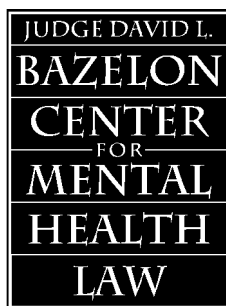


UNDER COURT ORDER

What the Community Integration Mandate
Means for People with Mental Illnesses

The Supreme Court Ruling in OLMSTEAD v. L.C.



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The Bazelon Center for Mental Health Law is a national legal-advocacy organization representing low-income adults and children with mental disabilities. We promote their full integration into the community by protecting their rights to choice and dignity and expanding their access to health and mental health services, housing, employment and income support. Our strategies include system-reform litigation, legislative and policy advocacy, public education and constituency-building. The Bazelon Center publishes materials interpreting major federal laws and regulations; staff attorneys provide training and technical assistance to lawyers, protection and advocacy agencies, consumer/survivor organizations and other advocates for low-income individuals and families.

The Bazelon Center's legal and policy staff was able to produce this paper thanks to the support of our general program provided by the John D. and Catherine T. MacArthur Foundation, the Public Welfare Foundation and many individuals, law firms and other organizations. We are also deeply grateful to the Nathan Cummings and Retirement Research Foundations for their special support of our work on behalf of L.C. and E.W. in the Supreme Court's review of their case.

To obtain additional copies of UNDER COURT ORDER or learn about other Bazelon Center publications on issues affecting children, adults and older adults with mental disabilities, send your mail address or fax number to request a publications list or visit our website: www.bazelon.org.

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FOREWORD

In June 1999, following the United States Supreme Court's decision in the case of *Olmstead v. L.C.*, a group of legal advocates who work on behalf of people with physical and mental disabilities met to discuss the implications of the ruling.

During those discussions, a consensus emerged that states should be given the opportunity to demonstrate their commitment to complying with the requirements of the Americans with Disabilities Act (ADA), as spelled out by the Supreme Court. The organizations represented in the meeting agreed that advocates should expect states to engage in a meaningful planning process that results in implementation of policies to eliminate unnecessary institutionalization (with the caveats regarding fundamental alteration that the court described). Any states that have blatantly failed to do so by July 26, 2000, the anniversary of the ADA's signing, might then appropriately be challenged for failure to comply with the ADA. By that date, states should have developed comprehensive and effective plans for eliminating—or at least minimizing—unnecessary institutionalization.

This publication is designed to:

- summarize for mental health advocates and state policymakers the import of the *L.C.* ruling with respect to mental health policy;
- describe the various mechanisms open to states to increase their resources for community based services for persons with mental illness;
- provide information and support for policies for which advocates should press within their state systems in order to improve access to community services for all individuals who are at risk of unnecessary institutionalization and for those who are currently institutionalized unnecessarily.

October 1999

UNDER COURT ORDER

What the Community Integration Mandate
of the Supreme Court Ruling in *Olmstead v. L.C.*
Means for People with Mental Illness

INTRODUCTION

In June 1999, the Supreme Court ruled, in *Olmstead v. L.C.*,¹ that it is a form of discrimination under the Americans with Disabilities Act (ADA) when states fail to find community placements for individuals with disabilities, thus causing them to remain in institutional settings. Some 76,000 individuals with serious mental illnesses are currently residents of state mental hospitals. Many thousands more live in nursing homes and others are inappropriately institutionalized in jails.

To comply with the court's ruling, states must develop comprehensive plans to end unnecessary institutionalization. They also need to implement those plans at a "reasonable pace." States failing to do so run the risk of litigation against which they would be hard-pressed to defend.

The *L.C.* decision opens up significant opportunities for expanding community mental health systems and for real and substantial policy changes in the states. As this paper explains, states must make serious efforts to find new resources in order to provide opportunities for community living for people with serious mental illnesses who do not need institutional care.

This paper summarizes the ruling and its relevance to mental health policy. It also offers information on where states might find the necessary resources to move forward with substantial expansion in new and effective community options.

L.C. represents a very significant opportunity for advocates of real and substantial improvement in services to support community integration for people with serious mental illness.

THE RULING

The *L.C.* decision plainly establishes that unnecessary segregation of people with disabilities in institutions is a form of discrimination under the ADA. Like other forms of disability discrimination, it is presumptively unlawful; the state must remedy the discrimination unless it can establish certain defenses.

The Supreme Court stated that unnecessary institutional placement perpetuates unfounded assumptions that people with disabilities are incapable or unworthy of participating in society. Secondly, the justices found, institutional confinement severely curtails opportunities for participation in everyday activities, such as family and social activities, work and educational options, economic independence and cultural enrichment. To remedy this type of discrimination, the court stated that the ADA requires states to serve individuals with disabilities in community settings rather than in segregated institutions, when this is appropriate and reasonable in light of certain factors.²

While rendering unnecessary institutionalization presumptively unlawful, the *L.C.* decision does afford states—and other potential defendants—a defense to *L.C.* claims. A state is not required to transfer an unnecessarily institutionalized person to the community if doing so would fundamentally alter the state's program. Whether serving particular individuals in a more integrated setting would require a fundamental alteration depends on:

- (1) the cost of providing community services to the individuals,
- (2) the resources available to the state, and
- (3) the state's need both to maintain a range of facilities and to distribute services in an evenhanded way.

As an example of how a state might establish a defense in a case under *L.C.*, the court said that the state could demonstrate a defense if it had:

a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

Where such a plan is in effect, the court also made clear that individuals may not jump to the top of the waiting list by bringing a lawsuit.

The ruling in *L.C.* addresses a case where two women, L.C. and E.W., had already been institutionalized and were at risk of re-institutionalization. Also affected by the ruling, however, are individuals who have not been institutionalized but are at risk of unnecessary institutionalization due to lack of community services. This is a potentially large population in any state. State plans to place qualified individuals in less restrictive settings should therefore also accommodate this at-risk group, or the state will continually find itself with a significant population unnecessarily institutionalized. It will then be out of compliance with the *L.C.* ruling.

If a state fails to adopt an effective plan, or fails to implement the plan, litigation is an option. The national disability community and its legal advocates have established July 26, 2000, the anniversary of the ADA, as the date by which states should have developed and begun implementing comprehensive and effective plans aimed at eliminating unnecessary institutionalization.

OBLIGATIONS ON STATES

While a state is not obliged to assume an “undue burden” in its pursuit of integrated services for people with serious mental illnesses, nothing in *L.C.* requires community placements to be “cost-neutral.” Indeed, the entire tenor of the decision is to the contrary. The court recognizes that needless institutionalization is a wrong that the ADA was designed to redress. It is clear that an accommodation under the ADA can be reasonable even if it imposes costs.

The court did not identify when it would be “too costly” for a state to provide services in the community. (The issue was not before the court.) Instead, the court identified relevant factors, the most significant being the resources available to the state to fund community services. While the existing community services system constitutes one available resource, the court made clear that other resources must also be counted. The *L.C.* decision anticipates the reallocation of resources to fund community placements.

In evaluating what resources are available to finance community placements, states need to look both at services that are currently funded and at how community services might be funded if the state took action to maximize its budget. These “available resources” can include resources that the state could obtain by aggressively

seeking additional funds—from the legislature, by restructuring its Medicaid program or through similar strategies.

Accordingly, in order to comply with the ADA’s integration mandate, states must:

- have effective plans for identifying institutional residents who could be in more integrated community settings;
- develop and implement these plans to ensure that all such residents are placed in the community at a “reasonable pace”;
- identify how funds necessary to implement these plans could be obtained, including potential new resources for community services; and
- take steps to obtain new resources—for example, by accessing available federal funds and requesting resources from the state legislature, so that individuals may be moved off waiting lists at a reasonable pace.

POPULATIONS AFFECTED

L.C. applies to the following groups of individuals whose impairments result from mental illness:

- long-stay patients in state psychiatric hospitals who do not need to be there;
- children in residential treatment centers who could be served in community settings if services were available;
- residents in nursing homes who can appropriately be served in the community;
- individuals who frequently cycle in and out of hospitals, as a result of a lack of community services;
- individuals institutionalized through incarceration in jail as a result of failure to provide mental health services; and
- any other individuals who are receiving services in an unnecessarily segregated setting.

To develop an effective plan, states must assess the number of people who could reside in more integrated community settings and the services these individuals require. The court indicated that a state may generally rely on the “reasonable

assessments” of its own professionals. However, there are situations in which state professionals’ decisions about the appropriateness of community services may not be reasonable. The plaintiffs in *L.C.* relied on assessments by their own treating professionals, but independent assessments are also valid.

States might begin by counting individuals in institutions who are already on waiting lists for community placement, but for whom no appropriate community referral has been identified. However, it is not uncommon for institutions to judge an individual “not ready” for the community solely because no suitable community placement is currently available. Evaluating an individual’s appropriateness for a community placement on the availability of services (or “slots”) is not a “reasonable” assessment of community readiness. The assessment must be based on the individual’s capacities and needs and on whether appropriately crafted community services can meet those needs.

CREATING THE PLAN

A state is not required to have a single plan covering the needs of all people with disabilities. A state may have different plans to address different populations, as long as the needs of all individuals who are unnecessarily institutionalized are addressed. National advocacy groups for people with disabilities have prepared a proposed Template of Key Elements to be considered when developing a comprehensive state plan. The template can be obtained from the National Association of State Protection and Advocacy Systems.³

As the state moves to meet its new obligations under *L.C.*:

- the planning process should move expeditiously, and should involve consumers, families and other advocates;
- the planning process should be accompanied by some immediate effort to expand the state’s capacity for serving people in the community;
- the plan, to be comprehensive, must address the placement needs of all individuals in the “program” at issue (such as the program for serving individuals with mental illnesses);
- the plan must be funded, or it will not be “effective” (a plan that cannot be implemented because of insufficient resources is no plan at all);

- the plan must ensure the identification of individuals who are needlessly confined and identify both the services they require and the cost of those services. Without such information, the state has no means even to evaluate, let alone assure the reasonableness of the pace by which people are moved from the institution to the community;
- the effectiveness of the plan must be evaluated in order to monitor its impact; and
- the plan must ensure quality care in the community to prevent individuals' unnecessary return to institutions and promote the community integration mandated by the ADA.

The state must also ensure that placements occur at a "reasonable pace." This may vary from state to state, but in the end it will depend on how swiftly the state is capable of moving people to the community. For this reason, the plan must include time frames for achieving its intended outcomes. One important aspect might be the development of standards for "reasonable pace" that vary by specific populations, such as children, adults with long-term care needs or adults with acute episodes.

Given that the ADA is a civil rights mandate, states must move individuals at the fastest pace that is feasible and that would not require a fundamental alteration.

PAYING FOR COMMUNITY TREATMENT

The state plan will have to address both existing and potential resources to avoid unnecessary institutionalization. Potential resources include an array of federal and state programs that can be dedicated to enabling individuals with mental illnesses to live in the community. This section summarizes these sources of funding and explains the relevant policy steps states need to take to secure these funds.

Only if a state makes every effort to obtain funds can it make an effective argument that it is in compliance with *L.C.* or that doing more is too costly and represents a fundamental alteration to the mental health program, thus threatening the state's ability to provide services in an evenhanded manner.

Recently, there has been renewed emphasis on reducing the use of long-term hospital care, especially for people with the most severe mental illnesses.⁴ Improved community treatments, such as psychiatric rehabilitation, consumer peer support and

intensive case management programs, have become more widely available. Helping to fuel this movement are continuing concerns over the relative ineffectiveness and therapeutic limitations of inpatient care, including the dependencies it creates, and the fact that community care is generally no more expensive than institutional care.

Resources to meet the expansion of community services required under *L.C.* are available to states from several sources, including:

- Medicaid’s optional services for adults—targeted case management and rehabilitation;
- Medicaid coverage for services furnished in small community residential programs of fewer than 16 beds;
- Medicaid’s array of comprehensive community services for children, mandated through the Early and Periodic Screening, Diagnosis and Treatment requirement of the law;
- Medicaid Home- and Community-Based Care Services Waiver;
- expanding Medicaid eligibility through various options and waivers of federal rules—home- and community-based service waivers (Section 1915(c) of the Social Security Act), research and demonstration waivers (Section 1115), the option to cover people who are medically needy under Medicaid, and coverage of children with serious emotional disorders under the “Katie Beckett” option (Section 1902(e)(3));
- redirected resources created by closing or significantly downsizing state mental hospitals, which can be applied toward the cost of community care;
- federal block grant funds;
- federal housing assistance programs;
- federal disability benefits under the Supplemental Security Income (SSI) program; and
- state general fund appropriations for mental health services.

The following sections explain how states can use these various programs to fund their community service systems.

Medicaid Services for Adults

Federal Medicaid law gives states several important options for covering community services for people with mental illnesses. These are:

- rehabilitation services option—covers a wide array of individualized community services;
- targeted case management—can be specifically targeted to individuals with a serious mental illness, and can be even more specifically targeted to individuals with a serious mental illness who are also being discharged from an institution or who are in a group at high risk of unnecessary institutionalization (as defined by the state);
- assertive case management, including outreach and 24-hour-a-day access to community services; and
- group homes of fewer than 16 beds (covers services but not room and board, which must be offset through other means, such as SSI benefits).

REHABILITATION SERVICES

Nearly all states already cover psychiatric rehabilitation services under the Medicaid option for “other diagnostic, screening, preventive and rehabilitative services (Section 1905(a)(13) of the Social Security Act). However, according to the latest (1998) data, 11 states have *not* elected to cover such services.⁵ The following states could secure additional resources to comply with *L.C.* by adding psychiatric rehabilitation to their state Medicaid system:

Connecticut	Kentucky
Georgia	Montana
Idaho	Nevada
Indiana	New Jersey
Iowa	Utah

States that do provide the psychiatric rehabilitation services option often do not have the services available statewide or have a restricted definition of covered activities. All states should re-examine their Medicaid psychiatric rehabilitation option, since these services are key to successful community living for people with serious mental illnesses.

TARGETED CASE MANAGEMENT SERVICES

Targeted case management is one of the most flexible options in Medicaid. It can be targeted to a specific population and does not have to be offered statewide. Federal law explicitly states that such services can be targeted to individuals who are “chronically mentally ill.” Twenty-four states do *not* target intensive case management services toward adults with mental illnesses.⁶ These states are:

Alaska	Louisiana
Arizona	Maine
Arkansas	Massachusetts
California	Nebraska
Colorado	Nevada
Connecticut	New Mexico
Delaware	Oregon
Idaho	South Carolina
Indiana	Tennessee
Iowa	Utah
Kansas	Washington
Kentucky	

These states could better meet their obligations under *L.C.* by providing targeted case management services.

ASSERTIVE CASE MANAGEMENT AND ASSERTIVE COMMUNITY TREATMENT

Intensive case management and its variations, such as assertive community treatment (ACT), are important services for individuals with serious mental illnesses, particularly in their transition from institutional placements.⁷ Intensive case management is a term encompassing a range of programs, and at its best exemplifies good community care based on person-centered planning and the individual’s full participation.

On June 7, 1999, Sally Richardson, Director of Medicaid Services for the federal Health Care Financing Administration (HCFA), issued a letter to state Medicaid Directors informing them that assertive community treatment and assertive

case management “can be supported under existing Medicaid policies and a number of states currently include ACT services as a component of their mental health service packages.” The letter further emphasizes that “consumer participation in program design and the development of operational policies is especially key in the successful implementation of ACT programs.”⁸

In support of these programs, HCFA took note of the evidence of the effectiveness of assertive case management and assertive community treatment in reducing inpatient care among high-risk individuals, making these programs particularly relevant to the population affected by *L.C.* Several studies support improvements in clinical and social outcomes as a result of intensive case management programs; these studies suggest that both assertive community treatment and assertive case management are superior to conventional case management for high-risk cases.⁹

The 33 states that have been identified as providing ACT programs at this time are shown in the table on page 30. Other states should review their Medicaid rules to ensure that intensive case management services are covered.

States with ACT Programs as of October 1999

State	Number of Programs	State	Number of Programs	State	Number of Programs
Alabama	4	Maryland	14	Rhode Island	6
Alaska	2	Massachusetts	2	South Carolina	6
Arizona	5	Michigan	86	South Dakota	2
Arkansas	1	Minnesota	1	Tennessee	4
California	3	Missouri	8	Texas	1
Connecticut	6	Montana	3	Vermont	9
Delaware	11	New Hampshire	10	Virginia	3
Florida	4	North Dakota	6	West Virginia	0
Idaho	6	Ohio	5	Wisconsin	67

State	Number of Programs	State	Number of Programs	State	Number of Programs
Illinois	7	Oklahoma	1	Wyoming	3
Indiana	7	Oregon	1	District of Columbia	1
Kentucky	1	Pennsylvania	3		

GROUP HOMES

Many of the individuals covered under *L.C.* have been confined in institutions for years. A number have quite serious disorders that may require the services and supports of a community group home. While the majority of people with mental illnesses can live in independent housing with appropriate services and supports, some will require 24-hour-a-day programming in small community residences.

Although Medicaid law specifically excludes from coverage services in psychiatric institutions for adults ages 22-64, group homes are not covered by this “Institutions for Mental Diseases” (IMD) rule. As IMDs, state mental hospitals, private psychiatric hospitals and nursing homes that serve a disproportionate number of individuals with mental illnesses are not eligible for Medicaid reimbursement for services to adults. However, at the state’s option, adults over age 64 may be covered in such facilities, and children under age 22 have access to psychiatric hospital services.

Facilities of 16 or fewer beds, such as group homes, are not considered IMDs under Medicaid law. Accordingly, while group homes are not a separately defined Medicaid service and states may not claim reimbursement for the cost of room and board, they may bill Medicaid for necessary group home staff and for other mental health services provided to group home residents.¹⁰

States can increase their resources for community services, avoiding unnecessary institutionalization, if they make these policy changes to secure Medicaid funding for services in group homes.

COVERAGE OF NEWER MEDICATIONS

An important part of the treatment for a mental illness is access to the newer “atypical” medications for psychiatric disorders. These drugs have significantly fewer and less severe side effects; they are also more effective than older antipsychotics.

On February 12, 1998, Sally Richardson sent a letter to state Medicaid directors regarding the advantages of using newer medications for persons with schizophrenia on Medicaid. On June 7, 1999, she pointed out that this directive applies equally when states contract for services under Medicaid, such as with managed care entities.

In the February 12 letter, HCFA informed states that they must respond within 24 hours to prescription requests for the newer atypical antipsychotic medications. The letter also said that states must have procedures to ensure that in emergencies at least a 72-hour supply of the requested medication is made available.

In addition to being in violation of the Medicaid statute, a state that fails to provide adequate access to the atypical medications in compliance with these federal Medicaid rules will have weakened its defense under the ADA that it is unable to provide necessary services for all individuals who are or are at risk of unnecessary institutionalization.

NURSING HOME PLACEMENTS

Under the Nursing Home Reform Act,¹¹ states are required to screen individuals being considered for nursing home placement to ensure that they need that level of intensive nursing care. Individuals who do not need such a level of care should be diverted into appropriate community placements. In many states, there are individuals residing in nursing homes who may be eligible for community care.

L.C. applies to Medicaid-financed nursing facilities just as it does to state hospitals, and states must ensure that individuals unnecessarily institutionalized in these facilities (or those at risk of such unnecessary institutionalization) are included in their planning for *L.C.* compliance.

Home- and Community-Based Services Options

Medicaid law permits states to request from the HCFA a waiver of standard Medicaid rules in order to furnish a broad array of home- and community-based services for individuals who would otherwise be in a Medicaid-covered institution.

Because of the federal rule that does not allow payment for services in an Institution for Mental Diseases (IMD), this option is extremely difficult to use for adults age 22-64 who are in hospitals or specialized nursing facilities that are considered IMDs.

However, the home- and community-based services waiver is available to states for the following populations: children through age 21 (see the child services section below), adults over age 64 in states that have elected the optional IMD service under Section 1905(a)(14), or adults of any age who reside in nursing facilities covered under Section 1905(a)(4)(A).

For adults, only Colorado has a home- and community-based waiver focusing specifically on individuals with serious mental illness. Colorado's waiver serves adults who would otherwise be in nursing home care (but not in an IMD), most of whom are over 60. Other states may include this population within the scope of a broader waiver, but anecdotal information suggests this is extremely rare.

Medicaid Services for Children

Medicaid law mandates that states provide a full array of federally authorized services to children, when medically necessary. However, many states have failed either to develop specific rules defining those services for Medicaid providers or to issue billing instructions. This makes it very difficult for children to access services to which they are entitled under federal law.

Children who are unnecessarily institutionalized or at risk of unnecessary institutionalization require a full array of intensive community services. Such services to assist the child and support the family are covered under federal law through the rehabilitation services category. In addition, these children will need access to acute hospitalization, crisis services and clinic care (including office-based therapies and medications). Few states have acted to describe this array of services in their Medicaid rules.

A recent study by the Bazelon Center of child mental health services definitions under Medicaid found a number of problems in a great many states.

- Day and visit limits on mental health services in Medicaid managed health care plans are not accompanied by any clear policies for ensuring that families whose children need more are aware of their right to access all medically necessary Medicaid services, and there are no procedures to

ensure children of easy access to medically necessary services beyond these limits.

- Definitions of covered services under fee-for-service Medicaid are very limited. Traditional hospital and outpatient medical and clinical treatment is clearly defined in nearly all states. However, intensive community-based services, essential to complying with *L.C.*, are far less well defined. The following services need to be specifically defined and listed in Medicaid rules in order to ensure that the services can be accessed and paid for. For example, the following child services are defined as Medicaid-reimbursable in some but not all states:

Day treatment	42 states
Targeted case management	42 states
Intensive home-based services	35 states
School-based day services	30 states
Independent-living skills training	30 states
Therapeutic foster care	18 states
Family support, sometimes called wraparound	18 states
Family respite	12 states
Therapeutic recreational services	9 programs
Therapeutic nurseries	7 programs
Summer camps/summer programs	5 programs
Therapeutic preschools	3 programs

- Only three states have secured home- and community-based services waivers for children with mental health care needs: Kansas, New York and Vermont. Two others, Maryland and Ohio, have applied for such waivers.

Home- and community-based care waivers, authorized under Section 1915(c) of the Medicaid statute, permit a broad and flexible array of community services to be provided to children in lieu of institutional placement. These waivers have been used extensively for individuals with developmental disabilities as a mechanism to fund deinstitutionalization and could provide substantial resources to states.

For more information on state rules under Medicaid, see the Bazelon Center publication *Making Sense of Medicaid for Children with Serious Emotional Disturbance* (see the list of resources on page 33).

Expansion of Medicaid Eligibility

One way to increase funding for community-based alternatives to institutional care is to ensure that all groups of children and adults who can be covered under Medicaid are included in the state Medicaid plan. Under federal law, states have the option of expanding significantly the number of people eligible for Medicaid. States should review all their Medicaid-eligibility policies to ensure that they are enrolling the populations most in need of community mental health services so as to avoid unnecessary institutionalization.

THE MEDICALLY NEEDY OPTION

For example, both children and adults can benefit from the optional Medicaid category for covering the medically needy. Under this option, individuals who would be eligible for Medicaid in their state except for their income and/or resources can “spend down” by incurring medical expenses that are then offset against their income until they meet a state-defined income level.

According to HCFA, in 1997 14 states did *not* cover the medically needy in their Medicaid programs. While some of these states may by now have added this group to their coverage, the rest could greatly expand the reach of Medicaid in meeting the needs of individuals diverted from unnecessary institutionalization. States without the medically needy Medicaid eligibility option in 1997 were:

Alabama	Colorado
Alaska	Delaware
Arizona	Indiana

Mississippi	Ohio
Missouri	South Carolina
Nevada	South Dakota
New Mexico	Wyoming

Several other options are available for establishing different income and resource limits for certain groups, and in some states special rules exist for individuals who receive supplemental security income (SSI) to access Medicaid.

OPTIONS TO COVER CHILDREN

For children, there a number of very significant eligibility options (some also include pregnant women). States can elect to cover:

- infants up to age 1 and pregnant women with family incomes no more than 185% of poverty;
- children between 1 and 6 in families with incomes up to 133% of poverty;
- children born after September 30, 1983 with family incomes up to 100% of poverty;
- under Section 1902(e)(3), children who would be eligible for Medicaid if they were institutionalized but who could live in the community with their families if they received home- and community-based services;
- children under the medically needy option; and
- children with family incomes up to 200% of poverty (slightly higher in some states) if the state elects to use Medicaid as its approach to providing services under the Child Health Insurance Program (CHIP).

THE CHILD HEALTH INSURANCE PROGRAM (CHIP)

CHIP offers states a very significant resource for providing health and mental health care coverage for children in low-income families who were not, at the time of enactment of CHIP, eligible for Medicaid under their state's rules. States have two choices of how to accomplish this goal: they can include CHIP children as an eligible group under Medicaid or they can create a separate health insurance program for them.¹² These are not exclusive options; states may choose to cover some CHIP children under Medicaid and offer others a health plan.

Providing CHIP coverage through Medicaid, contrasted with the limited mental health benefits available under the typical private insurance plan, can ensure children with serious mental or emotional disorders of access to a broad array of services while giving the state access to federal matching funds for these services even after the state's CHIP allotment has been fully spent. This is because all CHIP-eligible children who are covered under Medicaid have the same entitlements as any other Medicaid child. Yet only 34 states have provided Medicaid coverage for any CHIP-eligible children, and only 21 have covered all of their CHIP-eligible children under Medicaid. As of June 1999, 23 states and territories have Medicaid expansion programs, 15 have separate state-designed CHIP programs and 13 have a combination of Medicaid expansion and a state-designed program.

■ States covering all CHIP-eligible children under Medicaid are:

Alaska	Nebraska
Arkansas (plan not yet submitted, using a Medicaid waiver)	New Mexico
District of Columbia	North Dakota
Hawaii	Ohio
Idaho	Oklahoma
Indiana	Rhode Island
Iowa	South Carolina
Louisiana	South Dakota
Maryland	Tennessee
Minnesota	Virginia
Missouri	Virgin Islands
	Puerto Rico

- States that cover some CHIP-eligible children under Medicaid are:

Alabama	Maine
California	Michigan
Connecticut	New Hampshire
Florida	New Jersey
Illinois	Texas
Kentucky	West Virginia
Massachusetts	

- States that have failed to provide Medicaid coverage to CHIP-eligible children are:

Arizona	New York
Colorado	Nevada
Delaware	Oregon
Georgia	Pennsylvania
Kansas	Utah
Mississippi	Vermont
Montana	Wyoming
North Carolina	

States also have the authority to allow certain health care providers to “presumptively” enroll children in Medicaid who appear to be eligible based on their age and family income. This can be done based on the family’s declaration that its income is below the state’s Medicaid income-eligibility guidelines. The child can then be provisionally enrolled in Medicaid and begin receive services, while a full Medicaid application with the necessary information is prepared and submitted (this must be done by the end of the following month).

States that fail to cover all eligible children under Medicaid are losing the opportunity to secure federal matching funds for the home- and community-based services these children need.

Redirecting State Hospital Spending

One of the most straightforward ways to finance community services for individuals who would otherwise be needlessly institutionalized is to redirect institutional funds to community services.

Since 1955, states have been reducing the capacity of their state psychiatric institutions. However, until quite recently they accomplished this by reducing the size of the hospitals, not by closing them down. More recently, states have begun to close entire institutions, freeing up considerable state resources that can be redirected to support community living. For example, more state psychiatric hospitals were closed in the first half of the 1990s than in the 1970s and 1980s combined.¹³ Since 1990, a total of 40 such hospitals have been closed.

Recent experience in Indiana demonstrates how such an approach can produce both positive outcomes for individuals and savings for the state.¹⁴ Indiana closed a hospital that was housing individuals with serious mental illness who had a mean length of stay of over eight years. After the hospital closed, most went to some form of 24-hour care or monitoring in the community and were served by programs providing intensive levels of service. The state also provided three years of special funding to local community programs specifically to ease the transition for these individuals. This funding, redirected from hospital spending, allowed communities to meet the needs of discharges without squeezing them into existing treatment slots or adding to already overstrained community programs.

The individuals benefited from services in more integrated settings and showed positive outcomes, such as improved functioning and quality of life. Savings for the state were significant. Per-person costs went from \$68,400 for a year's hospital care to \$40,600 for those placed in the community. However, some individuals were placed in alternative institutions (such as a nursing homes, which do not represent community integration), whose costs were a little higher. As a result, the overall average cost for the year following closure was \$55,417 per person discharged. Still, this represented a saving of 19 percent of funds expended to maintain these individuals in the state hospital.

State Appropriations

Should eliminating unnecessary institutionalization require additional resources, states are not in a strong position to argue that they cannot afford to increase their own appropriations.

Community mental health services are generally no more expensive than institutional care. However, to shift a system from over-reliance on institutions to one that provides more appropriate and more effective community services requires an investment in the community services. Start-up costs, along with the need to ensure that people continue to receive care while new community options come on line, have hampered states' ability to ensure that resources follow individuals into the community. Until community services are up and running, Medicaid and other sources of reimbursement cannot be tapped. Accordingly, states may need to make a direct appropriation of their general funds for this purpose.

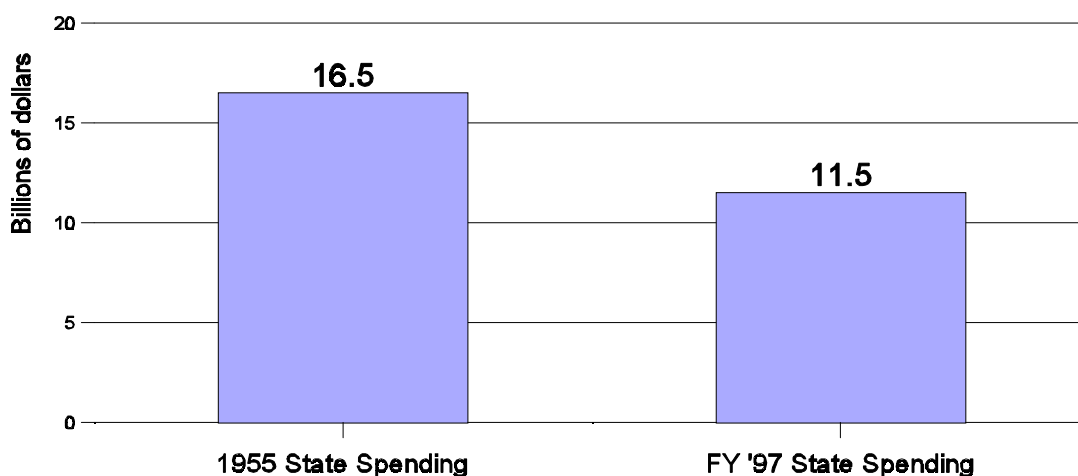
But far from meeting these obligations, states have been reducing spending on mental health services over past years. For example:

- *State only* appropriations for mental health services are significantly lower today (adjusted for inflation and growth in population) than they were in 1955, when most people with mental illness were warehoused in state institutions.¹⁵ Given that institutions provided little in the way of real treatment at that time, it would be expected that state expenditures for mental health would have grown, as new interventions and new medications were made available.
- State appropriations for mental health have lost ground, by 7 percent, between 1990 and 1997. This is true for nearly every state, as shown in the comparison of states adjusted for inflation in Table 1.
- State appropriations for mental health have been falling in relation to other state spending. Spending on mental health has grown more slowly than (1) total state-government spending, (2) state-government spending on health and welfare and (3) spending on corrections.¹⁶ During the 1990s, state mental health spending grew by 33 percent, but total state spending grew 56 percent, spending on health and welfare services grew by 50 percent and spending on corrections, by 68 percent. As a result, the proportion of all state spending allocated to mental health services fell 15 percent from

1990 to 1997 (from 2.12 percent of state spending in 1990 to 1.81 percent in 1997). This is a decline of 13 percent.¹⁷

The overall change in real purchasing power for state mental health appropriations between 1955 and 1997 is shown in the chart below. While other funds supplement these state expenditures (for example, the federal Medicaid match and the federal mental health block grant), these falling numbers represent a reduction of states' own efforts over the past 42 years.

**Comparison of State Commitment to Mental Health
1955 (adjusted for medical inflation and population) and 1997 Spending**



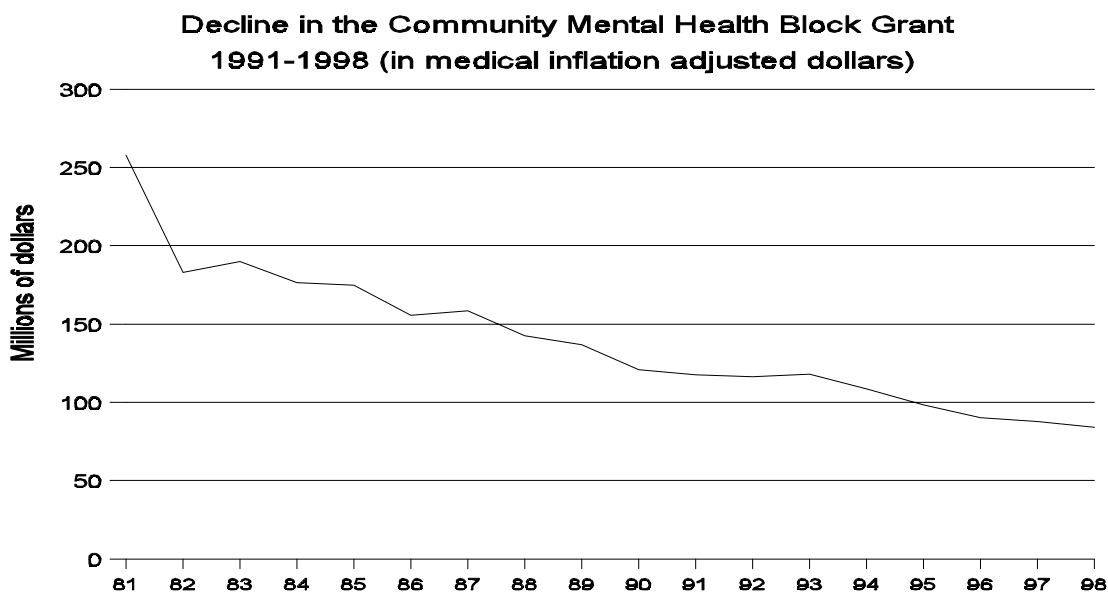
Accordingly, it would hardly be a fundamental alteration in programming for states to increase their appropriations for community mental health services in order to comply with the Supreme Court's ruling in *L.C.* As explained earlier, investment in community services has the potential to bring about long-term savings by enhancing states' ability to tap into federal dollars, making increased investment in developing community services even more important.

Federal Block Grant

The federal government, through the Supreme Court's ruling in *L.C.*, has clarified the duties of states to provide appropriate community services in lieu of institutional care for people with mental illness. It would be appropriate, at this time, for the federal government itself to increase its financial contribution to spending on

community mental health services through the major mental health services program, the Community Mental Health Services Block Grant.

Over the past 18 years, federal appropriations for the mental health block grant have fallen in real terms. In 1980, community mental health centers received \$293 million in annual federal appropriations—a small amount in overall mental health spending, but nonetheless an important proportion of the resources available for community care. However, even that modest amount looks significant today. In 1981, when the community mental health law was repealed and the mental health block grant was enacted to replace it, spending was reduced 14 percent. Following this substantial cut, the block grant has continued to drastically lose ground to inflation, as the graph below illustrates.



The federal government could, and should, do more to assist states in meeting the needs of individuals who are unnecessarily institutionalized or at risk of unnecessary institutionalization. In January 1999, the administration requested that Congress increase appropriations for the mental health block grant by \$70 million. Such an increase, while helpful, is far short of the level needed to restore lost spending power for the block grant. Advocates should urge the administration and the Congress to increase federal appropriations for the block grant to \$1 billion. This

would raise spending on mental health to a level more commensurate with spending under the substance abuse block grant (\$1.585 billion).

Housing

Perhaps the most critical need for people moving out of institutions is a decent place to live. The Supreme Court itself was concerned that the *L.C.* ruling not lead to further homelessness.

Federal programs are available to help people with very low incomes live in decent, safe and sanitary housing while paying only 30 percent of their income for rent. According to a recent report,¹⁸ people with mental illnesses are among the poorest in the nation. If they leave state institutions with no other resources beyond federal SSI disability payments, they cannot afford even modest rental housing. In most communities across the country, their rent burden would be more than 50 percent of their monthly SSI benefit. Clearly, successful transition to community living will require rental subsidies or other resources to assure decent housing.

The federal government provides two forms of assistance that states can tap into for housing for people with mental illnesses: mainstream federal public and subsidized housing programs and specialized programs, such as “elderly and disabled” housing and the Section 811 Supported Housing program.

Although access to these housing opportunities has been diminished in the 1990s by policy changes and funding cuts, the Section 8 tenant-based program is the primary mainstream resource available for people with disabilities and remains an important potential resource. Despite policies that permit subsidized housing to be designated as “elderly only” and other cutbacks in funding for housing for people with disabilities, state mental health authorities can be active partners with Public Housing Authorities and nonprofit groups to secure Section 8 vouchers to support community integration under *L.C.*

SECTION 811 SUPPORTIVE HOUSING FOR PEOPLE WITH DISABILITIES

The Section 811 Supportive Housing for People with Disabilities program is similar to, and in fact grew out of, the Section 202 program (Supportive Housing for the Elderly). Section 811 is intended to allow individuals with disabilities to live

independently by increasing the supply of rental housing with supportive services and related facilities. The program also allows the sponsor to get project rental assistance, which can cover any part of the HUD-approved operating cost of the facility that is not met from project income.

The program provides grants to nonprofit organizations to develop and construct or rehabilitate rental housing with supportive services for very low-income individuals with disabilities. Section 811 provides funds for housing for very low-income people between the ages of 18 and 62 who have disabilities, including people with physical or developmental disabilities or chronic mental illnesses and disabled families. A companion Mainstream Program awards funding for Section 8 rental vouchers and certificates to very low-income people with disabilities.

Any public housing authority (PHA) established under state law can apply for up to 100 Section 8 rental vouchers or certificates under the Mainstream Program..

COMMUNITY DEVELOPMENT BLOCK GRANT AND HOME PROGRAMS

Communities have the authority, although it is rarely exercised, to expend federal grant funds under the Community Development Block Grant (CDBG) and HOME programs to support the development of new housing and to provide rental assistance for people with disabilities. Because each community's funds are allocated through the local and state Consolidated Plan processes, it is essential that mental health departments articulate the need generated under *L.C.* by formally participating in these processes. Earlier this year, HUD Secretary Andrew Cuomo issued new instructions to HUD staff and grantees to take further steps to include people with disabilities and their advocates in the planning process.

MCKINNEY HOMELESSNESS PROGRAMS

While many individuals with mental illnesses are at imminent risk of homelessness, HUD policy currently excludes those in psychiatric hospitals longer than 30 days from the eligibility definition of "homeless individual." This means that people with longer-term hospitalizations are ineligible for any housing resources under the Stewart B. McKinney Homeless Assistance Act.¹⁹ HUD's interpretation further states that the only people who have been hospitalized for more than 30 days

who can still meet the eligibility definition of “homeless individual” are those whose planned discharge date is within the next seven days and who will be discharged to the streets or to a shelter due to lack of housing.

This policy encourages irresponsible and clinically inappropriate discharge planning. It is a significant problem that people with long-term hospital stays are being denied these options, particularly because much of the McKinney-funded housing is more integrated, less restrictive housing. Advocates continue efforts to amend this law to make these programs more accessible to people with disabilities who are leaving long-term institutional placements.

Nonetheless, McKinney Act homeless programs may still be a significant resource for individuals at risk of long-term institutionalization, but who have not just been released from a hospital stay as long as 30 days or more.

Supplemental Security Income

Individuals with disabilities resulting from a severe mental illness are eligible for federal disability benefits under the Supplemental Security Income program (SSI). Those needlessly institutionalized or at risk of needless institutionalization are very likely to be eligible for these benefits. Individuals who qualify receive a monthly federal cash allowance (currently up to \$500 per month, rising to \$512 in January 2000) and in most states automatically become eligible for Medicaid. SSI cash assistance can be used for housing costs, food and other necessities.

A state can improve the income level of individuals on SSI, and thus increase their chance of being able to afford housing, by supplementing the federal payment. Currently, only 19 states supplement the federal SSI benefit.

The following 30 states and DC do **not** offer any supplements:

Alabama	Iowa
Arkansas	Illinois
Arizona	Indiana
Colorado	Kansas
Delaware	Kentucky
Florida	Louisiana
Georgia	Massachusetts
Hawaii	Maryland

Missouri	South Carolina
Mississippi	Tennessee
Montana	Texas
North Carolina	Utah
North Dakota	Virginia
New Mexico	West Virginia
Nevada	District of Columbia
Oregon	

However, of the states that do offer supplements, some offer minimal amounts. State supplements should be at least 10 percent of the federal benefit. The following states currently provide supplements below this level:

Maine	Pennsylvania
Michigan	South Dakota
Nebraska	Washington
New Hampshire	Wyoming
New Jersey	

States can improve access to SSI for unnecessarily institutionalized people by facilitating applications for benefits as individuals are discharged from a hospital. By entering into agreements with local Social Security offices, state institutions can arrange for SSI applications to be filed prior to discharge so that benefits may begin immediately upon release from the hospital.

For those who are institutionalized through frequent hospitalizations, an SSI rule that permits continued payment of benefits for up to three months of hospitalization is very important. If a physician certifies that the individual is expected to be discharged within three months, and the individual needs the cash benefit in order to keep his/her living arrangement in the community, then SSI benefits need not be cut off when someone is hospitalized. States should ensure that all case managers in state hospitals are aware of the rules permitting continuation and assist SSI recipients in securing the necessary documentation from a physician.

For extensive information on SSI rules for children, see the Bazelon Center's *Advocate's Guide to SSI for Children*, listed in the Resource section.

CONCLUSION

L.C. requires that states act to end discrimination against people with mental illnesses or other disabilities by unnecessarily causing them to be institutionalized. To demonstrate compliance with this legal mandate, states must develop comprehensive plans to identify individuals who are or are at risk of being institutionalized unnecessarily. Such plans must address the need to fund appropriate community care. A state's plan should address how the state can increase community resources by expanding covered services under Medicaid, expanding Medicaid eligibility, redirecting state hospital spending, making full use of federal block grant resources, accessing federal programs to support housing in community settings for persons with mental illnesses and ensuring that all children and adults who are disabled by mental illnesses receive the SSI benefits to which they are entitled. Finally, states should commit an increased level of funding from their own general fund for provision of appropriate community care for individuals with mental illnesses.

People with mental disabilities have been waiting for more than 40 years for the appropriate array of community-based services they expected when states began down-sizing their large, inhumane institutions. *L.C.* does not raise a new issue; it merely clarifies the legal basis under the Americans with Disabilities Act for ensuring alternative community services, and it requires states to act now.

Consumers with mental illness, and their families and advocates, will be watching closely to see how states respond.

CHECKLIST ON STATE ACTIONS

States need to act promptly to comply with the Supreme Court's decision in *L.C.* At a minimum, a state should review its policies with respect to the following programs and sources of funds in order to secure the resources it will need to avoid unnecessary institutionalization:

- The state Medicaid plan covers targeted case management and psychiatric rehabilitation services for adults, and these two services are well defined for children entitled to them through the EPSDT mandate.
- The state Medicaid plan reimburses for intensive case management, including assertive community treatment.
- The state has, or will develop, a request for a Medicaid home -and community-based services waiver.
- Services furnished to residents of group homes are Medicaid-reimbursed.
- There are no restrictions on prescription of appropriate medications for mental illnesses, including the newer "atypical" antipsychotics, and individuals are not required first to fail on older, less effective drugs.
- The state routinely screens nursing home residents and individuals referred for nursing home placement, and provides alternative community services for those who do not need nursing home level of care.
- Medicaid-eligibility rules have been expanded so as to cover:
 - individuals who are medically needy;
 - children with serious emotional disturbance under the Katie Beckett option;
 - children ages 0-18 in families with incomes up to 100 percent of poverty;
 - children ages 0-6 in families with incomes up to 133 percent of poverty;
 - CHIP-eligible children.
- The state will reduce spending on its state facilities as the census is reduced and has a plan for resources to be transferred into community services as the hospital census declines.
- The executive branch has requested appropriate increases from the legislature for mental health spending in order to comply with *L.C.*

- The state uses federal block grant funds for individuals who might otherwise require institutionalization.
- The state has sought resources under Section 811, Supportive Housing program, to provide rental assistance for individuals who might otherwise be unnecessarily institutionalized.
- The state has appropriate discharge planning to avoid homelessness for individuals discharged from state psychiatric facilities and has sought resources for housing individuals at risk of long-term institutionalization under the McKinney Act.
- The state has policies and procedures that ensure that all eligible individuals with serious mental illnesses have assistance in applying for Supplemental Security Income or Social Security Disability Insurance benefits to which they may be entitled, including procedures for collaboration between hospitals and local Social Security offices.
- The state provides a supplement to the basic federal SSI benefit.

TABLE 1
Comparison of State Mental Health Agency Expenditures for
1990 and 1997 in Constant Dollars & Per Capita Expenditure in 1997

STATE	FY 1990 TOTAL	FY 1997 TOTAL	FY 1997 PER CAPITA
ALABAMA	78,922	72,010	47.47
ALASKA	20,236	16,534	79.12
ARIZONA	50,901	107,505	68.48
ARKANSAS	31,226	26,637	29.90
CALIFORNIA	641,373	659,188	58.10
COLORADO	56,283	77,401	56.71
CONNECTICUT	121,888	114,531	99.14
DELAWARE	18,620	18,830	73.14
D.C.	82,741	62,338	336.50
FLORIDA	247,022	225,443	43.80
GEORGIA	166,441	123,377	47.00
HAWAII	21,212	34,318	84.89
IDAHO	10,445	12,431	29.20
ILLINOIS	200,409	216,505	51.47
INDIANA	99,358	82,331	39.63
IOWA	24,134	29,170	28.93
KANSAS	44,686	53,302	58.72

STATE	FY 1990 TOTAL	FY 1997 TOTAL	FY 1997 PER CAPITA
KENTUCKY	43,624	48,505	35.32
LOUISIANA	61,125	66,602	43.38
MAINE	42,079	38,859	88.29
MARYLAND	149,224	136,156	76.00
MASSACHUSETTS	257,126	195,201	90.19
MICHIGAN	349,022	298,175	87.30
MINNESOTA	123,534	143,915	86.91
MISSISSIPPI	44,182	53,967	56.12
MISSOURI	92,428	107,349	56.38
MONTANA	11,566	28,942	93.49
NEBRASKA	23,370	22,598	38.79
NEVADA	20,487	26,301	44.60
NEW HAMPSHIRE	35,800	41,083	99.02
NEW JERSEY	225,020	196,146	69.11
NEW MEXICO	17,657	18,983	31.35
NEW YORK	1,084,293	720,178	112.57
NORTH CAROLINA	154,159	161,564	62.35
NORTH DAKOTA	13,092	10,659	47.68
OHIO	226,112	204,805	51.76
OKLAHOMA	57,551	47,188	40.53

STATE	FY 1990 TOTAL	FY 1997 TOTAL	FY 1997 PER CAPITA
OREGON	58,881	78,002	68.13
PENNSYLVANIA	344,023	287,264	67.52
RHODE ISLAND	25,745	21,898	62.99
SOUTH CAROLINA	90,780	84,050	64.04
SOUTH DAKOTA	13,376	13,986	54.39
TENNESSEE	71,626	43,488	22.91
TEXAS	196,591	264,425	38.76
UTAH	18,047	19,961	27.81
VERMONT	15,614	19,289	92.38
VIRGINIA	140,356	114,149	48.98
WASHINGTON	106,476	154,467	78.74
WEST VIRGINIA	21,670	14,817	23.02
WISCONSIN	91,222	80,190	43.81
WYOMING	7,997	7,267	43.06
AVERAGE	120,583	111,809	64.31

BAZELON CENTER RESOURCE MATERIALS

All may be purchased online at <http://store.bazon.org>.

- *Making Sense of Medicaid for Children with Serious Emotional Disturbance and Where to Turn*. 1999. \$27 plus \$4 shipping for the two-volume set.
- *The Advocate's Guide to SSI for Children*. May 1998. 760 looseleaf pages in binder; also on searchable CD-ROM. \$75 each; \$120 for both, plus \$11 shipping.
- *SSI—Help for Children with Disabilities*. 1998 Written for families, handbook explains how children can qualify for SSI under revised federal law and regulations. Available in English and Spanish. \$3 each for 1-5 copies, \$2.65 each for 6-24 copies and \$2.30 each for 25 or more.
- *What "Fair Housing" Means for People with Disabilities*. 1999. Guide for tenants, landlords and advocates compares protections of housing rights of people with mental or physical disabilities in three federal laws: the Fair Housing Act as amended in 1988, Americans with Disabilities Act and Section 504 of the Rehabilitation Act. \$4 plus \$2 for shipping; bulk discounts available.
- *Digest of Cases and Other Resources on Fair Housing Act*. 1997, updated on the Bazelon Center's website. \$9.35 plus \$4 shipping.
- *At Home: Strategies for Serving Older People with Mental Disabilities in the Community*. 1995. Excerpts in conversational form the replication of successful models and advocacy strategies for quality programs for older adults in the community. \$11.50 plus \$4 shipping.
- *Rights of Elders with Mental Disabilities to Community-Based Services*. 1996. Offers legal handles for advocates. \$9.95 plus \$4 shipping.
- *Making Child Welfare Work: How the R.C. Lawsuit Forged New Partnerships to Protect Children and Families*. July 1998. An account of system reform from the bottom up—the rededication of a bureaucracy to focus on children and families. \$12.50 plus \$4 shipping.
- *Opening Public Agency Doors*. 1995. Report of a successful model collaboration between state agencies and mental health consumers for ensuring equal access by people with mental illness to state benefits and services, in compliance with the Americans with Disabilities Act, Title II. \$8.50 plus \$4 shipping.

NOTES

1. 119 S. Ct. 2176 (1999).
2. *Id.* at 2190.
3. Contact Elizabeth Priaulx, National Association of Protection and Advocacy Systems, 900 Second Street, N.E., Suite 211, Washington, D.C. 20002. 202/408-9514 (elizabeth@napas.org).
4. Kamis-Gould, E., Hadley, T.R., Rothbard, A.B., et al: A framework for evaluating the impact of state hospital closing. *Administration and Policy in Mental Health* 1995: 22:497.
5. *Making Medicaid Work to Fund Intensive Community Services for Children with Serious Emotional Disturbance*, Bazelon Center for Mental Health Law, Washington D.C., July 1994; *Medicaid Financing for Mental Health and Substance Abuse Services for Children and Adolescents, Technical Assistance Publication Series Number 2, Financing Subseries, Volume I*, Center for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration, Rockville, Md.1993; and unpublished data from Bazelon Center for Mental Health Law.
6. *Id.*
7. The Bazelon Center strongly opposes the integration of forced treatment approaches in intensive case management programs, such as the version of Program for Assertive Community Treatment (PACT) promoted by some groups. All services should be voluntary and responsive to individual consumer choice and preferences.
8. The Bazelon Center strongly supports this emphasis by the Health Care Financing Administration on the need to involve consumers in services planning.
9. Lehman, A.F., Steinwachs, D.M., Patterns of usual care for schizophrenia: initial results from the schizophrenia patient outcomes research team (PORT) client survey. *Schizophrenia Bulletin*, 1998; 24(1):11-32.
10. See Section 1905(I) of the Social Security Act.
11. Nursing Home Reform Act, OBRA 1987 as amended. 42 U.S. §1396r(e)(7).
12. The state Children's Health Insurance Program (CHIP) is Title XX of the Social Security Act, enacted under the Balanced Budget Act of 1997, Pub. L. 105-33, 111 Stat. 251 (1997), title IV, subtitle J.
13. National Association of State Mental Health Program Directors, State Mental Health Agency Profile System Highlights: Closing and Reorganizing State Psychiatric Hospitals: 1996. NASMHPD, Alexandria, VA 1997.
14. McGrew, J. H., Wright, E. R., & Pescosolido, B. A., Closing of a state hospital: An overview and framework for a case study. *Journal of Behavioral Health Services & Research*, 26:3 August 1999, 236-245.

15. Note: State spending figure includes state and local appropriations for mental health and excludes the federal match for Medicaid, the federal mental health block grant, first- and third-party payments and other non-state sources. Lutterman, T., Hiram, A. and Poindexter, B., *Funding Sources and Expenditures of State Mental Health Agencies, Fiscal Year 1997*, National Association of State Mental Health Program Directors Research Institute, Inc. Alexandria, VA. 1999, Table 23.

16. *Id.*

17. *Id.*

18. *Priced Out in 1998*, Consortium for People with Disabilities Housing Task Force and the Technical Assistance Collaborative (1999).

19. Stewart B. McKinney Homeless Assistance Act, 42 U.S.C. § 11301.