

New Hampshire Consumer-Directed Personal Care: A Gap Analysis

Prepared by:

David Frydman, JD

Michele Winchester, JD

**Institute for Health Law and Ethics
Franklin Pierce Law Center**

April 2005



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The New Hampshire CPASS¹ project identified system “gaps” that impact a consumer-directed long-term care (LTC) service model. Focus groups identified gaps in the personal care services system, services that are at the heart and origin of consumer direction in the State. This analysis begins with an overview of consumer-directed personal care (CDPC), followed by a discussion of the gaps identified by focus groups and initial recommendations to address the gaps.

This document was developed under Grant No. 18-P-91613/1-01 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, the contents herein do not necessarily represent the policy of the U.S. Department of Health & Human Services, and you should not infer endorsement by the Federal government. Please include this disclaimer whenever copying or using all or any part of this document in dissemination activities.

Consumer-Directed Personal Care: An Overview

Consumer Direction

Consumer-directed models of home- and community-based LTC services are at the forefront of LTC changes across the nation. A consumer-directed service is one in which the LTC consumer has choice and control over LTC services. The term “consumer-directed” describes a continuum of approaches to decision-making, service control, and autonomy. For example, “cash-and-counseling” models offer the consumer control over: service budgeting; the hiring and training of service providers; and the structuring of service plans and schedules. An agency-model, on the other hand, may merely offer the consumer participation in the development and implementation of the care plan. Consumer-direction policy is rooted in the premise that consumers should have the power to decide the types of LTC services that they need, who delivers the services, and when and how the services are delivered. This premise is essential to independent living.

Consumer-Directed Personal Care

At the heart and origin of the consumer-direction movement in LTC is personal care services. Personal care is assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL). ADLs are basic personal activities, including bathing, dressing, transferring from bed to chair, toileting, mobility, and eating. IADLs include housekeeping, cooking, shopping, laundry, medication management, money management, and communication. Personal care assistance is non-medical in nature and a type of care easily broken away from the medical model of care that typically involves

professional oversight. Its non-medical nature easily made personal care the cornerstone of the consumer-direction movement.

The Benefits of the Consumer-Directed Model of Services

Research on consumer-directed models of care shows significant benefits associated with consumer direction and the cash-and-counseling model demonstrates this well. In a cash-and-counseling model, the consumer receives a flexible monthly allowance to purchase disability-related goods and services. The consumer also receives counseling to plan and manage these responsibilities. (The consumer may also designate a representative to act in his or her behalf within this model.) Cash-and-counseling demonstration projects are clearly showing benefits to the consumer-directed model of care.

Findings from the national Cash and Counseling Demonstration² show an increase in satisfaction and a reduction in unmet needs for LTC consumers in self-directed cash and counseling programs when compared to consumers receiving agency-directed services. Demonstration projects are ongoing in Arkansas, New Jersey and Florida. Findings from the project show:

- Higher satisfaction with caregiver reliability, schedule and performance;
- Higher satisfaction with the consumer-caregiver relationship;
- Less reporting of unmet needs;
- Care at least as safe as agency-directed care;
- Higher consumer satisfaction with life; and
- Meeting recipient needs better and at no greater cost per month than incurred under the traditional agency model.³

New Hampshire Consumer-Directed Personal Care

New Hampshire consumers receive Medicaid coverage for CDPC through three separate eligibility programs —

1. A Medicaid State Plan program, Personal Care for Adults with Severe Disabilities, administered through Granite State Independent Living (GSIL);
2. The Home and community-based care waiver for the elderly and chronically ill (HCBC-ECI); and
3. The Home and community-based care waiver, in-home supports for children with developmental disabilities (HCBC-IHS).

See chart below

Enacted into State law in 1979, the GSIL program is the oldest consumer-directed program in New Hampshire.⁷ In 2000, New Hampshire enacted the law authorizing HCBC-ECI and HCBC-IHS consumer-directed services, although actual service availability is more recent. The 2000 law provides the more detailed State definition of consumer-directed services —

- Personal care services under which the eligible consumer or his or her representative is responsible for:
 - (a) Participating in the development of the eligible consumer's service plan;
 - (b) Selecting the eligible consumer's personal care services provider;
 - (c) Setting the terms and conditions of work;
 - (d) Training, supervising, and evaluating the personal care services provider; and
 - (e) Terminating his or her relationship with the personal care services provider.⁹

CDPC	Eligible Consumer:
GSIL	<i>18 years of age or older; his/her own legal guardian; dependent upon wheelchair for mobility; medically stable and able to participate fully in activities of daily living; able to select and direct the personal care attendant in the implementation of a personal care plan; and, able to live in a non-institutional environment without the need for 24-hour care, but requires a minimum of 2 hours of medically oriented care per day.</i>⁴
HCBC-ECI	<i>18 years of age or older and meets the eligibility requirements for HCBC-ECI waiver services (nursing facility level of care).</i>⁵
HCBC-IHS	<i>Child with a developmental disability and meets eligibility requirements for HCBC-IHS services (intermediate care for the mentally retarded level of care).</i>⁶

Gaps That Impact Consumer-Direction and Recommendations

While the consumer-directed service model is clearly the preferred service model for many people with disabilities and their families, as with any innovation issues arise in its implementation. New Hampshire focus groups identified issues or “gaps” in the state’s CDPC service. The gaps and recommendations are presented here in the following categories: service availability; consumer-attendant relationship issues; ancillary issues; and isolation.

Service Availability

Focus group identified the lack of service availability as a gap impacting CDPC services. Factors affecting service availability are: a PCA shortage; service funding limitations; and lack of back-up coverage.

1. Workforce Shortage. New Hampshire, like most of the nation, has experienced a direct-care workforce shortage and PCAs are a significant part of that workforce.¹⁰ Several factors contribute to the severity of the shortage.

- **Lack of competitive wages.** The personal care service is an important and difficult job with a low and noncompetitive wage. In 2004, the average hourly starting wage for a PCA in New Hampshire is \$9 per hour, a figure significantly below the New Hampshire living wage and the wage for other unlicensed positions.

“Living wage” is defined as income sufficient to meet a household’s basic needs. Estimations of living wage consider the cost of basic needs in a particular region of the state for different household types and sizes. Basic needs include: food; rent; utilities; telephone; clothing and household needs; transportation; child care; health care; a small personal expense

allowance (3% of the household budget); and savings (5% of the household budget).¹¹

Consideration of the typical PCA household is fundamental in determining an appropriate wage. Approximately 35% of New Hampshire direct caregivers are single mothers with 2 or more children.¹² For a single parent with two children, the New Hampshire Small Business Development Center calculates a living wage ranging from \$16.57 per hour in Coos County to \$19.49 per hour in Hillsborough County, figures that are 84% and 116% higher, respectively, than the average starting wage of \$9.00 per hour.

Other unlicensed personnel earn significantly higher hourly wages. For example, in 2001, the mean hourly wage for PCAs in New Hampshire was \$8.39 and mean hourly wages in other non-licensed sectors were—¹³

Janitors/cleaners	\$ 9.83
Baggage porters/bellhops	\$10.81
Landscaping/grounds keeping	\$11.03
Telemarketers	\$11.20
Switchboard operators	\$10.55
Door-to-door sales/street vendors	\$17.60
Meter readers	\$15.87
Mail clerks (not Postal Service)	\$10.20

- **Lack of employee benefits.** Few PCAs receive health insurance benefits as the cost is prohibitive both for the employer and the PCA employee. The cost of health insurance is prohibitive as a combined result of low reimbursement rates for the PCA service and high health insurance costs. Medicaid is the primary payer of PCA services. In 2004, the New Hampshire Medicaid reimbursement rate for PCA

services is \$16 per hour. Less the \$9, or so, for employee wage, the amount remaining from the reimbursement is quickly expended in employer tax contributions, worker's compensation payments, and other employer and administrative costs.

PCA employers, often small firms, clearly do not have enough funds remaining after wages to purchase costly health insurance benefits. In its 2004 survey of employer health benefits, the Kaiser Family Foundation found:

- The average monthly premiums for single and family health insurance coverage in the Northeast were \$316 and \$871, respectively; and
- The average monthly employee premium contribution in the Northeast was \$53 for single coverage and \$196 for family coverage. Additionally, workers in small businesses (3-199 workers) also face higher deductibles than workers in larger businesses.¹⁴

At the current New Hampshire Medicaid reimbursement rate for the PCA service, it is highly unlikely that the PCA employer will institute employee health benefits for the PCA. In light of the wage, it is also unlikely that the PCA would find the average employee contribution and deductible affordable.

- **Compensation prohibits PCAs from working more than 40 hours per week.**

Consumers often receive approval under Medicaid for coverage of more than 40 hours per week of PCA services. As the current Medicaid reimbursement rate is barely sufficient to meet standard employee wage and employer costs, it is grossly insufficient to pay for overtime hours at a rate of time and one-half. In response, employers cap the number of working hours for a PCA to at or below 40 hours per week.

In addition to the factors listed above,

other factors also influence PCA availability, including lack of career advancement opportunities, the physically demanding nature of the work, and inadequate recognition and appreciation. The result is that employers experience recruitment difficulties and high turnover rates and consumers experience serious gaps in service availability.

Recommendations: New Hampshire must invest in the PCA workforce to improve service availability. Low wages, lack of benefits, and no overtime pay significantly impact recruiting and retaining workers. To address these problems, New Hampshire should:

- **Enact wage pass-through legislation to increase compensation for PCAs to a livable wage or better.** Wage pass-through is an allocation of funds passed through Medicaid reimbursements for the express purpose of increasing PCA compensation.¹⁵ At least, twenty one states have implemented such programs.¹⁶ Michigan, a state showing success with the pass-through, reports that over a 13 year period its wage pass-through law has resulted in a 61% increase in wages and a 20% reduction in turnover rates.¹⁷

New Hampshire should institute a wage pass-through to raise the PCA wage to a livable wage or better. Studies have identified key design elements for a wage pass-through law and these include: the express size of the salary increase; a clear identification of the worker group targeted; a definition of provider flexibility in the implementation; whether provider participation is optional or mandatory; the type of accountability required; whether the pass-through will be integrated into the ongoing wage structure; and how and when to educate providers on the program.¹⁸

- **Invest in assuring health care coverage for PCAs.** New Hampshire must invest in health care for this critical workforce upon

which so many rely. To this end, partners in this project explored affordable health care coverage mechanisms and GSIL now provides small health reimbursement arrangements¹⁹ for the PCA employee. Due to the currently low PCA wage, it is also likely that children of PCAs are eligible for the subsidized State Children's Health Insurance Program, Healthy Kids Silver, and PCA parents are being informed of its availability and how to apply.

- **Fund overtime pay.** There is a need to find ways to fund overtime pay for PCAs to ensure fair compensation to a very valuable workforce and to ensure the availability of needed services for the consumer. It is reasonable for the PCA to expect overtime pay and, therefore to include that reasonable expectation in the Medicaid rate setting analysis for the personal care service reimbursement. To effectively calculate overtime in a reimbursement rate, providers should collect and report data on the amount of overtime requested and needed in a given year.

2. Low service spending limits for consumers. Under New Hampshire Medicaid, HCBC consumers have limits on service spending that restrict overall service availability and that are significantly lower than federal law allows. Federal law allows HCBC expenditures up to the average cost of comparable institutional care. Pursuant to New Hampshire law RSA 151-E:11, under HCBC-ECI, elders and adults with disabilities may not exceed a spending cap of 50% of the average annual cost of services for nursing facility care. Under HCBC-IHS, children are limited to an average \$20,000 spending limit. Although consumers under both HCBC waivers require an institutional level of care, they do not have the financial coverage necessary to fully access that level of care.

Recommendation: New Hampshire should allow Medicaid recipients to access the service funding that would have been available

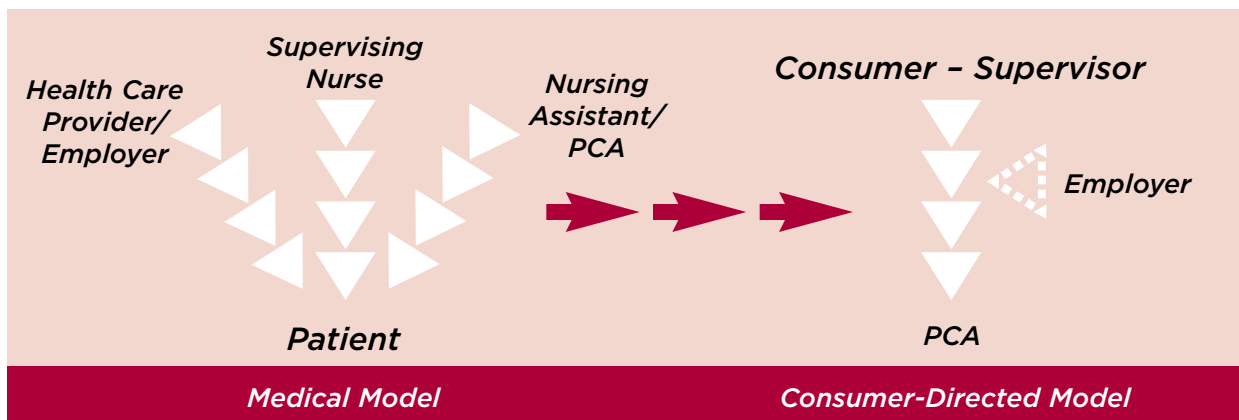
if the recipient were to have entered institutional care. To do this, the State must amend RSA 151-E:11 to allow recipients to access the full cost allowance for an institutional level of care. The same level of spending should be available for children under HCBC-IHS. A safeguard against unnecessary spending is that each recipient receives coverage under an individualized plan of care for only that care that a HCBC nurse deems necessary for the recipient's health and safety.

The state budget process also prevents people from using long term care resources in the community. The Medicaid nursing home state budget line item is separate from the line item for the HCBC-ECI waiver. New Hampshire should amend the law to allow the Department of Health and Human Services to shift resources from the nursing home line item into the HCBC-ECI budget when necessary to enable a person to receive services in the preferred and less expensive community setting.

3. Lack of back-up PCA coverage.

Consumers report a lack of back-up PCA coverage, which seriously impedes the activity of the consumer who is dependent upon a PCA for transferring, eating, dressing, and more. Poor job incentives, high turnover rates, and a workforce shortage result in a high no-show rate and insufficient back-up coverage. Consumers report they are often left without back-up coverage when their PCA fails to report. For a consumer, this may mean being unable to get from wheelchair to bed, going without one or more meals, or being unable to dress for work.

Recommendation: To ensure consumer safety and independence, there is a need to structure back-up coverage systems for PCAs. To this end, project partners are piloting a back-up system with the University of New Hampshire, with University students as back-up PCAs and using federal work study dollars to supplement cost.



Consumer-Attendant Relationship Issues

CDPC introduces a new type of relationship in health and LTC. Traditionally, the personal care service was delivered through a medical model of care with a beneficent philosophy and with a traditional employer model of relationships— employer, supervisor, care provider and patient. Each participant in the service relationship had a separate role and the aim was to care for the patient according to accepted practice standards and employer policy.

Today, CDPC introduces a non-medical framework that emphasizes the autonomy of the person. In today's model the consumer takes on the dual role of consumer and supervisor. The employer is somewhat removed from the overall relationship, now providing only management training for the consumer, payroll services, and quality assurance oversight. The personal care provider is now a non-medical paraprofessional trained and supervised by the consumer. In CDPC, the consumer identifies the care needed, as well as how and when the care is provided.

While consumers clearly prefer the consumer-directed model, the relationship structure for this model is still evolving, as are related supports and training. Focus groups identified arising issues.

1. Care Recipient/Care Provider Relationship versus Employer/Employee Relationship. Focus groups report that consumers are often unsure how to cope

with the dual relationship of care recipient/ care provider and supervisor/employee relationship. The personal nature of the first creates a private and intimate relationship. The latter often requires clear borders and distance.

2. Consumer Autonomy verses PCA Beneficence. Focus groups report that the PCA often imposes onto the consumer the PCA's own feelings or ideas as to what the consumer wants or needs and this creates a struggle between the two people. The struggle is apparently between the PCA operating from the traditional beneficent or paternalistic position and the consumer maintaining an autonomous position.

3. Settling Disputes through a Proper Chain of Command. Consumers report that the PCA may raise employee complaints to the employer agency rather than or before raising those complaints with the consumer/ supervisor. Typically the workplace has a chain of command which employees must follow when making requests or registering complaints. The immediate supervisor is usually the first respondent in that chain. In CDPC, the consumer is the immediate supervisor and should be the first to address requests and complaints. However, PCAs are bypassing the consumer and taking supervisory matters to the agency employer.

Each relationship issue is difficult and each compounds the other. However, consumers need to keep these relationships in balance and maintaining the balance is not

readily achievable with normally acquired life skills, at least not at the present time. In this regard, the consumer-directed system is still on a fairly steep learning curve. It is likely that some of these issues will lessen or dissolve as relationship roles become clearer. However, supports and training are needed in the interim to relieve current tensions and to help establish and solidify roles.

Recommendation: The employer agency should explore each relationship issue with both the consumer and the PCA to identify the causes of the behaviors in question. When the consumer initiates consumer-directed services, employer agencies should train consumers on management techniques to address these issues. The employer agency should also provide complimentary training to the PCA and agency management. A peer support system should also be structured to supplement the training and to offer continued support to the consumer.

Ancillary Issues

Focus groups have identified a number of factors that negatively impact the life of the consumer and detract from the consumer-directed lifestyle. These “ancillary” factors are related to services, goods, or accommodations that are needed by the consumer.

1. Layering Consumer-Directed and Agency-Directed Services. Consumers who elect a consumer-directed approach to services are often forced to layer consumer-directed and agency-directed services, proportionally lessening consumer control over services and the level of consumer accommodation. Service funding streams and regulatory structures often prohibit or restrict consumer-direction. If, for example, a consumer requires nursing services on an intermittent basis, the consumer must obtain those services through a home health agency. While federal law allows direct hire of a nurse, New Hampshire Medicaid regula-

tions require that nursing services be provided through a home health agency. As a result, the consumer receives nursing services at the time and in the manner the agency elects or is able to deliver those services, rather than at the time or in the manner that is convenient for the consumer. When a consumer must layer consumer-directed services with agency-directed services the outcome is a diluted version of consumer direction.

Recommendation: Implement “cash and counseling” (C&C) service models and service regulations that maximize consumer-direction. To maximize consumer direction, service systems must maximize consumer control over funding and services. C&C service models coupled with changes in service regulations maximize the level of consumer direction.

As discussed above, C&C is a model in which the consumer directs spending for services. In this model the consumer receives a cash benefit or voucher, along with counseling, to purchase LTC services and items. C&C allows people to prioritize their LTC spending to accommodate 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 C&C model has been successfully implemented both in the Medicaid program and in private insurance coverage.²⁰ Implementation of a C&C model under Medicaid is most easily achieved through an Independence Plus waiver; in fact, the New Hampshire HCBC-IHS waiver is a successful C&C model for children.

To fully maximize consumer direction, changes in state service regulations will also be necessary. As with nursing services, the agency-directed system often forces people to comply with a prescribed package of services that does not match their needs and is

likely more costly than necessary. Changes in service regulations that allow direct hire of a nurse, for example, ensure greater consumer direction and control over services.

2. Assistive Technology and Home Modification Costs. When consumers utilize Medicaid coverage for costly assistive technology and home modification costs, they reduce their access to coverage for other needed services. Assistive technology and home modification costs are allowable costs under Medicaid HCBC waivers. However, when the state deducts these high costs from the consumer's HCBC services allowance, the consumer is often left with insufficient funds for service coverage for the remainder of the fiscal year.

Compounding this problem is a HCBC allowance limit that is already too low. As discussed above, while federal law only limits annual HCBC average per capita spending per consumer to the average institutional cost of care,²¹ New Hampshire law further limits the average HCBC-ECI cost to 50% of the cost of nursing home care. Deducting high-cost assistive technology or home modifications from this limited coverage leaves insufficient funding for needed service coverage, which may create an unsafe situation and potentially force people into unwanted and higher cost institutional care.

Recommendation: Identify and change regulatory mechanisms to except the cost of assistive technology and home modifications from the annual cost calculation for the individual consumer under HCBC waiver programs. In addition, identify funding sources other than Medicaid HCBC waiver funding that might be used to meet the costs of costly assistive technology and home modifications.

3. Limited Transportation. Public transportation resources in New Hampshire are seriously inadequate, significantly impacting the everyday lives of people with disabilities.

For all people, transportation is an essential element to ensuring independence, mobility, employment, health care, and community participation; it is no different for people with disabilities who are without independent transportation. Additionally, for the low-income PCA, public transportation is not only a cost-effective means of mobility, but also access to employment.

Today, both disability and income are predictors of transportation problems. Nationally, roughly one third of people with disabilities report inadequate transportation as a problem and, not surprisingly, the problem is highest for people with severe disabilities.²² From an income perspective, almost half of all people who earn \$15,000 or less report transportation as a problem.²³ Approximately one-quarter of people with incomes between \$15,000 and \$35,000 report transportation problems and most of these are people with disabilities.²⁴

Recommendation: In order to maximize the use of available state and federal resources, it is critical to coordinate all existing transportation funding so that transportation is not provided for specific populations of people but coordinated to serve them all in the most efficient and effective way. A local transportation agency, or one lead agency with a specialization in transportation, should coordinate transportation services within the local area.

Enact legislation on the oversight and channeling of transportation funding, including Medicaid and other human service transportation funds, through regional transportation agencies or brokers. While state agencies and local providers recognize the need and value of transportation coordination, the requirement to share power and control over resources is often best supported through legislative mandate. Many consider the Kentucky legislation on human service transportation to be model legislation.²⁵

Also, the State should support and learn from regional coordination projects currently under way in New Hampshire.

In July of 2004, Governor Benson established the Governor's Task Force on Community Transportation.²⁶ The Task Force is expected to develop and provide recommendations on a coordinated state policy and plan to establish an interconnected, accessible, statewide transportation system. Support of this work is important.

4. Lack of Available and Accessible Housing. There is a serious lack of accessible and affordable housing in New Hampshire. This creates an enormous barrier for people with disabilities to live in their communities and lead consumer-directed lives. The recent New Hampshire Nursing Home Transition Project highlighted these problems. In this project, people who needed accessible apartments were often forced to remain in nursing homes for eight months or more until a suitable apartment was available. Some were forced to relocate, as the housing that became available was in different areas than where the person had previously resided. Additionally, as the New Hampshire statewide vacancy rate for all rental housing is below 2%, it is not unexpected that housing is difficult to find. Lack of accessible housing coupled with a low vacancy rate creates a dire situation.

New Hampshire has already taken some steps to expand affordable housing to people with disabilities. New Hampshire developed the Home of Your Own program that enables people with developmental disabilities to purchase their own housing.

Also, in its Section 8²⁷ (rental assistance) administrative plan, the New Hampshire Housing Finance Authority (NHHFA) developed a priority one preference for people who are eligible for the Medicaid HCBC program or who would otherwise need to live in an institutional setting. The

NHHFA will also raise the Section 8 payment standard for these people to 120%, as a reasonable accommodation, if needed to pay for an apartment. However, while this makes apartments more affordable, it does not address the lack of accessible units.

Recommendation: New Hampshire needs to expand the availability of accessible and affordable housing. Specific recommendations include:

- Develop better mechanisms to notify people who need accessible units when units are available. To this end, GSIL and NHHFA are developing a web site on which landlords and management companies may notify the public when accessible units become available.
- Through this project, NHHFA has changed its management review of affordable housing to ensure compliance with Section 504 occupancy requirements. Section 504 is a federal mandate and requires providing people who need accessible units access to the units when people who reside in them but do not need them are moved to the next available non-accessible unit.
- The primary funding programs for affordable housing today are supported through IRS tax breaks, such as Low Income Housing Tax Credits and Mortgage Revenue Bonds, and these programs do not require compliance with Section 504. Therefore project partners are working towards the adoption of local management policies which will require all affordable developments in New Hampshire to comply with the Section 504 occupancy requirements even if funded with non-federal funds.
- New Hampshire needs to allocate more resources that allow tenants with disabilities to modify non-accessible apartments into accessible apartments.
- Finally, and most importantly, New Hampshire needs to target additional

housing resources to expand the availability of accessible and affordable housing. While the most direct mechanism to achieve this end would be to allocate funds specifically for this purpose, this may not be politically feasible, as additional resources do not exist. Rather, New Hampshire may modify its development scoring criteria for the competitive allocation of the limited affordable housing development resources that exist. These funding resources include HOME funds, CDBG funds and Low Income Housing Tax Credits. Modified scoring criteria would allow developments that produce more than the required number of accessible units to score higher than those projects that do not. By scoring higher, developers proposing higher proportions of accessible units will be more likely to access the limited available resources for affordable housing development. A caution to this approach is to structure the scoring advantage of developing additional accessible units so that the result is not promotion of developments with an over-concentration of people with disabilities which would result in buildings that were “disability ghettos.” Through this approach more accessible units may be constructed while still preserving integration.

5. Home Health. Consumers report and a state audit report confirms, that consumers are not receiving all of the home health services that they require. The Office of the Legislative Budget Assistant (LBA) reports that not all consumers participating in the HCBC-ECI waiver are receiving all of the needed services listed in their plans of care.²⁸ The services in the plans of care are the services consumers require to remain in the community and do so safely. The LBA found that 86% of consumers received fewer services than called for in their plans of care. This lack of services was also reflected in state expenditures for services, as the state expended only 64% of the funds allocated

for the authorized services listed in the plans. The lack of services in the community is so grave consumers may be counseled to enter institutional care.

Recommendation: To the extent that this lack of services is a reflection of a direct-care workforce shortage, recommendations have already been made. However, the Department of Health and Human Services should quantify and document this lack of services. This data is critical to assessing the quality and safety of HCBC services, to determining needed HCBC funding, and to quantifying the investment effort necessary to develop a sufficient and quality HCBC service system. A data collection and reporting system should be mandated relative to HCBC services. A bill, HB 712, was retained in the Legislature to study this matter.

Isolation

Focus groups report that isolation is a serious problem for many people with disabilities in the community. Some of the barriers to consumer-directed services that have been listed above contribute to isolation, such as, lack of PCA availability and lack of transportation. Removal of these barriers may very well lessen isolation, although removal of these barriers alone will not resolve it.

Focus groups report that for many with disabilities, there is a serious absence of meaningful community connection. As a result, people often do not feel that they are part of the broader community. Such isolation is not only unwelcome, but also unhealthy.

Recommendation: People with disabilities and their families need tools to educate communities about disability, tools that will help them remove the barriers to community inclusion. Peer support groups should also be put in place. The ongoing Littleton Model Community Project will model mechanisms to achieve better community integration for people with disabilities.

Next Steps

As identified here, there are many gaps in the implementation of consumer-directed services for people with disabilities. In the next stage, project partners will work to

implement the identified recommendations and improve the ability of all people in New Hampshire to live consumer-directed lifestyles.

- 1 CPASS is Community-Integrated Personal Assistance Services and Supports.
- 2 The Cash and Counseling demonstration project is supported by the United States Department of Health and Human Services and the Robert Wood Johnson Foundation.
- 3 Leslie Foster, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson, *Improving the Quality of Medicaid Personal Assistance through Consumer Direction, Health Affairs, web edition (Mar. 26, 2003)*; Stacy Dale, et al., *The Effects of Cash and Counseling on Personal Care Services and Medicaid Costs in Arkansas*, Health Affairs, web edition (Nov. 19, 2003).
- 4 N.H. Rev. Stat. Ann. § 161-E:1; N.H. Code of Admin. R. Ann. He-W 552.02.
- 5 Relative to HCBC-ECI eligibility, New Hampshire administrative rules provide:
 - (a) Every New Hampshire Medicaid-eligible individual shall be eligible to receive HCBC-ECI services if he/she:
 - (1) Is at least 18 years of age;
 - (2) Meets the categorical and medical eligibility requirements for nursing facility service coverage as specified in He-W 658.06 and the level of care requirements as specified in He-W 590;
 - (3) Would require long term nursing facility institutional placement in accordance with He-W 590, but not placement in an intermediate care facility for persons with mental retardation or in intermediate care facility for persons with mental illness, unless HCBC-ECI services are provided;
 - (4) Meets the following appropriateness of care criteria as determined by the division of elderly and adult services (DEAS):
 - a. The individual is residing in a setting that is free of readily observable hazards where the services included in the support plan can be provided without compromising the individual's or the provider's health or safety;
 - b. Formal and/or informal supports are available; and
 - c. Services contained in the support plan are available from providers who meet the requirements of He-E 801.09;
 - (5) The cost of HCBC-ECI services, combined with an allowance for acute care costs in accordance with 42 CFR 441.302, is less than the average annual payment for nursing facility services as determined in accordance with He-W 593;
 - (6) Is not an inpatient of a hospital or a nursing facility (NF) except that respite care involving the temporary placement of an individual in a NF may be provided as a component service of HCBC-ECI services;
 - (7) Has needs that can be met with community services at a cost that is the same as, or lower than, the Medicaid cost of nursing facility services;
 - (8) If the cost of the services offered through the HCBC-ECI program in He-E 801.03(a)(7) is higher than the average per diem Medicaid cost of nursing facility care in New Hampshire, the option of receiving HCBC-ECI services shall not be offered to the individual;
 - (9) Pays to the department of health and human services (DHHS) the monthly cost share payment, determined in accordance with He-E 801.06, toward the cost of HCBC-ECI services;
 - (10) Has chosen, or whose representative has chosen, with the demonstration of informed consent, HCBC-ECI services as an alternative to institutional care;
 - (11) Has approved, or his or her representative has approved, with the demonstration of informed consent, the support plan described in He-E 801.05, and the support plan has been approved by a physician or an advanced registered nurse practitioner; and
 - (12) Has signed, or whose representative has signed, an authorization to release information.
N.H. Code of Admin. R. Ann. He-E 801.03.
- 6 Relative to HCBC-IHS eligibility, New Hampshire Administrative Rules provide:
 - (a) In-home supports shall be available to any person under the age of 21 who lives at home with his or her family and who:
 - (1) Is found to be eligible for services by an area agency pursuant to He-M 503.05 for individuals aged 3 to 21 or pursuant to He-M 510 for individuals under the age of 3;

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- (2) Is found to be eligible for medicaid by the Department of Health and Human Services pursuant to He-Ws 601 through 690, as applicable;
- (3) Requires one of the following:
- Services on a daily basis for:
 - Performance of basic living skills;
 - Intellectual, communicative, behavioral, physical, sensory motor, psychosocial, or emotional, development and well being;
 - Medication administration and instruction in, or supervision of, self-medication by a licensed medical professional; or
 - Medical monitoring or nursing care by a licensed professional person; or
 - Services on a less than daily basis as part of a planned transition to more independence or to prevent circumstances that could necessitate more intrusive and costly services; and
- (4) Has a combination of 2 or more individual factors or a combination of one individual factor and one parent factor which complicate care of the individual or impede the ability of the care giving parent to provide care, including:
- Individual factors of:
 - Lack of age appropriate awareness of safety issues so that constant supervision is required;
 - Destructive or injurious behavior to self or others;
 - Condition that significantly impedes the ability of the care-giving parent to provide care;
 - Inability to participate in local community childcare or activity programs without support(s); or
 - Inconsistent sleeping patterns or sleeping less than 6 hours per night and requiring supervision when awake; or
 - Parent factors of:
 - Age of either parent being less than 18 years or above 59;
 - Physical or mental condition which impedes the ability of the care giving parent to provide care;
 - Care responsibilities for other family members with disabilities or health problems;
 - Founded child neglect or abuse as determined by a district court pursuant to RSA 169-C:21; or
 - Availability of only one parent for care giving; and
- (5) Agrees to make the payment toward the cost of care, if applicable.
- (b) A person who is living in an institution or who is receiving services under He-Ms 517 or He-M 522 or He-E 801 shall not be eligible for services under He-M 524.
- (c) The division shall deny in-home supports if it determines that the provision of services will result in the loss of federal financial participation for such services.
- 7** N.H. Rev. Stat. Ann. 161-E.
- 8** N.H. Rev. Stat. Ann. 161-I.
- 9** N.H. Rev. Stat. Ann. 161-I:2.
- 10** Rebecca Crosby Hutchinson, *New Hampshire's Care Gap, The Healthcare Workforce Shortage*, The Direct Care Workforce Initiative, N.H. Community Loan Fund (Feb. 2001).
- 11** New Hampshire Basic Needs and a Livable Wage, Josiah Bartlett Center for Public Policy (2000).
- 12** Rebecca Crosby Hutchinson, *New Hampshire's Care Gap, The Healthcare Workforce Shortage*, The Direct Care Workforce Initiative, N.H. Community Loan Fund (Feb. 2001).
- 13** The Occupational Employment Statistics (OES) Program, *2001 New Hampshire Occupational Employment and Wages* (Jan. 2003). Based on fourth quarter 2001 surveys.
- 14** Employer Health Benefits, 2004 Annual Survey, The Kaiser Family Foundation and Health Research and Educational Trust (2004).
- 15** Paraprofessional Healthcare Institute, *Wage Pass-Through Legislation: An Analysis*, Workforce Strategies, No. 1 (Apr. 2003).
- 16** Paraprofessional Healthcare Institute, *Wage Pass-Through Legislation: An Analysis*, Workforce Strategies, No. 1 (Apr. 2003).
- 17** Paraprofessional Healthcare Institute, *Wage Pass-Through Legislation: An Analysis*, Workforce Strategies, No. 1 (Apr. 2003).
- 18** Paraprofessional Healthcare Institute, *Wage Pass-Through Legislation: An Analysis*, Workforce Strategies, No. 1 (Apr. 2003).
- 19** Internal Revenue Service, Revenue Ruling 2002-41 (July 15, 2002); Internal Revenue Service, Health Reimbursement Arrangements, Notice 2002-45 (July 15, 2002).
- 20** Robyn I. Stone, *Providing Long-Term Care Benefits In Cash: Moving To A Disability Model*, 20:6 Health Affairs 96 (2001).
- 21** 42 U.S.C. § 1396n(c).
- 22** N.O.D./Harris Survey of Americans with Disabilities (2000).
- 23** N.O.D./Harris Survey of Americans with Disabilities (2000).
- 24** N.O.D./Harris Survey of Americans with Disabilities (2000).
- 25** See Ky. Rev. Stat. § 281.870 et seq., Human Service Transportation Delivery.
- 26** Executive Order 2004-6.
- 27** "Section 8" refers to the federal rental assistance program, the Housing Choice Voucher Rental Assistance Program. The program is administered at the federal level by the United States Department of Housing and Urban Development.
- 28** Division of Elderly and Adult Services Home and Community-Based Care Audit Report, New Hampshire Office of the Legislative Budget Assistant (April 2003).

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Chenell Drive - Concord Main Office

21 Chenell Drive
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603.228.9680
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603.225.3304 (fax)

Iron Works Road - Concord

84 Iron Works Road
Concord, NH 03301-2295
603.224.1130
800.470.1130
603.228.5614 (fax)

Franconia

461 Main Street
PO Box 895
Franconia, NH 03580-0895
603.823.5772
800.588.5772
603.823.5402 (fax)

Keene

Emerald Court
100 Emerald Street, Suite B
Keene, NH 03431
603.355.1208
877.680.4826
603.357.2775 (fax)

Manchester

50 Bridge Street, Suite 101
Manchester, NH 03101-1630
603.624.0600
800.733.4033
603.647.0665 (fax)

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23 Factory Street, Suite 6
Nashua, NH 03060-3092
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603.883.5134 (fax)

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