualified for services in the community.

The plaintiffs argued that Delaware operates its service system in violation of Medicaid law, the ADA and the

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\(^\text{13}\) Located at: cms.hhs.gov/states/letters/smd11001.pdf

\(^\text{14}\) Located at: arct.com/WaitingListComplaint0203.htm.

\(^\text{15}\) Go to arct.com/new.html for more information.
U.S. Constitution, thereby leading to the “denial of necessary care and services, inappropriate placement in state institutions, restraint [of] ... liberty without due process, unnecessary and needless deterioration and regression in health status, the loss of opportunities to maximize self-determination and independence, and the loss of opportunities to live in integrated settings and to receive programs and services development in accordance with professional standards.”

The plaintiffs claimed that Delaware violated: (a) §1902(a)(8) of the Act by failing to provide Medicaid services with reasonable promptness and denying individuals the opportunity to apply for services; (b) Title II of the ADA and §504 of the Rehabilitation Act by not furnishing services in the most integrated setting. The complaint also alleged that Delaware does not have a “comprehensive effectively working plan” for placing qualified persons in less restrictive settings and was not moving its waiting list at a reasonable pace, as provided by the Olmstead decision; (c) §1902(a)(10) of the Act by not providing Medicaid services in adequate amount, duration and scope; (d) the Due Process Clause of the 14th Amendment to the Constitution and 42 U.S.C. §1983; and, (e) §1915(c)(2)(C) of the Act by not providing a choice between ICF/MR or waiver services.

In September 2003, the parties announced that they had arrived at an agreement to dismiss the lawsuit. In April 2004, the plaintiffs submitted a notice of dismissal to the court. This notice was based on a Memorandum of Understanding (MOU) agreed to by the parties. The MOU provides for the state to fund 79 new community residential placements in FY 2005, including placements for 24 Stockley residents. It also provides that the state will add a new waiver program to provide supports for persons who live with their families. The agreement also commits the state to collaborate with the plaintiffs to improve waiting list management and needs assessment as well as take other steps to strengthen community infrastructure. The MOU provides that the state will place additional Stockley residents in the community and seek increased funds to expand home and community services. In August 2004, the court approved the settlement.


In 1992, a class action complaint was filed (as Doe v. Chiles et al.) on behalf of individuals who had been wait-listed for ICF/MR services. The Doe complaint asserted that Florida violated federal Medicaid law by not furnishing ICF/MR services with reasonable promptness to eligible Medicaid recipients with developmental disabilities. In March 1998, the U.S. 11th Circuit Court of Appeals upheld the District Court’s 1996 ruling that wait listing individuals for ICF/MR services violated federal Medicaid law (see above). A second complaint – Prado-Steiman (98cv06496) – was filed by The Advocacy Center (Florida’s P&A agency). This complaint directly challenged Florida’s policies in operating its HCBS waiver program for people with developmental disabilities (especially by not furnishing needed services) and was amended to contest the state’s wait listing individuals. In August 2001, the District Court approved a settlement agreement in the Prado litigation that provided that all individuals waiting for services in July 1999 would receive services by 2001 and for the state to make substantial changes in the operation of its waiver program.

Led by Governor Jeb Bush, Florida has undertaken a major expansion of its HCBS waiver program for people with developmental disabilities. Since Bush took office in 1998, funding for developmental disabilities services has tripled and now exceeds $1 billion. Between 1998 and 2001, the number of persons participating in Florida’s waiver program for people with developmental disabilities doubled from 12,000 to 24,000. Among its other provisions, the Prado settlement agreement includes an “operational definition” of how the state will comply with the reasonable promptness requirement.

While Florida has made major strides in expanding community services, new issues have arisen since the settlement was reached, including the emergence of a “post-Prado” waiting list that reportedly has reached 15,000 individuals. These individuals sought services after July 1999 and, hence, are not covered by the settlement.

In March, 2002, the Advocacy Center filed a 20-page Notice of Material Breach of the Prado settlement, contending that systemic problems have led to the authorization of services that are “less than necessary to provide services in the community and in small facilities.” The letter outlined deficiencies in the Florida service system in eighteen areas including: provider development and access in various geographic areas, quality assurance, service delivery timelines, and due process. Florida’s Office of the Attorney General denied that the state had broken the terms of the agreement in “any material or systemic way.” Following attempts to mediate the issues, in July 2003 the Advocacy Center moved that the court to continue its jurisdiction, based on material breach of the settlement agreement. In March 2004, the court rejected the plaintiffs’ motion, finding that none of the alleged breaches warranted the court’s continued jurisdiction.

Makin. In December 1998, the Hawaii Disability Rights Center – state’s P&A agency – filed this class action complaint (98cv997) on behalf of 700 wait-listed individuals in the U.S. District Court for Hawai’i. The complaint alleged that the state’s practice of wait listing individuals for HCBS waiver services violated federal Medicaid law and the ADA. The state challenged the applicability of the ADA, arguing that the U.S. Supreme Court’s Olmstead decision dealt with only institutionalized persons. The district court rejected this argument by reasoning that the lack of community services would leave institutionalization as the only option available to individuals.

In April 2000, the state and plaintiffs forged a settlement agreement wherein the state agreed to increase the number of individuals served in the state’s HCBS waiver program by approximately 700 individuals over the three-year period ending June 30, 2003. By June 2002, approximately 560 additional individuals had been served. The agreement also provided that the state would not change its eligibility policies but would make other changes, including employing person-centered planning methods to identify the supports that individuals should receive.

Disability Rights Center. In September 2003, the Disability Rights Center completed its evaluation of the implementation of the settlement agreement. As a result of this evaluation, the Center filed a new class action complaint (03-00524) seeking declaratory and injunctive relief based on its view that the state has not complied with the Makin settlement agreement. In essence, the Center alleges that the state policies and practices have caused 300 Makin class members class to remain on the waiting list. The Center contends that the state furnished services to individuals who sought services after the settlement agreement rather than to the class members and, in FY 2002, reverted funds that could have been used to serve the class members. Moreover, the Center argues that some class members are not receiving the full range of services that they require. The plaintiffs claim that the state’s policies and practices violate: (a) the ADA; (b) §504 of the Rehabilitation Act; (c) the Constitution’s procedural due process provisions; (d) §1902(a)(8) of the Act; (e) §1915(c)(2)(A) by furnishing inadequate waiver services; and, (f) provisions of Hawai’i state law. The plaintiffs are asking the court to order the state to move individuals – including class members – off the waiting list at a reasonable pace, defined as furnishing services to them within six months and also rule that the state’s failure to adopt a comprehensive plan that assures the waiting list moves at a reasonable pace is unlawful. The parties are in settlement discussions. Absent a settlement, trial is scheduled for July 2005.


This lawsuit (00-cv-5392) was filed in September 2000 by a private attorney in the U.S. District Court for of Northern Illinois on behalf of five named plaintiffs with developmental disabilities eligible for but not receiving Medicaid long-term services. The complaint alleged that Illinois did not furnish Medicaid services with reasonable promptness nor afford individuals freedom of choice to select between ICF/MR and HCBS waiver services. The suit also alleged violations of other provisions of the Social Security Act, the ADA, §504 of the Rehabilitation Act and the 14th Amendment to the U.S. Constitution. The plaintiffs asked the court to “issue preliminary and permanent injunctive relief requiring the Defendants … to offer the Plaintiffs the full range of ICF/MR services or HCBS waiver services and other services for which they are eligible within 90 days or some other specifically defined, reasonably prompt period.”

In response, the state moved to dismiss, claiming immunity under the 11th Amendment and challenging the plaintiffs’ other claims. In May 2001, siding with the state, the court dismissed the plaintiffs’ ADA claim because the complaint was filed against public officials whereas Title II of the ADA speaks to the policies of a “public entity.” However, the court rejected the state’s arguments concerning the other claims, including sovereign immunity.

In February 2002, the court dismissed the lawsuit, deciding that the plaintiffs’ main claim was their lack of access to residential services near their families. The court was persuaded by the state’s arguments that (a) federal law does not require that a state arrange for services on the basis of proximity to family and (b) the services the plaintiffs sought might be available elsewhere in Illinois. The court also ruled that the plaintiffs lacking standing to bring the lawsuit.

In March 2002, the plaintiffs appealed the dismissal to the 7th Circuit Court of Appeals. The plaintiffs asked the Circuit to review the district court’s rulings on the Medicaid, ADA, and Rehabilitation Act claims and argued that facts unearthed during trial showed that the
state was not in compliance with federal law. In June 2002, the U.S. Department of Justice (USDOJ) Civil Rights Division submitted an amicus brief. The brief focused only on the district court’s dismissal of the ADA claim. The brief noted that the dismissal was based on a previous 7th Circuit ruling that USDOJ contended was in error. USDOJ argued that there was ample support for the proposition that individuals may sue public officials not just public entities in federal court to enjoin violations of the ADA.

In July 2002, another amicus brief was filed by the American Civil Liberties Union (ACLU) of Illinois, Equip for Equity (the Illinois P&A agency), and a coalition of Centers for Independent Living. This brief also argued for reinstating the ADA claim and that the district court paid insufficient attention to the interplay of Illinois’ policies and their impact on access to services in the most integrated setting in dismissing the ADA claim. The brief urged the Circuit to “leave for another day the many larger legal questions … regarding whether the Illinois system for providing services … complies with federal law.”

In October 2002, the state replied, again arguing that the plaintiffs lacked standing to bring suit and also that there was no enforceable federal requirement that individuals receive services in close proximity to their families. Next, the defendants asserted that their only responsibility under federal Medicaid law was to “provide appropriate rates of payment” but not to ensure that individuals receive necessary services. Finally, the state asserted that it had not waived 11th Amendment rights and urged dismissal of the lawsuit on sovereign immunity grounds.

In April 2003, the Circuit decided that the district court erred in finding that the plaintiffs lacked standing to pursue their Medicaid claims but upheld the lower court decision to reject these claims, ruling that federal law did not dictate that services be available near the individual’s family home. The Circuit also conceded that its prior ruling that suits brought under the ADA must be filed against public entities rather than state officials had been in error, based on decisions elsewhere.

But, the Circuit ruled that the district court erred in ruling that the plaintiffs lacked standing to sue under the Rehabilitation Act. The Circuit set aside the dismissal of the plaintiffs’ Rehabilitation Act and ADA claims. The Circuit remanded the lawsuit and “commended” to the district court the Olmstead decision, especially pointing to that part of the decision that provided "if... the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated," the state would not be violating Title II.18

In July 2004, the parties announced that they had arrived at a stipulated settlement of the lawsuit. The details of this settlement are not available but reportedly its scope is limited to the provision of services to the named plaintiffs. The court then dismissed the case.19


In February 2002, the Kentucky Division of Protection and Advocacy filed a lawsuit (02-CV-00023) in the U.S. District Court for Eastern Kentucky on behalf of four people with mental retardation and their family caregivers against the Cabinet for Health Services along with the Departments for Medicaid Services and Mental Health and Mental Retardation. The lawsuit charges that Kentucky has improperly wait listed individuals for Medicaid services.20 The plaintiffs also sought class certification on behalf of an estimated 1,800 wait-listed persons. In recent years, the Kentucky legislature has substantially boosted funding in order to reduce the waiting list but a long waiting list remains.

The plaintiffs argue that, even though they are eligible for ICF/MR level services, they have been wait-listed and have indefinite prospects for receiving services. They also complain that even individuals in emergency status are unable to receive services promptly despite their priority status. The complaint claims that Kentucky is violating: (a) §1902(a)(10)(A) of the Act for failing to provide ICF/MR level services to all Medicaid beneficiaries who are eligible for them; (b) §1902(a)(8) for failing to furnish services with reasonable promptness; (c) §1902(a)(10)(B) for making ICF/MR level services available to some Medicaid beneficiaries but not all; (d) Title II of the ADA and §504 of the Rehabilitation Act by failing to serve individuals in the most integrated setting; and, (e) §1915(c)(2)(C) by not giving eligible individuals a practical choice between ICF/MR or other available alternatives through the HCBS waiver program.

In March 2002, the District Court granted class certification and ruled in plaintiffs’ favor on other motions over state objections. The class is “all present and

18 The opinion is on the 7th Circuit’s web site at: ca7.uscourts.gov/op3.fw. Enter case number 02-1730.
19 A new lawsuit has been filed in Illinois concerning access to residential services. See in Part IV of this report.
20 More information is at kypa.net/community/Olmstead/waitinglist_1.html.
future Kentuckians with mental retardation and/or related conditions who live with caretakers who are eligible for, and have requested, but are not receiving Medical Assistance community residential and/or support services.” In June 2002, the 6th Circuit Court of Appeals denied the state's petition appealing the class certification. Trial was scheduled for January 2005.

However, in December 2004, the state filed a last-minute motion to dismiss, thus delaying the start of trial. The court turned down this motion on February 11, 2005. Kentucky P&A reports that the court “upheld our position on every provision of Medicaid law that we alleged in our case. In addition, the Court ruled that our claims under the Americans with Disabilities Act (ADA) and Section 504 were still viable. It also ruled that the state’s attempt to limit the Olmstead ruling to people in institutions was misplaced.”

In particular, the court affirmed that federal Medicaid law unambiguously confers individually enforceable rights under the provisions of §1902(a)(10)(A), §1902(a)(8) and §1915(c)(2)(C) and that §1905(a)(15) – in combination with other provisions – confers an individually enforceable right to ICF/MR services. The court also rejected the state’s arguments to throw out the ADA and §504 claims. Trial is being rescheduled.


In August 2001, a complaint (01-CV-00159) was filed in the U.S. District Court for Maine on behalf of three adults with developmental disabilities waiting for services was filed against the Maine Departments of Human Services (the Medicaid agency) and Behavioral and Developmental Services (which administers Maine’s HCBS waiver program). The lawsuit charged that the state did not furnish services to people with developmental disabilities in a “reasonably prompt” manner. Class-action certification was sought on behalf of 1,000 adults with developmental disabilities who were not receiving timely services.

In November 2001, the court denied the state’s motion to dismiss the lawsuit on 11th Amendment sovereign immunity grounds. The court portrayed the state’s arguments for dismissal as “while intellectually intriguing, are a didactic exercise in historical legal formalisms, apparently inspired by the musings of Justice Scalia ....” The Court pointed to previous 1st Circuit decisions that affirmed federal court jurisdiction in these types of lawsuits. In May 2002, the Court certified the class action over the state’s objections. The state petitioned the 1st Circuit to review the class action certification. In July 2002, the 1st Circuit rejected the petition.

In May 2003 the parties filed a joint motion asking the court to approve a settlement that they had worked out. In July 2003, the court approved the agreement. The agreement is effective January 2004 and the court will retain jurisdiction through December 2006. For purposes of the agreement, the class is defined as: “all developmentally disabled individuals who: (1) are current or future recipients of Medicaid in the State of Maine; (2) are no longer entitled to receive benefits and services through the Maine public school system; and (3) are eligible to receive intermediate care facilities and/or other services for the mentally retarded, or care under the Home and Community-Based Waiver Services for Persons with Mental Retardation.”

The agreement provides that the state will furnish Medicaid state plan day habilitation and case management services within 90-days to all individuals who had sought them in the past. In the case of individuals who newly qualify for services, the agreement provides for their receiving case management and day habilitation services within no more 225 days. When individuals also qualify for the waiver program and require “residential training services,” the agreement defines “reasonable promptness” as starting services in no more than 18-months. This timeframe reflects the state’s experience about the amount of time it takes to develop a residential setting that matches the needs and preferences of an individual, although state officials note that often less time is required. However, the agreement does not require the state to expand the waiver program over and above the already approved number of slots.


This class action complaint was filed in March 1999 (originally as Anderson v. Cellucci) by private attorneys on behalf of the plaintiffs and their families who were dissatisfied with the state’s pace in reducing its waiting list. The complaint asserted that Massachusetts violated federal Medicaid law and the ADA by failing to provide residential services with reasonable promptness to otherwise eligible individuals and by wait-listing them indefinitely. While the state had reduced the waiting list, the plaintiffs sought to accelerate the expansion of residential services.

In July 2000, the District Court issued a summary judgment in the plaintiffs’ favor, ruling that the state was required to furnish Medicaid residential services with reasonable promptness. But, the Court certified a

21 A description of the agreement and its full text are located at: drcm.org/rancourt.html
narrower class than proposed by the plaintiffs who had asked that it include all individuals wait listed for Medicaid residential services along with persons who would be eligible for them in the future. The Court narrowed the class to individuals already participating in the HCBS waiver program who were wait listed for residential services or wait listed persons not served in the waiver program who could be accommodated under its participant cap. The Court directed the state to furnish residential services to class members within 90-days or, if not feasible, to propose a plan to comply with the reasonable promptness requirement.

In November 2000, the parties agreed in principle to a settlement. In January 2001, the court approved a settlement agreement. The agreement modified the class to include all individuals wait listed as of July 2000, regardless of whether the person was receiving or would be eligible to receive HCW waiver services. The modified class had 2,437 members, including 1,961 waiting for out-of-home residential services only, 266 waiting for both residential and non-residential services (e.g., day services), and 210 waiting for non-residential services only. Under the agreement, the state committed to provide residential services to 300 more individuals in FY 2001 using already appropriated funds. Over the next five years (FY 2002 – 2006), the state agreed to seek funding to provide residential services to an additional 1,975 individuals at a pace of 375 – 400 persons per year. Individuals who do not receive residential services right away would receive “interim services” (in-home, family support and other services) until residential services became available. The parties also agreed to procedures for preparing residential and interim service plans. Over the five-year period 2002 – 2006, the state committed $355.8 million in total funding to expand services. Since the settlement was arrived at, each year additional funds have been appropriated in accordance with the agreement.


Filed in 1996 by the Montana Advocacy Program (the state’s P&A agency), this complaint alleged that Montana violated federal Medicaid law, the Americans with Disabilities Act integration mandate and the U.S. Constitution by failing to provide community services to residents of the state’s two public MR/DD institutions and individuals in the community at risk of institutionalization.

Court action stalled for a variety of reasons, including off and on settlement negotiations between the parties, the ill-health of the presiding judge, and a one-year stay pending the U.S. Supreme Court’s Olmstead decision. In August 2001, the presiding judge declared all the pending motions moot, deciding that starting over with a fresh set of motions would expedite the case. The parties submitted new briefs in May 2002. The lawsuit was narrowed to a class of an estimated 200 individuals served at Montana’s two public institutions (Eastmont Human Services Center and Montana Developmental Center (MDC)) since August 1996. The remaining claims concerned community integration under the ADA, the Rehabilitation Act, and the U.S. Constitution. Meantime, in its 2003 session, the Montana legislature approved the closure of Eastmont and the Center closed in December 2003. The parties arrived at a mediated settlement agreement that in February 2004. The agreement provides that the state will move 45 MDC residents into community living arrangements over the next four years. MDC currently serves approximately 90 individuals. The state also agreed to: (a) the repeal of a Montana law that allows court commitment of individuals who have “near total care” requirements. This law has been a leading source of new admissions to state facilities; (b) commit $200,000 annually for crisis prevention and intervention services to help maintain people in the community and reduce crisis admissions to MDC; (c) make improvements in MDC services; (d) improve its community quality assurance program; and, (e) take additional steps to strengthen community services for individuals with developmental disabilities.


In May 2003, six individuals with developmental disabilities filed suit (03-cv-03189) against the Nebraska Department of Health and Human Services in the U.S. District Court for Nebraska. The lawsuit charges that Nebraska has impermissibly wait listed individuals for waiver services and, furthermore, that the state’s policies result in inadequate services being furnished to a large percentage of waiver participants. The plaintiffs are represented by private attorneys and Nebraska Advocacy Services, the state’s P&A. Class action certification also is sought for.

All present and future individuals with developmental disabilities in Nebraska who are eligible for Medical Assistance Home and Community-Based Services but either are not receiving funding for such services, or are not receiving sufficient funding for such services to reasonably achieve the purpose of the service, assure the class member’s health and safety, or ensure progress toward independence, interdependence, productivity and community integration.

22 The settlement agreement and related materials are located on Montana Advocacy Program website at: www.mtadv.org.
The lawsuit alleged that about 800 individuals were waiting for services in Nebraska. In addition to seeking services for these individuals, the lawsuit challenges the state’s methods for authorizing services under its program. The state uses assessment results to set the number of hours of services a person may receive. The plaintiffs contend that this method is flawed because it leads to a large but unknown percentage of individuals not receiving enough hours of services to meet essential health and safety needs and/or make progress in achieving their individual goals.

The plaintiffs claim that the state violates: (a) the ADA and §504 of the Rehabilitation Act because the waiting list does not move at a reasonable pace and Nebraska does not have an effective working plan as called for in the Olmstead decision; (b) §1902(a)(8) of the Act by denying individuals the opportunity to apply for the waiver program and not providing services with reasonable promptness; (c) §1902(a)(10)(B) because the state’s service authorization mechanism impermissibly restricts the amount, duration and scope of services; (d) §1915(c)(2)(A) because the mechanism does not assure the health and welfare of waiver participants [N.B., The plaintiffs also allege that the state violates the requirements spelled out in CMS Olmstead Letter #4]; (e) Nebraska state law and regulations that require assisting individuals to achieve critical life outcomes; and, (f) the U.S. and Nebraska Constitutions and federal Medicaid law by not providing adequate due process protections and the right to a Medicaid Fair Hearing.

By way of relief, the plaintiffs want the court to direct the state to prepare and implement a comprehensive effective working plan that moves the waiting list at a reasonable pace, immediately provide waiver services to eligible individuals up to the number of waiver slots presently available, expand the program to serve more persons over the next three years, and revamp its service authorization mechanism.

In July 2003, the state moved to dismiss the ADA and §504 claims. The state argued that it enjoys sovereign immunity protection against lawsuits brought under the ADA and has not discriminated against individuals under either the ADA or §504. Furthermore, it asserted that the ADA, §504 and the Olmstead decision do not require a state to increase its spending for community services. Since none of the defendants are institutionalized, the state argued that they cannot make Olmstead-related claims.

In August 2003, the plaintiffs replied to the state’s motion to dismiss. They argued that, by accepting federal Medicaid funds, the state waived sovereign immunity. They also disputed the state’s interpretation of the Olmstead decision on several grounds, including the state’s assertion that it applies only to institutionalized persons. The plaintiffs also filed an amended complaint.

In October 2003, the state filed another motion to dismiss. The state reiterated its arguments concerning the ADA and §504 claims and again asserted sovereign immunity. In addition, the state contended that plaintiffs’ grievances were more properly addressed through state administrative appeals processes, which are subject to state judicial review. The state also disputed the validity of plaintiffs’ claims under federal Medicaid law. Finally, the state argued that claims based on Nebraska state law are outside the jurisdiction of federal courts in litigation brought under the provisions of §1983.

In early November 2003, the plaintiffs replied to the state’s motion to dismiss, disputing each of the state’s arguments. Later in the month, the state filed its reply brief, reasserting its arguments in support of dismissal.

In July 2004, the plaintiffs filed the motion for class certification. The plaintiffs estimate that the class now includes 1,400 individuals who waited for services for more than 90 days and 2,200 persons who are receiving inadequate community services or at risk of having their services reduced.

In August 2004, the court denied the state’s motion to dismiss the case. In September 2004, the state appealed this decision to the 8th Circuit Court of Appeals (04-3263). The district court has suspended further proceedings until the 8th Circuit hands down a ruling. The Circuit scheduled oral arguments for March 2005.


In January 2002, the Disabilities Rights Center (the state’s P&A agency) filed a class action complaint in Hillsborough County Superior Court, arguing that New Hampshire failed to provide adequate community-based services for people with developmental disabilities. The suit alleged that there are “well over 500 individuals” in the proposed class, including 325 Medicaid-eligible individuals wait-listed for services and a large number of persons who receive inadequate or inappropriate services. The plaintiffs demanded that the state furnish a “comprehensive array” of individualized community services.

The suit charged the state has not developed an adequate system of community services and programs, “including sufficient numbers of ICF/MR and other community living arrangements that meet the individualized needs of persons with developmental disabili-
ties...” The suit asked the court to order the state to furnish improved services not only for the wait listed persons but also for individuals who receive services but have been “...left to languish in inappropriate and, sometimes, overly restrictive placements.” The plaintiffs expressed dissatisfaction with the state’s attempts to develop programs and services for this group, portraying such efforts “piece-meal and inadequate.”

This lawsuit was filed in state rather than federal court and relies both on state and federal law as its basis. In particular, the suit claims that the state is violating: (a) New Hampshire law (RSA 171-A:13) which provides that “every developmentally disabled client has a right to adequate and humane habilitation and treatment including psychological, medical, vocational, social, educational or rehabilitative services as his condition requires to bring about an improvement in condition within the limits of modern knowledge”;
(b) §1902(a)(8) of the Act for waiting listing otherwise eligible persons and §1902(a)(3) for failing to provide a Fair Hearing for individuals whose claim for Medicaid services has not been acted upon with reasonable promptness; (c) Title II of the ADA for not having developed a sufficiently comprehensive program so that all persons with developmental disabilities can “remain in the community with their family and friends,” thereby putting them “at risk of being provided with inadequate, inappropriate or overly restrictive programs and services”; (d) the 5th and 14th Amendments to Constitution and 42 U.S.C. §1983 for abridging the plaintiffs’ due process rights; and, (e) the 14th Amendment for violating individuals’ right to equal protection by serving some individuals but wait-listing others.

In April 2002, the court denied the plaintiffs’ petition for injunctive and declaratory relief. The plaintiffs’ petition included six requests that covered class certification and called for the state to offer all eligible plaintiffs community services within 90 days. The court concluded that the petition did not meet New Hampshire’s tests for such relief. Deciding that the “proposed class members’ claims... include claims that extend far beyond those of the named plaintiffs,” the court also denied class certification.

In a subsequent proceeding, the court reversed itself concerning class certification. But, then in March 2003, the court again decided to deny certification, ruling that the proposed class was too broad and likely included individuals whose service needs were different and therefore might have different interests.

The plaintiffs appealed the denial of class certification to the New Hampshire Supreme Court, which refused to hear the appeal. The parties then agreed that the lawsuit would be treated as a voluntary non-suit without prejudice (i.e., the plaintiffs are free to refile later) and the case was dismissed (Priaulx, 2004).


This lawsuit (99-00021) was filed in January 1999 in the U.S. District Court for New Mexico by the state’s P&A agency with the support of The Arc of New Mexico. The class action complaint alleged New Mexico violated federal Medicaid law and the ADA by failing to provide Medicaid services in the community to eligible individuals with disabilities, thereby causing them to go without services or forcing them to accept institutional services. The proposed class included: (a) people with developmental disabilities wait-listed for HCB waiver services; (b) persons served in ICFs/MR who would benefit from waiver services; (c) persons served in nursing facilities who want community services; and, (d) wait-listed persons with disabilities who seek access to the state’s waiver for persons who are aged or disabled.

In April 2000, the court rejected the state’s motion to dismiss the lawsuit on sovereign immunity grounds and upheld the plaintiffs’ right to access to waiver services with “reasonable promptness.” In May 2000, the state asked the 10th U.S. Circuit Court of Appeals to reconsider of its immunity claim. Under federal judicial rules, an appeal based on a sovereign immunity claim stays further lower court action until the appeal is decided. Finally, in August 2001, the 10th Circuit denied the state’s appeal.23

In September 2001, the state moved again to dismiss the complaint, arguing that the lawsuit was moot because all the original named plaintiffs either were receiving waiver services or deceased. The state also challenged the P&A’s standing to pursue this litigation in its own right. In November 2001, the P&A filed a counter brief, arguing that it had standing under federal law to pursue the lawsuit and filed a motion to amend the original complaint.

In July 2002, the plaintiffs moved for summary judgment, contending that the “case presents a simple, straight forward question of law: Are the Defendants required to provide Medicaid waiver services to all eligible individuals with reasonable promptness? The law is clear and unequivocal: the defendants are so required.” In support, the plaintiffs pointed out that 2,600 individuals were wait listed for the state’s HCBS waiver program for people with developmental disabilities. The program served 2,300 individuals and has a federally approved cap of 3,200. There were

23 Decision is at: laws.findlaw.com/10th/002154.html
2,500 persons wait listed for the state’s HCBS waiver program for individuals who are disabled or elderly; that program served 1,500 individuals or 450 fewer than the federally-approved “cap.” The plaintiffs also noted that the average period that persons with developmental disabilities must wait for services was worsening and might reach 60-months. The plaintiffs argued that these facts were ample evidence that New Mexico did not furnish waiver services with reasonable promptness. The plaintiffs also took the state to task for not properly taking applications for waiver services. Instead, individuals are assigned to a “Central Registry” and eligibility is only determined once their name comes up. The state portrayed individuals on the Registry as having “applied to be considered” for waiver services rather than actual applicants. The plaintiffs argued this practice violates Medicaid law.

In August 2003, the court granted the plaintiffs’ motion for summary judgment, ruling that the state had not furnished waiver services with reasonable promptness. However, the court decided that the Medicaid reasonable promptness requirement extends only so far as there are funds and waiver slots available but not beyond such limits. Thus, the court’s ruling did not require that the state expand its program to serve all people on the waiting list. The court noted that the state had in the past not made full use of all available funds and admonished it to step up its efforts to diligently deploy its resources to serve as many individuals as possible each year.

The plaintiffs submitted a proposed order to implement the ruling. In October 2003, the state challenged the proposed order, which asked that the court to enter a permanent injunction to require that the state comply with applicable federal laws. The state argued that its policies met the parameters that the court spelled out in its August 2003 ruling. The state also contended that the proposed order went beyond the court’s ruling because it would require the state to serve more people in its waiver programs than the funds appropriated by the legislature. The state counter proposed that the court enter judgment in its favor.

In November 2003, the plaintiffs replied that the state had misconstrued the court’s August 2003 order. They asserted that the order provided that: (a) the state must promptly determine the eligibility of applicants rather than entering their names into a registry for future consideration when waiver slots become available and (b) the state must serve all eligible individuals until it reaches its federally-approved participant cap, irrespective of whether the legislature has earmarked the necessary dollars.

In February 2004, the court entered its judgment. The court ordered the state to allocate waiver slots as soon as they become available and determine an individual’s eligibility for waiver services within 90 days. It also ordered that the state provide waiver services within 90-days of finding that a person is eligible for waiver services. It also ordered the state to spend all funds appropriated for waiver services within the year appropriated. New Mexico advocates expected that 300 – 500 individuals will come off the waiting list as a result of this decision.

In September 2004, the plaintiffs filed a motion for the court to hold the state in contempt. The plaintiffs argue that the state is violating the court’s order to offer waiver services up to the federally approved participant limit for each waiver program. In October 2004, the state responded, arguing that the plaintiffs misunderstood the court’s February ruling and that the state’s obligation to furnish waiver services goes only so far as the funds it has available, not the waiver participant limit. The state urged the court to dismiss the plaintiff’s new motion.

17. Ohio: Martin et al. v. Taft et al.

Filed by Ohio Legal Rights Services (OLRS - the state’s P&A agency) in 1989, this class action complaint (89cv0362) alleges that Ohio violates Medicaid law as well as the ADA by failing to provide integrated residential services to all persons with developmental disabilities eligible for them. In 1993 the court rejected the state’s motion to dismiss the ADA claim on the basis of an 11th Amendment sovereign immunity defense, holding that Congress, in this instance, had the authority to abrogate immunity. In 1998, the parties agreed to a motion to stay further district court proceedings in the hope of working out an agreement to expand services. However, in July 2000, OLRS filed a motion for partial summary judgment asking the Court to find that the state is violating the ADA integration mandate because its Medicaid waiver waiting list is not “moving at a reasonable pace.”

In September 2002, the Court ruled on various motions. The Court denied the state’s motion to dismiss on sovereign immunity grounds and upheld some of the plaintiffs’ claims. However, the Court turned down the plaintiff motion for partial summary judgment. The Court urged the parties to settle the lawsuit, which had dragged on for more than a decade.

In June 2004, the parties announced that they had arrived at a settlement agreement. The class affected by this agreement included: “[A]ll mentally retarded or

24 The settlement agreement and associated press releases are located at: olrs.ohio.gov/asp/olrs_MartinSettle.asp.
developmentally disabled Ohioans who are, or will be, in need of community housing and services which are normalized, home-like and integrated, and a subclass who, in addition to being members of the class, are or will be, Medicaid recipients.” The agreement focused on providing community-integrated services to individuals who reside in state-operated residential centers, nursing homes, and large ICFs/MR.

Under the terms of the agreement, Governor Taft, in his FY 2006 and FY 2007 executive budget, agreed to propose “…the elimination of intermediate care facilities for the mentally retarded under the State of Ohio’s Medicaid [state] plan.” If the legislature approves legislation authorizing this action, the state then will submit a waiver request to the U.S. Department of Health and Human Services that would afford all ICF/MR residents the right to choose the setting in which they receive services. The agreement also provided that the state would earmark waiver slots to support the community transition of ICF/MR and nursing facility residents with developmental disabilities. The state also agreed to survey state developmental center and ICF/MR residents to determine the number who want to transition to the community. A fairness hearing was scheduled for September 2004.

The proposed settlement unleashed a torrent of protest. Dozens of objections to the settlement were filed with the court over the summer. The objections to the settlement revolve around the proposed elimination of ICF/MR services from the Ohio Medicaid program. The objectors, many of whom are ICF/MR residents and their guardians, believe that this step will undermine their entitlement to these services under federal law. The objectors petitioned the court to decertify the class, arguing that the agreement and the plaintiff attorneys do not adequately represent their interests. The high volume of objections led the court to cancel the fairness hearing. In response, the state and the plaintiffs filed “points of clarification” concerning the agreement and, in October 2004 filed a memorandum in opposition to dissolving the class. The state and the plaintiffs contended that the settlement maintains the ability of individuals to continue to reside in their current living arrangements but would clear the way for Ohio to come into compliance with the ADA’s integration mandate.

Additional plaintiff objectors have filed motions to dissolve the class. The controversy concerning the proposed settlement has continued to grow.25 In December 2004, Governor Taft announced that the state was withdrawing its objections to decertifying the class.26 If the class is dissolved, the proposed settlement would be nullified. The Taft Administration expressed the view that the policy changes incorporated in the settlement agreement are more properly addressed in the legislative arena.

In mid-February 2005, the court – over the objections of the ever-growing number of parties – appointed a Special Master to attempt to broker a new settlement agreement.

18. Oregon: Staley et al. v Kulongoski et al.

Filed in January 2000, this complaint (00cv00078) alleged that the state violated federal Medicaid law and the ADA by failing to furnish Medicaid long-term services to otherwise eligible individuals with developmental disabilities with reasonable promptness. In September 2000, the parties agreed to settle the lawsuit. The U.S. District Court for Oregon approved the settlement agreement in December 2000.

The settlement agreement was designed to implement the Universal Access Plan. The Plan provided that all eligible adults would receive at least a basic level of supports. The parties agreed that the settlement would include not only the named plaintiffs but also “all other similarly-situated individuals with developmental disabilities under the federal Medicaid program.” The settlement extended to 2007 and provided that the state would increase community funding by a cumulative total of $350 million. Under the agreement, the number of persons receiving “comprehensive services” (including 24-hour residential services) would grow by 50 per year over and above the number of individuals who receive such services due to emergencies. The state also agreed to furnish comprehensive services to all individuals in crisis. The number of persons receiving “support services” (defined as “in-home and personal supports costing up to $20,000 per year”) would increase by 4,600 over the agreement’s six-year period. Also, the agreement called for making additional investments in system infrastructure.

In its 2001 session, the Oregon Legislature funded the first two-years of the settlement. Also, to implement the plan, Oregon launched a new “self-directed support services” waiver program. But, Oregon experienced a steep drop in state revenues, leading to deep cuts in spending. In August 2002, the Oregon Advocacy Center (the state’s P&A agency) warned that it was prepared to return to court to seek relief under the material breach provisions of the settlement if budget cut-

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26 See: odmrdd.state.or.us/Includes/Press_Releases/MartinDecert.pdf
backs led the state not to fund the agreement. In February 2003, the state imposed a moratorium on enrollments in its waiver programs. By then, about 3,000 individuals were participating in the supports waiver.

In October 2003, the parties presented a modified settlement agreement to the court. The modified agreement acknowledged that Oregon’s severe budget crisis meant that the agreement’s timetable could not be followed. Under the modified agreement, the state was given until 2011 to fully implement the original agreement. The pace of expansion of both comprehensive and support services was slowed but the agreement still provides that in the end all eligible individuals would receive at least support services. The modified agreement provides for an additional 500 persons to receive support services each year through June 2007, when the number of persons served is expected to reach 5,122 individuals compared to 3,112 in June 2003. The agreement provides that all eligible persons will receive support services by June 2009. The modified agreement also preserves the network of support brokerages that Oregon created for individuals who receive support services. The parties agreed that the modified settlement was preferable to re-opening the litigation. In January 2004, the court gave its approval to the modified agreement because the affected class members raised no objections.


In May 2002, the Philadelphia-based Disability Law Project and two private attorneys filed a class action complaint (02-CV-03426) in the U.S. District Court for Eastern Pennsylvania against the Department of Public Welfare on behalf of four individuals who contend that Pennsylvania has not furnished ICF/MR services in small community group homes under the Medical Assistance program.”

The state filed moved to dismiss the complaint and opposed to class certification. The state argued that the complaint did not satisfy the test for bringing a lawsuit under §1983 because there is no federally enforceable individual right to ICF/MR services in small community residences and the reasonable promptness requirement applies in the “aggregate” but not to individuals. In July 2002, the plaintiffs urged the Court to deny the motion to dismiss, arguing that ICF/MR services are an individual entitlement under federal law and citing several federal court decisions that declared reasonable promptness is an enforceable individual right. The plaintiffs also argued that Congress had affirmed the enforceability of these rights.

In January 2003, the district court dismissed the lawsuit, accepting the state’s arguments. The court based its dismissal on: (a) its view that Medicaid law does not confer an individually enforceable right to services and, hence, the action does not meet the criteria for bringing a lawsuit under §1983. The court ruled that the Medicaid Act has an “aggregate” focus (e.g., whether the state is following its overall plan) rather than an “individual focus;” (b) the availability of a mechanism for individuals to appeal adverse decisions (the Fair Hearing process) means that an action cannot be brought under §1983, based on the Supreme Court’s decisions; and, (c) in any case, the court found that federal Medicaid law does not require that a state furnish ICF/MR services in small community group homes, and, thus, the plaintiffs cannot assert a right to such services. The court concluded that the “individuals referenced [in the lawsuit] are merely beneficiaries, not persons entitled to privately enforce the statute.” The court also concluded that only the federal government could sue the state over the operation of its Medicaid program.

In January 2003, the plaintiffs appealed the dismissal to the 3rd Circuit Court (03-1226). Ilene Shane, director of the Disabilities Law Project said, “We’re appealing because we believe it’s not a correct decision. If this decision were to be followed, it would reverse 30 years of jurisprudence where people with disabilities have litigated their rights.” Several organizations filed amicus briefs in support of the appeal, including AARP, Arc US, Families USA, and others.

In May 2004, the Circuit Court handed down a “precedential” opinion in this appeal. In a nutshell, the Circuit Court reversed the district court ruling. The

27 Information concerning the modified settlement agreement as available on the Oregon Advocacy Center’s website: www.oradvocacy.org/staley2003.htm.

28 The opinion is at: ca3.uscourts.gov/opinarch/031226p.pdf.
Circuit ruled that – the Gonzaga decision notwithstanding – federal Medicaid law conferred individually enforceable rights under the Social Security Act provisions that were the basis of the lawsuit’s legal claims.

In November 2004, the plaintiffs filed an amended complaint in district court, reasserting their right to receive ICF/MR services with reasonable promptness.


Brown. Filed in July 2000 by the state’s P&A agency, this class action complaint (00cv00665) alleges that Tennessee has violated federal Medicaid law by not furnishing ICF/MR or HCB waiver services with reasonable promptness to otherwise eligible individuals with developmental disabilities. The complaint estimated that about 850 individuals were wait listed for waiver services.

People First. In March 2001, People First of Tennessee filed another class action complaint (01cv00272), also in the U.S. District Court for Middle Tennessee. This complaint asserts that the state: (a) has failed to provide ICF/MR or HCB waiver services with reasonable promptness; (b) violates the ADA by failing to make reasonable modifications and accommodations so that individuals (including institutionalized persons) are served in the most integrated setting; (c) does not comply with §1902(a)(10) of the Act since it has not made ICF/MR or waiver services available to all eligible persons; (d) has denied individuals the right to apply for or be made aware of Medicaid services; (e) has discriminated against people with disabilities by not permitting all otherwise eligible persons to obtain services for which they are entitled, in violation of the ADA; (f) violates §1902(a)(3) of the Act and the Due Process Clause of the U.S. Constitution’s 14th Amendment by not providing individuals written notice of denial of Medicaid services, thereby preventing them from exercising their appeal rights; (g) has denied individuals free choice in receiving HCB waiver or ICF/MR services; and, (h) violates the Individuals with Disabilities Education Act by denying Medicaid payment for services to which school-age children are entitled.

The complaint alleged that approximately 2,000 persons with developmental disabilities were waiting for waiver services in Tennessee. The plaintiffs contend that the state has given insufficient attention to a growing backlog of people who need community services because most new resources are committed to placing residents out of state-operated institutions to comply with court orders in earlier institutional treatment lawsuits (People First v. Clover Bottom, et. al and United States of America v. State of Tennessee).

Status. In May 2003, the presiding judge asked the parties to consider consolidating both cases. The court arranged for a mediator and halted further activity pending the outcome of mediation. The court also denied both sets of plaintiffs’ and the state’s motions for summary judgment.

In February 2004, the Court gave its provisional approval to separate settlement agreements in both cases. These agreements are described below. A fairness hearing was held in April 2004 to hear objections to the agreements. In June 2004, the Court gave its final approval to the agreements.

Brown Settlement. Under the terms of this agreement, the state has agreed to formulate and seek federal approval of a new Self-Determination HCBS waiver program to serve individuals wait listed for services. The aim of the agreement is to eliminate or substantially reduce the waiting list. The new waiver program would provide up to $30,000 in services to each person and designed to give individuals (or, their families, if appropriate) latitude in selecting and directing their services. This funding is to be supplemented, if necessary, by additional short-term crisis and/or one-time diversion dollars to provide temporary additional services. The agreement provides that the new program would serve 600 individuals in its first year of operation and an additional 900 persons in the second year. Beyond the second year, the parties will reach agreement concerning further expansion of the program to address unmet needs. The agreement directs the state to offer services through the new waiver program on a priority basis to individuals who are in crisis or have urgent needs. In the event that a person’s needs cannot be met through the self-determination waiver, the individual will have the option to choose services through another waiver program.

The agreement also provides for the further expansion of the state’s current HCBS waiver program. Moreover, persons who remain on the waiting list are to receive $2,280 per year in “consumer-directed support” funding. The agreement also commits the state to implementing a Medicaid targeted case management program to specifically support individuals on the waiting list. The agreement provides for additional improvements in community services infrastructure.

People First Settlement. This settlement agreement acknowledges and complements the Brown settlement. The focus of this agreement is to “assure that all Ten-
nessee citizens who might be eligible for waiver services are given a reasonable opportunity to learn of the availability of waiver services and to apply for them.” The state has agreed to conduct a public information campaign to provide information to individuals who might be Medicaid-eligible regarding the waiver programs. The state also is to compile information concerning the number of individuals with mental retardation who are eligible for Medicaid waiver services but not receiving them.


In September 2002, eleven individuals and The Arc of Texas filed a class action complaint in the United States District Court for Eastern Texas against the Commissioners of the Texas Health and Human Services Commission (THHSC), the Texas Department of Mental Health and Mental Retardation (TDMHMR) and the Texas Department of Human Services (TDHS). The complaint charges that Texas has failed to “provide the plaintiffs and other Texans with mental retardation and developmental disabilities with community-based living options and services to which they are legally entitled that meet their needs.” The lawsuit asks the court to direct Texas to expand Medicaid home and community-based waiver services.

By way of background, THHSC is the Texas Medicaid Agency; TDMHMR operates the state’s Medicaid home and community-based services (HCS) waiver program for persons with mental retardation; TDHS operates the Community Living Assistance and Support Services (CLASS) Medicaid waiver program for persons with developmental disabilities other than mental retardation. Advocacy Inc., the state’s P&A agency, filed the complaint.

The complaint charges that about 17,500 people with mental retardation are wait listed for the HCS waiver program (which presently serves about 4,600 individuals) and another 7,300 individuals have requested but not received CLASS waiver services (the program serves about 1,800 individuals). The plaintiffs seek certification of a class that would include “all persons eligible to receive Medicaid waiver services, who have requested but not received waiver services with reasonable promptness.” The class also would include 11,000 individuals served in ICFs/MR who “are eligible to be considered for the kind of residential services that will enable them [to] become more fully integrated into the community.” This class is the largest proposed in a waiting list lawsuit to date.

The complaint charges that the state is violating: (a) §1902(a)(10)(A) of the Act by failing to make ICF/MR level services available in an adequate amount, duration and scope to all eligible persons; (b) §1915(c)(2)(C) by failing to provide individuals a choice between institutional and home and community-based services; (c) §1902(a)(8) by (i) not allowing individuals to apply for waiver services and instead wait listing them and (ii) not furnishing services to eligible individuals with reasonable promptness; (d) the 14th Amendment to the U.S. Constitution by not affording individuals equal protection; (e) the Due Process Clause of the U.S. Constitution; (f) the ADA and §504 of the Rehabilitation Act by failing to provide services in the most integrated setting. The state filed a motion to dismiss. In March 2003, the court granted the state’s motion to transfer the lawsuit to the Western District of Texas. (03-CV-231)

In May 2003, the Western District court issued an order that addressed eleven motions filed by both sides. First, the court denied the state’s motion to dismiss The Arc of Texas as a plaintiff in the litigation. The court, however, granted the state’s motions to dismiss the plaintiffs’ claims with respect to most provisions of Medicaid law, including comparability, HCBS waiver program freedom of choice, and reasonable promptness. With respect to these claims, the court held that states were authorized to limit the number of persons who participate in a waiver program and, thus, individuals cannot assert an enforceable right to such services once the waiver participant limit had been reached. But, the court turned down the state’s motion to dismiss the plaintiffs’ claims concerning due process under Medicaid law and the U.S. Constitution as well as the ADA and §504 claims. The court found that, with respect to these claims, the plaintiffs had individually enforceable rights and, hence, could seek redress in federal court under the provisions of §1983. In this part of the decision, the court relied heavily on the Olmstead decision, although it noted that the fundamental alteration defense might stand as a substantial barrier to the plaintiffs’ ultimately prevailing. The court also turned down the state’s sovereign immunity claims.

In June 2003, the state appealed the parts of the decision that ran against it to the 5th Circuit Court of Appeals (03-50608), once again claiming that sovereign immunity insulates the state from lawsuits based on the ADA and §504. As a result, district court proceedings were stayed until the Circuit disposed of the state’s interlocutory appeal. The Circuit allowed the U.S. Department of Justice to intervene on behalf of the plaintiffs. In its brief, USDOJ urged the court to turn down the appeal, arguing that it is well-established that states may be sued in federal court for alleged violations of both the ADA and §504. A

30 The brief is at: usdoj.gov/crt/briefs/mccarthy.pdf.
coalition of national organizations, including ADAPT, The Arc of the United States, the American Association of People with Disabilities and others, also petitioned the court to file _amicus_ brief on behalf of the plaintiffs. The court heard oral arguments in April 2004.

In August 2004, the three-judge panel handed down a split 2-1 decision. This decision solely addressed the relatively narrow issue of whether state officers are proper defendants in a lawsuit brought under Title II of the ADA.\(^{31}\) Texas had argued that only public entities could be sued under Title II. The panel ruled that state officers could be sued in their official capacity, a ruling that is consistent with similar rulings in other cases. The panel refused to hear the state’s arguments to dismiss the remaining claims, because such issues were not proper subjects for interlocutory appeal. In September 2004, the state petitioned for the appeal to be heard _en banc_ by the full Circuit Court. In December 2004, this petition was denied and the case remanded to the district court for further action. The state considered but decided against pursuing an appeal of the Circuit Court decision to the U.S. Supreme Court. The lawsuit will now go to trial.

22. Utah: D.C. _et al._ _v._ Williams _et al._

In December 2002, the Utah Disability Law Center (the state’s P&A) filed suit (02cv01395) against the Utah Department of Health and the Division of Services for People with Disabilities in the U.S. District Court for Utah on behalf of nine individuals and the Arc of Utah challenging the wait listing of persons with developmental disabilities for waiver services. The plaintiffs argue that wait listing violates federal Medicaid law, the ADA, and §504. Class certification is sought for roughly 1,300 individuals who have been found to have an immediate need for services but have been wait listed.

Plaintiffs contend that the state has: (a) refused to provide medically necessary waiver services to individuals; (b) failed to operate its Medicaid program in the best interest of recipients, as required in §1902(a)(19) of the Act; (c) not operated its Medicaid program to assure that services are sufficient in amount, scope and duration; (d) violated §1915(c)(2)(C) by not making waiver services available to individuals who qualify for ICF/MR services; (e) violated §1902(a)(8) of the Act by not making services available with reasonable promptness; (f) violated the ADA’s integration mandate by placing individuals at risk of institutionalization; and, (g) violated §504 of the Rehabilitation Act. The plaintiffs seek declaratory and injunctive relief in the form of an order that the state to develop a plan to serve wait listed individuals.

In January 2003, the state moved to dismiss the complaint, contending that:

“[the] plaintiffs lack standing because they have no protected right to HCBS waiver services. Specifically, plaintiffs possess no protected right to HCBS waiver services because of the upper limit [on the number of participants] and other Medicaid limitations placed on HCBS waiver services, and the substantial discretion granted [the state] in administering and providing HCBS waiver services.”

The state argued that, because federal law allows it to limit the number of individuals served in its waiver program, people wait-listed for the waiver cannot have an enforceable right to waiver services. Since they lack such a right, the state contended that the reasonable promptness requirement does not apply. Also, absent a right to waiver services, the state argued that plaintiffs do not have standing to bring suit under §1983. With respect to the plaintiffs’ claim that the state is violating §1915(c)(2)(C) by not giving individuals eligible for ICF/MR services a choice of waiver services, the state argued that it is only obligated to inform individuals of “feasible alternatives, if available under the waiver.”

If services are not available, then a “feasible alternative” does not exist. The state also asserted that the Supreme Court’s _Olmstead_ ruling does not apply because “plaintiffs are not being held in institutional placements against their will, [and hence] the ADA and Rehabilitation Act are inapplicable.” Lastly, the state argued that, in order to serve all wait-listed individuals, it would be forced to make a “fundamental alteration” by having to shift funds away from other programs in order to meet the needs of the plaintiffs.

The state pointed out that ADA regulations as well as the _Olmstead_ decision “allows states to resist modifications that entail a ‘fundamental alteration’ of the state’s services and programs.”

In March 2003, the plaintiffs filed a memorandum opposing the motion to dismiss. They contended that the HCBS waiver program is no different than any other Medicaid service and, therefore, the state cannot waitlist individuals. The plaintiffs also disputed the state’s _Olmstead_ interpretation, pointing out that other courts had found that the integration mandate applies to both individuals who are institutionalized and persons at risk of institutionalization.

In August 2003, the court addressed the pending motions. It decided to grant class certification. How-

\(^{31}\) Opinion is at: caselaw.lp.findlaw.com/data2/circs/5th/0350608pv2.pdf. For a discussion of this decision, see: healthlaw.org/pubs/courtwatch/200409.fifthcircuit.html
ever, the court threw out the plaintiffs’ Medicaid claims, following the district court’s reasoning in the Pennsylvania 
Sabree lawsuit that the Medicaid Act does not grant individually-enforceable rights based on the Supreme Court’s 
Gonzaga decision. The court then took up the state’s motion to dismiss the ADA and §504 Rehabilitation Act claims. It rejected the state’s argument that such claims may only be pursued by institutionalized persons and denied the motion to dismiss the claims. It also rejected the state’s sovereign immunity defense. Trial had been scheduled for March 2005 but has been delayed for about two months.

23. Virginia: Quibuyen v. Allen and Smith
Filed in December 2000 in the U.S. District Court for Virginia by a coalition of attorneys, this complaint alleged that the state impermissibly wait-listed individuals already enrolled in the state’s HCBS waiver program rather than furnishing the additional services that they required including residential services. The complaint argued that Virginia imposed limits on services to waiver participants that “…are foreign to the statutory and regulatory Medicaid scheme, and indeed are inimical to it in that they establish additional unapproved barriers for otherwise eligible persons to obtain assistance to which they are entitled under federal law.” Especially at issue was a June 1999 directive by the Department of Medical Services that restricted the circumstances when additional services (including residential services) would be provided. The directive limited new or expanded services only when a person no longer can remain in the family home due to caregiver incapacity or other critical situations. The complaint argued that this and other policies led to impermissible wait listing of persons for services for which they were otherwise eligible. In September 2001, the state agreed to change its policies so that individuals would receive all the services that they have been determined to require. As a result, the plaintiffs agreed to dismiss the lawsuit.

The Arc of Washington State. Filed in November 1999 in the U.S. District Court for Western Washington, this class action complaint (99cv5577) charged that Washington violated Medicaid law and the ADA by failing to provide long-term services with reasonable promptness to persons with developmental disabilities. The complaint alleged that there are several thousand individuals with developmental disabilities in need of Medicaid funded services but not receiving them and current Medicaid recipients who could benefit from additional services.

In rulings in this lawsuit, the court decided that: (a) eligibility for ICF/MR services is not sufficient to establish an entitlement to waiver services but (b) Medicaid law requires services to be furnished with reasonable promptness. In December 2000, the Court granted the state’s motion for summary judgment to dismiss the plaintiffs’ ADA claims. The plaintiffs claimed that the ADA requires that, if a state makes waiver services available to some individuals, it must furnish services to all similarly situated individuals. The Court ruled that the ADA cannot serve as the basis for ordering a state to increase the number of individuals who receive waiver services because such an order would constitute a “fundamental alteration.”

In April 2001, the parties reached a settlement and submitted it to the court in August. The agreement hinged on action by the Washington legislature to authorize $14 million in funding to expand services in FY 2003 and annualize these dollars to $24 million in future years. The legislature approved the first installment. The agreement also called for the parties to identify additional dollars to serve more individuals in the next biennium. Some 1,800 individuals were expected to benefit from the agreement.

But, in December 2002, the court rejected the settlement agreement. Washington Protection and Advocacy Services (WPAS, which represents institutionalized individuals in two other lawsuits) and Columbia Legal Services (which represents individuals in the Boyle v. Braddock litigation described below) objected to the settlement. Both parties argued that the agreement did not assure that the class members (including individuals they represent) would receive the services that they require. The court was persuaded by these arguments and expressed additional reservations about the settlement. As a result, the court rejected the settlement, dissolved the class, and lifted its stay on proceedings.

In June 2003, the court dismissed the lawsuit entirely, following much the same reasoning upon which it dismissed the Boyle lawsuit. The court decided that The Arc of Washington State did not have standing to bring the lawsuit. In moving for dismissal, the state argued that the case was no longer “ripe” for decision because the state was in the process of changing its waiver program. The court accepted this argument. Next, as it had in dismissing the Boyle lawsuit (see below), the court decided that the plaintiffs had not exhausted their

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32 The Court’s decision is located at [arcwa.org/arc_lawsuit_12-2-02.htm](http://arcwa.org/arc_lawsuit_12-2-02.htm).
administrative remedies. Finally, the court ruled that its intervening into how the state administers its programs would cause “needless conflict with the state’s administration of its own regulatory scheme.” In July 2003, the Arc of Washington appealed the dismissal to the 9th Circuit (03-35605). The parties completed the submission of briefs to the Circuit in February 2004. In July 2004, the state moved that the Circuit dismiss the appeal. This case has been consolidated with Boyle for purposes of oral argument.

Boyle v. Braddock. This class action complaint (01cv5687) was filed by Columbia Legal Services in December 2001 in the U.S. District Court for Western Washington. The complaint alleges that Washington has failed to furnish or make available the full range of services offered through the Community Alternatives (HCBS waiver) Program (CAP) to program participants. The plaintiffs cited examples of individuals not receiving necessary services or not being informed of services offered in the program. This complaint somewhat paralleled the Arc of Washington State v. Quasim complaint but focused exclusively on the alleged problems that current waiver participants have in accessing the full range of CAP services. The proposed class is composed of all current or future CAP participants.

Specifically, the complaint alleged that the state has: (a) violated §1902(a)(8) of the Act by not advising waiver participants of the availability of CAP services, failing to instruct them on how to request such services and not approving or providing needed services; (b) violated the requirement that the state put into place necessary safeguards to protect the health and welfare of participants; (c) failed to provide or arrange for appropriate assessments; (d) not furnished necessary services with reasonable promptness; (e) not permitted participants to exercise free choice of providers; (f) failed to provide participants with adequate written notice and an opportunity for a Fair Hearing when their service requests are denied, reduced or terminated; and, (g) deprived individuals of their property interest in Medicaid services without due process of law in violation of the 14th Amendment.

Proceedings in this case were stayed while the court weighed the settlement agreement in Arc of Washington State v. Quasim. When the court rejected that settlement, it lifted the stay on proceedings. State officials declared to the court that waiver policies had changed to make it clear that lack of funding “...is not a valid reason to deny a needed service to someone on the ... waiver.” They also declared that they had made numerous other changes to waiver policies that addressed issues raised by the plaintiffs.

The state opposed class certification and raised other objections to the lawsuit. The state argued that changes already made in CAP in response to a CMS review had addressed the plaintiffs’ issues. Also, the state asserted that it was converting CAP to four separate waiver programs and, hence, certifying the class with respect to the CAP program would be inappropriate. The state also argued that there is no right of private action to enforce individual claims for Medicaid services in any event. Finally, because each person’s situation should be addressed individually, the state contended that class certification would be inappropriate.

In April 2003, the court dismissed the case after denying class certification. The court concluded that the issues in question were the proper subject of state administrative procedures, which also provide for state judicial review in Washington. The plaintiffs countered that the issues in dispute were more properly addressed in a class action context and appealed the dismissal (03-35312) to the 9th Circuit Court.

This case has been consolidated with Arc of Washington State for purposes of oral argument. Circuit proceedings in both Arc of Washington State and Boyle had been suspended while the parties explored a mediated settlement. In mid-February, the parties notified the Court that they could not arrive at a settlement.

25. West Virginia: Benjamin H. et al. v. Ohl

This class action complaint (99-0338) was filed in April 1999 in the U.S. District Court for the Southern District of West Virginia and alleged that West Virginia violated federal Medicaid law and the ADA by failing to provide Medicaid long-term services with reasonable promptness to eligible individuals. In July 1999, the court quickly granted the plaintiffs’ motion for a preliminary injunction based on its finding that the plaintiffs were likely to prevail at trial based solely on the requirements of Medicaid law. The state was ordered to develop a plan that would eliminate waiting lists; establish reasonable time frames for placing persons in the waiver; allow persons to exercise their freedom of choice in selecting institutional or home based care; and, develop written policies to inform persons of the eligibility process along with policies and forms to afford proper notice and an opportunity for a fair hearing when applications for ICF/MR level services are denied or not acted on with reasonable promptness.

In March 2000, the court approved agreements between the parties to address the topics spelled out in

33 CMS has since approved this change.
34 The decision is at: healthlaw.org/pubs/199907benjamin.html
the preliminary injunction.\textsuperscript{35} West Virginia agreed to increase the number of individuals with developmental disabilities who receive HCB waiver services by 875 over a five-year period. The parties also agreed on revised procedures concerning service applications and giving individuals proper notice concerning the disposition of their applications. The state also submitted an application to HCFA to renew its HCBS waiver program, incorporating policy changes based required by the agreement and boosting the number of persons served. This request was approved in December 2000.

The court dismissed this case in August 2002 but retained jurisdiction to enforce its orders.

D. Lawsuits Involving Individuals with Other Disabilities

There also have been several lawsuits filed on behalf of individuals with other disabilities who are seeking community services. In general, the legal issues raised in these lawsuits parallel those in lawsuits concerning persons with developmental disabilities. These lawsuits have been filed by nursing facility residents who want to be in the community as well as persons with disabilities who face institutionalization due to the lack of home and community services.

1. Florida: Dubois et al. v. Rhonda Medows et al.

In April 2003, three individuals with traumatic brain or spinal cord injuries filed a class action complaint (03-CV-107) in the U.S. District Court for Northern Florida against the Florida Agency for Health Care Administration and Department of Health alleging that the state has violated Medicaid law and the ADA by failing to provide them Medicaid-funded long-term services in the community. These individuals had sought but not received community services through Florida’s Brain or Spinal Cord Injury (BSCI) waiver program. The lawsuit alleges that there are 226 (and possibly more) individuals impermissibly wait-listed for services. One plaintiff resides in a nursing facility; the other two plaintiffs are in the community at risk of institutionalization. The plaintiffs are represented by Southern Legal Counsel, a Gainesville non-profit public interest law firm and National Health Law Project attorneys.\textsuperscript{36}

The plaintiffs argue that they all have sought but been denied BSCI services due to lack of funds even though it is alleged that only a little more than one-half of the program’s approved slots are used. As a result, they have been unnecessarily segregated in nursing homes or are at imminent risk of segregation. The complaint charges that Florida has violated: (a) the ADA for failing to provide individuals with disabilities services in the most integrated setting and not administering its waiting list so that it moves at a reasonable pace; (b) §504 of the Rehabilitation Act; (c) §1902(a)(8) of the Act for not making home and community services available with reasonable promptness; (d) §1915(c)(2)(C) for failing to give individuals the choice between institutional and HCB waiver services; and, (e) the U.S. Constitution and Medicaid law by not affording the plaintiffs the opportunity to apply for services. Class certification also was sought.

In May 2003, the state moved to dismiss the lawsuit, contending that, although its federally-approved HCBS waiver application had 300 “slots,” the state had the latitude not to use all of them if appropriations were insufficient. In addition, the state argued on various grounds that, even if slots were available, it was not necessarily the case that the plaintiffs would be next in line to receive services. The state also objected to the plaintiffs’ ADA and Rehabilitation Act claims.

In June 2003, the plaintiffs opposed the state’s motion to dismiss. The plaintiffs argued that the state’s motion was flawed in several respects, including raising issues that more properly should be addressed at trial. The plaintiffs pointed out that their claims might be remedied if the state had a comprehensive working plan for placing individuals in the community and a waiting list that moved at a reasonable pace, as provided in the Olmstead decision.

In March 2004, the court ruled on various motions. Specifically, the court denied the state’s motion to dismiss, finding that the plaintiffs’ claims had potential merit. The court also approved class certification, defining the class as: “All individuals with traumatic brain or spinal cord injuries who the state has already determined or will determine to be eligible to receive BSCI Waiver Program Services and have not received such services.”

The lawsuit is being mediated. The parties are working toward finalizing a settlement agreement.


In January 2003, private attorneys filed a class action complaint (03-CV-288) in the U.S. District Court for Northern Georgia on behalf of individuals with physical disabilities who reside in nursing homes or are at risk of nursing home placement if not furnished community services. The plaintiffs contend that Georgia’s policies cause them to be unnecessarily segregated when they could be supported in the community. The complaint alleges that “[i]n the three and one-half

\textsuperscript{35} The settlement order is at healthlaw.org/docs/benh_order.pdf.

\textsuperscript{36} Background information concerning the suit is at: newswise.com/articles/2003/4/SLC_PIL.html.
years since the *Olmstead v. L.C.* decision, the State has made no significant effort to operate its long-term care services in an even-handed manner so that persons who need [home and community-based] services have this option.” The *Olmstead* decision concerned the unnecessary institutionalization of Georgians with disabilities.

The plaintiffs are persons who have severe physical disabilities and, except in one instance, reside in nursing facilities. They assert that, with appropriate supports, they could live in the community. Georgia operates two waiver programs — the Community Care Services Program and the Independent Care Waiver Program — for persons with disabilities. The plaintiffs are wait-listed for these waivers; however, the waiting lists are quite lengthy. In their complaint, the plaintiffs contend that Georgia spends about five times as much on institutional as community services.

The plaintiffs allege that Georgia’s policies violate: (a) ADA and §504 of the Rehabilitation Act due to the state’s failure to furnish services in the most integrated settings and its utilization of discriminatory criteria and methods of administration in its programs; (b) §1915(c)(2)(C) of the Act for failing to provide timely and adequate notice to individuals who might benefit from waiver services and provide individuals freedom of choice between institutional and waiver services; and, (c) §1902(a)(8) of the Act for failing to promptly provide community services to individuals.

In April 2003, the state answered the complaint, denying that its policies violated the plaintiffs’ rights. The state also argued that the complaint did not state a claim for relief that the court could grant.

In August 2004, the plaintiffs filed a class certification motion. The proposed class would include all persons with physical disabilities who: “(1) are qualified to receive long-term health-care and supportive services under Medicaid and state-funded programs administered by the state, and, (2) would prefer, and are qualified (with or without reasonable accommodations) to receive such services in a more integrated setting than a nursing home … but (3) are either unnecessarily confined and segregated in nursing homes, or on community-based services waiting lists that do not move at a reasonable pace.”

Also in August, the state moved to dismiss the plaintiffs’ Medicaid Act and Title II ADA claims. With respect to the Medicaid Act claims, the state argued that, based on the Supreme Court’s *Gonzaga* decision, the plaintiffs do not have standing because the Medicaid Act does not confer individually enforceable rights. With regard to the ADA, the state contended that Congress exceeded its authority when it enacted Title II and thus its provisions cannot be applied to the administration of the state’s waivers. This challenge to Title II prompted the U.S. Department of Justice to intervene as an *amicus*.

In September 2004, the plaintiffs responded to the state’s motion to dismiss the Medicaid Act and ADA Title II claims. They argued that the Medicaid Act provisions at issue clearly include “rights creating” language and, therefore, satisfy the Supreme Court’s tests for bringing action under §1983. They also contended that Congress did not exceed its authority in enacting Title II and, thus, Title II is applicable to Medicaid services. The court has not ruled on the outstanding motions by either party.

3. Indiana: Inch et. al. v. Humphrey and Griffin

In July 2000, the Indiana Civil Liberties Union filed this class action lawsuit in Marion County Superior Court on behalf of individuals with disabilities who reside in nursing homes or who are at risk of nursing home placement but want to live in integrated settings with services from Indiana’s HCB waiver for individuals who are elderly or disabled. The Indiana Family and Social Services Administration is the defendant. The lawsuit alleged that 2,000 individuals with disabilities are either on waiting lists for community services or suffering “unjustified institutional isolation” and, hence, experiencing discrimination prohibited by the ADA. The complaint pointed out that Indiana spent less than 9% of its elderly and disabled budget to support individuals in integrated home and community settings. It further alleged that new enrollments in the state’s community programs had been closed for two years and new applications were not being taken. The plaintiffs argued that people in nursing home facilities or at risk of nursing home placement must be given the choice of waiver services rather than *de facto* limited to institutional services. The plaintiffs sought preliminary and permanent injunctions to enjoin the state from continuing violations of the ADA and direct that Medicaid eligible individuals be offered community services.

In June 2003, the parties arrived at a settlement that applies to all nursing facility residents eligible for Indiana’s waiver program and individuals at imminent risk of nursing facility placement. The state has agreed to expand the waiver to serve an additional 3,000 individuals and provide more information about community services to nursing facility residents. This settlement reflects Indiana’s plan to reduce the use of nursing facilities in favor of expanding community services. In addition, the “settlement sets out specific criteria for assessing the community support needs of class members and requires the state to develop a
quality assurance plan for completing these assessments and discharges.” (Priaulx 2003)

In December 2000, a second class action complaint was filed in St. Joseph County Superior Court (South Bend) on behalf of individuals with developmental disabilities placed in nursing facilities due to the lack of HCBS waiver services. In September 2004, this lawsuit was settled. The state agreed to provide waiver services to 450 nursing facility residents with developmental disabilities over the next eight years. It is estimated that there are about 1,900 nursing facility residents with developmental disabilities statewide. In addition, the state agreed to meet face-to-face with the guardians of these residents to provide them with information about community alternatives.

   Kentucky: Watson et al. v. Weeks et al.

These lawsuits are similar. Both were filed in response to state actions to narrow eligibility for Medicaid long-term services in order to reduce state spending to address budget deficits. In each instance, the state raised the threshold level of assessed functional impairment necessary to qualify for Medicaid long-term services. This caused individuals with disabilities and older persons to lose eligibility. Predominantly but not exclusively, the persons affected by these actions are supported in the community through the HCBS waiver program rather than nursing facilities. In both cases, the plaintiffs challenge whether the state’s modified standards for determining eligibility are reasonable under the provisions of §1902(a)(17) of the Act and whether the state properly terminated the services of these individuals. In both cases, federal courts are asked to rollback the new restrictions.

Oregon. Eligibility for long-term services is based on an assessment mechanism. There are 17 “levels” of assessed need. In February 2003, as part of its efforts to balance its budget, the state cut off services to individuals who qualified for long-term services at lower levels of assessed need. This action caused several thousand individuals to potentially lose their eligibility; most of whom were receiving waiver services. The state, however, provided that these individuals could ask for a reassessment. This resulted in services being restored for many but not all individuals. In the budget for the current biennium, the Legislature directed that services be resumed for individuals in all but six levels of need. However, the net effect of these changes still was to narrow eligibility and cause individuals to lose services. In implementing these cuts, the Oregon Department of Human Services amended its HCBS waiver to incorporate these changes.

In response to the eligibility restriction, the Oregon Advocacy Center filed suit in February 2003 in the U.S. District Court for Oregon (03-227) to enjoin the state from terminating benefits for affected persons. OAC argued that the state’s assessment process was flawed and, consequently, failed to constitute a reasonable standard for determining eligibility under federal law. OAC also argued that the state had not properly notified individuals that their eligibility would be terminated. In June 2003, the court turned down the request for a preliminary injunction. The court reasoned that Oregon was free to reduce its HCBS waiver because it is optional. In addition, relying on the Gonzaga decision, the court decided that affected individuals did not have an enforceable right to services. Immediately, OAC appealed the denial of the injunction to the 9th Circuit Court (03-35545).37

The magistrate judge assigned the case prepared “Findings and Recommendations,” recommending that the court dismiss all the plaintiff motions, based on the optional nature of waiver services and the interpretation that individuals do not have individually enforceable rights for Medicaid services. In June 2004, the district court accepted the magistrate judge’s findings and recommendations, dismissed the plaintiff motions and granted the state’s motion to dismiss. Meantime, because the state’s budget picture has brightened somewhat, in April 2004 the Oregon Legislature approved restoring additional two levels of assessed need, effective July 2004. In August 2004, the plaintiffs appealed the dismissal to the 9th Circuit (04-35704). Oral argument has not yet been scheduled.

Kentucky. In January 2003, Kentucky made $250 million in Medicaid cuts in order to balance its budget. Among those cuts was an action to eliminate both nursing home and waiver services for individuals who had a “low intensity level of care.” This cut took effect in April 2003 and was expected to reduce Medicaid spending by $41 million.

In October 2003, Kentucky Legal Services Programs filed a class action complaint (03-68) in the U.S. District Court for Eastern Kentucky seeking preliminary and permanent injunctions to rollback the eligibility change.38 Attorneys with the National Senior Citizens Law Center assisted in this litigation. KLS alleges that the change in program eligibility criteria resulted in about 200 nursing facility residents and 1,200 HCBS waiver participants who are elderly and/or disabled losing eligibility. In addition, about 600 waiver

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37 Both the state and OAC briefs are located at: nsclc.org/news/03/07/appeal_watson.htm
38 Various materials, including the original complaint can be accessed at: nsclc.org/news/04/april/kentucky_preliminj.htm
applicants were denied services as a result of the change. As in the Oregon lawsuit, the plaintiffs challenge the state’s method of assessing individuals and whether the state’s procedures for terminating benefits met Medicaid and Constitutional requirements. The claims in this lawsuit roughly parallel those in the Oregon litigation.

In October 2003, the state moved to dismiss. In its motion, the state argued that the changes it made were well within the discretion afforded states in operating the Medicaid program. In addition, the state argued that the plaintiffs lack standing to bring suit in federal court because the Medicaid Act does not confer enforceable rights. The state also contended that, if it were required to roll back the changes, it might have no other choice but to eliminate its waiver program.

In November 2003, the plaintiffs moved for class certification and, in early December, responded to the state’s motion to dismiss. The plaintiffs disputed the state’s contention that the Medicaid Act does not confer enforceable rights, citing 6th Circuit rulings and other cases that ran counter to the state’s arguments.

In early January 2004, newly elected Governor Ernie Fletcher signed an emergency order to reverse many of the changes that triggered the lawsuit. While encouraged by this step, the plaintiffs contended that the state had not gone far enough. As a consequence, they continued to press their case. In January 2004, the plaintiffs moved for a preliminary injunction, asking the court to require the state to roll its policies back to those in effect prior to the April 2003 change. In February 2004, the state filed a motion opposing the injunction and submitted a proposed order to dismiss the lawsuit.

In March 2004, the court ruled on the state’s motion to dismiss and the plaintiffs’ motion for a preliminary injunction. The court denied the state’s motion, finding that federal Medicaid law provides the plaintiffs with individually enforceable rights. The court agreed with the plaintiffs’ contention that Medicaid’s comparability requirement (§1902(a)(10) (A) of the Act) and statutory provisions concerning the HCBS waiver program require that a state must make waiver services available to individuals who qualify for nursing facility services. The court also agreed with the plaintiffs that “there is no precedent that a state can alter eligibility for a mandatory Medicaid service simply because the state does not wish to pay the price required to provide the service to all eligible recipients.” The court further observed that “reducing benefits to qualified recipients by manipulating eligibility standards in order to make up for budget deficits is unreasonable and inconsistent with Medicaid objectives since it exposes recipients to ‘whimsical and arbitrary’ decisions ...” The court then granted the plaintiffs’ motion for a preliminary injunction and ordered the immediate restoration of benefits to all persons who had lost them. In a separate order, the court also granted class certification.

In June 2004, the court gave its preliminary approval to a settlement agreement. Under the agreement, the State committed to adopt revised eligibility regulations for nursing facility and waiver services. The plaintiff attorney characterized these rules as more liberal than the rules in effect prior to the April 2003 change that triggered the lawsuit. The settlement also provides for a re-evaluation of persons who were denied services under the previous rules. In August 2004, the Court gave final approval to the settlement agreement but decided to retain jurisdiction in the case for a period of two years.

5. Louisiana: Barthelemy et al. v. Louisiana Department of Health and Hospitals

In April 2000, five individuals (two with developmental disabilities and three with physical disabilities) along with Resources for Independent Living filed a complaint (00cv01083) in the U.S. District Court for Eastern Louisiana against the Louisiana Department of Health and Hospitals (DHH) alleging that the state was violating the ADA and §504 of the Rehabilitation Act by restricting the availability of services to “unnecessarily segregated settings” (i.e., nursing facilities). The plaintiffs with non-developmental disabilities sued for access to the state’s elderly and disabled and/or personal care attendant waiver programs; the plaintiffs with cognitive disabilities wanted access to Louisiana’s developmental disabilities and personal care attendant waiver programs. The plaintiffs charged that Louisiana spends “90% of its Medicaid funds on institutional services.” They asked the Court to: 1) grant class action status to Louisiana’s with disabilities who are unnecessarily institutionalized and 2) find the state in violation of the ADA and §504 of the Rehabilitation Act.

In August 2001, DHH Secretary David Hood unveiled a settlement agreement that provided for boosting state spending by $118 million over a four year period, provide community services to 1,700 more individuals and reduce waiting time for services to 90 days or less. The settlement plan submitted by DHH, agreed to by the plaintiffs and approved by the court addressed four broad areas: (a) reducing the waiting time for community-based services; (b) supporting people to make informed choices about service options; (c) adding a Medicaid state plan personal care services option; and, (d) instituting individualized long-term
care assessments through a new single point of entry system. The class certified for the agreement is composed of: “all persons with disabilities who are receiving Medicaid-funded services in nursing facilities, or who are at imminent risk of being admitted to a nursing facility to receive such services, who have applied for Medicaid-funded services in the community through one or more Medicaid-funded home and community-based waivers …, who have not been determined ineligible for such community-based services, and who have not received such Medicaid-funded community-based services.” In the agreement, the state committed to eliminate the waiting list for waiver services by 2005.

The agreement was later modified to delay the addition of entitled personal care services to the Medicaid state plan until July 2003; in exchange, the state agreed to add 500 more “slots” to its three waiver programs for adults with disabilities. The Louisiana Nursing Home Association objected to the personal care coverage but the court turned the objection aside. As a result of the expansion of waiver services, waiting lists have been reduced substantially.

In 2003, DHH submitted a $38 million request to the Louisiana legislature to fund the addition of personal care to the Medicaid state plan. But, the legislature balked at this request. Instead, it appropriated $28 million, instructed DHH to delay adding personal care to the Medicaid state plan, and directed state officials to return to court to seek a modification of the settlement agreement to expand waiver programs in lieu of adding personal care to the state plan. The Legislature expressed concern about the long-range costs of adding a new entitlement to the state’s Medicaid program. The plaintiffs warned that they would regard failure to implement this part of the settlement as a material breach.

In July 2003, as directed by the legislature, the state filed a motion to amend the settlement agreement. The state proposed to expand waiver programs to serve an additional 2,000 individuals instead of adding personal care coverage. In support, the state pointed out that more class members would qualify for waiver services than the state plan service because the waiver program has higher income eligibility thresholds. Also, the state argued that class members could access a wider range of services through the waiver. The state argued that the proposed expansion was sufficient to serve all remaining individuals waiting for services and individuals who would be likely to seek services in the near to mid-term. Lastly, the state argued that the legislature has shown a willingness to underwrite the costs of expanded waiver services and thereby using the waiver program to meet the needs of class members would provide stable funding.

The Louisiana Advocacy Center (LAC), which represents the plaintiffs, opposed changing the agreement. The plaintiffs argued that – absent an entitled personal care benefit – there was a danger that waiting lists would reemerge in Louisiana. In August 2003, LAC moved that the court enforce the settlement agreement. In its motion, LAC argued that was no material change to justify a change in the agreement. LAC pointed out that the coverage of personal care services had been expressly included in the settlement agreement to ensure that individuals have immediate access to services whether or not waiver slots were available. LAC also pointed out that the personal care benefit would provide more hours per week of services than were available through the waiver program and, furthermore, individuals served in the waiver program could also access state plan personal care benefits. LAC urged the court to order the state to implement state plan personal care services as rapidly as possible.

National AARP filed an amicus brief in support of the LAC motion. In the meantime, nursing home interests moved to intervene in support of the state’s proposed modification, expressing concern that the activating the personal care option might put their businesses at risk. In August 2003, the state replied to the plaintiff motion in opposition. The state reiterated that it was not seeking to escape its obligations but only to alter how services are provided.

In September 2003, the court denied the state’s motion to modify the settlement, directed it to comply with the settlement order and rejected the nursing home request to intervene. However, the court turned down the plaintiffs’ request that the court enforce the settlement agreement. DHH affirmed it would comply with the court order. The Legislature then gave DHH officials the go ahead to submit a Medicaid plan amendment to add personal care but directed that DHH return to the Legislature for approval in the event that CMS required modifications in the plan amendment.

After encountering some initial difficulties securing CMS approval of the plan amendment, the state got the go ahead to offer personal care in January 2004. State officials expected that 2,300 individuals would receive personal care by June 2004. Reportedly, within three weeks of the program’s launch, the state had received 1,000 applications. However, due to delays in

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39 A press release announcing the initiation of the program is at: 
dhh.state.la.us/news.asp?Detail=216

40 For more information concerning the “successes and challenges” stemming from this lawsuit, please go to 
ad vocacyla.org/whatsnew.html.
processing applications, LAC returned to court in July 2004 to demand that the state establish timelines for prompt action on requests for personal care services. In August 2004, the state opposed the plaintiff motion that the court intervene to enforce the agreement. The state argued that it had done all that was possible to expand services and court intervention was not appropriate. Later that month, the court refused to intervene.


In March, 2002, six individuals and five advocacy organizations filed a lawsuit (5-02-00044-DWM) in the U.S. District Court for Western Michigan to overturn the state’s freeze on enrollments to the MIChoice Program, a Medicaid waiver program for persons with disabilities and seniors otherwise eligible for nursing facility services. The approved capacity of the MIChoice program was 15,000 individuals. As a result of an October 2001 freeze on enrollments, the plaintiffs contended that fewer than 11,000 individuals were participating in the program even though service demand remained high. The lawsuit was filed by Michigan Protection and Advocacy Services and the Michigan Poverty Law Program with support by a coalition of disability advocacy organizations.

The plaintiffs advanced two major legal claims. The first is that the freeze on enrollments violates the ADA by forcing individuals to seek nursing facility care rather than receive services in the most integrated setting. The second claim was that Michigan – under the terms of the waiver as approved – cannot close enrollments so long as fewer than 15,000 individuals participate. The plaintiffs also claim that Michigan did not provide individuals a choice between institutional and waiver services, maintain a proper waiting list for the MIChoice program, and violated the reasonable promptness requirement. The proceedings were put on hold to give newly-elected Governor Granholm’s administration time to formulate its position concerning the litigation. The Governor subsequently announced that she was reopening program enrollments to a limited extent.

In December 2003, the parties submitted a proposed settlement agreement to the court. In part, the agreement provides that the state will: (a) provide for no less than $100 million in funding for MIChoice in the current fiscal year, ask the legislature to approve a change in Medicaid policy that would permit an additional $25 million to be allocated to MI Choice, and pursue additional changes that might result in yet another $25 million to be allocated to the program; (b) distribute informational materials concerning MI Choice services to individuals receiving Medicaid long-term care services and make them available to future applicants; (c) ensure that individuals choosing between waiver and institutional services are provided information about the full-range of available long-term services, including MIChoice; (d) adopt uniform medical/functional eligibility criteria that apply equally to waiver and nursing facility services; (e) develop procedures regarding the maintenance of waiting lists and obtain CMS approval for these procedures; (f) seek more funding for transitional services to individuals moving from nursing facilities to the community; and, (g) establish a Medicaid Long Term Care Task Force to develop options to expand the availability of home and community services and improve long-term services. In February 2004, the Court approved the settlement agreement.


In May 2002, the Coalition for Citizens with Disabilities filed a class action complaint (02cv00475) on behalf of the five nursing facility residents in the U.S. District Court for Southern Mississippi alleging that Mississippi’s policies lead to the unnecessary segregation of individuals with disabilities in nursing homes by not making home and community services available to them. The named defendants are the state’s Division of Medicaid and the Departments of Human Services and Rehabilitation Services. Plaintiffs allege that the state is violating: (a) the ADA and §504 of the Rehabilitation Act by failing to provide Medicaid services in the most integrated setting; (b) the Medicaid Act by not informing individuals who qualify for nursing facility services of feasible alternatives to institutionalization and thereby denying them the freedom to choose home and community services as an alternative; (c) §1902(a)(8) of the Act by not providing services with reasonable promptness; and, (d) §1902(a)(30)(A) by not making payments for Medicaid services that are “consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers.” (Priaulx, 2004). The court granted class certification in September 2003. Trial was scheduled to begin in October 2004. However, the parties informed the court that they have arrived at a settlement agreement. The details of this agreement are not available and its status is unclear.

8. New Hampshire: Bryson et al. v. Shumway and Fox

In December 1999, two persons with neurological disabilities who reside in nursing facilities but are wait-listed for the New Hampshire’s Acquired Brain Disorder (ABD) “model” HCBS waiver program filed a class action complaint (99-cv-558) in the U.S. District
Court for New Hampshire to gain access to community services. The plaintiffs alleged that the program is operated with “inadequate, capped funding through the HCB/ABI program, arbitrary limits [on] home health and other HCB services, and lack of coordination between the various public and private agencies which administer the Medicaid program.”

The plaintiffs argued that “states must ensure that services will be provided in a manner consistent with the best interests of the recipients” and that a state’s Medicaid program must be “sufficient in amount duration, and scope to reasonably achieve its purpose.” Moreover, they argued that the state’s “administration of the HCB/ABI program, which results in a failure to provide [HCB] services to eligible Medicaid recipients in a timely manner, defeats the purpose of the program and is insufficient in the amount, duration, and scope to reasonably achieve its purpose.” The plaintiffs made additional claims, including: 1) failure to provide Medicaid services in a “reasonably prompt manner;” 2) violation of the ADA by making mainly facility-based services available to eligible persons; and, 3) the due process clause of the 14th Amendment as well as other provisions of Medicaid law.

In October 2001, the court handed ruled on both parties’ motions for summary judgment. It dismissed two of the seven counts in the complaint, ruled that the state’s Medicaid program must serve no fewer than 200 individuals, and is insufficient in the amount, duration, and scope to reasonably achieve its purpose.” The court deferred judgment on three additional claims, including: 1) failure to provide Medicaid services in a “reasonably prompt manner;” 2) violation of the ADA by making mainly facility-based services available to eligible persons; and, 3) the due process clause of the 14th Amendment as well as other provisions of Medicaid law.

In December 2001, the court entered a final order. It found that HCBS waiver services must be furnished with reasonable promptness and that individuals are entitled to model waiver services until 200 persons are served. Federal law provides that the Secretary of Health and Human Services may not limit model waiver programs to fewer than 200 individuals. The order incorporated a stipulated agreement between the parties that eligible individuals be enrolled in the program within twelve months of their date of eligibility.

The state appealed the district court ruling to the 1st Circuit Court of Appeals. In October 2002, the Circuit ruled that the district court erred in its interpretation of §1915(c)(10) of the Social Security Act. The district court interpreted the statute to require that a model waiver program must serve no fewer than 200 individuals. The Circuit found that this provision instead barred the Secretary of HHS from denying a state’s request to serve up to 200 individuals but that a state could limit the number of individuals in a model waiver to fewer persons. The Circuit also noted that the state was obligated to furnish waiver services to individuals with reasonable promptness up to the limit it had established, characterizing the waiver participant cap as a limitation on eligibility. The Circuit affirmed the plaintiffs’ standing to pursue their claims in federal court under §1983. The Circuit affirmed the plaintiffs’ standing to pursue their claims in federal court under §1983.

Upon remand, the parties renewed their motions for summary judgment. In March 2004, the court denied both motions. In its order, the court pointed out that the 1st Circuit’s decision had effectively reduced the legal issues to those that revolve around the ADA and the principles laid down in the Olmstead decision. The court noted that its task was now to sort out New Hampshire’s policies in light of the Olmstead decision, a task that would require it to grapple with several complex questions, including whether New Hampshire’s waiting list is moving at a reasonable pace and the dividing line between “reasonable modifications” and “fundamental alteration.” The court indicated that it would not necessarily confine its consideration of these issues to the ABI waiver but might take into account the overall resources that might be available to meet the plaintiffs’ needs. In denying the motions for summary judgment, the court noted that neither party had presented sufficient evidence to permit it to rule on the ADA/Olmstead claims. Trial is scheduled for May 2005.


Filed in the U.S. District Court for the Western District of Washington in 2000 (00-cv-00944), this lawsuit challenged Washington State’s policy of not extending eligibility for its Medicaid Community Options Program Entry Services (COPES) HCBS waiver program.

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41 This decision is found at: nhd.uscourts.gov/ (by searching “opinions” for keyword “Bryson”).

42 The Circuit Court decision is at ca1.uscourts.gov/cgi-bin/getopn.pl?OPINION=02-1059.01A.
to “medically needy” individuals. Washington State limited eligibility for this program to individuals who are “categorically needy,” including persons whose income is less than 300% of the federal SSI benefit. Medically needy individuals (e.g., persons whose income exceeds categorically needy levels but who may spend down their income to qualify for Medicaid) may not participate in this program but they are eligible for nursing facility services. In this instance, the plaintiff had been participating in the COPES program but a slight increase in his income caused his status to change to medically needy. The state initiated action to terminate him from the COPES program and suggested that the plaintiff seek care in a nursing facility. The plaintiff filed suit, arguing that the state’s policy violated the ADA because he could not continue to receive services in his own home. The complaint was certified as a class action.43

In 2001, the district court ruled in the state’s favor. The Court found that the state was exercising its prerogative under the Medicaid Act to limit the services it provides to medically needy individuals. Under Medicaid law, coverage of medically needy individuals is optional for the states. In addition, a state is not required to offer the same services to medically needy persons that it offers to categorically needy beneficiaries. In light of this latitude, the district court decided that the state’s policy did not violate the ADA.

In 2001, the plaintiffs appealed this decision to the 9th Circuit (01-35689). In May 2003, a three-judge Circuit Court panel reversed the decision by a 2-1 margin and remanded the lawsuit back to the district court for reconsideration.44 The majority based its reversal on the ADA “integration mandate,” deciding that Washington’s policy of offering only nursing facility services

43 Another lawsuit challenging a state’s Medicaid financial eligibility policies for home and community-based services is Hermanson et al. v. Commonwealth of Massachusetts et al (00-cv-30156). This class action complaint challenged the state’s policy of applying more restrictive financial eligibility criteria to seniors than working age adults with disabilities. In essence, Massachusetts permitted younger persons with disabilities to qualify for Medicaid without spend down if their income did not exceed 133% of poverty but older persons faced spend down requirements when their income exceeded 100% of poverty. As a consequence, older persons could less readily access Medicaid personal assistance services than younger persons and, thus, the plaintiffs argued, were placed at greater risk of institutionalization. The plaintiffs claimed this policy violated the ADA’s integration mandate and its non-discrimination provisions. This lawsuit was settled in February 2003 when the state agreed to adopt more liberal financial eligibility criteria for older persons who need personal assistance. (Priaulx, 2003)

44 Decision is at: caselaw.findlaw.com/data2/circs/9th/0135689P.pdf

45 The dissent is included in the file containing the majority opinion at the foregoing URL.
III. Community Placement of Institutionalized Persons

A. Overview

There is a long history of litigation concerning institutionalized persons with disabilities, dating back to the landmark Alabama Wyatt v. Stickney lawsuit in 1970. In developmental disabilities services, this litigation revolved mainly around the conditions of public institutions and their lack of adequate and appropriate services. Over time, this litigation increasingly came to focus on the question of the necessity of institutional placement and led to court directives to place institutional residents in the community. There has been similar litigation concerning individuals confined to state mental health facilities.

The U.S. Supreme Court’s historic 1999 Olmstead decision ruled that the unnecessary segregation of individuals with disabilities in institutions constitutes prohibited discrimination under the ADA. In its majority opinion, the Court concluded that Title II of the ADA requires a state to place institutionalized persons with disabilities in community settings when: (a) the state’s treating professionals have determined that a community placement is appropriate; (b) the transfer from an institution to a more integrated setting is not opposed by the affected individual; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state along with meeting the needs of other persons. In the wake of the Olmstead decision, there have been several lawsuits concerning persons served in public institutions.

This part of the report tracks some of the lawsuits where the issue of the community placement of institutionalized persons has been engaged and where the principles set down by the Supreme Court are being adjudicated. In these lawsuits, Medicaid policy is typically not the main focus of litigation, although the Medicaid program might help underwrite the costs of community placement. Also included are lawsuits concerning individuals with mental disabilities who reside in nursing facilities where issues concerning community placement have arisen.

We also acknowledge that there have been several lawsuits filed to oppose the community placement of institutionalized persons with developmental disabilities. Many of these lawsuits have been filed in state court by institutional parent groups who are sometimes aligned with public employee associations. Often, these lawsuits revolve around the question of the standing of guardian parents to refuse consent for community placement. The outcome of some of these lawsuits has been to slow but not halt the closure of state facilities.

B. Description of Lawsuits


In October 2003, two residents of the Southeast Arkansas Human Development Center filed suit (03-CV-812) in the U.S. District Court for Eastern Arkansas against state officials to challenge the constitutionality of the admission and discharge procedures at Arkansas’ six large institutions for persons with developmental disabilities. The plaintiffs claim that the state’s not providing for judicial hearings to determine whether they must continue to be confined at a Human Development Center violates the Due Process and Equal Protection clauses of the 14th Amendment. Under Arkansas state law, the parents of an individual with mental retardation may petition for their voluntary admission to a state facility and persons so admitted may be discharged at the request of parents. However, there is no provision for judicial review of the continued placement of an individual at a facility. The plaintiffs are asking the court to declare Arkansas’ policies unconstitutional and to direct the state to institute appropriate judicial review procedures. This complaint was filed on behalf of the plaintiffs by the Arkansas Disability Rights Center, the state’s P&A.

In February, 2004, the court turned aside the state’s motion to dismiss the lawsuit. While dismissing the plaintiffs’ Equal Protection claims, the court decided that there was a potential basis for their Due Process claims. In addition, the court permitted an association of Human Development Center families to intervene. In March 2004, the plaintiffs filed a second amended complaint. In July and August 2004, the plaintiffs and the state moved for summary judgment.

In November 2004, the court ruled on summary judgment motions. It decided that Arkansas admission policies met due process tests but ordered the state to develop post-admission review procedures to ensure that individuals admitted as a result of a parent/guardian petition would not be unnecessarily confined in an HDC when they have been determined to benefit from community placement.

46 It is worth noting that, in December 2003, the Wyatt case was dismissed 33-years after the complaint was originally filed. The court found that Alabama had satisfactorily implemented a settlement agreement that was entered into in 2000. For more information: bazelon.org/newsroom/12-15-03wyatt.htm.

47 There is additional information at: arkdisabilityrights.org/law/alerts.html
2. California: Davis et al. v. California Health and Human Services Agency et al.

In 2000, a class action complaint was filed in the U.S. District Court for the Northern District of California on behalf of present and potential residents of Laguna Honda Hospital (a 1,200-bed nursing facility in San Francisco). This lawsuit was triggered when plans were announced for a $400 million renovation of the facility. The complaint argued that the City and County of San Francisco (which operates the facility) along with several state agencies were violating federal Medicaid law and the ADA by denying individuals with disabilities access to community services and thereby forcing them to remain or become institutionalized. Plaintiffs are represented by a coalition of disability and advocacy organizations. The US Department of Justice also filed a friend of the court brief in support of the plaintiffs. In August 2001, the Court rejected San Francisco’s motion to dismiss the lawsuit. The facility has been the subject of an ongoing investigation by USDOJ under the provisions of the Civil Rights for Institutionalized Persons Act (CRIPA). In April 2003, USDOJ wrote the City of San Francisco that it had found the operation of the facility did not comport with the principles enunciated by the Supreme Court in Olmstead decision. USDOJ faulted discharge planning at the facility and noted that many residents had been identified who could be served in a more integrated setting. It urged the City to increase the availability of home and community services and make other changes. Absent resolution of these issues, USDOJ warned that the Attorney General might institute a lawsuit to correct the deficiencies.

In December 2003, the court gave preliminary approval to settlement agreements between the plaintiffs, the city and the state. Under the agreement, the city will launch a targeted case management program to assess current residents and potential admissions to the facility to determine whether other community alternatives could be furnished to them instead. Also, the city agreed to furnish information about community services to current residents and take additional steps to encourage the use of community alternatives. In addition, California will revamp its pre-admission screening program for individuals with psychiatric disabilities to place greater emphasis on community alternatives to nursing home placement. The settlement, however, does not stop the renovation of the facility, which began in November and is expected to be completed in 2007. The plaintiffs have reserved the option to refile elements of the lawsuit that involve the community placement of facility residents. This option might be invoked if sufficient community alternatives are not provided.

3. California: Capitol People First et al. v. California Department of Developmental Services et al.

This class action complaint was filed in January 2002 in Alameda County Superior Court by California Protection and Advocacy, Inc. on behalf of 12 individuals with developmental disabilities served in state Developmental Centers or other large congregate facilities (including nursing facilities), three community organizations and two taxpayers. The lawsuit was filed against the Departments of Developmental Services, Health Services and Finance along with California’s Health and Human Services Agency and the 21 nonprofit Regional Centers that manage community services for people with developmental disabilities. The lawsuit charges that California has caused thousands of individuals to be “needlessly isolated and segregated” in large congregate public and private facilities and further contends that the lack of appropriate community services causes persons with disabilities to be put at risk of institutionalization. The plaintiffs argue that California’s policies violate the state’s Lanterman Act (especially its “integration mandate”) and Constitution along with the ADA, federal Medicaid law, §504 of the Rehabilitation Act and the federal Constitution. The Lanterman Act governs the delivery of services for persons with developmental disabilities and requires that all eligible persons be provided services. The plaintiffs have asked the court to certify a class of “all Californians with developmental disabilities who are or will be institutionalized, and those who are or will be at risk of institutionalization in either public or private facilities, including but not limited to, the Developmental Centers, skilled nursing facilities, intermediate care facilities (ICF/DDs), large congregate care facilities, psychiatric hospitals or children’s shelters.” If the class is certified as proposed, it would include roughly 6,000 persons residing in large congregate facilities and an estimated 400 individuals who are at risk of institutionalization each year. According to the plaintiffs, some 1,000 of the 3,700 persons served at the state’s Developmental Centers have been recommended for discharge to the community but continue to be inappropriately institutionalized.

The lawsuit asks the Court to order sweeping changes in California’s services for people with developmental disabilities. Information also is available at: [Link]

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48 The complaint is located at dredf.org/final.html.
49 A description of the settlement agreement along with the agreements are located on the Bazelon Center website at: bazelon.org/newsroom/1-5-04davis_settlement.htm. More information also is available at: pai-ca.org/BulletinBoard/DavisvslHHSettlement.htm.
disabilities, including requiring the state to offer the full range of Medicaid home and community-based services to individuals and strengthening other dimensions of community services.\(^\text{30}\) In March 2002, the court decided to treat the lawsuit as “complex litigation” (2002038715) and assigned it a division expressly charged with handling such cases. In November 2002, the California Association of State Hospital Parent Councils for the Retarded (CASH/PCR) and the California Association for the Retarded (CAR) petitioned to intervene in the litigation. These associations are composed of parents of individuals served in state-operated facilities. They sought intervenor status because they do not believe that the defendants will adequately represent the interests of institutionalized persons who might be endangered by community placement. This petition was opposed by the plaintiffs along with some Regional Center defendants. In January, 2003, the Court gave the parents leave to intervene but confined the scope of their intervention to the “parameters of the complaint.” The court admonished the intervenors not to attempt to enlarge the issues in the litigation and confine themselves to two issues: “ensuring that the legal rights of parents to participate in the planning process and the ability of professionals to recommend placement in developmental centers are not adversely affected by any judgment in this action.”

In August 2003, the state defendants (as distinct from the Regional Center defendants) filed a motion for summary adjudication concerning the plaintiffs’ Lanterman Act claim to enforce the Act through court-issued “writs of mandate.” The state argued that the Lanterman Act creates only discretionary duties upon the state defendants and thereby the court cannot compel action because the Act does not create a “mandate duty” with respect to alleged violations. In addition, the state filed a motion to throw out the plaintiffs’ claim that the state’s policies violate the federal Medicaid Act.

In November 2003, the court handed down tentative rulings on the state’s motions. With respect to whether the Lanterman Act creates a mandateable duty that courts can enforce through writ proceedings, the court decided in the state’s favor and dismissed this cause of action. However, the Court noted that its dismissal did not address “whether Defendants are in compliance with the Lanterman Act or whether it can be enforced through other means.” The Court also dismissed plaintiffs’ claims alleging violations of the federal Medicaid Act. The Court was persuaded by the state’s argument that the Medicaid Act does not create a right of private action for individual beneficiaries, concluding that the Act “merely describes what states must do to ensure continued [federal] funding and authorizes the Secretary to withhold or limit Medicaid payments to a state in violation of [its] provisions.” In reaching this conclusion, the Court was persuaded by the federal district court decision in the Utah DC v. Williams litigation (see above) where the Court decided that the application of the U.S. Supreme Court’s Gonzaga decision led to the conclusion that the Medicaid Act does not confer individually enforceable rights. Still to be decided are the plaintiffs’ other claims, including their claims under the ADA and Rehabilitation Act as well as federal and state constitutional claims.

In December 2003, the Court clarified its November decision. The Court decided that, while it could not use a writ of mandate to remedy any wrong under the Lanterman Act, there was the potential that it could use injunctive relief to remedy violations of the Act. In addition, the Court gave the plaintiffs more time to fashion their petition for class certification. January 2004, the state filed a motion arguing that injunctive relief also could not be used to remedy violations of the Lanterman Act and asked the court to dismiss claims based on the Act. In February 2004, the court denied the state’s motion. Also, in February 2004, the plaintiffs filed their motion for class certification and a hearing on the motion was scheduled for April 2004.

In April 2004, the state petitioned the California Court of Appeal in San Francisco to stay proceedings in the lawsuit until the court could review the lower court’s Lanterman Act rulings. The Court of Appeal granted the stay. In its petition, the state once again argued that the Lanterman Act does not create a judicially enforceable “mandate” that requires people with disabilities to be served in the least restrictive setting. Instead, the statute should be regarded as merely intent language with implementation of the Act left to state and regional center discretion. The Court of Appeal issued a writ vacating the lower court’s Lanterman Act rulings. However, the Court gave the plaintiffs the leeway to amend their complaint to reinstate a violation of the Lanterman Act as a cause of action.

In July 2004, the plaintiffs filed an amended complaint. They also petitioned the court to reinstate their claims of violations of the Medicaid Act, citing rulings in other cases that ran contrary to the court’s view that Medicaid beneficiaries do not have individually enforceable rights, based on the Gonzaga decision. The State objected to the reassertion of Lanterman Act claims in the amended complaint. A hearing was held in late September concerning the reinstatement of the

\(^{30}\) More information is at pai-
ca.org/BulletinBoard/Index.htm#CPF
Medicaid Act claims and the state’s objections to the renewed Lanterman Act claims.


This 1998 class action complaint (98cv673) was filed in the U.S. District Court for Southern Florida and sought a declaratory judgment and permanent injunction to prevent the state from unnecessarily institutionalizing individuals with developmental disabilities in violation of the ADA integration mandate, §504 of the Rehabilitation Services Act, Medicaid law, and the U.S. Constitution. In March 1999, the U.S. District Court for the Southern District of Florida certified the Plaintiffs’ proposed class of: "all persons who on or after January 1, 1998, have resided, are residing, or will reside in DSIs [Developmental Services Institutions] including all persons who have been transferred from [institutions] to other settings, such as ICF, group homes, or SNFs but remain defendant's responsibility; and all persons at risk of being sent to DSIs."

Florida appealed the class certification to the 11th Circuit. In 2000, The 11th Circuit agreed that the proposed class was overly broad and remanded the case to the district court with instructions to certify the class as composed of “all individuals with developmental disabilities who were residing in a Florida DSI as of March 25,1998, and/or are currently residing in a Florida DSI who are Medicaid eligible and presently receiving Medicaid benefits, who have properly and formally requested a community-based placement, and who have been recommended by a State-qualified treatment professional or habilitation team for a less restrictive placement that would be medically and otherwise appropriate, given each individual's particular needs and circumstances.”

After extended negotiations and with the assistance of a mediator, the parties arrived at a settlement agreement. In July 2004, a final proposed agreement was presented to the court for review. The agreement provides that, by June 2005, the state will prepare a plan to close Gulf Coast Center and close the facility by 2010. Coupled with the closure of Community of Landmark (another DSI located in Opa Locka) that is slated for June 2005, the agreement will reduce from four to two the number of facilities that Florida operates. The agreement also provides for earmarking HCBS waiver “slots” to accommodate the transition of individuals from DSIs to the community, beginning in FY 2005.

The September 2004 notice of the proposed settlement agreement triggered numerous objections from groups and individuals interested in preserving institutional services. In December 2004, court held a fairness hearing concerning the proposed settlement.


This 1994 lawsuit (CCB-94-880) was filed in the U.S. District Court for Maryland against Maryland Department of Mental Health and Hygiene by institutionalized persons who had a traumatic brain injury or another developmental disability and were demanding that the state provide community services to them. The plaintiffs’ alleged that Maryland violated (a) the U.S. Constitution by unnecessarily confining them to institutions and (b) the ADA by not furnishing them services in the most integrated setting. In 1996, the Court denied both parties’ motions for summary judgment. Finally, in September 2001, the court dismissed the lawsuit, finding that Maryland had made a good faith effort to (a) meet the needs of the plaintiffs and (b) accommodate individuals in the community.

This lawsuit was filed prior to the Olmstead decision. The district court’s final decision came after the Olmstead decision and hinged in part on the court’s view that ordering Maryland to step up its efforts to support individuals in the community would cause a “fundamental alteration” in the state’s programs for individuals with disabilities. In arriving at this conclusion, the court noted that Maryland had substantially reduced the number of persons served in its institutions and increased community services. With respect to the plaintiffs, the court noted that the state had tried to arrange community services on their behalf, sometimes successfully but sometimes not. The court decided that ordering the state to step up its efforts would lead to increased expenditures in the short run and thereby affect the state’s capacity to serve other individuals. In the court’s view, this result would lead to a fundamental alteration and thereby exceed the parameters laid down by the Supreme Court.


In October 1998, a complaint was filed on behalf of seven Massachusetts residents with mental retardation and other developmental disabilities who were served in nursing facilities. The plaintiffs contended that they were denied alternative community placements or “specialized services” mandated by the federal Nursing Home Reform Amendments enacted in the Omnibus Budget Reconciliation Act of 1987. The law directed that states arrange alternative placements for inappropriately placed residents with developmental disabilities or mental illnesses or, if the person opts to remain in a nursing facility, furnish specialized ser-
vices that addressed their impairments. The plaintiffs also alleged that the failure to provide such services violated of Title II of the ADA.

In October 1999, the state agreed to offer community residential services and specialized services to nursing home residents with developmental disabilities under the terms of a mediated settlement agreement. The state consented to underwrite community placements to class members (858 individuals) unless it was determined that an individual could not “handle or benefit from a community residential setting.” These placements would take place over a multi-year period.

In 2000, the plaintiffs filed a motion asking the court to find the state in violation of the agreement concerning the provision of specialized services to individuals still residing in nursing facilities. In March 2001, the court ruled that the state was required to furnish specialized services sufficient to ensure “active treatment.” The court found that, if the services furnished by a nursing facility did not meet the active treatment standard, the Department of Mental Retardation was obliged to furnish supplementary services. In May 2002, the court granted the plaintiffs injunctive relief and ordered that all class members receive services that meet the “active treatment” standard. The state then appealed this ruling to the 1st Circuit on 11th Amendment sovereign immunity and other grounds.

In January 2003, the Circuit rejected the state’s appeal. In a nutshell, the court held that, under federal law, specialized services, including “active treatment” must be furnished to all individuals who need them. The state also had argued that the nursing home reform provisions did not confer a private right to action. The court rejected this argument, holding that the legislation in fact did confer a private right to action, enforceable through the federal courts.


In September 1999, Michigan’s P&A agency filed a complaint in state court on behalf of six individuals with developmental disabilities and/or mental illnesses served in nursing facilities but who wanted services in the community. In June 2000, this litigation was referred to the U.S. District Court for Western Michigan. The plaintiffs’ counsel estimated that there were 500 individuals with cognitive disabilities in nursing facilities who could be served in the community. The plaintiffs alleged that Michigan was violating the “Nursing Home Reform Act of 1987” and the ADA. This complaint was similar to Rolland v. Romney (see above) except that it included persons with a wider range of cognitive impairments. The Court turned down the state’s motion to dismiss the suit on sovereign immunity grounds. The parties then settled. The state agreed to “assure the appropriate and timely community placement of individuals determined to not require nursing facility care. (Priaulx, 2004).


In July 2003, Disability Advocates, Inc. filed a complaint (03cv03209) in the U.S. District Court for Eastern New York against Governor Pataki, the Department of Health and Office of Mental Health claiming that the placement of individuals with mental illnesses in large “adult homes” violates Title II of the Americans with Disabilities Act and §504 of the Rehabilitation Act by causing their needless institutionalization in substandard facilities when their needs could be more appropriately and effectively met in integrated residential settings. In part, this lawsuit was prompted by the revelations of substandard care in adult homes in a 2002 series of N.Y. Times articles.

“Adult homes” are facilities intended to provide room and board, housekeeping, personal care and supervision to residents. The costs of these facilities are underwritten by resident funds, including state SSI supplement payments. Residents of such facilities include individuals with physical disabilities. In New York, there also are a large number of facilities where a high percentage of residents are persons with serious mental illnesses. Facilities are labeled “impacted homes” when 75% or more of the residents have a mental illness. The lawsuit targets 26 such facilities in New York City that have more than 120 beds where an estimated 4,000 persons with mental illnesses reside. Statewide, it is estimated that 12,000 individuals with mental illnesses are served in such facilities. While adult homes nominally provide limited services to residents and are not classified as mental health facilities, residents of these facilities also receive Medicaid-funded health and mental health services from other vendors. The plaintiffs charge that these services do not adequately or appropriately meet the needs of adult care home residents.

The plaintiffs charge that impacted adult homes are

52 The decision is at laws.findlaw.com/1st/021697.html and discussed in greater depth in a Bazelon Center for Mental Health Law release (bazelon.org/newsroom/2-3-03rolland.htm.)

53 Disability Advocates, Inc. is an agency under the Protection and Advocacy for Individuals with Mental Illness Act. Co-counsel include New York Lawyers for the Public Interest, Inc., the Bazelon Center for Mental Health Law, MFY Legal Services and Urban Justice Center.

54 Go to bazelon.org/issues/disabilityrights/nycomplaint/index.htm to view the complaint and obtain additional information.
segregated institutional settings and as such fall under the purview of the ADA, §504 and the Olmstead decision. The plaintiffs point out that New York State also funds integrated “supported housing” living arrangements that are better geared to meeting the needs of people with serious mental illnesses. However, supported housing is in short supply. Citing studies conducted by the state, the plaintiffs allege that the costs of supporting individuals in supported housing arrangements are no greater than the overall costs of adult care homes (taking into account resident payments and other Medicaid services). Since residents could be served in a more integrated setting, the plaintiffs are asking the court to order the state to expand the availability of supported housing as well as order the state to improve conditions in adult homes.

In October 2003, New York Attorney General Spitzer replied to the complaint, disputing nearly all the allegations made in the complaint. The state argued that the plaintiffs lack standing to bring the complaint and also argued that the plaintiffs who reside in adult homes have not been determined by the state’s treating professionals as appropriate for a more integrated community setting and, thus, do not fall under the ambit of the Olmstead decision. Also, the state argued that the relief sought by the plaintiffs would lead to a fundamental alteration. Next, the state asserted an 11th Amendment sovereign immunity defense. Lastly, the state argued that the complaint is barred – in whole or in part – because the alleged violations fell outside the statute of limitations. Therefore, the state urged the court to dismiss the complaint but has not yet filed a formal motion for dismissal. Over the past several months, proceedings have been dominated by disputes concerning discovery issues.


In October 2003, a class action complaint (03-cv-08331) was filed in the United States District Court for Southern New York alleging that New York State is violating Title II of the ADA and §504 of the Rehabilitation Act by failing to furnish treatment services that would permit individuals with serious and persistent mental illnesses who also have a chemical addiction to be released from New York City jails.55 The plaintiffs allege that they have been discriminated against because other similarly situated individuals who have a chemical addiction but no or minor mental illness are released to community treatment programs more quickly. This complaint was brought on behalf of the plaintiffs by a coalition of organizations, including the Bazelon Center for Mental Health Law, the New York Legal Aid Society and the Urban Justice Center.

The plaintiffs are persons charged with violating the conditions of their parole or post-release supervision. Typically, they committed technical parole violations. The complaint alleges that these individuals have been recommended for placement in a residential treatment program in lieu of incarceration. However, a dearth of available residential treatment placements causes them to be needlessly incarcerated. The complaint charges that the lack of residential treatment programs results in these individuals languishing in jail, being sent to prison and fated to being trapped in a “vicious cycle between jail and the streets.” The plaintiffs are seeking relief in the form of New York State’s expanding supervised housing programs that serve and treat individuals with co-occurring disorders, either in the form of community residences or supported housing programs. The plaintiffs allege that the costs of needlessly confining these individuals are substantial and the dollars spent on incarceration should be redirected to underwriting community services for them.


In December 2000, the Oregon Legal Center filed suit (CV-00-01753) in the U.S. District Court for the District of Oregon on behalf of ten state psychiatric institution residents, contending that the state’s own treating professionals had found these individuals to be ready for community discharge but they continued to be institutionalized due to the lack of suitable community placements. The plaintiffs alleged that the state is violating Title II of the ADA, §504 of the Rehabilitation Act and the 14th Amendment’s Due Process Clause. In the plaintiffs’ view, this lawsuit revolved around issues analogous to those addressed in the Olmstead decision. The plaintiffs sought class certification.

The state moved for dismissal on various grounds, including 11th Amendment sovereign immunity. In September 2001, the court denied the state’s motion for dismissal. The state then appealed to the 9th Circuit Court of Appeals (01-35950). In May 2002, the 9th Circuit decided to take the appeal. In May 2003, the Circuit rejected the state’s appeal and remanded the case back to the district court for further action.56

In December 2003, the parties agreed to settle. In January 2004, the court gave its preliminary approval to the settlement. The agreement applies to the class as individuals who were civilly committed to an Oregon psychiatric hospital as of December 1, 2003, had not

55 The complaint and a discussion of the lawsuit are at: bazelon.org/newsroom/10-21-03rikers.htm.

56 The decision is at: caselaw.findlaw.com/data2/circs/9th/0135950P.pdf.
been discharged within 90-days of a “ready-to-place” determination by a treatment team, and had consented to community treatment. The agreement provides that the state will create 75 new community placements by June 2005 and establish a special $1.5 million fund to provide supplemental resources to facilitate the placement of individuals who have conditions that are barriers to community reintegration. At least 31 individuals are expected to be placed in the community by June 2005. In March 2004, the court approved the settlement agreement and dismissed the case but retained jurisdiction to enforce compliance with the agreement.


In September 2002, the U.S. District Court for Eastern Pennsylvania ruled against the plaintiffs in the Frederick L. v. Department of Public Welfare class action complaint. The plaintiffs are residents of Norristown State Hospital who claim that their continued institutionalization at a state facility – despite recommendations for community placement – violates the ADA and § 504 of the Rehabilitation Act. The Court ruled that the plaintiffs’ circumstances fell within the criteria spelled out in the Olmstead decision. However, the Court decided that accelerating the pace of community placement would lead to increased expenditures and thereby potentially result in reductions in services to other individuals. The Court decided that this would constitute a “fundamental alteration” and thus ruled that it could not grant relief under the ADA. In reaching its decision, the Court relied in part on the decision handed down in the Maryland Wasserman v. Williams litigation (see above).

In October 2002, the plaintiffs appealed this decision to the 3rd Circuit of Appeals (02-3721). In December 2002, fourteen former state mental health directors submitted an amicus brief on behalf of the plaintiffs. They argued that the district court had adopted too narrow a view concerning the financial implications of accelerated community placement by failing to take into account the potential to offset costs by employing Medicaid funds to hold down the state’s costs of supporting individuals in the community. They pointed out that the hospital was funded with state dollars (federal law prohibits Medicaid funding of “Institutions for Mental Disease”) but Medicaid funding could be used to underwrite the costs of community services. The Circuit heard oral arguments in October 2003.

In April 2004, the Circuit Court handed down its opinion. In what it characterized as a “precedential” opinion, the court vacated the district court’s judgment and remanded the case back to the district for further proceedings. The Circuit Court decided that, in order to establish a “fundamental alteration” defense under Olmstead, a state had to demonstrate that it had a comprehensive working plan in effect to assure that going forward individuals would be served in the most integrated setting. The Court expressed the view that budgetary and cost considerations alone were an insufficient to support a fundamental alteration defense. While acknowledging Pennsylvania’s prior efforts to reduce reliance on institutional settings and expand community services, the court pointed out that “past progress is not necessarily probative of future plans to continue deinstitutionalizing.” The court observed: “After all, what is at issue is compliance with two federal statutes enacted to protect disabled persons. The courts have held states throughout the country responsible for finding the manner to integrate schools, improve prison conditions, and equalize funding to schools within the respective states, notwithstanding the states’ protestations about the cost of remedial actions. The plaintiffs in this case are perhaps the most vulnerable. It is gross injustice to keep these disabled persons in an institution notwithstanding the agreements of all relevant parties that they no longer require institutionalization. We must reflect that on that more than a passing moment. It is not enough for DPW to give passing acknowledgment of that fact. It must be prepared to make a commitment to action in a manner for which it can be held accountable by the courts.”

While not disagreeing with many of the findings made by the district court, the Circuit directed the district court to request Pennsylvania to make “a submission that the district court can evaluate to determine whether it complies with this opinion.”

In September 2004, the District Court entered a judgment in favor of the state and dismissed the case. The court found that the state’s deinstitutionalization plan and planning process “deserve the protection of the fundamental alteration defense.” The court rejected the plaintiffs’ contention that the state’s plans were not sufficiently concrete. The plaintiffs have appealed this judgment to the 3rd Circuit (04-3859).

57 The agreement is described in more detail in the Oregon Advocacy Center’s newsletter, available at: gradvocacy.org/staff/newslet/OAC2004Winter.pdf.
58 The brief is at: centerforpublicrep.org/page/94546
60 This decision is available at: paed.uscourts.gov/documents/opinions/04D0294P.pdf.

In September 2000, Pennsylvania Protection and Advocacy (PPA) filed suit (CV-00-1582) in the U.S. District Court for Middle Pennsylvania on behalf of the residents of South Mountain Restoration Center (SMRC), a state-operated nursing facility that serves elderly individuals who have severe mental disabilities, many of whom have experienced long-term institutionalization. PPA contended that SMRC residents could be served in more integrated community settings and, hence, their continued institutionalization violated both Title II of the ADA and § 504 of the Rehabilitation Act. PPA petitioned the court to appoint an independent expert to identify SMRC residents who could be placed in the community and direct the Department of Public Welfare to commence a program of community placement.

In January 2003, the court ruled in the state’s favor and dismissed the lawsuit. In its ruling, the court noted that both parties agreed that many SMRC residents could be served in the community. The state, however, argued that the costs involved in serving these individuals in the community would require a “fundamental alteration” in its programs for persons with mental disabilities because community placement would lead to net increased spending and, thereby, require shifting dollars from services provided to other individuals with mental disabilities to accommodate the placement of SMRC residents.

The court was swayed by the testimony of a defense expert who calculated that the average costs of community placement would exceed average costs at SMRC and, further, that costs of community placement would not be completely offset by reduced expenditures at SMRC. Based on its reading of the Olmstead decision, the court decided that the predicted increase in expenditures necessary to pay for community placements but continue to operate SMRC, in fact, would cause a fundamental alteration. PPA had urged the court to take a broader view of the fundamental alteration question by considering not only the budget for services for persons with mental disabilities but also take into account the overall state budget and other spending within the Department of Public Welfare. The Court rejected this approach, again relying on its interpretation of the Olmstead decision that it should confine itself to the effects on the dollars allocated for services for persons with mental disabilities.

In February 2003, PPA appealed the decision to the 3rd Circuit (03-1461). In November 2003, the Circuit Court agreed to a PPA request to hold this appeal in abeyance pending the outcome of the Frederick L appeal (see above). Following the decision in the Frederick L appeal, the court lifted the stay on proceedings. PPA then filed its appellant brief in June 2004. Oral arguments were heard in October 2004.

13. Other Litigation

Other litigation in this arena has included lawsuits concerning individuals who have a mental illness who are served in state mental health facilities. Some of these lawsuits include the Charles Q v. Houston and Kathleen S v. Department of Public Welfare litigation in Pennsylvania as well as certain California lawsuits. Also in Pennsylvania, the Helen L. v. Dedario litigation raised “Olmstead”-like issues: namely, the access of nursing facility residents to community waiver services (specifically personal assistance/attendant care). In 1995, the 3rd Circuit Court of Appeals held that the state’s failure to provide services in the most integrated setting appropriate to a person’s needs violated the ADA. Additionally, the Court held that the provision of waiver services to the plaintiff would not fundamentally alter the nature of the waiver program because the services the plaintiff needed were already provided in the waiver program.

61 This decision is at: ahcua.com/lawsuit/federal/didario.
IV. Limitations on Medicaid Home and Community Services

A. Overview

“Access to benefits” lawsuits revolve around whether Medicaid beneficiaries can obtain services and supports that they have been approved or are entitled to receive. Litigation in this arena includes lawsuits that argue that low state payment rates prevent beneficiaries from finding a personal assistant or other workers to provide needed services. The Medicaid statutory issues concerning the interplay among payments, adequacy, quality, and access to benefits/services are discussed in detail in a National Health Law Project paper. There have been many cases where the availability and quality of services available through the Medicaid EPSDT for children with disabilities has been at issue.

These lawsuits contend that state policies or practices concerning the operation of community programs constitute barriers to individuals obtaining authorized services. In some cases, these barriers are alleged to violate the ADA, either because they force individuals to accept institutional services due to a shortage of community services while there is more generous state funding for institutional services, thereby discriminating against people who want community services. In the Arizona and California lawsuits, the plaintiffs also allege that state’s funding practices violate §1902(a)(30)(A) of the Social Security Act, which requires states to make payments for Medicaid services sufficient to ensure their availability to Medicaid beneficiaries. In particular, §1902(a)(30)(A) provides that the “State plan for medical assistance must … provide such methods and procedures relating to the … the payment for care and services under the plan … as may be necessary … to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area.” HCBS waiver programs are not exempt from §1902(a)(30)(A).

As in other dimensions of Medicaid law, issues have arisen concerning whether §1902(a)(30)(A) confers enforceable rights. As discussed below, the district court found in the Sanchez v. Johnson litigation that this provision is not enforceable through a §1983 action and dismissed the lawsuit. That decision is now on appeal to the 9th Circuit as is the decision in another California case (Clayworth) where a different district found that §1902(a)(30)(A) is enforceable. In March 2004, the 1st Circuit Court of Appeals handed down a ruling that §1902(a)(30)(A) is not enforceable, based on the U.S. Supreme Court Gonzaga decision. This ruling is noteworthy because the 1st Circuit abandoned its previous position that §1902(a)(30)(A) was enforceable and in light of its other post-Gonzaga decisions upholding the enforceability of various other provisions of Medicaid law. Clearly, this dimension of Medicaid law is very unsettled.

B. Description of Lawsuits


In January 2000, the Arizona Center on Disability Law and the Native American Protection and Advocacy Agency filed a class-action complaint (00-cv-67) in the U. S. District Court for Arizona arguing that Medicaid payment rates for direct service professionals (attendants) in the community are insufficient to attract enough providers to ensure that Medicaid services are available to persons with disabilities. Among its other claims, the lawsuit argues that the state is violating §1902(a)(30)(A) by failing to make payments sufficient to attract enough providers to meet the needs of Medicaid recipients. The plaintiffs also claim that the state also is violating other Medicaid requirements, including: 1) reasonable promptness; 2) amount, duration and scope; and, 3) freedom of choice. Also, the plaintiffs argue that Arizona violates Title II of the ADA and §504 of the Rehabilitation Act because the lack of sufficient community support workers puts individuals with disabilities at risk of institutionalization. The District Court granted class certification. The bench trial was conducted in October 2003.

In August 2004, the court ruled in favor of the plaintiffs, finding that Arizona violated §1902(a)(30)(A) by not providing enough attendants to

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62 Located at: healthlaw.org/docs/200009IssueBriefHCBC.pdf
63 There has been a high volume of litigation in the arena of EPSDT benefits. There is considerable information about this litigation at healthlaw.org/children.shtml#EPSDT. The National Health Law Project has released a very useful paper (Fact Sheet: Medicaid Early and Periodic Screening, Diagnosis and Treatment: Recent Case Developments — available at: healthlaw.org/pubs/200402 EPSDT.cases.pdf) that describes many of important cases that concerning EPSDT and discusses trends in how courts have decided these cases.
64 This ruling concerned the Massachusetts Long Term Care Pharmacy Alliance v. Ferguson lawsuit. The ruling is available at: laws.findlaw.com/1st/031895.html and is described in an article at: healthlaw.org/pubs/200403.firstcircuit.html.
65 The complaint and related materials can be found at: acdl.com/ball.html.
meet the needs of Medicaid beneficiaries. Specifically, the court found that Arizona’s payments were insufficient to assure “equal access” and “quality of care.” The court ordered that the state: must provide each beneficiary attendant care “without gaps in service” and offer a rate of pay that is sufficient to “attract enough health care workers to deliver all of the services for which the individual qualifies.” However, the court stopped short of specifying the amount that the state must pay. The court also ordered the state to make additional improvements in its program. The court ordered the parties to file schedules to carry out the directives contained in its order by September 30, 2004.

In late August 2004, the state moved to request a new trial and asked for a stay in the proceedings, pending its appeal of the decision to the 9th Circuit. In September, the state filed its appeal (04-16963). Circuit Court action on the appeal is on hold pending the district court’s disposition of the state’s request for a new trial.

2. Arkansas: Pediatric Specialty Care, Inc. et al. v. Arkansas Department of Human Services et al.

In November 2001, the Arkansas Department of Human Services (ADHS) announced plans to cut back Medicaid benefits due to budget shortfalls. Among other actions, ADHS proposed eliminating distinct state plan coverage of early intervention day treatment and therapy furnished to children with developmental disabilities ages 0-6. These services are furnished as part of the state’s Child Health Management Services (CMHS) program by specialized providers. Three of these providers and three affected families filed suit in the U.S. District Court for Eastern Arkansas to enjoin ADHS against eliminating these early intervention services. In December 2001, the district court granted a permanent injunction debarring ADHS from removing the listing of these services from the state plan, reasoning that the federal requirements concerning Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandated that these services be provided so long as they had been ordered by a physician and would result in the “maximum reduction of medical and physical disabilities and restoration of the child to his or her best functional level.” State officials argued that they had the “legal right to decide whether to include the services” in the state’s Medicaid program. They also contended that the services would continue to be available, although not in the form of a distinct program.

ADHS appealed the injunction to the 8th Circuit. In June 2002, the Circuit ruled that Medicaid-eligible children have a right to early intervention services and that ADHS “must pay part or all of the cost of treatment discovered by doctors who first diagnose and evaluate the children.” The Circuit decided that federal law does not require ADHS to specifically identify the services at issue in its Medicaid state plan. However, so long as the services are determined as necessary by a physician, it must pay for them since federal law mandates that Medicaid-eligible children receive physician-ordered services whether the state has formerly listed them or not. The Circuit also reminded “the state that it has a duty under §1902(a)(43) of the Social Security Act] to inform recipients about the EPSDT services that are available to them and that it must arrange for the corrective treatments prescribed by physicians. The state may not shirk its responsibilities to Medicaid recipients by burying information about available services in a complex bureaucratic scheme.” The Court remanded the case to the district court to revise the injunction and consider the remaining plaintiff claims.

In November 2002, the district court issued a new order. The thrust of this order was to continue a revised injunction to compel the state to continue to furnish the disputed services. In his order, Judge Wilson expressed chagrin concerning state actions, which in his view were attempts to end-run the injunction. The state then filed a motion asking for a modification of the order, arguing that it had secured federal approval for a Medicaid state plan amendment that complied with the 8th Circuit decision and the effect of the new order might be that the state would not receive federal Medicaid funds for day treatment services under the amended state plan. The plaintiffs countered, arguing that the change in the Medicaid plan coupled with other state actions would have the effect of sharply reducing access to the services or putting new obstacles in the way of families’ obtaining the services. The plaintiffs also asked that the Court to review changes that the state might propose in the future to ensure that they would not eliminate the disputed services.

In December 2002, the district court modified its order, finding that the latest order was not inconsistent with the 8th Circuit ruling. The court continued the injunction directing the state to continue to provide the services and also applied the order to the federal Centers for Medicare and Medicaid Services (CMS) and ordered CMS to continue to provide federal Medicap.

66 The decision also is located at: acdl.com/ball.html.

caid funding for the services. But, the court declined to directly supervise the state’s administration of these services, again enjoined the state to continue to provide and pay for early intervention and related services and barred the state from implementing changes in the provision of these services. In part, the court based its injunction on the provisions of §1902(a)(30)(A) of the Social Security Act, reasoning that the changes that the state had in mind would affect access to services and that the implementation of any changes had to be preceded by a study to determine their impact.

ADHS appealed the revised order to the 8th Circuit; CMS filed its own appeal concerning the order. In its appeal, ADHS protested that its removal of the distinct state plan coverage of early intervention services did not in any way mean that children could not obtain them. CMS concurred and also argued that the district court’s order was improper on a number of grounds. The plaintiffs have countered that ADHS is engaged in an ongoing effort to “deconstruct” the services that they furnish. The Circuit Court heard oral arguments in January 2004.

In April 2004, the 8th Circuit ruled on the appeal. It dismissed CMS as a party to the litigation. It upheld the district court’s injunction on procedural due process grounds, concluding that the injunction against the state’s making changes in its program was proper “until a full impact study on the effect of terminating the [CMHS] program is completed.”

In July 2004, a fourth amended complaint was filed. This complaint alleges that a prior authorization system that ADHS implemented for CMHS has been operated to arbitrarily deny necessary services to children in order to cut state expenditures. The revised complaint names the Arkansas Foundation for Medical Care (the state’s Professional Review Organization (PRO)) as a defendant because it operates the prior authorization system. The state moved to dismiss this complaint, arguing that it had the authority to determine the medical necessity of CMHS. In February 2005, the court rejected the state’s motion, concluding that the plaintiffs had established a sufficient basis to proceed to trial to determine whether the prior authorization system resulted in the impermissible denial of services to children. The state has appealed this ruling to the 8th Circuit.


Filed in May 2000 in the U.S. District Court for Northern California on behalf of individuals with developmental disabilities, this complaint (00cv01593) alleges that California has “established and maintained highly differential payment and wage and benefit structures between the institutional and community-based components of California’s developmental disability services program, which has the effect of subjecting people with developmental disabilities to unnecessary institutionalization and segregation.”

The plaintiffs – persons with disabilities, provider and advocacy organizations – claim the state, in creating payment differentials, violates Title II of the ADA, both with respect to the integration mandate and other regulations “prohibiting a public entity from providing different or separate aids, benefits or services to individuals with disabilities of to any class of individuals with disabilities that is provided to others.” Additionally, the plaintiffs point out that ADA regulations prohibit public entities from “utilizing criteria or methods of administration ... that have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability.” As a result, they allege that California has discriminated against the plaintiffs by “utilizing criteria and methods of administration that discriminate against people with disabilities by [offering] low wages for direct care and professional staff.”

Claims based on Medicaid law include the allegation that state payments for community services are insufficient to assure efficiency, economy, and quality of care and enlist sufficient qualified providers to ensure access to services as required by §1902(a)(30)(A). The plaintiffs petitioned the court to order the state to improve its community services payment and benefit structure and correct other problems that are alleged to lead to unnecessary institutionalization.

In August 2001, the Court certified the lawsuit as a class action. In September 2001, the Court rejected the state’s motion for partial summary judgment to dismiss the plaintiffs’ claims with respect to §1902(a)(30)(A). The state argued that neither people with disabilities nor providers may bring a lawsuit in federal court to enforce these provisions. In March 2002, the plaintiffs filed a motion for summary judgment. The motion for summary judgment asked the court to issue “an order enjoining defendants at least to double current community direct care wages

68 This ruling is located at caselaw.lp.findlaw.com/data2/circs/8th/031015p.pdf.
69 This complaint may be found at sanchezvsjohnson.org/lawsuit.html. Other materials are found at sanchezvsjohnson.org/updates.html.
70 The Court’s class certification order is at sanchezvsjohnson.org/order1593.html.
71 This motion is located at sanchezvsjohnson.org/summary.html.
and benefits, making them substantially equal to institutional direct care wages and benefits and index them to meet defendants’ future, continuing duties under federal statutes.”

In August 2002, District Court Judge Claudia Wilken turned down the plaintiffs’ motion for summary judgment but ruled that the issues raised by the plaintiffs did not constitute violations of the ADA or §504 of the Rehabilitation Act. Judge Wilken also denied the state’s motion to dismiss the case on sovereign immunity grounds. She then ordered that the case proceed to trial. The remaining trial issues concerned whether California’s payments are sufficient to enable providers to furnish quality services and individuals to be able to access to necessary services, as required by §1902(a)(30)(A).

In August 2003, the state filed a motion asking the court to reconsider its decision that the plaintiffs could seek relief in federal court for the alleged violations of Medicaid law. In its motion, the state argued that, in light of the Gonzaga decision, the court should conclude that neither individuals nor providers have enforceable rights under the Medicaid Act. Also, the state filed proposed findings of law and fact. In its proposed findings of law, the state implicitly urged the court to find that its policies and practices in fact had not violated §1902(a)(30)(A).

In January 2004, Judge Wilken dismissed the lawsuit. She agreed with the state’s argument that the federal Medicaid Act does not confer individually enforceable rights but instead has an aggregate focus. She based her decision on her application of the U.S. Supreme Court’s Gonzaga decision to the provisions of §1902(a)(30)(A) and decisions in other cases (including the Pennsylvania Sabree decision and another Northern District lawsuit concerning the application of §1902(a)(30)(A)) (California Association of Health Facilities v. State Department of Health Services (03-736)).

Characterizing Judge Wilken’s decision as “fatally flawed,” the plaintiffs appealed the dismissal to the 9th Circuit in early February 2004 (04-15228). The plaintiffs expect to rely on a December 2003 U.S. District Court for Eastern California decision in lawsuits that also concerned Medicaid payments. In that litigation, the district court also wrestled the implications of the Gonzaga decision concerning whether §1902(a)(30)(A) conferred individually enforceable rights for which Medicaid recipients and providers could seek federal court intervention under §1983. Based on its reading of legislative history, the court decided that Congress intended to confer individually enforceable rights under §1902(a)(30)(A) for beneficiaries but not Medicaid providers. Based on this conclusion and other 9th Circuit decisions, the court then granted the plaintiffs a preliminary injunction that prevented California from implementing Medicaid rate cuts that were slated to go into effect January 1, 2004. The Sanchez plaintiffs filed their appellant brief in May 2004. The Court heard oral arguments in the Sanchez, Clayworth and CMA appeals on December 8, 2004. The Sanchez plaintiffs have petitioned the Court for additional time to present oral argument concerning the ADA and §504 claims.


This lawsuit (03-01580) was filed in the U.S. District Court for the District of Central California expressly to halt Los Angeles County’s plan to close Rancho Los Amigos National Rehabilitation Center, a county-operated facility that furnishes specialized inpatient and outpatient services to individuals with disabilities. The plaintiffs sought and obtained from the court a preliminary injunction to halt the closure, contending that, if the facility were closed, they would be left without access to medically necessary services. The plaintiffs based their claims on federal Medicaid law (arguing that they would be unable to obtain services covered by California’s Medicaid program) and the ADA (arguing that the county’s action was discriminatory because it treated people with disabilities differently than other Medicaid recipients from instituting a 5% across the board rate reduction in Medicaid (Medi-Cal) payments as part of the state’s efforts to cut its budget deficit. The state has appealed both decisions to the 9th Circuit (04-15498 and 04-15532), which has consolidated the appeals and instructed the state to submit its opening brief by May 5, 2004. Since both cases concern preliminary injunctions against the state, it is likely that they will receive expedited consideration.

74 This decision is located at: 207.41.18.73/caed/DOCUMENTS/Opinions/Levi/03-2110.pdf. In the decision, the court noted that interpreting the legislative history surrounding §1902(a)(30)(A) posed some difficulties. Once the court decided that Medicaid beneficiaries could bring a federal action to block rate cuts that might harm them, it relied on the standards set down by the 9th Circuit in its 1997 Orthopaedic Hospital v. Belshe decision (located at: laws.findlaw.com/9th/9555607.html) in deciding that the state’s rate cut was improper.

72 Marty Omoto, Legislative Director, California UCP (August 9, 2002). “CA UCP Legal Update: Sanchez v. Johnson Case: Federal District Court Orders Case to Trial; Judge Denies Plaintiffs’ Summary Judgment Motion, Ruling Partially in Favor of State.”

73 The lawsuits are: Clayworth et al. v. Bonta et al. (03-2110) and California Medical Association et al. v. Bonta et al. (03-2336). Both of these lawsuits were filed to prevent California
who did not face a similar loss of access to services). The county appealed the injunction to the 9th Circuit Court of Appeals (03-55765).

In February 2004, the Circuit upheld the preliminary injunction, concluding that the plaintiffs were likely to succeed on the merits of their ADA claim. The court agreed that, absent the injunction, the plaintiffs faced potential harm. The Circuit also noted that the district court decision did not mean that the county could not ultimately close the facility but, instead, if it were to close the facility, it had to ensure that comparable services would be available to the plaintiffs.


In November 2002, three Medicaid beneficiaries with disabilities filed a lawsuit (02-CV-1968) against the Connecticut Department of Social Services (DSS, the state’s Medicaid agency) alleging that the state was refusing to pay for durable medical equipment they need to improve their health and live independently. The plaintiffs argue that the state has adopted “an unwritten and unpublished policy of denying Medicaid payment for any equipment not covered by the federal Medicare program,” thereby impermissibly restricting access to necessary equipment. The plaintiffs sought a preliminary injunction and class certification. The plaintiffs are represented by New Haven Legal Assistance Association and Connecticut Legal Services.

In 1997, the New Haven Legal Assistance Association filed a similar lawsuit (DeSario v. Thomas) challenging Connecticut’s practice of limiting payment for medical equipment to items included on a list established by DSS. Ultimately, this case was settled by the state’s agreeing to periodically update its list of covered items and allow individuals to obtain unlisted items when necessary. This litigation also prompted the Health Care Financing Administration (now CMS) to clarify its policies concerning the coverage of medical equipment, including requiring states to provide individuals “a meaningful opportunity for seeking modifications of or exceptions to a State’s pre-approved list.” This policy was promulgated via a September 1998 State Medicaid Director letter.

In this lawsuit, the plaintiffs alleged that the Department was once again employing an arbitrary list to deny individuals of equipment that is necessary for them to function in the community and thereby increase their risk of institutionalization. In particular, the plaintiffs alleged that Connecticut’s policies violated: (a) §1902(a)(17)(A) of the Social Security Act which requires that the state apply reasonable standards in determining eligibility for services; (b) the goals of the Medicaid by denying payment for DME necessary for individuals to attain and maintain independence and self-care; and, (c) Medicaid requirements that bar limiting the scope of coverage based on a person’s specific medical condition. In March 2003, the Court turned down the plaintiffs’ request for a preliminary injunction. The parties arrived at a tentative settlement in September 2003. In December 2003, the court approved the agreement. Under the agreement, the Department of Social Services has issued a revised provider bulletin concerning DME and beneficiary rights to appeal adverse determinations.

6. Illinois: Jackson et al. v. Maram

In January 2004, three individuals residents filed a class action complaint (04-0174) against the Illinois Department of Public Aid in the U.S. District Court for the Northern Illinois contending that the agency impermissibly denies motorized wheelchairs to nursing facility residents in violation of federal Medicaid law, the ADA and §504 of the Rehabilitation Act. The plaintiffs have been denied motorized wheelchairs even though rehabilitation hospitals have determined that the plaintiffs would benefit from them. As a consequence, the plaintiffs contend that they are unnecessarily confined to the nursing homes in which they reside. In contrast, the plaintiffs point out that individuals who are not in nursing facilities are authorized to receive Medicaid-funded motorized wheelchairs. The lawsuit was filed on the plaintiffs’ behalf by Access Living of Metropolitan Chicago, an Independent Living Center.

The plaintiffs contend that the state’s policy to not provide motorized wheelchairs to nursing home residents violates the requirements of the federal 1987 Nursing Home Reform Act, §1902(a)(10)(B) by not making Medicaid services available to all beneficiaries who require them, the ADA (by virtue of discriminatory treatment of individuals with disabilities and encouraging unnecessary segregation of nursing facility residents), and §504 because the state’s policies discriminate on the basis of disability.

The state moved to dismiss and in opposition to class certification. Both motions adopted the position that Medicaid law, the ADA, and the Rehabilitation Act do not give the plaintiffs enforceable rights that may be pursued through a §1983 action. In August 2004, the court granted the motion for class certification.

76 Located at: cms.hhs.gov/states/letters/smd90498.asp
77 http://www.equipforequality.org/news/equalizer/06legalhighlight.php
Court proceedings are suspended for the time being to permit the parties to explore the potential for settlement.

7. **Illinois: Bertrand et al. v. Maram et al.**

Filed on January 31, 2005 in the U.S. District Court for the Northern District of Illinois, this lawsuit (05-0544) charges that Illinois impermissibly restricts the access to Community-Integrated Living Arrangement (CILA) residential services in its HCBS waiver program for persons with developmental disabilities. This is a class action complaint. It follows on the heels of a non-class action complaint (Drzewicki v. Maram et al. (04-CV-7164) that raised the same issue but which the state agreed to settle.

Like the predecessor complaint, this lawsuit contends that Illinois is violating the reasonable promptness requirement at §1902(a)(8) of the Social Security Act and is at odds with the policies set forth in CMS Olmstead Letter #4, which provides that a state may not deny covered waiver services to waiver participants who require them. In particular, the plaintiffs contend that Illinois’ policy of limiting the availability of CILA services to persons who satisfy the state’s emergency or priority placement criteria is an impermissible limitation on access to services.

On February 22, 2005, the state answered the complaint. The state argued that Medicaid law does not confer individually enforceable rights and, consequently, the plaintiffs do not have standing to bring an action in federal court. The state also advanced the defense that the criteria it uses to regulate access to CILA services were contained in its waiver application to CMS and that CMS had approved the application.

8. **Indiana: Collins et al. v. Hamilton et al.**

In 2001, the Indiana Civil Liberties Union filed a class action lawsuit against state officials for failing to provide child and youth long-term residential treatment in psychiatric residential treatment facilities (PRTF). The plaintiffs argued that Indiana’s refusal to provide such services violated federal Medicaid law because PRTF services are a recognized Medicaid benefit and, hence, must be furnished to all eligible children and youth when “medically necessary” under the federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate. The district court ruled in plaintiffs favor, deciding that the provision of PRTF services was mandatory when medically necessary. The court permanently enjoined Indiana from denying these services.

In 2002, the state appealed this decision to the 7th Circuit Court of Appeals (02-3935), arguing that it had decided to exclude such services for various reasons. In November 2003, the Circuit Court rejected the state’s appeal and upheld the district court decision. The court found that the EPSDT mandate requires that a state must furnish any Medicaid coverable service that is medically necessary.


In October 2002, Interhab and five other community service providers filed a class action lawsuit in Shawnee County District Court (02C001335) against the Kansas Department of Social and Rehabilitation Services (SRS) claiming that the state’s payments are insufficient to meet the needs of people with developmental disabilities and thereby violate Kansas and federal law. Interhab is an association of Kansas community service providers. The plaintiffs assert that community services were underfunded by $88 million. The lawsuit also seeks damages for alleged underfunding in previous years; such damages might total $300 million, according to the plaintiffs.

The lawsuit claims that the state has violated the state’s 1996 Developmental Disabilities Reform Act (DDRA), which the plaintiffs argue mandates that the state provide “adequate and reasonable” funding for community services. In particular, the plaintiffs point out that the DDRA made it Kansas policy that:

“…this state …assist persons who have a developmental disability to have: (a) Services and supports which allow persons opportunities of choice to increase their independence and productivity and integration and inclusion into the community; (b) access to a range of services and supports appropriate to such persons; and (c) the same dignity and respect as persons who do not have a developmental disability.” (K.S.A. 39-1802).

The DDRA also provides that SRS establish “a system of adequate and reasonable funding or reimbursement for the delivery of community services that:

“requires an independent, professional review of the rate structures on a biennial basis resulting in a recommendation to the legislature regarding rate adjustments. Such recommendations shall be adequate to support: (A) a system of employee compensation competitive with local conditions; (B) training and technical support to attract and retain qualified employees; (C) a quality assurance process which is responsive to consumers’ needs and which maintains the standards of quality service (D) risk management and insurance costs; and (E) program management and coordination responsibilities.” (K.S.A. 39-1806)

78 The decision is at: [http://caselaw.findlaw.com/data2/circes/7th/023935P.pdf](http://caselaw.findlaw.com/data2/circes/7th/023935P.pdf)
The plaintiffs charge that the required rate review was not conducted and the wage rates upon which SRS bases payments are inadequate. As a result, provider agencies are unable to recruit and retain qualified staff to meet the needs of individuals. In addition to violating the DDRA, the plaintiffs also charge that SRS has violated §1902(a)(30)(A) of the Social Security Act by not making payments sufficient to ensure that “consumers of community programs and services have access to high quality care.” The plaintiffs also are advancing an equal protection claim under both the U.S. and Kansas Constitutions by contending that the state discriminates between community providers and its own institutions by funding similar services differently. The plaintiffs also allege breach of contract.

The plaintiffs are asking the court to: (a) review all payment rates for the period 1996 – 2003; (b) order the state to pay for all “underfunding” during that period; (c) enjoin the state to pay “adequate and reasonable reimbursement rates”; (d) enjoin the state to establish a rate setting methodology that complies with federal and state law; and (e) enter a judgment directing SRS to reimburse all costs incurred by the plaintiffs in delivering services, including hourly wages and benefits that reflect the amounts paid to other workers in each locality. In December 2002, the state filed motions to dismiss the federal and state law claims.

In January 2003, the plaintiffs amended the complaint and asked the court to issue a temporary restraining order to block payment and other funding cuts ordered in August and November 2002 by outgoing Governor Bill Graves to address the state’s mounting budget deficit. Included in these cuts were developmental disabilities HCBS waiver rate reductions.

In February 2003, the court turned down the defendant’s request for a temporary restraining order. The Court ruled that there was no evidence that the state acted “arbitrarily, capriciously or unreasonably in [its] choices of program reductions.” While acknowledging that the budget cuts “appear potentially harmful,” the “court could not conclude that its interference would not do more harm than good to the public interest if it issued a temporary restraining order.” With the rejection of the request for a temporary restraining order, activity in this litigation has returned to the issues raised in the original complaint. The court has heard oral arguments concerning various motions over the past few months.

At a September 2003 hearing, the court observed that it was struggling to understand the issues in the case, including the complexities of the funding of community services in Kansas and whether the plaintiffs had the right to make the claims they had. The court allowed two individuals with developmental disabilities who receive services to be added as plaintiffs.

The court decided to allow the lawsuit to go forward, rejecting the state’s motion to dismiss except for the claims for retrospective recovery of funds under federal law. In January 2004, the plaintiffs once again asked the court for a temporary restraining order, temporary and permanent injunctions and the appointment of a special master. The court turned down these requests. Over the past several months, the plaintiffs and the state have filed numerous motions, including motions by the state to dismiss plaintiff claims.

10. Louisiana: Malen v. Hood

This class action complaint was filed in December 2000 against the Louisiana Department of Health and Hospitals in the U.S. District Court for the Eastern District of Louisiana. At issue in this case was the state’s proposed method of implementing a new “Children’s Choices” HCBS waiver program for children with severe disabilities. The new waiver program offers a dollar-capped set of benefits that is less broad than that offered under Louisiana’s pre-existing HCBS waiver program. The state had proposed that, if a child were on the waiting list for Louisiana’s existing HCBS waiver program for people with developmental disabilities, the family would have to agree to give up the child’s place on that waiting list if they accepted enrollment in the new waiver program. Families objected to this proviso because it meant that their children would be disadvantaged if they needed more intensive services. Plaintiffs contended that this requirement was impermissible under federal law.

When the lawsuit was filed, federal officials had not yet decided whether to approve the new program. Subsequently, CMS determined that the state’s proposal concerning the waiting-list proviso could not be approved. The state then removed the proviso and CMS approved the waiver request. The Children’s Choices program has since been implemented and the lawsuit has been settled.


Filed in June 2000, this complaint (00-116-B-C) alleged that Maine violated federal Medicaid law by failing to furnish medically necessary EPSDT services to children with mental disabilities. The lawsuit was filed by private attorneys in collaboration with Maine Equal Justice Partners, Inc. Maine’s Disability Rights Center joined the lawsuit as a named plaintiff. The lawsuit argued that federal law requires the state to arrange for medically necessary EPSDT services –
including in-home mental health services – in a reasonably prompt manner. Consequently, at issue was Maine’s assuring access to non-waiver Medicaid services for children. Under federal law, a state may not limit the availability of medically necessary EPSDT services. The lawsuit also contended that Maine’s payments for services were insufficient to ensure their availability when and as needed and thereby the state is violating §1902(a)(30)(A). As a consequence, the plaintiffs argued that 600 Maine children with mental disabilities had been wait listed for services or could not obtain entitled services.

In July 2001, the District Court granted the plaintiff’s motion for class action certification. In May 2002, the parties reached a settlement. Reportedly, the settlement provides that children who need services will be evaluated more quickly and no child will wait more than six months to receive approved treatment and services.

12. Minnesota: Association for Residential Resources in Minnesota et al. v. Goodno et al. and Masterman et al. v. Goodno

Both of these lawsuits seek to halt Minnesota’s “rebasing” the amount of funds it allocates to counties for HCBS waiver services for persons with mental retardation and related conditions. In each case, the concern is that rebasing will result in a reduction of funds to individuals. The Association for Residential Resources in Minnesota (ARRM) filed its lawsuit (03-cv-2438) in the U.S. District Court for the District of Minnesota in March 2003. ARRM asked the court to issue a temporary restraining order (TRO) to halt the rebasing until the court could decide the issues in the lawsuit. In March 2003, the court issued the TRO. In April 2003, the court held a hearing concerning the ARRM motion for a preliminary injunction to halt the rebasing and issued the requested TRO. In August, the Court dissolved the TRO and denied an ARRM motion for a new TRO. However, in September 2003, the court agreed to the Masterman plaintiffs’ petition to issue a new TRO. This TRO did not halt the method of rebasing but simply provided that no reduction to the budgets of individual waiver participants could take place because of rebasing until the Court could hear the merits of the ARRM motion for a temporary injunction. With respect to this lawsuit, the parties are in preliminary settlement discussions before the discovery phase begins. The ARRM lawsuit was dismissed in November 2004 after the parties arrived at a settlement agreement.

In April 2003, four individuals and Arc Minnesota filed a similar lawsuit (03cv2939) asking for a preliminary injunction to halt the rebasing. The Minnesota Disability Law Center (the state’s P&A agency) filed this lawsuit on behalf of the plaintiffs. The plaintiffs contend that the payment rebasing will result in “irreparable harm.” It appears that the plaintiffs also argue that rebasing will adversely affect their choice between HCBS waiver and institutional services as well as undermine meeting the essential needs through the waiver program. This lawsuit was transferred to the judge hearing the ARRM lawsuit.

The state filed a motion to dismiss the lawsuit. In its motion to dismiss, the state argued that: (a) the plaintiffs have no right of private action under §1983 to pursue their Medicaid claims under §1902(a)(10)(B) (comparability), §1915(c)(2)(A) (assurance of the health and welfare of HCBS waiver participants), and §1902(a)(1) statewideness of the Social Security Act; (b) plaintiffs lack standing because they cannot show that concrete or imminent injury has resulted from rebasing; and, (c) the plaintiffs’ ADA claim fails because it attempts to expand the ADA’s integration mandate beyond its basic parameters by arguing that the lack of identical funding between institutional and community services is discriminatory.

In October 2003, the Court heard arguments concerning the plaintiffs’ request that the court issue a preliminary injunction to halt the rebasing. The state opposed this motion, contending that sufficient funds were now available in the waiver program to ensure that no deep cuts would be made and that the administrative appeals process afforded individuals sufficient protection should their services be reduced.

In January 2004, the court turned down the plaintiffs’ motion for a preliminary injunction and dissolved the temporary restraining order against implementation except in the case of the individual plaintiffs. The court decided that it could not continue to block the rebasing, especially because the lawsuit was not a class action. At the same time, however, the court denied the state’s motion to dismiss, except for one claim. The court rejected the state’s contention that the Gonzaga decision undermined the plaintiffs’ standing to bring suit. The Court also rejected the state’s request to dismiss the ADA and §504 claims. The Court also expressed the view that the rebasing decision might be at odds with Medicaid statutory provisions concerning the operation of HCBS waiver programs, noting “That Congress has allowed states to limit the number of

79 See also healthlaw.org/pubs/200006release.html.

80 At med.uscourts.gov/opinions/carter/2001/GC_07022001_1-00cv116_Risinger_v_Concannon.pdf

81 The decision is at: www.nysd.uscourts.gov/courtweb/pdf/D08MNXC/04-00195.PDF
people served by waivers does not mean that Congress meant to allow states to underserve those actually on the waiver, or treat waiver recipients differently, or excuse states from assuring the health and safety of waiver recipients. Most importantly, it does not evidence that Congress did not intend Medicaid recipients to benefit from the Medicaid program.”

In June 2004, the state and the Masternath plaintiffs filed a joint motion asking the court to dismiss this litigation, based on a settlement agreement that they had reached. Under the settlement agreement, the state agreed to increase county allocations over the next two years and issue new guidelines to counties in establishing individual budgets. The state also agreed to contract with an independent consultant to establish a new funding methodology for the waiver program.


In September 2002, eight individuals and the Montana Association of Independent Living Services, Inc. (M.A.I.D.S.) filed a class action lawsuit in state court against Governor Judy Martz and the Department of Public Health and Human Services alleging that the state’s payments for community services are inadequate and thereby violate the Montana Constitution and other laws concerning the provision of services to individuals with developmental disabilities. The proposed class includes: (a) all persons who receive community services but are at risk of being institutionalized because of the closure, reduction or termination of their services and (b) institutionalized persons who should be served in the community but cannot due to inadequate payments. M.A.I.D.S. is an association of 34 community developmental disabilities provider agencies that furnish HCBS waiver services. The plaintiffs are persons who receive community services. Some persons are served in community residences; others live on their own or with their families.

In the complaint, the plaintiffs argue that state institutional staff is paid between 23 and 38% more than their community counterparts, even though community workers perform much the same work. This wage disparity is alleged to cause high turnover among community workers and providers have a difficult time recruiting workers. As a result of these problems, it is alleged that providers are increasingly unable to meet the needs of many of the individuals they serve, thereby placing individuals at high risk of institutionalization. In addition, the complaint alleges that low payments prevent the placement of institutionalized persons who could be supported in the community.

The plaintiffs argue that the wage disparity between institutional and community workers results in violations of: (a) provisions of Montana law that require the administration of state and federal funds in a fashion that ensures the proper fulfillment of their purpose, including assisting people with developmental disabilities to live as independently as possible and securing “for each developmentally disabled person such treatment and habilitation as will be suited to the needs of the person and assure that such treatment and habilitation are skillfully and humanely administered with full respect for the person’s dignity and personal integrity in a community-based setting whenever possible;” (b) provisions of Montana law that set forth the state’s policy aims with to people with developmental disabilities, including supporting individuals to live as independently as possible in the least restrictive setting; (c) state statutory provisions that require uniform payment for Medicaid-covered services “where the actual cost of, quality of, knowledge and skills for the delivery of, and availability of, Medicaid-covered services is equivalent or similar;” and, (d) provisions of the Montana Constitution, including equal protection.

The plaintiffs are seeking preliminary and permanent injunctions to bar the state from maintaining the current disparity in wages and benefits between institutional and community workers. It is estimated that eliminating the disparity in wages and benefits would cost about $20 million.


Filed in June 2003 in the Franklin County Court of Common Pleas, this lawsuit charges that Ohio is violating federal Medicaid law by interfering with the right of individuals to choose their service provider and is not administering Medicaid services for people with developmental disabilities uniformly in all parts of the state. The lawsuit was filed by Ohio’s private provider association and individual provider agencies against the Departments of Job and Family Services (Ohio’s Medicaid agency) and Mental Retardation and Developmental Disabilities (ODMRDD, which administers the state’s HCBS waiver programs for people with developmental disabilities) as well as the superintendents of several county boards of mental retardation and developmental disabilities that administer services locally as well as the Ohio Association of County Boards of Mental Retardation and Develop-

82 The settlement is described in more detail at: arcminnesota.com/Rebasing Setlement.htm.

83 For additional information, go to oprav.org/ and then look under “What’s New” to access documents concerning the lawsuit, including the complaint which is at: oprav.org/pdf/Lawsuit-MemorandumSupport.PDF
mental Disabilities. At issue in this litigation is the legitimacy of Ohio counties operating Medicaid-funded community services in a fashion that varies county-to-county and, hence, results in disparate treatment of individuals. In 2001, the Ohio legislature directed ODMRDD to promulgate rules to ensure uniform administration of Medicaid services in all counties. To date, such rules have not been adopted and the lawsuit was triggered when private providers faced the prospect of having to sign new contracts with each county by June 30, 2003, even though, in their view such contracts are not legal.

In a press release concerning this lawsuit, the executive director of the provider’s association said:

“Federal law is very clear on this point. Medicaid must be administered uniformly across the state. The fact that the State of Ohio has abdicated its responsibility to write uniform administrative rules does not mean that county boards, which also are substantial service providers in addition to their Medicaid administration roles, can assume powers that are not properly theirs. What we have here is an attempt by county boards and their associations to hijack state law for their own purposes, even though the result will be that individuals with mental retardation and developmental disabilities will not get the same quality of services from county to county.”

The plaintiffs asked the court to grant injunctive relief to prevent the county boards from forcing them to sign contracts that they do not regard as legal or withhold payments.

With respect to the injunctive relief, in a June 2003 order, the court directed that county boards and providers should reach mutual agreements to either extend or revise the terms of existing service contracts or otherwise resolve their differences under the state’s dispute resolution statute. In the event that the board and providers do not agree, or choose not to enter into a new contract or amend an existing contract, the court instructed both sides to continue to operate under existing contracts, day-to-day until ODMRDD, as the ODJFS designee, promulgates the overdue rules governing service contracts. However, the order also made it clear that a provider’s agreeing to continue an existing contract or enter into a new contract with a county board would in no way limit the plaintiffs’ pursuing their claims regarding the underlying lawfulness of the contracts.

So far, rules that would address the underlying issues in this litigation have not been adopted by the state.

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**15. Oklahoma: Fisher et al. v. Oklahoma Health Care Authority et al.**

In 2002, Oklahoma decided that it would limit to five the number of prescribed medications that participants in the state’s “Advantage” HCBS waiver program for people with disabilities and older persons could receive in order to reduce spending to address the state’s budget deficit. Previously, there was no limit on the number of medications that Advantage participants could receive, a policy that also was in effect for nursing facility residents. Medicaid beneficiaries not served in nursing facilities or participating in the waiver program are subject to a three-prescription limit. Oklahoma’s Advantage program covered prescribed drugs over and above this limit as an additional “extended pharmacy” benefit. In limiting prescribed drugs to five per month, the state amended its waiver program to curtail the number of medications provided under the extended pharmacy benefit.

The Oklahoma Disability Law Center immediately filed suit (02-cv-762) in the U.S. District Court for the Northern District of Oklahoma, arguing that limiting the number of medications violated the ADA and §504 because the state continued to allow nursing facility residents an unlimited number of medications. The plaintiffs argued that the state’s policy was discriminatory. The district court, however, granted summary judgment to the state, deciding that the plaintiffs could not maintain a claim under the ADA because they were not institutionalized or at risk of institutionalization. The plaintiffs appealed this decision to the 10th Circuit Court of Appeals. In July 2003, the Circuit reversed the summary judgment and remanded the complaint to the district court.

The Circuit ruled that the district court had erred in interpreting the ADA and the Olmstead decision as only apply to institutionalized persons or individuals at risk of institutionalization. The Circuit pointed out that Title II applied to all publicly-operated programs that serve people with disabilities. The Circuit also questioned the district court’s reasoning that requiring the state to reinstate unlimited prescribed medications would constitute a fundamental alternation. The Circuit noted that, if the effect of the limit were to force individuals to seek care in nursing facilities, the state would incur higher costs because such services are more expensive than waiver services. Since the plaintiffs had not based their original claims on Medicaid law, the Circuit refused to rule on alleged violations of Medicaid requirements that they raised on appeal. These claims revolved around the effect of the waiver of comparability that states receive when they operate

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84 The order is at: oprn.org/pdf/Judge McGrath Order.PDF

85 Decision located at: laws.findlaw.com/10th/025192.html
an HCBS waiver program and their argument that such a waiver does not extend to other non-waiver Medicaid services. The Circuit noted that these issues would have to be addressed by the district court.

In November 2003, this lawsuit was settled by the parties and dismissed. The Oklahoma Health Care Authority revised its policies concerning prescribed drugs, increasing the prescription limit to six per month for all adult Medicaid beneficiaries. In the case of HCBS waiver participants, in addition to the six prescriptions, they also may have up to seven additional generic prescriptions. Persons who require additional medications may request them through a prior authorization process that will include a clinical review of all the individual’s prescribed drugs.


This lawsuit was filed in March 2002 in the Commonwealth Court of Pennsylvania by a coalition of agencies that furnish services to individuals in ICFs/MR and/or Pennsylvania’s HCBS waiver program for people with mental retardation. The plaintiffs contended that Pennsylvania has depressed payments for ICF/MR services and held down waiver funding by predicating funding levels on inadequate compensation of direct care workers. As a result, the plaintiffs argued that they are not furnished an appropriate level of services due to high staff turnover and workforce instability. They also cited a federal review of Pennsylvania’s HCBS waiver program that questioned the adequacy of the state’s payments for services. The plaintiffs asked the Court to order the state to “fairly, reasonably and lawfully reimburse providers … to ensure the quality, and continuity, of care provided by these providers.”

In particular, the lawsuit contended that the state is in violation of: (a) the State’s Public Welfare Code and implementing regulations that require providers to be paid for “reasonable costs”; (b) §1902(a)(30)(A) because payments are insufficient to ensure the quality of care; (c) federal Medicaid requirements by not providing an effective and timely process for the reconsideration of payment rates; and, (d) equal protection under the Pennsylvania Constitution by providing for higher payments to publicly-operated programs than for services furnished by non-state agencies. The plaintiffs asked the Court to order that the state ensure that fair and reasonable direct care staff costs are reimbursed and updated. The plaintiffs also asked for the appointment of a Master to oversee this process. The federal law claims were subsequently dropped by the plaintiffs.

In July 2003, the Commonwealth Court dismissed the lawsuit. The Court found that the plaintiffs had not exhausted their available administrative remedies under Pennsylvania law and, until they had, the issues raised in the lawsuit were not ripe for judicial review.


Filed in 1993, this lawsuit alleged that Texas was not meeting its obligations in furnishing EPDST services to children. In 1996, the state entered into a voluntary consent decree that would be enforceable by the court. The decree required the state to institute detailed procedures to comply with the decree. In 1998, the plaintiffs returned to court, arguing that the state was not living up to the decree. The court agreed and then moved to enforce the decree, prescribing detailed requirements that the state would have to meet. This prompted the state to appeal the district court’s enforcement of the decree to the 5th Circuit Court of Appeals. In particular, Texas claimed that it should not be held to the decree because its requirements went well beyond those contained in federal Medicaid law and the decree was not enforceable under the 11th Amendment. The 5th Circuit ruled in the state’s favor, deciding that the decree could not be enforced unless the state voluntarily waived its 11th Amendment immunity.

The plaintiffs then petitioned the U.S. Supreme Court to reverse the 5th Circuit’s decision. The plaintiffs contend that the state’s agreeing to the consent decree amounted to a waiver of sovereign immunity and, therefore, the state could not back out of the decree. This litigation raised significant concerns about the enforceability of consent decrees and settlement agreements and thereby their role in resolving litigation.96 The Supreme Court granted the petition (02-628) and heard oral arguments on October 7, 2003. During the oral arguments, several Justices expressed serious reservations concerning the 5th Circuit’s decision.

On January 14, 2004, the Court handed a unanimous decision reversing the 5th Circuit decision.97 Writing for the Court, Justice Kennedy wrote: “Federal courts are not reduced to approving consent decrees and hoping for compliance. Once entered, a consent decree must be enforced.”

96 For more information, go to: journalism.medill.northwestern.edu/docket/action.lasso?-database=docket-&layout=lasso-&response=%2fdocket%2fdetail.srch&-recordID=33149&-search. This site describes the issues at play and contains links to the plaintiff petition and amici briefs in support of the plaintiffs.
97 The decision is at: laws.findlaw.com/us/000/02-628.html
Note Concerning Sources
We scan news articles and other sources for developments concerning the filing of lawsuits in the disabilities arena. We access court websites for updates concerning the status of lawsuits and to obtain primary source documents when they are available on the court’s website. In most cases, federal court documents are only directly available to individuals that have set up a fee-based U.S. PACER system account. To the extent that lawsuits and/or court decisions are posted on websites that are accessible to the general public without charge, we include links in the report. Usually, we do not report on a lawsuit until we have the actual complaint in hand. We also appreciate it when readers of this report alert us that a lawsuit has been filed or when there are new developments in a case.

References


Resources
National Health Law Project (NHeLP) – Health Activist Court Watch Project is an excellent source of information about litigation that bears on access to health and other long-term services. Its web-site is www.healthlaw.org/courtwatch.shtml.