

THE POLICY RESOURCE CENTER

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REAL CHOICE
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The Policy Resource Center (PRC) at the Institute for Health, Law, and Ethics was established in 2002 under a Real Choice Systems Change Grant from the Centers for Medicare and Medicaid Services. The mission of the PRC is to identify barriers to real choice and consumer directed services for elders and persons with disabilities and to recommend reforms in policy, regulatory structure and practices. PRC partners include: Consumers, Institute on Disability at UNH, Granite State Independent Living, The DD Council, and the New Hampshire Department of Health and Human Services (Divisions of Elderly and Adult Services, Behavioral Health and Developmental Services and the Office of Health Planning and Medicaid).

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HOME AND COMMUNITY-BASED LONG-TERM CARE FINANCING AND THE WOODWORK EFFECT

"I think it is very important at the very beginning of my remarks to meet this line of reasoning head on. The community is not an alternative to the institution. Rather, the institution is an alternative, and a very specialized alternative, to community living."

Testimony of James J. Callahan, Jr.^a - Hearing, Special Committee on Aging, U.S. Senate, 1977

Despite a preference for home and community-based long-term care (LTC) services, state legislatures limit Medicaid coverage of these services and often do so for fear of the "woodwork effect." The home and community, rather than an institutional setting, has long been recognized as the LTC setting of choice for people of all ages and is often more cost effective. Problematically, home and community-based care (HCBC) service coverage is often unavailable. When service coverage is available, services are often grossly insufficient due in large part to an underdeveloped service system. Today, Medicaid is the primary payer of LTC services and, as such, significantly affects choice, development and availability of LTC services within states. A major obstacle to enhancing Medicaid coverage of HCBC services is the belief that a woodwork effect will drive Medicaid LTC costs upward. Legislators believe that if Medicaid coverage for HCBC services is widely available, many people who now rely on unpaid help from family and friends will "come out of the woodwork" and ask for Medicaid coverage for their home care. In response to this belief, legislatures often limit the availability of Medicaid HCBC coverage.

This brief explores the possibility and impact of a woodwork effect in New Hampshire and concludes that while the total number of individuals who access Medicaid LTC services may increase, New Hampshire should expand the availability of Medicaid HCBC^b services for all of the following reasons:

- ◆ Any woodwork effect in New Hampshire would be relatively minor because of the state's low poverty rates, low disability rates, and already high participation rate in Medicaid LTC.
- ◆ New Hampshire may provide more Medicaid HCBC coverage for an increased number of individuals and still reduce the total Medicaid LTC cost.
- ◆ By building a strong HCBC infrastructure, New Hampshire will encourage private-pay individuals both to use HCBC and to avoid Medicaid estate planning and premature spend-down for Medicaid eligibility.
- ◆ A strong HCBC infrastructure will support and sustain informal caregiving.
- ◆ A strong HCBC infrastructure will serve more individuals who need LTC assistance.

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^bFor the purposes of this brief, New Hampshire HCBC means home and community-based care services for the elderly and chronically ill (HCBC-EI), for people with developmental disabilities (HCBC-DD), for people with acquired brain disorders (HCBC-ABD), and in-home supports for children with developmental disabilities (HCBC-IHS). HCBC-IHS is a new program in 2003.

MEDICAID LONG-TERM CARE FINANCING

Medicaid is the primary payer for LTC services, and LTC costs account for the largest portion of Medicaid spending. In New Hampshire, Medicaid provides coverage for nearly 70% of all nursing facility residents.¹ In 2001, New Hampshire Medicaid LTC spending, including HCBC, accounted for 41% of total state Medicaid spending or \$358,376,475.²

However, a breakdown of costs shows that New Hampshire spends more on institutional LTC than it does on HCBC. In 2001, Medicaid nursing facility expenditures were \$209 million (\$166.64 per capita) and Medicaid HCBC expenditures were significantly less at \$146 million (116.30 per capita). The state spent roughly 30% more on nursing facility care than on HCBC. This spending disparity is even greater for elders and adults with physical disabilities where more than 90% of Medicaid LTC spending was for nursing facility care compared to less than 10% for HCBC.¹

NEW HAMPSHIRE MEDICAID LTC COSTS (Federal and State Funds - 2001)

Nursing Facility	\$209,805,127 (59%)
Home/Community	\$146,424,410 (41%)
Total	\$358,376,475 (100%)

Note: Home/Community costs are the sum of personal care, HCBC, and home health care costs.

Source: Burwell, The Medstat Group, Inc. (2002).

THE DIFFERENCE IN SPENDING BETWEEN LONG-TERM CARE SETTINGS

The difference in spending between LTC settings is in part due to a difference in mandates under federal law. Federal law requires that states provide nursing facility coverage under Medicaid and therefore states may not deny nursing facility coverage when needed and requested by a Medicaid-eligible individual. However, federal law allows states to limit Medicaid HCBC coverage.

New Hampshire chooses to spend more of its Medicaid LTC resources on nursing facility care despite the fact that HCBC services are preferred and often less expensive. A New Hampshire resident who is eligible for Medicaid may readily receive nursing facility care. When that same person elects to receive care at home, the individual may be placed on a wait list for services. The number of Medicaid HCBC recipients is limited ("capped") to a specific number of people but the number of Medicaid nursing facility residents are not. Additionally, a funding cap is imposed on HCBC services and that cap may be significantly less than the alternative cost of institutional care.

BARRIERS TO EQUAL ACCESS TO HOME AND COMMUNITY-BASED CARE

There are political, logistical, and philosophical barriers to equal access to LTC settings under Medicaid.³ Political barriers include the influence of a strong nursing facility lobby, as well as home health care opposition to non-agency services such as consumer-directed personal care and independent case management. Logistical barriers include identifying revenue both to fund needed services and to build a solid and reliable HCBC system infrastructure, as well as address system management issues. Philosophical barriers include deep-seated beliefs about what is "right" or "safe" to do and what will work in practical terms. Importantly, a notable belief fueling these barriers is the fear of the woodwork effect.

One concern for legislators, no matter where the money is coming from, is the "woodwork effect" – the fear that more people will show up to claim the attractive new home and community-based benefits than the state can handle. To avoid that, the New Hampshire legislature capped the number of people who can be helped.

Source: State Legislatures Magazine, April 2000.

WHAT IS THE WOODWORK EFFECT?

Legislators postulate that if Medicaid coverage for HCBC services is widely available, many people who now rely on unpaid help from family and friends will "come out of the woodwork" and ask for Medicaid coverage for their home care. Legislators assume that among the "woodwork" people are those who would never enter a nursing facility, even if eligible for one, and therefore the state would never have had a mandate to cover their services. The belief is that in the end the state will pay LTC costs for more people than it did in the past and, as a result, increase aggregate Medicaid LTC expenditures (total institutional spending and HCBC spending).

DESPITE A WOODWORK EFFECT, CAN STATES SAVE MONEY BY SHIFTING LTC SPENDING TO HCBC?

Experts agree that the woodwork effect occurs and research shows a potential increase in aggregate LTC spending when HCBC Medicaid coverage is more available.⁴ However, states with mature HCBC programs have demonstrated that the woodwork effect is exaggerated and results in cost savings. Furthermore, the New Hampshire Division of Elderly and Adult Services concluded that there was no woodwork effect in its analysis of the state's efforts to increase utilization of community care alternatives between 1998 and 2002.⁵

States have already demonstrated the cost-effectiveness of home and community-based LTC despite a woodwork effect.

◆ **Maine:** In shifting its LTC system toward HCBC, Maine's total LTC spending for elders and adults with physical disabilities declined from \$284.7 million in 1995 to \$264 million in 1998. In this same time period, the number of clients served increased from 19,093 to 23,346.⁶

◆ **Colorado, Oregon, and Washington:** The Lewin Group estimated substantial Medicaid LTC cost savings when Colorado, Oregon, and Washington lowered their nursing facility use and increased the use of HCBC services.⁷ In 1994, the three states saved between 9% and 23% of projected LTC costs. Oregon reinvested its savings in building the system, serving more people and strengthening the HCBC infrastructure. In 1998, Oregon served 75% of Medicaid consumers and 70% of all adults with disabilities in HCBC settings.⁸

◆ **Kansas:** Kansas successfully demonstrated the cost-effectiveness of HCBC programs for people with physical disabilities through a program that has been operational since 1984. In 1998, the state reported a prior year savings of \$24,579,932, a figure that included a woodwork factor of 25%.⁹

WHAT FACTORS INFLUENCE THE MAGNITUDE OF THE WOODWORK EFFECT IN NEW HAMPSHIRE?

While it is difficult to predict how many people may come out of the woodwork, available facts indicate that if a woodwork effect occurred in New Hampshire, it would be relatively minor. Some facts about unmet needs are already known or may be fairly accurately deduced. For example, there are three HCBC programs for adults with disabilities and only two have waiting lists. It is also logical to assume that many high-end LTC users, such as people dependent upon ventilators, are predictably already receiving Medicaid coverage and would not contribute to a woodwork effect. Other contributing facts include low poverty and disability rates, an already high Medicaid LTC participation rate, lower incentives for Medicaid planning, slower spend-down to Medicaid eligibility in the HCBC setting, and a strong and committed informal care system.

Low Poverty Rate: New Hampshire has the lowest percent poverty in the United States and is significantly less poor than states that have cost-effectively absorbed a woodwork effect. Medicaid is a needs-based program and eligibility is based on poverty status. From 1999 to 2001, New Hampshire had the lowest state three-year average poverty rate at 6.2%.¹⁰ The three-year poverty rates for the states that have cost-effectively absorbed a woodwork effect—Colorado, Kansas, Maine, Oregon, and Washington—are significantly higher, ranging from 9% to 11.8%.

Low Disability Rate: New Hampshire has a lower percentage of people with disabilities,¹¹ including a lower percentage of self-care disabilities, than there are nationally and a lower percentage than occurs in four of the five states that have cost-effectively absorbed a woodwork effect. Only 16.9% of the New Hampshire non-institutionalized population age 5 and over has a disability and only 1.8% has a self-care disability. This is comparable to Colorado (16.3% and 1.9%, respectively) and significantly lower than the rates of disability in the other four states that have cost-effectively absorbed a woodwork effect.

High Medicaid LTC Participation Rate: New Hampshire already covers more Medicaid LTC participants per 1,000 population than are covered nationally and more than are covered in four of the five states that have cost-effectively absorbed a woodwork effect. In 1997, New Hampshire covered 9.35 Medicaid LTC participants per 1,000 population, more than the national mean of 8.61. Colorado, Maine, Oregon and Washington covered 8.96, 8.36, 8.04 and 7.68 per 1,000 population, respectively.

	% People in Poverty 3-Year Average 1999-2001	% People with Disability 2000	% Self-Care Disability 2000	Medicaid LTC Participants per 1,000 Population – 1997
US	11.6%	19.3%	2.6%	8.61 Mean
New Hampshire	6.2%	16.9%	1.8%	9.35
Colorado	9.0%	16.3%	1.9%	8.96
Kansas	10.1%	17.6%	2.3%	13.04
Maine	10.3%	20.0%	2.5%	8.36
Oregon	11.8%	18.8%	2.5%	8.04
Washington	10.4%	18.2%	2.4%	7.68

Source: Poverty in the US: 2001, US Census Bureau (2002); Census 2000; Leblanc, et al., Medicaid 1915(c) Home and Community-Based Services Waivers Across the States, Health Care Financing Review (Winter 2000).

In New Hampshire, compared to other states and the nation as a whole, fewer people are financially eligible; fewer people are medically eligible; and more people are already Medicaid LTC recipients. Based on these factors alone, any woodwork effect must be significantly smaller than that already demonstrated in states that have successfully and cost-effectively absorbed an increased number of Medicaid LTC recipients.

Reduced Medicaid Estate Planning and Spend-Down through Home and Community-Based Care. People who elect HCBC rather than nursing facility care are less likely to impoverish themselves through "Medicaid estate planning" (MEP) and spend-down and are therefore less apt to rely on Medicaid coverage. Through MEP, many divest themselves of assets to meet Medicaid financial eligibility requirements at the time of nursing facility entry. Despite laws that prohibit and penalize MEP, loopholes allow it to continue. Those who do not undertake MEP, spend down assets quickly in high-cost nursing facilities.

MEP. While it is difficult to measure the extent of MEP empirically, a recent Connecticut study looked at the factors that influence why people undertake MEP.¹² Connecticut, a state similar to New Hampshire in income and poverty rankings, is believed to be one of the most active states in MEP. The study found that disincentives to MEP were: (1) losing control of assets; (2) a Medicaid stigma; and (3) a perceived immorality with MEP. Nothing lessens these disincentives for the individual drawn to HCBC. Moreover, many may consider losing control of assets a far greater disincentive if remaining in their own home and the Medicaid stigma to be far more visible in the community.

Incentives to undertake MEP were: (1) estate preservation and (2) protection of the community spouse. MEP is typically linked to the high cost of nursing facility care, a "one-price-fits-all" high cost. HCBC is a more affordable cost with potentially less impact on the estate, as it is a cost for only needed services and a cost offset by unpaid caregiver resources. HCBC is also the LTC option with a significantly smaller fiscal impact on the spouse of the LTC user, again providing less incentive to engage in MEP.

Spend-Down. Greater utilization of HCBC options may not only reduce MEP, but the lower cost of HCBC will slow the rate at which individuals spend down their resources on LTC services and become financially eligible for Medicaid.

HCBC Expansion does not Result in Substitution of Formal Care for Informal Care. Demographic projections forecast some future substitution of formal care for informal care, yet research shows that informal caregiving remains in place when formal caregiving is introduced. A key assumption of the woodwork effect is the substitution of formal care for informal care. Realistically, there is an expectation of some substitution in light of the fact that demographically the number of unpaid caregivers is expected to decrease. More women, the usual unpaid caregivers, will work outside of the home and there will be fewer children to care for elderly parents as the result of childless marriages, smaller families and higher divorce rates. By 2020, for example, the number of elders living alone and without living children or siblings will be twice the number of 1990.¹³

Nevertheless, when available, most studies show little erosion in informal caregiving when formal care becomes available through public or private financing.¹⁴ Studies show that when formal caregiving is substituted for informal caregiving, the substitution is minor and temporary.¹⁴ Minor impacts occur, for example, when there has been a strong reliance on friends and neighbors for care rather than family. An example of a temporary impact is when the primary caregiver is sick or unavailable. When substitution occurs, it is more likely to occur in the types of tasks performed, the elder informal caregiver taking on the less physically demanding tasks, for example. These formal substitutions support and sustain the involvement of the informal caregiver.

WHAT FACTORS COUNTER CONCERNS ON THE WOODWORK EFFECT?

Certain factors offset the woodwork effect. One factor is the informal caregiver's need for support. Another important factor is the economic reality that the HCBC infrastructure requires sufficient demand and reimbursement to achieve stability and solvency.

Informal Caregivers Need Supports to Stay in Place and to Become Stronger. Contrary to political discourse, informal care is not "free." Rather, it results in costs to both families and to the state's economy. Informal care often negatively impacts the employment and health of the informal caregiver, directly affecting families and indirectly impacting the state's economy. The informal caregiving system needs support to remain in place. Lack of supports weakens a very valuable system.

Families and friends willingly provide care but cannot do it alone. Seventy six percent of caregiving is informal caregiving. Most caregivers are age 45 or older and have low to moderate family incomes. At least half have competing demands of employment, children under the age of 18, or both. Most provide care outside of their own household. Additionally, caregiving impacts physical and mental well-being.

Informal caregivers need assistance with specific caregiving tasks, assistance at specific times of the day, and time away from caregiving. Caregivers may need assistance, for example, with physically demanding, medically complex or personal care tasks. Caregivers need assistance at specific times of the day, for example, to support employment or sleep. For emotional well-being, caregivers need time to themselves. This assistance typically comes in the form of respite, adult day care, personal care, funding for home and vehicle modification, and caregiver education and training.

The HCBC Infrastructure Will Remain Weak without State Investment. Over-reliance on "free," informal care prevents the development of a stable and solvent HCBC infrastructure. A solid HCBC infrastructure is dependent upon a sufficient demand for services and sufficient reimbursement. As Medicaid is currently the primary payer of LTC services, it follows that Medicaid significantly affects both HCBC demand and system solvency. Without a strong HCBC infrastructure, private pay consumers will continue to rely primarily on higher-cost nursing facility care. Private pay nursing facility residents will ultimately become Medicaid LTC coverage recipients through quick spend-down of assets due to high facility rates, through MEP, or both.

INFORMAL CAREGIVER FACTS

- ◆ 63% are age 45 and over.
- ◆ 27% have low family income (less than \$20,000); 41% have moderate income (\$20,000-\$50,000)
- ◆ Half are employed and 2 out of 5 are employed full time.
- ◆ About 1 in 5 is employed and has children under age 18.
- ◆ One quarter are parents providing care to individuals under age 65.
- ◆ 54% of caregivers provide care outside of their own household.

Source: Lisa Marie Alexih, et al., Characteristics of Caregivers Based on the Survey of Income and Program Participation, The Lewin Group (2001).

The state must invest in the HCBC system to ensure its availability and to begin to release the system's dependency on Medicaid. Oregon found that a significant benefit to a strong Medicaid HCBC model is that private consumers also choose community-based care at a much higher rate. Many private payers in Oregon opt for community care over institutional care because the option is less expensive, provides quality care and ensures more personal independence.⁸ This increased utilization by the private payer accelerated the growth of the Oregon HCBC option.

CAN THE STATE CONTROL THE FINANCIAL IMPACTS OF THE WOODWORK EFFECT?

Strategies exist that allow states to absorb any woodwork effect that might occur and to do so with cost savings. Strategies that New Hampshire could incorporate include:

1. Instituting comprehensive and independent case management to help consumers to find the most appropriate care, to monitor spending,⁷ and to ensure the use of all available resources.⁷
2. Developing stronger family support systems to sustain and strengthen informal caregiving.
3. Allowing consumers to direct the spending of their LTC budgets so they can most efficiently and effectively utilize those resources, such as in a "cash and counseling" LTC model.¹⁵
4. Eliminating barriers for high-need individuals to utilize lower-cost community alternatives rather than forcing individuals into more expensive institutional settings. This includes, for example, eliminating HCBC-ECI cost caps that limit HCBC costs to 33% of the average cost of nursing facilities.¹⁶
5. Investing in the development of a strong HCBC infrastructure to encourage greater utilization by private pay individuals and to reduce MEP and premature spend-down of assets that result in Medicaid dependence.

CONCLUSION

While as legislators have proposed, expanding HCBC coverage under New Hampshire Medicaid may result in a woodwork effect, it is not likely to be a fiscally injurious effect. Other states have shown that the woodwork effect may be absorbed cost-effectively and there are sufficient facts to show that a woodwork effect in New Hampshire may be relatively minor. Compared to most other states, New Hampshire has low poverty and disability rates and an already high Medicaid LTC participation rate. It is also likely that there will be less of a demand upon Medicaid as people who opt for the lower-cost HCBC may be less likely to become impoverished through MEP practices or rapid asset spend-down. Importantly, studies also show that the availability of formal care does not displace informal care.

There are also factors that offset the woodwork effect, as well as mechanisms to control the effect. Offsetting the woodwork effect is the need to support a valuable informal caregiving system in order to sustain and strengthen that system. Also offsetting the woodwork effect is the need to invest in the HCBC system to solidify its infrastructure in order to ensure its availability to all payers and to lessen its dependency on Medicaid. Finally, New Hampshire can lessen the impact of the woodwork effect through proven strategies, such as case management, consumer-directed services, family support, and elimination of barriers to HCBC coverage that force the utilization of higher-cost nursing facility care.

Note: This brief addresses the traditional woodwork effect, a fear of increased aggregate costs that result when additional individuals access services when community options are more readily available. A related concern, increased utilization of community-based services by individuals already receiving community services, will be addressed in a future brief.

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