



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



COST-EFFECTIVENESS OF HOME AND COMMUNITY-BASED LONG-TERM CARE SERVICES

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Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared by HHS's ASPE/DALTCP. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the ASPE Project Officer, Pamela Doty, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: Pamela.Doty@hhs.gov.

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This background paper was originally written in April 1999, several months before the Supreme Court's Olmstead ruling. Prior to publication in June 2000, Medicaid statistics reported in the paper were updated to reflect the most recent (1999) information available on state expenditures on long-term care, including percentage of spending on home and community-based services relative to institutional care.

Substantial contributions for this report were received from K. Charlie Lakin of the University of Minnesota, Research and Training Center on Community Living/Institute on Community Integration to the section specifically addressing services for the developmentally disabled/mentally retarded. The views expressed in this report are strictly those of the authors, and not necessarily that of the U.S. Department of Health and Human Services.

TABLE OF CONTENTS

BACKGROUND: MEDICAID LONG-TERM CARE SERVICES	1
How Much Does Medicaid Spend on Long-Term Care? How Much is for Home and Community-Based Services as Compared to Institutional Care?	1
What Options do States Have in Medicaid for Covering Home and Community-Based Services?	1
How Many States Offer Home and Community-Based Care and How Much do They Spend?	2
Medicaid 1915(c) Home and Community-Based Waiver Services.....	3
Medicaid Personal Care Services: The State Plan Option.....	3
Why Do States Elect to Use One or the Other of These Medicaid Coverage Options?	4
Waiting Lists are Permitted	5
Setting Waiver Cost Limits.....	6
Average Per Capita Spending	7
Waiver Eligibility.....	7
The “Cold Bed Rule”	8
Can Home and Community-Based Services Substitute for Nursing Home Care?.....	8
Cost-Effective Compared to What?.....	8
 RESEARCH FINDINGS ON THE COST-EFFECTIVENESS OF HOME AND COMMUNITY-BASED SERVICES COMPARED TO NURSING HOME SERVICES	 10
Studies Focusing on Alternatives to Nursing Home Care for the Elderly and Disabled	10
Studies Focusing on Alternatives to Institutional Care for the Mentally Retarded/Developmentally Disabled Population	17

Research on Alternatives to Institutionalization for the Severely and
Persistently Disabled Mentally Ill Population 21

BIBLIOGRAPHY 24

BACKGROUND: MEDICAID LONG-TERM CARE SERVICES

How Much Does Medicaid Spend on Long-Term Care? How Much is for Home and Community-Based Services as Compared to Institutional Care?

Medicaid is the major source of public funding for long-term care services. Medicaid spending on long-term care services in FY 1999 totaled \$62.4 billion. Of this amount, \$36.4 billion was spent on nursing home care. Approximately \$9.6 billion was spent on institutional services for people with mental retardation (intermediate care facilities for the mentally retarded or ICFs/MR). \$16.4 billion was spent on services provided in home and community-based settings.

Medicaid expenditures for home and community-based services include spending on Medicaid-funded home health services, personal care services, and home and community-based waiver services.

Thus, in FY 1999, expenditures for home and community-based services accounted for 26.2 percent of all Medicaid long-term care expenditures.

Although a majority of Medicaid expenditures on long-term care are for nursing homes and ICFs/MR, the picture is quite different if the focus is shifted to the number of clients served. The most recent comparative data available on numbers of Medicaid beneficiaries receiving various types of long-term care are from 1995: Medicaid home and community-based services programs for the elderly and disabled (Medicaid home health, personal care services and home and community-based services waiver programs) served a total of 1,847,369 recipients--as contrasted with 1,036,833 in nursing homes. Thus, 64 percent of Medicaid recipients who are elderly and disabled long-term care clients received some type of home and community-based services. (Ladd et al., 1999) Similarly, about the same percentage of individuals with mental retardation/developmental disabilities (MR/DD) receiving Medicaid long-term care services receive these services in home and community-based settings rather than ICFs/MR. (Lakin, personal communication, 1999).

What Options do States Have in Medicaid for Covering Home and Community-Based Services?

- **Coverage of home health services is mandatory.** Home health services encompass registered nurse, licensed rehabilitation therapist and home health aide services delivered through certified home health agencies. In FY 1999, Medicaid expenditures for home health services totaled \$2.2 billion.

- **In contrast, state coverage of other home and community-based waiver and personal care services is at the discretion of the states.**
- Under **home and community-based waivers**, states may request Health Care Financing Administration (HCFA) approval to cover non-professional services such as personal care, homemaker/chore services, home-delivered meals, adult day care, habilitation services, or any other services the state believes are alternatives to institutional care for a specified number of recipients who are considered to be "at risk" of requiring institutional care.
- Services provided under home and community-based services waivers need not be offered state-wide and they may be targeted only to certain populations (e.g., elderly and physically disabled adults, persons with MR/DD, ventilator-dependent children, persons with severe mental illness, persons with HIV/AIDs). States may have one or more waiver programs targeted at different populations.
- **Medicaid personal care services** may be provided as a optional benefit under the state plan. This benefit covers only personal care. When personal care services are provided under the plan as an optional service, as contrasted with a waiver, they must be made available state-wide and they must be provided to all Medicaid eligibles who meet need criteria.
- States may elect to use either or both of these coverage options.

How Many States Offer Home and Community-Based Care and How Much do They Spend?

All states have one or more programs that finance home and community-based services for individuals with chronic functional disabilities (Ladd et al., 1995; Ladd et al., 1999). The major source of financing for these programs is Medicaid. Other funding sources include Title III of the Older Americans Act, the Social Services Block Grant, and state appropriations.

There are, however, dramatic differences across states and by target population (aged/disabled or mentally retarded/developmentally disabled). For example, Oregon spends 45 percent of its total long-term care expenditures for the elderly and disabled on home and community-based services, whereas Tennessee spends 97 percent of its elderly and disabled long-term care expenditures on nursing homes.

Among state Medicaid long-term care programs for persons with MR/DD, 17 states spent more than two-thirds of expenditures on individuals residing in ICFs/MR, whereas in eight states more than two-thirds of Medicaid long-term care expenditures are spent on services in home and community-based settings.

Nationally, 18.2 percent of long-term care spending for the elderly and disabled is for home and community services, while 37.5 percent of long-term care expenditures for people with MR/DD services is in home and community-based settings rather than in institutions. (John Drabek, ASPE/DHHS, tabulation of HCFA data for 1997.)

Medicaid 1915(c) Home and Community-Based Waiver Services

As mentioned in the previous paragraph, all states have at least one Medicaid funded home and community-based services program. In FY 1999, home and community-based services waiver spending across the states totaled \$10.6 billion.

Nationally, three-quarters of all home and community-based waiver spending is for services for individuals with MR/DD. However, a number of states have chosen the Medicaid 1915(c) waiver option as their primary mechanism for funding home and community-based services for aged/disabled, including Oregon, Washington, Wisconsin, Colorado, and Minnesota.

Three services account for nearly four-fifths of all 1915(c) waiver expenditures: habilitation, personal care, and homemaker services. Case management is a covered service in more than two-thirds of waiver programs, but accounts for only about 6 percent of waiver expenditures. Similarly, respite care is available in 60 percent of waiver programs but accounts for less than 2 percent of expenditures. (Miller et al., 1999).

1915(c) Home and Community-Based Services waiver authority has been available since 1981. States which choose to cover these services must submit a waiver request to HCFA. HCFA approves state waiver requests after reviewing them to ensure the statutory and regulatory requirements have been met.

Medicaid Personal Care Services: The State Plan Option

Thirty states and the District of Columbia include a personal care services benefit in their Medicaid state plans. The personal care benefit is used primarily by elderly and younger physically disabled persons. In FY 1999, Medicaid spending under the personal care state plan option totaled \$3.5 billion.

Where a state elects to provide the personal care services benefit, it is available to all those enrolled in the states Medicaid program who meet the criteria for personal care. Thus, it is not possible for the personal care services benefit to have a waiting list. Aggregate annual funding is open-ended because states must serve all eligibles. However, states may set coverage limits. These coverage limits may be imposed regardless of need. In other words, states are under no obligation to provide the full amount of personal care services that a disabled Medicaid-eligible individual may require in order to have all of his or her needs for assistance met. Neither is a state

required to provide a sufficient level of personal care services to ensure that the recipient can live safely in the community. In many programs, personal care services providers who determine that coverage limits prevent them from providing the level of service which the provider considers necessary to maintain a given client safely in the community may legally refuse to provide these services to that client.

The personal care benefit has been available in Medicaid since the mid-1970s. Examples of states which have chosen to provide home and community-based services for the elderly and disabled predominantly through the personal care services benefit are New York, California, Texas, and Arkansas. These states also have smaller 1915(c) home and community-based waiver programs for the aged and disabled.

States are not required to limit coverage of personal care services to individuals who qualify for nursing home admission. There is also no statutory requirement that the personal care services benefit demonstrate cost-effectiveness or budget neutrality vis a vis spending on nursing home care. In some states, a doctor's order is sufficient to establish need for personal care services. In other states, individuals' needs for assistance with basic and/or instrumental activities of daily living (ADLs and IADLs) are assessed and coverage is authorized only if an established threshold of severity of disability has been met. Some states provide personal care to clients with one or more Activity of Daily Living (ADL) dependencies (i.e., "personal care" needs); others require two or more ADL dependencies. Still others use a standardized assessment instrument that assigns "points" to various ADL and IADL dependency measures; individuals can satisfy the coverage requirements with a variety of combinations of ADL/IADL assistance needs. Some measures of service need consider only "hands-on" assistance; others include stand-by assistance or verbal cuing.

Why Do States Elect to Use One or the Other of These Medicaid Coverage Options?

States that choose the personal care services option can simply submit a state plan amendment to elect this benefit.

States may choose the personal care services option if they wish to serve everyone in the state who meets the functional need criteria. Unlike the waivers, the personal care benefit is not restricted by Federal law to persons who are in need of an institutional level of care. Also, under the personal care benefit, states need not make calculations about cost neutrality with respect to institutional care.

States have two motives for choosing to use a home and community-based services waiver rather than the personal care services option. First, services coverage under the personal care benefit is far more restrictive than the waiver program, since it only covers personal care attendant services. The home and community-based services waiver permits coverage of a broader range of services, including services such as habilitation which are unique to the needs of individuals with MR/DD. Second, some

states fear the possibility of runaway spending under the personal care option since it is available for all who meet the qualifying criteria. The home and community-based services waiver mechanism permits states to cap aggregate as well as per capita expenditures. States are held to a "budget neutrality" standard under the waiver but states themselves have some ability to define that standard and can change it by submitting an amended waiver request to HCFA.

Waiting Lists are Permitted

- The number of clients who may be served annually in a home and community-based waiver program is limited to the number of unduplicated recipients that the state has requested and had approved by HCFA; however, there is no requirement that states serve this maximum number of recipients. For example, Florida currently has Federal approval to serve approximately 42,000 recipients annually across several different home and community-based waiver programs; however, the legislature has appropriated funds sufficient to serve only about 22,000.
- For administrative/managerial purposes, states typically determine the maximum number of clients who can be served at any given point in time so as not to exceed--as individual clients go on and off the program over the course of the year--the maximum annual number of federally approved (or state authorized) waiver recipients. This maximum "caseload" is commonly referred to as the number of available waiver "slots." Generally speaking, slots are assigned to the various case management agencies that are responsible for administering the program at the local level (that is, each agency is allocated a fixed number of "slots" and given a budget predicated on the number of "slots" the agency has been allocated). Once all slots have been filled, new applicants are placed on a waiting list. Before a new client may be admitted to the program, a "slot" must be vacated.
- In theory, a case management agency might be able to admit additional clients to the program in excess of its approved "slots"--if it could more economically provide benefits--thereby lowering average per capita spending (e.g., using volunteers to provide respite services). Otherwise, the agency would exceed its budget allocation. Because going over budget for a case management agency and its providers is viewed as taking a risk that excess services will never be reimbursed, case management and provider agencies tend to be quite reluctant to admit clients over and above the "slots" they are budgeted to serve. The state agency in charge of the waiver program might not reimburse the case management agency--and the providers it contracts with to provide the actual services--for costs in excess of its authorized budget.
- The state agency might deal with such a situation by transferring unused funds (if there are any) from another case management agency's budget elsewhere in the

state. It may also request that HCFA increase the number of people the state may serve under the waiver. Alternatively, the state agency might decide to go to the state legislature to request a supplemental budget appropriation (which the legislature might or might not be willing to grant). The state agency would also need to consider whether or not such a request for a supplemental appropriation would result in annual spending under the waiver that would exceed the home and community-based services waiver standard for "budget neutrality."

- Clients on waiting lists for these waiver programs are frequently served in state only companion programs which provide average benefit levels less than half the state's share of average Medicaid benefits in the waiver programs.

Setting Waiver Cost Limits

- Under Federal Medicaid law, average annual expenditures per capita for waiver clients may not exceed average annual Medicaid spending on institutional residents (i.e., a nursing home, ICF/MR, or acute care hospital). Thus, the annual aggregate expenditures for a home and community-based waiver program targeted on the aged/disabled population may not exceed annual per capita Medicaid costs for individuals in nursing homes (including expenditures on nursing home care, hospital care, physician services and all other Medicaid spending on such clients) times the number of waiver recipients that the state has requested and been approved by HCFA to serve.
- If a state makes expenditures under the waiver that actually exceed budget neutrality, HCFA will not necessarily take disallowances (i.e., deny reimbursement for the Federal share) for expenditures in excess of budget neutrality so long as the state takes swift corrective action--to ensure that subsequent expenditures will fall below this cap or, alternatively, to amend the state's waiver to obtain a higher budget neutrality standard. However, states believe that HCFA is legally entitled to take disallowances if it chooses and that HCFA might choose to do so. Accordingly, state officials believe that they are placing the state in a financially risky position if they allow their home and community-based waiver program expenditures to exceed the "budget neutrality" caps.

This is one reason why, within the states' own administrative and legislative processes, states may decide to set annual expenditure caps for 1915(c) waivers which are lower than the maximum spending that HCFA would recognize as satisfying the statutory requirement of "cost-effectiveness" or "budget neutrality." They do this in one or both of the following ways: (1) by establishing coverage limits which will ensure average per capita home and community-based services spending considerably less than 100 percent of average per capita institutional costs and/or (2) by appropriating fixed annual budgets for the state share of Medicaid waiver expenditures which do not provide funding sufficient to fill all

approved waiver slots. States which adopt such an approach do so in order to protect themselves from coming anywhere near a level of annual spending that would exceed "budget neutrality."

Average Per Capita Spending

In 1995, average monthly spending per capita for clients receiving services in "aged/disabled" home and community-based waivers across all states with these waivers was \$485 per month. In contrast, average monthly spending per Medicaid-covered nursing home resident was \$2,426.14. Average per capita spending under the personal care services benefit was \$589 per month. (Ladd et al., 1999). Comparable figures for average per capita spending on individuals with MR/DD under the waiver are not available.

Waiver Eligibility

- The Federal statute authorizing home and community-based services waivers refers to clients who may be served under the waiver as individuals who "but for" the waiver services would require care in nursing homes or other institutional settings. Strictly speaking, this language implies that states may only serve those clients in waiver programs whom the state is certain would enter nursing homes or other institutional care settings if the waiver services were not provided. As a practical matter, however, it is no simple matter for states to determine prospectively which clients who are eligible for Medicaid services in nursing homes would actually enter nursing homes or ICFs/MR in the absence of waiver services.
- Whether a state would actually have to pay for institutional services for all clients eligible for institutional care in the absence of home and community-based waiver services is complicated by the fact that many states have closed down ICFs/MR so that the bed supply in such facilities is steadily declining. This reached the point by June 1997 that in one-third of all states (17), the number of people with MR/DD enrolled in home and community-based waiver programs outnumbered the ICF/MR population by more than 4 to 1. Thus, it would be impossible for many MR/DD clients currently receiving services under the waiver to be served in institutional settings. An analogous situation is now developing with respect to the availability of nursing home beds for the aged and disabled in some states. In Oregon, for example, there are now more than twice as many Medicaid aged and disabled clients receiving 1915(c) waiver-funded home and community-based services as there are Medicaid-funded residents of nursing homes.

The "Cold Bed Rule"

Throughout most of the first dozen or so years of the 1915(c) waiver program, the Office of Management and Budget required HCFA to take the availability of nursing home and ICF/MR beds into account in approving state requests for home and community-based waiver slots. States were often asked to document that nursing home or ICF/MR beds equal to the number of new waiver slots being requested would be closed (or, alternatively, had been approved for construction under "Certificate of Need" requirements but would not be built). This requirement--known as the "cold bed" rule--was widely criticized for limiting the expansion of home and community services. However, early in the Clinton Administration, an agreement was reached with the National Governors' Association that HCFA would no longer take institutional bed supply into account in reviewing states' waiver requests and this change was reflected in the most recent (1994) HCFA regulations.

Can Home and Community-Based Services Substitute for Nursing Home Care?

In principle, either the personal care services benefit or the home and community-based services waiver programs could provide highly disabled Medicaid eligible individuals with an alternative to nursing home placement. However, in practice, there are limitations on the effectiveness of these programs in deterring nursing home admissions.

In an effort to ensure cost-effectiveness, states may impose per capita cost limits that make it difficult to meet some individuals' functional assistance needs unless the individual has access to supplemental informal help. This is especially likely if an individual requires 24 hour supervision and on-call assistance.

Cost-Effective Compared to What?

- The average private pay cost for a year of nursing home care is now estimated to be \$46,000 (Wiener and Stevenson, 1998). However, Medicaid does not pay private pay rates. The relationship between private pay and Medicaid rates varies from state to state; average Medicaid rates are at least 25 percent and perhaps as much as 33 percent lower than private pay rates. In addition, most Medicaid-covered nursing home residents have some personal income from Social Security, private pensions, and other sources which must be applied toward the cost of nursing home care. Typically, such private income covers from one-quarter to one-third of a Medicaid nursing home resident's monthly bill.

Per capita Medicaid spending on nursing home care averaged \$2,426 per month in 1995 (Ladd et al., 1999). This means that if the average state spent more than this amount per month on home and community-based services for an individual

client, they would likely to be spending more than they would have spent had that same individual entered a nursing home. Requiring clients to apply their private income toward the costs of home and community-based services--as would be required in the nursing home--is impractical because when an individual resides in the community all or most of those funds are needed to cover basic living expenses.

- Many states will authorize monthly personal care services or home and community-based services waiver benefit levels in individual cases which are far in excess of average per capita, monthly benefits. Some individuals in some states may receive services that cost in excess of what Medicaid would have paid had they been institutionalized. However, even in Oregon, one of the most generous states, coverage limits are such that spending for home and community-based services under the waiver will not exceed \$1,500-\$1,800 per month for any individual client. Individuals who require more services to maintain them safely in the community must enter nursing homes. Only one state--New York--routinely authorizes personal care services benefits costing \$1,500 per month or more for severely disabled clients. For a small percentage of clients in New York with very intensive service needs, the monthly cost of personal care services is well in excess of what nursing home care would cost.
- One reason why states tend to be reluctant to authorize coverage amounts that would bring average per capita spending on home and community services up to the full amount of the average per capita nursing home payment on nursing home care is that they believe that, on average, individuals who reside in the community as opposed to nursing homes may make greater use of other Medicaid-covered medical services (e.g. physician visits, emergency room visits, home health agency services) than those residing in nursing homes where the "medical model" provides for access to a certain amount of professional medical attention and this cost is included in the daily nursing home rate.
- In 1995, average monthly per capita spending under home and community-based waivers for the aged/disabled exceeded \$1,000 in only a handful of states: Hawaii-\$1,229 for 404 individuals, Maine-\$1,075 for 1,225 individuals, New York-\$1,187 for 23,021 individuals, and North Carolina-\$1,030 for 7,648 individuals. Average monthly per capita personal care services spending also exceeded \$1,000 in only a handful of states: D.C.-\$1,126 for 866 individuals, Massachusetts-\$1,725 for 5,717 individuals, New Hampshire-\$1,370 for 126 individuals, New York-\$1,055 for 125,991.

RESEARCH FINDINGS ON THE COST-EFFECTIVENESS OF HOME AND COMMUNITY-BASED SERVICES COMPARED TO NURSING HOME SERVICES

Studies Focusing on Alternatives to Nursing Home Care for the Elderly and Disabled

During the late 1970s and early 1980s, the Federal Government sponsored a series of randomized controlled experimental and quasi-experimental design demonstrations to test the cost-effectiveness of home and community-based services as a substitute for nursing home use. Most of these demonstrations were Medicaid "1115" research and demonstration projects. They served as the experimental prototypes for the Medicaid home and community-based services waiver program, although Congress enacted the 1915(c) waiver legislation in 1981, several years before the research for these demonstrations was completed and the findings were known.

The best known of these projects is the National Channeling Demonstration, which tested two different models of financing and delivering home and community-based services in six sites each (Kemper et al., 1988). However, HCFA and the National Center for Health Services Research also sponsored more than a dozen other state or region-specific demonstrations. The best known of these are the National Center for Health Services Research Day Care/Homemaker study, the South Carolina LTC demonstration, Georgia Alternative Health Services (AHS), Connecticut Triage, ACCESS in Rochester, New York, and New York's "Nursing Home Without Walls." In the early 1980s, the Health Care Financing Administration contracted with Berkeley Planning Associates to carry out a cross-cutting evaluation of 13 projects that were conducted under either Medicaid 1115 and/or Medicare 222 research and demonstration waivers (Berkeley Planning Associates, 1984). Kemper et al. (1987) provides an overview and meta-analysis of 15 federally-sponsored demonstration projects testing home and community-based alternatives to institutionalization, including the Channeling Demonstration.

The National Channeling Demonstration data were widely disseminated in the late 1980s in the form of a public use data-tape. Several researchers (Greene, 1993; Weissert, 1993) have developed sophisticated computer models which simulate alternative targeting and benefit levels and/or changes in service mix. The purpose of the modeling is to determine whether any such changes might have yielded different outcomes with regard to Channeling's cost-effectiveness.

In the mid-1980s, the Health Care Financing Administration contracted with La Jolla Management Corporation to conduct an evaluation of the early experience of the Medicaid 1915(c) waiver program. The evaluation focused on the Georgia Community

Care Services Program (which was built upon the state's experience with the Georgia Alternative Health Services Demonstration) and three waiver programs in California (the California Multipurpose Senior Services Program which targeted the elderly, the California In-Home Medical Care Waiver, which targeted ventilator-dependent children, and the California Developmentally Disabled Services Waiver, which targeted the developmentally disabled/mentally retarded.) (Clinkscale and Vertrees, 1986; Vertrees et al., 1989).

In recent years, efforts to evaluate the cost-effectiveness of home and community-based waiver programs have focused on the widely admired programs in Oregon, Washington, Wisconsin, and Colorado. These studies have employed historical trend data to project what nursing home and total aggregate long-term care costs might have been in the absence of these programs (GAO, 1994; AARP/Lewin, 1996; Weissert et al.). There is no analogous evaluation research literature on the cost-effectiveness of Medicaid personal care services programs.

A review of the research literature on the cost-effectiveness of home and community-based services alternatives to nursing home care yields the following major findings:

1. *The "woodwork" effect seriously impedes the cost-effectiveness of home and community-based services.*

Research and demonstration projects that used controlled experimental or quasi-experimental designs to evaluate the cost-effectiveness of home and community-based services under the above programs and demonstrations found that expanding access to these services did not succeed in reducing--and indeed most often increased--aggregate long-term care expenditures (that is, total long-term care spending, including spending for nursing home and home and community-based services combined).

A review of 15 separate research and demonstration studies on the cost-effectiveness of home and community-based services alternatives to nursing homes (Kemper et al., 1987) found that:

"Small reductions in nursing home costs for some [clients] are more than offset by the increased costs of providing expanded community services to others who, even without expanded services, would not enter nursing homes."

The HCFA sponsored cross-cutting evaluation of federally-sponsored demonstrations conducted under Medicaid 1115 and/or Medicare 222 research and demonstration authority (Berkeley Planning Associates, 1984) had already reached a similar conclusion. Only two of the thirteen projects studied demonstrated cost containment after the incremental cost of case management and expanded community services were considered. The authors concluded that these two projects (South Carolina CLTCP and On Lok CCODA) did not raise total costs because they targeted services on individuals who had both high levels of functional impairment

and high risk of nursing home placement. Other projects were unsuccessful in achieving cost containment because, though the individuals served were financially and functionally "eligible" for nursing home placement, they actually had a low likelihood of entering nursing homes in the absence of formal home care.

This finding which has been confirmed in numerous other reviews of individual studies (Weissert et al., 1988; Weissert and Cready, 1989; Kane et al., 1998), has become widely known as the "woodwork effect."

In one randomized design demonstration (Georgia AHS) it was determined that of every five participants who received home and community-based services as an alternative to nursing home care, two would not have actually entered nursing homes in the absence of the experimental intervention. Other demonstrations did even more poorly in prospectively identifying the applicants for home and community-based services for whom the services truly served as a deterrent to nursing home admission. For example, Vertrees et al. (1989) estimated that targeting efficiency in the Georgia 1915(c) HCBS waiver (which was based on the Georgia AHS demonstration) was greater by a factor of ten that of the California Multipurpose Senior Service Program (also a demonstration that became a 1915(c) waiver program).

2. *Narrow targeting, low average benefit levels (taking into account availability of informal supports), and a strong emphasis on services provided in alternative residential facilities can increase the chances that home and community-based services programs will achieve budget neutrality.*

Controlled experimental and quasi-experimental design evaluations of research and demonstration programs suggest that home and community-based services programs can achieve budget neutrality--but only under certain circumstances. Programs in which increased spending on home and community-based services was offset by reductions in nursing home spending shared the following attributes:

- They restrained spending on case management. (E.g., the South Carolina demonstration which achieved budget neutrality spent \$49 per client, on average, for case management as compared to \$85-\$145 per client in the other demonstrations which increased aggregate long-term care costs).
- They provided services only to clients judged to be at high risk of nursing home admission. (E.g., applicants who were already in nursing homes or who had applied for nursing home admission and had passed pre-admission screens qualifying them for nursing home placement).
- They kept benefit levels low. That is, per capita spending for home and community-based services was substantially less, on average, than per capita spending for nursing home care.

- Available services included residential care alternatives to nursing homes or ICFs/MR (e.g., "board and care" or other small group homes).
- They emphasized low cost approaches to the provision of services-- approaches that minimized administrative overhead and kept labor costs down by employing low-wage non-professionals wherever possible.

Unfortunately, abiding by these requirements in the design of home and community-based services programs results in very restrictive eligibility for these programs and also places less emphasis on "home care" (as distinct from "community-based" residential settings other than nursing homes) than many elderly and disabled persons would prefer.

Kemper et al. (1987) drew the following policy implications:

"In light of the demonstration results, the issue of eligibility criteria changes from one of targeting efficiency--for whom will cost reduction through substitution of community care for nursing home care be greatest--to one of equity--who deserves the limited community care that society can pay for."

Vertrees et al. (1989) evaluated four 1915(c) waiver programs and found that none were budget neutral. These researchers concluded that if HCBS programs must be "budget neutral" in order to be considered successful, they will fail the test. However, they also questioned the appropriateness of judging the value of HCBS by this criterion alone:

"No one requires that Medicaid hospital payments or expenditures for physician services be budget neutral. In other words, these programs [HCBS waiver programs] actually should ultimately be judged against broader social criteria in order to determine if the good that is done by them outweighs their cost by more than the good that could be obtained by spending the same amount of money in alternative ways."

Medicaid law continues to require that 1915(c) waiver program expenditures cannot exceed projections of the total expenditures for institutional services in the absence of HCBS alternatives. Wiener and Stephenson (1998) note that this requirement drives states to impose restrictions on access to HCBS. For example,

"In order to mitigate the 'woodwork effect,' states must limit use of home and community-based care to those who otherwise would be institutionalized without services. Thus, Colorado first screens all home and community-based services waiver applicants to determine whether or not they would qualify for nursing home coverage based on their severity of functional disability. Colorado then employs a second screen to assess the likelihood that a given individual will actually enter a nursing home. Only those applicants who pass both screens receive home and community services. This process is criticized by some as making it more difficult to obtain home and community-based services than to

obtain nursing home care, which reinforces the institutional bias of the delivery system."

Kane et al. (1998) take a more optimistic view:

"Undoubtedly, there is validity to the concerns about a woodwork effect, but Oregon and other states that have heavily invested in alternatives found this effect was not overwhelming and could be offset by efficiencies in [home and community-based services] HCBS programs." These authors go on to state that: "The woodwork effect could be a greater problem in states with a low level of current provision and high poverty rates, thus creating a pent-up demand for service--for example, Alabama and Georgia, but even then a carefully targeted and managed program with available and well-priced services should, in the long run, reduce overall long-term care costs while serving more people."

According to Kane et al. (1998), Oregon found that 2.6 people needed to be served in home and community settings (including alternative forms of residential care) to eliminate a single nursing home bed. In other words, Oregon officials are convinced that it is necessary for a state to stimulate a certain amount of "woodwork effect" in order for Medicaid-funded home and community services to have enough impact in terms of achieving systemic reform that it becomes possible to actually begin to reduce the availability of nursing home beds.

3. *The goal of achieving "budget neutrality" poses difficult trade-offs and often requires the imposition of unpopular limitations on access to home and community services.*

Research on cost-effectiveness of home and community services since the late 1980s has typically focused on helping program administrators fine-tune targeting and assessment criteria and determine the most appropriate benefit levels and service mix. Reconciling the inherent contradiction between targeting services to persons at greatest risk of nursing home admission, providing the right types of services, while also keeping per capita costs down is a difficult balancing act.

Weissert (1993) has estimated that in order to offset the "woodwork effect" and achieve budget neutrality, average benefit levels in home and community-based services programs should not exceed 20 percent of nursing home costs. Wiener and Stephenson (1998) note that, in Colorado, cost-effectiveness concerns have limited the average per recipient Medicaid cost of in-home and alternative care facilities to 16 percent and 14 percent respectively of the average per recipient Medicaid expenditure for nursing home care.

However, there is a significant trade-off between targeting services on the high risk population and providing home and community-based services benefits that are well under what would be spent on nursing home care if the eligible individual actually entered a nursing home. Individuals who lack strong informal supports often require high benefit levels to remain in the community. Programs that strictly limit per capita

spending to keep home and community services benefit levels low may only be able to offer adequate services to individuals who have substantial access to informal supports--and these individuals are those most likely to be able to avoid nursing home placement in the absence of home and community-based alternatives. The only effective response appears to be to take the availability of informal care into account in assessing need for publicly-funded services. Under these conditions, very high benefit levels are reserved for highly disabled persons who live alone and lack access to informal care. Clients with substantial access to informal support receive low benefit levels, even when they are severely disabled.

Some re-analyses of Channeling data (Greene et al., 1993) suggest that home and community services might have proved to be a cost-effective substitute for nursing home care if the service mix had emphasized home-delivered skilled nursing services rather than personal care for those most at risk of nursing home admission. Medicaid recipients of 1915(c) waiver services may also receive additional skilled services via the Medicaid funded home health services benefit. These Medicaid home health services must be included in a state's calculations of cost-effectiveness for 1915(c) waiver services. However, if elderly and disabled waiver clients also access Medicare-financed home health benefits (most Medicaid eligible elderly are also eligible for Medicare but most younger disabled are only eligible for Medicaid), the cost of these services is not included in 1915(c) waiver cost-effectiveness calculations.

4. *Recent research is leading policymakers more and more in the direction of emphasizing home and community services in residential care alternatives to nursing homes such as adult foster care homes, assisted living facilities, and other board and care settings.*

Some recent studies based on historical trend analysis suggest that, by investing in home and community-based services, certain states (Oregon, Washington, Colorado) have avoided building nursing home beds that otherwise would have been built. (GAO, 1994; AARP/Lewin, 1996). In several of these states, the nursing home beds which projections indicate would have been built in the absence of home and community services were replaced by beds in other residential care facilities including assisted living, adult foster care, and other board and care facilities. For example, in Oregon, approximately one-third of home and community-based services clients are served in alternative residential facilities (i.e., adult foster homes, assisted living facilities or other board and care settings).

Use of alternative residential care settings can result in Medicaid costs savings for three reasons: (1) Alternative residential facilities charge less than nursing homes because they provide fewer medical services, (2) spend-down to Medicaid by private payers is slowed because per diem costs are lower, and (3) Medicaid is not responsible for paying the room and board portion of daily costs in these alternative residential settings, whereas Medicaid must pay these costs in nursing homes. To the extent that Medicaid savings accrue primarily from covering room and board

costs in alternative residential savings via other payment sources (mainly SSI cash assistance payments which are all but eliminated when eligible individuals enter nursing homes), use of residential alternatives represents a cost shift rather than a true cost savings.

Lakin et al. (1998) reports that the number of persons with mental retardation or other developmental disabilities in nursing homes continues to decrease slowly. Individuals with MR/DD in nursing homes make up only 6.8 percent of all persons with these conditions who receive Medicaid long-term care services including home and community-based services, ICF/MR or nursing home care.

5. *Home and community services provided in a Medicaid client's own or a relative's home may reduce nursing home use, when services are provided in the context of a managed long-term care system.*

The nation's first statewide capitated long-term care Medicaid program--the Arizona Long-Term Care System (ALTCS) appears to have operated cost-effectively while offering an expanded home care option (Weissert et al., 1997). Because the ALTCS was implemented statewide, an evaluation could not be conducted using a within-state control or comparison group. Accordingly, the evaluators developed a sophisticated statistical model to simulate estimated costs in the absence of home and community-based services. Coefficients for institutionalization risk factors were estimated in a logistic regression model developed using national data. These were applied to characteristics of Arizona clients. A similar methodology was used to estimate lengths of nursing home stays. Lengths of stay by the ALTCS' nursing home users were regressed on their characteristics using an event history analysis model. Coefficients for these characteristics from the regression analysis were then applied to HCB services clients to estimate how long their nursing home stays would have lasted, had they been institutionalized. The results suggested that home care did substitute for some nursing home use that would otherwise have occurred because total observed days of nursing home care among ALTCS clients were less than the estimated days of nursing home use predicted by the model. The authors observed:

"These findings should be very encouraging for advocates of home care. With its structural features, the ALTCS program appears to have finally been able to encourage actual substitution of HCB services for nursing facility care. The most important features include a capitated program contractor with overall responsibility for costs of both nursing facility and home care; a limit on how much the program contractors could spend, set at an average for all patients; a competitively bid price; and incentives to spend less rather than more for care. These features appear to have achieved what previous fee-for-service home care efforts failed to achieve: low-cost home care and cost-effective substitution of home care for nursing home care."

However, because Arizona is such an unusual state (the only state that never implemented a traditional Medicaid program), the authors raised a number of

questions about whether the findings from Arizona would hold up if the same approach were tried elsewhere. They recommend that other states experiment cautiously with the Arizona approach:

"Preferably, states would try these features out in a few counties at a time to permit comparison of program effects on case mix of nursing home clients, nursing home occupancy rates, services used, client outcomes, and costs per poor and near-poor resident and per enrollee. The dramatic savings seen in Arizona certainly may not be realized in states with more mature Medicaid programs, but at least the incentives for inefficiency built into traditional fee-for-service home care arrangements would be replaced by a system with fewer perverse incentives. The ALTCS approach deserves to be tried out and studied elsewhere."

6. *It is difficult-indeed it is virtually impossible-to design and conduct research that truly measures cost-effectiveness as distinct from "cost-shifting" from one program to another, from state to Federal funds, and from formal to informal care.*

Cost-effectiveness of home and community-based services is almost always measured in terms of Medicaid expenditures only. However, from the earliest studies (ASPE, 1981), analysts have repeatedly observed that, in a broader conceptual framework, "cost-effectiveness" estimates would also consider the impact on other public programs such as Medicare, SSI, and Food Stamps. These studies have not been done because it is too difficult and costly to obtain the necessary data. Some analysts also insist that research on the cost-effectiveness of alternatives to institutionalization ought to take into account the role of informal caregivers in subsidizing the costs of services in "at home" settings. That is, a true comparison of costs on either side of the home and community services/nursing home ledger should assign a dollar value to the hours of unpaid care provided by informal caregivers.

Studies Focusing on Alternatives to Institutional (ICF/MR) Care for the Mentally Retarded/Developmentally Disabled Population

The Federal Government has shown considerably less active interest in evaluating the relative cost-effectiveness of home and community services versus institutional services (ICF/MR) for persons with MR/DD despite the fact that three-quarters of home and community-based services recipients are individuals with MR/DD. The reasons for the limited interest is not wholly clear, but may be influenced by the commitment of most states to dramatically reduce institutionalization of persons with MR/DD, often under court order, irrespective of "cost-effectiveness" considerations. Related to this movement toward reducing the use of institutional services, which nearly halved state institution populations between 1985 and 1997 (-48.8 percent), came institutional expenditures that were highly inflated by the resulting inefficiencies (expenditures doubled between 1987 and 1997). As a result, the cost-effectiveness

standard of being less expensive than state institutions, which dominate ICF/MR expenditures, was a dubious standard at best. Still there has been some research that has attempted to control for similar "baskets" of comparable services in institutional and community services. These studies that have also attempted to establish controls on the characteristics of service users have generally found expenditures for the recipients of community services to average between 75 percent and 95 percent of the expenditures for persons in institutional settings (Cambell and Heal, 1995; Greenberg et al., 1985; Knobbe et al., 1995; Schalock and Fredericks, 1990).

Because of the commitment to depopulate larger institutions, the relevant cost-effectiveness comparisons between ICF/MR and home and community-based services for persons with MR/DD are obtained by focusing on "community" ICF/MR (4-15 residents) and home and community-based services. Community ICFs/MR house a relatively small, but growing, portion of the total number of ICF/MR residents (35.6 percent) and an even smaller proportion (16.8 percent) of the combined community ICF/MR and home and community-based services recipients. But community ICFs/MR reflect the only arguably comparable alternative to home and community-based services for persons with MR/DD.

There have been only a limited number of studies that have directly compared home and community-based services and community ICF/MR costs and effects for comparable services and comparable populations. One such study was conducted in Minnesota for the Minnesota legislature and later published (Stancliffe and Lakin, 1998). In that study, 187 persons who began in state institutions were tracked over a four year follow-up period. The study included 71 persons who remained in state institutions, 42 persons who moved to the community with home and community-based services, and 74 persons who moved to community ICFs/MR. Although no statistical differences were evident in the three groups in demographic, diagnostic, functional or behavioral characteristics, analysis of co-variance was used to further control their comparability. The results of the study showed community ICFs/MR (versus home and community-based services) to have 15 percent higher expenditures when characteristics of residents were controlled (\$199.75 per day versus \$174.36). No statistically significant outcomes differences were noted among community ICF/MR and home and community-based services recipients on a range of community integration, social relationship and consumer choice variables.

A study by Conroy (1996) compared the cost-effectiveness of community ICFs/MR and alternative community living arrangements financed by home and community-based services in Pennsylvania. This study employed matched samples of 51 persons each from community ICFs/MR and in community-based living arrangements, matched on aged, gender, and adaptive and challenging behavior index scores. Thirty-five outcome measures were employed in the study, including measures in the areas of behavioral progress, choice-making, community integration, quality of home environment, health and health care indicators, and life safety. None of the 35 outcomes favored the ICFs/MR, while 10 favored the community living arrangements. In contrast to the Minnesota study which found lower cost, but not significantly different

outcomes for the home and community-based services, this study found better outcomes for the home and community-based financed services but no adjusted per capita cost differences (\$66,529 for the ICFs/MR and \$64,370 for the home and community-based services groups respectively).

Finally, there have been efforts to examine whether, on a national level, increased funding of home and community-based services resulted in reductions in ICF/MR use (Lakin, 1998). The so-called "woodwork effect" may be most pronounced for persons with MR/DD, although it must be noted that the "woodwork effect" is a very simplistic notion in light of the complex social, political and administrative factors involved.

First, the "fact" of the woodwork effect: In June 1982, the end of the first state fiscal year in which states had access to both the ICF/MR program and home and community-based services alternative, there were 140,684 persons receiving ICF/MR services and 1,381 home and community services recipients with MR/DD. Fifteen years later, in June 1997, there were 126,697 persons receiving ICF/MR services and 223,164 persons with MR/DD receiving home and community-based services. The years in between show a remarkably stable number of ICF/MR residents and a steadily growing home and community services program, until repeal of the "cold bed" standard, at which time home and community-based services growth has been dramatic. Between 1982 and 1992, the home and community-based services program grew at an average of 6,100 recipients per year and between 1984 and 1992, the average annual growth in recipients was slightly less than 17 percent per year. With reduction of the "cold bed" scrutiny between 1992 and 1997, home and community-based services grew at an annual growth rate of 29 percent. Relatedly, although ICF/MR expenditures remained substantially greater than home and community-based services expenditures (\$9.996 billion versus \$5.965 billion in FY 97), ICF/MR expenditures grew by only \$1.1 billion (12 percent) between 1992 and 1997 (albeit with decreasing total recipients), while home and community-based services expenditures grew by \$4.3 billion (260 percent). (Prouty and Lakin, 1998.)

In part, this growth may reflect a "woodwork effect." About two-thirds of all ICF/MR services in 1997 were provided in large institutions (16 or more residents). These are indisputably undesirable services for the vast majority of persons with developmental disabilities. Many if not most families would endure substantial hardship to avoid having their children or other relatives with MR/DD reside in such facilities. Indeed, as described above, although the total size of the ICF/MR program decreased by only slightly since 1982 (0.99 percent), the number of residents in large ICFs/MR decreased by 38 percent (from 130,970 to 81,553), while the number of residents in small ICFs/MR residents increased by 365 percent (from 9,714 to 45,144). Growth of residents in the small, community ICFs/MR growth would have been even greater if New York, Massachusetts and other states had not "decertified" hundreds of small community ICFs/MR and begun to finance their services under their home and community-based services programs. Clearly, the movement toward community-based

long-term care options and the ability to finance such options under Medicaid has contributed greatly to the demand for Medicaid long-term care services.

It should be recognized, however, that much of the growth in Medicaid financed community services involves state decisions to incorporate previously state financed services under Medicaid. States efforts to do so, and their ability to leverage budgets by shifting existing state financed services into Medicaid where the Federal Government shares 50 percent or more of the costs has contributed to rapidly expanded access to services for persons with developmental disabilities. For example, between 1993 and 1997, the numbers of people with developmental disabilities receiving out-of-home residential services grew from 291,855 to 342,244 (Prouty and Lakin, 1998).

Two main conclusions can be drawn from this research on expansion of home and community-based services for individuals with MR/DD.

1. *In contrast to long-term care services systems for the elderly and disabled, state MR/DD systems have evolved far beyond the traditional "cost-effective alternatives to institutional care" paradigm.*

In the service system for persons with MR/DD, a totally different perspective is evident. States are moving toward a community service system in which Medicaid is used efficiently to cost-share service expenditures. At the same time, states have had to develop criteria for setting budget limits, other than the criterion of serving persons "at risk" of institutional admission. In MR/DD systems there are substantial waiting lists for community services (estimated at 83,000 people waiting for residential services in 1997). States do not make those desiring services demonstrate or contend that they will otherwise go into institutions, the states are on record as desiring that people are spared that debilitating experience. Instead states are faced with creating priorities for people waiting community services, based on factors such as immediacy of need (crisis), severity of disability, length of wait, and so forth.

2. *Despite the expansion of home and community services, state MR/DD systems continue to rely heavily on residential care settings (including certified ICFs/MR), but they have created systems in which both the character and cost of residential services have been dramatically altered. Thus, the emphasis is now on small facilities rather than large "institutional" ones. At the same time, availability of "at home" services has made it possible for most children with MR/DD to remain with their parents so that most persons with MR/DD in residential settings are adults.*

Instead of relying predominantly on very large residential care settings, most clients in residential care now live in settings with no more than 16 beds. These smaller facilities (some of which are certified ICFs/MR others of which are non-certified community facilities) are more "cost-effective" providers of residential care than the

large institutions. In addition, funding for "at home" services has fundamentally changed the age profile of persons with MR/DD residing in residential care.

It is worth noting that the proportion of the total U.S. population receiving out-of-home residential services for persons with MR/DD in 1997 (126.2 per 100,000) is not appreciably different than the number in 1967 (130.4 per 100,000) or 1977 (118.8 per 100,000). What has changed dramatically is the percentage of children and youth in out-of-home residential placements. In 1977, there were an estimated 91,180 children and youth (0-21 years) with MR/DD in out of home residential settings. This was 36.8 percent of all 247,780 persons with MR/DD receiving residential care. In 1997, children and youth with MR/DD in out-of-home residential services numbered an estimated 24,299, only 7.1 percent of all 342,244 persons receiving out-of-home residential services. This may be attributable in part to the estimated 61,935 persons receiving services while living in their family home (most of whom are presumed to be children). It is also true that the effects of home and community-based services in realizing such outcomes cannot be separated from the effects of special education entitlement in one's local schools, SSI for poor families (including SSI payments specifically for very severely disabled children), state family subsidies, and other social financial, and psychological supports that have been made available to families with members with MR/DD.

Research on Alternatives to Institutionalization for the Severely and Persistently Disabled Mentally Ill Population

The research literature on home and community-based services versus mental hospital treatment for the severely and persistently disabled mentally ill is quite different in focus from the studies reviewed above on home and community-based services for the elderly and disabled and for the individuals with MR/DD. The most important difference is that the studies on the mentally ill population are primarily concerned with assessing the efficacy of alternative treatments and treatment settings in improving the functioning of the severely and persistently mentally ill, in alleviating symptoms of severe mental illness, and in reducing the frequency and severity of certain highly undesirable behaviors associated with mental illness (in particular, behaviors on the part of the mentally ill individual that are judged to pose a threat to his or her safety or to the safety of others). Cost-effectiveness is always addressed in the context of comparative treatment efficacy. Current research on treatment alternatives for the severely and persistently mentally ill is also informed by the lessons that many researchers draw from several decades of experience with "deinstitutionalization." (That is, the concerted effort which began after World War II to avoid long-term institutional placements in mental hospitals and to return long-term residents of state mental hospitals to the community or to place them in alternative residential settings).

Hargreaves and Shumway (1989) observe that: "The legacy of deinstitutionalization hangs heavily over services efficacy research. ...Our understanding of the causes and treatment of the serious mental illnesses is improving.

A sense of urgency has arisen about providing better care for this core group of the mentally ill, not because they share a common etiology or respond to similar treatments, but because as a group they are the most ill, the least able to support themselves or pay for their care, and the most likely to become a public burden."

These same authors found in a review of the services efficacy literature on alternative treatments for serious mental illness that: "The studies of alternatives to hospital treatment showed good consistency in their results. This is especially remarkable because individual studies are flawed in a number of respects ... and the studies examined a wide variety of treatments in different settings with disparate patient groups. One may conclude that caring for severely ill psychiatric patients in ways that avoid or shorten traditional hospital treatment is, on average, at least equally effective and may be more effective than standard use of hospital care. Well organized services using alternatives to hospitalization can cost less, sometimes much less, without incurring offsetting social or private costs, and may provide greater improvement in symptoms or social functioning."

The authors go on to state some caveats, however: "Although this relatively global question is coming to some closure, it represents a simplistic concept of community services that focuses too specifically on crises leading to hospital admission. Also, few researchers have compared different alternatives to hospital admission or studied community settings in which particular mixes of strategies may be most cost-effective."

Additional caveats concern the need for and the difficulty of providing for sustained community treatment over long periods of time: "Experience has suggested that the availability of community treatment programs is not sufficient, in and of itself, to ensure sustained adjustment of the severely and persistently disabled. For this reason continuity of care ... has become a common goal of services to the mentally ill. The concept of continuity includes continuing treatment that is (a) comprehensive, offering access to a variety of services; (b) flexible, consistently responsive to clients' changing needs in scope, intensity, and location of services; and (c) is characterized by ongoing communication and interaction among different treatment providers." Case management has been promoted as the best way to increase continuity of care. However the authors note that a review of studies of case management yields mixed results which suggest that the efficacy of case management may depend greatly on variations--which are poorly understood and documented--with respect to how case management is actually carried out and the service system environment in which case management takes place." The authors also stress the need for broader social services such as housing, welfare application assistance, transportation, and recreation services as the context in which long-term treatment of severe mental illness in the community is most likely to have positive outcomes and to be successful in avoiding further hospitalizations.

A more recent literature review of different models of community care involving case management (Mueser et al., 1998) suggests that substantial progress has been

made over the past decade in understanding how specific models of case management may improve the efficacy of community treatment for the severely and persistently mentally ill. The authors reviewed 75 studies. They concluded that: "Most research has been conducted on the assertive community treatment (ACT) or intensive case management (ICM) models. Controlled research indicates that the above models reduce time in the hospital and improve housing stability, especially among patients who are high service users. Both models also appear to have moderate effects on improving symptomology and quality of life; however, most studies also suggest little effect on social functioning, arrests and time spent in jail, or vocational functioning. Studies on reducing or withdrawing ACT or ICM services suggest some deterioration in gains. Research on other models of community care is inconclusive.

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