
Status Report:

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

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NOTE: This report describes litigation in various states concerning Medicaid services for people with developmental disabilities. The report is updated and reissued periodically as developments warrant. When you receive a new update, you may discard the previous version since the report is cumulative. Please e-mail the author at gsmith@hsri.org if there are new developments concerning litigation not included in this update. **Material added since the September 5, 2001 update is highlighted.**

I. Introduction

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

Since 1998, 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 lawsuits involve obtaining community services for institutionalized persons, most have been filed on behalf of individuals in the community who need but are not receiving home and community services. The lawsuits challenge the practice of wait listing individuals for home and community services by asserting that federal Medicaid law and the Americans with Disabilities Act (ADA) dictate that states provide home and community services promptly to eligible individuals in the most integrated setting. This litigation centers on community – rather than institutional – services and potentially has enormous implications.

This report tracks three not necessarily mutually exclusive categories of lawsuits:

- **“Waiting List” Lawsuits** that claim a state has failed to provide Medicaid long-term services with “reasonable promptness” to otherwise eligible persons with developmental and other disabilities;
- **“Olmstead” Lawsuits** that argue 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 are approved to receive or cannot access such services.

The report describes the legal issues raised by these lawsuits and provides summaries of lawsuits that have been filed along with their status as of November 2001 (along with descriptions of settlement agreements when they have been reached). Links to additional information on the Internet also are provided wherever possible. Each time an update is issued, the links are checked to confirm that they are still “live.” The report 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, the legal and policy implications of this litigation will come into sharper focus.

II. Background

Large institutions once dominated public developmental disabilities systems. Today, nationwide and in almost all states, large institutions serve only a small fraction of persons who receive taxpayer-supported services. The vast majority of individuals now receive community services. 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 spending was devoted to community services (Braddock *et al.*, 2000).

By and large, funding for 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 governed by “available appropriations.” Except in a few states (most notably California), increases in the number of individuals who qualify for services do not automatically trigger increases in funding. The steady growth in funding nationwide is evidence that state policy makers have supported expanded access to community services for people with developmental disabilities.

During the 1990s, there was a massive infusion of Medicaid dollars into community service systems, mainly by way of the Medicaid home and community-based services (HCBS) waiver program. Nationwide, the number of individuals with developmental disabilities participating in the HCBS waiver program shot up from about 45,000 in 1990 to 291,000 by 2000 (Prouty, Smith, and Lakin, 2001). Spending for HCB waiver services for people with developmental disabilities grew more than ten-fold to \$9.6 billion in 2000. Increased Medicaid HCBS waiver dollars have been pivotal in expanding community services in nearly all states.

Each state has the latitude to decide the services and supports it will offer through the HCBS waiver program. Moreover, federal Medicaid law and policy allow a state to limit the number of individuals served in its waiver program. Thus, HCBS waiver programs can be “sized” to take into account the matching funds a state has available.

The 1990s also saw an upsurge in the number of individuals with developmental disabilities seeking services. Various factors – mainly demographic – lie behind this increased demand (Smith, 1999). Despite significant growth in funding for community services, waiting lists emerged and often have persisted at high levels in many states. Several states (e.g., New York, Maryland, and Pennsylvania) have launched multi-year initiatives to expand community services and reduce their waiting lists. But, often, states have not been able to keep pace with rising service demand. As a result, waiting lists have lengthened or persist at high levels even while the number of individuals served has grown. Individuals and families have grown increasingly frustrated at waiting long periods to obtain services. It is not surprising that this frustration has boiled over into the filing of lawsuits.

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. But, such efforts largely were unsuccessful. Courts typically ruled that neither state nor federal law created an entitlement to services and have upheld state laws limiting services to available appropriations.

By and large, such lawsuits did not raise claims with respect to federal Medicaid law. Indeed, until recently, there has been relatively little litigation concerning any aspect of the operation of the HCBS waiver program even though the program now is more than two decades old. Since states generally were regarded to have broad discretion in furnishing Medicaid home and community services, there seemed scant basis for seeking federal court intervention to require states to expand access to them.

The “waiting list” lawsuits filed mainly since 1998 challenge the premise that states have unfettered authority to limit the availability of Medicaid long-term services. The lawsuits assert that key provisions of federal law oblige a state to furnish Medicaid home and community services to otherwise eligible individuals as needed. 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 Olmstead v. L.C. litigation – the ADA also is cited as grounds that states must furnish individuals home and community services in the most integrated setting.

The Olmstead decision itself also has sparked new lawsuits by institutionalized persons seeking home and community services. These lawsuits demand changes in state policy so that individuals served in nursing facilities and other institutional settings can obtain home and community services in the most integrated setting.

Finally, still other lawsuits challenge state policies and practices that the plaintiffs contend result in individuals being unable to access the full-range of community services to which they are 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 community services.

In almost all instances, Medicaid beneficiaries have filed these lawsuits in federal court. In most cases, federal courts have accepted jurisdiction in such litigation but not universally. Some states have claimed that they are immune from such lawsuits under the provisions of the 11th Amendment to the U.S. Constitution. With rare exceptions, the federal courts have rejected these claims. We outline issues concerning federal court jurisdiction in the endnote to this report.

The question of access to home and community services now is engaged in the context of federal Medicaid and other laws. This litigation stems from consumer frustration with having to wait an indefinite period of time to obtain services.

III. Waiting List Lawsuits

A. Overview and Basis

“Waiting list” lawsuits assert that a state violates federal law when it does not promptly provide Medicaid long-term services (i.e., ICF/MR or waiver services) to eligible individuals. The lawsuits attack the practice of wait listing individuals to receive services at some future date rather than right away. Federal court intervention is sought 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 (ADA) and Section 504 of the Rehabilitation Services Act of 1973 along with the 14th Amendment to the U.S. Constitution are cited as the basis for these lawsuits. A thorough discussion of the central legal issues raised in these lawsuits can be found at the following website: http://www.healthlaw.org/pubs/200005FactSheet_hcbw.html. The specific legal claims in each lawsuit vary.

In general, waiting list lawsuits rely 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 obtain waiver services, s/he must meet the state's institutional eligibility criteria. 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 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 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 policy permits a state to limit the number of individuals who receive HCB waiver services. That is, a state may "cap" the number of individuals who participate in the program. However, federal law contains no equivalent authority for a state to limit the number of persons who may receive institutional services. If HCB waiver services are unavailable, it is presumed that eligible individuals will have unfettered access to institutional services.

Waiting list lawsuits rely on the statutory requirement that a state must provide Medicaid services (including institutional services) to eligible individuals with "reasonable promptness." In particular, §1902(a)(8) of the Social Security Act and related federal regulations require that a state make a prompt eligibility determination when a person applies for services. Federal courts have interpreted this requirement to mean that a state must furnish Medicaid services with reasonable promptness once the person's application is approved. A discussion of the legal issues concerning §1902(a)(8) is located at <http://www.healthlaw.org/pubs/200101promptness.htm>. The regulatory standard for processing Medicaid applications 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 11th U.S. Circuit Court 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 allow a state to "wait list" individuals for ICF/MR services indefinitely. Florida had sought to restrict 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: 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 11th Circuit, it frequently is cited in lawsuits filed in other federal circuits.

The 11th Circuit decision spoke directly to ICF/MR but not HCB waiver services. Most waiting list lawsuits seek access to Medicaid home and community services. In these lawsuits, the plaintiffs usually rely on the interconnection in federal law between institutional and HCB waiver services. In particular, the plaintiffs argue that a person's eligibility for ICF/MR services also extends to "equivalent services" (e.g., services furnished through an HCBS waiver

program). That is, 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 requirements have the right to opt to receive waiver services instead.

In some cases, the plaintiffs point out that, when a state limits the availability of both ICF/MR and HCB waiver services, eligible individuals are unable to obtain either type of service. Plaintiffs also have argued that the practice of wait listing individuals violates §1902(a)(10) of the Social Security Act since the state is failing to make available Medicaid long-term services on a “comparable” basis to all eligible Medicaid beneficiaries, either by furnishing such services to some but not all eligible persons or by making institutional but not community services available.

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 allowing them to submit formal applications for HCB waiver services or not making a formal determination concerning such applications. Plaintiffs argue these practices violate §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 14th Amendment to the U.S. Constitution.

Some (but not all) lawsuits claim that a state’s not making community services available on equal footing with institutional services violates Title II of the ADA (along with Section 504 of the Rehabilitation Services Act of 1973). Title II requires public agencies to provide services in the “most integrated setting” appropriate to a person’s needs. Plaintiffs assert that Title II mandates that eligible individuals have access HCB waiver services on equal footing with institutional services. Plaintiffs also argue that participant caps effectively limit long-term services to institutional settings, thereby denying individuals access to services in the most integrating setting as required by the ADA.

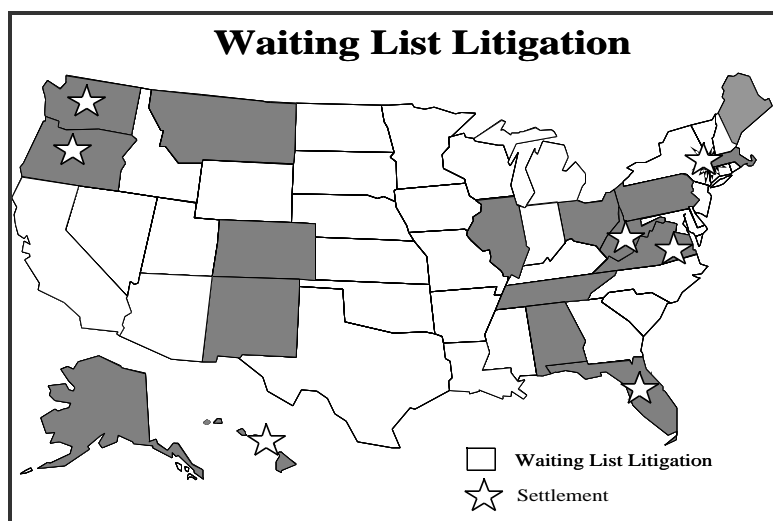
Where federal courts made decisions in these cases, the rulings have been based principally on Medicaid law rather than the ADA. For example, in the West Virginia Benjamin H. litigation, the federal District Court decided that the plaintiffs’ claims concerning Medicaid law alone were sufficient to justify its issuing a preliminary injunction against the state without the court’s taking up the issues raised by the plaintiffs concerning the ADA.

B. Description of Lawsuits

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

Settlements have been reached in seven lawsuits (Florida (in one of two lawsuits), Hawai’i, Massachusetts, Oregon, Washington, Virginia and West Virginia). Such agreements spell out steps to address the underlying issues in a fashion satisfactory to the parties. The federal district

court with jurisdiction over a lawsuit must approve the agreement. Before such agreements can be put into effect, they also require executive and legislative branch concurrence. In settlements, the state typically has agreed to increase the number of individuals who receive Medicaid HCB waiver services over a multi-year period (e.g., three to five years). The agreements usually acknowledge that a large-scale expansion of community services takes time to implement. Depending on the case, the agreement also may include revisions in state policies and practices concerning the processing 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, the circumstances that might cause the agreement to be voided (e.g., insufficient funds are appropriated to implement the settlement), and how disputes 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 14th Amendment to the U.S. Constitution by failing to furnish ICF/MR or HCBS waiver services to eligible individuals. The plaintiffs are persons wait listed for HCBS waiver residential and/or daytime services.

Specifically, the plaintiffs contend that Alabama's limiting the number of persons with mental retardation who may receive Medicaid long-term services violates: (a) the requirement that such services must be furnished with reasonable promptness per §1902(a)(8); (b) the requirement that Medicaid services be furnished to all eligible individuals on a comparable basis, as provided in §1902(a)(10)(B); and, (c) 42 USC §1983 and the 14th 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) HCB waiver services differ from other optional and mandatory Medicaid services and, thus, are not subject to the same requirements; (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 11th 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 (A01-0027--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 14th Amendment to the U.S. Constitution by failing to provide Medicaid services to eligible children and adults with developmental disabilities but 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 these federal requirements.

In particular, the lawsuit asserts that Alaska's policies and practices in wait listing individuals violate the ADA's integration mandate as well as Medicaid's "reasonable promptness" requirement. The plaintiffs assert that Alaska also is violating Medicaid requirements by not properly processing applications for Medicaid services or affording individuals the opportunity to appeal adverse decisions concerning service authorization or changes in services that individuals previously were 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 and 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 cited March 2000 state figures that showed that 2,700 individuals were wait listed for residential services, including 1,149 persons judged as needing such services soon. 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 no services or are getting a more limited array of services via the state's "Support Living Services" waiver program (another HCB waiver program principally for individuals who live with their families or on their own).

In response to the complaint, the state filed a motion to dismiss. To date, the court has not ruled on either the original complaint or the motion to dismiss, even though more than a year has passed since the complaint was filed. In June 2001, the plaintiffs renewed their motion for the court to issue an injunction requiring the state to furnish services with reasonable promptness. In order to move this litigation along, the complaint has been reassigned to a magistrate.

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. 11th Circuit Court of Appeals upheld the District Court's 1996 ruling that the state's practice of wait listing individuals for ICF/MR services violated federal Medicaid law (see above). A second complaint – Prado-Steiman – was filed by The Advocacy Center (Florida's Protection and Advocacy agency). This complaint directly challenged Florida's operation of its HCBS waiver program for people with developmental disabilities. A settlement agreement has been reached in Prado-Steiman that provides for all individuals who were waiting for services on July 1, 1999 to be served by 2001. There are an estimated 23,000 individuals affected by this agreement. In August 2001, the District Court approved the settlement agreement.

Led by Governor Jeb Bush, Florida has undertaken a major expansion of developmental services, including its HCBS waiver program for people with developmental disabilities, in order to improve access to services. Between 1998 and 2000, the Florida legislature appropriated an additional \$230 million in state funding to expand access to services. In its past session, the legislature approved an additional \$78 million. Florida negotiated a Section 1915(b)(c) waiver agreement with HCFA to expand access to HCB waiver services for eligible individuals. Among its other provisions, the Prado-Steiman settlement agreement includes an “operational definition” of how the state will comply with the reasonable promptness requirement. As of this date, there has not been a final disposition of Does v. Bush lawsuit. In August 2001, the 11th Circuit handed down a decision overturning the District Court’s finding that the state was in contempt of its order concerning the prompt provision of ICF/MR services (<http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=11th&navby=case&no=9914590MAN>).

5. Hawai’i: Makin et al. v. State of Hawai’i.

The state’s Protection and Advocacy Agency filed this class action complaint in December 1998. The complaint alleged that the state’s practice of wait listing individuals for HCB 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.

In April 2000, the state and plaintiffs forged a settlement agreement wherein the state agreed to increase the number of individuals participating in the state’s HCBS waiver program by approximately 70% over a three-year period. In its 2000 session, the Hawai’i legislature approved an additional \$4.3 million in funding to underwrite the first stage of this expansion. In its 2001 session, the legislature appropriated additional funds in order to meet the terms of agreement. The settlement agreement may be accessed at <http://www.pixi.com/~pahi/stlmnt.htm> or <http://mano.icsd.hawaii.gov/doh/settlement.pdf>.

6. 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 sought but did not receive HCBS waiver services. The lawsuit alleges that Illinois has not furnished Medicaid services to eligible individuals with reasonable promptness as required by federal 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 ADA, Section 504 of the Rehabilitation Act of 1973 and the 14th Amendment to the U.S. Constitution.

The lawsuit calls for the Court to “issue preliminary and permanent injunctive relief requiring the Defendants ... 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.”

In response, the state filed a motion to dismiss, including a claim that the U.S. Constitution's 11th Amendment gave the state immunity from being sued in federal court. The state also challenged the merits of plaintiffs' other claims. On May 1, 2001, Senior District Judge John F. Grady ruled on the state's motion. Siding with the state, Judge Grady dismissed the plaintiffs' claim alleging a violation of the ADA. Judge Grady based this ruling on the fact that the complaint had 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 compelling concerning the plaintiffs' other claims. In particular, the Court was not persuaded by the state's claim of sovereign immunity. Judge Grady's May 1 ruling is available at the plaintiff attorney's website: <http://www.illinoisclassaction.com/>. On August 21, 2001, Judge Grady rejected the state's motion to quash the plaintiffs' subpoenas of information from the state's intake agencies. On November 15, 2001, there will be an evidentiary hearing to determine whether to certify the complaint as a class action. The website also has other information concerning this litigation.

7. Maine: Rancourt et al. v. Maine Department of Human Services et al.

In August 2001, a complaint (01-CV-159) was filed in the U.S. District Court for the District of Maine (Bangor) on behalf of three adults with developmentally disabilities wait listed for services. The lawsuit was filed against the Maine Department of Human Services (the state's Medicaid agency) and the Department of Mental Health, Mental Retardation and Substance Abuse Services (the state's developmental disabilities agency which administers Maine's HCBS waiver program). The lawsuit contends that the agencies are not meeting the requirement to furnish services to people with developmental disabilities in a "reasonably prompt" manner. Reportedly, class-action certification will be sought on behalf of reportedly 1,000 adults with developmental disabilities in Maine who are not receiving timely services.

8. Massachusetts: Boulet et al. v. Cellucci et al.

This class action complaint was filed in March 1999 (originally as Anderson et al. v. Cellucci et al.). Private attorneys filed this complaint on behalf of the plaintiffs and their families who were dissatisfied at the pace at which the state was 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 instead was wait-listing persons indefinitely. While the state had made significant progress in reducing its waiting list from a peak of almost 3,000 individuals in 1998, the plaintiffs filed the lawsuit 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. 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 these class members within 90-days or, if doing so was infeasible, to propose a plan to bring the state into compliance with the reasonable promptness requirement. This ruling is recapped at

<http://www.protectionandadvocacy.com/massdis.html> and may be read in its entirety at <http://www.specialtylaw.com/SDP0106/CASES/0705.HTM>.

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 modified the class the Court certified to include all individuals who were wait listed as of July 14, 2000, regardless of whether the person was receiving or would be eligible to receive HCB 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 terms of the agreement, the state agreed to provide residential services to an additional 300 individuals during 2000-2001 using funds already appropriated by the legislature. Over the next five years (FY 2002 – 2006), the state committed to seek funding sufficient to extend 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 developing residential and interim service plans. 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 has committed \$355.8 million to expand the availability of services to the class members.

9. Montana: Travis D. et al. v. Eastmont Human Services Center.

Filed in 1996, this complaint alleged that Montana was in violation of federal Medicaid law by failing to provide community services to residents of the state’s two public MR/DD institutions who would benefit from HCB waiver services. In 1998, the plaintiffs sought to expand the scope of the complaint to include other individuals who had been wait listed for services. The complaint was filed by the state’s Protection and Advocacy Agency (The Montana Advocacy Program). 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.

Court action in this litigation stalled for various reasons, including on and off settlement negotiations between the parties and the ill-health of the presiding judge. In June 2001, the plaintiffs filed an amended class action complaint. The amended complaint draws into sharper focus the waiting list dimensions of the litigation. In August, the case was reassigned to another judge who has committed to move it along. In late August, the newly-appointed presiding judge declared all the pending motions moot and gave the parties until October 15, 2001 to file new motions, deciding that starting over with a fresh set of motions would expedite his consideration of the issues.

10. 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 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 otherwise eligible individuals with disabilities, thereby causing them to go without services or forcing their seeking 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 home and community-based waiver services [Note: New Mexico no longer

operates large state institutions; the proposed class members are served in small ICF/MR group homes]; (c) persons with other disabilities (both elderly and others) served in nursing facilities who would want community services; and, (d) persons with other disabilities in the community seeking 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 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 HCB waiver supports with state plan option services. In part, the state based its motion to dismiss the lawsuit on sovereign immunity claims under the 11th Amendment to the U.S. Constitution. In response to the district court's decision, in May 2000 the state appealed the decision to the 10th U.S. Circuit Court of Appeals in Denver, asking for reconsideration of the state's 11th Amendment sovereign immunity claim. Under federal judicial rules, an appeal based on a sovereign immunity claim stays further district court consideration of a case. Finally, in August 2001, the 10th Circuit handed down its decision and denied the state's appeal, finding that the complaint fell within federal court jurisdiction. The 10th Circuit's decision is at <http://laws.findlaw.com/10th/002154.html>.

On September 28, 2001, the state filed a new motion with the District Court to dismiss the complaint. In this motion, the state argued that the lawsuit was moot because all the original named plaintiffs either are presently receiving HCB waiver services or deceased.

11. 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 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 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 begin.

12. 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 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 settlement agreement was approved by the District Court in December 2000. Detailed information concerning the agreement may be accessed at <http://oddsweb.mhd.hr.state.or.us/Pubs/settlement/settlement.htm>.

The settlement agreement implements Oregon's Universal Access Plan, which was submitted to the Oregon Legislature in February 2000.

The Plan is designed to ensure that all individuals who need publicly funded services will receive at least a baseline level of supports. 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. 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 because of 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 agreement's six-year period. In addition, the settlement agreement calls for reducing case management workload from its current 1:95 ratio to 1:45 and making additional investments in system infrastructure.

A Universal Access Planning Committee was established in 2000 and continues to be active. The Committee's minutes and other information concerning the implementation of the plan are found at: <http://www.open.org/~arcoforg/uapc.htm>. In its 2001 session, the Oregon Legislature approved funding for the first two-year phase of the Universal Access Plan. However, implementation of the plan has been delayed pending approval by the federal Centers for Medicare and Medicaid Services of the HCBS waiver requests required to put the plan into operation.

13. Pennsylvania: Gross et al. v. Houston

Filed in July 1999, this class action complaint alleged that Pennsylvania violated federal Medicaid law by failing to provide ICF/MR or equivalent residential services to otherwise eligible individuals by instead improperly wait listing 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 designed by state officials and key stakeholders. Development of this plan preceded the lawsuit's filing. Information concerning Pennsylvania's wait 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); 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. Pennsylvania secured federal approval to launch the P/FDS waiver program on July 1, 2000. Through this program, individuals obtain flexible consumer-directed services and supports so long as their overall cost does 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 years of the program's operation and 3,448 in the year ending July 1, 2001.

The plaintiffs argued that Pennsylvania was required to serve under the terms of the approved waiver to serve 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 alleged that there were 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 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 decision, the Court raised questions about the standing of the current plaintiff (Pennsylvania Protection and Advocacy, Inc) to pursue this litigation (this decision is at <http://www.paed.uscourts.gov/documents/opinions/01D0239P.HTM>).

14. 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 estimated 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 ADA.

People First. In March 2001, People First of Tennessee filed its own 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 with reasonable promptness; (b) is in violation of the ADA by failing to make reasonable modifications and accommodations so that individuals (including institutionalized persons) can obtain services in the most integrated setting; (c) is out of compliance with §1902(a)(10) of the Social Security Act since it has not made ICF/MR or waiver services available to all eligible 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 people with disabilities by not permitting all otherwise eligible persons to obtain services for which they are eligible, in violation of the ADA; (f) is in violation of §1902(a)(10) of the Social Security Act and the Due Process Clause of the 14th 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 of appeal; (g) has denied individuals the ability to exercise free choice in receiving HCB waiver or ICF/MR services; and, (h) has violated the Individuals with Disabilities Education Act by denying Medicaid payment for services to which school-age children are otherwise entitled.

The 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 contend, give insufficient attention to the growing backlog of people who need home and community services because most new resources are 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*).

15. 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, this complaint alleged that the state has impermissibly wait-listed individuals already enrolled in the state's HCBS waiver program to receive additional services, including residential services. In particular, the complaint argued that Virginia had 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 was 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 alleged that this and other policies led to wait listing waiver participants for the receipt of services that they are otherwise eligible to receive.

In September 2001, the state agreed to change its policies so that waiver participants would receive all the services that they have been determined to require. As a result, the plaintiffs agreed to dismiss the lawsuit.

16. Washington: The Arc of Washington State et al. v. Lyle Quasim et al.

Filed in November 1999, this class action complaint charged that Washington violated federal Medicaid law and the ADA by failing to provide Medicaid long-term services with reasonable promptness to eligible individuals with developmental disabilities. The complaint alleged 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 in this litigation, the District Court determined that: (a) eligibility for ICF/MR services is not sufficient to establish an entitlement to HCB waiver services but (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 dismiss 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 cannot serve as the 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.

In April 2001, the parties arrived at a settlement agreement. The agreement was submitted to the federal court in August 2001 and must be approved by the court. It also hinges on action by the Washington legislature to authorize additional dollars when it convenes in January 2002. Legislative leaders have indicated their support for the agreement. Under the agreement, some

\$14 million in additional funding to expand services would be provided in FY 2003 and these dollars would be annualized to \$24 million in subsequent years. The agreement also calls for the parties to identify additional dollars to meet the needs of more individuals in the next biennium. Initially, 1,800 individuals are expected to benefit from this funding. An announcement concerning the agreement may be found at: <http://www.wa.gov/dshs/mediareleases/pr01218.shtml>. The full text of the agreement is located at http://www.arcwa.org/lawsuit_settlement1.htm. A summary of the agreement is located at http://www.arcwa.org/press_release.htm.

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

Filed in April 1999, this class action complaint alleged that West Virginia 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 quickly granted the plaintiffs' motion for a preliminary injunction based on its finding that the plaintiffs were likely to prevail at trial solely based on the requirements of federal Medicaid law. This decision is located at: <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 in 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 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 a set of agreements between the parties to address the topics spelled out in the preliminary injunction. The Court's settlement order may be found at http://www.healthlaw.org/docs/benh_order.pdf. In particular, 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 a process for enabling individuals to apply for services and receive proper notice concerning the disposition of their applications. 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 waiver program. This request was approved in December 2000. See also the final section for a discussion of issues related to payment rates raised in this litigation.

IV. "Olmstead" Litigation

A. Overview

In June 1999, the U.S. Supreme Court handed down its historic decision in the Olmstead v. L.C. litigation, ruling that unnecessary segregation of individuals with disabilities in institutional facilities 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 the needs of other persons. This decision is at <http://supct.law.cornell.edu/supct/html/98-536.ZS.html>. More materials 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 Medicaid services (<http://www.kff.org/content/2000/2185/OlmsteadDecision.pdf>. Federal Centers for Medicare and Medicaid Services (CMS) materials describing the steps that the Agency is taking to follow-up on the Court's ruling can be accessed at <http://www.hcfa.gov/medicaid/olmstead/olmshome.htm>.

“Olmstead” litigation means lawsuits that principally aim at securing access to Medicaid community services for institutionalized persons with disabilities. In other words, these lawsuits raise issues similar to those decided in the Olmstead litigation. In developmental disabilities, there is a long history of litigation predating the Olmstead decision that led to the community placement of institutionalized persons. This litigation established that institutionalized persons should be discharged from large public facilities when their needs could be met in a less restrictive setting. The Olmstead decision furnishes another basis for “deinstitutionalization” litigation as well as clearly establishing that individuals with disabilities (developmental, cognitive or otherwise) served in other institutional settings (e.g., nursing facilities or privately-operated ICFs/MR) also have a right to services in the “most integrated setting.”

As noted in the 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 principally (but not always exclusively) seek community services for institutionalized persons, mainly on behalf of persons with disabilities (including developmental disabilities) served in nursing facilities. Some of these lawsuits (e.g., the Indiana Inch litigation) also include individuals in the community who want home and community services but claim that the lack of such services effectively restricts them to institutional services. 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 noted that, if a state had and was implementing such a plan, then the state might be in 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 11th Circuit Court of Appeals. 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.” 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 Marion County Superior Court (not 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 want 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” and, hence, experiencing discrimination 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 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 argues 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 institutional services. The plaintiffs seek preliminary and permanent injunctions to enjoin the state from continuing to violate the ADA and direct that Medicaid eligible individuals be offered Medicaid long-term services in their homes and communities. This complaint is at: <http://groups.yahoo.com/group/CAL-DDCOMMIMP/files/indiana.doc>. 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 who have been placed in nursing facilities due to the lack of availability of HCB waiver services.

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 the availability of 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; the plaintiffs with cognitive disabilities want access to Louisiana’s developmental disabilities and personal care attendant waiver program. The plaintiffs pointed out that Louisiana spends “90% of its Medicaid funds on institutional services” while spending only a small amount on community-based services. The plaintiffs 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.

On August 16, 2001, Louisiana Department of Health and Hospitals Secretary David Hood unveiled a proposed settlement that would boost state spending \$118 million over the next four years to provide community services to 1,700 more individuals and reduce the waiting time for such services to 90 days or less. The settlement plan submitted by DHH and approved by the plaintiffs addresses four broad areas: (a) reducing the waiting time for community-based services; (b) allowing people to make informed choices about their service options; (c) the addition of a personal care services option; and, (d) individual long-term care assessments that will eventually include a single point of entry system. The state would spend an additional \$18 million to extend services to 650 people and \$32 million in 2003 for another 650 people. In 2004 and 2005, the state would spend \$34 million to expand services to an additional 400 individuals. The state also would expand outreach programs to inform elderly and disabled individuals about community-based services. More information concerning the proposed settlement is located at: <http://www.dhh.state.la.us/NEWS/BarthelemySettlement.htm>.

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 was 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 were 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 “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 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 estimated that there were 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 (i.e., 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: Bryson, Shepardson, et al. v. Shumway and Fox

In December 1999, two persons with neurological disabilities who reside in nursing facilities but are wait listed for services provided under New Hampshire’s Acquired Brain Injury (ABI) HCBS waiver program filed a class action complaint to gain access to community services. [Note: a 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) 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 argue 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 to eligible persons, is violating Title II of the Americans with Disabilities Act and the related regulations; and, 3) the “due process” clause of the Fourteenth Amendment as well as other provisions of federal Medicaid law.

On October 23, 2001, U.S. District Court Judge Steven J. McAuliffe handed down a decision concerning plaintiff and state motions for summary judgment in this case. The decision may be found at: <http://www.nhd.uscourts.gov/> (by searching “opinions”). Judge McAuliffe dismissed two of the seven counts in the complaint, ruled in the plaintiffs’ favor on a third and decided a fourth was moot. However, he deferred judgment on three central issues in the complaint: (a) whether wait listing individuals violates Medicaid law concerning furnishing services with reasonable promptness; (b) whether New Hampshire’s policies are at odds with the ADA; and,

(c) whether the state's policies violate Section 504 of the Rehabilitation Act. In this decision, Judge McAuliffe rejected that the state's motion to dismiss the complaint on 11th Amendment grounds. With respect to the three remaining issues, the trial phase of this litigation is slated to start December 3, 2001.

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 3rd 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 have been approved 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 includes lawsuits that contend that a state's payment rates are so low as to prevent recipients from being able to find personal assistance 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 located 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 litigation differs from "waiting list" or "Olmstead" litigation principally because it revolves around individuals already authorized to receive Medicaid community-based services. However, some waiting list lawsuits (e.g., Quibuyen in Virginia) raise 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 cases, these barriers are alleged to violate the ADA, either because they force individuals to seek institutional services since they cannot obtain services in the community or a state provides more generous funding for institutional than community 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 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 Center on Disability Law and the Native American Protection and Advocacy Agency 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 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 claim that the state violates other Medicaid requirements, including: 1) reasonable promptness; 2) amount, duration and scope; and, 3) freedom of choice. Additionally, the plaintiffs argue that Arizona violates 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 amended complaint can be found at <http://www.acdl.com/pdfs/BallAmendedComplaint.pdf>. A memorandum in support of certifying the complaint as a class action is at: <http://www.acdl.com/pdfs/BallMemo.pdf>. The District Court has granted class-action status. In addition, the American Association of Retired Persons has lent its support to the plaintiffs. Other information concerning the litigation can be found at <http://www.acdl.com/legalnews.html> and the complaint also is described 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, 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 federal Medicaid law include the allegation that the state has failed to make payments for community-based services sufficient 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) 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 lead to unnecessary institutionalization. The text of this complaint may be found at <http://oaksgroup.org/complaint/>. Other materials concerning this complaint are located at: <http://groups.yahoo.com/group/CAL-DDCOMMIMP/files/Sanchez/>. There are no settlement discussions underway and the 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 did not receive 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, required 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 may 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 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 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 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. Maine: Risinger et al. v. Concannon et al.

Filed in June 2000, this complaint (00-116-B-C) alleges that Maine is in violation of federal Medicaid law by failing to furnish medically necessary Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services to children with mental disabilities. The lawsuit was filed by private attorneys in collaboration with Maine Equal Justice Partners, Inc. The Disability Rights Center of Maine joined the lawsuit as a named plaintiff. The lawsuit argues 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 is Maine's assuring access to non-waiver Medicaid services for children rather than via an HCBS waiver program. Under federal law, a state may not limit the availability of EPSDT services. The lawsuit also

contends that Maine's payments for services are insufficient to ensure that they will be available when and as needed and thereby the state is in violation of §1902(a)(30)(A). As a consequence, the plaintiffs argue that 600 Maine children with mental disabilities have been wait listed for services or are unable to receive services to which they are otherwise entitled. More information about this lawsuit is at <http://www.healthlaw.org/pubs/200006release.html>.

In July 2001, the District Court granted the plaintiff's motion to certify the lawsuit as a class action. This decision is at http://www.med.uscourts.gov/opinions/carter/2001/GC_07022001_1-00cv116_Risinger_v_Concannon.pdf. Reportedly, the state will appeal this decision.

6. 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 concerning 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 need 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. There has been relatively little preceding litigation concerning state administration of Medicaid HCB services. As a consequence, it remains uncertain about 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

As previously noted, some states have argued that plaintiffs cannot seek federal court intervention concerning the provision of Medicaid services. These states argue that the 11th Amendment prevents individuals from suing states in federal court.

Federal Medicaid law itself does not provide explicitly 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 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, an 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 give beneficiaries the right to seek redress in federal court, plaintiffs 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” when state officials are alleged to have violated the Constitution or federal law. Dating back many years, federal courts – including the U.S. Supreme Court – have affirmed that lawsuits may be brought in federal court in cases involving Medicaid law when the plaintiffs seek prospective relief from alleged violations.

Federal court rulings concerning whether the federal courts may serve as a venue where beneficiaries can bring suit against a state almost always have been decided against the state. On a fairly consistent basis, most courts have rejected state appeals based on the sovereign immunity protection (e.g., as witness the 10th Circuit’s recent decision in the New Mexico Lewis litigation). But, in other instances, they have not. An inventory of decisions concerning this complex topic may be found 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 very controversial ruling in a Medicaid lawsuit (Westside Mothers v. Haveman). This decision cited several grounds for concluding that Medicaid beneficiaries cannot not seek redress through the federal courts for alleged violations of federal Medicaid law. This lengthy 95-page decision is at the following site: <http://www.mied.uscourts.gov/JudgesOpinions/Cleland/rhc99-cv-73442.pdf>. This decision is being appealed to the 6th Circuit Court of Appeals. There is more detailed discussion of the issues raised in this case at <http://www.nsclc.org/westsiderejected.htm>

The issues at play in this arena are very complex because they involve fundamental Constitutional questions concerning the extent to which states can be compelled to comply with federal laws and mandates by federal courts.

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