

Addressing Long Waits for Home and Community-based Care Through Medicaid and the ADA

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Tami has complex ophthalmic, orthopaedic, gastro-intestinal, and neurological care needs. Her doctors say it is a miracle she has reached age six. Tami cannot talk or walk, and she needs ongoing physical therapy. Tami is bed-ridden and needs 24-hour care. She lives at home, communicating through eye movements and interacting as an important member of her family. Tami's private insurance has been covering her home health care, but it has now reached its limits. Tami's family is looking to the Medicaid program to cover the care that Tami needs, but Medicaid says it will pay for only seven hours of home care each day.

Daniel is 14 years old. He suffers from emotional illness, including psychoses and depression. Prior to October 1999, he was cared for at home by in-home workers, funded through Medicaid. He was functioning well. However, the Medicaid agency cut back on his coverage. Daniel's condition deteriorated, and he was initially placed in a state psychiatric hospital and, subsequently, has been bouncing between the hospital and residential group home settings – a scenario which will likely continue unless his Medicaid home-based care is reinstated.

Chad is a 32-year-old man with traumatic brain injury. With home health and personal care assistance, Chad can live in his own apartment. However, his condition demands consistency and a focus on social behavior. Unfortunately, the individuals who are providing services to Chad through the Medicaid program are untrained and have exhibited inappropriate behavior. On one occasion, Chad's mother was summoned to the apartment, only to find a 19-year-old care provider passed out on the sofa, naked from the waist down with beer cans strewn around him.

Introduction

These stories are taken from the docket of cases recently handled by the National Health Law Program, a public interest law firm. While the differences in these cases are apparent, there are common threads running through them. All of these individuals are disabled, of limited income, and dependent on the state Medicaid program to cover the costs of their necessary health

care. Each has ongoing health care needs. None of them need to be institutionalized, however, because each can be cared for in less restrictive home and community-based settings. All three cases raise a number of troubling questions about how state Medicaid agencies are implementing federal requirements for covering home and community-based services.

This article focuses on the growing advocacy movement to identify and address these issues. These efforts represent a progression in advocacy, which has previously focused on improving conditions for those living in institutions and more recently evolved to target the elimination of unnecessary institutionalization.¹ Building upon these activities, individuals with disabilities, their families and advocates are now seeking to improve the scope, availability, and quality of home and community-based services, particularly for persons with limited incomes who are dependent on the Medicaid program. Parts I and II of this article provide a background overview of the issues and to Medicaid eligibility and services for persons needing home based care. In Part III of the article, recent and ongoing federal court cases will be used to illustrate how provisions of the Medicaid Act are being used to expand and improve the availability of home and community-based services. Part IV of the article discusses the growing importance of the Americans with Disabilities Act and the Rehabilitation Act in securing appropriate home and community-based services.

¹ *See, e.g.*, *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999); *Helen L. v. DiDario*, 46 F.3d 325 (3d Cir. 1995). Advocacy also has focused on challenging denials of Medicaid eligibility and services for individual claimants. *See, e.g.*, *Ash v. Ohio Dep't of Human Serv.*, 126 Ohio App.3d 211, 709 N.E.2d 1257 (Ohio App. 4 Dist. 1998); *Leach v. Comm'r*, 1995 WL 495907 (Va. App., Aug. 22, 1995); *Madsen v. Dep't of Health & Welf.*, 114 Idaho 182, 755 P.2d 479 (Idaho App. 1988).

I. The Changing Face of Health Care Delivery

Health care today is quite different from the care provided thirty-five years ago, when Medicaid was enacted into law. At that time, health care – and, thus, Medicaid – was heavily focused on the provision of institutionally-based services.² Over the past three decades, remarkable technological and pharmacological advances have occurred.³ Individuals who would not have lived thirty-five years ago are living today. Many of these individuals have complex medical needs, while others – particularly adolescents – present an intertwined array of psychosocial problems that are difficult to treat.⁴ Many of these individuals are able to live and be cared for at home.⁵

While often less expensive than institutional care, home and community-based care is still a financial drain on families. Private insurance provides limited assistance – in terms of

² See, e.g., NATIONAL CONFERENCE OF STATE LEGISLATURES, DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL ASSISTANCE REPORT FOR LEGISLATORS 2-4 (2000) (available from <http://www.ncsl.org/programs/health/Forum/pub6683.htm>); AMERICAN FEDERATION OF STATE MUNICIPAL AND COUNTY EMPLOYEES, OPENING NEW DOORS: THE TRANSITION FROM INSTITUTIONAL TO COMMUNITY CARE 1-2 (1999) (available from <http://www.afscme.org/pol-leg/opend02.htm>); Fred Thomas, *Ambulatory and Community-Based Services*, 20 HEALTH CARE FINANCING REV. 1 (Summer 1999).

³ See, e.g. KAISER FAMILY FOUNDATION, LONG-TERM CARE, MEDICAID'S ROLE AND CHALLENGES 3 (Nov. 1999) (available from Kaiser Family Foundation, Washington, DC).

⁴ See Paul W. Newacheck et al., *An Epidemiologic Profile of Children with Special Health Care Needs*, 102 PEDIATRICS 117 (July 1998).

⁵ See, e.g., ROBERT PROUTY AND K. CHARLIE LAKIN, RESIDENTIAL SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES STATUS AND TRENDS THROUGH 1998 (on file with University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration) (1999) (stating that the number of individuals with developmental disabilities in public institutions has declined from 149,892 in 1977 to 51,485 in 1999).

both the amount and depth of coverage provided and the length of time that benefits are offered.⁶ As a result, Medicaid is increasingly being looked upon to cover the costs of providing institutional and community-based services. Medicaid is now the single largest payment source for the developmentally disabled, and it is the program that many persons with mental illness and mental retardation rely upon.⁷ Caring for these individuals has become expensive, costing Medicaid over \$18 billion in 1995.⁸

Not surprisingly, Medicaid agencies are looking for ways to control costs. Most states have reduced costly institutional care by shifting some public funding to home and community settings. They have done so, in part, through the use of Medicaid home and community-based waivers.⁹ States have taken these actions delicately, however, concerned that people who are being cared for in institutions or by family members will “come out of the woodwork” and place heavy demands on limited Medicaid budgets. As a result, most states offer only limited numbers of waiver slots, for example 200 slots per year. Medicaid beneficiaries who would otherwise qualify for community-based care have been placed on waiting lists when these slots become full.

Moreover, states have enjoyed almost unchecked flexibility in how they will administer

⁶ See KAISER FAMILY FOUNDATION, LONG-TERM CARE, MEDICAID’S ROLE AND CHALLENGES 6-10 (Nov. 1999) (available from Kaiser Family Foundation, Washington, DC).

⁷ See NATIONAL CONFERENCE OF STATE LEGISLATURES, DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL ASSISTANCE REPORT FOR LEGISLATORS 7 (1999) (available from <http://www.ncsl.org/programs/health/Forum/pub6683.htm>).

⁸ *Id.*

⁹ These waivers are discussed in some detail, *infra*.

their home and community-based services – so long as the federal government does not find the states’ actions to be illegal or too expensive. States have caused waiting lists for home health services to grow by decreasing the number of slots allocated to their waiver programs and by keeping allocated slots unfilled. States have failed otherwise to provide children and nursing-home eligible adults with medically necessary, Medicaid-covered home care services. States are also allowing home care facilities to operate with inadequate direct care staff, and Medicaid beneficiaries cannot find home care providers. Beneficiaries and their advocates increasingly are asking whether these situations violate the Medicaid Act.

The need to clarify the role of Medicaid in providing home and community-based services has been made all the more pressing by the U.S. Supreme Court’s *Olmstead v. L.C. ex rel. Zimring* decision, which holds the Americans with Disabilities Act to prohibit states in their public programs from unnecessarily institutionalizing persons with disabilities.¹⁰ Among other things, *L.C.* found a need for states to have a “comprehensive, effectively working plan” for placing qualified individuals in less restrictive settings and waiting lists that move at a “reasonable pace.”¹¹ As states develop these comprehensive plans, institutional placements over a range of settings will require review. For example, states will need to assess whether persons have been inappropriately placed in state psychiatric hospitals, nursing homes, intermediate care level facilities, and prisons. Medicaid will play a central role. Not only do state Medicaid programs receive and provide major funding for both institutional and home and community-

¹⁰ 527 U.S. 581 (1999). This case is often referred to as *Olmstead*; however, in this article, it is called *L.C.*, to acknowledge the plaintiffs.

¹¹ *Id.* at 605-06.

based services, but those who qualify for Medicaid have a legal entitlement to receive appropriate services as required by the Medicaid Act.¹²

II. Overview of the Medicaid Program for Individuals Needing Home and Community-based Care

A. Medicaid Eligibility – Fitting into a Category

Not all persons who are poor and who need home health care are eligible for Medicaid. Rather, to obtain a Medicaid card, an individual must have limited income *and* fit into an eligibility category. For persons with ongoing home health care needs, five eligibility categories are used most frequently.

First, in most states, individuals who are receiving Supplemental Security Income (SSI) on the basis of disability automatically qualify for Medicaid.¹³ To be disabled, a person must have a “medically determinable physical or mental impairment which results in marked and severe functional limitation, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”¹⁴

The second and third likely eligibility categories involve children who are not living with their biological parents. State Medicaid programs must cover all children who qualify for title

¹² See 42 U.S.C.A. § 1396a (Supp. 2000).

¹³ See 42 U.S.C.A. § 1396a(a)(10)(A)(i)(II) (Supp. 2000). SSI was created in 1972 to provide cash assistance to the aged, blind and disabled who have limited income and resources. SSI provides a uniform federal payment, and states have the option to supplement this payment. Eleven states do not provide Medicaid automatically to persons receiving SSI. Under section 1902(f) of the Social Security Act, these states use their 1972 state assistance eligibility rules in determining Medicaid eligibility. See 1972 Social Security Amendments Act, Pub. L. No. 92-603, § 209(b), 86 Stat. 1381 (1972). The states are referred to as “209(b) states.” The eleven states are Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia.

¹⁴ See 42 U.S.C.A. § 1382c(a) (1999).

IV-E foster care payments.¹⁵ States that participate in title IV-E adoption assistance also are required to provide Medicaid as part of the adoption assistance.¹⁶ Children in these mandatory eligibility groups are important for purposes of home and community-based services because they are more likely to have suffered neglect or abuse and to have behavioral health care needs.¹⁷

Fourth, states may choose to cover disabled children (age 18 or younger) who are living at home and do not qualify for SSI or state supplementary payments because their parents' income is too high.¹⁸ States choosing this option are allowed to waive rules for counting parental income requirements which otherwise would make the child ineligible for Medicaid.¹⁹ States may exercise this option only if: (a) the child would qualify for SSI or state supplementary payments if he or she were in a medical institution; (b) the child requires a hospital or nursing facility level of care; (c) home care is medically and otherwise appropriate; and (d) the estimated

¹⁵ *See Id.* § 1396a(a)(10)(A)(i)(I) (Supp. 2000). Children are eligible for title IV-E payments if their biological parents would have qualified for AFDC under the AFDC rules in effect on July 16, 1996. States have the option to extend Medicaid to other groups of children in foster care. *See Id.* § 1396a(a)(10)(A)(ii)(VIII) .

¹⁶ *See* 42 U.S.C.A. § 1396a(a)(10)(A)(i)(I) (Supp. 2000).

¹⁷ *See, e.g.,* Committee on Early Childhood, Adoption, and Dependent Care, *Developmental Issues in Foster Care for Children*, 91 PEDIATRICS 1007 (May 1993); Neal Halfon and Linnea Klee, *Health and Developmental Services for Children with Multiple Needs: Children in Foster Care*, 9 YALE L. & POL'Y REV. 71 (1991); Neil J. Hochstadt, *The Medical and Psychosocial Needs of Children Entering Foster Care*, 11 CHILD ABUSE & NEGLECT 53 (1987).

¹⁸ *See* 42 U.S.C.A. § 1396a(e)(3) (Supp. 2000). This option is sometimes referred to as the "Katie Beckett option." Under SSI rules, an institutionalized individual is not considered to be living in the same household as his or her parents or spouse after the first full month of institutionalization. 20 C.F.R. §§ 416.1161a, .1204a. Therefore, children whose parents' income or resources would place them above SSI limits if they lived at home often would be eligible for SSI, and thus, Medicaid, if they were institutionalized.

¹⁹ *See* 42 U.S.C.A. §1396a(e)(3) (Supp. 2000).

cost of home care would not exceed the estimated cost of appropriate institutional care.²⁰

States also have the option of covering the medically needy – individuals who fit into a federal benefit program category, such as the aged, blind, or disabled, but whose income or resources are above the eligibility levels for the benefit program.²¹ Such individuals can qualify for Medicaid if their income, minus incurred medical expenses, is less than the state’s medically needy income and resource levels.²² While states have a great deal of flexibility in how they operate their medically needy programs, states choosing this option must include ambulatory services for children under age 18.²³

II The Medicaid benefit package -- home and community-based services

A state that participates in the Medicaid program and receives federal matching funds for its Medicaid expenditures must comply with the provisions of the Medicaid Act and the regulations governing the program promulgated by the Secretary of Health and Human Services.²⁴ The Medicaid Act requires states to cover a number of home based services and

²⁰ *Id.*

²¹ *See* 42 U.S.C.A. § 1396a(a)(10)(C) (Supp. 2000). The following jurisdictions have medically needy programs: California, Connecticut, District of Columbia, Florida, Georgia, Hawaii, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, and Wisconsin. States electing the 209(b) option, *see* n. 13, *supra*, must have a medically needy program for the aged, blind, and disabled. *Id.* at § 1396a(f).

²² *See* 42 U.S.C.A. § 1396a(a)(17) (Supp. 2000).

²³ *See Id.* § 1396a(a)(10)(C)(ii), (iii).

²⁴ *See, e.g.,* Wilder v. Virginia Hosp. Ass’n, 496 U.S. 498, 502 (1990). All states have elected to participate in Medicaid.

allows states to cover others. This section of the article reviews these mandatory and optional services.

1. Mandatory home health services

The Medicaid Act requires states to provide for the “inclusion of home health services for any individual who, under the State plan, is entitled to nursing facility services.”²⁵ These are individuals 21 and older who are categorically needy, individuals 21 and older who are medically needy if the state covers nursing facility services in its medically needy program, and children under age 21 who are found to need nursing facility services through the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program (described below). For other Medicaid beneficiaries, the state has the option whether or not to cover home health services.

State Medicaid programs must cover the following home health services: (1) nursing services on a part time or intermittent basis, (2) home health aids, and (3) medical supplies.²⁶ The state may cover physical therapy, occupational therapy, speech pathology, and audiology services.²⁷

2. Optional home care services for adults

Medicaid allows states to cover and receive federal matching funds for other home care services for individuals age 21 and older. The most important of these services for individuals

²⁵ See 42 U.S.C. §1396a(a)(10)(D) (Supp. 2000).

²⁶ See 42 C.F.R. § 440.70. The Medicaid beneficiary does not need to be homebound in order to receive home health services. HCFA, Dear State Medicaid Director -- Olmstead Update No. 3 (July 25, 2000) (available at <<http://www.hcfa.gov/medicaid/olmstead/smdltrs.htm>>).

²⁷ *Id.*

needing home and community-based care are: private duty nursing services,²⁸ physical therapy and related services,²⁹ “other diagnostic, screening, preventive and rehabilitative services,”³⁰ personal care services,³¹ case-management services;³² and respiratory care services for specified ventilator dependent individuals.³³

Medicaid also includes as an optional service home and community care for low income “functionally disabled elderly individuals.”³⁴ This service allows the state to provide a range of services, including homemaker/home health aide services, chore services, personal care services, nursing care services, respite care, training for family members in managing the individual, adult day care, and day treatment for persons with chronic mental illness.³⁵ Functional disability is determined by the elderly individual’s need for assistance with activities of daily living (e.g. toileting, transferring, or eating) or by having a diagnosis of Alzheimer’s Disease and a need for

²⁸ See 42 U.S.C.A. § 1396d(a)(8) (Supp. 2000).

²⁹ *Id.* § 1396d(a)(11).

³⁰ *Id.* § 1396d(a)(13). This includes “any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level[.]” *Id.*

³¹ *Id.* § 1396d(a)(24).

³² *Id.* §§ 1396d(a)(19), 1396n(g)(2).

³³ *Id.* §§ 1396d(a)(20), 1396a(e)(9).

³⁴ *Id.* §§ 1396d(a)(22), 1396t.

³⁵ *Id.* § 1396t(a).

assistance with daily living.³⁶ Funds for this program are limited to a specified appropriation each year.³⁷

States can also elect to provide “community supported living arrangements services” for the developmentally disabled.³⁸ This option allows the state to choose among the following services: personal assistance, training and habilitation services, 24-hour emergency assistance, assistive technology, adaptive equipment, and supportive services needed to aid an individual to participate in community activities.³⁹ Developmental disability is decided based on the individual’s condition and on their living arrangements.⁴⁰ Funds for the program are limited to specified annual appropriations.⁴¹

3. Early and Periodic Screening, Diagnosis and Treatment services for children

The Medicaid Act requires states to provide comprehensive Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services to categorically eligible children under age 21.⁴² As part of EPSDT, states must provide eligible children with health care, diagnostic services, treatment, and other measures “to correct or ameliorate defects and physical and mental

³⁶ *Id.* § 1396t(c).

³⁷ *Id.* § 1396t(e), (m).

³⁸ *Id.* §§ 1396d(a)(23), 1396u.

³⁹ *Id.* § 1396u(a).

⁴⁰ *Id.* § 1396u(b).

⁴¹ *Id.* § 1396u(j).

⁴² *Id.* §§ 1396a(a)(10), a(a)(43), d(a)(4)(B), d(r). For in depth discussion of EPSDT, see JANE PERKINS AND SUSAN ZINN, TOWARD A HEALTHY FUTURE: ENSURING EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT FOR POOR CHILDREN (Apr. 1995) (available from National Health Law Program, Los Angeles, CA).

illnesses and conditions[.]”⁴³ The state must include within the scope of EPSDT benefits any service that it potentially could cover for adults under the Medicaid Act, even if it does not in fact cover that service for adults. This means that otherwise optional services, such as personal care services, case management services, rehabilitation services, the optional home health care services, and physical and related therapies, must be covered for a child when needed to correct or ameliorate their condition.⁴⁴ Moreover, the state must “arrang[e] for ... corrective treatment” for children’s identified needs.⁴⁵ Thus, while the state generally is required only to pay for Medicaid-covered services when medically necessary, a state must arrange for EPSDT for needy children.⁴⁶ In addition, the agency must ensure timely initiation of treatment, generally within an outer limit of six months after the request for screening services.⁴⁷

4. Home and community-based waiver services

The Medicaid Act allows states to obtain waivers from the federal Department of Health and Human Services (DHHS) that excuse compliance with otherwise applicable federal laws.⁴⁸

⁴³ 42 U.S.C.A. § 1396d(r)(5).

⁴⁴ *See Id.*; *Id.* §1396d(a).

⁴⁵ *Id.* § 1396a(a)(43)(C).

⁴⁶ *See* GEORGE ANNAS, ET AL., AMERICAN HEALTH LAW 186-87 (1990). *See also, e.g.*, *Doe v. Pickett*, 480 F. Supp. 1218, 1221 (S.D.W.Va. 1979) (EPSDT “imposes on the states an affirmative obligation to see that minors actually receive necessary treatment and medical services”).

⁴⁷ *See* 42 C.F.R. § 441.56(e) (1999).

⁴⁸ *See* 42 U.S.C.A. § 1396n(c); 42 C.F.R. § 440.180 et seq.. *See generally* 42 U.S.C.A. § 1396a(a)(21) (“[I]f the State plan includes medical assistance in behalf of individuals 65 years of age or older who are patients in public institutions for mental diseases, [a State plan for medical assistance must] show that the State is making satisfactory progress toward developing and implementing a comprehensive mental health program, including provision for utilization of

The goal of these waiver programs is to provide services to persons at home or in the community and thereby avoid placing them in a hospital or nursing facility. To this end, waivers can be used to access Medicaid services that are normally not available to Medicaid beneficiaries, including case management, homemaker/home health aides, personal care, adult day health, habilitation and respite care.⁴⁹ Through these waiver programs, states can elect to offer different groups different sets of services, offer the services in only certain geographic locations, and waive certain rules for counting income to make sure more individuals are eligible.

There are three major types of home and community-based waivers. The first type of waiver allows states to provide the services to individuals who, but for the waiver services, would be institutionalized in a hospital, nursing facility, or intermediate care facility for the mentally retarded (ICF-MR).⁵⁰ Second, waivers can be used to provide home and community-based care services to individuals over age 65 who, but for the waiver services, would be institutionalized in a nursing facility.⁵¹ The third type of waiver is used to provide home and community services to children under age five who are infected with AIDS or who are drug dependent at birth.⁵²

To obtain and maintain any of these waivers, states must provide assurances to DHHS

community mental health centers, nursing facilities, and other alternatives to care in public institutions for mental diseases”).

⁴⁹ See 42 C.F.R. § 440.180 (1999).

⁵⁰ See 42 U.S.C.A. § 1396n(c) (Supp. 2000); 42 C.F.R. § 441.300 et. seq., § 440.180 (1999).

⁵¹ See 42 U.S.C.A. § 1396n(d) (Supp. 2000); 42 C.F.R. § 441.350 et. seq., § 440.181 (1999).

⁵² See 42 U.S.C.A. § 1396n(e) (Supp. 2000).

that: (1) necessary safeguards have been taken to protect the health and welfare of recipients and to assure financial accountability for funds expended on the services provided; (2) under the waiver, the state will spend less per capita than without the waiver; and (3) the state will annually provide information to DHHS on the waiver's impact on the type and amount of medical assistance provided and on the health and welfare of recipients.⁵³ In addition, states providing waiver services for individuals who, under the first two types of waivers, would otherwise be institutionalized, must evaluate each recipient's need for institutional services and inform a recipient determined to be likely to need institutional services that alternatives under the waiver are available and may be chosen by the recipient.⁵⁴

There are currently 240 home and community-based waiver programs in existence.⁵⁵ Between 1990 and 1998, the number of persons with mental retardation/developmental disability who received services through home and community-based waiver programs increased by more than 200,000 persons.⁵⁶

III. Advocacy to expand and improve the availability of Medicaid home and community-based services

Despite the number of Medicaid eligibility and service options available to states, there are waiting lists for the home and community-based services. As noted, *supra*, there are various

⁵³ *See Id.* §§ 1396n(c)(2), n(d)(2), n(e)(2).

⁵⁴ *See Id.* §§ 1396n(c)(2), n(d)(2).

⁵⁵ Arizona is a technical exception because its home and community-based waivers are authorized as part of its unique section 1115 demonstration waiver program.

⁵⁶ *See* NATIONAL CONFERENCE OF STATE LEGISLATORS, DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL ASSISTANCE REPORT FOR LEGISLATORS 5 (2000) (available at www.ncsl.org/programs/health/Forum/pub6683.htm).

reasons for these waiting lists, including state budgetary constraints and provider shortages. But while these waiting lists have persisted for years, they are increasingly being challenged by individuals with disabilities and their families and advocates. In this part of the article, recent and ongoing federal court cases are used to illustrate three important Medicaid Act requirements that are being cited in the advocacy movement to expand and improve the availability of home and community-based services, requirements for : (1) timely provision of home and community-based services and free choice of services, (2) comprehensive home based treatment services for children and youth under age 21, and (3) pre-admission screening to prevent the inappropriate institutionalization of people with mental disabilities in nursing homes.

A. Reasonable promptness and free choice in the delivery of services

One of the most common problems that Medicaid beneficiaries experience is lengthy delays in obtaining home and community-based services. In a number of states, beneficiaries have been placed on waiting lists, sometimes for years. Courts increasingly are being asked whether these long delays violate the Medicaid Act requirement that "assistance shall be furnished with reasonable promptness to all eligible individuals."⁵⁷ Interestingly, the "reasonable promptness" provision was originally enacted in the Social Security Act (of which Medicaid is a part) to address the hardship caused when needy individuals were placed on waiting lists or otherwise denied public assistance, despite the fact that they had been found

⁵⁷ 42 U.S.C.A. § 1396a(a)(8) (Supp. 2000). *See also* 42 C.F.R. § 435.930 ("agency must: (a) furnish Medicaid promptly to recipients without any delay caused by the agency's administrative procedures; [and] (b) continue to furnish Medicaid regularly to all eligible individuals until they are found to be ineligible...."); *Id.* § 435.911 ("agency must establish time standards for determining eligibility and inform the applicant of what they are.").

eligible for that assistance.⁵⁸

Over the years, numerous courts have held the reasonable promptness provision to prohibit states from responding to administrative constraints by making beneficiaries wait for services.⁵⁹ *Doe v. Chiles*,⁶⁰ for example, held that Florida's waiting lists for intermediate care facility services violated the reasonable promptness requirement and ordered the state to establish a reasonable waiting period for ICF services not to exceed 90 days.⁶¹

In the home and community-based care context, plaintiffs are citing the reasonable promptness provision along with another Medicaid Act requirement, the "free choice" provision. The free choice rule says that when a state covers both institutional and waiver program services,

⁵⁸ See Conf. Rep. No. 2271, 81st Cong., 2d Sess. (1950), *reprinted in* 1950 U.S.C.C.A.N. 3287, 3482, 3507; H.R. Rep. No. 1300, 81st Cong., 1st Sess. 48 (1949) (decision by states "not to take more applications or to keep eligible families on waiting lists until enough recipients could be removed from the assistance rolls to make a place for them ... results in undue hardship on needy persons and is inappropriate in a program financed from federal funds"). See *Jackson v. Hackney*, 406 U.S. 535, 545 (1972).

⁵⁹ *E.g.* *Sobky v. Smoley*, 855 F. Supp. 1123, 1149 (E.D. Cal. 1994) ("insufficient funding by the State and counties of methadone maintenance treatment slots has caused providers . . . to place eligible individuals on waiting lists for treatment . . . precisely the sort of state procedure the reasonable promptness provision is designed to prevent"); *Linton v. Carney*, 779 F. Supp. 925, 936 (M.D. Tenn. 1990) (policy of limiting the number of nursing homes beds that could be used for Medicaid patients violated the reasonable promptness provision by causing those patients "to experience extended delays and waiting lists in attempting to gain access to long term nursing home care"); *Clark v. Kizer*, 758 F. Supp. 572, 580 (E.D. Cal. 1990), *aff'd in part and vacated in part on other grounds sub nom.*, *Clark v. Coye*, 967 F.2d 585 (9th Cir. 1992) (granting summary judgment on reasonable promptness claim where declarations of county public health officials indicated that a shortage of Medicaid-participating dentists caused frequent "delays in obtaining appointments for regular and emergency dental care[.]"); *Morgan v. Cohen*, 665 F. Supp. 1164, 1177 (E.D. Pa. 1987) (Medicaid-covered transportation services "must be furnished with reasonable promptness").

⁶⁰ 136 F.3d 709 (11th Cir. 1998).

⁶¹ *Id.* at 720.

it must inform eligible individuals about feasible alternatives, if available under the waiver, and allow individuals to choose whether they will receive care under the waiver program or in an institutional setting.⁶² In *Cramer v. Chiles*,⁶³ the court found that Florida had violated the reasonable promptness and free choice rights of developmentally disabled Medicaid beneficiaries. At issue was a new state plan that eliminated most placements in intermediate care facilities for the developmentally disabled. The court found the plan to be illegal because

it gives beneficiaries no real choice. The beneficiary must choose between (1) a Home and Community-based Waiver option which gives no assurance that the supports and services will meet individuals' needs, and (2) a hope for a future ICF/DD placement. The defendants have admitted that selecting an ICF/DD placement means going on a waiting list for decades unless new facilities are found.⁶⁴

While *Cramer* focused on the availability of ICF services and only tangentially dealt with home and community-based waiver services, subsequent cases are focusing directly on reasonable promptness, free choice, and the availability of home and community-based waiver slots. The first case, *Benjamin H. v. Ohl*,⁶⁵ challenges West Virginia's failure to make

⁶² See 42 U.S.C.A. § 1396n(c)(2) (Supp. 2000); 42 C.F.R. § 441.302(d) (1999).

⁶³ 33 F. Supp. 2d 1342 (S.D. Fla. 1999).

⁶⁴ *Id.* at 1352.

⁶⁵ Civ. Action No. 3:99-0338 (S.D.W.Va.) (pleadings on file with authors, the court's opinion and the settlement agreement are available at <<http://www.healthlaw.org/pubs/199907benjamin.html>>). In another case, *Wolf Prado-Steiman v. Bush*, Civ. No. 98-6496-CIV-FERGUSON (D. Fla. 2000) (Settlement Agreement) (on file with the authors), the parties have entered into an agreement, pending court approval. The agreement requires provision of home and community-based services in a timely manner. The state also agrees to develop and implement a direct care staff training program to ensure competency in direct care delivery, use a client based quality assurance system, launch citizen monitoring of community services, and undertake a comprehensive study to determine whether payment rates for community services are adequate. *Id.*

intermediate care level services adequately available to needy beneficiaries. The situation in West Virginia was unusual. Some years ago, the state legislature had declared a moratorium on any new ICF-MR/DD beds, in favor of the expansion of these services in the community. The state did, in fact, expand community offerings, in part through a Medicaid home and community-based waiver. However, in April 1999, the state limited the waiver program to emergency placements and submitted a waiver re-application to DHHS that sought only 25 slots a year for the next five years. These actions by the state resulted in immediate and growing waiting lists for intermediate care level services.

Medicaid beneficiaries argued that this turn of events meant that ICF-level services were simply not operating in the state in either institutional or community settings – even though the state included ICF-level services in its state Medicaid plan. In a lawsuit, the beneficiaries alleged violations of the free choice and reasonable promptness requirements. Ordering injunctive relief for the plaintiffs, the court was persuaded that, in this situation, the plaintiffs “are not confined to a limited choice. They have no choice at all, except to languish on a waiting list for one unavailable service or another.”⁶⁶ The court rejected the state’s claim that the Medicaid Act was not violated because the waiver alternative was not available due to the fact

⁶⁶ *Benjamin H.*, No. 3:99-0338, slip op. at 26 (S.D.W.Va. July 15, 1999). Compare *Makin v. Cayetano*, No. 98-0097 DAE (D. Haw., Nov. 26, 1999) (on file with the authors) (distinguishing *Benjamin H.* and finding free choice provision not violated where plaintiffs could choose to enter ICF-MRs). Because the record in *Makin* revealed that there were remaining unfilled slots available at the end of a previous year when the state had allowed unspent waiver appropriations to lapse without an explanation, the court allowed the plaintiffs to pursue their claim under 42 C.F.R. § 441.302(b), which requires the agency to assure financial accountability for funds expended under a waiver. *Makin*, slip op. at 31.

that the demand for slots exceeded the budget for the program. Citing *Martinez v. Ibarra*,⁶⁷ the court decided that feasible alternatives should be determined by the beneficiary's needs and treatment plan, and not solely by the funds available to service that plan.⁶⁸ In a March 15, 2000 order, both the free choice and reasonable promptness provisions were found to have been violated. The Court ordered the state to allow individuals to apply for waiver services without delay and to make eligibility determinations within 90 days. It also ordered waiting lists for waiver services to move at a reasonable pace, defined as 90 days from the date eligibility is determined.⁶⁹ During the pendency of the case, the West Virginia Medicaid agency also significantly increased the number of waiver slots that it was seeking from DHHS.

In *Boulet v. Cellucci*,⁷⁰ a federal court in Massachusetts issued summary judgement for the plaintiffs in a similar waiting situation and ordered the state Medicaid agency to provide the

⁶⁷ 759 F. Supp. 664, 669 (D.Colo. 1991).

⁶⁸ *Benjamin H.*, No. 3:99-0338, slip op. at 26 (S.D.W.Va. July 15, 1999). *See also* Lewis v. New Mexico Dep't of Health, 94 F. Supp. 2d 1217 (D.N.M. 2000) (rejecting the state's argument that neither the constitution nor statute creates a right to participate in the waiver program because, in the case, plaintiffs did not claim an absolute right to the waiver program but rather the right to have their applications processed with reasonable promptness).

⁶⁹ *Benjamin H.*, Civ. Action No. 3:99-0338 (S.D.W.Va) (Mar. 15, 2000, Order) (July 15, 1999, Memorandum Opinion and Order Re: Preliminary Injunction). *See also* Lewis v. New Mexico Dep't of Health, 94 F. Supp. 2d 1217 (D.N.M. 2000) (holding that plaintiffs have a private right of action to enforce reasonable promptness); *Roland v. Celluci*, 52 F. Supp.2d 231 (D. Mass. 1999) (interpreting the reasonable promptness requirement); *McMillan v McCrimon*, 807 F. Supp. 475 (C.D. Ill. 1992) (granting preliminary injunction on plaintiffs' claim that § 1396a(a)(8) required Medicaid agency to accept applications for home and community-based waiver program).

⁷⁰ Civ. Action No. 99-10617-DPW (D. Mass. July 14, 2000), *reprinted at* Medicare & Medicaid Guide (CCH) ¶ 300,517.

needed services within 90 days of the eligibility determination.⁷¹ *Boulet* plaintiffs were part of the home and community-based waiver program for persons who would otherwise require placement in an intermediate care facility for the mentally retarded. While receiving some services, plaintiffs had been waiting years for “residential habilitation services” – services that would provide assistance with acquiring, retaining, and improving skills related to activities of daily living. In their lawsuit, the beneficiaries argued that these long waits violated Medicaid’s reasonable promptness requirements. In response, the defendants argued that the state has the option of providing waiver services, and thus, individuals have no legal entitlement to such services and may not demand that the services be furnished promptly. The Court, however, rejected this position finding that once a state opts to implement a waiver program and sets out the eligibility requirements for that program, eligible individuals are entitled to those services and to the associated protections of the Medicaid Act, including reasonable promptness.⁷² It noted that requiring the state to inform individuals of their institutional and home and community-based care alternatives – the free choice requirement – would have little meaning if the eligible individuals were not also entitled to these alternatives.⁷³

In both *Benjamin H.* and *Boulet*, the state Medicaid agencies relied heavily on the fact that DHHS had approved their waivers with numerical caps on the number of waiver slots. However, both cases found that the existence of these caps does not allow the state total discretion in providing waiver services. In *Benjamin H.*, the court found that “Medicaid

⁷¹ *Id.*, slip op. at 47. The state was provided an opportunity to show cause why this 90 day time frame should not be used.

⁷² *Id.*

⁷³ *Id.* at 34.

provides entitlements.”⁷⁴ The rights of entitlement were violated when the state purported to cover ICF-related services but, in reality, made them available in neither institutional nor home-based waiver settings. To comply with the court’s ruling and address the situation, the state was, in effect, forced to expand home and community-based waiver slots because of the legislative moratorium on building new ICF beds. Meanwhile, in *Boulet*, plaintiffs already were receiving waiver services and so were viewed by the court as included under the cap. Granting individuals the additional waiver services they needed could not bring the state over the cap. Moreover, the Court accepted, apparently without argument, that the state could use a numerical cap and found the cap to operate as an eligibility requirement such that individuals who apply after the cap has been reached are not eligible for the home and community-based waiver service.⁷⁵ Significantly, neither *Benjamin H.* nor *Boulet* analyzed whether the states had appropriately determined their numerical limits or whether the numerical caps might violate some other Medicaid or Americans with Disabilities Act provisions.

B. Home care treatment services for children

Child health advocates have also used the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) provisions to obtain services for children who have been placed on home and community-based waiver waiting lists. Rather than attack the waiting lists

⁷⁴ *Benjamin H.*, Civ. Action No. 3:99-0338, slip op. at 24 (S.D.W.Va)(July 15 ,1999, Memorandum Opinion and Order Re: Preliminary Injunction).

⁷⁵ Civ. Action No. 99-10617-DPW, slip op. at 37 (D. Mass. July 14, 2000), *reprinted at* Medicare & Medicaid Guide (CCH) ¶ 300,517. *See also* Makin v. Cayetano, No. 98-0097 DAE, slip op. at 22, 28 (D. Haw., Nov. 26, 1999) (holding once the “population limits” of the waiver are reached, there is no entitlement to waiver services and the program is no longer an available alternative).

directly, these advocacy efforts seek to fill health care gaps with the fairly comprehensive range of services that EPSDT can provide. As discussed, *supra*, the EPSDT service package and coverage rules are broad – requiring states to cover any federal mandatory and optional service that is needed to correct or ameliorate a child’s physical or mental condition.⁷⁶ A major advantage of the EPSDT statute is that it is clearly written and has been enforced in a number of court decisions and settlements.⁷⁷ The disadvantage is that, on its face, the provision extends only to children under age 21.⁷⁸

Partial settlement of a Louisiana EPSDT case, *Chisholm v. Hood*,⁷⁹ promises a number of positive changes designed to enhance availability of case management services for children with mental retardation and developmental disabilities. “Case management” links the child with a trained case manager who assists her with obtaining needed home and institution-based health care and educational, vocational, and social services.⁸⁰ By focusing on case management, the settlement seeks to impact the delivery system at critical, first contact points for the child and assure that needed home and community-based services are arranged and delivered in a timely manner based on the child’s individual treatment plan. As a result of the *Chisholm* settlement,

⁷⁶ 42 U.S.C.A. § 1396d(r)(5) (Supp. 2000).

⁷⁷ See National Health Law Program, EPSDT Case Docket (Oct. 4, 1999) (posted at <<http://www.healthlaw.org>>).

⁷⁸ *But see, e.g.*, *Salgado v. Kirschner*, 878 P.2d 659, 179 Ariz. 301 (1994), *cert. denied*, 513 U.S. 1151 (1995) (discussion of EPSDT in case involving transplant for an adult).

⁷⁹ Civ. Action No. 97-3274 (E.D.La.) (Feb. 16, 2000, Stipulation and Order of Partial Dismissal) (on file with the authors).

⁸⁰ For provisions authorizing case management services, *see* 42 U.S.C.A. §§ 1396d(a)(19), 1396n(g)(2).

the state has agreed, among other things, to assure that Medicaid-participating case managers will possess minimum qualifications, handle a caseload of no more than 35 clients, and receive training on Medicaid and EPSDT services. The Medicaid agency will also mail notices of the availability of case management services to Medicaid-eligible families.⁸¹

The *Chisholm* court has also issued a partial summary judgment for plaintiffs, a ruling that will help ensure the actual availability of the home based services when case managers seek to arrange them.⁸² The plaintiffs sought this ruling because the state Medicaid agency was severely limiting the availability of occupational, speech, and audiological services (i.e. physical therapy and related services⁸³) to those allowed by school boards, and it prohibited the inclusion of these services as part of home health care.⁸⁴ In this August 21, 2000 ruling, the Court enjoined these limitations, finding them in violation of EPSDT provisions which require the state to “make available a variety of individual and group providers qualified and willing to provide EPSDT services.”⁸⁵

⁸¹ Civ. Action No. 97-3274 (E.D.La.) (Feb. 16, 2000, Stipulation and Order of Partial Dismissal).

⁸² *See Chisholm v. Hood*, Civ. No. 97-3274 (E.D. La., Aug. 21, 2000) (Order and Reasons) (Aug. 30, 2000, Partial Summary Judgment) (on file with the authors).

⁸³ For provisions authorizing physical therapy and related services, *see* 42 U.S.C.A. § 1396d(a)(11) (Supp. 2000); 42 C.F.R. § 440.110 (1999).

⁸⁴ *Chisholm v. Hood*, Civ. No. 97-3274, slip op. at 12-15 (E.D. La., Aug. 21, 2000) (Order and Reasons) (on file with the authors).

⁸⁵ *See Id.*, slip op. at 12-15, 21. The quoted Medicaid regulation may be found at 42 C.F.R. § 441.61(b) (1999).

In another case, *French v. Concannon*,⁸⁶ children in Maine who have severe mental impairments also used the EPSDT provisions to address long waits for needed services. A settlement was reached between the parties, achieving a number of positive results, including: (1) creation of a position within the Maine Department of Mental Health to identify children who are waiting for services and to ensure that treatment is being implemented; (2) revision of the EPSDT informational brochure and the EPSDT provider screening forms to allow for earlier identification of children with behavioral health needs, (3) hiring of additional case managers to assist these children with obtaining needed home care services, (4) streamlining the prior authorization process to allow for more timely provision of home health care, and (5) creation of a new provider category, “behavioral health specialist,” to increase availability of home care providers.⁸⁷

C. Pre-admission screening and services to avoid improper institutionalization

Federal pre-admission screening and annual resident review (PASARR) requirements prohibit nursing facilities participating in Medicaid from admitting a resident who is mentally ill or mentally retarded unless the state has determined, before admission, that the prospective resident requires the level of services provided by the facility and whether she requires specialized services.⁸⁸ PASARR also requires annual review of all nursing facility residents who are mentally ill or mentally retarded to determine whether their continued placement is

⁸⁶ No. 97-CV-24-B-C (D. Me.) (July 1998, Order of dismissal and agreement) (on file with authors).

⁸⁷ *Id.*

⁸⁸ *See* 42 U.S.C.A. § 1396r et seq. (Supp. 2000); 42 C.F.R. §§ 483.106, 483.112 (1999). PASARR applies to all potential residents, whether or not they are Medicaid eligible. *See* 57 Fed. Reg. 56452 (1992).

appropriate and whether they require specialized services.⁸⁹ If an individual requires specialized services, the State must provide or arrange for the provision of the specialized services and, if the individual is being discharged from a facility, assure that discharge is made to an appropriate setting where the specialized services will be provided.⁹⁰

Congress enacted the PASARR legislation in 1987, as part of the Nursing Home Reform Act,⁹¹ doing so because “[s]ubstantial numbers of mentally retarded and mentally ill residents were inappropriately placed in [nursing homes],” and “[t]hese residents often do not receive the active treatment services that they need.”⁹² It also noted that “for a number of these diagnoses, such as schizophrenia, depressive disorder, and anxiety disorders, active treatment in community settings [could] be appropriate.”⁹³ Congress thus devised PASARR to prevent and remedy the unnecessary admission and confinement of people with psychiatric and developmental

⁸⁹ See 42 U.S.C.A. § 1396r(b).

⁹⁰ See 42 C.F.R. §§ 483.118(c)(2)(iii), 483.130(m)(5) (1999). Medicaid law also requires that nursing facilities which plan to discharge a resident provide written notice of the planned transfer or discharge. See 42 C.F.R. § 483.12(a) (1999). People with mental disabilities have discharge planning rights, which include the right to assessment and planning regarding community services. Hospitals must have an “effective, ongoing discharge planning program that facilitates the provision of follow-up care.” 42 U.S.C.A. § 1395x(ee) (Supp. 2000); 42 C.F.R. §§ 482.21(b), 482.43 (1999). The goals of the discharge statutes are to avoid repeated institutional placement and to support the individual’s right to live safely in the community with appropriate supports.

⁹¹ Omnibus Budget Reconciliation Act of 1987, Pub. L. No. 100-203, §§ 4211-4218 (1987).

⁹² H.R. Rep. No. 391, 100th Cong., 1st Sess. 459-460 (1987), *reprinted in* [1987] U.S.C. C.A.N. 2313-2379, 2380.

⁹³ *Id.*

disabilities in nursing homes.⁹⁴

In *Rolland v. Celluci*,⁹⁵ a class action on behalf of nursing home residents with mental retardation and other developmental disabilities, the plaintiffs alleged that the State of Massachusetts violated the PASARR requirements and the Americans with Disabilities Act by failing to provide specialized services and community-based treatment in intermediate care facilities and community settings that were most appropriate to the plaintiffs' needs. The parties settled the case with an agreement that guarantees the right of all current Massachusetts residents of nursing facilities who can be safely supported in the community to leave the facility and live in integrated community settings.⁹⁶ In deciding whether someone can benefit from a community setting, the following factors will be considered:

- opportunities to interact with family and friends;
- accessibility to appropriate work or day supports;
- opportunity for meaningful participation in aspects of community life;
- the presence or absence of an advanced medical condition that would have a significant adverse impact on an individual's safety;
- the presence or absence of fragile health conditions such that the main supports are nursing services for medical and basic needs;

⁹⁴ *Id.* See also *Rolland v. Cellucci*, 52 F. Supp.2d 231, 234 (D. Mass. 1999) (explaining that legislation was “enacted to quell overutilization of nursing home care for those who are not in need of institutionalization”); *McNiece v. Jindal*, 1998 U.S. Dist. LEXIS 5635 (E.D. LA 1998) (noting the “apparent impetus for the [legislation] was the complaint that mentally ill and mentally retarded people were often being ‘warehoused’ in nursing homes where their needs were not met”). For in depth discussion of the PASARR requirements, see National Health Law Program, The Pre-Admission Screening and Annual Resident Review (“PASARR”) Program (Jan. 2000) (available at www.healthlaw.org).

⁹⁵ 52 F. Supp.2d 231 (D. Mass. 1999), *same case*, Civ. No. 98-30208-KPN (D. Mass., Jan. 10, 2000) (Memorandum with Regard to Approval of Settlement Agreement) (on file with authors).

⁹⁶ Civ. No. 98-30208-KPN (D. Mass., Jan. 10, 2000). The agreement also promises specialized services to all needy Massachusetts residents with mental retardation or developmental disabilities who currently reside in nursing facilities.

- the presence or absence of a substantial risk of substantial transfer trauma which cannot be mitigated by individual clinical intervention; and
- adequate levels of support in the community system to ensure safety.⁹⁷

The settlement provides for an independent expert to review the appropriateness and implementation of the state's community placement process, as well as individual determinations for placement and specialized services.⁹⁸ The agreement will cover a span of eleven years in which \$5 million will be spent per year to implement PASARR and improve and expand community and specialized services. Over the course of the agreement, the State will offer community, residential, and other supports appropriate to the needs of the class members. While this agreement represents a compromise on a number of issues, it provides conclusion to the lawsuit by ensuring that increasing numbers of individuals with mental retardation or other developmental disabilities will have an opportunity to live in integrated community settings rather than nursing facilities.

IV. The Growing role of anti-discrimination legislation in assuring community-based care

In recent years, the movement away from institutional care and toward home and community-based care has come to be seen as a civil rights issue. The broad integration mandates of the Americans with Disabilities Act and the Rehabilitation Act of 1973 provide strong enforcement mechanisms for furthering this movement. This part of the article will examine the integration provisions of those laws, how they apply in practice, and some of the hurdles advocates must overcome in the laws' effective enforcement.

⁹⁷ *Id.*

⁹⁸ *Id.*

A. Overview to the ADA

In the ten years since its enactment, the Americans With Disabilities Act (“ADA”)⁹⁹ has changed the landscape for people with disabilities. The ADA has given people with disabilities access to arenas of public life that were previously closed to them. Since enactment of the ADA, employers have had to re-examine old prejudices about the ability of people with disabilities to perform many types of jobs. Likewise, people with disabilities have found opportunities for advancement in occupations that were previously closed to them. All types of public accommodations, including medical offices, restaurants, retail stores, and office buildings, have had to re-think how to make their services available to all members of the public and how to remove barriers created by neglect or poor design of their programs or physical facilities.

The ADA’s five titles pertain to different arenas of opened access. Title I opens up employment opportunities and requires employers to permit reasonable accommodations in order that a person with a disability can perform a job.¹⁰⁰ Under Title II, governmental entities must open up government facilities and services to people with disabilities.¹⁰¹ Title II also requires public transportation that is accessible to people with disabilities.¹⁰² Public accommodations, including restaurants, theaters, stores, and doctors’ offices, must remove barriers and unequal treatment of people with disabilities under Title III.¹⁰³ Title IV requires telephone relay services

⁹⁹ 42 U.S.C.A. §§ 12101 *et. seq.* (1995 & West Supp. 2000)

¹⁰⁰ 42 U.S.C.A. §§ 12111-12117 (1995).

¹⁰¹ *Id.* §§ 12131-12134 (1995).

¹⁰² *Id.* §§ 12141-12165 (1995 & West Supp. 2000).

¹⁰³ *Id.* §§ 12181-12189 (1995 & West Supp. 2000).

to enable people with disabilities to communicate more effectively.¹⁰⁴ The ADA's Title V contains miscellaneous provisions including prohibitions against retaliation and coercion, abrogation of state immunity under the Eleventh Amendment, and certain exceptions to the ADA.¹⁰⁵ For purposes of this article, we will concentrate on the provisions of Title II.

Congress enacted the ADA under its power to regulate interstate commerce and apply the nondiscrimination provisions to the States under the Fourteenth Amendment.¹⁰⁶ Currently, advocates use the ADA to effect changes in discriminatory practices by both private entities and public entities, including state and local governments. Whether Congress may constitutionally apply the ADA to the States and abrogate states' immunity under the Eleventh Amendment will come before the U.S. Supreme Court in its next session.¹⁰⁷

The ADA defines disability as a physical or mental impairment that substantially limits one or more of the major life activities of an individual, and the definition includes individuals with a record of such an impairment or who are regarded as having such an impairment.¹⁰⁸ While the definition of disability applies to all titles of the ADA, Title II goes on to define a "qualified individual with a disability" as one who with or without reasonable modifications to rules, policies, or practices, or removal of barriers, meets the essential eligibility requirements

¹⁰⁴ 47 U.S.C. § 225 (1991 & West Supp. 2000).

¹⁰⁵ 42 U.S.C. §§ 12201-12213 (1995).

¹⁰⁶ U.S. CONST. Art. I, § 8, cl. 3; *Id.*, amend. XIV, § 5; 42 U.S.C.A. § 12101(b)(4) (1995).

¹⁰⁷ *See* Garrett v. Univ. of Alabama at Birmingham, Bd. of Trustees, 193 F.3d 1214 (11th Cir. 1999), cert. granted, 120 S.Ct. 1669 (U.S. Apr. 17, 2000) (No. 99-1240).

¹⁰⁸ 42 U.S.C.A. § 12102 (1995).

for the receipt of services or the participation in programs or activities provided by a public entity.¹⁰⁹ Such qualified individuals with a disability shall not, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity, or be subjected to discrimination by any such entity.¹¹⁰

Importantly, the ADA includes segregation of persons with disabilities as a form of illegal discrimination.¹¹¹ Congress made it the goal of the nation to “assure equality of opportunity, full participation, independent living, and economic self-sufficiency” for people with disabilities.¹¹² The regulations implementing these ADA provisions also require public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”¹¹³ The ADA’s prohibitions against segregation and endorsement of integration argue in favor of home and community-based service options that allow people with disabilities to leave segregated institutional settings in favor of all that life in the community has to offer.

B. The Rehabilitation Act of 1973

While the ADA tends to get much of the credit for eliminating much discrimination against people with disabilities, its predecessor, the Rehabilitation Act of 1973 (“Rehabilitation Act”), began the federal effort toward ending this discrimination. As the ADA’s applicability to

¹⁰⁹ *Id.* § 12131(2) (1995).

¹¹⁰ *Id.* § 12132 (1995).

¹¹¹ *Id.* § 12101(a)(2), (a)(5) (1995).

¹¹² *Id.* § 12101(a)(8) (1995). Discrimination is also found in “overly protective rules and policies.” *Id.* § 12101 (a)(5) (1995).

¹¹³ 28 C.F.R. § 35.130(d) (2000).

the States may become questionable, interest has grown in reviving use of the Rehabilitation Act.

Congress enacted the Rehabilitation Act to forbid discrimination against people with disabilities in federally-funded programs.¹¹⁴ In significant ways, the ADA and the Rehabilitation Act, as currently amended, parallel one another. The major difference is that the ADA applies to private and public entities of most types, while the Rehabilitation Act requires that the offending entity be a recipient of federal funding. Congress mandated that the ADA's protections be construed at least as extensively as those under Title V of the Rehabilitation Act.¹¹⁵ Except for in the employment context, the definition of an "individual with a disability" parallels that of the ADA.¹¹⁶ The Rehabilitation Act addresses discrimination in employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and public services in those activities funded by the federal government.¹¹⁷ Section 504 of the Rehabilitation Act makes it illegal for any "otherwise qualified individual with a disability," solely based on that disability to "be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by

¹¹⁴ 29 U.S.C.A. § 701 *et. seq.* (1999 & West Supp. 2000).

¹¹⁵ 42 U.S.C.A. § 12201(a) (1995).

¹¹⁶ 29 U.S.C.A. § 705(20)(A), (B) (1999 & West Supp. 2000). The Rehabilitation Act originally spoke of "handicapped persons." Under amendments to the Act, the definition and many other provisions were revised to reflect current terminology and to more closely parallel the ADA.

¹¹⁷ *Id.* § 701(a)(5) (1999).

any Executive agency or by the United States Postal Service.”¹¹⁸

The Rehabilitation Act, like the ADA, not only prohibits discrimination, but repeatedly states the Congressional policy of fully including and integrating people with disabilities into the mainstream of American society and encouraging self-sufficiency and full participation.¹¹⁹

“[A]ids, benefits, and services ... must afford handicapped persons equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement [as a nonhandicapped person], in the most integrated setting appropriate to the person’s needs.”¹²⁰

Similar to the Medicaid Act, the Rehabilitation Act was enacted under Congress’ power under the Spending Clause.¹²¹ Both Acts require the states to designate a sole state agency to administer state plans developed under the Acts,¹²² and, with limited exceptions, for the state plans to be in effect in all political subdivisions of the state.¹²³

C. Olmstead v. L.C.

In *Olmstead v. L.C. ex rel. Zimring*,¹²⁴ the Supreme Court clarified that segregating

¹¹⁸ *Id.* § 794(a) (1999 & West Supp. 2000). A “program or activity” includes “a department, agency, special purpose district, or other instrumentality of a State or of a local government.” *Id.* § 794(b)(1)(A).

¹¹⁹ *Id.* § 701(a)(3), (a)(6), (c) (1999).

¹²⁰ 45 C.F.R. § 84.4(b)(2) (2000).

¹²¹ U.S. CONST. art. I, § 8, cl. 1.

¹²² 29 U.S.C.A. § 721(a)(2) (1999 & West Supp. 2000); 42 U.S.C.A. § 1396a(a)(5) (West Supp. 2000).

¹²³ 29 U.S.C.A. § 721(a)(4) (1999 & West Supp. 2000); 42 U.S.C.A. § 1396a(a)(1) (West Supp. 2000).

¹²⁴ 527 U.S. 581 (1999) .

people with mental disabilities in an institutional setting, despite professional judgements that those individuals could live in the community and despite willingness of the individuals to live outside the institution, was discrimination in violation of the ADA. The case involves two women with mental disabilities who were voluntarily admitted to a state hospital in Georgia and confined for treatment in psychiatric units. Treatment professionals determined that both women could be cared for appropriately in community-based programs, but the women remained confined. Suit was brought under Title II of the ADA alleging that the State discriminated against the women when it failed to place them in community-based programs when the treatment professionals determined that such placement was appropriate. The suit asked that the court order the State to place the women in a community-based residential program.

The Court held that Title II of the ADA requires states to provide persons with mental disabilities with community-based treatment, rather than institutionalization, when treatment professionals have determined that community placement is appropriate, the affected individual does not oppose the placement, and the community placement can be reasonably accommodated, considering the State's resources and the needs of other persons with mental disabilities.¹²⁵ Isolation of persons with disabilities in institutions perpetuates unwarranted assumptions that these individuals are incapable or unworthy of contributing to life in the community.¹²⁶ Segregation also prevents individuals from enjoying the familial contacts and social, work, economic, educational, and cultural opportunities of everyday life.¹²⁷

¹²⁵ *Id.* at 587.

¹²⁶ *Id.* at 600 (citations omitted).

¹²⁷ *Id.* at 601.

The Court also allowed the State possible defenses to community placement. If a State can show that providing home or community-based care works a “fundamental alteration” of the State’s services for people with disabilities, the State may have a defense to integrating people with disabilities into the community. “Fundamental alteration” requires a court to look at two factors: 1) the cost factor – that is, the costs of providing community-based care; and 2) the equity factor – that is, the range of services that a State provides to people with mental disabilities and any inequitable distribution of resources away from others with disabilities.¹²⁸ We will consider these two factors below.

1. The Cost Factor

The *L.C.* court allows a State to raise the issue of cost, i.e., resources available to a State, as part of the “fundamental alteration” defense to an *L.C.*-type suit.¹²⁹ Implicit in the cost defense is the fact that most States have institutions and similar facilities for people with disabilities, and therefore certain fixed costs in their budgets for mental health care. Add to this fixed cost a legislature that may be reluctant to allocate funds to care for people with disabilities, and the cost defense could quickly hamper a discrimination challenge.

Burnam and Mathis point out the difficulties of the cost defense.¹³⁰ Most significantly, the Court was not clear how much cost was too much.¹³¹ The authors argue that “available

¹²⁸ *Id.* at 597. For discussion of the fundamental alteration defense, see Ira Burnim and Jennifer Mathis, *After Olmstead v. L.C.: Enforcing the Integration Mandate of the Americans with Disabilities Act*, 33 CLEARINGHOUSE REV. 633 (Mar.-Apr. 2000) [*Hereinafter*, “*After Olmstead*”].

¹²⁹ 527 U.S. at 606.

¹³⁰ *After Olmstead*, *supra* n. 128 at 640-644.

¹³¹ *Id.* at 640.

resources” should include not only those resources that a State has chosen to allocate to programs for people with disabilities, but also additional resources that the State may obtain through additional funding, optional programs, Medicaid waivers, and other resources.¹³² They also posit that courts should factor in the cost savings of community-based programs.¹³³

The cost defense is problematic for many reasons. First, cost would seem an odd factor in defending against the enforcement of civil rights protections.¹³⁴ Legislation to protect people with disabilities was modeled on other civil rights legislation,¹³⁵ but only the post-*Olmstead* ADA encounters the cost hurdle. Cost should be an unacceptable defense in a racial, sexual, or religious discrimination suit,¹³⁶ yet in the disability context, the Court has signaled a willingness to consider the cost of eliminating discrimination.

Second, the origins of the cost defense and the Court’s reliance on precedents regarding cost concerns are suspect.¹³⁷ When the House considered the ADA, the goal of integrating

¹³² *Id.* at 641.

¹³³ *Id.* at 643.

¹³⁴ See Lucille D. Wood, *Costs and the Right to Community-Based Treatment*, 16 YALE L. & POL’Y REV. 501 (1998). The author argues some of the differences between disability and other types of discrimination in regard to costs. She also discuss different cost approaches that the courts have taken.

¹³⁵ See *Alexander v. Choate*, 469 U.S. 287, 296 n.13 (1985)

¹³⁶ *But see* Sidney D. Watson, *Reinvigorating Title VI: Defending Health Care Discrimination – It Shouldn’t be so Easy*, 58 FORDHAM L. REV. 939 (1990).

¹³⁷ See Armen H. Merjian, *Bad Decisions Make Bad Decisions: Davis, Arline, and Improper Application of the Undue Financial Burden Defense Under the Rehabilitation Act and the Americans with Disabilities Act*, 65 BROOKLYN L. REV. 105 (1999). [Hereinafter *Merjian*]. The article argues that the cost defense is based on Court dictum which, through subsequent decisions, has been elevated to precedence.

people with disabilities into society was considered more important than cost considerations.¹³⁸

As Merjian points out, cost is only mentioned in the ADA in relation to program accessibility of existing facilities and communications.¹³⁹ Similarly, “reasonable accommodation” appears in the employment regulations, but not those provisions regulating community-based care.¹⁴⁰ Thus, the Court’s concern with cost may have little basis in law.

Third, home and community-based waivers often represent less expensive and more comprehensive alternatives to institutional care. A person with a disability provided with a home assistant to help with daily activities costs far less than the professional personnel needed to support the same person in an institutional setting. Fourth, factoring the State’s investment in institutions into the equation against home or community-based placement creates an inappropriate comparison. *L.C.* says that when treatment professionals determine that home or community-based care is appropriate and the person with disabilities agrees, the person has a right to this placement. Under these circumstances, institutional care would be an inappropriate placement. As such, the State’s costs for institutionalizing this person should be no more relevant than the State’s costs in any other programs it offers. Consideration of costs contradicts Congress’ clear intent to encourage integration of people with disabilities into the mainstream.

2. The equity factor

Under the second part of the state’s possible “fundamental alteration” defense to a

¹³⁸ See Americans with Disabilities Act of 1990: Report of the House Committee on the Judiciary, H.R. REP. No. 485, 101st Cong., pt. 3, at 50 (1990).

¹³⁹ *Merjian, supra*, n. 137 at 132-133; 42 U.S.C.A. § 12134(b) (1995); 28 C.F.R. § 39.150(2) (2000).

¹⁴⁰ *Merjian, supra* n. 137 at 119-120; 28 C.F.R. § 41.53 (2000).

discrimination suit, the Court requires consideration of the state's obligation to mete out services in an equitable manner.¹⁴¹ Comparison of the cost alone for providing community care for two individuals to the state's budget for mental health services would leave the state with no real defense.¹⁴² The Court's concern here is that if a state maintains a range of services and facilities to serve people with disabilities, including home and community-based waivers, a few individuals should not be able to leapfrog over others on waiting lists for the same service.¹⁴³

As Burnim and Mathis point out, the Court's concern with the needs of others with disabilities should not excuse a state from providing community-based placement just because there are others in the state with unmet needs.¹⁴⁴ Such an approach would always doom the plaintiffs' case. Since most, if not all, states already have some degree of unmet need, plaintiffs could only prevail against an equity defense if the state were to expend more resources to satisfy the unmet need. Requiring the state to expend more on care for people with mental disabilities to satisfy that unmet need would necessarily run afoul of the Court's concerns over the cost factor. The equity defense would become subsumed into the cost defense every time. The better approach entails having states create effective and comprehensive plans, with input from the disability advocacy community, for the noninstitutional care of people with disabilities in order to equitably distribute the state's mental health resources.

3. The *L.C.* aftermath

¹⁴¹ *L.C.*, 527 U.S. at 597.

¹⁴² *Id.* at 603-604.

¹⁴³ *Id.*

¹⁴⁴ *After Olmstead*, *supra* n. 128 at 646-647.

Despite its potential boundaries, advocates for people with disabilities generally have viewed *L.C.* as a watershed in encouraging community-based placement, when appropriate, over institutionalization. *L.C.* raises community-based care to a right, rather than a preference or a mere choice. A State that fails to consider and plan for community-based care runs the risk of being found to have discriminated against people with disabilities. *L.C.* indicates that a court might find ADA compliance if a state has a “comprehensive, effectively working plan” for providing services to people with disabilities in the most integrated settings and a waiting list that moves at a reasonable pace without a motivation to keep institutions full.¹⁴⁵

The states have not moved quickly to take advantage of this option. In light of *L.C.*, HCFA is encouraging states to incorporate community-based care into their state Medicaid plans and otherwise incorporate concerns for providing services to people with disabilities.¹⁴⁶ DHHS has also published guidance on how Medicaid can assist with transition of people with disabilities into the community.¹⁴⁷ Executive orders or legislative resolutions in seven states require those states to develop *L.C.* compliance plans by a date certain.¹⁴⁸ However, no state has

¹⁴⁵ *L.C.*, 527 U.S. at 605-06.

¹⁴⁶ See HCFA, State Medicaid Director Letter, January 14, 2000 and Olmstead Update No. 2, Questions and Answers, July 25, 2000. Both are available on the HCFA website, *supra*, n. 26.

¹⁴⁷ Olmstead Update No. 3, HCFA Update, July 25, 2000. Also available on the HCFA website, *supra*, n. 26.

¹⁴⁸ National Association of Protection and Advocacy Systems, OLMSTEAD PROGRESS REPORT: DISABILITY ADVOCATES ASSESS STATE IMPLEMENTATION AFTER ONE YEAR, July 25, 2000. Those states are Delaware, Hawaii, Illinois, Kentucky, Missouri, North Carolina, and Texas. The study is available through either the HCFA website or the NAPAS website.

yet developed a plan that meets the recommendations in the DHHS guidelines.¹⁴⁹

If and when states finally begin preparation for these plans, advocates for people with disabilities should have the opportunity to help shape the plans in ways that are effective for the needs of their clients as well as nondiscriminatory. Whether states will include advocates in the planning process remains to be seen.

The interplay between Medicaid and the ADA will also be clarified. Medicaid offers states significant federal matching assistance to offer an extensive package of mandatory and optional home care services for adults and a comprehensive scope of benefits for children. Given the Supreme Court's discussion in *L.C.*, states may be required to increase use of these Medicaid optional services and waiver programs and more aggressively to implement mandatory benefits. Moreover, in contrast to the potential cost factor limitations to obtaining community services through the ADA¹⁵⁰ the role of budgetary constraints is more settled in the Medicaid context. Congress enacted the Medicaid Act pursuant to the spending clause. As such, Congress has offered federal matching funds to states to provide medical care to the needy, but it has made that federal funding available with strings attached. Once a state elects to participate in Medicaid, it "must comply with the requirements imposed both by the Act itself and by the Secretary of Health and Human Services."¹⁵¹ Courts have repeatedly noted that "inadequate state

¹⁴⁹ *Id.*

¹⁵⁰ Justice Kennedy said that nothing about the ADA requires a state to create a community treatment program where none exists. Rather, decisions regarding the use and shifting of government funds are political decisions not within reach of the ADA. 527 U.S. at 612-13.

¹⁵¹ *Schweiker v. Gray Panthers*, 453 U.S. 34, 36-37 (1981). *See also Wilder et al. v. Virginia Hosp. Ass'n*, 496 U.S. 498, 500 (1990).

appropriations do not excuse noncompliance [with the Medicaid Act].”¹⁵²

In *Benjamin H. v. Ohl*, the state cited the ADA to argue that the court could not require it to expand the availability of community-based services through the Medicaid program. The court, however, noted that the authority for the ADA differs from the Medicaid Act.¹⁵³ Ordering relief to address Medicaid waiver waiting lists, the court put it this way:

Medicaid provides entitlements.... Budgetary constraints are no defense for the failure to provide Medicaid entitlements.... The reason is simple. States could easily renege on their part of the Medicaid bargain by simply failing to appropriate sufficient funds.¹⁵⁴

Thus, while states may be able to cite budgetary constraints to limit their accommodations to achieve integration under the ADA, budgetary constraints alone should not excuse a state from complying with the Medicaid Act.

Conclusion

Over the last thirty-five years, health care services and the funding for these services have evolved dramatically. Technology and other advancements enable individuals to live in home and community-based settings, while the Medicaid program offers a source of payments for these on-going health care needs. Unfortunately, states have been hesitant to embrace and implement the federal laws that, in some cases, require and, in others, allow for the coverage of necessary services. The states, like much of the general population, have been slow to catch up with the new possibilities and new attitudes about serving people with disabilities. This article

¹⁵² *See, e.g.* *Doe v. Chiles*, 136 F.3d. 709, 722 (11th Cir. 1998); *Alabama Nursing Home Ass’n v. Harris*, 617 F. 2d 388, 396 (5th Cir. 1980).

¹⁵³ No. 3:99-0338 (S.D.W.Va.) (June 30, 1999, Preliminary injunction transcript).

¹⁵⁴ *Benjamin H. v. Ohl*, No. 3:99-0338, slip op. at 25-26 (S.D.W.Va.) (July 15, 1999, Memorandum Opinion and Order on Preliminary Injunction).

has explained Medicaid eligibility for and coverage of these services and provided an overview to the emerging advocacy movement to enforce the Medicaid Act and anti-discrimination protections. In the coming years, this movement is sure to gain attention as it seeks to improve and expand the availability of home and community-based services for individuals who need them and integrate those individuals into the mainstream of American life.