

---

**Status Report:**

**Litigation Concerning Medicaid  
Services for Persons with Developmental Disabilities**

July 10, 2001

Prepared by:

Gary A. Smith

Director of Special Projects  
National Association of State Directors of  
Developmental Disabilities Services, Inc.

---

**NOTE:** This report describes the status of litigation in various states concerning Medicaid funded services for people with developmental disabilities. We update and reissue this report periodically as new developments warrant. When you receive a new update, you may discard the previous update since the report is cumulative. We make every effort to keep this report as up-to-date and complete as possible. **Material added since the May 2001 update is highlighted.**

---

## **I. Introduction**

Over the past thirty years, litigation concerning services for people with developmental disabilities has centered on large state-operated institutions. Lawsuits resulted in courts ordering many states to improve institutional services and living conditions and/or arrange the community placement of institutional residents. Although other factors also have been important, there is no doubt that institutional litigation has been a powerful force in reshaping public developmental disabilities service systems. Litigation led to a marked scaling back of the role that institutions play in public systems and accelerated the expansion of community services for people with developmental disabilities.

Over the past three years, there has been a flurry of lawsuits of a different sort. These lawsuits aim at securing prompt access to Medicaid home and community services for people with developmental and other disabilities. Although some of these lawsuits concern securing community services for institutionalized persons, most have been filed on behalf of individuals in the community who are seeking but not receiving home and community services. These lawsuits challenge the practice of wait listing individuals for home and community services by asserting that provisions of federal Medicaid law and the Americans with Disabilities Act dictate that states provide home and community services promptly to eligible individuals in the most integrated setting. This litigation revolves around community – rather than institutional – services and potentially has enormous implications for public disability service systems.

This Brief discusses three (not necessarily mutually exclusive) categories of lawsuits concerning access to Medicaid home and community services for people with developmental and other disabilities:

- **“Waiting List” Lawsuits** that claim a state has failed to provide Medicaid long-term services with “reasonable promptness” to otherwise eligible persons with developmental disabilities;
- **“Olmstead” Lawsuits** that claim institutionalized persons have been improperly denied the opportunity to receive community services in the “most integrated setting;” and,

- **“Access to Benefits” Lawsuits** that allege Medicaid recipients have not been provided services that they have been authorized to receive or are unable to access such services.

The brief discusses the legal issues raised by these lawsuits. It also provides summaries of lawsuits that have been filed along with their status as of July 2001 (including descriptions of settlement agreements where they have been reached). Links to additional information on the Internet also are provided where possible. Each time this report is issued, these links are checked to confirm that they are still “live.” The brief does not draw conclusions concerning the underlying legal issues. Many lawsuits have been filed only recently or are at different stages of the litigation process. As the courts make rulings or hand down decisions in these suits, the legal and policy implications of this litigation will come into sharper focus.

## **II. Background**

Large public institutions once dominated public developmental disabilities systems. Today, nationwide and in almost all states, large institutions serve only a small fraction of all persons who receive taxpayer-supported services. The vast majority of individuals now receive services and supports in their communities. As recently as 1988, the majority of public dollars earmarked for developmental disabilities services nationwide underwrote services in large congregate facilities. By 1998, 72% of all outlays for services were devoted to community services and supports. Between 1994 and 1998, state spending for community services increased by 49% in inflation-adjusted dollars (Braddock *et al.*, 2000).

Funding of community services has hinged on the willingness of state policy makers to support and underwrite expanded community services. Spending for developmental disabilities services has been regulated by “available appropriations.” Except in a few states (most notably California), increases in the number of individuals who qualify for services do not trigger automatic increases in funding. Hence, the substantial growth in funding provides evidence that state policy makers have supported expanded access to community services and supports for people with developmental disabilities.

During the 1990s, there was a massive infusion of Medicaid dollars into community service systems, principally by way of the Medicaid home and community-based services (HCBS) waiver program. The number of individuals participating in HCBS waiver programs for persons with developmental disabilities shot up from roughly 45,000 in 1990 to **291,000 by 2000** (Prouty and Lakin, 2001). Spending for HCBS waiver services for people with developmental disabilities grew almost ten-fold to reach **\$9.6 billion in 2000**. Increased use of Medicaid HCBS waiver dollars was pivotal in enabling the ongoing expansion of community systems in nearly all states.

Each state has latitude in deciding on the waiver services and supports it will offer to eligible individuals. Moreover, federal Medicaid law and policy permits a state to limit the number of individuals it will serve in a waiver program. Thus, HCBS waiver programs can be “sized” to take into account the matching funds a state has available. The HCBS waiver program has permitted states to expand the availability of Medicaid-funded community services voluntarily and at a measured pace.

The 1990s also saw an upsurge in the number of individuals with developmental disabilities seeking services due to many factors, mainly demographic (Smith, 1999). Despite significant increases in funding for community services, waiting lists emerged and persisted in many states. Several states (most notably, New York, Maryland, Pennsylvania and others) have launched

multi-year initiatives to expand community services in order to accommodate more individuals and reduce waiting lists that had built up. But, often states have been unable to keep pace with growing demand for services. As a result, waiting lists lengthened or persisted at high levels even though concurrently the number of individuals receiving services also grew. In many cases, individuals and families have become increasingly frustrated at having to wait long periods in order to access community services and supports. It is not surprising that this frustration with the lack of ready access to services has boiled over into lawsuits that seek to obtain services right away for individuals.

In the past, there have been sporadic attempts to secure court rulings that people with developmental disabilities have a right to services in the community. However, such efforts generally were unsuccessful except with respect to individuals who were class members in institutional litigation. Courts ruled that neither state nor federal law created an entitlement to services. State laws limiting services to available appropriations usually have been upheld.

By and large, previous lawsuits concerning access to services did not raise claims with respect to federal Medicaid law. Indeed, until fairly recently, there has been relatively little litigation concerning any aspect of the operation of the HCBS waiver program even though Congress first authorized the program two decades ago. Since states generally have been regarded as having broad discretion in furnishing Medicaid home and community services, there seemed scant basis for calling on the courts to require states to expand their availability.

The “waiting list” lawsuits that have been filed mainly in the past three years challenge the premise that states have unfettered discretion to limit the availability of Medicaid long-term services for people with developmental and other disabilities. The lawsuits assert that certain provisions of federal law create an affirmative obligation for states to furnish Medicaid home and community services to people with developmental and other disabilities on an as needed basis. The lawsuits bring into play several provisions of federal Medicaid law. In many cases – especially in the wake of the U.S. Supreme Court’s landmark ruling in the landmark Olmstead v. L.C. litigation – the federal Americans with Disabilities Act (ADA) also is cited as providing further grounds for courts to intervene to require that people with developmental and other disabilities have access to home and community services in the most integrated setting.

The Olmstead decision also has sparked more lawsuits seeking access to home and community services on behalf of institutionalized persons, principally individuals with disabilities who are served in nursing facilities. These lawsuits demand changes in state policy so that individuals presently served in nursing facilities and other institutional settings have ready access to home and community services if they desire services in the most integrated setting.

Finally, still other lawsuits challenge state policies and practices that the plaintiffs contend result in individuals in the community not being able to access the full-range of community services to which they are otherwise entitled. Some of these lawsuits contend that low state payments for services create barriers to securing authorized services. Others challenge state practices in rationing the availability of some types of community services.

In almost all instances, Medicaid beneficiaries have filed these lawsuits in federal court, asking the courts to compel states to adhere to the requirements of federal Medicaid law. In most cases, federal courts have accepted jurisdiction in such litigation but not universally. Some states have asserted that states are immune from such lawsuits under the provisions of the 11<sup>th</sup> Amendment

to the U.S. Constitution. Whether such lawsuits can be brought against states in federal court is a complex question. We outline some of the issues in the endnote to this report.

As a consequence, the issue of access to home and community services now is being engaged from the standpoint of federal Medicaid and other laws rather than state law. The lawsuits are propelled by consumer frustration with have to wait for an indefinite period of time to obtain services lists and the legitimate desire of people with disabilities (including institutionalized persons) to have ready, reliable access to services in the community.

### **III. Waiting List Lawsuits**

#### **A. Overview**

“Waiting list” lawsuits assert that a state violates federal law when it does not provide Medicaid long-term services (i.e., ICF/MR or waiver services) to individuals who otherwise have been determined eligible for them. These lawsuits specifically challenge the practice of wait listing individuals to receive Medicaid services at some future date rather than providing services right away. The plaintiffs in these lawsuits seek federal court intervention to direct the defendant state to furnish necessary Medicaid long-term services to all eligible individuals with “reasonable promptness.”

Key provisions of federal Medicaid law (Title XIX of the Social Security Act), Title II of the Americans with Disabilities Act (ADA) along with Section 504 of the Rehabilitation Services Act of 1973, and the 14<sup>th</sup> Amendment to the U.S. Constitution provide the basis for these lawsuits. A reasonably complete discussion of the central legal issues raised in these lawsuits is found at [http://www.healthlaw.org/pubs/200005FactSheet\\_hcbw.html](http://www.healthlaw.org/pubs/200005FactSheet_hcbw.html). However, the specific legal claims in each lawsuit vary.

In general, waiting list lawsuits are based on the interconnection in federal Medicaid law (§1915(c) of the Social Security Act) between institutional (nursing facility or ICF/MR) services and the HCBS waiver program. Federal law provides that a state may offer HCB waiver services as an alternative to institutional services. In order for a person to receive waiver services, s/he must be determined to meet the state’s eligibility criteria with respect to institutional services. The same (or equivalent) eligibility criteria must be used for both institutional and waiver services. A state may decide to offer HCB waiver services only to specified subcategories of persons (e.g., adults but not children) who meet institutional eligibility criteria. Lastly, when a person is offered waiver services, s/he has the freedom to choose between receiving institutional and waiver services. [N.B., See ASPE (2000) for a more detailed discussion of federal policy with respect to the operation of HCBS waiver programs.]

Federal law and regulation permit a state to limit the number of individuals who receive HCB waiver services. That is, a state may establish a “cap” on the number of individuals who may participate in the program. However, federal law contains no equivalent authority for a state to impose limits on the number of persons who can receive institutional services. A premise of the HCBS waiver statute is that recipients will have unfettered access to institutional services because such services are furnished under a state’s regular Medicaid program and, as such, must be furnished to individuals who have been determined to require them.

Most waiting list lawsuits rely on the requirement that a state must provide Medicaid state plan services (including institutional services) services to eligible individuals with “reasonable promptness” in order to challenge the practice of wait listing individuals. In particular,

§1902(a)(8) of the Social Security Act and associated federal regulations require that a state make a prompt determination when application is made for Medicaid services. Federal courts have interpreted the “reasonable promptness” requirement as also requiring a state to furnish the Medicaid services a person is entitled to receive with reasonable promptness once the person’s application is approved. A detailed discussion of the legal issues concerning §1902(a)(8) is located on the Internet at <http://www.healthlaw.org/pubs/200101promptness.htm>. With respect to processing Medicaid applications, the regulatory standard is no more than 90-days. Courts have ruled that wait-listing individuals indefinitely violates the intent of §1902(a)(8).

In March 1998, the 11<sup>th</sup> U.S. Circuit of Appeals handed down a watershed decision in the Florida Does v. Chiles (now Does v. Bush) litigation that made it clear that federal Medicaid law does not permit a state to “wait list” individuals for ICF/MR services indefinitely. The Court ruled that ICF/MR services were no different than any other non-waiver Medicaid service: namely, such services must be furnished with reasonable promptness to eligible applicants. Most waiting list lawsuits elsewhere have been filed on the heels of this decision. This decision is located on the Internet at <http://laws.findlaw.com/11th/965144man.html>. While the decision applies only to states in the 11<sup>th</sup> Circuit, it has been frequently cited in lawsuits filed in other federal circuits.

The 11<sup>th</sup> Circuit decision directly spoke to access to Medicaid institutional (ICF/MR) services rather than HCB waiver services. Most waiting list lawsuits seek to secure access to Medicaid home and community rather than institutional services. In these lawsuits, the plaintiffs rely on the interconnections in federal law between institutional and HCB waiver services. In particular, the plaintiffs argue that a person’s eligibility for ICF/MR services also permits the individual to access “equivalent services” (e.g., services furnished through an HCBS waiver program). In other words, when a person is found eligible for entitled ICF/MR services, such services or equivalent non-institutional Medicaid waiver services must be furnished without delay. In some lawsuits, plaintiffs also claim that §1915(c)(2)(C) of the Social Security Act requires that individuals who meet ICF/MR level of care eligibility tests have the freedom to choose between institutional (ICF/MR) and HCB waiver services. That is, a person eligible to receive ICF/MR services has the right to opt instead to receive waiver services.

In some cases, plaintiffs point out that a state has imposed limits on the availability of both ICF/MR and HCB waiver services and, therefore, effectively caused eligible individuals to be unable to obtain either type of service. In some suits, plaintiffs also contend that the practice of wait listing individuals violates §1902(a)(10) of the Social Security Act because the state is failing to make available Medicaid long-term services on a “comparable” basis to all eligible Medicaid recipients, either by furnishing such services to some but not all eligible individuals or making institutional but not community services available to recipients.

Waiting list lawsuits also have challenged state practices with regard to handling applications for Medicaid services. Plaintiffs have asserted that states have effectively denied individuals the right to apply for Medicaid long-term services by not permitting individuals to submit formal applications for HCB waiver services or by not making a formal determination concerning such applications. It is asserted that individuals seeking services are wait listed for community services rather than being allowed to file a formal application. Plaintiffs contend that this practice violates §1902(a)(3) of the Social Security Act (by denying individuals their right to appeal a denial of Medicaid eligibility or services) along with the due process protections afforded by the 14<sup>th</sup> Amendment to the U.S. Constitution.

Some (but not all) lawsuits include claims that a state's not making community services available on at least equal footing with institutional services violates Title II of the ADA (along with Section 504 of the Rehabilitation Services Act of 1973) that requires public agencies to provide services in the "most integrated setting" appropriate to the needs of the individual. Plaintiffs assert that the ADA mandates that eligible individuals must be able to access HCB waiver services on equal footing with institutional services. Plaintiffs also have contended that the caps which states impose on the number of persons who can receive HCB waiver services effectively limit the availability of long-term services to institutional settings, thereby denying individuals services in the most integrating setting as required by the ADA.

Where federal courts have issued decisions in these cases, the rulings have been based mainly on provisions of Medicaid law rather than the claims under the ADA. For example, in the West Virginia Benjamin H. litigation, the federal District Court decided that the plaintiffs' claims with respect to Medicaid law provided sufficient basis to justify issuing a preliminary injunction against the state without the court's taking up the issues raised by the plaintiffs with respect to the ADA.

## **B. Description of Lawsuits**

As of July 2001, waiting list lawsuits had been filed in sixteen states. Each of these lawsuits is summarized below. Some lawsuits (e.g., Mandy R in Colorado) principally seek the provision of residential services for wait-listed individuals. Other lawsuits (e.g., Brown in Tennessee and Benjamin H in West Virginia) aim at securing enrollment to the state's HCBS waiver program so that wait-listed individuals can access any of the services made available in a state's program.

Settlement agreements have been reached in five lawsuits (Florida (in one of two lawsuits), Hawai'i, Massachusetts, Oregon and West Virginia). These settlement agreements spell out steps to address the underlying issues in a fashion satisfactory to the parties. The federal district court with jurisdiction over the lawsuit must approve the settlement agreement. In the settlement agreements, typically the state has agreed to increase over a multi-year period (e.g., three to five years) the number of individuals who will be furnished Medicaid HCB waiver services. The agreements recognize that large expansions of community services take time to implement. Depending on the case, the agreement also may include revisions in state policies and practices concerning the disposition of applications for services or the order in which the state will offer services to wait-listed persons. Settlements also describe how the parties will interact during the agreement's implementation along with the circumstances that might cause the agreement to be voided (e.g., insufficient funds are appropriated) and how disputes concerning implementation will be addressed, including returning to court if need be.

### **1. Alabama: Susan J. et al. v. Siegelman et al.**

In July 2000, a civil complaint was filed in U.S. District Court for the Middle District of Alabama, Northern Division (CV-00-S-918-N) on behalf of six named plaintiffs with mental retardation. The lawsuit alleges that Alabama has violated federal Medicaid law, 42 USC §1983, and the 14<sup>th</sup> Amendment to the U.S. Constitution by failing to furnish ICF/MR or HCBS waiver services to these otherwise eligible individuals. The plaintiffs are persons who are on the state's waiting list for HCBS waiver services. They are seeking residential and/or day habilitation services.

Specifically, the plaintiffs contend that Alabama's policy of limiting the number of persons with mental retardation who may receive Medicaid long-term services: (a) violates the requirement that such services must be furnished with reasonable promptness, as spelled out in §1902(a)(8) of the Social Security Act; (b) violates the requirement that Medicaid services must be furnished to all eligible individuals on a comparable basis, as provided in §1902(a)(10)(B); and, (c) violates 42 USC §1983 and the 14<sup>th</sup> Amendment to the U.S. Constitution by depriving individuals of their right to obtain services.

The State has filed a motion to dismiss the complaint. In its motion, the state argues that: (a) services furnished through an HCBS waiver program differ from optional and mandatory Medicaid services and, thus, are not subject to the same requirements as pertain to other Medicaid services; (b) states have the authority to limit the number of individuals who may receive services through an HCBS waiver program; and, (c) the plaintiffs have no enforceable right under federal or state law to the services they are seeking and, thereby, an action cannot be brought against the state in federal court under the provisions of the 11<sup>th</sup> Amendment to the U.S. Constitution.

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

A private attorney filed this lawsuit (A01-027 CV) on behalf of 15 named plaintiffs in January 2001 in the U.S. District Court for the District of Alaska. The lawsuit asserts that Alaska has violated federal Medicaid law, the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the 14<sup>th</sup> Amendment to the U.S. Constitution by failing to provide Medicaid services to eligible children and adults with developmental disabilities and instead wait listing such persons for services indefinitely. The lawsuit petitions the court to order the state to take all necessary steps to comply with federal requirements.

In particular, the lawsuit asserts that Alaska's policies and practices of wait listing individuals for services violate the ADA's integration mandate as well as the "reasonable promptness" requirements contained in Medicaid law. The plaintiffs assert that Alaska also is violating Medicaid requirements by not properly processing applications for Medicaid services or affording individuals the chance to appeal adverse decisions with respect to obtaining services or changes in services that individuals previously have been authorized to receive.

## **3. Colorado: Mandy R. et al. v. Owens et al.**

Private attorneys in collaboration with The Arc of Colorado filed this class action complaint in the U.S. District Court for the District of Colorado in August 2000. The complaint asserts that Colorado has violated federal Medicaid law, the ADA along with Section 504 of Rehabilitation Services Act of 1973, and the U.S. Constitution by failing to provide Medicaid residential services with reasonable promptness to eligible individuals with developmental disabilities. The complaint cites March 2000 state figures that showed that 2,700 individuals were wait listed for residential services, including 1,149 persons who had been judged as needing such services within 12-months. The proposed class would include "all current and future Colorado residents with developmental disabilities who are eligible for, but are not receiving, residential placement and related services under the Colorado Medicaid program." The class would include persons who have been wait-listed for what Colorado terms "comprehensive services" (a "package" of HCB waiver services that includes out-of-the-family-home residential services) but currently receive a more limited array of services and supports through the state's "Support Living

Services” waiver program (a separate HCB waiver program that provides more limited benefits for individuals who live with their families or on their own).

In response to the complaint, the state has filed a motion for dismissal. However, to date, the District Court has not scheduled hearings on either the original complaint or the state’s motion to dismiss.

**4. Florida: John/Jane Does v. Bush et al. and Wolf Prado-Steiman et al. v. Bush et al.**

In 1992, a class action complaint was filed (as Does v. Chiles et al.) on behalf of individuals who had been wait-listed for ICF/MR services. The Does complaint asserted that Florida violated federal Medicaid law by failing to furnish ICF/MR services with reasonable promptness to otherwise eligible Medicaid recipients with developmental disabilities. In March 1998, the U.S. 11<sup>th</sup> Circuit Court of Appeals upheld the District Court’s ruling that the state’s practice of wait listing individuals for ICF/MR services violated federal Medicaid law (see above). The Prado-Steiman litigation was brought by The Advocacy Center (Florida’s Protection and Advocacy agency) filed the Prado-Steiman lawsuit. A settlement agreement has been reached in Prado-Steiman. The agreement provides that the state will serve all individuals who were waiting for services on July 1, 1999 by 2001.

Under the leadership of Governor Bush, Florida has embarked on a major expansion of developmental services, including its HCBS waiver program to improve access to services in response to these lawsuits. Funding for developmental services has increased by approximately \$360 million over the past two years. Florida has negotiated a Section 1915(b)/(c) waiver agreement with HCFA to provide expanded access to HCB waiver services for eligible individuals. Among its other provisions, the settlement agreement includes an “operational definition” of how the state will comply with the reasonable promptness requirement. However, as of this date, there has not been a final disposition of Does v. Bush lawsuit.

**4. Hawai’i: Makin et al. v. State of Hawai’i.**

This class action complaint was filed in December 1998 by the state’s Protection and Advocacy Agency. The complaint alleged that the state’s practice of wait listing individuals for HCB waiver services violated federal Medicaid law and the Americans with Disabilities Act. The state challenged the applicability of the ADA, arguing that the U.S. Supreme Court’s Olmstead decision pertained only to institutionalized persons. The District Court rejected this argument by reasoning that the unavailability of community services would leave institutionalization as the option available to individuals.

In April 2000, the state and plaintiffs entered into a settlement agreement wherein the state agreed to increase the number of individuals who would be served in the state’s HCB waiver program by approximately 70% over a three-year period. In its 2000 session, the Hawai’i legislature approved \$4.3 million in funding to underwrite the first stage of this expansion and is expected to approve an additional \$8 million in funding this year to meet the terms of agreement. The text of the settlement agreement may be accessed at <http://www.pixi.com/~pahi/stlmnt.htm>.

**5. Illinois: Boudreau et al. v. Ryan et al.**

On September 1, 2000, a lawsuit – Boudreau et al. v. Ryan et al. (00-C-5392) – was filed in the United States District Court for the District of Northern Illinois on behalf of five named plaintiffs with developmental disabilities who are eligible for Medicaid services and have sought HCBS waiver services but not received them. The lawsuit alleges that Illinois has not furnished

Medicaid services to eligible individuals with reasonable promptness as required under Medicaid law and furthermore has not accorded eligible individuals freedom of choice in selecting between ICF/MR and HCB waiver services. The suit also alleges violations of other provisions of the Social Security Act, Title II of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973 and the 14<sup>th</sup> Amendment to the U.S. Constitution.

The suit calls for the Court to “issue preliminary and permanent injunctive relief requiring the Defendants, their successors in office, agents, employees, and all persons acting in concert with them, to offer the Plaintiffs the full range of ICF/MR services or home and community-based waiver services and other services for which they are eligible within 90 days or some other specifically- defined, reasonably prompt period.” The suit also alleges “... the State has created additional barriers to prevent or discourage potentially eligible persons from seeking Medicaid services.”

The state filed a motion to dismiss. The state argued that the lawsuit should be dismissed for several reasons, including the protection afforded states under the U.S. Constitution’s 11<sup>th</sup> Amendment granting states sovereign immunity from being sued in federal court. The state also challenged the merits of the plaintiff’s claims with respect to the applicability of other federal laws. On May 1, 2001, District Judge John F. Grady ruled on the motion to dismiss. Siding with the state, Judge Grady dismissed the plaintiffs’ claim alleging a violation of the Americans with Disabilities Act. Judge Grady based this ruling on the fact that the complaint has been filed against public officials acting in their official capacity whereas Title II of the ADA speaks to the policies and practices of a “public entity.” However, Judge Grady did not find the state’s arguments persuasive with respect to dismissing the plaintiffs’ other claims. In general, he found that the plaintiffs’ other claims fall within the jurisdiction of the federal courts and potentially have merit as matters of law or the state’s basis for dismissing a claim revolved around questions of fact that were the proper subject for subsequent proceedings. Judge Grady’s May 1 ruling can be viewed/downloaded from the plaintiff attorney’s website: <http://www.illinoisclassaction.com/>.

## **6. Massachusetts: Boulet et al. v. Cellucci et al.**

This class action complaint was filed in March 1999 (originally the complaint was filed as Anderson et al. v. Cellucci et al.). Private attorneys filed this complaint on behalf of the plaintiffs and their families who were dissatisfied with the pace at which the state was reducing its waiting list. The complaint asserted that the Commonwealth of Massachusetts violated federal Medicaid law and the ADA by failing to provide residential services with reasonable promptness to otherwise eligible individuals but instead wait listed persons indefinitely. When the lawsuit was filed, approximately 3,000 persons were waiting for residential services in Massachusetts. Since then, the waiting list has been reduced to fewer than 2,500 individuals, of whom approximately 2,200 were waiting for residential services. Over the past four years, Governor Cellucci and the state legislature have earmarked additional dollars to reduce the waiting list as well as fully fund the state’s “Turning 22” program to ensure that services are available for youth when they transition from special education services. The waiting list for residential services includes individuals who already participate in the state’s HCBS waiver program (but who do not receive residential services) as well as individuals who do not.

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. However, the Court certified a narrower class than originally proposed by the plaintiffs. The

plaintiffs had asked that the class include all individuals presently wait listed for Medicaid residential services as well as persons who might be eligible for such services in the future. The Court narrowed the class to individuals presently participating in the state's HCBS waiver program who had been wait listed for "residential habilitation" services or wait listed persons not served in the HCBS waiver program who could be accommodated under the waiver program's participant cap. In its July ruling, the Court directed the state to furnish residential services to class members within 90-days or, if the state could demonstrate that doing so was not feasible, to propose a plan that would bring the state into compliance with the reasonable promptness requirement. **This ruling is recapped at: <http://www.protectionandadvocacy.com/massdis.html>.**

In November 2000, the state and the plaintiffs reached agreement in principle to settle the lawsuit. On December 19, 2000, the parties entered into a formal settlement agreement. The settlement agreement would modify the class the Court certified to include all individuals who were wait listed for Department of Mental Retardation services as of July 14, 2000, regardless of whether a person was receiving or would be eligible to receive HCB waiver services. The modified class has 2,437 members, including 1,961 who were waiting for out-of-home residential services only, 266 who waiting for both residential and non-residential services (e.g., day services), and 210 were waiting for non-residential services only. Under the terms of the agreement, the state has agreed to provide residential services to an additional 300 individuals during the current fiscal year using funds already appropriated by the legislature. Over the next five years (FY 2002 – 2006), Governor Cellucci has committed to seek funding sufficient to extend residential services to an additional 1,975 individuals at a pace of 375 – 400 persons per year. Wait listed persons who do not receive residential services right away will receive "interim services" (in-home, family support and other services) until residential services become available. The parties also agreed to processes for developing service plans both for residential and interim services. The agreement commits the state to increase funding for services from current levels by \$114 million in 2006 when the agreement is fully implemented. Over the five-year period 2002 – 2006, Massachusetts is committing \$355.8 million to expand the availability of services.

#### **7. Montana: Travis D. et al. v. Eastmont Human Services Center.**

Filed in May 1998, this complaint alleges that Montana is in violation of federal Medicaid law by failing to provide HCB waiver services to wait listed individuals in the community along with residents of the state's two public MR/DD institutions who would benefit from HCB waiver services. The complaint was filed by the state's Protection and Advocacy Agency. As a consequence, this lawsuit falls into both the "waiting list" and "Olmstead" categories. When the lawsuit was filed, approximately 600 persons were waiting for HCB waiver services. The Court has yet to rule on motions in this case. Reportedly, settlement discussions are underway. Meantime, there has been a steady reduction in the number of individuals served at Montana's two large public facilities. By the end of the upcoming biennium, the census of both facilities is slated to be reduced to 88.

#### **8. New Mexico: Lewis et al. v. New Mexico Department of Health et al.**

This lawsuit was filed in January 1999 by state's Protection and Advocacy agency in collaboration with The Arc of New Mexico. The class action complaint alleges New Mexico has violated federal Medicaid law and the Americans with Disabilities Act by failing to provide Medicaid services in the community to otherwise eligible individuals with disabilities, thereby

causing them to go without services or forcing them to seek institutional services. The proposed class includes: (a) people with developmental disabilities who have been wait-listed for HCB waiver services; (b) persons served in ICFs/MR who would benefit from home and community-based waiver services [Note: New Mexico no longer operates large state institutions; the proposed class members are persons served in small ICF/MR group homes]; (c) persons with other disabilities (both elderly and others) served in nursing facilities who would prefer to receive services in the community; and, (d) persons with other disabilities in the community who want access to the state's HCB waiver program for persons who are aged or disabled. Hence, this lawsuit spans both the "waiting list" and "Olmstead" categories.

In 2000, there were approximately 190 individuals with developmental disabilities who were waiting residential services in New Mexico and others wait listed for other services. The entire class may total upwards of 3,000 individuals. In April 2000, the federal district court rejected the state's motion to dismiss the lawsuit and upheld the plaintiffs' right to access to HCB waiver services with "reasonable promptness" – essentially lumping Medicaid-financed waiver supports with state plan option services. In part, the state based its motion to dismiss the lawsuit on sovereign immunity claims under the 11<sup>th</sup> Amendment to the U.S. Constitution. In response to the district court's decision, in May 2000 the state appealed the decision to the 10<sup>th</sup> U.S. Circuit Court of Appeals in Denver, asking for reconsideration of the state's 11<sup>th</sup> Amendment defense. Under federal judicial rules, an appeal based on a sovereign immunity claim stays further district court consideration of a case. Information concerning this litigation and its current status is located on the Internet at: <http://www.arcnm.com/IndexPages/GettingToKnow/Lewis.htm>. As of the date of this update, the 10<sup>th</sup> Circuit had not ruled on the state's appeal.

#### **9. Ohio: Martin et al. v. Taft et al.**

Filed by Ohio Legal Rights Services (ORLS - the state's Protection and Advocacy agency) in 1989 (as Martin v. Voinovich), this class action complaint alleges that Ohio is in violation of Medicaid law as well as the ADA by failing to provide integrated residential services to all persons with developmental disabilities who are eligible to receive them. Notably, in relation to state sovereignty and the ADA, in 1993 the court rejected the state's motion to dismiss the ADA claim on the basis of states' 11<sup>th</sup> Amendment sovereign immunity, holding that Congress, in this instance, had the authority to abrogate such constitutionally guaranteed immunity. In 1998, the parties agreed to a motion to stay further district court proceedings in this litigation in the hope that an agreement could be worked out to expand the availability of services. However, in July 2000, ORLS 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." It is unclear when the trial phase of this litigation will take place.

#### **10. Oregon: Staley et al. v Kitzhaber et al.**

This complaint was filed in January 2000. This lawsuit was not filed as a class action complaint. The complaint alleged that the state was violating federal Medicaid law and the Americans with Disabilities Act 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. Detailed information concerning the agreement may be accessed at <http://oddsweb.mhd.hr.state.or.us/Pubs/settlement/settlement.htm>. The settlement agreement would implement Oregon's Universal Access Plan, which was submitted to the Oregon Legislature in February 2000. The parties agreed that the settlement

would apply not only to the named plaintiffs but also “all other similarly-situated individuals with developmental disabilities under the federal Medicaid program,” thereby treating the lawsuit as a class action. The settlement agreement extends to 2007. The agreement provides that the state will increase funding for developmental disabilities services by a cumulative total of \$350 million over the period of the agreement. Under the terms of the agreement, the number of individuals receiving “comprehensive services” (which include 24-hour residential services) would increase by 50 per year over and above the number of individuals who would receive such services due to crises or emergencies. The state agreed to continue its policy of furnishing comprehensive services to all individuals who require them due to 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 six-year period of the agreement. In addition, the settlement agreement calls for reducing case management workloads from its current 1:95 ratio to 1:45 and making additional investments in system infrastructure.

A broad-based Universal Access Planning Committee was established in 2000 and continues to be active. The Committee’s minutes are found at: <http://www.open.org/~arcoforg/uapc.htm>. The Oregon Legislature approved additional dollars for the current biennium to fund the first two years of the Universal Access Plan.

#### **11. Pennsylvania: Gross et al. v. Houston**

Filed in July 1999, this class action complaint alleges that the Commonwealth of Pennsylvania has violated federal Medicaid law by failing to provide ICF/MR or equivalent residential services to otherwise eligible individuals and instead has instead improperly wait listed such persons. A few months earlier, a non-class action complaint (Elizabeth M et al. v. Houston) also was filed seeking residential services for a small number of named plaintiffs. Court-related activity concerning Gross is in suspense as a result of Governor Ridge’s commitment to provide an additional \$850 million in funding over the next five years to reduce and/or eliminate the state’s waiting list for services as spelled out in a multi-year waiting list reduction plan that was worked out between the state and key stakeholders. Development of the state’s waiting list reduction plan preceded the filing of this lawsuit. Information concerning Pennsylvania’s waiting list reduction plan may be found at <http://www.dpw.state.pa.us/omr/pdf/mrwaitlist1.pdf>.

In August 2000, the Disability Law Project filed a class action complaint (Delong et al. v. Houston (00-CV-4332); this complaint is now Pennsylvania Protection and Advocacy, Inc. v. Houston) in the United States District Court for the Eastern District of Pennsylvania concerning the state’s implementation of its Person/Family Directed Supports (P/FDS) waiver program. In 1999, Pennsylvania secured federal approval to launch the PFDS waiver program on July 1, 2000. Under the PFDS waiver program, individuals may receive flexible services and supports so long as the overall costs of such supports do not exceed \$20,000 in any year. The PFDS waiver program is one element of the Commonwealth’s multi-year waiting list reduction initiative. As approved, Pennsylvania could serve up to 3,382 individuals in the first three year of the P/FDS waiver program’s operation and 3,448 in the year ending July 1, 2001.

The lawsuit contended that Pennsylvania was required to serve under the terms of the approved waiver 3,392 persons during 1999-2000 but the Commonwealth allocated fewer “slots” to its county mental health and mental retardation offices and thereby did not permit all individuals who might benefit from P/FDS waiver services to receive them. When the suit was filed, about 2,400 individuals were participating in the program. The plaintiffs argue that there are upwards

of 10,000 individuals who might benefit from P/FDS waiver services. The complaint asked the Court to certify a class composed of “[a]ll Pennsylvania Medical Assistance recipients who are eligible for Pennsylvania’s Person/Family Directed Support Waiver but who are not receiving services under that waiver.” The complaint also contended that Pennsylvania has violated federal Medicaid law (but makes no citations of specific provisions of the law) by: (a) failing to fully implement the P/FDS waiver program; (b) failing to allow individuals to apply for services through the P/FDS waiver program; and, (c) failing to allow evaluations of individuals for P/FDS Waiver services and allowing them to choose what services they want.

Pennsylvania filed a motion asking the Court to dismiss the lawsuit. In March 2001, the Court denied this motion. However, in its opinion, the Court cast doubt on the standing of the current plaintiff (Pennsylvania Protection and Advocacy, Inc) to continue to pursue this litigation.

**12. Tennessee: *Brown et al. v. The Tennessee Department of Mental Health and Developmental Disabilities and Rukeyser* and *People First of Tennessee v. Neal et al.***

**Brown.** Filed in July 2000 by the state’s Protection and Advocacy Agency, this class action complaint 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 estimates that about 850 individuals have been wait listed for HCB waiver services. This complaint relies solely on provisions of Medicaid law and the U.S. Constitution for its basis and makes no claims based on the Americans with Disabilities Act.

**People First.** In March 2001, People First of Tennessee filed its own distinct class action complaint in the U.S. District Court for the Middle District of Tennessee. This complaint asserts that the state: (a) has failed to provide ICF/MR or HCB waiver services to eligible individuals with reasonable promptness; (b) is in violation of the Americans with Disabilities Act by failing to make reasonable modifications and accommodations so that individuals (including institutionalized persons) can obtain services and supports in the most integrated setting; (c) is not in compliance with §1902(a)(10) of the Social Security Act since it has not made ICF/MR or waiver services available to all otherwise eligible Medicaid beneficiaries with developmental disabilities; (d) has denied individuals the right to apply for or be made aware of Medicaid services; (e) has discriminated against some individuals with disabilities by not permitting all other wise eligible persons to obtain services for which they are eligible, in violation of the Americans with Disabilities Act; (f) is in violation of §1902(a)(10) of the Social Security Act and the Due Process Clause of the 14<sup>th</sup> Amendment to the U.S. Constitution by not providing individuals written notice of denial of Medicaid services and, thereby, preventing them from exercising their right to appeal such a denial; (g) has denied individuals the ability to exercise free choice in receiving home and community waiver services or ICF/MR services; and, (h) has violated the Individuals with Disabilities Education Act by denying Medicaid payment for services to which school-age individuals are otherwise entitled.

The petitioners’ complaint alleged that approximately 2,000 persons with developmental disabilities were waiting for HCB waiver services in Tennessee. And, while the State’s approved HCB waiver program has a participant cap of 5,581 for FY 2000-01, only 4,312 individuals had been enrolled in the program as of November 1, 2000, with a projected enrollment of 4,476 by the end of the fiscal year. The State defendants, the petitioners contended, are giving insufficient attention to the growing backlog of demand for home and community services because most new

resources are being committed to placing residents out of state-operated institutions in compliance with court orders in several earlier institutional treatment lawsuits (*People First v. Clover Bottom, et. al* and *United States of America v. State of Tennessee*).

### **13. Virginia: Quibuyen v. Allen and Smith**

Filed in December 2000 in the U.S. District Court for the District of Virginia by a coalition of attorneys, the complaint alleges that the state has refused to furnish necessary HCBS waiver services to current waiver participants and instead impermissibly wait listed individuals to receive such services. In particular, the complaint argues that Virginia has imposed restrictions on furnishing services to HCBS 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 is a June 1999 directive issued by the Virginia Department of Medical Services that restricted the circumstances under which additional services (including residential services) could be authorized on behalf of waiver participants. The directive limited the provision of new or expanded services to situations when an individual no longer can remain in the family home due to caregiver incapacity or other critical situations. The complaint alleges that this and other policies have lead to wait listing waiver participants for the receipt of services that they are otherwise eligible to receive.

In a related development, the Office of Civil Rights (OCR) within the U.S. Department of Health and Human Services is reported to be investigating whether Virginia is violating a 1999 Supreme Court decision that guarantees that the mentally retarded receive services in a reasonable time. OCR has received multiple complaints from Virginia families who were approved for services but have not received them. HHS officials said the investigation also is looking to see whether the state has violated the Americans With Disabilities Act by using waiting lists to delay services.

### **14. Washington: The Arc of Washington State et al. v. Lyle Quasim et al.**

Filed in November 1999, this class action complaint alleges that Washington is in violation of federal Medicaid law and the ADA by failing to provide Medicaid long-term services with reasonable promptness to otherwise eligible individuals with developmental disabilities. The complaint alleges that there are several thousand individuals with developmental disabilities in need of Medicaid funded services or current Medicaid recipients who would benefit from additional services.

In rulings thus far in this litigation, the District Court has determined that: (a) eligibility for ICF/MR services does not suffice to establish an entitlement to HCB waiver services and (b) Medicaid law in fact does require services to be furnished with reasonable promptness. In December 2000, the Court granted the state's motion for a summary judgment to deny the plaintiff's ADA claims. The plaintiffs had claimed that the ADA requires that, if a state makes HCB waiver services available to some individuals with disabilities, it must furnish such services to all similarly situated individuals. The Court ruled that the ADA is not a basis for ordering a state to increase its limit on the number of individuals who may receive HCB waiver services because such an order would require the state to make a "fundamental alteration" in its services. The Court also ruled on three other motions. The plaintiffs have indicated that they intend to raise two additional issues: (a) that current HCBS waiver participants are not receiving all

services to which they are entitled and (b) persons who are eligible for ICF/MR services have not received them with reasonable promptness.

The parties agreed to postpone the trial phase of this litigation while they parties explore for the potential for arriving at a settlement agreement.

#### **15. West Virginia: Benjamin H. et al. v. Ohl**

Filed in April 1999, this class action complaint alleged that West Virginia had violated federal Medicaid law and the ADA by failing to provide Medicaid long-term services with reasonable promptness to otherwise eligible individuals. In July 1999, the District Court granted the plaintiffs' motion for a preliminary injunction based on its conclusion that the plaintiffs were likely to prevail at trial based solely on the requirements of federal Medicaid law. This decision is located at the following website: <http://www.healthlaw.org/pubs/199907benjamin.html>. The defendants were ordered to develop a compliance plan that would eliminate waiting lists, establish reasonable time frames for placing persons into the waiver program, allow persons to exercise their freedom of choice in selecting institutional or home based care; develop written policies to inform persons of the eligibility process, and develop written policies and forms to afford proper notice and an opportunity for a fair hearing to those persons whose applications for ICF/MR level services are denied or not acted on with reasonable promptness.

In March 2000, the Court approved a series of agreements between the parties to address the topics spelled out in the preliminary injunction. In particular, West Virginia has agreed to increase the number of individuals who will receive HCB waiver services by 875 over the next five years. The parties also agreed on a process for enabling individuals to make application for services and receive proper notification concerning the disposition of the application. The state submitted an application to HCFA to renew its home and community-based waiver program for persons with developmental disabilities. The renewal request incorporated policy changes stemming from the agreement, including the expansion of West Virginia's program. This waiver renewal request was approved in December 2000. See also the final section for a discussion of issues related to payment rates in this litigation.

#### **16. Similar Lawsuits Involving Individuals with Other Disabilities**

So far most "waiting list" litigation has centered almost exclusively on services for people with developmental disabilities, although the New Mexico Lewis litigation spans multiple populations with disabilities. In 1996, a lawsuit (Joy W. v. Houston) was filed in the U.S. District Court for the Western District of Pennsylvania to require the state to furnish HCB waiver personal care services to an estimated 700 persons with disabilities. The plaintiffs contended that a waiver program approved by HCFA has the same status as other services a state offers as medical assistance under its state Medicaid plan and, thus, failure to provide medical assistance with reasonable promptness to all eligible individuals violates federal Medicaid law. However, this case did not go trial because the state and the plaintiffs quickly entered into a settlement agreement to furnish personal assistance/attendant care services to all persons on the waiting list and to all other persons who qualify under the waiver.

## IV. “Olmstead” Litigation

### A. Overview

In June 1999, the U.S. Supreme Court issued its historic ruling in the Olmstead v. L.C. litigation, ruling that unnecessary segregation of individuals with disabilities in institutional facilities constitutes prohibited discrimination in violation of the ADA. In its majority opinion, the Supreme 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 the needs of other persons with disabilities. This decision may be found at <http://supct.law.cornell.edu/supct/html/98-536.ZS.html>. Additional materials concerning this case and its potential implications are at <http://www.protectionandadvocacy.com/lcolmste.html> as well as numerous other websites. In March 2000, the Kaiser Commission on Medicaid and the Uninsured published a Policy Brief concerning potential implications of the Olmstead decision on the provision of Medicaid services. This Policy Brief is located on the Internet at: <http://www.kff.org/content/2000/2185/OlmsteadDecision.pdf>. Federal Center for Medicare and Medicaid Services (CMS) materials describing the steps the Agency concerning this ruling are located at <http://www.hcfa.gov/medicaid/olmstead/olmshome.htm>.

By “Olmstead” litigation, we mean lawsuits that principally are intended to ensure access to Medicaid community services on behalf of institutionalized persons with disabilities (even though some of these lawsuits were filed prior to the Olmstead decision). In other words, these lawsuits have raised issues similar to those decided in the Olmstead litigation. In developmental disabilities, there is a long history of litigation prior to the Olmstead decision (and, in fact, the enactment of the ADA) that led to the community placement of institutionalized persons. This litigation more or less established that institutionalized persons should be discharged from large public facilities when their needs can be addressed in a less restrictive setting. The Supreme Court’s decision furnishes an additional basis for “deinstitutionalization” litigation as well as clearly establishing that individuals with disabilities (developmental, cognitive or otherwise) served in other types of institutional settings (e.g., nursing facilities or privately-operated ICFs/MR) also have the right to receive services in the “most integrated setting.”

As noted in preceding section, some of the “waiting list” lawsuits (e.g., Travis D. and Lewis) include institutionalized persons in the plaintiff class. There have been additional lawsuits filed that are principally (but not always exclusively) intended to secure community services for institutionalized persons, principally persons with disabilities (including developmental disabilities) who are served in nursing facilities. Some of these lawsuits (e.g., the Indiana Inch litigation) also concern individuals in the community who are seeking to access home and community services but claim that the lack of such services effectively restricts them to receiving services in an institutional setting. Whether the volume of these lawsuits will grow is uncertain and may hinge on the extent to which states develop “comprehensive, effectively working plans” to address the needs of institutionalized persons who might benefit from community services. In its decision, the Supreme Court indicated that, if a state had such a plan and it was being implemented, then the state might be regarded to be compliance with the ADA. Institutionalized persons who believe that their access to community services has been denied may file a

complaint with the DHHS Office of Civil Rights instead of seeking redress through the federal courts. Individuals in several states have filed such complaints.

## **B. Description of Lawsuits**

### **1. Florida: Brown et al. v. Bush et al.**

This is 1998 class action complaint seeks a declaratory judgment and permanent injunction to prevent the state from unnecessarily institutionalizing individuals with developmental disabilities in violation of the ADA integration mandate, Section 504 of the Rehabilitation Services Act of 1973, federal Medicaid law, and the U.S. Constitution. In March 1999, the U.S. District Court for the Southern District of Florida adopted wholesale Plaintiffs' proposed class and certified the class as: "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 SNF's but remain defendant's responsibility; and all persons at risk of being sent to DSIs."

Florida appealed the District Court's class certification to the 11<sup>th</sup> Circuit Court of Appeals. The 11<sup>th</sup> 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." Reportedly, the parties are negotiating a gradual reduction in the number of persons served in Florida's DSIs.

### **2. Indiana: Inch et. al. v. Humphrey and Griffin.**

In July 2000, this class action lawsuit was filed by the Indiana Civil Liberties Union in Indiana's Marion County Superior Court (rather than federal district court) on behalf of individuals with disabilities who currently reside in nursing homes and/or who are at risk of nursing home placement but who desire to live in integrated settings by receiving services available through Indiana's HCB waiver program for individuals who are elderly or disabled. The Indiana Family and Social Services Administration is the named defendant in the lawsuit. The lawsuit alleges that 2,000 individuals with disabilities are either on waiting lists for community services or suffering "unjustified institutional isolation," discrimination that is prohibited by the ADA. The complaint further states that Indiana spends less than 9 percent of its of elderly and disabled budget to support individuals in living in integrated home and community settings. It further alleges that new enrollments in the state's elderly and disabled programs have been closed for two years and new applications are not being taken.

The suit contends that people in nursing home facilities or at risk of nursing home placement must be given the choice of HCB waiver services rather than *de facto* being limited to receiving services only in institutional settings. The plaintiffs seek preliminary and permanent injunctions to enjoin the state from continuing to violate the ADA and require that Medicaid eligible individuals be offered Medicaid long-term services in their homes and communities. In December 2000, another class action complaint was filed in St. Joseph County Superior Court (South Bend) on behalf of individuals with developmental disabilities who have been placed in

nursing facilities due to restrictions on the availability of HCB waiver services for persons with developmental disabilities.

**3. Kentucky: Doe v. Kentucky Cabinet for Human Services**

This class action lawsuit alleged that Kentucky was not properly administering the mandated Medicaid Pre-Admission Screening and Resident Review (PASRR) process with respect to individuals with mental retardation served in general-purpose nursing facilities. Under federal PASRR requirements, a state must take steps to furnish appropriate specialized services for persons with mental disabilities who reside in general-purpose nursing facilities and/or arrange for their community placement if nursing facility services are not appropriate. The litigation was dropped after the state and Kentucky Protection & Advocacy hammered out an agreement to employ a consultant to evaluate the state's PASRR process and make recommendations. So far, it is been determined that a potentially large number of nursing facility residents with mental retardation are inappropriately served in such facilities and should be offered services in the community.

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

In April 2000, five individuals (two with a developmental disability and three with physical disabilities) along with Resources for Independent Living filed a complaint against the Louisiana Department of Health and Hospitals alleging that the state is violating the ADA and Section 504 of the Rehabilitation Act by restricting available services to "unnecessarily segregated settings" (i.e., nursing facilities). The plaintiffs with non-developmental disabilities are suing for access to the state's elderly and disabled and/or personal care attendant waiver programs while the plaintiffs with cognitive disabilities seek access to Louisiana's developmental disabilities and personal care attendant waiver program. The plaintiffs point out that Louisiana spends "90% of its Medicaid funds on institutional services" while spending only a small amount on community-based services. The plaintiffs have asked the court to: 1) grant class action status to Louisianans with disabilities who are unnecessarily institutionalized and 2) find the state in violation of the ADA and Section 504 of the Rehabilitation Act. Reportedly, settlement discussions are taking place.

**5. Massachusetts: Rolland et al. v. Cellucci et al.**

In October 1998, a complaint was filed on behalf of seven Massachusetts residents with mental retardation and other developmental disabilities who reside in nursing facilities. The plaintiffs contended that they were denied alternative community placements or "specialized services" as mandated under the annual resident review (ARR) provisions of the 1987 Nursing Home Reform Law (contained in the Omnibus Budget Reconciliation Act of 1987). The law directed that states arrange alternative placements for inappropriately placed residents with developmental disabilities or who have a mental illness or, if the person chooses to remain in a nursing facility, furnish specialized services. The plaintiffs also alleged that the failure to provide such services constituted a violation 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 with the plaintiffs. The state agreed to underwrite community placements to members of the class (approximately 858 individuals) unless it is determined that an individual cannot 'handle or benefit from a community residential setting.' The placement

process is structured to take place over a multi-year period. In FY 2000 – 2001, \$5.6 million was earmarked to start the placement process. The case and the settlement agreement are described in more detail at the following web site: <http://www.protectionandadvocacy.com/Rollandsum.htm>.

Late last year, the Plaintiffs filed a motion asking the Court to find the state in violation of the settlement agreement with respect to 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 that nursing facility residents were receiving services that met “active treatment” requirements. The Court found that, if the services furnished by a nursing facility did not meet the active treatment standard, the Department of Mental Retardation is obligated to furnish supplementary services.

#### **6. Michigan: Olesky et al. v. Haveman et al.**

In September 1999, Michigan’s Protection and Advocacy Agency filed a complaint in state court on behalf of six individuals with developmental disabilities and/or mental illness who resided in nursing facilities but sought services in the community instead. In June 2000, this litigation was referred to the U.S. District Court for Western Michigan. The plaintiffs’ counsel estimates that there are 500 individuals with cognitive disabilities in nursing facilities who instead could be served in the community. The plaintiffs allege that Michigan is violating the “Nursing Home Reform Act of 1987” and the ADA. This complaint is similar to the Massachusetts Rolland v. Cellucci (see above) except that it includes persons with a wider range of cognitive impairments (including individuals who have a mental illness or another neurological disorder). The Court turned down the state’s motion to dismiss the case on sovereign immunity grounds. Reportedly, settlement discussions are underway.

#### **7. New Hampshire: Bonnie B et al. v. Shumway**

In December 1999, two persons with neurological disabilities who reside in nursing facilities but are wait listed for services provided under the State of New Hampshire’s Acquired Brain Injury (ABI) home and community-based waiver program filed a class action complaint to gain access to community services. [Note: a similar prior New Hampshire case -- Heartz v. Morton – concerned an individual in a similar situation.] The plaintiffs allege that the New Hampshire Division of Developmental Services (DDS) (the agency responsible for administering the state’s ABI waiver program as well as the state’s waiver program for persons with developmental disabilities) operates its long term services programs with “inadequate, capped funding through the HCB/ABI program, arbitrary limits home health and other HCB services, and lack of coordination between the various public and private agencies which administer the Medicaid program.”

The plaintiffs contend 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.” Furthermore, they argue 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 also cite the following grounds for the suit: 1) failure to provide needed Medicaid services in a “reasonably prompt manner;” 2) the state, in providing mainly facility-based services, is violating Title II of the Americans with Disabilities Act and the related USDOJ

regulations; and, 3) the “due process” clause of the Fourteenth Amendment as well as related provisions in federal Medicaid law.

## **8. 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 home and community-based waiver services (specifically personal assistance/attendant care). In this litigation, the 3<sup>rd</sup> Circuit Court of Appeals held that the state’s failure to provide services in the most integrated setting appropriate to the individual’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 needs are already provided within the scope of the waiver program. A California class action complaint (Davis v. California) also has been filed on behalf of residents at Laguna Honda Hospital (a 1,200 bed nursing facility in San Francisco) that argues that the City and County of San Francisco along with several state agencies are violating federal Medicaid law along with the ADA by denying individuals with disabilities access to community services and thereby forcing them to remain institutionalized.

## **V. “Access to Benefits” Litigation**

### **A. Overview**

“Access to benefits” lawsuits revolve around the ability of Medicaid recipients to obtain services and supports that they already have been authorized to receive. For example, while a person’s HCB waiver plan of care may authorize the individual to receive a service, he or she may be prevented from obtaining the service due to budget restrictions and/or other obstacles.

Litigation in this arena has included lawsuits contending that a state’s payment rates are so low as to prevent recipients from being able to find workers to furnish personal assistance services. The Medicaid statutory issues concerning the interplay among payments, adequacy, quality, and access to benefits/services are described in a paper that may be accessed on the National Health Law Web site at: <http://www.healthlaw.org/docs/200009IssueBriefHCBC.pdf>. In other cases, the availability and quality of services available through an HCB waiver program also has been the subject of litigation.

This type of litigation differs from “waiting list” or “Olmstead” litigation because it revolves around individuals who already are in the community and have been authorized to receive Medicaid community-based services. However, some waiting list lawsuits (e.g., Quibuyen in Virginia) concern similar issues. These lawsuits argue that state policies or practices concerning the operation of community programs constitute barriers to individuals obtaining authorized services. In some of these cases, these barriers are alleged to be violations of the ADA, either because (a) they force individuals to be institutionalized because they cannot obtain services in the community or (b) a state provides more generous funding for institutional than 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 that are sufficient to ensure their availability to Medicaid recipients.

## **B. Description of Lawsuits**

### **1. Arizona: Ball et al v. Biedess et al.**

In January 2000, the Arizona and the Native American Protection and Advocacy Agencies filed a class-action complaint in federal district court arguing that Medicaid payment rates for direct service and support professionals (attendants) in the community are insufficient to enlist enough providers in order to ensure that Medicaid services are available to persons with disabilities who are eligible and authorized to receive them. Among other claims, the lawsuit argues that the state is in violation of §1902(a)(30)(A) of the Social Security Act by failing to make payments sufficient to attract enough providers to meet the needs of Medicaid recipients. The plaintiffs also make claims that the state is violating other Medicaid requirements, including: 1) reasonable promptness; 2) amount, duration and scope; and, 3) freedom of choice. Additionally, the plaintiffs argue that the Arizona is violating Title II of the ADA and Section 504 of the Rehabilitation Act because the lack of a sufficient pool of community-based support staff puts individuals with disabilities at risk of institutionalization.

The District Court has granted class-action status as requested by the plaintiffs. In addition, the American Association of Retired Persons has lent its support to the plaintiffs. There is a further discussion of this case in a newsletter at <http://www.acdl.com/pdfs/apr2001AA.pdf>.

### **2. California: Sanchez et al. v. Johnson et al.**

Filed in May 2000 in the U.S. District Court for the Northern District of California on behalf of individuals with developmental disabilities, this complaint alleges that the state of 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 such payment differentials is violating 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.” Based on this prohibition, 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 federal Medicaid law include the allegation that the state has failed to make payments for community-based services that are sufficient to assure efficiency, economy, and quality of care and enlist enough qualified providers to ensure access to services as required by §1902(a)(30)(A) of the Social Security Act. The plaintiffs have asked the court to order the state to improve its community service system’s payment and benefit structure and correct other problems that might lead to unnecessary institutionalization. The text of this complaint may be found at <http://oaksgroup.org/complaint/>. At present, there are no settlement discussions underway and this complaint reportedly is scheduled for trial in early 2002.

### **3. Florida: Wolf Prado-Steiman et al. v. Bush et al.**

One of the central topics addressed in this lawsuit was the allegation that individuals who participated in Florida's HCB waiver program were not actually receiving the full range of services that they needed or were authorized to receive. The lawsuit alleged that Florida denied or did not make available HCB waiver services to participants, even though services had been authorized in the person's service plan. In May 2000, the parties entered into an 18-point settlement agreement that, in addition to committing Florida to provide the full-range of HCB waiver services to program participants, requires the state to take a wide variety of steps aimed at improving the quality of HCB waiver services, including improving support coordinator workload ratios and undertaking a study of HCB waiver payment rates. Information concerning this settlement agreement can be found at: <http://www.advocacycenter.org/news/sep1100a.htm>.

### **4. 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" Medicaid home and community waiver program for children with severe disabilities. The new waiver program offers a dollar-capped set of benefits that is less broad than offered under Louisiana's present waiver program. The state had proposed that, if a child were on the waiting list for Louisiana's current HCB 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 proposal because it meant that their children would be disadvantaged if they needed more intensive services than offered under the new waiver program. Plaintiff's contended that this requirement was impermissible under federal law.

When the lawsuit was filed, the federal officials had not made a final decision to approve the new program. Subsequently, CMS determined that the state's proposal with respect to the waiting-list status of children could not be approved. The state then removed this provision. CMS then approved the request and the Children's Choices program is now being implemented. Presumably, the issues raised in the class action complaint are now moot.

### **5. West Virginia: Benjamin H et al. v. Ohl**

Lastly, we note that a claim was added by the plaintiffs in this lawsuit aimed at requiring the state to increase its payments rates for HCB waiver services. This claim was based on both the ADA as well as Medicaid law. However, the District Court ruled that the plaintiffs did not marshal sufficient evidence in support of their claim. The court nonetheless expressed strong concerns regarding the interplay between the adequacy of payment rates and meeting the needs of recipients of Medicaid long-term services. As a result, West Virginia officials have committed to conducting a thorough review of the state's payment rates.

## **VI. Conclusion**

These lawsuits obviously raise many issues concerning the interplay between federal and state policies with respect to the provision of home and community services to people with developmental and other disabilities. Federal courts are being asked to decide whether Medicaid eligible individuals with disabilities are entitled to receive home and community services if they have been determined to require or are already receiving institutional services. In addition, the

courts are being asked to rule on the extent to which states are obligated to ensure access to authorized services by Medicaid home and community services recipients.

Many of the issues posed to the courts in these lawsuits are new because there was relatively little preceding litigation concerning state administration of Medicaid home and community services. As a consequence, it remains uncertain the extent to which this litigation will lead to alterations in the fundamental parameters under which states offer such services.

The unifying theme of this litigation is the desire of people with disabilities to obtain ready and reliable access to home and community services. The litigation sends strong messages to policy makers concerning the expectations of people with disabilities.

#### **ENDNOTE:**

#### **THE QUESTION OF FEDERAL COURT JURISDICTION IN LITIGATION ALLEGING VIOLATIONS OF FEDERAL MEDICAID LAW**

Despite the high volume of lawsuits that have been filed in the federal courts by Medicaid beneficiaries asking that federal courts compel a state to comply with various provisions of Medicaid law, it is not a completely settled matter that such lawsuits may be brought in federal court. There are complicated Constitutional questions involved.

Federal Medicaid law itself does not contain any provision for a beneficiary to seek redress through the federal courts for alleged state violations of federal Medicaid law or regulations. Federal Medicaid law only requires that states make available to beneficiaries an administrative appeals process (called Fair Hearings) through which a beneficiary can appeal adverse decisions concerning eligibility or the provision of services. Many states provide that, when a beneficiary is not satisfied with the outcome of his/her appeal, the appeal may be advanced to state court. In addition, it is well settled that the federal government itself may not enforce the provisions of federal Medicaid law by bringing suit against a state. If a state is not complying with federal Medicaid law and regulations, the sole direct enforcement remedy available to the federal government is to withhold or deny payments to the state.

Since federal Medicaid law does not directly extend beneficiaries the right to seek redress in federal court, the plaintiff beneficiaries must rely on other provisions of the U.S. Constitution and/or federal law in order to bring suit in federal court. One such law is 42 U.S.C. §1983, a post-Civil War law that grants a citizen a “cause of action” for violations of the Constitution and federal laws. In Medicaid litigation, plaintiffs frequently claim that federal courts have jurisdiction under this law’s provisions due to alleged violations of the 14<sup>th</sup> Amendment to the U.S. Constitution (due process) that have deprived them of their “property right” to Medicaid benefits and, of course, alleged state violations of federal Medicaid law.

State defendants often argue that federal courts do not have jurisdiction to accept such lawsuits and thereby enforce the requirements of Medicaid law due to the provisions of the 11<sup>th</sup> Amendment of the U.S. Constitution. The 11<sup>th</sup> Amendment generally confers “sovereign immunity” on states from suits by private parties and also prohibits the federal courts from asserting jurisdiction in such suits. Hence, states often contend that aggrieved beneficiaries have no standing to sue states for alleged violations of Medicaid law and that federal courts, thereby, do not have the authority to accept such cases or order the state to take remedial action. Beneficiary plaintiffs, however, argue that 42 U.S.C. §1983 pierces “sovereign immunity” and,

states – by accepting federal Medicaid funds – have implicitly consented to waive sovereign immunity and, hence, expose themselves to redress in the federal courts.

Federal court rulings concerning whether the federal courts may serve as a venue where beneficiaries can bring suit against a state have gone both ways. Most typically, courts have found plaintiffs' arguments persuasive. But, in other instances, they have not. A running inventory of decisions concerning this complex topic may be found on the Internet at: [http://www.healthlaw.org/pubs/1983docket.html#1396a\(a\)\(8\)](http://www.healthlaw.org/pubs/1983docket.html#1396a(a)(8)). In March 2001, the U.S. District Court for the Eastern District of Michigan handed down a ruling in a Medicaid lawsuit (Westside Mothers v. Haveman) that cited several grounds for concluding that Medicaid beneficiaries may not seek redress through the federal courts for alleged violations of federal Medicaid law. This lengthy 95-page decision is available on the Internet at the following site: <http://www.mied.uscourts.gov/JudgesOpinions/Cleland/rhc99-cv-73442.pdf>. This decision is being appeal to the Circuit Court of Appeals.

The issues at play in this arena are very complex because they involve fundamental Constitutional questions concerning the extent to which the federal government (and thereby the federal courts) can compel states to comply with various federal laws and mandates.

### ***References***

Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services (2000). Understanding Medicaid Home and Community Services: A Primer. Washington DC.

David Braddock, Richard Hemp, Susan Parish, Mary C. Rizzolo (April 2000). The State of the States in Developmental Disabilities: 2000 Study Summary. Chicago: University of Illinois at Chicago, Department of Disability and Human Development.

Robert Prouty and K. Charlie Lakin (eds.) (2001). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

Gary Smith (1999). Closing the Gap: Addressing the Needs of People with Developmental Disabilities Waiting for Supports. Alexandria VA: National Association of State Directors of Developmental Disabilities Services.