Fact Sheet: Accessing Medicaid Home and Community-based Services

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March 2000

I. Background

Health care today is quite different from the care provided 35 years ago, when Medicaid was enacted into law. Individuals who would not have lived 35 years ago are living now. Many of these individuals are, in fact, able to live at home due to the technological and pharmaceutical advances of the last decades. Moreover, individuals who need intermediate levels of care are able to live at home, instead of being warehoused in inappropriate institutional settings.

While often less expensive than institutional care, home and community-based care can be a financial drain on families. Private insurance provides limited assistance – in terms of both the amount and depth of coverage provided and the length of time that benefits are offered. As a result, Medicaid plays a pivotal role in providing home and community-based services.

Many states have reduced institutional placements and/or closed institutions in favor of paying for services in home and community settings. At the same time, however, states are concerned that Medicaid coverage of home-based services will create a "woodworking" effect, whereby individuals who are currently being provided care by family members will "come out of the woodwork" and apply for these services through Medicaid. This concern over institutional verses home and community care is in the midst of some confusion as states grapple with how to implement the U.S. Supreme Court's *Olmstead v. L.C. ex rel. Zimring* decision. *L.C.* finds the Americans with Disabilities Act to prohibit states in their public programs from unnecessarily institutionalizing persons with disabilities. And while *L.C.* is not a Medicaid case *per se* (the plaintiffs in the case were Medicaid beneficiaries), the case does have obvious implications for state Medicaid programs.

This fact sheet discusses important Medicaid and Americans with Disabilities Act protections that are designed to ensure the availability and accessibility of home and community-based services for adults and children.[1] It provides examples from the recent cases to illustrate

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[1] The PASARR program, which also includes provisions to protection institutionalized and home-based individuals was discussed in the January 2000 fact sheet, entitled "The Pre-Admission Screening and Annual Resident Review ("PASARR") Program."

how these provisions are being enforced and, in so doing, offers strategies for advocates seeking to improve home and community-based services for their clients in light of the Medicaid Act's requirements and the recent *L.C.* decision.

II. The Legal Provisions

This section of the fact sheet focuses on three Medicaid services that, depending on the service, states either can or must provide: home and community-based waivers, Early and Periodic Screening, Diagnosis and Treatment, and home care for persons entitled to nursing facility services. This section also summarizes the ADA and the recent *L.C.* decision.

A. Home and community-based waivers

Section 1915(c) of the Social Security Act enables states to request waivers of applicable federal law in order to provide certain services to persons at home or in the community.[2] The goal of these programs is to provide individuals with a better quality of life by allowing them to live in their homes or in a community setting rather than 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.[3] In a home or community-based setting, these services may include case management, homemaker/ home health aides, personal care, adult day health, habilitation and respite care.[4]

The federal waiver programs enable states to waive certain Medicaid requirements, including statewideness, comparability, and certain income and resource rules. Through these waiver programs, states can elect to cover a limited number of individuals, offer different groups different sets of services, offer the services in only certain geographic locations, and waive deeming requirements to make sure more individuals are eligible. There are a number of different types of home and community-based waivers:

- Waivers to provide services to individuals who, but for the waiver services, would be institutionalized in a hospital, nursing facility, or intermediate care facility for the

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[2] "[I]f the State plan includes medical assistance in behalf of individuals 65 years of age or older who are patients in public institutions for mental diseases, [a State plan for medical assistance must] show that the State is making satisfactory progress toward developing and implementing a comprehensive mental health program, including provision for utilization of community mental health centers, nursing facilities, and other alternatives to care in public institutions for mental diseases. 42 U.S.C. §1396a(a)(21).

[3] 42 C.F.R. §440.180(h).

[4] 42 C.F.R. §440.180.

mentally retarded.[5]

- Waivers to provide home care services for individuals over age 65 who live in areas with a shortage of nursing facility beds and who would be institutionalized but for the provision of services.[6]

- Waivers to provide home care services for children under age five who are infected with AIDS or who are drug dependent at birth.[7]

- Waivers to provide home and community-based care to the functionally disabled elderly.[8]

To obtain and maintain these waiver programs, states must provide assurances 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) the state will evaluate a recipient's need for institutional services; (3) the state will 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; (4) under the waiver, the state will spend less per capita than without the waiver; and (5) the state will annually provide information to the Secretary of Health and Human Services (HHS) on the impact of the waiver on the type and amount of medical assistance provided and on the health and welfare of recipients. States do not have to provide these assurances for waivers to provide care for the functionally disabled elderly.[9]

There are currently 240 home and community-based waiver programs in existence. All states except Arizona have a least one such waiver program.[10] Between 1990 and 1998, the number of persons with MR/DD who received services through a home and community-based waiver program increased by more than 200,000 persons.[11]

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[5] 42 U.S.C. §1396n(c); 42 C.F.R. §441.300 et. seq., §440.180.

[6] 42 U.S.C. §1396n(d); 42 C.F.R. §441.350 et.seq., §440.181. Note that under 42 U.S.C. §1396u, community-supported living arrangements are available for developmentally disabled individuals.

[7] 42 U.S.C. §1396n(e).

[8] 42 U.S.C. §1396d(a)(22); 42 U.S.C. §1396t(l).

[9] 42 U.S.C. §1396n(c)(2).

[10] Arizona is a technical exception because its home and community-based waivers fall within its section 1115 demonstration waiver.

[11] National Conference of State Legislators, *Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators* at 5 (2000) (available

B. Early and Periodic Screening, Diagnosis and Treatment (EPSDT)

A full discussion of EPSDT is beyond the scope of this fact sheet, and only highly relevant provisions are outlined here.[12] EPSDT is a mandatory Medicaid service for children under age 21. If a problem is detected by a health care provider, then the child is entitled to EPSDT treatment. Significantly, treatment includes medical services and treatments to "correct or ameliorate" the mental or physical condition (thus not necessarily cure it).[13] Moreover, the state must include in its scope of EPSDT benefits any services that it could cover for adults, 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, transportation services, and physical and related therapies, must be covered for a child when needed to correct or ameliorate their condition.[14] Regulations implementing the EPSDT program require treatment to be initiated as the medical condition demands, but within an outside limit of six months.[15] Thus, a number of children's needs can be met through the EPSDT program even if there is not a waiver program or waiver slot open at the time.

C. Home services for persons eligible for nursing care

For most adults, home health services are optional Medicaid services that the state does not have to include in its state Medicaid plan. However, 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."[16] This oft-overlooked provision is important because it requires states to include home health services for this population even if it has not exercised the option of covering home health services for the remaining adult Medicaid population.[17]

D. The ADA and *L.C.*

The Americans with Disabilities Act (ADA) provides that no qualified individual with a

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at www.ncsl.org/programs/health/Forum/pub6683.htm).

[12] EPSDT was the subject of the March 1999 fact sheet, entitled "Early and Periodic Screening, Diagnosis and Treatment." It can also be found at www.healthlaw.org./pubs/19990323epsdtfact.html.

[13] 42 U.S.C. §1396d(r)(5).

[14] *Id.*; 42 U.S.C. §1396d(a).

[15] 42 C.F.R. §441.56(e).

[16] 42 U.S.C. §1396a(a)(10)(D).

[17] For the regulatory definition of home health services, *see* 42 C.F.R. §440.70.

disability shall be denied the benefit of services, programs or activities of a public entity or be discriminated against because of the disability.[18] In the context of institutionalization, the ADA mandates that a public entity shall administer services, programs or activities in the most integrated setting appropriate to the needs of disabled individuals.[19] This means that persons with disabilities should be able to interact with non-disabled persons to the fullest extent possible.[20] Additionally, under the ADA, public entities are required to make "reasonable modifications" to avoid "discrimination on the basis of disability" unless those modifications would "fundamentally alter the nature of the service, program or activity."[21]

In addressing the problems of access and availability to home and community-based waiver programs in Georgia, the U.S. Supreme Court recently determined in *Olmstead v. L.C. ex rel. Zimring* that states are required under the ADA to operate public programs in a non-discriminatory manner and furnish services in the most integrated setting.[22] The Court stated that unjustified isolation could be regarded as discrimination based upon disability, and it determined that states are required to provide community-based services for persons who otherwise would be entitled to institutional care when: (a) treatment professionals determine that such placement is appropriate; (b) the affected person does not oppose such treatment; and (c) placement can be reasonably accommodated, taking into account the resources available to the state and needs of others who are receiving state-supported disability services.[23] According to the Court, states are obligated under the ADA to make "reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless . . . making the modifications would fundamentally alter the nature of the service, program or activity."[24] Whether the modification would fundamentally alter the program is based upon three factors: (1) the cost of providing services to the disabled individual in the most integrated setting, (2) the state's resources, and (3) the effect the provision would have on the state's ability to meet the needs of others with disabilities.[25] The Court indicated that a state can establish compliance with Title II of the ADA if it can demonstrate that it has an effective working plan for placing qualified individuals with disabilities in less restrictive settings, and it has a waiting

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[18] 42 U.S.C. §12132.

[19] 28 C.F.R. §35.130(d).

[20] 28 C.F.R. pt. 35, App. A, p. 450.

[21] 28 C.F.R. §35.130(b)(7).

[22] 119 S.Ct. 2176 (1999).

[23] *Id.* at 2184-85.

[24] *Id.* at 2188-89. *See* 42 C.F.R. §35.130(b)(7).

[25] *Id.*

list that moves at a reasonable pace not influenced by the state's interest in keeping its institutions fully occupied.

The Department of Health and Human Services is encouraging states to develop equitable plans and to actively involve individuals with disabilities and their representatives in the design, development and implementation of a comprehensive working plan.[26] Substantively, a state's plan should develop assessment procedures to ensure that disabled individuals have an opportunity to make informed choices about the type of intermediate care they receive in addition to facilitating proper transition of qualified individuals into community-based settings. To encourage states to develop comprehensive, effective working plans in response to *L.C.*, the Robert Wood Johnson Foundation is offering states planning grants up to $100,000. To qualify, the state agency must have (a) the capacity and resources to develop a plan in collaboration with other relevant state and local agencies and consumer groups and (b) a preliminary conceptualization of what organizing vehicles the state might use for managing, organizing, delivering, and monitoring community-based services. Applications for this grant are due April 19, 2000 and the grants will be approved by early June 2000.

III. Recent Litigation

Medicaid beneficiaries' quality of life can improve remarkably with Medicaid funding of home and community-based services. But while so many waiver programs exist to allow individuals to remain in a home or community setting, they have been a source of frustration for advocates and disabled individuals in many states because of the long waiting lists for participation in the programs. States have allowed waiting lists for home and community-based services to grow long by: (1) decreasing the number of slots for waiver programs; (2) keeping a number of allocated slots unfilled; (3) failing to provide children and nursing-home eligible adults with home-based services while they are on these waiting lists; (4) failing to inform individuals of their due process rights when home and community-based services are denied or not acted upon with reasonable promptness; and (5) allowing operating facilities without adequately trained direct care workers. These activities have resulted in an increasing number of lawsuits.[27] Two of these cases, from Maine and West Virginia, are discussed here.

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[26] *HCFA*, Dear Medicaid State Director letter, January 14, 2000, pg. 3.

[27] *See also,* Roland v. Celluci, 52 F. Supp.2d 231 (D. Mass. 1999), and Chisholm v. Hood, Civ. Action No. 97-3274. *Roland* was recently settled, guaranteeing the right of all current residents of nursing facilities who can be safely supported in the community to leave nursing facilities and live in integrated community settings. In *Chisholm*, a settlement was also reached between the parties. A number of positive changes will result, including: (1) children with mental retardation and developmental disabilities will receive necessary case management services; (2) the Department of Health and Hospitals will mail notices of the availability of case management services to members of the class and will include information on available Medicaid and EPSDT services that would be helpful to individuals with mental retardation; and

A. Obtaining services for children through EPSDT

Plaintiffs in *French v. Concannon*, suing on behalf of Medicaid eligible children with severe mental impairments who needed home and community-based services, filed a complaint alleging that the state Medicaid agency failed to provide EPSDT-covered services to children and their families in a timely manner.[28] Because of this, children waited months and sometimes years for services, including case management, in-home aides, medication monitoring and mental health counseling, or otherwise were institutionalized. A settlement was reached between the parties, achieving a number of positive results, such as (1) revision of the EPSDT brochure and the EPSDT provider screening form, (2) hiring of additional case managers, (3) streamlining of the prior authorization process, (4) creation of a new provider category "behavioral health specialist," and (5) creation of a position within the Department of Mental Health to identify children needing services and to ensure that treatment is being implemented.

B. Obtaining services for children and adults through waiver programs

In West Virginia, plaintiffs filed the *Benjamin H. v. Ohl* to challenge the failure of the state to make intermediate care level services adequately available to needy beneficiaries. The situation in West Virginia was unusual. First, some years ago, the state legislature had officially declared a moratorium on any new ICF-MR/DD beds, in favor of the expansion of these services in the community. The state did, in fact, expand community offerings, in part through a Medicaid home and community-based waiver program. However, in April 1999, the state Medicaid agency abruptly changed this policy by limiting its waiver program only to "emergency" placements and submitting a waiver re-application to HHS that sought only 25 slots a year for the next five years. The result was expansion of already-existing waiting lists for home and community-based waiver placements.

Plaintiffs in the suit alleged that these waiting lists meant that ICF-level services were simply not operating in the state and alleged violations of Medicaid provisions requiring beneficiaries to be given a choice of waiver or institutional placement,[29] and to be given the right to apply for services without delay and to obtain services with reasonable promptness.[30] The

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(3) case managers will possess certain minimum qualifications, will only handle a caseload of 35 clients and will be trained on Medicaid and EPSDT services.

[28] No. 97-CV-24-B-C (D. Me. July 1998)(order of dismissal and agreement) (Clearinghouse No. 51,989).

[29] 42 U.S.C. §1396n(c).

[30] 42 U.S.C. §1396a(a)(8).

plaintiffs also alleged violations of Medicaid Act due process protections,[31] EPSDT, and the ADA.[32] The federal district court determined that the situation violated the Medicaid Act because: (1) beneficiaries must have a choice of receiving services in an institution or in the community; (2) beneficiaries must have an opportunity to apply for Medicaid without delay; (3) beneficiaries must receive services with reasonable promptness; and (4) beneficiaries must be given notice as well as an opportunity to be heard if their claims are denied or not acted upon properly.[33] In a March 15, 2000 order, the Court ordered the state to assure that waiting lists move "at a reasonable pace," defined to be initiation of services within 90 days of the date that eligibility for the services is determined.[34] The parties were able to agree to a set of due process notices and the Court also ordered that these be used. In addition, West Virginia increased the number of waiver slots that it was seeking from HHS.

Thus, while *Benjamin H.* does not directly discuss the ADA or *Olmstead v. L.C. ex rel. Zimring*, it does have notable ramifications for the state's activities in implementing the post-*L.C.* ADA. Specifically, *Benjamin H.* has defined "reasonable pace" for moving the waiting list in the context of this particular home and community based program to be within 90 days.[35] Moreover, as a case focusing on the Medicaid Act, the Court has noted the diminished role of budgetary constraints in dictating the provision of entitlement services.[36]

IV. Conclusion

The statutory protections, coupled with recent case law development, mean that advocates should focus attention on home and community-based services. In addition to working on the *L.C.* plan developments noted above, advocates can be involved in Medicaid home and community-based waiver applications and re-applications. In this role, advocates can urge states to review the services of all residents in Medicaid-funded institutions and to assess home-based needs of the population to determine whether the waiver is appropriately targeted. Advocates can provide information on client status to both the state and HHS during the waiver review process. Advocates can call on the state to hold public hearings targeted to and accessible to the

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[31] 42 U.S.C. §1396a(a)(3), 42 C.F.R. §483.420(a)(c).

[32] 42 U.S.C. §12132.

[33] Civ. Action No. 3:99-0338 (S.D. W.Va., Memorandum Opinion and Order entered July 15, 1999; Order entered March 15, 2000).

[34] Civ. Action No. 3:99-0338 (S.D. W.Va., Order entered March 15, 2000).

[35] *Id.*

[36] Civ. Action No. 3:99-0338 (S.D. W.Va., Memorandum Opinion and Order entered July 15, 1999).

disability community to obtain suggestions and comments on the waiver application. If issues are not adequately aired, advocates can work with other organizations to sponsor their own hearings.

On behalf of individual clients with disabilities, advocates should continue to file requests with their state agency for participation in the home and community-based waiver program. They should monitor their clients' situations and conduct follow-up to ensure that clients are being placed in the most appropriate setting in a timely manner.

While ensuring that states fulfill the Medicaid and *L.C.* requirements, advocates must constantly monitor states' efforts to provide home and community care and transition qualified disabled individuals into home and community settings at a reasonable pace. To the extent that the state is not satisfying either Medicaid or ADA provisions, tailored litigation, such as the cases described above, can be considered.