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# THE POLICY RESOURCE CENTER

## INSTITUTE FOR HEALTH, LAW, AND ETHICS AT FRANKLIN PIERCE LAW CENTER

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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# THE POLICY RESOURCE CENTER

## INSTITUTE FOR HEALTH, LAW, AND ETHICS

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### FINANCING LONG-TERM CARE FOR PEOPLE WITH DISABILITIES

Financing long-term care (LTC) is a key policy and budget issue both in New Hampshire and nationally. Debates focus on who should bear the financial burden of LTC or how the burden should be distributed. This brief looks at what LTC is, its importance to people with disabilities, LTC financing mechanisms, the economy and LTC, and recommendations for change.

#### WHAT IS LONG-TERM CARE?

*"Long-term care" is:*

- ◆ A range of medical and non-medical services, from personal care to nursing care;
- ◆ Provided in the home, the community, or a facility (e.g., nursing home or assisted living);
- ◆ Sufficient to rehabilitate or compensate for loss of independent physical or mental functioning;
- ◆ For people of all ages with a chronic illness or disability (physical, mental, or developmental);
- ◆ For a short period of time to a lifetime; and
- ◆ Necessary so that an individual may function at his or her maximum level of ability.

Often the term "long-term care" is used to refer to nursing home care for elders. Here "long-term care" refers to a broad range of services provided to people of all ages, of all disabilities, in all settings.

#### LONG-TERM CARE AND DISABILITY

LTC is a fact of routine daily life for many people with disabilities and necessary for their full participation in society. Historically, people received LTC services in institutions, such as nursing homes, intermediate care facilities or psychiatric hospitals. Our society has long since recognized the value of community living and the value of an individual's right to choose where to live. Today, people with disabilities choose to remain in their homes and part of their communities. *LTC in the home and community allows people with disabilities to:*

- ◆ Live independently;
- ◆ Participate fully in society;
- ◆ Achieve economic self-sufficiency; and
- ◆ Enjoy equal opportunity.

#### LTC SERVICES:

- ◆ Transfer an individual with a spinal injury out of bed in the morning and into bed at night.
- ◆ Enable a child with cerebral palsy to attend school.
- ◆ Provide job support to an individual with autism learning a new job.

Problematically, many do not currently receive the LTC services that they need. At the core of this LTC problem is an insufficient and fragile LTC financing structure coupled with an already weak LTC community infrastructure which will become weaker without financing. Exacerbating this problem is that the number of people with disabilities is growing as a result of improved medical knowledge and technology, as well as the general aging of the population, and the overall cost of LTC services is spiraling.

## LONG-TERM CARE FINANCING MECHANISMS

LTC financing is very limited. Unpaid caregivers provide most LTC services. Most LTC financial coverage is out-of-pocket or Medicaid coverage. LTC insurance coverage is minimal. *Importantly, private health insurance plans and Medicare do not cover LTC services.*

### ► Unpaid (Informal) Caregiving

The value of unpaid caregiving far surpasses public or private coverage. An estimated 23% of Americans provide informal care.<sup>1</sup> The 1997 estimated national economic value of unpaid care for adults was \$196 billion, a figure stunting same year spending of \$115 billion on home and nursing home care.<sup>2</sup>

### ► Out-of-Pocket payment

Out-of-pocket spending accounted for 14% of total health care spending in 2002.<sup>3</sup> Research shows that families with members who have a chronic illness are 2.6 times more likely than other families to spend \$1,000 out-of-pocket annually for medical care.<sup>4</sup> Out-of-pocket spending rises when there is more than one chronic condition.<sup>4</sup>

### ► Long-Term Care Insurance

LTC insurance pays for less than 7% of the nation's LTC costs. Marketed since the mid 1980s, LTC insurance provides coverage for a minimum of 12 consecutive months. Purchase barriers include consumer understanding and affordability, as well as a pre-existing disability.

### ► Medicaid

Medicaid is the largest single payer for LTC services. In 2001, New Hampshire Medicaid LTC expenditures amounted to \$358,376,475 (State and federal funds), 59% toward institutional care, and 41% toward home-and-community care.<sup>5</sup> Medicaid LTC spending accounted for 69.4% of State nursing home spending and 40.9% of total State Medicaid spending.<sup>5,6</sup>

## MEDICAID "CAUGHT IN THE CROSSFIRE"

Medicaid budgets are cost-cutting targets across the nation. Medicaid is a federal-state funding partnership with basically three coverage programs in one: (1) insurance coverage for low-income children and pregnant women, (2) wrap-around coverage for low-income elders on Medicare, and (3) acute and long-term care coverage for people with disabilities and frail elders. Under federal law, Medicaid is meant to provide coverage for rehabilitation and other services so that people may attain and retain capability for independence or self-care.<sup>7</sup> As such, Medicaid financing is specifically targeted to LTC coverage for people with disabilities. Of great concern today, Medicaid is a target for balancing state budgets. Importantly, the core of the problem is not Medicaid. Instead, Medicaid is "caught in the crossfire" between decreasing state revenues and increasing health care spending.

## HEALTH CARE SPENDING, MEDICAID SPENDING, AND THE ECONOMY –

National health care spending grew at a rate of 8.7% in 2001, the fastest rate since 1991.<sup>3</sup> In the states, health care spending is second only to education spending, accounting for an average of 20% of state costs.<sup>3</sup> Medicaid spending accounts for most of state health care spending. The most common factors driving the rise in Medicaid spending are: (1) prescription drug costs, (2) increased enrollment in an economic downturn, (3) a rise in the cost and use of medical services, and (4) LTC.<sup>8</sup> The highest cost groups are the elderly and disabled, accounting for roughly 2/3 of Medicaid spending.

In line with the nation, the New Hampshire Center for Public Policy Studies (NHCPPS) concludes that two of the six programs fueling New Hampshire spending increases are Medicaid programs. The 2003 general fund budget for Medicaid provider payments is \$99.4 million. Medicaid nursing home and home health care payments are budgeted at \$62.7 million in 2003, although notably home care costs are expected to amount to only one-tenth of nursing home costs.<sup>9</sup>

The Congressional Budget Office projects what most believe to be an unsustainable Medicaid growth rate of 12% in 2002 and 9% for the next 10 years. The states' response is to reduce Medicaid spending through: constraints in benefits, eligibility or provider rates; prescription drug action; increases in beneficiary cost sharing; or "Medicaid maximization" strategies involving provider taxes, upper payment limits, or disproportionate share hospital payments. New Hampshire is similarly responding to its rising Medicaid costs.

Will these strategies work? Medicaid maximization is beneficial in the short term but federal constraints and oversight will likely diminish its future value. The other strategies are private sector cost-cutting techniques which when implemented in Medicaid have significant repercussions.

- ◆ Provider payment constraints mean fewer Medicaid providers and reduced access to needed services for our most economically and medically vulnerable populations. Reduced access has grave health consequences and effectively little, if any, cost savings.
- ◆ Constraints mean significant cost shifting to hospitals that shift to insurance companies to employers and finally to employees. It is effectively a back-door tax.
- ◆ Medicaid cut-backs mean an impact on the State's economy through a loss in federal matching funds (\$103 million in 2003),<sup>9</sup> through job loss and through decreased economic activity.<sup>10,11</sup>

Importantly, policymakers must remember that it is health care spending that is the problem and Medicaid is only a part of health care spending. Experts caution with a hard lesson from the past—controlling costs through one component of the health care system is not a sustainable control.<sup>12</sup> Sustainable control requires effort from the government, consumers, employers, providers and private insurers.<sup>12</sup> It requires incremental reform to the structure and process of health care delivery, including LTC, to reduce waste and inefficiencies.<sup>12</sup>

## **RECOMMENDED NEW HAMPSHIRE LONG-TERM CARE FINANCING REFORM**

New Hampshire must implement real solutions to its LTC financing problem. Realistically, LTC services must occur. Realistically, federal assistance must also occur, both in the form of fiscal aid and through elimination of the higher-cost federal institutional bias in Medicaid. Ultimately, however, New Hampshire must also reform its Medicaid LTC structure and process.

LTC reforms must constrain cost, usage and the effect of a growing disability community. Three strategies are key to this goal—(1) implement a cash-and-counseling model of LTC financing, (2) implement quality case management, and (3) build a strong community-based family support infrastructure. All support lower-cost home-and-community care.

### **► Cash and Counseling Model of LTC Financing**

Cash and counseling (C&C) is a consumer-directed finance model in which the care recipient receives a cash benefit or voucher, along with counseling, to purchase LTC services and items. Often the LTC system forces people to comply with a prescribed package of services that does not match their needs and is likely more costly than necessary. C&C allows people to prioritize their LTC spending to meet their needs and to do so within a fixed budget. It is flexible and permits choice in services and providers, especially important when service needs and availability change over time.

The cash and counseling finance model has been successfully implemented in the Medicaid program and in private insurance coverage.<sup>13</sup> Interim evaluations of current Medicaid demonstration projects in Arkansas, New Jersey and Florida are very positive.<sup>14</sup>

### **► Service Coordination and Case Management**

Health care utilization surged upward 3.8% in 2001 (1.6% annual increases 1993–2000).<sup>3</sup> Quality service coordination and case management, including disease management, reduces unnecessary service utilization in both acute and LTC. Interim findings in the New Hampshire Nursing Home Transition Project show significant cost savings when moving people out of nursing homes and into the community through good service coordination.

### **► Community-Based Family Support Infrastructure**

The number of people with disabilities is expected to continue to grow and it becomes more critical to build supports for our most valuable LTC resource, the unpaid informal caregiver. Caregiver support prevents higher-cost out-of-home care, by allowing caregivers to remain physically and emotionally able to provide care and to remain employed. *Studies show:*

- Frequent help from children with personal care reduces elder nursing home entry by 60%,<sup>15</sup>
- Women ages 55–67 who help elder parents with basic personal activities, chores or errands, need to cut back their work hours by 367 hours per year or 41%,<sup>16</sup> and
- Being an elder caregiver experiencing emotional strain is a risk factor for mortality.

New Hampshire needs a solid support infrastructure (both paid and voluntary) to support family and other informal caregivers.

A better Medicaid LTC financing structure is needed for the economic health of New Hampshire and to ensure that people with disabilities live independently, participate fully in society, achieve economic self-sufficiency, and enjoy equal opportunity.

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HOME AND COMMUNITY-BASED LONG-TERM CARE is:

- A range of medical and non-medical services, from personal care to nursing care;
- Provided in the home or the community;
- Sufficient to rehabilitate or compensate for loss of independent physical or mental functioning;
- For people of all ages with chronic illness or disabilities (physical, mental or developmental);
- For a short period of time to a lifetime; and
- Necessary so that an individual may function at his or her maximum level of ability.

MEDICAID COVERAGE of home and community-based long-term care is provided through 3 routes: (1) Medicaid State Plan, (2) Home Care for Children with Severe Disabilities, and (3) HCBC waivers.

## THE 4 NEW HAMPSHIRE HCBC WAIVERS

- HCBC-DD (developmental disability)
- HCBC-ECI (elderly & chronically ill)
- HCBC-ABD (acquired brain disorder)
- HCBC-Children with developmental disabilities

## MEDICAID ELIGIBILITY FOR HOME & COMMUNITY-BASED LONG-TERM CARE

Medicaid State Plan	Home Care for Children with Severe Disabilities (HC-CSD)	HCBC Waiver
1. General Requirements 2. Categorical Requirements 3. Financial Requirements	1. General Requirements 2. Categorical Requirements 3. Financial Requirements 4. Requires the level of care provided in an institution 5. Cost of care is no more than the institutional cost of care	1. General Requirements 2. Categorical Requirements 3. Financial Requirements 4. Requires the level of care provided in an institution 5. Cost of care is no more than the institutional cost of care

**General Requirements** include residency, social security number, developing potential income.

**Categorical Requirements** include being blind, disabled or aged.

**Financial Requirements** include asset tests for income and resources.

## MEDICAID LONG-TERM CARE SERVICES

Medicaid State Plan & HC-CSD	HCBC Waiver (services vary with waiver)	
Home Health Nursing Services Nursing Assistant Services Medical Supplies & Equipment Personal Care Physical, Occupational & Speech Therapies	Adult Day Care Case Management Crisis Intervention Environmental Modifications Habilitation Home Health	Homemaker Personal Care Personal Emergency Response Respite Supported Employment

## MEDICAID LONG-TERM CARE COST COMPARISONS – FY 2001

	Nursing Home Care	Waiver Care
Total Cost	\$209,805,127	\$137,743,635
Cost Per Capita (state population)	\$166.64	\$109.41
Number of Participants	4,962	4,301
Average Cost Per Participant	\$42,282	\$32,026
Number on Wait List as of 9/30/03	0	348 for HCBC-DD 14 for HCBC-ABD

## A C R O N Y M S & G L O S S A R Y

<b>Activities of Daily Living (ADLs)</b>	Basic personal activities, including bathing, dressing, transferring from bed to chair, toilet assistance, mobility and eating.
<b>Acquired Brain Disorder (ABD)</b>	A disabling disruption in brain functioning that impairs a person's ability to function in society. It may be the result of external trauma, anoxic/hypoxic injury, infectious disease, brain tumor, intracranial surgery, a stroke, toxic exposure or a neurological disorder.
<b>Adult Day Care</b>	A daytime community program that provides health and social support services to adults with functional impairments in a protective setting.
<b>Case Management</b>	Assess needs, create service plans, and coordinate and monitor services and resources. The case manager may operate independently or may be an employee of a public or private agency.
<b>Center for Medicare and Medicaid Services (CMS)</b>	The section of the United States Department of Health and Human Services that oversees the Medicaid program.
<b>Developmental Disability</b>	A disability attributable to mental retardation, cerebral palsy, epilepsy, autism, a learning disability, or other condition found to be closely related to mental retardation and originates before age 22.
<b>Environmental Modifications</b>	Modifications or additions to a home environment or vehicle to ensure safety, access or compliance with building or vehicle codes.
<b>Habilitation</b>	Assistance and training in the home or community to: maintain/improve basic living skills, vocational activities, and community activities; enhance social and personal development; and maintain/improve communication skills, mobility skills, and physical and psychological health.
<b>Home- and Community-Based Care Waiver (HCBC Waiver or 1915(c) Waiver)</b>	A tool to provide long-term care services in the home and community as an alternative to institutional care, at the same or lower cost. CMS "waives" the state's compliance with certain federal laws. For example, the State may design a package of services that meets the needs of a certain group of people, such as elders. Without a waiver the State would have to provide those services to all Medicaid recipients at a potentially much higher cost.
<b>Home Care for Children with Severe Disabilities (HC-CSD)</b>	Medicaid eligibility option that provides coverage for long-term home care for children as an alternative to institutional care. (This is often referred to as Katie Beckett eligibility.)
<b>Instrumental Activities of Daily Living (IADLs)</b>	Includes housekeeping, cooking, shopping, laundry, medication management, money management, and communication.
<b>Medicaid (Title XIX)</b>	Federal- and state-funded program of medical assistance.
<b>Medicare (Title XIII)</b>	Federal health insurance program for people age 65 and over (and certain people with disabilities under age 65).
<b>Personal Care</b>	Assistance with ADLs and IADLs.
<b>Respite</b>	Short-term care (from a few hours to a few days) by a trained caregiver to allow family caregivers some time away from their caregiving role.
<b>Wait List</b>	List of people waiting to receive HCBC waiver services. The State caps the number of people who may receive HCBC waiver services at one time.