Results from
New Hampshire's LIFE Account
Feasibility Study and Implementation Plan

Published by Community Economic Development Press
School of Community Economic Development
Southern New Hampshire University
2500 North River Road
Manchester, NH 03106

Dedication

This monograph is dedicated to Lauri DeMayo, a quiet leader and advocate in the independent living movement. A firm believer in the LIFE Account concept, Lauri viewed LIFE Accounts as a way to reduce out of pocket medical expenses, act as a savings program to address transportation needs, or a mechanism to help cover insurance premiums for personal care attendants. Unfortunately Lauri's life was cut short due to sudden illness. However, her memory lives on. Thank you Lauri for your work on this project. Thank you to all who volunteered to participate in interviews, focus groups and surveys that made this feasibility study possible.

~

The project staff also wish to express sincere appreciation to Lee Bezanson, Technical Assistance provider, for her exceptional work on this project.

This product was developed in collaboration with the University of New Hampshire, Institute on Disability with funding provided by the Centers for Medicare and Medicaid Services (CMS), Grant No. 11-P-92489/1-01 (CDFA No. 93.779). The contents do not necessarily represent the official opinion of CMS, and no endorsement should be inferred.

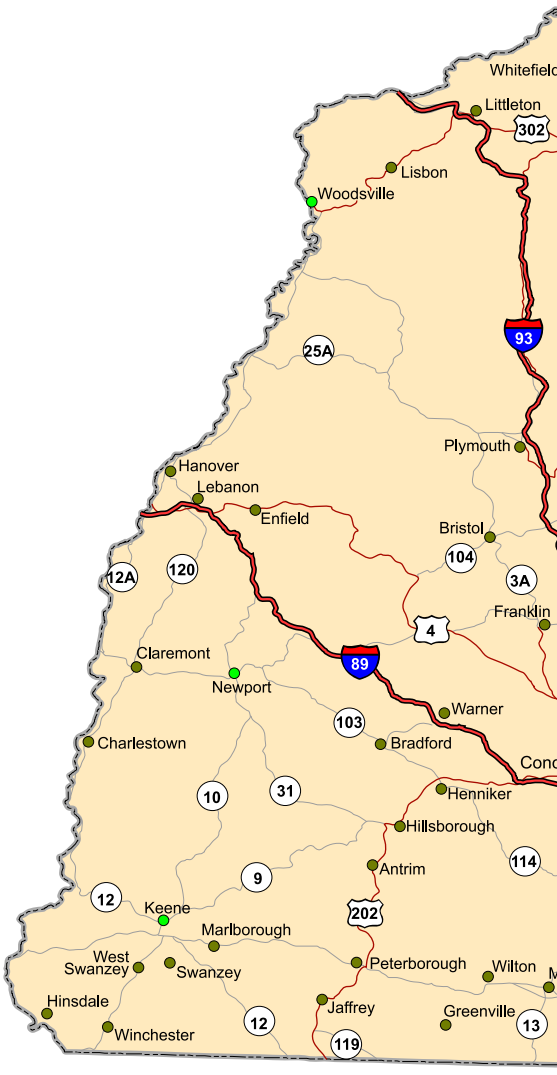
INTRODUCTION

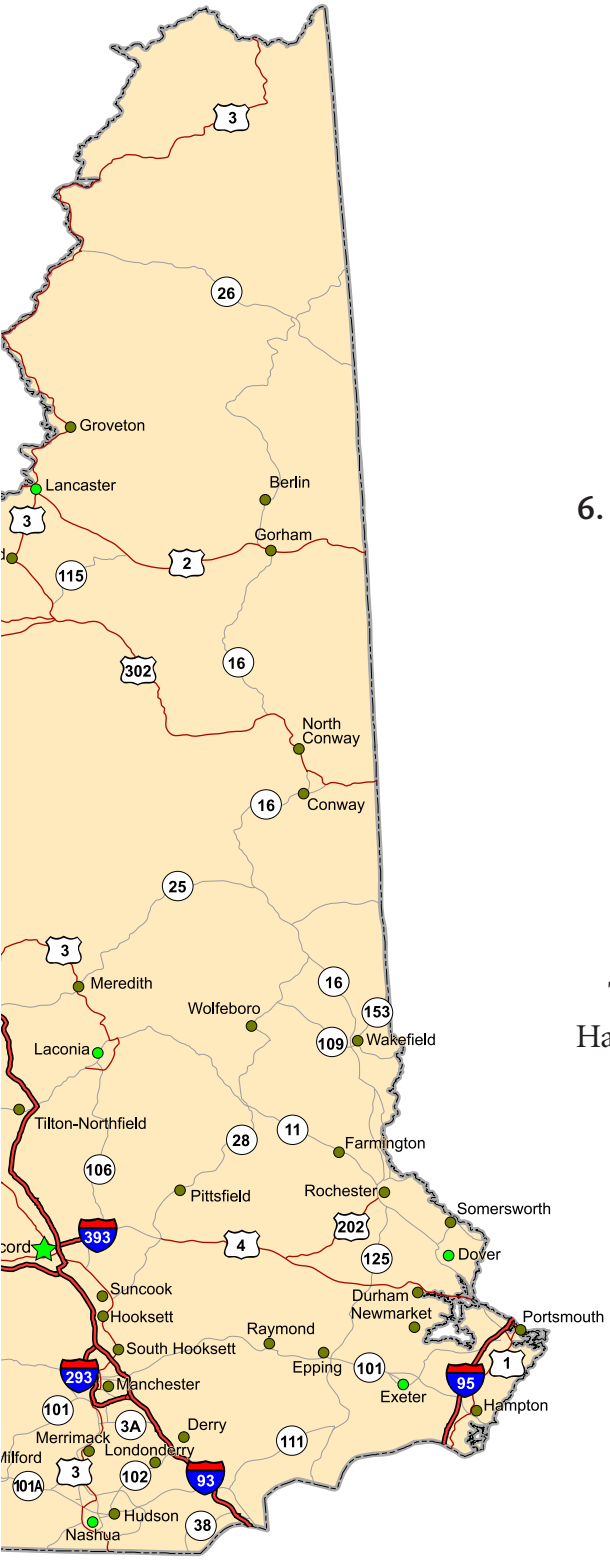
In June 2001, President Bush launched the New Freedom Initiative outlining his clear intent "to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life." As part of this initiative, the President authorized funds for Real Choice Systems Change Grants to states to help design and implement improved ways of providing community supports and services to enable children and adults of any age who have a disability or long-term illness to live and participate in their communities.

The University of New Hampshire, Institute on Disability, and the Center for Community Economic Development & Disability at Southern New Hampshire University were granted a three year award to develop the Living with Independence, Freedom, and Equality (LIFE) Feasibility Study and Implementation Plan. This three-year award was made possible as part of the 2004 Real Choices Solicitation sponsored by the U.S. Department of Health and Human Services, Centers of Medicare and Medicaid Services, Grant No. 11-P-92489/1-01 (CDFA No. 93.779). The project team included Tobey Partch-Davies, M.S., Director, Center for Community Economic Development & Disability; Michael Swack, Ph.D., former Dean, School of Community Economic Development; Steven Mendelsohn, J.D., Senior Tax Researcher; Michelle Winchester, J.D., Institute for Health, Law, and Ethics, Franklin Pierce Law Center; Kathleen Bates, B.A., Policy Advocate; Reginald Giroux, B.A., M.S., Policy Advocate; and Lee Bezanson, J.D., Technical Assistance Provider, Boston College Graduate School of Social Work. The project began October 1, 2004, and commenced as a result of a one year, no cost extension on September 30, 2008.

The goal of the LIFE Account project was to develop a viable savings program for children and adults with disabilities who self direct their own Medicaid funded, community-based, long term care services for the improvement of qualify of life and community participation, without disqualifying beneficiaries from necessary medical or public benefit programs. To that effect, the feasibility study included several policy studies, exploratory research activities, and program design efforts, the objectives of which were designed to capture knowledge and understandings from multiple points of view, including, but not limited to a) individuals and families with disabilities, b) agencies facilitating self-directed services, and administrators of Medicaid programs. Each project element attempted to shed light on relevant policy, program, and cultural implications that may have an impact on LIFE Account viability as summarized below.

1. **Assessment of Asset Accumulation Models of Practice.** This activity area consisted of taking an inventory of available asset accumulation models available in the fields of community economic development and rehabilitation practice for possible integration into the program model. The intent of this work was to guide the theory of change and conceptual framework for LIFE Accounts. The product of this exercise is the publication *Life Accounts & Asset Development: Making Connections in Theory and Practice* by Tobey Partch-Davies. See page 5 for more information.
2. **True costs and benefits of self-directed care.** This article profiles the experiences of individuals with disabilities from a consumer point of view. See page 19 for more information.
3. **Assessment of Federal Tax Policy.** This activity area consisted of an analysis of tax law considerations that must be taken into account, particularly as they relate to resource accumulation, third party contributions, tax favored accounts, and program design recommendations. The product of this exercise is *Federal Tax Implications of LIFE Accounts,* by Steven Mendelsohn. See page 31 for more information.
4. **Assessment of New Hampshire Policy Context.** This activity area consisted of a review of the treatment of existing asset accumulation models in public benefit eligibility, consumer direction in New Hampshire Medicaid, and identification of challenges and recommendations for LIFE Accounts. The product of this exercise is *The LIFE Account & New Hampshire Law and Policy,* by Michelle Winchester. See page 45 for more information.





5. **Primary Research Study.** This study consisted of three parts: a) consumer survey, b) focus group study, and c) key informant interviews. The results of this study indicate that in principle, all stakeholders, including individuals with disabilities, agencies, and bureau administrators agree that LIFE Accounts are a worthwhile instrument for addressing issues related to social inequality of persons with disabilities. However, resource constraints at both the household and systems level of analysis challenge program viability due to the fact that consumers and agencies alike are required to make do with less. These findings suggest that Medicaid funding alone is not enough to operationalize the intended outcome for LIFE Accounts. Implications and recommendations are discussed. The product of this study is *Stakeholders or Shareholders? Findings from the New Hampshire LIFE Account Primary Research Study.* See page 59 for more information.

6. **LIFE Account Feasibility Study and Implementation Plan.** This study is the culmination of the policy analyses, primary research and program design activities for the New Hampshire LIFE Account Study. It includes a discussion of current policy, alternative policy, and the recommending policy action necessary for making LIFE Accounts viable. Finally, implementation efforts are proposed for short and long term needs essential for improving the financial stability, quality of LIFE, and community participation of individuals with disabilities. The product of this study is the *LIFE Account Feasibility Study and Implementation Plan.* See page 79 for more information.

The chapters that follow render the respective findings of the New Hampshire LIFE Account Project.

LIFE ACCOUNTS AND ASSET DEVELOPMENT:

Linking Theory and Practice

By Tobey Partch-Davies, M.S.

Introduction

For many children and adults with disabilities, public benefit programs comprise an essential social safety net. Programs providing cash benefits, housing subsidies, food stamps, fuel assistance, medical insurance, and long-term care play a critical role in meeting individuals' day-to-day needs. However, these programs also present structural obstacles to personal autonomy, and inhibit the ability of individuals with disabilities to participate fully in the broader community. Reliance on public programs often forces individuals to adapt their lifestyle to the services available[1], and forces them to limit their earnings in order to maintain their eligibility for essential healthcare and income supports. The limitations inherent in public benefits programs pose a significant challenge to contemporary disability policy promoting *equality of opportunity*, *full participation, independent living*, and *economic self-sufficiency* (Silverstein, 2000, Olmstead vs. L.C.).

1 It is not uncommon for children with disabilities to attend school out of district, for the number of hours in an adult's work day to be limited by program providers, or for delivery of personal attendant services to be determined by staff availability, rather than by the individual's needs.

To address these challenges, a variety of federal initiatives have been introduced to increase personal autonomy and expand individual choice. These initiatives include the *Ticket to Work* and *Work Incentives Improvement Act of 1999,* the *New Freedom Initiative,* and multiple federal and state demonstration projects that are designed to empower people with disabilities by expanding consumer-directed health care options, and by offering financial incentives for people who work.[2]

This brief explores the importance of linking three autonomy-compatible social welfare programs for persons with disabilities: 1) Medicaid-funded self-directed long-term supports, 2) Social Security and Medicaid work incentives, and 3) Asset Development. While each of these federal programs is designed to promote the social and economic ideals discussed above, we have found that *combining* the practices of these programs offers individuals with disabilities far greater benefits and more desirable outcomes than can be achieved through any one initiative alone. The links between self-directed services, work incentives, and asset building are especially relevant to the LIFE Accounts Savings Program recently proposed by the *Presidential New Freedom Initiative.*

Self-directed long-term supports

LIFE Accounts

The Living with Independence, Freedom, and Equality (LIFE) Accounts Savings Program(s) is part of the Centers for Medicare and Medicaid Services (CMS) Presidential New Freedom Initiative. Under the CMS 2004 Real Choice Solicitation, Wisconsin and New Hampshire were awarded funds over three years to study the demand and viability of establishing LIFE Account savings programs for children and adults enrolled in Medicaid-funded long term service options. *LIFE Accounts are to date a proposition*, envisioned as personal savings accounts owned and directed by individual beneficiaries. This federal initiative conceivably will allow up to 50% of end-of-the-year savings from a self-directed Medicaid community based service budget to be deposited into an individual's LIFE savings account. In addition, outside parties may deposit limited

2 Numerous states have established Medicaid Buy-In options that promote employment by allowing people with disabilities to retain access to Medicaid and earn higher levels of income and accumulate more in savings than previous policy allowed. The Cash & Counseling Demonstration project that tested consumer-directed health care in Arkansas, New Jersey, and Florida is now being replicated in 12 states (11 new states were funded under an expansion of the original Robert Wood Johnson Demonstrations and one new state is being funded by the Retirement Research Foundation). The Social Security Administration is also piloting demonstrations in a number of states, these include: a) Youth Transition Projects testing expanded options for Earned Income Exclusions, Plans for Achieving Self Support (PASS), and Individual Development Accounts and b) Benefit Offset demonstrations for SSDI beneficiaries.

contributions designated for identified eligible uses into the account. A specific intent of Life Accounts is to keep healthcare and cash benefit programs intact while individual savings are accumulated; deposits in LIFE Accounts will be excluded from income and resource tests for Medicaid, Supplemental Security Income, and other means-tested programs (LIFE Accounts-The Next Leap Forward in Home & Community Based Services, 2005.). Federal and state authorizations are required in order to establish LIFE Account Savings programs for beneficiaries.

In the United States, it is extraordinarily difficult for individuals with disabilities to take advantage of economic opportunities; it is hard to imagine another group that is more marginalized. The LIFE Accounts Savings Program represents an important advance in the evolution of Home and Community-Based Services. While the modest savings permitted through LIFE Accounts can be potentially life changing for persons with disabilities; the program does not impose additional costs to Medicaid. LIFE Accounts will enable individuals to accumulate personal savings that can be used to purchase such items as transportation, assistive technology, medical co-pays, and other basic goods and services that are disallowed under Medicaid's current policy.

Emergence of Self-Directed Service Options

Self-directed service options are becoming increasingly popular across the country (Crowley, 2003). Flanagan and Green attribute the origins of these service options to the independent living and disability rights advocates who provided the philosophical underpinnings for consumer-directed models of personal care assistance (Flanagan & Green, 1997). Participant-driven models of long-term care and individual budgeting also have emerged from the developmental disability community; recent examples include the Cash and Counseling demonstration projects, sponsored by the Robert Wood Johnson Foundation and co-funded by the assistant Secretary for Planning and Evaluation, and the Administration on Aging. The success of these programs and of demonstration projects under the New Freedom Initiative, along with the 1999 US Supreme Court decision in *Olmstead v. L.C.,* have resulted in a significant expansion nationally in the use of self-directed service models. These models include Independence Plus waivers, the replication of the Cash and Counseling Demonstration projects in twelve states, and the development of several new Deficit Reduction Act (DRA) State Plan models that offer consumer-directed options.

At the heart of self-directed service options is respect for an individual's autonomy.[3] Persons with disabilities, and families who take responsibility for directing their Medicaid-funded long-term care have greater choice and control over most aspects of their services. This is in sharp contrast to the medical model of long-term care where nearly all decision making responsibility is assumed by professionals. Self-directed service options are based upon the premise that individuals with disabilities and their families are responsible decision makers who are capable of understanding and managing their support needs, including hiring, training, and supervising their direct service workers, as well as directing resources to purchase goods and services that contribute to the individual's autonomy and independence (Crowley, 2003, Mahoney, 2005; Flanagan & Green, 1997).

This paradigm shift in the provision of services affords individuals and families greater freedom and flexibility in managing their support needs in ways that suit their lifestyle and personal preferences. Under self-directed services, individuals and families often work in conjunction with a fiscal agent or intermediary who assists with the administration of individual service budgets, and assumes some employer tasks. For example, fiscal agents may assist with payroll administration, regulatory compliance, program accountability, and compliance with health and safety regulations (Flanagan et al, 1997). Several studies have found increased consumer satisfaction, as well as cost-effective decision making, among individuals who direct their own support services; suggesting that for many people, self-directed service options may offer a more desirable and less expensive alternative to traditional long-term care.

The majority of beneficiaries in home and community based services qualify for Social Security and Medicaid; for this population, lack of employment or underemployment and poverty are common denominators. A LIFE Account Savings Program may provide an incentive for individuals and families who leverage informal community supports and use Medicaid resources effectively. With a LIFE Account, individuals are allowed to accumulate savings for emergencies or to put towards intermediate and long term goals, without jeopardizing the integrity of the home and community based program. The ability to accrue savings would help to cushion financial blows associated with rising prices, especially for fuel, and out of pocket costs for medical expenses that are not reimbursed by Medicaid or Medicare. Savings also could be used to purchase goods and services, such as transportation, that are needed to gain entry into the workforce.

3 In the case of a child, familial autonomy.

A recent study reviewing the purchasing choices of participants in the original Cash and Counseling program found that people who self-directed their services displayed wise purchasing behavior (Mahoney et al, 2005). Individual budgets were used for a broad array of goods and services, including the purchase of used motor vehicles and assistive technology, and to cover out of pocket medical expenses. The study found that participants in self-directed service options made purchases that increased their independence, mobility, safety, and their capacity to perform daily living tasks (Mahoney et al, 2005).

In considering the use of self-directed options for Medicaid funded long-term care, one aspect of personal autonomy is often overlooked. While personal money management is a critical element of self-directed services, many Social Security and Medicaid beneficiaries have representative payees who make financial decisions for them (Cabula, 2004). According to Cabula, the assignment of a representative payee imposes significant restrictions on the ability of beneficiaries to control their own lives (Cabula, 2004).

Representative payees may act on behalf of beneficiaries who are under the age of 18 or who are found to be legally incompetent by a court of law (Procedure and Operations Manual System). In some cases, SSA may determine that particular beneficiaries should be assigned representative payees; however, these decisions can be appealed, and do not carry the same weight as findings in a court of law. For people with developmental disabilities or individuals with substance abuse problems, community agencies are likely to request or be appointed to serve as representative payee. Agency staff who serve as representative payees monitor the person's income and benefits, and are responsible for ensuring timely payment for housing and supportive living arrangements. It can be argued that agencies acting as representative payees provide crucial protection for people with disabilities who might otherwise be financially exploited. These concerns are particularly relevant given changes in bankruptcy laws and credit deregulation that suggest consumers with the least financial knowledge or access to affordable credit options are at greater risk of predatory lending practices and other forms of financial exploitation.

As increasing numbers of people choose self-directed services, it is essential to figure out how to balance the individual's desire for increased independence with the need to provide safeguards for persons who may be at risk of exploitation. Research suggests that education and counseling are the best approaches for accomplishing this. Recent studies found that personal money management and credit counseling improves health outcomes, financial well-being, and money management practices among distressed consumers (O'Neil, B., Sorhaindo, B., Xiao, J., Garman, E.T., 2005). Education and credit

counseling have been found to be particularly effective when conducted on an individualized basis (Elliehausen, Lundquist, and Staten, 2003). In particular, programs that emphasize effective coping skills and offer help with financial management practices can increase an individual's sense of personal control (Into, 2003). People with disabilities must be given opportunities for economic advancement that validate their role as consumers, mitigate financial risk through education and counseling, and help them to establish credit with credible financial institutions.

Social Security and Medicaid work incentives

A number of work incentives exist for individuals and families in current Social Security and Medicaid policies. These incentives are designed to promote employment and greater economic self-reliance among beneficiaries. A study sponsored by the Social Security Administration, the Vermont Division of Vocational Rehabilitation, and Dartmouth College found that were significant increases in the mean earnings for Social Security Disability beneficiaries who received benefits planning services, even when controlling for demographic predictors, such as the type of disability, age, and gender (Tremblay, Smith, Xie & Drake, 2002; Tremblay & Smith, 2004). Those who received benefits planning services increased their quarterly earnings from approximately $540 at the time of enrollment, to $900 per quarter (Tremblay *et al,* 2004). In designing a LIFE Account Savings Program, it is important to identify existing wage and savings incentives in current policy in order to effectively link resources across programs, and address potential undesirable outcomes associated with implementation. While there are a number of work incentives that could complement LIFE Account Savings, this section considers those incentives designed to promote substantial elevations in income and accumulation of resources.[4]

Social Security Disability Insurance (SSDI)

To be eligible for SSDI, individuals must be determined medically disabled, have earnings below the federal Substantial Gainful Activity level (2006 SGA level is $860; for recipients who are blind it is $1,450), and have paid enough quarterly Social Security taxes (FICA) to have "insured" status. Adults with disabilities who are not eligible for insured status may still be eligible for Social Security under the Disabled Adult Child (SSDAC) category. A beneficiary's SSDI or SSDAC check is based primarily on the amount of taxes contributed to the Social Security system.

4 This brief only summarizes the work incentives. For more details, please visit www.ssa.gov to access The Red Book on Social Security Work Incentives. Also reference the Medicaid State Plan for state specific Medicaid information on resource and income standards and long-term support options.

Plans for Achieving Self Support (PASS)

PASS is a mechanism that allows children and adults eligible for SSI or SSDI (and who could qualify for SSI) to temporarily shelter income or resources for an identified employment goal intended to increase the person's economic self-reliance. To utilize this program, the beneficiary must submit a PASS to the Social Security Administration that includes: a) a feasible employment goal, including an occupational title and estimated earnings; b) steps for measuring progress on the employment goal, c) a timeline for completion, d) sources and uses of the income or resources set aside in the PASS account, and how these will be used to fulfill the employment goal; and e) anticipated expenses that include how these costs were calculated.

PASS has proven to be an effective means for allowing beneficiaries to accrue savings to purchase the goods or services necessary for obtaining employment; the result has been a higher level of economic self-sufficiency for these individuals. Given the intent of the program, PASS cannot be used to accumulating savings for home ownership or other property or equipment, unless these can be justified as necessary for achieving an employment goal.

Student Earned Income Exclusion (SEIE)

SEIE is a work incentive option (available to people under the age of 22 who qualify for SSI and who regularly attend school. SEIE allows students to exclude up to $1,460 in 2006 of earned income per month before applying the Earned Income Exclusion (a general exclusion of $20 and an earned monthly income exclusion of $65). SEIE and Earned Income Exclusion can be used in combination; however, the maximum annual exclusion is $5,910. Students apply for the SEIE at their local SSA office, and are required to regularly submit a statement of school attendance, employment records, and pay stubs.

1619(a) and (b)

Section 1619 of the Social Security Act is a special benefit status for recipients of Supplemental Security Income (SSI) who earn in excess of Substantial Gainful Activity (SGA). 1619(a) status allows people who meet the SSI definition of disability to receive SSI payments and Medicaid benefits when their earnings are above SGA, but below the SSA's Break Even Point (BEP). 1619(b) allows for continued Medicaid eligibility for people who no longer are eligible for SSI cash payments due to earned income above BEP levels, but below the threshold amount. The threshold amount is the income test for financial eligibility for the 1619(b) program, which is $38,727. 1619(b) also maintains SSI eligibility for cash benefits should the beneficiary's earnings fall. If beneficiaries' earnings rise above threshold amounts, if a medical recovery is determined, or if resources are in excess due

to unearned income, they may be disqualified for the program. (Note: In this instance, so long as the individual maintains employment, it is very likely that they would be eligible for the MEAD program; although the connection to the SSI cash benefit program would be lost and the individual would be required to seek medical redetermination for eligibility should they lose their job).

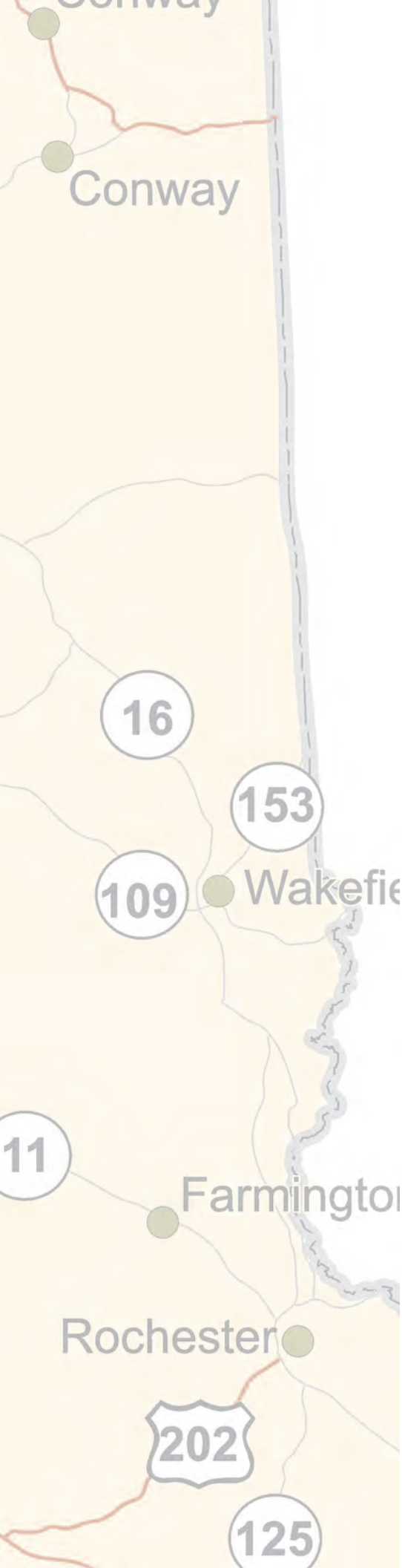
Although under 1619 (a) and (b) allowable income limits are quite high, resource limits remain at $2,000 for an individual receiving SSI, and may be less for Medicaid recipients depending upon which program for which they qualify. If the beneficiary is eligible for Home and Community Based Services and will be self-directing under this option, he or she may be required to contribute to the cost of care. Medicaid programs and the resource limits will vary from state to state.

For example, people who qualify for straight Medicaid would follow the Section 1619 as noted above. However, if income from other sources is higher than income limits in the regular Medicaid program, the individual may qualify under "Medicaid In and Out", and have a "spend down" they must meet in order to qualify for Medicaid each month. Individuals whose medical needs qualify them for Home and Community Based Services under the Developmental Disability Services; Acquired Brain Disorder Option; or the Elderly and Chronically Ill waiver, and whose monthly income is higher than their standard of need, are responsible for paying a "cost of care" based upon personal income.

The Assets for Independence Act-Individual Development Accounts (see below) under the Social Security Protection Act of 2003 provides an incentive for 1619(b) beneficiaries to deposit earned income, thereby reducing their countable income, and potentially re-qualifying them for SSI cash benefits. This option allows beneficiaries to deposit as much of their earned income in an AFIA-IDA as possible (CFED, 2002), and also allows them to save in a PASS. For example, a 1619 (b) beneficiary could have an AFIA-IDA designated for a first time home purchase and save in a PASS for an employment goal. Both savings options are temporary and intended to improve an individual's ability to improve economic self-reliance and reduce dependence on public benefits.

Medicaid Buy In Programs

Medicaid Buy In programs are different from other Medicaid assistance categories in that states have the option to establish a higher level of earned income and savings from earned income than are allowable in the regular Medicaid program and in Home and Community Based Service options. These programs have substantially improved the financial landscape for beneficiaries. Prior



to the establishment of Medicaid Buy In, workers with disabilities – even those considered under-employed – risked losing vital Medicaid health care coverage if they earned or saved too much.

Asset Development

Increasingly, asset development is considered a necessary component of contemporary welfare policy (Sherraden, 1991). According to Sherraden, income-only solutions to welfare in the form of transfer payments (i.e., Temporary Assistance to Needy Families, Supplemental Security Income) are only part of the equation, and may encourage consumption and dependency rather than personal savings and self-reliance. Research on asset development initiatives has found that people who earn low incomes are capable of saving money, and that having an Individual Development Account has positive social and economic outcomes, including economic stability and increased civic participation and community involvement (Beverly, S., & Sherraden, M., 1997).

Over the past few years, the development of inclusive asset building initiatives for persons with disabilities have become a priority among advocates and other stakeholders (TWWIIA Panel, March 2005). Rule changes within Social Security brought about through the 2003 Assets for Independence Act (AFIA), the Balanced Budget Act of 1997, and the Ticket to Work and Work Incentives Improvement Act of 1999, create the opportunity for people to accumulate savings from employment while still maintaining their eligibility for federal benefit programs including Medicaid, Food Stamps, and some subsidized housing programs (CFED, 2002; Sweeney, 2004).

There has been a growing interest among scholars to research the effectiveness of asset development to address the needs of people with disabilities; of particular interest is the effect that asset accumulation has on empowerment, self-sufficiency, and economic self-reliance (Putnam, M., Sherraden, M., *et al,* 2005).[5]

Across the country, disability service organizations, community development credit unions, community development financial institutions, and volunteer income tax assistance programs are engaging in a variety of collaborative initiatives. These efforts include the Asset Accumulation and Tax Policy Project sponsored by the National Institute on Disability for Rehabilitation Research; Tax Facts, a national multi-site pilot study with the Internal Revenue Service and the Ford Foundation; and several Youth Transition Projects sponsored by the Social Security Administration. These and other tax credit programs are often combined with Individual Development Accounts (see below) to help low-income individuals and families.

5 Putnam, M., Sherraden, M., Edwards, K, Porterfield, S., Wittenberg, D., Holden, K., Saleeby, P.W.. Building Financial Bridges to Economic Development and Community Integration: Recommendations for a Research Agenda on Asset Development for People with Disabilities. Journal of Social Work in Disability & Rehabilitation, Vol. 4(3) 2005.

Individual Development Accounts

Individual Development Accounts are temporary matched savings accounts for workers who earn at or below 200% of poverty and who have liabilities under $10,000 (excluding a primary home and primary vehicle). The majority of IDA programs have been established as a result of the Assets for Independence Act (AFIA), a federal program that provides matching funds to eligible participants who are saving for first time homeownership, business, or post-secondary education. IDA participants make a minimum monthly savings deposit with a participating institution, which is later matched and accumulated in a reserve fund. IDA participants receive financial education and attend regularly scheduled asset based trainings that are specifically geared to their goal. For example, a person who has an IDA for a home purchase would participate in first time home buyer education and training on household maintenance. (While these accounts provide a valuable opportunity to develop assets, it is important to point out that an individual must have income from earnings in order to open an IDA.)

Currently, only TANF-IDAs and AFIA-IDAs are excluded from resource tests for Supplemental Security Income, and other federal benefit programs, including Medicaid, Food stamps, Section 8 housing, etc.[6],[7] Privately funded IDAs are available and offer savings that can be used for a variety of purposes including home repair, automobile purchases, and job training. There are private programs that are structured specifically for the working poor, including families who earn too much to qualify for AFI-IDA. Unfortunately, SSI and Medicaid *include* privately funded IDA's in their resource calculations; this could potentially disqualify individuals with these accounts from receiving SSI or Medicaid benefits.

A LIFE Account could augment assets made possible through the AFIA-funded IDA's by building reserves that would help to cover home maintenance expenses, resources to reinvest in businesses, or tuition or supplies necessary for post-secondary education and training. Moreover, LIFE Accounts could accept limited contributions from private IDAs to substitute as deposits of earned income – a source of savings for a much needed purchase, and something that currently AFIA-funded IDA's do not allow.

6 For more information about the treatment of IDAs in federal benefit programs, refer to the 2002 Federal IDA Briefing Book: How IDAs Affect Eligibility for Federal Programs. Corporation for Enterprise Development.

7 See Social Security Administration Program Operations Manual System (POMS) at http://s004a90.ssa.gov/apps10/poms.nsf/aboutpoms.

Earned Income Tax Credit

The Earned Income Tax Credit (EITC) reduces the tax burden for low and moderate income workers, supplements wages, and provides an incentive for employment (Lopez-Soto & Sheldon, 2005; Center for Budget and Policy Priorities, 2005). EITC refunds are generally excluded from resource tests in federal benefit programs because they are not considered income, and are only counted as a resource after nine months from the date they are received. For the 2008 tax season, workers who have two or more children at home, and have earned income of $38,646 could claim an EITC of up to $4,824. Workers who have more than one child at home and have an income of $33,995 are eligible to receive a credit of as much as $2,917. Workers between the ages of 25 and 64, with no qualifying children and whose incomes are below $12,800, can qualify for a credit of up to $438.

Although eligible households can claim the credit at any tax filing site, the IRS SPEC Offices support free Earned Income Tax Credit outreach and tax filing services in every state through designated community based Volunteer Income Tax Assistance programs. Volunteers are trained and certified in tax law, and prepare tax returns free of charge. Other private organizations, including the American Association of Retired Persons (AARP) also provide tax filing assistance for seniors and people with disabilities. A number of these tax filing programs have gone on to build coalitions to help individuals maximize their refunds by linking them with financial institutions, IDA programs, affordable housing efforts, and responsive lending programs.

Summary

In recent years, a number of federal and state initiatives have been developed to help people with disabilities and their families exercise greater choice and control over their resources. Unfortunately, these programs are complex to navigate and vary considerably from state to state (e.g., Medicaid, IDA programs). As self-directed models of long-term support become more widely available, attention must be directed to helping individuals with disabilities and their families with everyday financial decision making.

To become economically self sufficient, people with disabilities must be able to compete in the labor market without losing vital benefits, and have access to financial education, counseling, support, and saving options that can help them maximize their income. This will require rethinking the use of representative payees for individuals with disabilities. Historically, representative payees have protected vulnerable people from financial exploitation; in our current landscape, representative payment services must be reevaluated to

determine how they can assist people with disabilities to establish a positive credit history, understand and access supports for managing their financial affairs, take advantage of work incentives, and access money management strategies.

Moving forward, benefits planning must be included as a critical component in establishing asset development options. Offering individuals the opportunity to accrue savings and providing them with individualized financial counseling substantially improves economic self-reliance, while decreasing reliance on public benefits. LIFE Accounts, in coordination with other asset accumulation efforts, hold great promise for not only improving financial security, but also for increasing personal autonomy and enhancing an individual's quality of life.

References

Beverly, S., & Sherraden, M. (1999). Institutional determinants of saving: Implications for low-income households. *Journal of Socio-Economics,* 28, 457-473.

Cebula, R. (2004). Policy and Practice Brief: Representative Payment. Employment and Disability Institute Collection. Ithaca, NY: Cornell University.

Cebula, R. (2004). Work Study and Supplemental Security Income (SSI). Employment and Disability Institute. Ithaca, NY: Cornell University.

Crowley, J. (2003). An overview of the independence plus initiative to promote consumer-direction of services in Medicaid. Kaiser Commission on Medicaid and the Uninsured. Washington, D.C.: Georgetown University.

Flannagan, S.A., & Green, P.S. (1997). Consumer-directed personal assistance services: Key operational issues for state CD-PAS programs and using intermediary service organizations. Cambridge, Ma: The MEDSTATE Group.

Lombe, M. (2006). Social participation and rural/vulnerable communities: Does asset ownership matter? Independent Living Research Utilization.

Lopez-Soto, E. and Sheldon, J. (2005). The Federal Earned Income Tax Credit: A work incentive that puts more money in a paycheck and saves on taxes. Ithaca, NY: Cornell University.

O'Neill, B., Sorhaindo, B., Xiao, J.J., & Garman, E.T. (2005). Health, financial well-being, and financial practices of financially distressed consumers. *Consumer Interests Annual,* Vol. 51, 80-82.

Putnam, M., Sherraden, M., Edwards, K., Porterfield, S., Wittenburg, D., Holden, K., Saleeby, P.W. (2005). Building financial bridges to economic development and community integration: Recommendations for a research agenda on asset development for people with disabilities. Journal of Social Work in Disability and Rehabilitation, Vol. 4(3), 61-83.

Sheldon, J.P., Golden, T.P. (2004). The Benefits Planner: Assistive Technology Can Make Work A Reality – Funding for Work-Related AT Through Special Education Programs, VESID, Medicaid, Medicare, and SSI's PASS Program. Employment and Disability Institute Collection. Ithaca, NY: Cornell University.

Sheldon, J.P., and Golden, T.P. (2004). The Benefits Planner: Public and Subsidized Housing – Housing Subsidies and Work Incentives for Tenants with Disabilities. Employment and Disability Policy Institute Collection. Ithaca, NY: Cornell University.

Silverstein, Robert (2000). Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy. *Iowa Law Review,* Volume 85/No.5.

Smith, J., Tremblay, T. (2004). Social Security Administration State Partnership Initiative, Year Six Report. Vermont Work Incentives Initiative. Vermont Division of Vocational Rehabilitation.

Uttermohlen, T., Miller, L. (2003). *Special Medicaid beneficiaries.* Vol.10, Updated January, 2006. Richmond, VA: Virginia Commonwealth University.

Mahoney, K. & Bezanson, L. How the cash & œunseling experience may inform the New Hampshire LIFE account grant prepared for New Hampshire LIFE account policy forum. June 29, 2005.

THE TRUE COSTS AND BENEFITS OF SELF-DIRECTED CARE

by Kathleen Bates, B.A.

The American Dream is "that dream of a land in which life should be better and richer and fuller for everyone, with opportunity for each according to ability or achievement."

—James Truslow Adams

I know when James Truslow Adams wrote about the American Dream in his 1931 book, *Epic of America,* he was not talking about me or anyone else who is part of the 20% of Americans who have disabilities. For much of our nation's history, people with disabilities have been condemned to a life of misery and isolation, often forced to live in institutions apart from their community.

Today things have changed. Groundbreaking legislation and policy advancements such as the *Americans with Disabilities Act,* the *Olmstead Act,* and President Bush's *New Freedom Initiative,* along with the development of community-based supports and the Independent Living movement, have made the American Dream possible for *all* citizens. While the door of opportunity has been opened, we as a society still need to learn how to value all human potential, especially that of people who live with disabilities. This something that should be important to everyone, as disability does not discriminate. Disability is found in every culture and at every

level in society. At any time, any one of us could sustain a disability.

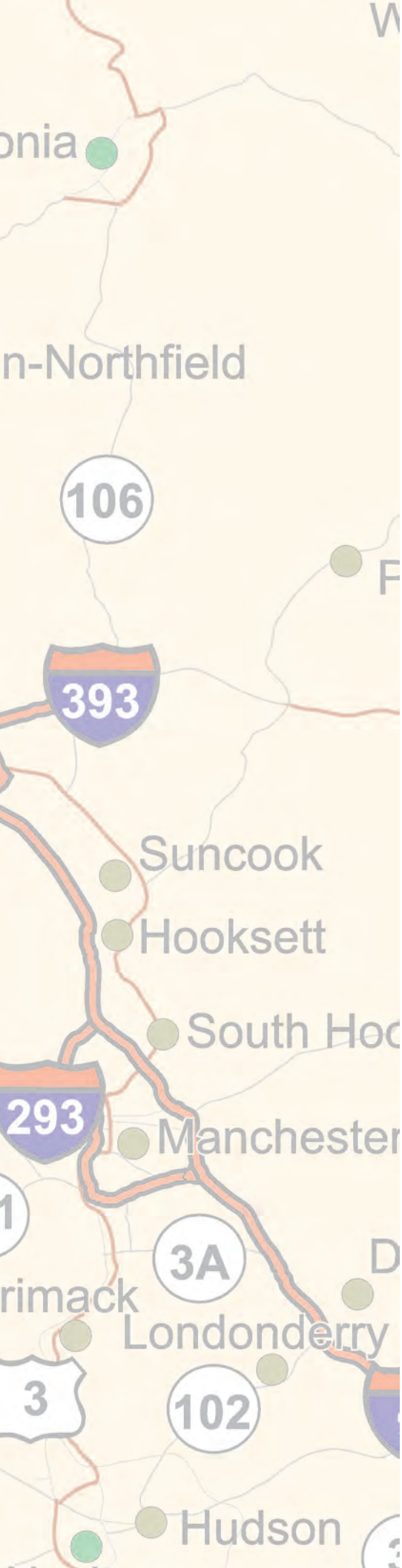
My dreams are very ordinary. I want a life that includes working in a job that makes me happy, owning my own home, and having family and friends with whom to share my life. I want to have enough money to pay my bills, to take a real vacation once in a while, and to be able to retire and still live comfortably. Most importantly, I want to be able to choose my own path. This can be difficult for anyone, but it is especially challenging when you rely on the assistance of personal care workers to help you meet your most basic needs, including getting out of bed, showering, and dressing.

Despite my disability, I do not believe in the concept of independent living. More accurately, I believe in "interdependent living." It takes a lot of support to live in the community and each of us depends on someone else to succeed. Support comes in many forms. Natural support is the neighbor who gets your mail or the brother who plows your driveway in the winter. Agency support is the nurse from the home-health care agency who checks in on you and takes your blood pressure. Consumer-directed support allows the individual with a disability to interview and hire his/her own personal care workers. For many people who require a combination of services, one kind of support is not adequate. Too often, support systems do not include back up coverage for when care providers fail to show up. Like others who live with a disability and rely on support every day, I have to develop my own backup plan for when support systems fail.

This article explores the challenges people who have disabilities experience when managing their personal care programs. It also examines the positive aspects of choosing self-directed care.

Long-term care options

When you think of long-term personal care options, imagine a spectrum. At one end is institutional care, such as a nursing home where personal care might be guaranteed, but the individual has little or no say in when and how this care is delivered. At the other end of the spectrum is fully consumer-directed support where the individual is completely in charge of managing his or her care. Programs providing consumer-directed care are based upon the philosophy that the person who experiences the disability is the expert about that disability and about his or her own life and unique needs. These programs believe that the individual is the one most qualified to direct his or her personal care. The long-term care programs lying between these two ends of the spectrum offer services with varying degrees of consumer choice and control.



Granite State Independent Living (GSIL) administers New Hampshire's Personal Care Attendant (PCA) program, a consumer-directed option for people needing long-term care. To access this program, an individual must be eligible for New Hampshire Medicaid, have a severe physical disability, and use a wheelchair for mobility. People receiving services through the PCA program must need at least two hours of hands-on personal care a day, including assistance with range of motion exercises and activities such as showering, dressing, and using the bathroom. Participants must be at least 18 years of age, their own legal guardian, and able to self-direct their care.

Individuals also may receive consumer-directed personal care services through Medicaid's Home and Community-Based Care waiver (HCBC). This waiver is intended to allow individuals who might otherwise be placed in institutional settings to receive supports that enable them to live in their community. The waiver includes a Personal Care Service program (PCSP) that is similar to the PCA program, except supports are also provided in community settings, not just in the person's home. For example, PCSP workers can drive individuals to work or take them grocery shopping. An authorized personal care service representative can assist individuals who are unable to self-direct their care. In New Hampshire there are several agencies that are certified to provide PCSP services. Children with disabilities who are eligible for the Developmental Disabilities waiver also may receive PCSP services; parents are responsible for managing the PCSP workers who assist their children.

Agency-directed care and consumer-directed care share similarities, but also have some key differences. To be admitted to either an agency-directed or consumer-directed program, a person must have a medical assessment that is conducted by a nurse. The assessment identifies the services needed and the time required to provide this support; this information becomes part of the individual's service plan. Both agency-directed care and consumer-directed care require a 60-day check-in; the individual's doctor is asked to certify the need for personal care supports. With agency-directed care, the individual does not hire his or her personal care workers and often does not even meet workers before they arrive to provide personal care services. In agency-directed programs, such as traditional home health care services, personal care workers must be licensed nursing assistants. This is not a requirement for individuals using self-directed care, and as a result, those directing their own care have a larger pool of workers from which to choose.

It should be noted that while self-directed care offers the individual greater choice and control, it is not for everyone. Managing your own personal care programs is a lot of responsibility and can be very stressful.

To meet my personal care needs, I use different types of services. I have a PCA program through Granite State Independent Living, and with this agency, I am a co-employer for those who provide my care. In the PCA program, I place ads in the newspaper, interview applicants, hire, and manage my personal care workers. GSIL handles the workers' compensation, background checks, and tax information for my employees. I also use Smart Care, a PCSP program that is consumer-directed. Again, I am the one who decides who works for me and I participate in the development of my care plan. In this case, however, I choose from applicants who have already been interviewed and hired by an agency. Because it has been difficult for me to find workers for afternoons when I don't need as much help, I work with a health care agency; they send a home health aide to help me with lunch and using the bathroom. I don't advocate for one service over another; I have been fortunate to have a variety of personal care options and I need them all in order to live successfully in the community. Even with all of these options, there are still times I need to call on my friends and family for backup help.

All across New Hampshire there are people who depend upon personal care services, here are four of their stories.

Daniel has to get to work

It's 6:00 am and Daniel's personal care attendant has just called in. She says her car has broken down on the highway and she won't be able to come and help him with his morning routine. Daniel, who has a spinal cord injury, said when he doesn't have the help he needs to get out of bed, "It throws a whole monkey wrench into it. For health reasons, this can cause some serious problems. If I don't get out of bed, that can cause respiratory problems. If I don't get moved, that can cause pressure problems with my skin. And I miss work, so it affects my income. It throws off basically the whole day. It could throw off the whole week."

There have been a number of occasions when Daniel has enlisted friends and family members to assist him with his personal care needs. He has a good backup system, but noted that asking for help can put stress on his personal relationships, "That affects someone else's life and that can cause a whole host of other problems."

Daniel finds that the biggest challenge to managing his personal care program is recruiting workers. Personal care assistants are paid a

low hourly wage and receive no benefits. Daniel said it is hard competing with other low-paying employers like Wal-Mart, where workers don't have nearly as much responsibility. Daniel has had some luck finding workers who take the job as a stepping stone to entering the medical profession. But nursing students who work as personal care attendants while in they are in school, eventually graduate and move on to a better paying positions.

Daniel considers self-directed care a great option because it offers flexibility and can either be used independently or be combined with agency-driven care. He cautioned, however, that self-directed care requires a significant personal commitment. Daniel devotes five to ten hours a week to recruiting his workers, completing timesheets, and other tasks related to managing the staff who work for him. Daniel finds that working with a traditional home health agency is fine for support at home, but does not offer the flexibility he needs for support at his job. At work, Daniel uses self-directed personal care for assistance with lunch, using the bathroom, and administrative assistance. He said, "This allows me to function and hold down a job – just like everyone else. When the system works, it works very well."

Priscilla's rent is going up

Priscilla, who lives in an assisted living community, says she is 92 years young. Her apartment is beautifully decorated with paintings and sculptures that she created. With her rent going up, Priscilla says she is worried she will have to move to a nursing facility that accepts Medicaid. With a little smile and a gleam in her eye, Priscilla told me, "I hope I run out of me before I run out of money."

Last fall Priscilla became gravely ill. On her doctor's recommendation, hospice came into her home to help her with her care. Priscilla said, "My workers were so nice, but I improved instead of dying, so they decided to graduate me." Hospice care was discontinued, but Priscilla had grown accustomed to the extra help and companionship. Through a friend, Priscilla met and hired Emily, who now comes in regularly to help. "She is a good companion. She's a good worker," Priscilla said. "I consider her my friend." Priscilla decides how she spends her days, and because she can afford to employ Emily with her own money, Priscilla enjoys many freedoms that her neighbors do not. "She takes me in her car to my doctor or dental appointments," Priscilla said. "Sometimes we go to an art show or do something else I really want to do. She liberates me."

Annie wants to be more involved with her community

Annie is very friendly and loves visiting with her neighbors when she is out doing errands. Annie has a degree in Behavioral Science and was employed for a short time as a peer facilitator. While Annie has

volunteered for organizations that focus on disability issues, she really would like to become involved with her hometown's Main Street program. Annie said with a bit of frustration, "I know it is hard for people with disabilities to get jobs, but I am just as concerned about not being able to make a volunteer commitment, if my personal care attendant isn't there to get me out of bed."

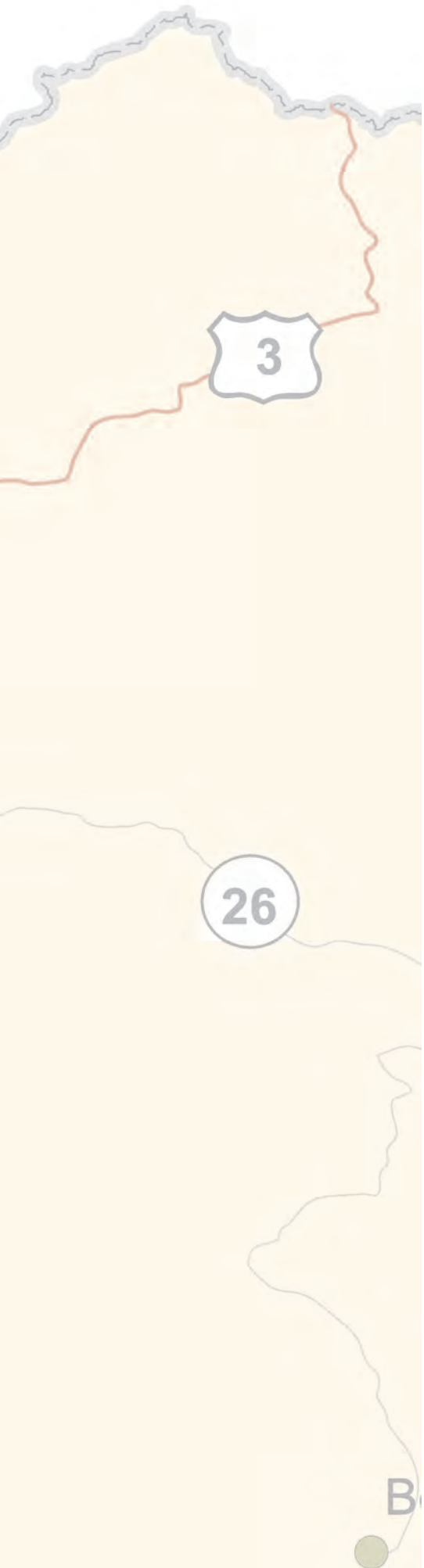
Self-directed care is important to Annie because it allows her to have a say in who works for her. She wants her personal care workers to understand that she relies on them to accomplish her goals. "My goals are pretty simple: to be a productive citizen in my community whether I get paid or not."

There are many reasons why finding and keeping a job is a challenge for people who have disabilities. Those of us who rely on personal care assistants are afraid that we will let employers down if we are unable to get to work. It is not like calling in sick, you're fine; you just can't get out of bed. It's frustrating. In Annie's case, paid employment is not the issue. She wants a fulfilling life doing something that is meaningful to her. Working or volunteering in the city where she has lived for 42 years is important to her, but it is impossible without reliable personal care. "Knowing I have reliable PCAs is a win-win situation," Annie said. "If I am happy with the work they do, they in turn are happy. They help me to be able to go out in my community and show the outside world that I am just as important as any other member of society."

Life Is Complicated

Mary, a mother of eleven-year-old triplets, isn't sleeping well. She's lying in bed, listening for Amy her daughter who has cerebral palsy, has no neck control, and if she rolls over, her head may get stuck between the mattress and the wall - a situation that can be life threatening. Amy is non-verbal, but able to make enough noise to let her mother know she needs her. When Mary hears Amy, she goes in and re-positions her, and returns to bed. Before Mary can fall back asleep, her son, Jacob, who also has cerebral palsy, crawls into the room. Mary gets up and helps him get to the bathroom.

Even on a full night's sleep – something that rarely happens – mornings in this household are demanding. While Mary gets her other daughter Alice, who has attention deficit hyperactivity disorder up and ready for school, a licensed nursing assistant comes to help with Amy and Jacob. Both of these children use power wheelchairs, wear body jackets for support and to correct their scoliosis. Amy has difficulty swallowing and uses a feeding tube. Jacob can feed himself, but needs a feeding tube when he is ill. Both children take numerous daily



medications that Mary prepares for them. Mary said that on the mornings when she has no support, "Nothing else gets done. I am there totally as a caregiver. I'm not really even a Mom."

Finding and keeping support workers is a challenge. Mary said, "We are on number forty-two for staff – my husband just numbers them now. We've gone through about thirty others that just couldn't handle it." The family uses a healthcare agency to place ads in local newspapers and take care of background checks and worker's compensation. Mary is responsible for interviewing, hiring, and managing Amy and Jacob's caregivers. She spends about six hours a week scheduling and communicating with support staff. "I want them to really be there and look at us as a family. If Jacob says he needs to use the bathroom, then they need to be able to get Amy settled and take Jacob to the bathroom."

While Alice, Amy, and Jacob have special needs, they are typical in all the ways that matter. They each have their own friends and interests. Amy loves books, plays, and musicals. Jacob likes action movies. Alice loves hip-hop music and dancing. Mary has worked hard to make sure her children have the same opportunities as children who don't have disabilities. This hasn't always been easy. When the triplets were in the second grade, Mary tried to enroll them in religious education classes. Three different churches refused to allow Amy and Jacob to participate in classes because of their disabilities. Eventually the family found a church that welcomed the children and they were able to make their first communion. The special needs religion class that the church created also was able to accommodate several other children with disabilities who were in the congregation. "Father Bob really put his neck on the line for us," Mary said. "He was told by the Bishop that he could lose his job if he did this. He did it anyway."

Despite all the time and effort required, Mary plans to continue to manage Amy and Jacob's care until they can do this for themselves. "The more visible my kids are, the more accepted they will be," she says. "We want to be recognized as a family first, not as the family with the disabled kids. That's only part of who we are, but that's not all that we are."

They work for me because they like me.

Lucy, who is self-employed, is a teacher and an advocate. She leads an active life despite needing a wheelchair to get around. "The hardest part about living on your own," she said, "is hiring personal care attendants."

Last year Lucy spent $340 on newspaper ads for personal care attendants. "Sometimes no one answers ads for weeks and you have to

hire the first person who comes to the door, even if your gut tells you that it is not going to work out," she said.

Lucy talked about what happens when things don't work out, "My care attendant failed to show up for her evening shift. I had to go to my neighbor, who at the time was a complete stranger and ask for help. I had not been able to go to the bathroom for 12 hours and I would not have been able to go to bed. I was lucky that my neighbor had some experience in personal care assistance and was able to help me. This was not the only time that something like this has happened to me."

Two weeks later, Lucy offered her neighbor a job as a personal care attendant and she accepted. This was only possible because Lucy self-directs her care and is able to choose who she hires, something that is not an option with agency-directed care. Lucy observed, "Self-direction is really hard sometimes, but on the other hand, I have met some incredible people that ended up working for me because they like me, not because an agency told them they had to work for me."

What should be done?

Inevitably, if you have a disability, you lose some freedom and choice. Being able to direct your own care gives you back some of that choice and control. While managing personal care can be stressful and complicated, and there are times when the system fails, many of us who have disabilities still find that the benefits of self-directed care outweigh the drawbacks.

"Community-based care is a great option," Daniel explained, "I think the state should look hard at investing in the (Medicaid) infrastructure because it's a cost effective way to provide services. It's just another option for folks – it gives people more choice." Generally, community-based supports are less costly than institutional settings. Work force issues, however, present very real challenges to providing quality care. At the heart of quality community services are the direct support workers who, in many cases, are not paid a livable wage and do not have health care or other benefits. Currently there are direct support workers whose salaries are so low that they qualify for public assistance; of nursing home aides and home health aides who are single parents, 30-35 % receive food stamps.[1] To meet the growing need for community-based care will require investing in the workforce. Offering higher wages, training, and benefits would make direct care a respected profession and a viable career choice.

Full participation in the community is everyone's right. We must continue to make the public aware of the importance of providing

[1] William J. Scanlon, *GAO Testimony: Nursing workforce: Recruitment and retention of nurses and nurse aides is a growing concern* (Washington, DC: General Accounting Office, May 2001).

quality community-based services, and offering people the opportunity to manage their own supports. One of the best ways to advocate for ourselves and for our families is to educate our elected representatives. Mary talked about hosting legislative coffees, "My representatives have met my kids. I discussed with them the fact that I am *expected* to be a caregiver because my children have disabilities. This is something I can't get paid for. The way the system is set up now my children will never leave." Mary also has written letters to representatives and testified at legislative hearings about New Hampshire's lack of nursing care. Mary would like her children to live as independently or interdependently as possible. When her children become young adults, she would like to see them be able to leave home and go out on their own. With the right supports Mary feels they can succeed.

Those interviewed shared their frustrations with the lack of adequate back-up support for personal care. Lucy said, "New Hampshire needs a statewide back-up system for direct supports, some place that people who have disabilities can call if their support worker fails to show up. It would be a dream come true to have all the organizations that provide direct support come to the table to figure out this vital issue. We need to create a system where you could call a toll free number and talk with a real person who could help you connect with someone in your community who would provide direct support when it is needed. A provider network that is similar to New Hampshire's transportation collaborative could be the solution. It would be good for everyone; workers could get more hours and people with disabilities would get their needs met."

With advances in medicine and technology, people are living longer, and as a result, requiring more supports and services over a longer time period. As we move away from the medical model and the inevitability of nursing home placements for older adults and individuals with disabilities, quality in-home supports and services will become more important for everyone.

How can LIFE Accounts help?

As part of his 2004 New Freedom Initiative, President George W. Bush proposed the Living with Independence, Freedom, and Equality (LIFE) Account Feasibility Study and Implementation Plan program. The Centers for Medicare and Medicaid Services sent out a request for proposals to the states to develop LIFE Account models. New Hampshire and Wisconsin were awarded three-year grants to develop LIFE Account feasibility plans.

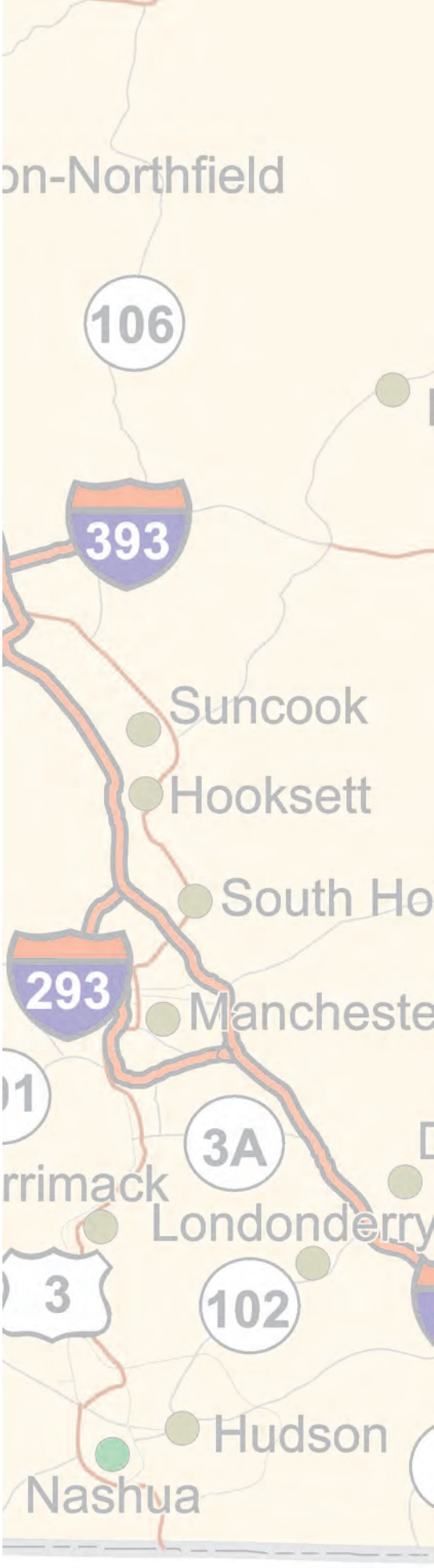
Participating in a prospective LIFE Account program enables an individual with a disability to build financial resources. In theory, to

be eligible for a LIFE Account, individuals must live in the community, receive Medicaid, and self-direct their personal care. Under this program, individuals manage their own Medicaid service budget, and make decisions about how this money is spent. If, at the end of the year, there are any savings from the individual's self-directed service budget, half of the money is deposited in the person's LIFE Account, and half is returned to the state. It is anticipated that this program will offer an incentive for individuals to effectively manage their long term support needs, and to increase their use of natural supports. For example, if a person whose service budget includes transportation costs, and rides to work with neighbors or co-workers, there will be end of the year savings from his Medicaid budget that can be put into a LIFE Account. (It should be noted that conceptually, money accrued in a LIFE Account cannot be used to exclude participants from other public benefits programs including Medicaid or Supplemental Security Income.)

For those who qualify, this program is a great option. However, in New Hampshire there are many more individuals and families with disabilities who also could benefit from this type of savings program. For example, the State's Bureau of Developmental Services offers a consolidated services option that allows adults with developmental disabilities, and parents and legal guardians supporting minor children to oversee individual service budgets, and to make purchasing and staffing decisions in accordance with Individual Service Plans. These budgets are assigned a dollar value, and it makes sense to let individuals or families who spend less than what is budgeted share in these savings.

There are other people with disabilities, including people who qualify for the Elderly and Chronically Ill Waiver and state-only Medicaid for Personal Assistance Services, who also could benefit from a program of this sort. While these individuals do not have a service budget per se, they are still able to realize savings by making greater use of natural supports – family members, neighbors, or church volunteers – to provide personal care. Providing an incentive for these individuals to find alternatives to costly agency supports will save the service system money. This is especially important given our rapidly aging population – by 2030, a full 20% of U.S. citizens will be over age 65 – with an increased demand for services, we will need to make the best use of limited resources.

As anyone with a disability can tell you, fully participating in the community costs money. Traditional Medicaid programs do not pay for accessible transportation or many items that enhance community participation. People with disabilities are often the poorest in our society and have difficulty finding resources to meet even their most



basic needs (She, P. & Livermore, G., 2006). Money that is saved in a LIFE Account or similar program will give individuals with disabilities greater freedom, increased opportunities, and ultimately lead to an improved quality of life.

Saving is hard work. In order to have end of the year savings that can be deposited in a LIFE Account, an individual must either go without a service, or find a less expensive way to obtain it. The dollars in an individual's LIFE Account must be designated for something that will increase the person's independence in the community, but if we are really talking about *living with independence, freedom, and equality*, should there be any restrictions on how these assets can be used?

The individuals interviewed for this project shared their ideas for how they might use their LIFE Account. "A LIFE Account would help tremendously," Mary said. "The money could be used for things that are not readily available to my children now such as computers, a tracking system for transfers, or a little extra money for fun." When Annie was asked how she would spend LIFE Account savings, she had a very difficult time answering. She said, "I have no idea because I never have extra money." After thinking about it for a while she added, "It would be really great to save for a van because I get tired of waiting for the bus all the time." Asked the same question, Lucy replied "I would use the extra money to cover the cost of having my personal care assistant accompany me to advocacy conferences."

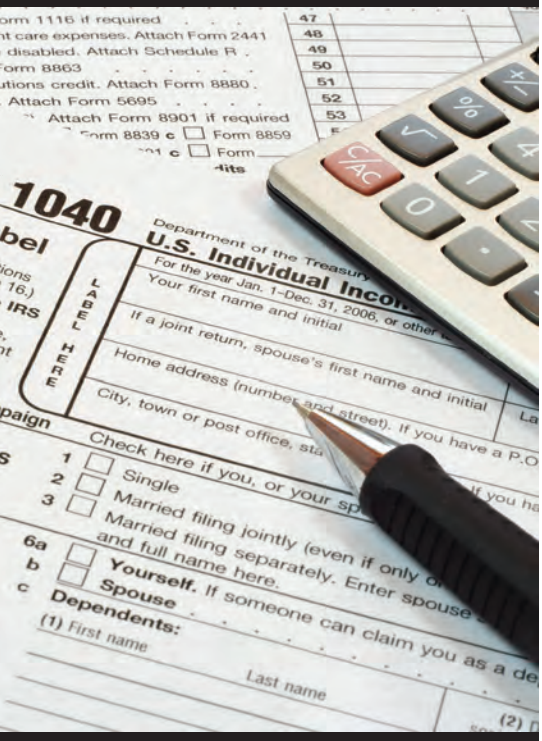
Conclusion

People with disabilities are the experts about their own lives. We are the ones who are most qualified to choose what kind of services we need and who will provide them. Self-directed personal care programs, the ability to manage service budgets, and LIFE Accounts all help us to have more choices and greater control. Programs like these also increase access to the community and promote community participation. Our communities are stronger when everyone is involved. In a strong community each person helps the other to succeed; some of us just need a little more support.

In his 2007 speech to University of New Hampshire graduates, President Clinton talked about how we can all learn from the African concept of *ubuntu* – I am because you are. Clinton stated, "We do not exist alone; therefore for us to ignore one another's problems is a travesty." He noted that in the central African highlands when people greet one another they simply say, "I see you." President Clinton concluded, "All problems can be solved if we just see each other. There is nothing beyond the reach of our common endeavor. All we have to do is remember it is our *common* endeavor."

FEDERAL TAX IMPLICATIONS OF LIFE ACCOUNTS

by Steven Mendelsohn, J.D.



Introduction

No law currently defines or authorizes Living with Independence, Freedom, and Equality (LIFE) Accounts. Yet, they are a vibrant concept likely to gain momentum and formal recognition in the near future.

If and when LIFE Accounts are established and defined by Congress, that enabling legislation will almost certainly include clarification on their tax status as well. In the meantime, that potential status must be determined largely by analogy to similar vehicles or instruments that are recognized by our law and that are specifically addressed by tax laws.

In order to do this, a number of assumptions must be clearly stated. First, we assume that the LIFE Account will be created for the benefit of individuals, probably at or shortly after birth. Second, we assume that it will initially be funded either by public funds, by private funds, or by a mix of the two; and that it will be subject to augmentation, either through earnings on the seed money, or through further contributions over the course of the individual's childhood. Third, we assume that the account will vest either at some specified point in time (such as reaching the age of 21), or upon the occurrence of a given event (such as graduation from or otherwise leaving secondary school or college), or when it is timely for the funds to be used for a specified purpose (such as putting a down payment on a house). Fourth, we assume that ownership of the account will be vested in the beneficiary, but that control will rest

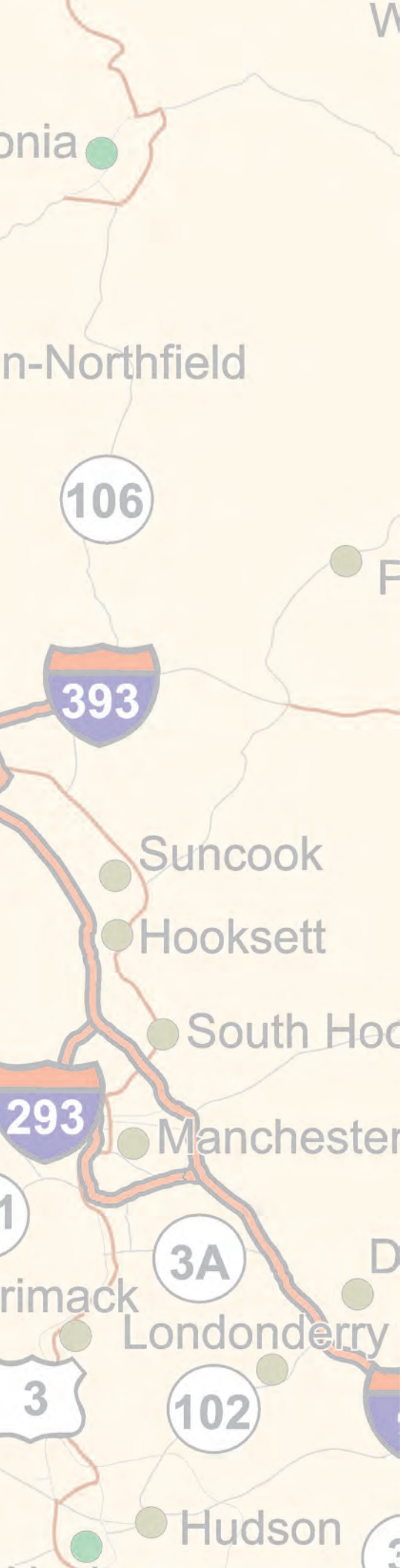
with parents, institutional trustees, or others until some specified point. Fifth, we assume that some tax advantage will be derived to those contributors or beneficiaries who comply with the rules governing these accounts; or put another way, that some penalty will apply in the case of premature or otherwise unauthorized withdrawals, or withdrawals made for impermissible uses.

The Inescapability of Tax Dimensions

Outside the tax law, there are few effective mechanisms for ensuring the integrity of the LIFE Accounts concept. Imagine, for example, what would happen if retirement savings accounts were not created and governed by the tax law? In the absence of tax deferral, no one would have any incentive to create them, and once created, no one would have any incentive to hold them to retirement age. This is why the tax law, either through specific amendment or through analogy to existing provisions, will have to play an important role in the formulation of the LIFE Account concept.

There is one exception to the role of the tax law. In the case of persons of limited means who are dependent on governmental transfer programs for their sustenance, or indeed in the case of individuals who, whether impoverished or not, receive cash or in-kind benefits under Federal Programs (including insurance benefits under Medicare or Medicaid), the lever for enforcing compliance with LIFE Account requirements could be disincentives built into these programs. If participation in the LIFE Account program is coordinated with eligibility for other benefit programs, especially for people who owe and pay little or no tax, these benefit programs could take the place of the tax law in enforcing program integrity.

Of course, other bodies of law can also be brought into play, including even the criminal law, which is generally one of the bulwarks for enforcement of compliance with tax law. But for purposes of this paper, we will concentrate on the tax law, seeking to determine what advantages it might offer, what sanctions it might apply, and what distinctions it might make within the framework of the five assumptions stated above.



EXISTING ASSET ACCUMULATION MODELS

Plan for Achieving Self-Support (PASS)

The PASS or PASS Plan as it is often called, is a statutory vehicle through which recipients of the needs-based Supplemental Security Income Program (SSI) can accumulate savings for designated purposes without running afoul of the strict income and resource limitations governing that program. Pursuant to the Social Security Administration's (SSA) approval of a plan, SSI recipients are permitted to divert specified portions of earned or unearned income into accounts for specified periods of time and for designated purposes. Such funds are not "countable" for the purposes of the income and resource limitations of the program.

PASS plans have no independent tax status and can be said to be transparent to the tax code. In other words, money put into a PASS, or money earned on such contributions is treated no differently than if it had not gone into the PASS. If the money has come from a taxable source, if the individual's income is above the threshold dollar amount for tax liability, and if other deductions or credits are not available to offset the income then it would be taxable. If it has come from a nontaxable source, such as from nontaxable gifts,[1] then its initial tax-exempt status would likewise not be altered by its placement in a PASS. Of course interest earned is taxable just as it is if the funds have been placed in an ordinary account.

Individual Development Account (IDA)

The Individual Development Account (IDA) is one model readily cited for the proposed LIFE Account. Accordingly, analysis of its tax-related features and its tax implications may prove particularly useful.

Because an IDA can be made-up of funds emanating from three sources, the tax status of each must be considered. The first source which must be present in all IDAs are earnings from employment. All known IDA models require that some contribution from earnings be at their core; and hence, all such models require that an individual be working in order to participate. Since earnings from employment are included in income for tax purposes, the key question is whether by putting some of these earnings into an IDA, the employee obtains any tax benefits. Unlike retirement, education savings, or health savings accounts discussed below, the answer is no. Nothing will change in the tax treatment of income from earnings as a result of its being placed into an IDA.

There are instances where the line between earnings, training stipends, and other kinds of payments become blurred. Under the

1 Internal Revenue Code (hereinafter IRC) Sec. 102.

general welfare doctrine, certain payments that are made to individuals because of need and other than as compensation for services[2] are excludible from taxable income. Included in this category are payments made by State Welfare Programs under the TANF Program, provided such payments comply with a number of technical and procedural requirements.[3]

It is conceivable, given the imperfect overlap between the two laws creating and governing IDAs (namely, TANF and the Assets to Independence Act (AFIA) that some nontaxable receipts to individuals can meet the IDA definition of earnings, and hence be eligible to serve as the core of the IDA while being untaxed as income.

In such cases, putting the money in an IDA once again has no effect on its tax status. It doesn't become taxable by reason of that disposition. But when we come to a second source of funds making up an IDA, the issue becomes more complex.

The second source of funds making up an IDA are the interest or dividends accrued on the contributions from earnings (or from earnings equivalents). Whatever the taxability of the original income upon its receipt by the accountholder, any interest or dividends earned on the money are taxable.[4]

No sooner do we make this categorical statement than we have to qualify it. Remembering that IDAs are transparent to the tax system, we must acknowledge the possibility that an IDA accountholder might invest the funds in, say, a tax-exempt Municipal Bond Fund. The dividends or interest earned in such a Fund (not, of course, the Capital Gains) are tax exempt in an IDA just as they would be outside of one. The IDA is transparent.

But what about the third source of IDA contributions – matching funds? Matching funds are critically important to the success of IDAs because matching funds are what give the savings their leverage value. A three-to-one match is the equivalent of a 300% rate of return on one's investment. At those rates, poverty may become fashionable again.

The tax treatment of matching funds is an issue both for the giver and the recipient. Turning to the recipient – the accountholder. First, one's initial reaction would be to assume that matching funds, especially if provided by government, would be excluded from taxability by reason of coming under the general welfare exception. After all, they are provided to facilitate societal purposes such as education, business startup, employment, and/or home ownership, and they are provided to people of limited means, usually by virtue of

2 See General Welfare Exception Summary of Authority, at Internal Revenue Manual (hereinafter IRM) Sec. 488.1 (summarizing 45 relevant revenue rulings the court cases between 1955 and the present).
3 IRS Notice 99-3, 1999-1 C.B. 271.
4 IRS Revenue Ruling (hereinafter Rev. Rul.) 99-44, 1999-44 I.R.B. 549.

participation in other programs that are more or less tightly means-tested and targeted. However, there is a problem with this and that problem goes back to the core element of work. These matching funds are not forthcoming in the absence of core funds contributed by the accountholder from employment. It is this core contribution that makes the third-party component into "matching" funds. So the question becomes, does this linkage to employment convert the matching funds into compensation for services? If they do, even with the limitation to people of limited means, they probably will not qualify for tax exemption under the general welfare doctrine.

Beyond general welfare, there is another general premise of tax law that governmental payments to citizens in furtherance of public programs or objectives are generally accorded nontaxable status. Again, the question here in the case of governmentally-funded, matching-funds payments is whether the linkage to employment is sufficient to overcome this general presumption.

In the case of TANF IDAs the answer almost certainly is *no.* Even if the accountholder has some taxable earnings, such as through compliance with mandatory work requirements, matching funds or other payments made under the auspices of the TANF program would remain tax-free. In the case of other IDAs, such as those created under the AIA, or those created pursuant solely to state law, the question awaits authoritative answer, but several factors lead to a measure of confidence that publicly-funded IDA matching-funds contributions will be federally-tax exempt under these conditions.

Of course, to the degree that the matching funds are not linked in amount or timing to either earnings or account contributions from earnings, the likelihood of a favorable tax determination is increased. But even if linked, it must be remembered that the purpose of the matching funds is not really compensation for employment. Rather, the purpose is to facilitate achievement of a given result that society deems desirable, and that, in fact, it cannot be achieved by employment alone or else you the need for the match. In addition to this reason for believing that public match is nontaxable to the recipient, there is another reason for believing this as well.

The IRS has ruled that matching fund contributions to IDAs from qualifying non-governmental sources are nontaxable to the recipient. The logic for this is not the general welfare exception, even though general welfare sometimes applies to nonprofit funders. No, in this case the rationale is that the matching funds are in the nature of a gift.[5] If the matching funds are deemed closely linked to employment or contingent on employment, the gift rationale will not apply. Thus, it appears that the IRS does not regard, and indeed should not regard, matching fund contributions as taxable, whatever their source.

As noted earlier, tax considerations emerge for nonprofit third-party funders as well as for the recipients of matching-fund IDA contributions. Can not-for-profit, 501 (c)(3) or otherwise tax-exempt organizations properly make contributions to IRAs without incurring tax penalties, and as importantly, can private individuals or nontax-exempt organizations make tax deductible contributions to IDAs under Sec. 170 of the Internal Revenue Code.

For not-for-profits the answer is straightforward. Providing that funding of IDAs plausibly come within their chartered and authorized purpose and scope of activity, there is no reason why they should not contribute to individuals' IDAs. However, if a foundation is chartered and organized to fund space explorations contributions to IDAs, except perhaps for people whose vocational goals are aeronautics, might represent a problem.

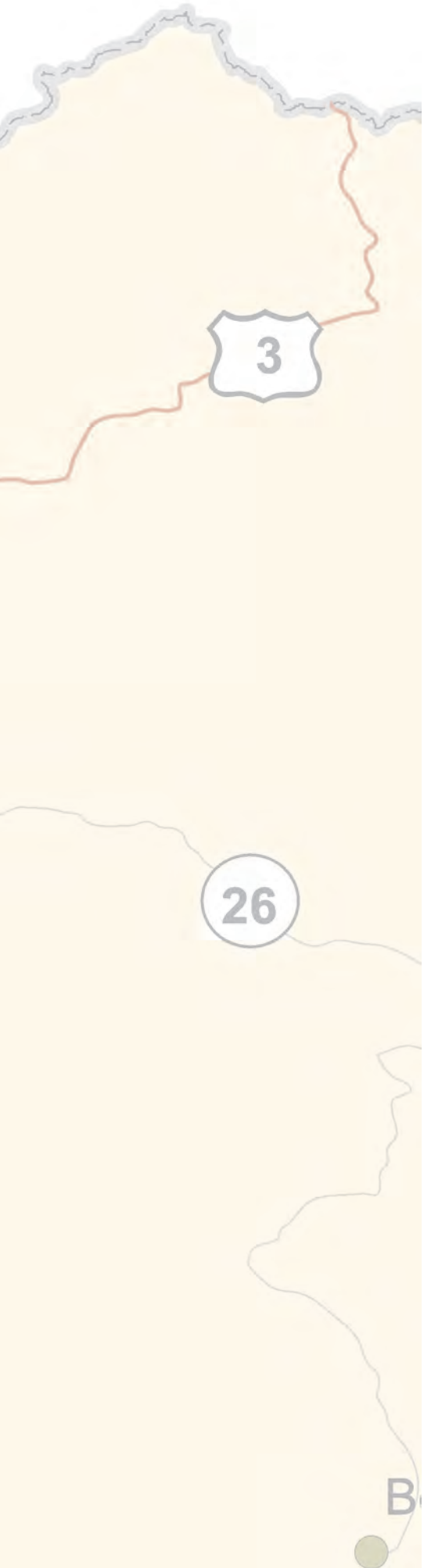
When it comes to matching-fund contributions by private individuals, the situation is more complex. Ordinarily the law is clear that contributions or donations made to other private individuals cannot qualify for tax deductibility to the donor. There are many ways, particularly in the context of family relationships or household status, that expenditures by one person on behalf of another can be tax-favored, but direct charitable contributions are generally not included among them.

If a private individual can find an appropriate nonprofit organization to serve as a conduit, then a contribution to that organization which is used to fund an IDA should qualify for deductibility to the donor. Here though care is still required, for if the contribution is made with knowledge and agreement by the recipient organization that it will be used for a given individual's benefit, then the transaction would run the risk of being declared a sham transaction. You can't create an IDA charity with just one beneficiary.

In order for the IDA concept to grow as many hope it will, additional conduits for matching-funds need to be created around the country. To facilitate the creation of IDA matching funds, and in due course, to facilitate the involvement of public/private partnerships in the funding of LIFE Accounts, creation of a federally-chartered corporation, modeled on the American Red Cross or the Corporation for National Service is recommended.

In the meantime, what about these other mechanisms for funding an individual's IDA? Taxpayers can claim a deduction for each of their dependents. If a person meets certain relationship and residency tests, a taxpayer who provides more than half of that individual's support can claim a dependent. The question therefore arises, whether matching contributions to that person's IDA would qualify

5 Id.



as support? Although no controlling authority has been found, the answer is almost certainly no. The range of expenses that come within the scope of "support" do not include anything becoming remotely close to IDA contributions or to contributions to any savings or asset-building efforts.

Well how about medical expenses? A taxpayer who pays the medical expenses for a dependent who does not file a return can deduct those medical expenses if they and the taxpayer's own medical costs add up to more than 7.5% of the taxpayer's adjusted gross income (AGI) and if the taxpayer itemizes. The problem, once again, is that there is no obvious way IDA contributions can be brought within the definition of deductible medical costs. This conclusion is bolstered by the fact that payment for medical care is not even one of the authorized purposes for having an IDA. So on balance, it would appear that the only way for a private individual to gain a tax benefit from contributing to IDAs is by contributing to some sort of fund maintained by a tax-exempt organization that provides such funds.

Still in need of resolution, though, is the question of the tax status of the proceeds of the matching funds in the account. Normally, this would have no implication for the donor, but of course the subject brings us back to the accountholder. Neither the source of the matching funds, nor the identity of the provider as governmental, not-for-profit or even private, have any impact on the taxability of the proceeds. Just as the money one earns on any gift is taxable, even though the original gift was not, so also is it with IDA matching funds. The proceeds earned on the matching funds, unless invested in a tax-exempt way, or unless offset by some other deduction (such as contributing them to an IRA) remain taxable.

There are certain rare cases in which gifts can be structured so that income earned from them in later periods of time is also tax deductible within the limits applicable to gifts. These are so rare and so complex that their applicability to IDAs are all but inconceivable.

Tax-favored Accounts

Thus far in discussing possible models for or approaches to the creation of LIFE Accounts, we have concerned ourselves with tax-transparent or tax-neutral vehicles. We next turn to examples of models that derive their incentives largely or solely from the tax system.

Retirement Savings Accounts (RSA)

There are many types of RSAs including those available to the self-employed; those available under employer-sponsored plans; those IRAs available to individuals; those that defer taxation on contributions and earnings until withdrawal; and those that offer no tax advantage for contributions, but treat all earnings as tax exempt

(Roths). From the standpoint of their possible relevance to or instructiveness in the design of LIFE Accounts, a few points emerge as important. First, little effort is made to target the opportunity created by tax-favored retirement savings to persons of lower-income or moderate means. Indeed, to the extent that someone must have some discretionary or disposable income after meeting basic costs in order to contribute to such an account, those earning the lowest incomes are almost by definition excluded. If eligibility for, or the practical capacity to participate in, LIFE Accounts were predicated upon the existence of family discretionary income, they would undoubtedly serve only to further widen the growing economic gulfs in our nation.

Retirement account tax benefits are contingent upon compliance with a number of rules; especially rules governing the timing of withdrawals. These age-driven events are supported by premature withdrawal penalties, but it is to be noted that age-based withdrawal opportunities (or indeed in many cases for people over 70), are quite different from event-triggered opportunities. Unlike the tax-favored education accounts described in subsec. 3 c, below, where the status of being in school, the "qualifying" nature of expenses being paid, and in some cases, the age of the beneficiary, all play a role in determining the tax status of distributions. Only age is relevant to retirement fund-distribution taxability (except where over age 70 minimum annual distribution requirements apply).

If LIFE Accounts are to be effective, clear goals will have to be established for the use of the funds, but at the same time they cannot, as is the case with the educational programs, be so restrictive as to exclude large numbers of children and families. On the other hand, use of age triggers alone is also restrictive, given the uncertainty of predictable correlations between objectives and age.

Health Savings Accounts

Based on two theories – one that people who pay for their own medical expenses will endeavor to keep costs down, and the other that high-deductible health insurance policies are cheaper than full-coverage insurance, HSAs have emerged as a tax-driven component of emerging national health policy. People who obtain high-deductible policies are allowed a tax deduction of up to $2,850 per person to cover their premiums and deductibles. If the money is not spent, they are allowed to retain much of it after a period of time.[6]

Although the HSA has proved attractive to a number of major stakeholders in the healthcare system, its glaring weaknesses highlight its limitations as a template for LIFE Accounts. The main problem is

6 IRC Sec. 222; see generally, IRS Pub. 969.

that only those who have the funds to be able to pay high deductibles can put those funds aside. Hence, the tax advantage is going largely to people who, by the very act of qualifying for it, prove, at least to some degree, that they do not necessarily need it. Except in a narrow range of employer-based plans that have adopted this approach, the provision does nothing for people who cannot afford health insurance.

Nevertheless, there are some features of the HSA that are instructive for LIFE planners. Mostly, the lessons they teach are cautionary. First, insurers or employers still control what goods or services are covered through their ability to define the terms of policies and the scope of coverage. It would be undesirable to grant comparable power to administering entities in LIFE Account settings, and it would moreover be difficult to identify what kind of entities would have the expertise to undertake such a role. Surely, financial institutions acting in a traditional custodial role would not be in a position, whatever the permissible uses of LIFE Account funds, to determine what does and what does not constitute a qualifying usage, and surely no one would want to vest this authority in governmental entities, at least not on a case-by-case, non-rules-based premise.

Tax-favored Education Funding

It is in the area of education that the most interesting analogies appear to exist. Methods for using the tax system to subsidize the cost of education have grown markedly in recent years. From a time when virtually no education-related costs (except those for in healthcare necessary in order for a person to obtain an education, but distinguishable from the education itself) were deductible, we have proceeded to the point where through a variety of provisions, ranging from Hope and Lifetime Learning Credit (HCTC), to qualified tuition programs (QTPs) to education savings accounts (ESAs) have emerged. These provisions variously accord deductibility to certain expenditures, tax-free growth to certain accumulations, and tax-exempt status to distributions to meet "qualified" covered costs.

These multiple approaches are too varied for extended discussion here. Among them the QTP, better-known as the Section 529 plan, and the Coverdell ESA[7], are the most pertinent insofar as they both facilitate asset accumulation. Both are flawed from the LIFE Account standpoint because they support asset-building only for formal education; but both utilize mechanisms that could prove highly relevant.

7 IRC Sec. 530; see also IRS Pub. 970.

What makes the 529 model intriguing is the role of state government or consortia of higher-education institutions in the creation of plans. The variety of plans that exist in various states attest to the potential of the model for a considerable degree of flexibility. While the range of costs that can be covered is defined by federal law, and while states do not accredit colleges, universities or vocational schools, the range of institutions that can participate, and hence, the range of goals that can be covered, do appear to be fairly broad. ESAs offer an even more valuable model in this connection because they cover elementary and secondary school expenses as well as the postsecondary expenses covered by QTPs, and because they allow for a greater degree of management by the account creator. Lastly, and of particular relevance to beneficiaries with disabilities, they provide a number of exemptions to the upper age limit for distribution (age 30) in the case of people described as "special needs" beneficiaries.

Under the ESA format, contributions made to the account which can be made by anyone including businesses or nonprofit organizations, are not tax deductible to the donor. What gives the accounts their leverage value is the tax-free growth of the proceeds, and the tax-exempt status of distributions if used to pay qualifying education expenses. Contributions to ESAs are limited to $2,000 per year per beneficiary, and contributions may not be made on behalf of a person past that person reaching the age of 18.

It would take comparatively little modification to broaden the ESA into something resembling what we think of as an LFA. A number of questions would need to be addressed for that to happen. As the last section of this paper then, let us return to where we began and examine a hypothetical LFA in light of the models and the issues described thus far.

The LIFE Account

Acting in concert, the Social Security Administration (SSA) and the Centers and Medicare and Medicaid Services (CMS) almost certainly posses the demonstration's project authority to establish and fund a viable LIFE Accounts experiment. Already, important feasibility studies such as are currently underway in New Hampshire and Wisconsin are helping to clarify the issues and dramatize the opportunities. Unfortunately, however, the Internal Revenue Service (IRS) has no comparable authority. The IRS has taken extraordinary steps to enhance financial education, both about such key provisions as the Earned Income Tax Credit (EITC)[8] and about related nontax

8 IRCSEC. 32; see generally, IRS Pub. 596.

matters such as IDAs[9],but the IRS has no power to alter tax laws in the way that would be required to implement a full-scale LIFE Account demonstration. Authority for such a project utilizing statutory principles of dollar-limitation and time-limitation already well-established in the tax law[10], and involving little financial risk to the Federal Treasury could readily be sought.

Source of Funds

The first question to be asked about any LIFE Account authorization would be from where the funds necessary to create the accounts will come. As indicated, family or personal social network resources can hardly be relied upon since primary reliance on these would only exacerbate the divide between haves and have-nots. This suggests some combination of public and philanthropic funds. Primary reliance on these resources would imply the use of eligibility standards aimed at ensuring that the most well-off people did not receive this direct or indirect taxpayer support. On balance, taking both the political and the economic dimensions of the subject into account, it will probably make most sense for everyone to receive the benefit.

Ownership of Funds

The funds used to establish the account could be owned in various ways. It would be possible to set up a single national account or fund in which everyone, either at birth or from some later age, will be enrolled and vested. This would function like Social Security, except it will not be contribution-dependent. In that case, establishment of the fund will pose no tax issues.

But if ownership is to be vested in the beneficiaries (though control of the funds obviously could never be placed in the hands of their beneficial owners if those owners were children), questions of the tax status of the startup funds will have to be addressed. Clearly, if the seed funding is to benefit lower-income individuals, and if the funds are to be required to be held in ways that will facilitate their growth over a period of time, any effort to tax the receipt of the initial funds will be counterproductive. Whether through assuming private ownership of the fund, the initial seed money will be tax deferred or fully deductible depends, of course, on other policy decisions regarding the structure and function of the account. If, for example, to take the extreme case, the account is designated for and rendered incapable of being touched until the beneficiary's retirement age, then the possibility for misuse will essentially not exist. In such case, the

9 e.g., IRM Sec. 22.30.1.
10 Compare, the Low-Income Housing Tax Credit or the Hybrid Vehicle Credit.

argument for permanent tax exemption is greater than in the case where tax deferral or conditional exemption need to be used as one means for assuring future compliance in the use of the funds. Such are the laws of compounding that even a fairly small sum deposited as seed money at birth will go a long way to resolving any long-term support issues associated with advancing age, although to be sure, by the time LIFE Accounts established on that basis matured, the baby-boom will have passed into history, and the demographics facing the country will be very different.

Nature of Beneficiaries

As indicated above, one approach will be to vest people, all or some as the case may be, with seed money at birth. But this is hardly the only viable approach. Any number of other predicates, including developmental events, disability, or numerous others, can serve as predicates. LIFE Accounts can be used as supplements to Medicaid, or can be integrated into cash-and-counseling initiatives of the kind currently receiving so much attention and support. LIFE Accounts could potentially be used to purchase annuities for those actuarially unlikely to be able to obtain self-sufficiency through employment. LIFE Accounts could be integrated with special needs trusts. In short, there are an endless number of ways they can be developed and used.

From a conceptual standpoint, vesting seed funding at birth still makes the most sense. To the degree that the funds would be left to grow and would need to be untouched (except perhaps under limited circumstances of imperative need) for specified periods of time, or until the occurrence of specified events, or until ripe for use in connection with predetermined purposes, the logic of funding at birth continues to be compelling.

Asset Accumulation

The miracle of compounding, particularly of tax-free compounding, lies at the heart of any LIFE Account initiative. Whether individually or societal owned, it is this process that gives the concept its leverage value, and not coincidentally, that would provide the increased savings rate and enhanced capital formation so necessary to the maintenance of American economic growth.

Means for maximizing fund growth consistent with prudent stewardship would have to be established. Unlike IRAs, it would serve no purpose to give individuals the discretion to mismanage their LIFE Accounts (mismanaging the lives is not preventable, alas), so some method for ensuring responsible stewardship would be required. If LIFE Accounts are designated for asset accumulation until retirement age, it is likely they would be accompanied by

commensurate reductions in Social Security, in which case guarantees for the integrity and availability of the funds would be all the more indispensable.

Distributions

Whether called distributions or withdrawals, tax issues will have to be confronted when provisions are made for the ultimate use of the funds by or directly for their beneficiaries. The technical options need little elaboration. Established principles of tax law and tax administration will readily encompass any decision, ranging from full taxability, to taxability at the capital gains rate, to taxability of some portion of the distribution, to taxability based on the overall income and resources of the beneficiary at distribution, to tax-favorable treatment of roll-over to the next generation. The answer to what should be done and when is a broad policy question to which tax law, oddly, can add little.

Cost Benefit

Lest we end on an anticlimactic note, it must so emphasized that the potential benefits of LIFE Accounts are truly enormous. Here is not the place to attempt to catalog or quantify them, except to note that our ability to recognize them is, in part, dependent on the cost benefit techniques, timeframes, and accounting assumptions we use. On the pay-as-you-go (pay-go in common parlance) approach that is likely to dominate federal budgeting in the near future, the key question becomes over what timeframes costs and benefits are measured. If upfront outlays must be offset immediately, then of course, any large-scale recourse to LIFE Accounts would be impossible, although limited experiments of the kind suggested above could likely be accommodated with short-term savings elsewhere in the Federal Budget. The trouble with even such experiments, though, is that considerable time is potentially required for the benefits to accrue. In the end, as was the case with Social Security seventy years ago, we may need to take the same leap of faith for those at the beginning of life that we did then for those nearing its completion. Even short of use for retirement, LIFE Accounts keyed to career development, home ownership, or other interim objectives will reveal themselves to be an effective, nonintrusive method for bringing the benefits of asset ownership to the largest possible number of Americans, if it is given a chance to work. Let the discussion proceed.

THE LIFE ACCOUNT & NEW HAMPSHIRE LAW AND POLICY

by Michelle M. Winchester, J.D.

Introduction

The purpose of this paper is to examine the potential LIFE Account in New Hampshire through an analysis of asset accumulation in the State's public benefit programs, including: current allowances for public benefit recipients; current challenges to maximizing asset accumulation; challenges to expansion; and gaps in Federal and State regulation and guidance. Recommendations on Federal and State action follow.

For the purposes of this discussion, the elements of the LIFE account assumed by Steven Mendelsohn are assumed here and summarized below.

1. A LIFE Account (Account) would be created for the benefit of individuals, probably at or shortly after birth.
2. The Account initially would be funded either by public funds, private funds, or a mix; it also would be subject to augmentation through earnings on the seed money or further contributions.
3. The Account would not be legally available.
   a. The account would vest:
      i. At a specified point in time (e.g., reaching age 21);
      ii. Upon the occurrence of a given event (e.g., graduation from secondary school or college); or

iii. When timely for the funds to be used for a specific purpose (e.g., home purchase down payment).

b. Ownership will vest in the beneficiary but control will rest with parents, institutional trustees, or others until some specified point.

4. Contributors or beneficiaries who comply with the rules governing these accounts would derive some tax advantage. In contrast, a penalty would apply in the case of a premature, unauthorized, or impermissible withdrawal.

New Hampshire treatment of asset accumulation models in public benefit eligibility

Plan for Achieving Self-Support

A plan to achieve self-support (PASS) is a plan designed for a particular individual to achieve a specific occupational goal.[1] The plan includes: a description of how the individual will achieve the goal; identification of the resources available to do so; and an explanation of how the PASS resources will be kept identifiable from the other assets of the individual. Initially, the plan may not be designed for more than 18 months; however, 18-month extensions are possible, up to a total of 48 months. The 48 month allowance is possible "to fulfill a plan for a lengthy education or training program designed to make the individual self-supporting."[2] Funds are those of the individual.

Federal law excludes the resources and income set aside for the plan.[3] The exclusion stops when the individual fails to follow the conditions of the plan, abandons the plan;, completes the time schedule of the plan; or reaches the plan goal.[4]

A Plan for Achieving Self-Support is an excluded resource under New Hampshire public benefit programs. From a policy perspective, it is important to note that this includes a Medicaid program exclusion. Despite its 209(b) Medicaid status, New Hampshire excludes income and resources set aside under an SSA-approved PASS when determining Medicaid eligibility.[5]

1 See 20 C.F.R. § 416.1226.
2 20 C.F.R. § 416.1226(d).
3 42 U.S.C. §§ 1382b(a)(4) & 1382a (b)(4).
4 20 C.F.R. § 416.1227.
5 He-W 654.12(g), He-W 656.04(b)(4).

The Individual Development Account (IDA)

In the Assets for Independence Act, Congress recognized that key components of economic well being include savings, investment, and asset accumulation.[6] These "improve economic independence and stability, connect individuals with a viable and hopeful future, stimulate development of human and other capital, and enhance the welfare of offspring."[7] Furthermore, Congress concluded that traditional public assistance policy that focused on income and consumption was rarely successful in promoting and supporting a transition to economic self-sufficiency.[8] Instead, income-based policy should be "complemented with asset-based policy because, while income-based policies ensure that consumption needs (including food, child care, rent, clothing, and health care) are met, asset-based policies provide the means to achieve greater independence and economic well-being."[9] The conclusion was that the "financial returns, including increased income, tax revenue, and decreased welfare cash assistance, resulting from *individual development accounts* [would] far exceed the cost of investment in those accounts."[10]

The outcome was enabling legislation for the "individual development account" (IDA) for the low-income public benefit recipient. The IDA is a trust or custodial account established by or on behalf of an individual that is intended to enable the individual to accumulate funds for one or more qualified purposes – postsecondary educational expenses, first home purchase, or business capitalization.[11] Payments from the fund must be made directly to the third party to whom the payment is due, rather than a distribution to the individual, thereby not resulting in countable income to the individual in the public benefit eligibility determination.[12]

The IDA is funded through contributions from the individual and matched by a qualified entity for one of the three qualified purposes.[13] The qualified entity is a 501(c)(3) non-profit organization or a state or local government agency acting in cooperation with the non-profit organization.[14] The IDA (contributions and accrued interest) is an excluded resource under Federal needs-based benefit programs.[15] Contributions by the individual must come from earned

6 P.L. 105-285, Title IV, Assets for Independence Act, § 402 (Oct. 27, 1998).
7 P.L. 105-285, Title IV, Assets for Independence Act, § 402 (Oct. 27, 1998).
8 P.L. 105-285, Title IV, Assets for Independence Act, § 402 (Oct. 27, 1998).
9 P.L. 105-285, Title IV, Assets for Independence Act, § 402 (Oct. 27, 1998).
10 P.L. 105-285, Title IV, Assets for Independence Act, § 402 (Oct. 27, 1998). (Emphasis added.)
11 42 U.S.C. § 604(h)(2)(A) & (B).
12 42 U.S.C. § 604(h)(2)(B).
13 42 U.S.C. § 604(h)(3)(A); 45 C.F.R. § 1000.2.
14 42 U.S.C. § 604(h)(3)(B).
15 42 U.S.C. § 604(h)(4).
16 42 U.S.C. § 604(h)(2)(C). See 26 U.S.C. § 911(d)(2) for the definition of earned income.

income, as that term is defined in the Internal Revenue Code.[16] A state may use a certain amount of TANF and Community Service Block Grant appropriations to fund an IDA.[17]

In accordance with Federal law, in the public benefit eligibility determination, New Hampshire treats: the IDA as an excluded resource;[18] qualified distributions as excluded income;[19] and unqualified distributions as lump sum income to the individual.[20]

Special Needs Trust

Self-Settled Special Needs Trust

In the Omnibus Budget Reconciliation Act of 1993 (OBRA 1993), Congress tightened restrictions on the divestiture of assets by elders with substantial means in order to qualify for Medicaid-covered nursing home care.[21] Notably, Congress exempted from those heightened restrictions the self-settled special needs trust (SNT), a mechanism to shelter resources that may be used to enhance the quality of life and fill coverage gaps in public benefit systems for trust beneficiaries with disabilities.[22]

Specifically, OBRA 1993:

Allowed penalty-free asset transfers to SNT trusts,[23] with some limitation on transfers by the beneficiary after age 65; and

Defined the SNT, exempted it from the otherwise standard treatment of self-settled trusts, and provided that this trust is an excluded resource in the Medicaid eligibility determination.[24]

As to the treatment of trust distributions, Congress left it to the law at hand.

Importantly, Congress clearly recognized that distributions from the SNT would occur, as it defined the trust as established "for the benefit" of the individual and required the inclusion of a Medicaid pay-back provision from the "amounts remaining in the trust" at the death of the individual.[25] Congress did not speak further to trust distributions, as distributions would be assessed under already established income methodology rules and, for the individual with a disability, the relevant Supplemental Security Income (SSI) income

17 42 U.S.C. § 604(h)(1); 42 U.S.C. § 9907(b)(1)(E).
18 Adult Assistance Manual, § 413
19 Adult Assistance Manual, § 513.
20 NH Code Admin. R. He-W 656.02; Adult Assistance Manual, § 513.
21 House Report No. 103-111, at 186 (1993).
22 See Medicare and Medicaid Budget Reconciliations, Hearings before the Subcomittee on Health and the Environment of the Committee on Energy and Commerce, House of Representatives, Serial No. 103-61 (March 31 & April 1, 1993) (Testimony by Brian Burwell of MEDSTAT Systems, Inc., p. 337; Comments by National Academy of Elder Law Attorneys, Inc., p.447.); Fiscal Year 1994 Budget Reconciliation Recommendations of the Committee on Finance, S. Prt. 103-37, p. 38 (June 1993); Omnibus Budget Reconciliation Act of 1993, Conference Report to Accompany H.R. 2264, p. 834 (Aug. 4, 1993).
23 42 U.S.C. § 1396p(c)(2)(B).
24 42 U.S.C. § 1396p(d)(4).
25 42 U.S.C. § 1396p(d)(4).
26 42 U.S.C. § 1396a(a)(17) (Supp. 2001); 42 C.F.R. § 435.601(b) (2001).

methodologies comported with the supplemental nature of the SNT trust.[26] In short, countable income under the SSI program is anything received in cash or in kind that the individual can use to meet the basic needs of food and shelter.[27]

Federal law requires that in determining financial eligibility for Medicaid, the State must apply the financial methodologies and requirements of the cash assistance program that is most closely categorically related to the individual's status or, when applicable, the more restrictive methodologies adopted under a 209(b) election.[28] New Hampshire is a 209(b) state. While there is no clear evidence that in 1972 New Hampshire elected more restrictive income methodologies on distributions from trusts generally or the SNT specifically, New Hampshire regulation has required that any distribution from a SNT made "to or for the benefit of the individual" be treated as unearned income to the individual.[29] This requirement has resulted in inevitable periods of ineligibility for Medicaid recipients. Informally, the State has excepted distributions made for educational or medical purposes, or for the administrative costs of the trust.

Third-Party Special Needs Trust

A third-party SNT is established with the assets of someone other than the beneficiary. It is a mechanism often employed by parents to supplement the basic provisions of public benefits without disturbing their child's public benefit eligibility. Very often these are established or funded upon the death of a parent, with the intent to continue to assist the child after death as the parent did in life. Like the self-settled SNT, a third-party SNT may provide for the goods and services not covered under public benefit programs. This is especially important for the parent who does not have the means to fully support a child yet does have the means to supplement the frugal lifestyle and limited services of public benefits and thereby improve the quality of life for the child over the child's lifetime.

28 42 U.S.C. § 1396a(a)(17) (Supp. 2001); 42 C.F.R. § 435.601(b) (2001). Pursuant to section 209(b) of Public Law 92-603 (1972), state Medicaid programs were allowed to maintain more restrictive financial methodology rules than those of the SSI program. Congress allowed this election at the time that the three adult assistance programs were streamlined into the one new SSI program. Concerned that the new eligibility criteria of the SSI program would result in thousands of new eligibles for state Medicaid programs, Congress permitted states, who so elected, to maintain their more restrictive Medicaid criteria if the criteria were in place in the state's January 1, 1972 Medicaid plan. New Hampshire is a 209(b) state and it elected more restrictive eligibility criteria relative to the adult programs, Old Age Assistance, Aid to the Needy Blind and Aid to the Permanently and Totally Disabled programs. 42 U.S.C. § 1396a(f) (Supp. 2001); 42 C.F.R. § 435.601(b) (2001); New Hampshire State Plan Under Title XIX of the Social Security Act, Supplement 5 to Attachment 2.6-A, TM No. 88-2.

29 NH Code Admin. R. He-W 656.04. See also Appeal of Emily Huff, 154 NH 414 (Nov. 28, 2006).

As the third-party SNT is not specifically defined or identified as an excluded resource in Federal public benefit law, the trust must be structured in such a way as to render the trust legally "unavailable" to the beneficiary.[30] SSI regulations and policy guidelines perhaps most clearly address this matter. "If the individual has the right, authority or power to liquidate the property or his or her share of the property, it is considered a resource; [i]f a property right cannot be liquidated, the property will not be considered a resource."[31] In summary, the SSI resource is an asset that meets the following criteria–

- The individual has ownership interest in the asset;
- The individual has the legal right to access (spend or convert) the asset; and
- The individual has the legal ability to use the asset for personal support and maintenance.[32]

New Hampshire public benefit law does not clearly define the legally "available" resource with all of the elements of the SSI definition. New Hampshire merely defines resources as "property which is owned by an individual and which are either personal property resources or real property resources."[33] The State policy is to treat the trust established with third-party assets as a countable resource to the extent that the individual "has access to the principal of the trust."[34] The State addresses ownership and accessibility to the asset and yet does not address the third SSI element, the legal ability to use the asset for personal support and maintenance.

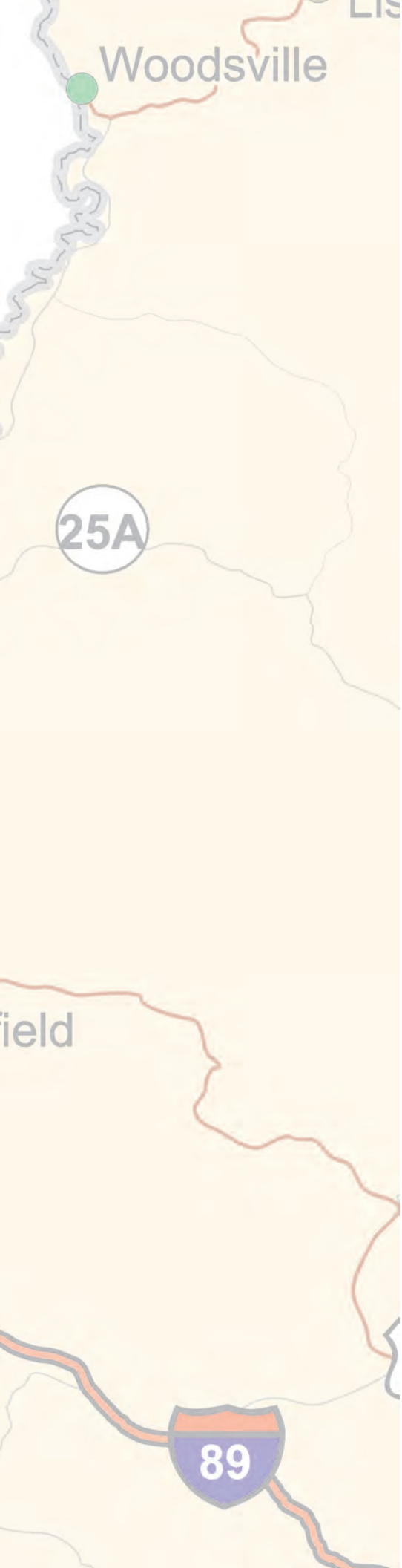
New Hampshire courts, however, like the majority of jurisdictions, find that third parties create an asset that is not "available" to the individual when a third party is the settlor of a discretionary nonsupport trust that is created with assets other than those of the individual.[35] In accordance, legal practitioners structure third-party SNTs as discretionary nonsupport trusts.

The treatment of distributions from a third-party trust is the same as that for the self-settled trust.

House Bill 273 (2007)

After years of contentious debate between the community and the NHDHHS over distribution assessment, the 2007 New Hampshire Legislature passed House Bill 273, enacting the requirement that distributions from self-settled or third-party trusts be assessed under

30 For example, see 42 U.S.C.A. § 1396a(a)(17)(B) (Supp. 2001); 20 C.F.R. § 416.120(c)(3) (2001); see also 20 C.F.R. § 416.1201(a) (2001).
31 20 C.F.R. § 416.1201(a)(1) (2001).
32 POMS, SI 01120.010.
33 N.H. Code Admin. R. He-W 601.146.
34 New Hampshire Adult Assistance Manual, § 411.
35 See Brahmey v. Rollins et al., 87 N.H. 290 (1935); Hanford v. Clancy, 87 N.H. 458 (1936).



SSI income methodology rules. This law greatly expands the potential uses of the SNT to improve quality of life for the individual with a disability.

Tax-favored accounts

Tax-favored asset development accounts, identified by Steven Mendelsohn, currently offer little to the New Hampshire public benefit recipient. In accordance with Federal law, retirement savings accounts, such as individual retirement accounts and Keogh Plans, are countable resources and must be spent down for financial eligibility purposes unless the recipient is eligible under the Medicaid buy-in program described in subsection E below.[36] (Otherwise, exception is made only for the contractual retirement plan established by an employer and preventing withdrawal.)[37] Health savings accounts and tax-favored education funding are not specifically addressed in State law or policy guidelines, nor has either resource yet risen to a notable level of discussion in the State.

Medicaid for Employed Adults with Disabilities (Medicaid Buy-In)

Established under the provisions of the Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999,[38] the New Hampshire Medicaid for Employed Adults Program eliminates some income and resource limitations for workers with disabilities buying into Medicaid. The core purpose of TWWIIA is to support employment for individuals with disabilities.

Congress and New Hampshire recognized the importance of Medicaid to the individual with a disability and made the necessary association to barriers to employment. Individuals with disabilities often cannot afford private market health insurance, are uninsurable, or are at great risk of incurring very high and economically devastating health care costs.[39] Additionally, standard health insurance plans do not provide coverage for many of the services necessary to independent living and working.[40] Fear of losing

36 N.H. Code Admin. R. He-W 656.04(a)(6); Adult Assistance Manual 411.
37 N.H. Code Admin. R. He-W 656.04(a)(6); Adult Assistance Manual 411.
38 PL 106-170 (Dec. 17, 1999); codified at 42 U.S.C. § 1396a(a)(10(A)(ii).
39 PL 106-170, § 2(a) (Dec. 17, 1999).
40 PL 106-170, § 2(a) (Dec. 17, 1999). See also NH House Bill 350 (2001).
41 PL 106-170, § 2(a) (Dec. 17, 1999). See also NH House Bill 350 (2001).
42 PL 106-170, § 2(b) (Dec. 17, 1999).

Medicaid coverage has been the greatest barrier to employment for this group.[41] TWWIIA reduces dependency on public cash assistance programs by enabling access to the Medicaid coverage so necessary to the individual with a disability.[42]

In 2008, State law allows the MEAD-eligible individual countable resources up to $24,076 ($36,114 for a married couple).[43] (This resource remains an excluded resource in post-MEAD eligibility.[44]) In addition to the enhanced resource limit, excluded resources include: retirement accounts (e.g., Individual Retirement Accounts and Keogh Plans), Medical Savings Accounts, and Employability Accounts (goods and services that will enhance the recipient's employability and are not otherwise reimbursable, excluded or allowed as a deduction).[45] Other than the contractual or legal obligations which apply to particular financial instruments, there are no Medicaid program limits on the use of these assets, other than those attached to the Employability Account. If a recipient uses Employability Account funds for other than allowable uses, the remainder of the account is designated a countable resource.

Consumer direction in New Hampshire Medicaid

There has been some discussion to limit the use of a LIFE Account to individuals in self-directing Medicaid programs. While many may benefit, many others would not.

As made more and more available under Federal law and policy, independence in the financial and service direction of long-term care is ever-increasing in New Hampshire's Medicaid home and community-based long-term care programs. "Consumer-directed" programs offer the individual everything from hiring, supervising, and firing personal care attendants to managing long term care budgets including a flexible "goods and services" benefit package. Important to this discussion, consumer direction also lends itself to developing skills in self-sufficiency, for those who are without those skills in care management, financial management, or both.

In New Hampshire, consumer direction has for some time been an inherent part of the State's four home and community-based care (HCBC) waivers.[46] These waivers provide long-term care coverage for

43 N.H. Code Admin. R. He-W 641.03(a)(6). This figure is adjusted annually to the Consumer Price Index.

44 N.H. Rev. Stat. Ann. § 167:6, IX.

45 N.H. Code Admin. R. He-W 641.03(c)(3).

46 The four home and community-based care waivers serve: (1) the elderly and chronically ill who require a nursing facility level of care; (2) individuals with developmental disabilities who require an ICF/MR level of care; (3) individuals with acquired brain disorders who require a nursing facility level of care; and (4) children with developmental disabilities who require an ICF/MR of care.

select groups – individuals with developmental disabilities, acquired brain disorders, and elders and adults with disabilities or chronic illnesses. Under the waivers, basic consumer-direction in personal care is available to all populations. The Independence Plus waiver for children with developmental disabilities also allows families to fully manage their long-term care budget. Additionally, as a project of the State's Real Choice Systems Change Grant, a cash and counseling model is under way for the HCBC program for the elderly and chronically ill.

Unfortunately, many New Hampshire Medicaid recipients are without access to self-directing programs. Those without access include: individuals with severe mental illness, individuals who do not require an institutional level of care, and children with severe disabilities that are not developmental disabilities.

Challeges

Asset Accumulation Options verses "Parity in Poverty"

Perhaps the greatest challenge to asset accumulation in New Hampshire is the ongoing struggle to securely establish policy that de-links disability and poverty. All too often the State establishes progressive policy in one program area and negates it with another policy in a separate program area. In recent years, the tension between the concept of de-linking disability and poverty and the concept of "parity in poverty" for public benefit recipients has frustrated progress for all parties involved. This has been especially apparent in discussions on the allowable uses of special needs trust assets and the evolution of policy in the Medicaid for Employed Adults with Disabilities program. The latter follows, as an explanation by example.

The Development and Regression of Policy for Medicaid for Employed Adults with Disabilities

As stated in Section II, in 2001 the New Hampshire Legislature enacted enabling legislation for the TWWIIA Medicaid buy-in program, titled Medicaid for Employed Adults with Disabilities (MEAD). Working with the New Hampshire disability community, the New Hampshire Department of Health and Human Services (NHDHHS) promulgated rules and initiated the program in 2002. Only two years later, the State began to roll back allowances under the still very young program. The original rule excluded the liquid assets allowable under MEAD from future non-MEAD Medicaid eligibility

47 NHDHHS Testimony to Joint Legislative Committee on Administrative Rules, p.69 (Feb. 4, 2005).

determinations, in the event the individual became unemployed; in 2004, the NHDHHS limited that exclusion to a six-month grace period following the loss of MEAD eligibility. This policy regression came only two years into the program and notwithstanding the fact that no Medicaid recipient had left the MEAD program with assets in excess of the standard Medicaid resource limit, $2,500. The reason for the change was a management decision to "build in greater parity with the other adult categories of medical assistance."[47] The NHDHHS did not view this as a "fundamental" change or contrary to the intent to de-link disability and poverty.[48] Yet parity in poverty was the goal –"[f]or those folks who no longer have the ability to work, it seems fair and just to the remainder of the people on Medicaid that, eventually, they are on equal footing."[49] However, the NHDHHS did recognize the disincentive to work this would create and "we would hope that people would avail themselves of . . . a financial planner or an attorney who could help them maximize those resources in a way that is excluded for purposes of the Medicaid resource computation. . . . by example, a special needs trust or an annuity."[50]

This significant shift in policy, after a mere two-year, problem-free period, regressed State disability policy for little to no gain on the part of the State. Clearly, $20,000 in liquid assets ($17,500 to be spent down) would not support an individual for a very long period of time. The community view was that during difficult times, when individuals are out of work, they should be able to use those savings earned under MEAD for as long as they can, to be self-sufficient, and not to be forced to first spend the resource down completely in order to become Medicaid-eligible again. The effect of this change was to disregard completely –

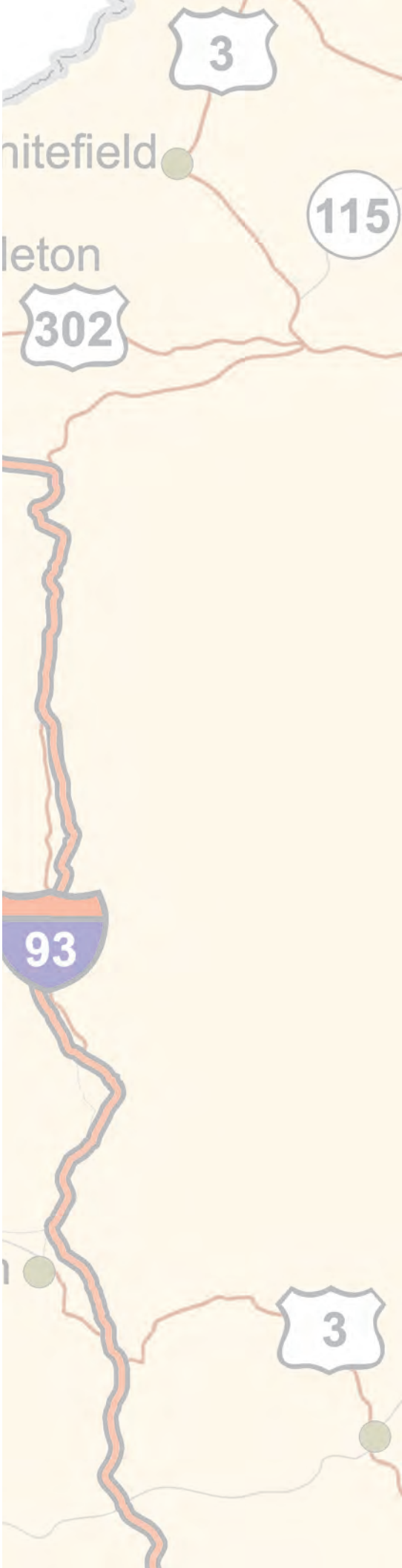
The importance of the fact that the individual tried to work;

That periods of failed health associated with disability, sometimes long, will occur;

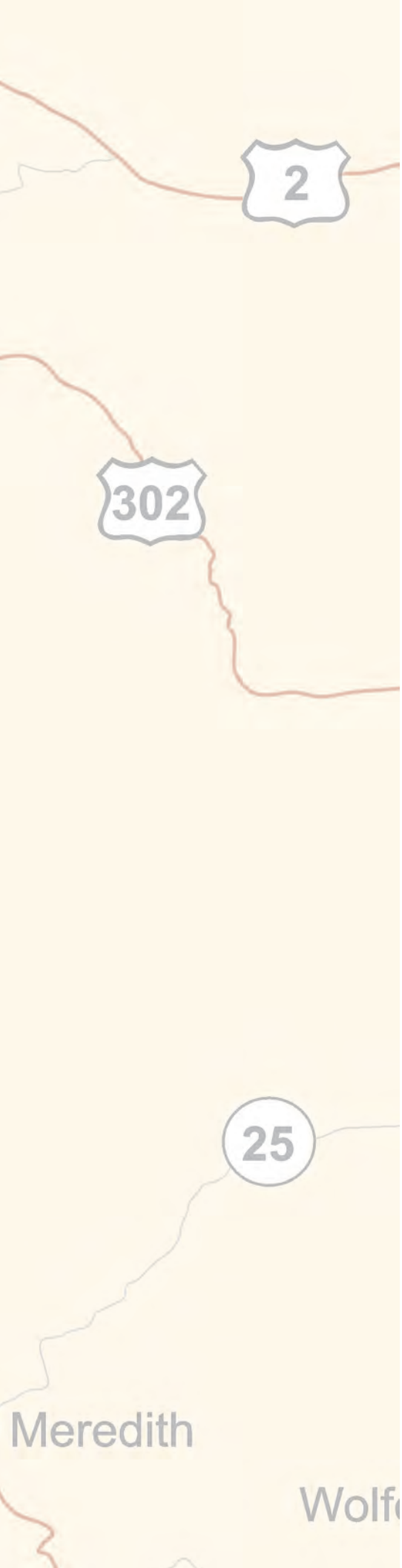
That to find another job may take a long while, as employers are less than eager to hire individuals with disabilities;

That if the asset were maintained, the individual would be self-sufficient for awhile longer and able to pay for the basic needs of food and shelter (and not use public cash assistance); and

That self-sufficiency would, at best, be short-lived as the MEAD resource cap is a small amount by cost of living standards today and for many the amount saved will be far lower than the cap, as the average income of MEAD recipients at the time of the policy change



48 NHDHHS Testimony to Joint Legislative Committee on Administrative Rules, p.71 (Feb. 4, 2005).
49 NHDHHS Testimony to Joint Legislative Committee on Administrative Rules, p.71 (Feb. 4, 2005).
50 NHDHHS Testimony to Joint Legislative Committee on Administrative Rules, p.72-73 (Feb. 4, 2005).
51 Robin E. Clark, Karin Swain and William J. Peacock, Evaluation of the MEAD Program: Feb. 1, 2002 through June 30, 2003 (Draft).



was approximately $450 per month.[51]

Fortunately, in the 2008 Legislative Session, the original resource policy was restored, while over much opposition by the NHDHHS.

Ever Changing Leadership

Political and regulatory leadership is ever-changing adding to the challenge of consistent, long-term policy development. The New Hampshire Governor and Legislature are elected every two years. The NHDHHS Commissioner is appointed every four years, a term that may potentially straddle the terms of as many as three Governors. The struggle and time-consuming effort to educate new leadership on the reality of disability sets progress back regularly, as does the loss of time it takes each new elected official or Executive appointee to acclimate to the position.

Expanse of the State Health and Human Service Agency

The size, multiple divisions, and many arenas of oversight are a combination of factors that maximize fractures and gaps in NHDHHS communications, public benefit eligibility policy, and disability policy. While the Bureau of Developmental Disabilities Services may lead the nation in progressive disability policy, the financial eligibility division remains unaware of or unconcerned with the challenges faced by individuals with disabilities. In the end, financial eligibility policy based on parity in poverty among public benefit recipients is based wrongly in the assumption that all public benefit recipients are on equal footing and have equal opportunity in employment, housing, transportation, and health care access. Therefore, often the result is one good, progressive policy negated by one bad, poorly informed policy.

209(b) Medicaid Status

The New Hampshire Medicaid 209(b) election allows the State to establish more restrictive financial eligibility standards in Medicaid than those employed under the Supplemental Security Income (SSI) program. In non-209(b) states, an individual with a disability eligible for SSI is automatically eligible for Medicaid. In New Hampshire, the State may employ more restrictive eligibility standards, as long as those standards are no more restrictive than those that it had in place on January 1, 1972. The extent of the 1972 standards remains unclear, as evidenced in recent litigation.[52]

The recent *Appeal of Emily Huff* brought to question the legality of the State standard for assessing distributions from special needs trusts for a young woman with a disability.[53] The income assessment standard for trust distributions was more restrictive than the SSI

52 See Appeal of Emily Huff, 154 NH 414 (Nov. 28, 2006).
53 Appeal of Emily Huff, 154 NH 414 (Nov. 28, 2006).

standard. The NHDHHS claimed allowance under its Medicaid 209(b) election, although evidence of the 1972 plan was not produced. The case was remanded to the NHDHHS Appeals Unit in order for the hearings officer to reconcile the income standard with Federal law, i.e., that the standard was in fact in place in an approved New Hampshire Medicaid state plan of January 1, 1972. As a result of the 2007 State legislation that eliminated the more restrictive standard for special needs trust distributions, deferring to the SSI standards, this question was left unanswered.

The scope of the 1972 New Hampshire Medicaid state plan remains unknown and therefore leaves the potential for more restrictive standards, challengeable only by litigation.

Allowable Use of Accumulated Assets

Current asset accumulation models severely limit uses of assets. The PASS resource must be used to achieve a specific goal of self-support. The IDA has broader uses – postsecondary educational expenses, first home purchase, or business capitalization. However, both limit uses and neither contemplate the unique needs of any one individual that may be better met outside these uses. In part this derives from the goal to assist an individual toward self-sufficiency, with a secondary effect of less dependence on public cash assistance. In part this also derives from a focus on poverty and not enough focus on disability and the "handicap" of that status.

For example, the IDA was conceptualized for a broad population of low-income public benefit recipients. The focus of the LIFE Account narrows further to the low-income individual with a disability. Therefore, it is important in the LIFE Account policy that the unique additional needs of that subset group be considered. While there is some assumption that the LIFE Account would have some specific purpose, there is certainly reason to leave the potential uses broad. This means allowable uses of the asset that go beyond postsecondary educational expenses, first home purchases, or business capitalization. Consideration must also be given to the significantly increased challenge for the individual with a disability to find, for example, employment, housing, transportation, and health care.

The challenge is to call for policy that will not necessarily result in fiscal savings initially. The challenge is to develop policy that would actually allow the individual with a disability to live a better quality life and still maintain public benefit eligibility. The challenge is to accept that this will not necessarily lessen reliance on cash and medical assistance programs until overall societal changes occur that remove the societal "handicaps" for this group of people.

Cost of Establishing Trusts

The cost of establishing trusts, like special needs trusts, is cost prohibitive for many. This is especially true when assets are small. Anecdotally, the cost to establish a trust is on average approximately $1,200 to $1,500 in New Hampshire. Today, this remains a barrier to asset development for the low-income, low-assets person.

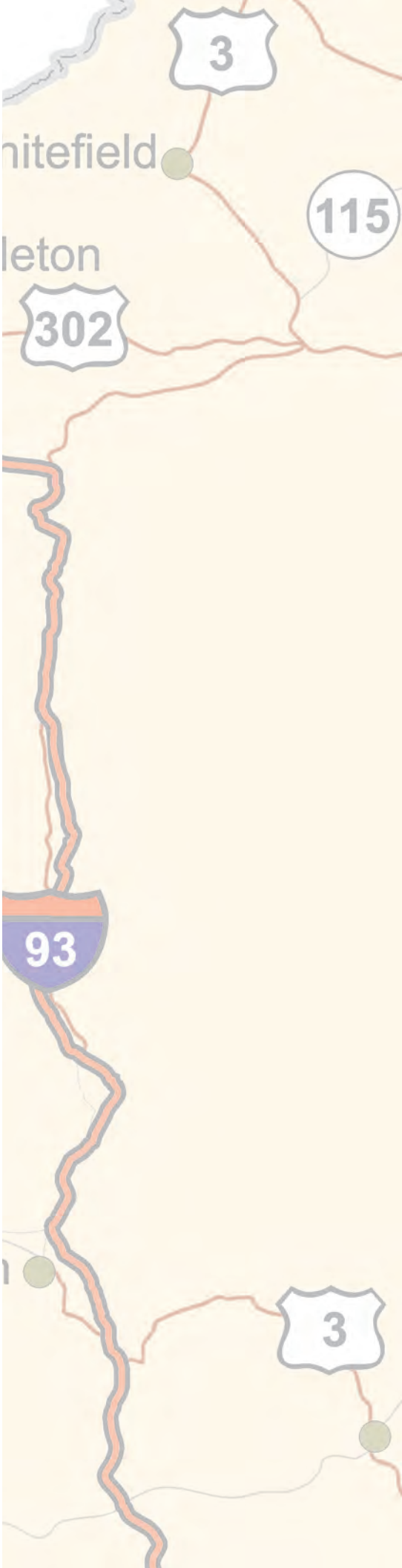
Potential to Limit the Use of LIFE Accounts to Self-Directing Medicaid Recipients

There is discussion about limiting the availability of the LIFE Account, as an excluded resource in public benefit eligibility, to those in self-directing Medicaid programs. The full intent of such a position is not fully clear to this writer. It may be that there is an expectation that self-directing programs will prove more cost effective and the LIFE Account a lure towards that that type of program and expanded self-sufficiency. However, many with severe disabilities are not served in self-directing programs and this is often because they do not even have access to these types of programs. In New Hampshire, individuals with severe mental illness, individuals who do not require an institutional level of care, and children with severe disabilities that are not developmental disabilities, all are without access to self-directing programs. For these individuals, who are equally deserving of the LIFE Account opportunity, access to self-directing programs would be yet one more "handicap" to independence outside of their control.

Recommendations

Enact Federal and State legislation to enable the LIFE Account and include:

- As in the Assets for Independence Act, recognition of key components of economic well being, including, savings, investment, and asset accumulation;
- Clear recognition of the disability "handicap" in employment, housing, transportation, health care, and more by a broad allowance of LIFE Account uses to meet individual needs and truly improve quality of life;
- Clear treatment of the account as an excluded resource and qualified distributions as excluded income in all public benefit programs, regardless of a state's 209(b) Medicaid status and change in leadership;
- Allow all individuals with severe disabilities to utilize the LIFE Account, not just those in self-directing programs;
- Ensure that LIFE Accounts survive an individual's changes in Medicaid eligibility, by working to achieve parity in enabling all individuals to achieve asset development rather than holding those back who try, and may not at first succeed, through "parity in poverty" policy;
- Allow use of low-cost custodial accounts for the LIFE Account, rather than requiring use of trusts that are costly to establish; and
- Allow the use of State revenue dollars as a match and tax credits to matching organizations, at the State and Federal level.
- Establish clear Federal and State rules on other asset accumulation models, including, Special Needs Trusts, Health Savings Accounts, and Tax-Favored Education Funding.



STAKEHOLDERS OR SHAREHOLDERS?

Findings from the New Hampshire LIFE Accounts Primary Research Study

by Tobey Partch-Davies, M.S.

Background

People with disabilities have long been deterred from accumulating personal savings and other liquid assets due to the fact that it may disqualify them from essential public benefits, such as Medicaid. Medicaid is the primary health care benefit for acute and chronic health care needs ranging from doctors' visits to long term care services, such as personal assistance (e.g., eating, hygiene, transfers). In order to qualify for Medicaid under the Medically Needy category, individuals must meet a four year disability definition and a financial definition of eligibility. Once eligible for Medicaid, individuals or households are limited in their ability to earn and to accumulate resources due to asset limits and income caps tied to healthcare (i.e., Medicaid) and cash assistance programs (i.e., Supplemental Security Income and Social Security Disability).

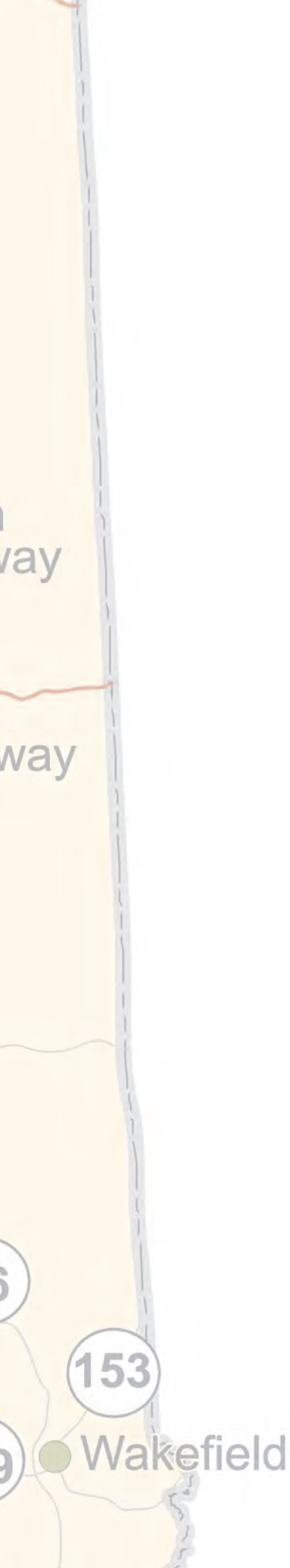
Historically, the income caps and asset limits have created a barrier to greater economic self reliance, forcing people to choose between health care and work. New legislation known as the Ticket to Work and Work Incentives Improvement Act of 1999 acknowledged these barriers, and encouraged states to de-link disability and poverty through the creation of "Medicaid Buy-In" programs that allow states to raise asset limit and income thresholds for people with disabilities who work, thereby creating an employment incentive. These changes, and those brought about by the Social Security Improvement Act of 2003, remove significant financial obstacles for people with disabilities. However, there remain significant program and policy barriers to saving for non-working age children with disabilities, people who are temporarily unable to work, and for caregivers of the same household – savings that are sorely needed to purchase items or services that could substantially improve independence and community participation among citizens with disabilities. Furthermore, advocates and federal and state policymakers are placing greater emphasis on moving away from program-based or institutional care for long term supports delivery (i.e., nursing homes, home health agency determined care) to models that promote individual/family choice and self-direction. This is based on the assumption that community-based supports and services will be less costly, more efficiently delivered, and more satisfying to consumers because they have greater control over their lives.

Purpose

The purpose of the Primary Research study described in this chapter was to examine the opportunities, barriers, and parameters associated with 1) the possible creation of a savings program for children and adults who self direct all of their Medicaid funded long term care services through four home care and community based Medicaid waiver programs in New Hampshire (In Home Supports waiver for children (IHS), Developmental Disabilities waiver (DD), Acquired Brain Disorder waiver (ABD), and the Elderly and Chronically Ill waiver (ECI)); and 2) to explore the barriers to self-directed services and strategies for addressing them through primary inquiry.

Components

This study included the following research components: a) key informant interviews; b) a focus group study including respondents representing consumers of services, agency staff, and program administrators who administer long term supports; and c) a survey questionnaire.



Research Questions

1. What are the conditions that impact an individual's/family's ability/desire to self-direct long-term care services?
2. What are the advantages or disadvantages of self-direction? What are the advantages and disadvantages of agency-delivered services?
3. What are the barriers to self-direction?
4. What would make it easier to engage in self-directed services?
5. What is the demand for a savings program?
   How many people would like to participate?
   What kinds of items or purposes would individuals like to save toward?
6. What program characteristics would be most desirable among potential participants?
   How would the savings program be structured?
   How much money could be saved without disqualifying people from public benefits?
   From what sources would savings be possible?
7. Are there viable strategies for sustaining a savings program?
8. Is there political will among stakeholder groups, state legislature, Congress, and state and federal policy administrators to implement a savings program?

Methods

Key Informant Interviews

Key informant interviews were carried out for the purpose of elucidating the current infrastructure available in the State of New Hampshire for self-directed services; discovering the barriers and facilitators to self-directed services at the individual and systems level; obtaining impressions about characteristics that distinquish self-directed models from traditional models of long term supports within each of the targeted waivers; determining how opinions or attitudes vary across different stakeholder groups about the advantages and disadvantages of traditional agency based services versus self-directed models; and exploring policy implications associated with the potential establishment of a savings program.

Participants in the schedule of key informant interviews included self-consenting adults who direct their own services, or adults considered "surrogates" for a Medicaid beneficiary; self-consenting adults who utilize agency-directed services (i.e., not self-directed services), program administrators within the Divisions of Developmental Services, Elderly and Adult Services and agency staff and other state and national experts in long-term care services.

Subjects were selected based on a purposeful sample beginning with state agency department directors and Other Qualified Agencies (community agencies serving as an intermediary for self-directed services). Project staff requested interviews with Division staff and program managers at Other Qualified Agencies, as well as by referrals to other potential respondents.

Interview Participants

A total of eleven people were formally interviewed for this study (n=11). Three respondents represented Self-Directing Adults, two represented surrogates or legal guardians, seven represented agency staff or program administrators. All subjects interviewed have many years of experience managing personal support services, either for themselves or administering programs for use by individuals with disabilities. All subjects have knowledge and experience with self-directed service options as well as agency-delivered service options.

Several additional interviews were requested; however, many individuals were reluctant to participate due to concerns associated with confidentiality, despite the assurances given in the Participant Informed Consent.

Focus Groups

The project conducted a stratified focus group study, recruiting a purposeful sample of subjects representative of two main groups: 1) Group I - consumers self-directing services who access one of the four waiver programs; and 2) Group II - agency personnel. Two focus groups were conducted with policy experts.

Sampling

Self-Directing Adults

One focus group was conducted with consenting adults who self-direct Medicaid long term supports through the state funded Personal Assistance Services and the Elderly and Chronically Ill waiver. Requests for participation were distributed through the Independent Living Center Peer Support program. The focus group lasted for approximately 1.5 hours. All subjects volunteered participation via written Participant Informed Consent and received a $25.00 gift certificate as a token of appreciation.

A total of nine individuals participated (n=9).

Agency Personnel

One focus group was conducted with agency personnel who provide traditional agency delivered services as well as self-directed service options for each of the four waivers (i.e. DD, ABD, ECI, and IHS). Requests for participation were distributed through

information flyers at the participating agency. The focus group lasted for approximately two hours. All subjects volunteered participation via written Participant Informed Consent. Subjects were not paid to participate. A total of seven people participated (n=7).

Focus Group Participants

A total of 16 people participated in focus group discussions. Nearly all of the subjects participating have many years of experience managing personal support services, either for themselves or administering programs for use by individuals with disabilities. Nearly all subjects have knowledge and experience with self-directed service options and agency-delivered service options.

Participants represented in the focus group for people who manage their own supports were from different geographical areas around the state, including urban and rural locations and were roughly evenly divided between men and women. The focus group with agency personnel consisted of all women who worked for one agency in one part of the state.

Data Analysis

Data from the in-depth interviews and focus groups were recorded, transcribed, and coded by two reviewers. Data was analyzed using the within case and cross case constant comparative method of analysis in order to yield thematic connections.

Major Themes

Given that the questions asked to key informants and to focus group participants were identical, and that the results of the focus groups generating consistent reactions, the major themes have been integrated to represent one report of qualitative findings.

On subjects' personal or professional background in long-term care, and how their experiences influenced their current perspective:

As reported above, all subjects interviewed have many years of experience managing personal support services, either for themselves or administering programs for use by individuals with disabilities. All subjects have knowledge and experience with self-directed service options and agency-delivered service options.

On what sets self-directed services apart from agency-delivered services:

There is widespread agreement that self-directed long-term support is about empowering individuals with disabilities to have choice and control over the type of services provided and how they are provided in

the context of their lives. Nearly every respondent commented on the flexibility the method affords from the standpoint of hiring, scheduling and training preferences, that is not available in the traditional service system.

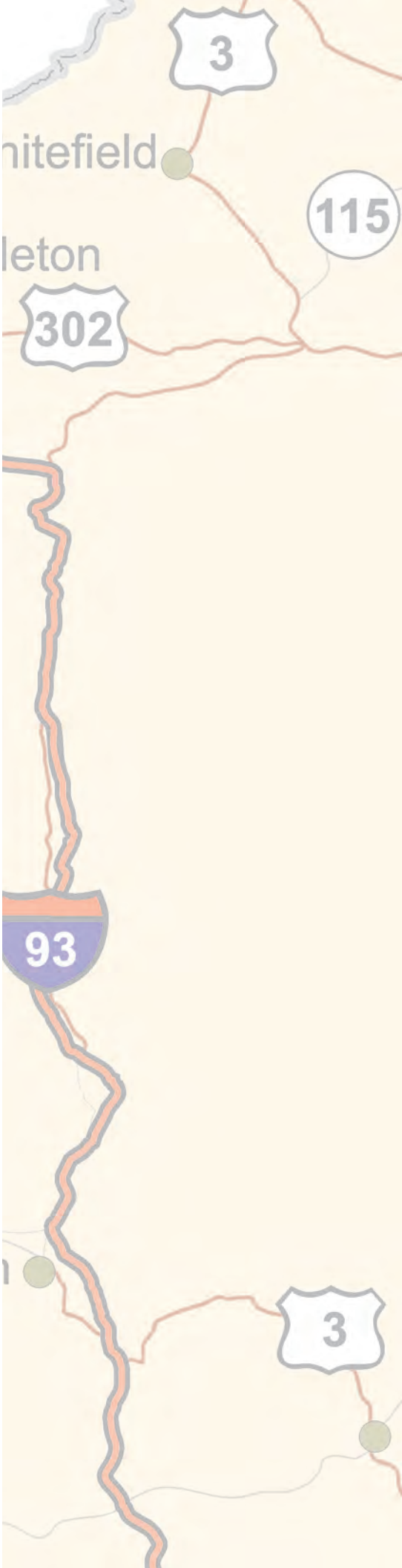
Distinctions are made between developmental services for children and adults with developmental disabilities from those options made available to people who are eligible for supports from the Elderly and Chronically Ill waiver. For those with developmental disabilities, the main catalyst for self-direction is acquiring the role of "budget manager" – controlling the dollars; whereas for people accessing services through the ECI or Personal Support Program, it is acquiring the role of employer. Both roles come with added responsibilities that aren't part of the traditional service system arrangement. While there are tradeoffs, for those who are willing to perform these roles, respondents indicate they tend to be more satisfied with their services.

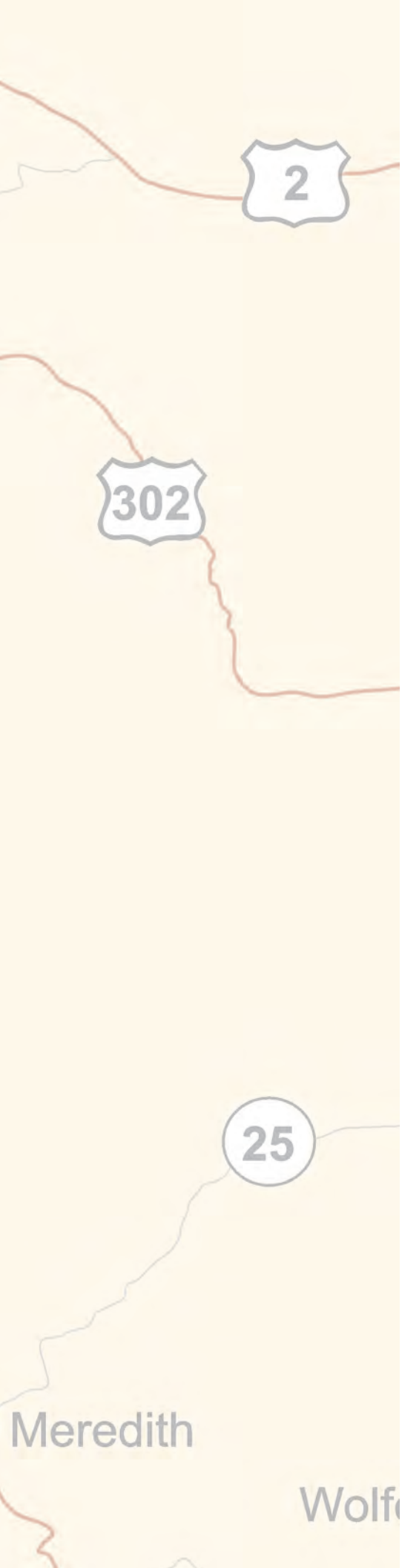
> *Like anything else, there are bumps here and there, but for an individual like myself, an independent arrangement works. I like the idea of training my staff the way I want to be taken care of . . . negotiating schedule arrangements . . . and the people I need.*

On the advantages and disadvantages of self-directed service models versus agency-directed models:

Schedule flexibility was viewed as a major advantage in the self-directed service model. It is very common for people to want less traffic in the home and fewer staff entering and exiting. Self-directed service options allow greater control over the number of people involved with providing the care as well as the timing of the service. This is very important to people. Dependable services are hard to secure in either scenario. Scheduling remains a source of conflict in both models that requires compromise due to the workforce challenges.

> *You don't want to depend on one person because people get so comfortable with you that they start telling you how to live. You need to protect yourself, and it's hard. Because the job is so personal, you get friendly and thinking that you are their friend, and you do care, but when you need to act professionally, and say, "I want my laundry done this way," or "if you are late, call me and let me know." There must be some balance.*





In many instances people use a combination of self-direction and agency-delivered services to achieve the mix of services they require.

I prefer self-directed services – it affords me much more flexibility – but I use both. I tend to use agencies for more medical needs, such as changing dressings, or for shots, things like that. But for everyday needs, like assistance at work, I use self-directed options because there are things I need my staff to do for me that workers from agencies won't allow them to do – the workers want to help me, but they can't because their employer won't allow them to and I end up stuck.

Several individuals with disabilities commented on power struggles with personal care attendents that seem to characterize agency-delivered services.

I'll have someone walk through the door with 25 years of experience working in a nursing home – they would know my care and tell me what I needed even if I never met them before – very aggravating – such power and control issues.
I prefer a clean slate, so I hire people with less experience so I can train them the way I want them to support me.

You don't want to get a nursing home attitude, and you have to help them get out of that, like them saying "I need to check your BM" – well, "why do you need to do that?" Sometimes it's better to find someone cold – but then they find out the hourly rate and they leave because another job can offer them 40 hours a week, insurance and paid holidays."

Occasionally unpleasant things happen in both approaches. One nurse I had through an agency said to me "sit back in your chair – I'm putting you to bed!" – that's what I mean about a power trip. They say you are in control, but you really aren't the one in control if you're the one naked on the floor. You can be the person in control after you get your clothes on, and in your chair. Hopefully you learn and prevent that from happening, but I don't argue with anyone when I'm sitting on the toilet or in the shower – I wait until I have my clothes on and I'm near a phone.

The self-directed service option is reported to have a significant impact on the family life.

They may not have friends, or opportunities to do things like typical kids, like join the soccer team or go to the movies at the age of 13. Many families are looking for these types of opportunities and in home supports allows them to use teenagers in the neighborhood . . . [for experiences] they wouldn't have had otherwise. It means a great deal to the child, but it's also had a great deal of impact on the family – it's changed their life.

On the people who self-direct their services:
Most of those interviewed have witnessed the transformation from institutional models of care (e.g. Laconia state school and other private institutional care facilities) to a community based service system. Although respondents acknowledge the progress that has occurred over the years, the system has had to adapt in recent years because young families, many of whom have benefited from the special education laws and enhanced social policies, have higher expectations than was thought to be achievable less than a generation ago.

It was a medical model. It's really not fair of me to make any comparison. It was a different time of life and I was too young to know what I needed, or be able to tell people what I needed. My mother was my best educator at telling people . . . she always told me "please tell me what you want . . . this is the only way that I can help you". With that type of encouragement, I learned how to direct people. I really don't think she realized what she was teaching me by saying that. It came natural to her – of course you should have a choice in the way that you live your own life.

Most people who select consumer-directed services tend to be people who can't seem to get their needs met conveniently through traditional means. Primary care givers have to work outside the home, so self-directed supports are a way to hire workers that allows family members to live with a loved one rather than move to institutional care.

The budget ultimately helps, but it's the need of something that can't be traditionally met between the hours of 9 and 3 that usually prompts people to seek consumer-directed services.

We did a home visit and a granddaughter was sitting in the kitchen and said that if the personal care services weren't provided, she would be in a nursing home. "She loves to cook, and she loves to sew . . . she could do neither of those things in a nursing home, and that would be the end of her." Those are the stories that drive us.

On the barriers of self-directed services:
There was widespread agreement that compensation and fringe benefit packages, or lack thereof, are highly problematic to retaining a qualified and responsive workforce. Shortages in nursing personnel and recruitment strategies is also a problem. Agency personnel report that there is a backlog of referrals, but due to nursing shortages, they can't keep up with referrals.

Agency executives cautioned that in the interest of fostering the autonomy of persons with disabilities, policies may be overlooking the spillover effects of creating an underinsured workforce.

> *A lot of things are being done to try and save money and not wanting consumers to be on the short end of the stick. But staff in the [self-directed program] are non-benefit employees . . . I can't help but question whether [the system] is compromising people and their ability to provide for themselves and not make them a burden or underclass of society.*

Professionalism is also a problem in some cases.

> *Sometimes I'm so desperate that I hire 18 year old girls – but then I have to be their mom. I'll be going to testify at the statehouse, and my aide will show up with a thong – her butt is hanging out! You need to tell them how to dress – no belly shirts, no cleavage.*

They report that financial constraints make it difficult for many organizations to operationalize self-directed services. Some agencies have consolidated as a means to save money, but respondents report that this has only limited the choices available.

> *"How can we say that people with developmental services have choice when fewer choices are available? Individuals and families need more information. It is not always a choice for people to choose their vendors. Some agencies embrace self-directed service options much more than others."*

The issue of heightened accountability and personal responsibility is viewed sometimes as an obstacle from a capacity point of view.

> *You get things about consumer direction and choice and control and all of this . . . you still have to fit into a medical model. The underpinnings of the regulations and the amount of paperwork . . . you're rejustifying every time a family submits something that we're going to pay for to confirm how it relates to the child's disability. We have to go down to every single level to approve something.*

On what would make it easier for more people to self-direct their own services:

There is widespread agreement that workforce issues must be addressed, but in doing so, models must be in keeping with self-directed service principles while meeting the legitimate needs of both persons with disabilities and workers. Respondents indicated that coordination efforts among agencies and with stakeholder groups is key for arriving at effective strategies. Some ideas presented included:

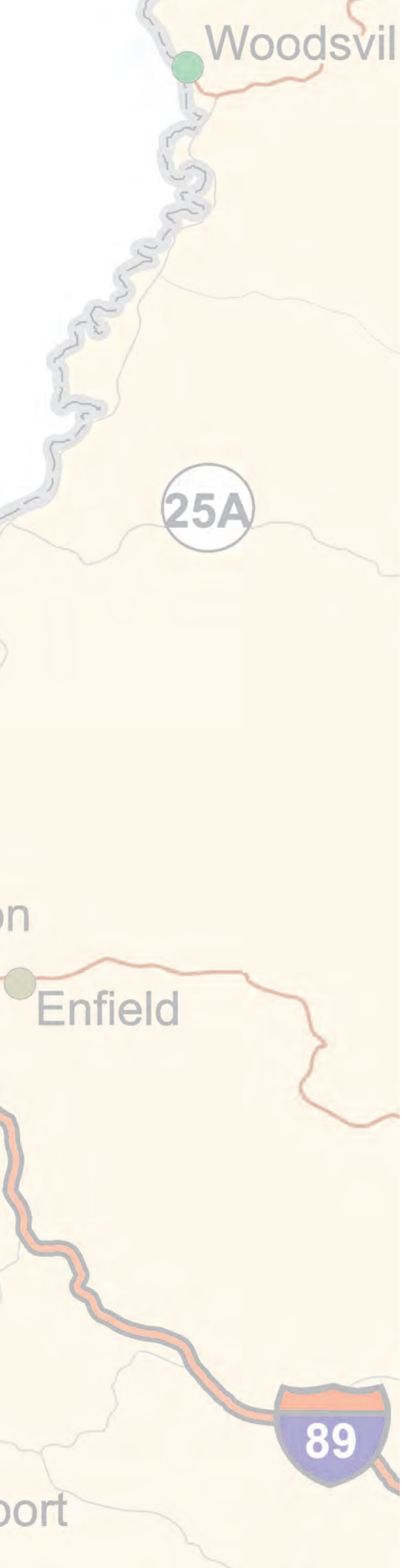
1. bundling hours across cost centers so if a person works for multiple people they can satisfy a full time equivalent position.
2. establishing shift differentials for weekends and holidays, snow storms, when reliable help is hard to find.
3. flexibility to pay people different rates of pay for unique skill sets and to reward reliable support.
4. developing a professional service that would recruit workers, field calls, and maintain an active list of worker characteristics. This would save time and save money (e.g. through joint advertising and allowing people to spend time in more productive ways rather than consistently on recruitment efforts.)

Several people acknowledged the time involved in coordinating their own care, whether through agencies or through self-directed models. While individuals have little choice but to coordinate this aspect of their life, it can be a costly endeavor, both from the standpoint of out of pocket expenses and opportunity costs related to the time involved.

> *I probably spend $300 a year in out of pocket advertising expenses related to hiring. I end up spending a lot more on food and coffee for support staff just to be polite and show [staff] I care because I have no other way to acknowledge it.*

Agency personnel report that it takes a strong commitment to organizational mission and leadership to expand access to self-directed service options.

> *Our director just works for the individuals we serve, and never loses sight of that. She is willing to change, willing to take on something new, she'll assess her risk and take chances. It comes from leadership – the board,and the people that surround her to make it effective.*



On the concept of a LIFE Account and how it would be perceived by stakeholder groups:

Agency professionals and consumers alike indicated that if Medicaid dollars are to be used for LIFE Accounts, the dollars would likely need to be justified as medically related in order to garner political support of policy makers. Some of the items that were identified as medical, but uncovered or only partially covered by Medicaid, included beds, prescription medication co-pays, alternative therapies, dental care, glasses, home equipment and home repair.

One agency administrator interviewed indicated that the social development aspects are harder to measure, but are essential to the health and wellbeing of people.

> *The social aspect isn't necessarily tangible, but what we foresee is a better quality of life – things like art, culture, visits with family and friends, like airline tickets to attend a child's wedding, or to stay active by taking music or Spanish lessons, these all have an impact on health and wellbeing.*

> *We have some situations where environmental modifications simply don't cover what a family needs because you can't add square footage to a home. Justifiably I hear that mom, I hear everything she is saying, I'm like "you do need a bedroom and bathroom downstairs so she can be independent" – this is a 16-year-old girl who shouldn't be bathed in a kitchen sink anymore, or have to sleep on the couch downstairs because she can't be lifted upstairs to her room. This family is really struggling financially.*

When learning that part of the motivation for LIFE Accounts is to reduce the need for human assistance, there was a great deal of reluctance and skepticism about the motivations behind it.

> *"Well, the account could help with a microwave, but I would still need help cutting vegetables – I guess it could buy Rosie the Robot from the Jetsons, in that sense, they could throw me on a conveyor belt."*

> *I can see maybe an environmental control unit maybe helping out, but I think it was the Cash and Counseling demonstration in Arkansas that gave people an extra $300 a month – very modest amount of money – and when you have nothing it makes a difference, but the reality is, that costs associated with people with chronic illness are much higher than the type of individual budgets I see in other systems. For people with high needs, they would be worse off and my fear is that it would backfire.*

I have no clue what my service costs are, so I have no idea what kind of arrangements I could work out. I would like to see how it might work.

On how a LIFE Account should be structured:
The items listed below illustrate the features of how the account should be structured to make it viable and politically palatable to consumers and policy makers and are in no particular order of priority.

- Accounts should be custodial with proper checks and balances in place (statements, accountings, etc.)
- Process should be as simple as possible (e.g. there are already so many administrative burdens for all involved)
- Should allow for personal and third party contributions – not dependent on Medicaid dollars
- Managed preferably by an intermediary fiscal agent (bank, credit union, or third party) to avoid conflicts of interest with agencies
- Restrictions on the amount of resources that can be accumulated
- Option of pre paid debit card to pay for approved uses (e.g. medical savings account)
- Use of the funds should tie in somehow with care plans
- Contingency plan should be in place on what qualifies as emergency use or for changes in the use of the dollars; where the dollars go if beneficiary were to die
- Flexibility to use the dollars for personal care services if needed
- Contingency plan to make sure that people aren't compromising their care in order to save funds
- Ability to structure use of the funds so that it can cover what is justifiable, but so that it allows consumers to pay the difference if the item that they want is more costly or a different make or model.

Survey

The purpose of the survey questionnaire was to gauge the potential desirability for a LIFE Account program, how it might be used, sources of contributions, and what the potential resources would be applied to in order to enhance the lives of participants.

The objectives of the survey were to confirm:

1. The number of people self-directing their services from participating agencies,
2. The number of people who wanted to self-direct their services,
3. The number of people interested in obtaining financial literacy,
4. The number of people applying savings and types of uses people would apply savings towards,
5. The number of people who would save money from particular sources of funds, and
6. The number of people who have difficulty saving money due to circumstances specified in the survey.

Survey Participants

At the time the survey study was implemented, participants who self-directed their services could not be isolated in aid categories and claims records from those who accessed services through agency-delivered means.[1] Therefore, the study targeted the survey to a purposeful sample of the self-directing population, rather than the preferred randomized method. The study relied on community partners, including Area Agencies and Other Qualified Agencies administering self-directed services, to distribute recruitment flyers and survey questionnaires. Due to the anticipated low response rate, a total enumeration of the self-directing population (estimated at 900) was attempted. Because other research efforts were underway in the state by other Real Choice grantees, as well as other research projects, we targeted the survey to three of the largest agencies in the state that were in locations that did not present a conflict with the other research initiatives.

The total modified number for enumeration was N= 860. The number of responses obtained was n=94, representing a response rate of 10%. Because all survey data was anonymous and not linked to Medicaid records, the only demographic characteristic available to describe the population is by aid category: 14 children qualified for In Home Supports (n=14); 13 adults qualified for the HCBC-DD waiver (n=13); 2 adults qualified for the HCBC-ABD waiver (n=2); 38 adults utilized HCBC-ECI services only (n=38); 7 individuals qualified for the State Option Personal Assistance Services (n=7); and 20 individuals utilized a combination of HCBC-ECI and PAS (n=20).

1 The one exception was the Personal Assistance Service program due to the fact that it is comprised of only individuals who self direct their services.

Instrumentation

The survey instrument utilized for this study was the exact instrument utilized by the Wisconsin LIFE Account project. Our protocols were not approved to merge individual level data between projects; however, the intent was to gather consistent data elements for this express purpose. Given that the survey was targeted specifically to people identified as self-directing their services via community partner agencies, the questions specific to self-direction (Q1-Q8) were asked as proxies or indicators regarding the perception of self-direction, rather than to validate the number of people self-directing.

Administering the survey by telephone was considered preferable over a self-administered mail survey. However, we did not have the resources to carry out a project of this nature. Despite the challenges, we implemented a self-administered survey. Participants received survey instructions, the anonymous survey questionnaire, Participant Informed Consent Forms, and postage paid return reply envelops. All participants had the option to contact the primary investigator by telephone if assistance was needed. Legal guardians completed the survey for minor children.

Analysis

Survey data was analyzed using descriptive statistics and cross tabulation. Chi-square tests were performed on a subset of the data to determine if there was an association between long-term supports and desire for 1) LIFE Accounts, 2) savings use, and 3) source of savings. Only statistically significant associations (i.e., those with a P value less than .05, and therefore indicative of a meaningful association between variables) are discussed in this report.

SURVEY RESULTS

Self-Direction. 73% of respondents confirmed that they self-direct their services (see Table 1). Even though all of the respondents participating were identified as self-directing their services, 27% of respondents indicated that they do not. Only 57% of respondents indicated that they are responsible for choosing how to spend the money authorized by Medicaid. Respondents self-directing their services through ECI and PAS were more likely to indicate that they are not responsible for determining how Medicaid dollars are spent. However, this same group is among the highest to report that they are responsible for hiring or firing their personal care assistants.

Table 1

			Responsible to choose services?		Total
			Yes	No	
Which type of long-term support?	In Home Supports	Count	12	2	14
			85.7%	14.3%	100%
	Consolidated-DD	Count	11	0	11
			100%	0%	100%
	Non-consolidated-DD	Count	1	0	1
			100%	0%	100%
	Consolidated-ABD	Count	1	1	2
			50%	50.0%	100%
	Non-consolidated-ABD	Count	1	0	1
			100%	0%	100%
	ECI-Only	Count	21	17	38
			55.3%	44.7%	100%
	PAS-only	Count	7	0	7
			100%	0%	100%
	ECI and PAS	Count	15	5	20
			75%	25%	100%
Total		Count	69	25	94
			73.4%	26.6%	100%

Financial Education. Only 28% of respondents indicated an interest in participating in a financial education program. Of those respondents, people self-directing through the Elderly and Chronically Ill waiver and the Personal Assistance Service option were the most interested.

Type of Desired Uses for Savings

Vacation. 39% of respondents indicated interest in saving for a vacation. 70% of individuals utilizing a combination of ECI & PAS services indicated an interest (14 out of 20), followed by 57% of respondents self-directing in the In Home Supports waiver (8 out of 14).

Home ownership. 36% of respondents indicated an interest in saving for a home. Those indicating the greatest interest were people self-directing using the combination of ECI & PAS (12 out of 20), followed by individuals self-directing through the Developmental Disabilities waiver (6 out of 13).

Home Modifications. 34% of respondents indicated an interest in saving toward home modifications. Individuals self-directing through a combination of ECI & PAS services showed the greatest interest at 50% (10 out of 20), followed by 43% of individuals served through the In Home Supports waiver (6 out of 14).

Automobile. Nearly 31% of respondents indicated interest in saving toward an automobile. The most interest came from individuals self-directing through a combination of ECI & PAS services (10 out of 20), followed by 21% of children accessing services through the In Home Supports waiver (3 out of 14).

Assistive Devices. Nearly 31% of respondents indicated interest in saving toward assistive devices. The greatest interest was expressed by children accessing services through the In Home Supports waiver (9 out of 14).

College Savings. 22% of respondents indicated an interest in saving for college. 50% of respondents self-directing through the In Home Supports waiver indicated the greatest interest in saving for college (7 out of 14), followed by respondents self-directing using a combination of ECI & PAS services (7 out of 20).

Personal Computer. 22% of respondents indicated an interest in saving toward a personal computer. This included 43% of respondents self-directing via the In Home Supports waiver (6 out of 14), followed by 36% of individuals self-directing through the Developmental Disabilities waiver (4 out of 13).

Self Employment. Only 18% of respondents indicated an interest in saving toward self employment goals. There was some interest from respondents in nearly every category of self-directed services.

Limitations that Prevent Individuals to Accomplish Savings Goals

Lack of Extra Income. Lack of extra income is the single most significant barrier that limits respondents' abilities from accomplishing their savings goals. 70% of individuals indicated lack of extra income as being problematic (66 out of 94 – see Table 2). Those who experience this problem most frequently are individuals accessing self-directed services via the ECI program only.

Table 2

			Does lack of extra money prevent you from having savings?		Total
			Yes	No	
Which type of long term support?	In Home Supports	Count	9 64.3%	5 35.7%	14 100%
	Consolidated-DD	Count	9 81.8%	2 18.2%	11 100%
	Non-consolidated-DD	Count	1 100%	0 0%	1 100%
	Consolidated-ABD	Count	2 100%	0 0%	2 100%
	Non-consolidated-ABD	Count	0 0%	1 100%	1 100%
	ECI-Only	Count	28 73.7%	10 26.3%	38 100%
	PAS-only	Count	4 57.1%	3 42.9%	7 100%
	ECI and PAS	Count	13 65%	7 35.0%	20 100%
Total		Count	66 70.2%	28 29.8%	94 100%

Asset Limits. 46% of respondents indicated Medicaid and SSI eligibility asset limits present an obstacle to saving. 70% of individuals self-directing through a combination of ECI & PAS services indicated this as being problematic (14 out of 20), followed by nearly 46% of respondents with developmental disabilities (6 out of 13).

Minimum Deposit Fees. Only 11% of respondents indicated minimum balance fees as being problematic to saving.

Assessing Demand for LIFE Accounts

79% of respondents indicated a desire to participate in a LIFE Account savings program if one became available (see Table 3). Among categories of self-directed care, interest among respondents ranged from 100% to 69%. People accessing In Home Supports, the Developmental Disabilities waiver and the Acquired Brain Disorder waiver indicated the highest demand, while people accessing the ECI waiver indicated the least interest.

Table 3

			Want a LIFE Account if available?		Total
			Yes	No	
Which type of long term support?	In Home Supports	Count	14 100%	0 0%	14 100%
	Consolidated-DD	Count	9 81.8%	2 18.2%	11 100%
	Non-consolidated-DD	Count	1 100%	0 0%	1 100%
	Consolidated-ABD	Count	1 50%	1 50%	2 100%
	Non-consolidated-ABD	Count	1 100%	0 0%	1 100%
	ECI-Only	Count	25 69.4%	11 30.6%	36 100%
	PAS-only	Count	6 85.7%	1 14.3%	7 100%
	ECI and PAS	Count	15 78.9%	4 21.1%	19 100%
Total		Count	72 79.1%	19 20.9%	91 100%

Sources of Savings Contributions

Savings from Employment. Only 24% of respondents indicated that they would deposit savings from employment into the LIFE Account.

Savings from Tax Refunds. Only 16% of respondents indicated that they would deposit savings from tax refunds into the LIFE Account. Those accessing services through the In Home Supports waiver were more willing to deposit funds from tax refunds (38.5%).

Savings from Social Security benefits. 54% of respondents indicated they would save funds from their Social Security benefits. Respondents accessing ECI/PAS and ECI Only services indicated the most interest in saving from Social Security benefits (17 out of 20 and 14 out of 38, respectively).

Savings from Relatives and Friends. 47% of respondents indicated that they would deposit funds provided by relatives. 40% indicated that they would save money contributed by friends.

Savings from Medicaid. 49% of respondents indicated that they would deposit savings from Medicaid. The greatest interest in saving from Medicaid was among individuals accessing services through the In Home Supports waiver (84%) and the Developmental Disabilities waiver (70%).

Assistance Completing the Survey. 59% of respondents had assistance completing the survey. Those who were most likely to access assistance were children accessing the In Home Supports waiver (legal minors) and individuals accessing services through the Developmental Disability waiver. 24% of respondents accessed assistance from legal guardians, 36% from family or caregivers, and 2% from a case manager.

Discussion

This survey study confirms that the majority of respondents in this study consider themselves as self-directing the services they receive from Medicaid. Although individuals who access ECI and PAS services were less likely to identify with responsibilities associated with Medicaid spending, it is clear that they are self directing due to their responsibilities associated with hiring and managing their staff, whereas individuals who access IHS and DD services are in charge of an individual budget.

A majority, 70% of respondents, indicated a desire to save in a LIFE account, if given the option. There is a statistically significant association for savings contributions from sources of earned income and from Medicaid. Respondents self-directing via ECI and PAS services were most likely to indicate the desire to allocate savings from employment. Respondents self-directing services through IHS and DD waivers were most likely to indicate the desire to allocate savings from Medicaid for the purpose of purchasing goods and services.

The type and use for desired savings is distributed across the spectrum of items presented. The only statistically significant association for savings is for vacation and assistive devices. The single most significant barrier to savings indicated by respondents is lack of extra money to save. Although this condition is problematic, only 28% of respondents (primarily individuals accessing ECI and PAS services) indicated an interest in accessing financial education.

The results of this study closely compare with the results that the Wisconsin LIFE Account survey study harvested (APH Healthcare, 2006). New Hampshire and Wisconsin respondents indicated a high desire to participate in a LIFE Account program; a low level of interest in financial education; no extra money as being the single most significant barrier to savings; and vacation as the most highly desired item to save toward.

Limitations

The results of the survey are not generalizable. At best, this study explores the desirability of a LIFE Account, and the possible uses, contributions and barriers to saving.

Implications

The results of this survey imply that sources and uses for savings need to be demand sensitive. Despite the strong desire to save for vacation, as confirmed by focus group and interview data there are a variety of savings uses that people have in my mind. Given that the lack of income is the most significant barrier to savings, it is important that the LIFE Account model take into consideration a variety of types of contributions to make the LIFE Account viable and capable of achieving the desired effects.

LIFE ACCOUNT FEASIBILITY STUDY

by Tobey Partch-Davies, M.S.

The New Hampshire LIFE Account project conducted a mix of policy analyses, primary research and program design activities for the purpose of establishing a savings program for individuals who self-direct their Medicaid funded long term support services, without disqualifying them from health and cash benefit programs.

This article summarizes current policy obstacles, identifies alternative policies, and recommends policy actions necessary for making LIFE Accounts viable in New Hampshire. Implementation efforts are proposed for short and longer term needs essential for improving people's financial stability and quality of life, and for bringing self-directed services to scale.

Problem Analysis

Lack of financial resources is one of the most serious problems that individuals face (National Organization on Disability/Harris Poll, 2000). A number of causes explain this core problem, the effects of which further compound the problem of poverty and social inequality of persons with disabilities.

By nature, means tested benefit programs, including Medicaid require that people be poor and in most cases stay poor in order to maintain healthcare eligibility. Federal and state policies that govern eligibility definitions place restrictions on the amount of income and financial

resources that can be accumulated, depending on the aid category. Currently, the only option in NH that allows an individual utilizing 1915(c) waiver services to accumulate more than $1,500 of liquid assets is the Medicaid for Employed Adults with Disabilities program (e.g. NH Medicaid Buy In program). However, this program requires that an individual work. If unemployed, or for those who are over the age of 64, there is a gap – no Medicaid program is available that allows an accumulation in excess of $1,500. According to the most recent analysis of the MEAD program, 1,761 people participated in the MEAD program (Clark and Samnaliev, 2005). Average monthly combined income was $1,112 ($400 earned and $712 unearned income). 11,417 participants who were not eligible for MEAD did qualify for Medicaid based on having income at or below the net income limit which would qualify them for assistance. (Clark et al). If eligible for the waiver, they had resources less than $1,500. (See Appendix I Target Populations for LIFE Accounts, and Appendix II for Medicaid Aid Categories.)

The 1915(c) waivers for In Home Supports (IHS), Developmental Disabilities (DD), Acquired Brain Disorders (ABD) and the Elderly and Chronically Ill (ECI) each have mechanisms in place for self-directed services. However, there are many more individuals who qualify for HCBC and Medically Needy categories than utilize self-directed service options. Individuals with mental illness and children with special medical needs or who are seriously emotionally disturbed do not have a resource base to draw from – self-directed services are limited to billable hours for medically necessary services, not available in individual budgets as is the case with DD, ABD and IHS services. This arrangement poses challenges to the CMS concept that only those who "self-direct all of their Medicaid funded long term supports." (See Appendix III for Testimony by Dennis Smith.)

As indicated in the results from the focus groups and interviews, individuals who self-direct their services have high out of pocket expenses associated with uncovered prescriptions, advertising expenses, incontinence supplies, and other basic costs associated with accommodation needs. Many goods and services that might improve an individual's quality of life are not reimbursed by Medicaid because they aren't assessed by Medicaid as medically necessary. In these cases, individuals experience the financial hardship necessary to cover the cost themselves, or do without. These expenses reduce the overall availability of resources, and reduce the standard of living. If gone without, lack of the resources perpetuates marginalization (e.g. by keeping people homebound).

Medicaid in general discourages asset transfers and third party contributions. Although Special Needs Trusts are available, these

resources are restricted to those individuals who have the financial means to cover the costs of legal fees, as well as to individuals intending to bequeath resources to a trust. However, unlike tax advantaged savings accounts, including 401(k)s, Coverdale Savings Accounts, and others, tax trust rates can be excessive depending on the size of the trust and related deductions (United Disabled for Economic Security, 2007; CCH Federal Estate & Gift Taxes, 2008). With the exception of Special Needs Trusts, there are no provisions in place that incentivize even modest, dedicated financial contributions for a child's future; doing so would disqualify children from Medicaid (e.g. Katie Beckett program). Several savings bill were proposed in 2007 and 2008 to enhance financial security for individuals with disabilities through the establishment of Disability Savings Accounts; however, to date, these bills have yet to obtain the support needed (H.R. 2370 Crenshaw; S.2743 Casey/Hatch; and S. 2741 (Dodd). (See Appendix III for Side by Side Analysis.)

Work incentives available within SSI and SSDI are advantageous for those who work and utilize them. But these programs don't take into account resource exclusions for those who are unable to work due to a chronic illness, or resource set asides for a minor child with disabilities who will no doubt experience a higher cost of living due to their disability and the augmentative support needs they require.

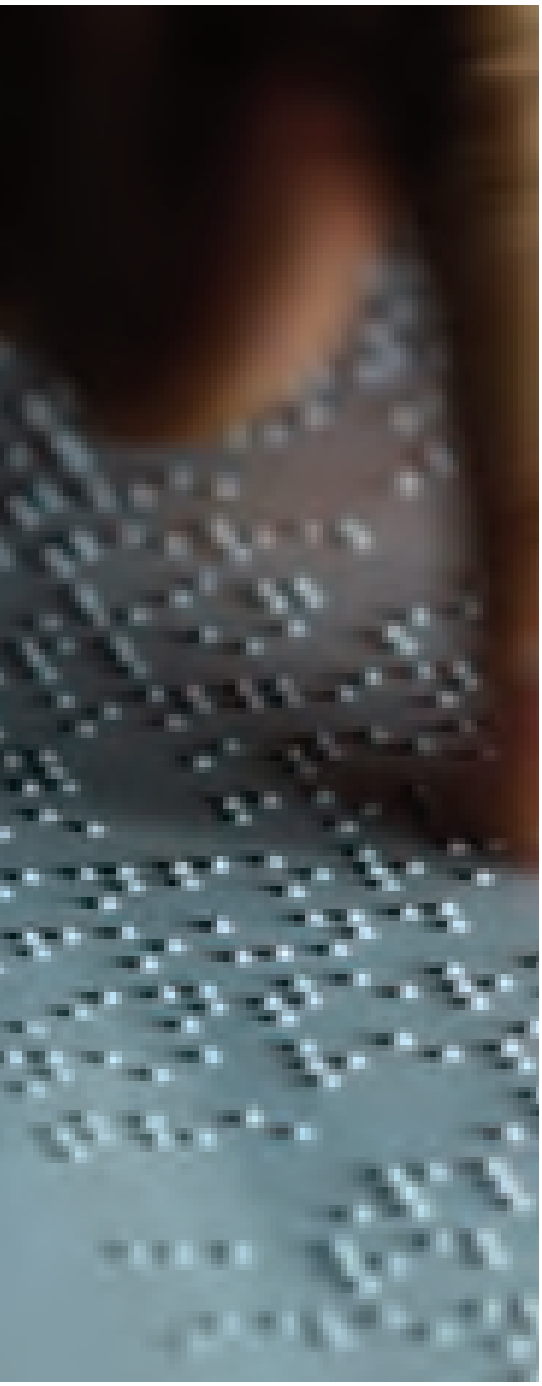
Similarly, Individual Development Accounts, Family Self Sufficiency programs, and tax credit programs have a work requirement. Although the programs are designed to enhance opportunities for financial self sufficiency, they preclude participation by those who have yet to attain employment, but may very well need financial resources to acquire employment. Moreover, uses of accumulated savings in IDA programs are limited to only those made possible by the Assets for Independence Act (AFIA), implying that the only savings uses allowed include those for home ownership, post-secondary education or business development. Although other "private" IDAs are available, including ones for home repair, car ownership, and others, they are prohibited by the Social Security Administration (POMS). One may believe that medical expense deductions on Schedule A would be of great benefit to persons with disabilities. However, a barrier exists in accessing this particular tax relief. The medical deduction's appearance on Schedule A rather than Form 1040 limits its use to those who either have catastrophic medical expense (in excess of the standard deduction), or those who own their own home and can claim other deductions. This benefit excludes many people with disabilities.

According to our survey study, users of self-directed services are very interested in participating in a LIFE Account program if one were to become available. However, individuals with high needs are reluctant and question the motivations behind the LIFE Account. Their experience advocating for civil rights and health policy improvements

and later having to contend with regressive policy set-backs that occur due to changes in political ideology and administrations raises skepticism.

There are problems with the implementation of self-directed services as well. Workforce retention is one such problem. It is harder for self-directed service models to compete when full time equivalent-positions are available in the private sector, complete with benefit packages (for profit and non-profit). Unless stakeholders come together to engage in viable business models that are in keeping with self-directed principles and aims, it will be challenging to bring self-direction to scale. Nevertheless, agency personnel and policy administrators recognize the frugality and responsible behavior of individuals and families who self-direct their services. While exact figures on the numbers of persons who self-direct are unavailable, it only makes sense, at least to the respondents interviewed for this study, that individuals and families would be "shareholders" in savings achieved as a result of efficient spending. However, the extent of priorities, the realities of doing more with less, and the sizeable state deficit makes it unlikely that Medicaid will be a dominant source in financing other goods and services unless doing so is at a minimum cost neutral, targeted, and consistent with the intent of the Medicaid program.

Income and asset poverty, and the structural obstacles that perpetuate poverty, represent an opportunity cost for individuals, families and society. Despite the developmentalist approach in contemporary disability policy, social welfare in general fails to recognize parity. The costs for opportunity are considerably higher among persons with disabilities because they are denied the freedoms to be socially equal. In the area of healthcare, education, employment, transportation, housing, political and legal representation and self determination, people with disabilities endure major sources of "unfreedoms," the effects of which result in fewer choices and less control. An essential, necessary addition to self-directed models of support are assets – individual and community based assets – that can help reduce these major sources of unfreedoms by bringing self direction to scale.



Evaluation Criteria for Selecting Preferred Policy for LIFE Accounts

The evaluation criteria listed below can help select the preferred policy for LIFE Accounts. Decision criteria were harvested from focus group and interview data, as well as policy experts.

Technically feasible – the policy is adequate and effective at achieving the desired result. Specific measures include 1) number and amount of people saving, 2) level of satisfaction, 3) changes in condition (participation, removal of barriers, etc.).

Equity based – The policy is available to all Medicaid participants regardless as to whether or not individuals self-direct their services. Access to self-directed services is not available in all aid categories, and for those who do self direct, few people direct all of their Medicaid funded services. An equity criterion recognizes that the benefits of the program should be available to all Medicaid participants in order to remove barriers to community participation. Specific measures include 1) cross disability access, 2) age, and 3) aid categories.

Targeted – The policy waives statewideness and comparability in the early stages of adoption in order to pilot the program model.

Politically viable – The policy is subject to the least political opposition and the greatest level of acceptability to political actors. Specific measures include: 1) non-negotiables, and 2) constraints.

Leverages resources – The policy enables integration of available infrastructure and resources in order to keep administrative costs down and increase effectiveness.

Cost neutral – The actual expenses to implement the policy are less or no more than the costs if no change in policy occurs.

Identification and Weighing of Alternative Policies

The matrix below illustrates the weights awarded to each option of the policy alternatives proposed. Weights with a "+" indicate a positive weight. Weights with a "-" indicate a negative weight. The policy with the most positive weights is the preferred policy. The rationale for the weights awarded is discussed below. The proposed policies are those actions that the state of New Hampshire may be able to take in absence of a federal law.

Policy Options	Technically Feasible	Equity Based	Targeted	Politically Viable	Leverages Resources	Cost Neutral
Option 1: Do Nothing	+	–		+	–	–
Option 2: 1915(c) expands permissible uses	+	–	+	+/–	+	+
Option 3: 1915(j) Offers goods and services	+	+	+	–	+	+
Option 4: Develop private Disability Savings Account	+	+	+	+/-	+	+
Option 5: Make no change in policy but Target Education and Training	+	+	+	+	+	+

Evaluation of Alternative Policies

Do Nothing

This is not an option. Despite some of the policy obstacles associated with Special Needs Trusts, work incentives and available asset building programs, people with disabilities lack awareness about the programs that are available. At the very least, awareness efforts should be targeted to educate individuals, families and community organizations so that people can access the programs that can help them advance economically. Specifically these include: IDAs, Earned Income Tax Credit, Advanced Earned Income Tax Credits, Family Self Sufficiency programs, Medicaid Buy In benefits, and others.

Establish "permissible purchases" within NH 1915(c) waiver programs.

Given that each of the options for self-directed services are made available in the 1915(c) waivers, use of these waivers and expanding them to include "permissible uses" that are consistent with the desired savings uses for the LIFE Account would be most reasonable and effective. The HCBS Waiver Authority would allow waiver authority for targeting as well as resource limits. Because the operationalization of self-directed services would remain consistent, political viability is likely from the actors involved so long as it remains cost neutral and doesn't increase Medicaid expenditures. These source of funds would leverage other work incentives and asset building programs so long as the sources were excluded from eligibility determinations of public benefits. This is possible so long as resources do not exceed the SSI $2,500 resource limit (currently the HCBC/APTD resource limit is $1,500). The $1,000 resource differential would need to be negotiated and would likely require language consistent with the intentions of the Medicaid program in order to be viable (for example, a Quality of Life Improvement Account).

Develop a 1915(j) State Plan Option via State Plan Amendment allowing states to waive statewideness and comparability; target eligibility and allow for other "goods and services."

The 1915(j) State Plan Option is in general the best match for LIFE Accounts from the standpoint of technical feasibility. It also provides for waivers of statewideness and for comparability. However, because all of the waivers in New Hampshire are based on 1915(c) already, it is unlikely that each of the Bureaus would pursue the 1915(j) option just to allow for LIFE Accounts. It would be more expeditious to accomplish "other permissible purchases" through the 1915(c) waivers.

Establish a private Disability Savings Account similar to an IDA product that could accept 3rd party contributions (from individuals or organizations) and would have tax advantages for the purpose of enhancing community participation and enhancing the quality of life of persons with disabilities.

The concept of a Disability Savings Account is technically feasible. There are numerous examples of custodial accounts already available (e.g. IDAs, Family Self Sufficiency accounts, PASS accounts, Employability Accounts within the MEAD program, etc.). Moreover, IDAs accept tax advantaged deposits from businesses by offsetting business enterprise and capital gains tax. The one drawback is that there is no mechanism in place to offer tax deductions or refundable credits to private individuals. Negotiating the account would require that SSI and Medicaid exclude the funds deposited from eligibility determinations and the fund size would need to be acceptable to the political actors involved. Because NH does not have a state income tax,

and at the present time the state has a budget shortfall, tax advantaged accounts are unlikely at this time unless the program is funded by the Tax Incentive Program available through the New Hampshire Community Development Finance Authority. In this case, the program will have to focus on outcomes specific to housing and jobs.

Target Education and Training

Several programs are already in existence that enable personal savings and asset accumulation. However, most of these programs are under-utilized by persons with disabilities. This policy option is attractive because it meets all of the established criteria. However, in this case, it still leaves out people who aren't working, or who are unable to work. In absence of legislating the private Disability Savings Account, this is the next best policy option, and one that can be acted on today for immediate impact.

Selection of Preferred Policy

In absence of federal law that enables a LIFE Account program, the preferred policy option is Option 4: Establish a private Disability Savings Account similar to an IDA product that could accept 3rd party contributions (from individuals and organizations) and give tax advantages for the purpose of enhancing community participation and enhancing the quality of life of persons with disabilities.

One of the challenges associated with the LIFE Account as originally conceived is that it only emphasizes people who self direct as deserving of savings accumulation. This emphasis raised concerns by from self-directed service advocates as well as policy analysts and agency personnel throughout the study implementation. Part of the reason this is true is due the equity based criteria frequently emphasized by policy makers to help ensure that the costs and benefits of public policies are distributed equally. However, despite the social progress made, people with disabilities are still considerably more disadvantaged than their same age peers, and need more financial resources to foster their capabilities, remove sources of unfreedoms, and defray a higher cost of living. As indicated by Mendelsohn *"activity for activity, accomplishment for accomplishment, it is more expensive to be a person with a disability than to be a person without one*" (2008). More specifically, public policy fails to recognize parity in community based care for persons with mental illness. Exclusion of persons with mental illness from benefiting from the LIFE Account option due to the fact that self-directed services are not currently available would reinforce this policy.

A Disability Quality of LIFE Account program would be established to be available to anyone with a disability who at the time of application is eligible for the Medicaid program.

LIFE ACCOUNT IMPLEMENTATION PLAN

The recommended action for the LIFE Account Implementation Plan has two components. The first is to engage in activities necessary to gain political momentum to move LIFE Accounts from just a concept to reality in New Hampshire. The second is to increase the utilization of economic security and asset building programs, including tax credits, Individual Development Accounts, and financial education resources available in local communities for improving financial stability and financial self sufficiency. Our plan is to conduct these activities concurrently. Several of the items are already underway.

Part 1. Gain Political Momentum

In absence of a federal law, the short-term plan is to 1) garner support from key stakeholders in order to establish the political will necessary to make modifications to existing rules, and 2) generate interest among potential funders to build a fund that would leverage other asset building resources and work incentives for persons with disabilities.

Listed below are the implementation steps necessary to move the LIFE Account concept forward in New Hampshire.

1. Track development of savings bills sponsored by Crenshaw, Casey/Hatch and Dodd. Meet with NH state senators and congresspersons to gain support. January 2009-ongoing
2. Re-engage self-advocates, parents and other concerned citizens and policy makers to develop an organizing and marketing campaign for a Disability Quality of LIFE Account. February 2009.
3. Circulate the feasibility study to key policy members and workgroups, including the Medicaid Infrastructure Grant, Medicaid Buy In workgroup, University Center of Excellence Advisory Committee, and local asset building coalitions (where applicable), and others. Ongoing.
4. Consult with CMS and DHHS personnel to explore modifications to the 1915(c) waivers to allow for other "permissible uses." March 2009.
5. Consult with the Social Security Administration to determine processes for waiving asset limits for participants in a LIFE Account. March 2009.
6. Consult with legal professionals for the purpose of establishing a fund to make matching contributions to LIFE Accounts. April 2009.
7. Meet with foundations including the NH Charitable Foundation, NH Endowment for Health, NH Community Development Finance Authority and private corporations for fundraising purposes. April 2009.
8. Integrate the LIFE Account/Quality of LIFE Saving Account into key public policy agendas in the state of NH. By June 2009.
9. Host regional Asset Summit for New England states, including interested members of the MIG-New England Partnership, Asset Building Coalitions, and Real Economic Impact Tour grantees. Incorporate a roundtable on LIFE Accounts with key state and federal officials, advocates and asset building experts. By August 2009.

Part 2. Increase Utilization of Available Economic Security and Asset Building Resources

One of the activities implemented in the final year of the project is the development of training and technical assistance on improving financial well being and asset building.

A key component of our implementation plan is to sustain these resources throughout the state of New Hampshire. Although the ability for persons on the HCBC waivers to accumulate more than the current asset allowances is still problematic, it is very likely that persons with disabilities are underutilizing services that could improve their financial stability, if not asset holdings.

Listed below are the implementation steps necessary to expand outreach, education and awareness about available resources.

1. In coordination with the New Hampshire Earned Income Tax Credit Alliance, the Real Economic Impact Tour, the Medicaid Infrastructure Grant, and the network of asset building coalitions in the state of NH, host a statewide kick-off Earned Income Tax Credit campaign to educate citizens about the tax credits and free tax preparation assistance available to persons with disabilities. January 2009 in process.
2. Disseminate Economic Opportunity Resource Maps statewide to key constituencies and local organizations. January 2009.
3. Expand partnerships across the state to engage in direct outreach, mailings, and media to encourage utilization of resources. Ongoing.
4. Continue implementing the REAL Opportunities online training. Ongoing.
5. Continue disseminating the BudgetWise newsletter. Quarterly.
6. Establish a workgroup to develop the Asset Summit hosted at the School of Community Economic Development (see Part 1, item 9). January 2009.
7. Establish public relations with media outlets. Ongoing.

Our authors

Kathy Bates, B.A. is a writer, an advocate and a teacher. She has a degree in Elementary Education from St. Andrews Presbyterian College in Laurinburg, North Carolina. She has been a featured speaker at numerous conferences and workshops around New Hampshire, and has worked with both children and adults with disabilities. For ten years she has been a group leader for the Leadership Series through the Institute on Disability, and has been an advisor for People First of New Hampshire. She is a well-known and respected advocate for people with disabilities in the areas of employment, person-centered planning, self-directed care, education, and disability rights. Ms. Bates recently started her own consulting business; *Wings and Wheels Consultant Services*.

Steven Mendelsohn, J.D., is an attorney and policy advocate working for over 25 years to advance full societal participation and economic self-sufficiency for Americans with disabilities. Through research, advocacy and public education in presentations, testimony, papers and books, he has worked in areas spanning information technology access to tax law to asset development.

Mr. Mendelsohn, a lifelong New Yorker who has recently moved to California, is the author of several books including Tax Options and Strategies for People with Disabilities. Since 2001, he has been the principal consultant to the National Council on Disability's annual progress report to the President and Congress. He is currently working with the National Disability Institute and the Real Economic Impact Tour in the effort to forge asset policies for the 21st century.

Tobey Partch-Davies, M.S., ABD/PhD, is founding director of the Center for Community Economic Development & Disability at Southern New Hampshire University's School of Community Economic Development. The Center conducts evaluation and applied research, policy analysis, planning, academic and practical training, and technical assistance on interdisciplinary projects that integrate theories of change consistent with best practice in CED and community based supports for individuals with disabilities. Program areas include asset building, employment and healthcare.

Michelle Winchester, J.D., is a health and long-term care policy analyst with the Institute for Health, Law and Ethics at the Franklin Pierce Law Center in Concord. She has held this position since 1998. The Institute employs its skills in legal and policy analysis to research, report, comment, and propose recommendations relative to the impacts of federal and state law, including government funding sources, on the integration and provision of quality health and social services to the people of New Hampshire.

APPENDIX I

NEW HAMPSHIRE DIVISION OF FAMILY ASSISTANCE PROGRAM FACT SHEET

7/07

This fact sheet is intended to provide you with basic information concerning eligibility, income, and resource requirements for each of the following programs: New Hampshire Employment Program (NHEP), Unemployed Parent Program (UP), Family Assistance Program (FAP); the State Supplement Programs which include Old Age Assistance (OAA), Aid to the Permanently & Totally Disabled (APTD), and Aid to the Needy Blind (ANB); the Medical Assistance Program (MEDICAID); the Food Stamp Program; Nursing Facility Care; Child Support Services; Qualified Medicare Beneficiaries (QMB), Specified Low Income Beneficiaries (SLMB/SLMB135); Child Care; Healthy Kids Medical Coverage for Children; Medical Coverage for Pregnant Women; and Medicaid for Employed Adults with Disabilities (MEAD).

By policy, different types of income and resources are either counted or not counted to determine eligibility. This can vary from program to program. In addition, there are amounts that can be subtracted from income. These also vary by program and are shown below as "disregards and deductions." Examples of income are wages, rental income, and most benefit income including Social Security and SSI. Examples of resources are cash on hand, bank accounts, stocks/bonds, and unoccupied real property. Applicants must verify income, resources, disregards and deductions, identity, citizenship or alien status, social security numbers, residency, and all other eligibility factors required by the specific programs of assistance.

If you think a family or individual may be eligible for one of our programs, please have them call, write, or visit the Department of Health and Human Services District Office nearest them for more details. Information is also available at www.dhhs.nh.gov.

PROGRAM TITLE	NH EMPLOYMENT PROGRAM (NHEP), UNEMPLOYED PARENT PROGRAM (UP), & FAMILY ASSISTANCE PROGRAM (FAP)	STATE SUPPLEMENT PROGRAM (OAA, APTD, ANB)	MEDICAL ASSISTANCE (MEDICAID)	FOOD STAMP PROGRAM	NURSING FACILITY CARE
DESCRIPTION	NHEP, UP, and FAP provide financial & medical assistance to needy families with dependent children in which one or both parents is disabled, deceased, unemployed, or absent from the home. Eligibility depends on income, resources, and expenses of a family. Families eligible for NHEP, UP, or FAP are automatically eligible for medical assistance. Able-bodied recipients of UP or NHEP financial assistance must meet NHEP work requirements. There is no mandatory work requirement for FAP. FAP is available to families with no able-bodied parents or when a relative other than a parent is caring for the child(ren).	The State Supplement program provides financial assistance to needy individuals who meet the definition of one of the following categories: 1. Old Age Assistance (OAA) - 65 years of age or older, or 2. Aid to the Permanently & Totally Disabled (APTD) - physically or mentally disabled and between the ages of 18 & 64, or 3. Aid to Needy Blind (ANB) - blind (no age limit) Eligibility depends on income, resources and living arrangement. Individuals eligible for State Supplement are also eligible for medical assistance.	The Medicaid program pays for certain health care costs (doctor and hospital bills, prescriptions, dental care for children, etc.) for individuals who meet the technical and categorical requirements of the NHEP/FAP or State Supplement programs, or MEAD. Children's coverage is called "Healthy Kids" (see other side). Adults and children with severe disabilities may also be eligible. If an individual meets all program requirements except is over the income limit, partial coverage can be provided under the In & Out program.	The Food Stamp program provides assistance to eligible families to purchase food items essential for good health. Eligibility for food stamps depends on the household's income, resources and expenses. Households must meet gross and net income limits. Households with a member who is elderly or disabled need only meet the net income test. Households with a member who is both elderly and disabled have higher gross income limits. If all members of the household receive SSI, NHEP/FAP financial assistance, and/or State Supplement, there are no income or resource limits. Most recipients must look for and keep a job. Able-bodied Adults Without Dependents (ABAWD) must also meet special ABAWD work requirements to receive more than 3 months of food stamps in a 36-month period.	The Medicaid program can cover the cost of nursing facility care for individuals who are unable to afford the cost. To receive payments for nursing facility care, an individual must: • meet the general, technical, categorical and financial requirements of a Medicaid program; and • have medical needs that require nursing facility care. Certain individuals meeting these requirements may be eligible to receive community-based services under one of several Home and Community-Based Care waivers instead of entering a nursing facility.
MONTHLY INCOME LIMITS	Group Size — Max Net Income* 1 — $489 2 — $556 3 — $625 4 — $688 *Less, if living in subsidized housing	Group Size — Net Income Limit 1 — $ 637 2 — $ 935 3 — $1,234 Applicants in Group Living Arrangements have higher income limits.	Group Size — Net Income Limit 1 — $591 2 — $675 3 — $683 4 — $691	Group Size — Maximum Gross Income — Maximum Net Income 1 — $1,062 — $ 817 2 — $1,430 — $1,100 3 — $1,799 — $1,384 4 — $2,167 — $1,667	The individual's net monthly income must be less than the Medicaid rate for the facility. The individual's income, after expenses and deductions, is used to offset the cost of care, with the balance paid by Medicaid.
RESOURCE LIMITS	The resource limits for NHEP, UP, and FAP financial assistance are: $1,000 for applicants, and $2,000 for recipients.	The resource limit for OAA, APTD and ANB financial assistance is $1,500. Certain life insurance policies and burial funds are not counted.	One person - $2,500 Two persons - $4,000 Three or more - $4,000 plus $100 for each additional person in the assistance group above two.	Households in which at least one member is disabled or age 60 or older: - $3,000 All other households: - $2,000	The resource limit for nursing facility care is $2,500.
DISREGARDS & DEDUCTIONS	• 20% of earned income for applicants • Child/Dependent Care Costs • Court-Ordered Child/Spousal Support • Self-Employment Expenses	• $13 standard disregard For working individuals: • $65 (APTD or OAA) or $85 (ANB), and • Impairment Related Work Expenses, and • ½ of remaining earned income	Deductions for NHEP/FAP and the State Supplement programs also apply for most Medical Assistance programs.	• Shelter • Utilities • Child/Dependent Care • Paid Child Support • Self-Employment Expenses • Medical for seniors and disabled • Standard household deduction	When determining cost of care: • $56 Personal Needs Allowance ($90 VA) • Allocation to dependents • Uncovered Medical expenses
OTHER ELIGIBILITY CRITERIA	Rights to child support are automatically assigned to the Department for NHEP and FAP, and NHEP/FAP clients must cooperate with child support requirements. There is a 60-month lifetime limit on receiving financial assistance through NHEP & UP.	Applicant must apply for SSI, and must agree to a lien on all real estate owned by the assistance group. If living together, a spouse's income, resources, and needs are considered when determining eligibility.	SSI is not counted as income. Medicaid applicants and recipients must cooperate with the Office of Child Support to obtain and enforce legal orders for medical support and to establish paternity for all children born out-of-wedlock.	Parents and children under age 22 living together are considered one household. Exceptions may be made if parents are over 60, disabled and receiving SSA/SSI, and for children aged 22 and older who purchase and prepare meals separately from their parents.	The nursing facility must be licensed and certified by the State of NH. If appropriate, the individual must apply for VA Aid and Attendance allowance benefits.

PROGRAM TITLE	CHILD SUPPORT SERVICES	CHILD CARE	HEALTHY KIDS FOR CHILDREN AND MEDICAL COVERAGE FOR PREGNANT WOMEN	QUALIFIED MEDICARE BENEFICIARIES (QMB)	MEDICAID FOR EMPLOYED ADULTS WITH DISABILITIES
DESCRIPTION	The Division of Child Support Services (DCSS) locates absent parents, establishes paternity and support orders, reviews orders to see if they meet NH guidelines, and enforces child support orders. These services are provided regardless of whether the noncustodial parent lives in NH or out of state. The DCSS collects and disburses child support payments. Methods to collect child support include interception of tax refund checks, mandatory wage withholding, interception of NH lottery prizes, and liens against property. The DCSS can also report delinquent payers to a credit bureau, and can request that a licensing board or agency suspend, revoke, or deny a payer's license if he or she is not in compliance with a legal order for support. Passports may also be suspended, revoked, or denied. The DCSS is mandated to provide child and medical support services to NHEP/FAP recipients and must provide medical support services to Medicaid-only recipients. In addition, the DCSS provides services to families that are not receiving public assistance. There is a separate application for these services. There is no fee.	The child care program helps pay for child care needed for training, education or employment. Costs are reimbursed up to established maximums that differ based on gross income, the age of the child and whether the care is provided by a contract center or non-contract provider. Higher payments may be available to providers who care for disabled children. (STEP 1) **MAXIMUM REIMBURSEMENT RATES** **Contract Child Care Center** Children under 3: up to $31.87/day for full-time care. up to $4.94/hour for part-time care. Children 3 yrs. through 12 yrs: up to $26.88/day for full-time care. up to $4.20/hour of part-time care. **Noncontract Licensed Child Care** Children under 3: up to $26.52/day for full-time care. up to $4.10/hour for part-time care. Children 3 yrs. through 12 yrs: up to $24.57/day for full-time care. up to $3.78/hour for part-time care. **Noncontract License Exempt** Children under 3: up to $22.47/day for full-time care. up to $3.47/hour for part-time care. Children 3 yrs. through 12 yrs: up to $18.22/day for full-time care. up to $2.73/hour for part-time care.	Children up to age 19 with income no higher than 185% of the federal poverty income limits can get medical coverage under the Healthy Kids-Gold program. Infants under age 1 with income higher than 185% but no more than 300% of federal poverty income limits can also get Healthy Kids-Gold coverage. There is no premium for Healthy Kids-Gold coverage. Children age 1 up to age 19 with income higher than 185%, but no more than 300%, of federal poverty income limits, can get medical insurance under the Healthy Kids-Silver program. There is a monthly premium for this insurance, and these children cannot currently be covered under any other medical insurance nor have had coverage in the last 6 months. Medical coverage is available to pregnant women of any age whose income is no higher than 185% of the federal poverty income limit. Parents, children, or pregnant women already receiving services at certain community agencies, such as hospitals, well child or prenatal clinics, and WIC may apply there for Healthy Kids or medical coverage for pregnant women.	Certain Medicare beneficiaries who are entitled to Medicare Part A insurance, and whose income is no more than 100% of the federal poverty level, may be eligible to have Medicare Part A and B premiums, deductibles and co-insurance costs paid. Some of these individuals may also be eligible for other programs, including Medicaid. **SPECIFIED LOW-INCOME MEDICARE BENEFICIARIES (SLMB/SLMB135)** Certain Medicare beneficiaries entitled to Medicare Part B but with higher incomes may be eligible for payment of all or part of their monthly Medicare Part B premiums. **Individuals with income between 100% and 120% of the federal poverty level** may be eligible for payment of their monthly Medicare Part B premiums and may also be eligible for other programs, including Medicaid. **Individuals with income between 120% and 135%** of federal poverty levels may be eligible for payment of the Medicare Part B premium, but cannot also be eligible for other Medicaid programs in the same month.	Medicaid for Employed Adults with Disabilities (MEAD) provides medical coverage to disabled working adults. MEAD has higher income and resource limits than other Medicaid programs and allows eligible recipients to return to work or increase their earnings. Some individuals who are eligible for MEAD may be required to pay a health insurance premium. To be eligible for MEAD, an individual must: • be 18 through 64 years old; • be employed or self employed for pay; • earn at least federal minimum wage and contribute to FICA; • meet MEAD income and resource criteria noted below; • meet ANB or APTD medical criteria; **or** • have a documented medical impairment that is included in the Social Security Administration's Listing of Impairments and that is expected to last 48 months or longer; **and** • enroll in cost-free health insurance if their employer offers it. Individuals and couples with income less than 150% of the federal poverty level are not required to pay a premium. Premiums are reduced by the cost of other health insurance.
MONTHLY INCOME LIMITS	None	Family Size / **Monthly Gross Income Limits** (Step 3) ≥190% PL 2 $2,168 3 $2,719 4 $3,270 5 $3,821 6 $4,372	Family Size / Monthly Maximum Income Limits (% of Federal Poverty) 185% / 300% 1 $1,575 / $2,553 2 $2,111 / $3,423 3 $2,648 / $4,293 4 $3,184 / $5,163	Monthly Income Limits (% of Federal Poverty) HH Size / QMB ≤100% / SLMB120 ≤120% / SLMB135 ≤135% 1 $851 $1,021 $1,149 2 $1,141 $1,369 $1,541	Monthly Maximum Income Limits 450% of Federal Poverty One person $3,829 Two or more persons $5,134
RESOURCE LIMITS	None	None	None	One person $4,000 Two or more persons $6,000	One person $23,421 Two or more persons $35,131
DISREGARDS & DEDUCTIONS	N/A	N/A	• $90 for each working individual • Court-Ordered Child/Spousal Support • Wage Garnishments • Child/Dependent Care Costs	• $65 of earned income • ½ of remaining earned income • $20 standard deduction	• ANB, APTD, or OAA deduction • Impairment Related Work Expenses • ½ of remaining earned income • Standard adult disregard • Employability account/medical savings account
OTHER ELIGIBILITY CRITERIA	NHEP/FAP with Medicaid, and Medicaid-only applicants/recipients must cooperate with the DCSS as a condition of eligibility.	An individual does not have to receive public assistance to receive help with child care. Child care must be necessary so that the parents can attend job training, look for a job or go to school or work.	Once eligible, pregnant women receive coverage through the 60th day post partum regardless of income. Children born to mothers receiving medical coverage at the time of birth are automatically eligible for up to one year so long as they remain with the mother in NH and mother remains eligible.	An applicant must also meet the general nonfinancial requirements/conditions of eligibility for Medicaid, such as filing an application, obtaining a Social Security number, etc. SSI is not counted as income.	An applicant must also meet the general nonfinancial requirements/conditions of eligibility for Medicaid. SSI is not counted as income when determining MEAD eligibility, but is counted when determining the premium amount.

APPENDIX II

Excerpt from the 2004 CMS Real Choice Systems Change Grant Solicitation2

LIFE ACCOUNT FEASIBILITY AND DEMONSTRATION

Purpose

The purpose of the LIFE Account Feasibility and Demonstration grant opportunity is to enable States to conduct studies assessing the feasibility of developing LIFE Account savings programs. CMS is offering this grant opportunity with the understanding that design elements discussed in this grant opportunity are under consideration only at this time. States may examine the feasibility of establishing and maintaining a program of individual savings accounts within which eligible Medicaid participants can build savings without affecting their eligibility or benefit levels for the State's Medicaid, Supplemental Security Income (SSI), Social Security Disability Income (SSDI), or any other Federal assistance program. The LIFE Account savings program is intended to enable people with a disability or chronic condition to become more independent by allowing eligible participants the opportunity to save for needed supports without losing their health coverage.

Background

CMS has been taking steps to enable States to allow beneficiaries greater direction over their community-based supports and increased opportunities for community living. Medicaid currently permits individuals to direct their own long-term supports through the *Independence Plus* initiative. In *Independence Plus* initiatives, State representatives work with individuals who have a disability to assess needs, develop plans of supports, and calculate the cost of such supports. Participating individuals have the opportunity to direct and control their own supports within (a) the bounds of the individualized budget established in agreement with the relevant State agency and (b) an overarching quality assurance system to ensure that essential needs are met.

Within such self-directed programs, individuals who self-direct their own supports might not benefit from the prudent purchasing or service management decisions that they make. Individuals may make cost-effective choices in arranging for services, yet any unspent funds in the individualized budget may be lost to the individual at the end of the year. For example, individuals may spend less for a service by hiring and supervising their own personal assistance workers rather than have such workers provided through a traditional agency, but then fail to make

other purchases with that savings by the end of the budget period—losing a valuable benefit of their prudent budget management.

One major barrier to optimal community living that Medicaid beneficiaries face is the inability to build meaningful savings for major purchases that would enhance their quality of life. Adults who self-direct Medicaid, community-based, long-term supports budgets, as well as families who direct such budgets for their Medicaid-eligible children, have expressed the desire to save for major purchases that would enhance the beneficiary's quality of life. Because such savings are a resource that could result in a loss of eligibility for Medicaid health coverage, SSI, SSDI, or other Federal assistance programs, Medicaid beneficiaries are generally not able to build any meaningful savings.

The President has proposed a LIFE Account savings program in his FY 2005 budget. The LIFE Account program is intended to reflect promising practices in self-direction and to remove barriers to saving for equipment and supports while allowing participants to maintain their health coverage and standard of living. The President's proposal would make changes to programs at the Federal level that would then enable States to design and implement LIFE Account savings programs.

Applicants are cautioned that the information presented here (a) represents LIFE Account design elements that are under consideration only, (b) is offered only to assist States prepare their proposals for this grant opportunity, and (c) may differ from any future, Congressionally-authorized, LIFE Account savings program. Some design elements under consideration for the LIFE Account savings program include:

1. The intent of the LIFE Account savings program is to enable participants to maintain their health coverage and standard of living while allowing them to build savings for purchases that will increase their independence and productivity.
2. Only individuals who are Medicaid-eligible, meet the Social Security definition of disability, reside in the community, and self-direct (for children, have a family member direct) all of their Medicaid, community-based, long-term supports will be eligible to establish a LIFE Account.
3. "Medicaid, community-based, long-term supports" means all Medicaid-reimbursable services under any home and community-based services waiver, personal care, and any other remedial care recognized under state law as community-based long-term support. It should be noted that Medicaid-reimbursable institutional, acute, and primary health care are excluded from this definition.
4. LIFE Account holders will be able to (a) retain a portion of savings from their self-directed Medicaid, community-based, long-term supports budget at year-end, (b) save earnings from employment, and (c) accept limited contributions from others.

5. Neither resources in or income from the LIFE Accounts will be counted in determining eligibility for SSI, SSDI, or any Federal assistance program, nor will such resources in or income from the LIFE Accounts be considered in establishing benefit levels under those programs for either the Account holder or for any members of the Account holder's immediate family.
6. LIFE Accounts, once established, will belong to the individual. However, limitations on the eligible sources of deposit established by the program remain in effect for as long as the individual's LIFE Account is open. Should an individual need to re-enroll in Medicaid, SSI, SSDI, or any Federal assistance program, funds in a LIFE Account will not be counted in determining eligibility or benefit levels.

APPENDIX III

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Sponsor/ Status	Rep. Ander Crenshaw (R-FL) originally introduced HR 2370 on May 17, 2007.	Senator Robert Casey (D-PA) originally introduced S 2743 on March 11, 2008	Senator Chris Dodd (D-MA) introduced originally introduced S. 2741 on March 11, 2008.	
Title	Financial Security Accounts for Individuals with Disabilities Act of 2007	Financial Security Accounts for Individuals with Disabilities Act of 2008	Disability Savings Act of 2008	
Purpose	Amends Subchapter F of chapter 1 of the Internal Revenue Code of 1986 by adding Part IX: Savings for Individuals with Disabilities	Amends Subchapter F of chapter 1 of the Internal Revenue Code of 1986 by adding Part IX: Savings for Individuals with Disabilities	The purpose of this act is to encourage and assist individuals and families to save funds for supporting individuals with disabilities. It provides secure funding for disability-related expenses to supplement benefits from private insurance, Medicaid, supplemental security income, employment, etc	
Savings Account Classification	A Financial Security Account (FSA) is a tax-exempt trust created exclusively for the benefit of a disabled beneficiary paying qualified disability expenses.	A Financial Security Account (FSA) is a tax-exempt trust created exclusively for the benefit of a disabled beneficiary paying qualified disability expenses.	A Disability Savings Account (DSA) is a trust created in the U.S. exclusively for the benefit of a disabled beneficiary.	Suggest including language specifying that the FSA is formed in the U.S.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Tax-Exempt Status	Income earned on the assets held in FSAs for disabled individuals is generally exempt from federal income taxation. The assets themselves are after-tax dollars. Note that, as an anti-abuse measure, FSAs are subject to the unrelated business income tax of section 511 of the Code.	Income earned on the assets held in FSAs for disabled individuals is generally exempt from federal income taxation. The assets themselves are after-tax dollars. Note that, as an anti-abuse measure, FSAs are subject to the unrelated business income tax of section 511 of the Code.	For DSAs with less than $250,000 of assets, income earned on the assets is exempt from taxation, aside from taxes imposed by section 511 (relating to the imposition of tax on unrelated business income of charitable organizations). DSAs over $250,000 are taxed the same as a qualified disability trust. The value of the DSA is determined if the daily value exceeds $250,000 for the majority of the days during the taxable year.	All three bills exempt income earned on assets held in these savings accounts from taxation. In the Dodd bill, every year the account exceeds $250,000 in assets it is subjected to taxation as a disability trust. 35% According to Section 511, any income earned by a tax-exempt organization from a regularly carried on activity that is unrelated to its charitable purpose is taxable income.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Coordination with Means-Tested Programs and Eligibility for Inclusion to Other Federal Programs	Money held or distributed by FSAs will not be treated as income or assets, and will not be used to determine eligibility for, or amount of benefits provided, any program funded by Federal funds.	Notwithstanding any other provision of Federal law that requires consideration of 1 or more financial circumstances of an individual, for the purpose of determining eligibility to receive, or the amount of, any assistance or benefit authorized by such provision to be provided 1 to or for the benefit of such individual, any amount (including earnings thereon) in any financial security account for an individual with a disability of such individual, and any distribution for qualified disability expenses (as defined in section 530A(b)(2)) shall be disregarded for such purpose with respect to any period during which such individual maintains, makes contributions to, or receives distributions from such financial security account.	For the purposes of determining eligibility for federal programs, any amount in a DSA will be disregarded. Applicable programs include: • Temporary assistance for needy families programs under Social Security Act (SSA) • State programs funded by parts B, D, and E of the SSA • SSA's supplemental security income program, • Medicaid • Food stamp programs, • supplemental nutrition programs under the Child Nutrition Act of 1966 • Child nutrition programs defined by the Richard B. Russell National School Lunch Act • Federal low-income housing assistance programs	These three bills state that Federal programs aiding citizens may not take into account whether or not a disabled individual has a disability/financial savings account. Dodd's bill spells out the specific programs whereas the Crenshaw and Casey/Hatch applies the blanket exemption.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Contribution Limits	Limit is $500,000. After the limit is reached, contributions will not be accepted. Contributions must be in cash.	Limit is $500,000. After the limit is reached, contributions other than rollovers will not be accepted. Contributions must be in cash. There is an inflation adjustment beginning after 2008 in which the cap is multiplied by the cost-of-living adjustment and rounded to the next lowest $1,000.	Limit is $1,000,000. After the limit is reached, contributions will not be accepted. Contributions must be in cash.	
Age Limit	Contributions after the beneficiary reaches the age of 65 are not allowed.	Contributions after the beneficiary reaches the age of 65 are not allowed.	A qualified beneficiary must be under the age of 65.	Crenshaw and Casey have added an age limit of 65 years old. Dodd's version only specifies that a DSA cannot be created for someone over 65.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Qualified Trustee	The trustee is a bank (as defined in section 408(n)), a parent or guardian of the designated beneficiary, a designee of a parent or guardian of the designated beneficiary, the designated beneficiary, or another person, who demonstrates to the satisfaction of the Secretary that the manner in which that person will administer the trust will be consistent with the requirements of this section.	The trustee is a bank (as defined in section 408(n)), a parent or guardian of the designated beneficiary, a designee of a parent or guardian of the designated beneficiary, the designated beneficiary, or another person, who demonstrates to the satisfaction of the Secretary that the manner in which that person will administer the trust will be consistent with the requirements of this section.	The trustee is a bank (as defined in section 408(n)) or another person who demonstrates to the satisfaction of the Secretary that the manner in which that person will administer the trust will be consistent with the requirements of this section or who has so demonstrated with respect to any individual retirement plan. A qualified individual is designated for the purpose of administering requests for distributions from the trust.	Crenshaw and Casey/Hatch include similar language. Whereas, the Dodd bill defines the trustee as another person deemed by the Secretary to administer the FSA.
Life Insurance Provision	The trust may receive life insurance payments (e.g. from a policy insuring the life of the parent of the beneficiary), but the assets of the trust may not be invested in life insurance.	Same	Same	All three bills have the same provision.
Commingling Assets	No commingling of assets with another property except in a common trust or investment fund.	No commingling of assets with another property except in a common trust or investment fund.	No commingling of assets with another property except in a common trust or investment fund.	All three bills have the same provision.

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Qualified Disability Expenses	Qualified disability expenses include: • Uncompensated costs for education • Medical and dental care • Community-based support services • Employment training and support • Moving, and assistive technology • After the disabled individual turns 18, this includes housing and transportation • Expenses may also include funeral, burial services and property	Qualified disability expenses include: • Uncompensated costs for education • Medical and dental care • Community-based support services • Employment training and support • Moving, and assistive technology • After the disabled individual turns 18, this includes housing and transportation • Expenses may also include funeral, burial services and property	Qualified disability expenses (called "qualified services or products" in the Dodd Bill) include: • Preschool education • Postsecondary education • Tutoring • Special education services • Training • Employment support • Personal assistance • Community-based support services • Respite care • Clothing • Assistive technology • Home modifications • Therapy • Nutritional management • Out-of-pocket vision/medical/dental expenses • Transportation expenses • Vehicle purchases and modifications • Insurance premiums • Habilitation, rehabilitation, funeral and burial services, and any other item allowed by the Secretary of the HHS Prohibited services and products includes: • Anything paid for by a third-party payer such as private insurance or Medicaid programs	The Dodd version has a more narrow list of qualified expenses. In terms of housing, the Dodd bill only allows distributions for home modifications. The other two bills provide for housing and transportation costs after the age of 18. With housing and transportation, the Crenshaw and Casey / Hatch lists are more comprehensive. The Dodd bill specifies that all expenses are to be paid using electronic transfer of funds.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Definition of Disability	An individual is an individual with a disability if such individual is receiving supplemental security income benefits under title XVI of the Social Security Act or an individual otherwise eligible to receive such benefits notwithstanding the income and assets tests required for eligibility for such benefits.	An individual is an individual with a disability if such individual is receiving supplemental security income benefits under title XVI of the Social Security Act or an individual otherwise eligible to receive such benefits notwithstanding the income and assets tests required for eligibility for such benefits.	Determined by the Commissioner of Social Security or the Disability Determination Service of a State to be: (I) blind (as determined under section 1614(a)(2) of the Social Security Act, but without regard to any income or asset eligibility requirements that apply under such title), or (II) disabled (as determined under section 1614(a)(3) of the Social Security Act, but without regard to any income or asset eligibility requirements that apply under such title, or under section 216(d) of such Act), and (ii) not been determined by the Commissioner of Social Security or the Disability Determination Service of a State to be no longer blind or disabled (as so defined). The term `Disability Determination Service' means, with respect to each State, the entity that has an agreement with the Commissioner of Social Security to make disability determinations for purposes of title II or XVI of the Social Security Act.	The Dodd bill spells out that the Commissioner of Social Security or state's disability determination service as the qualifying bodies. The Crenshaw and Casey/Hatch bills do not spell out who makes that determination.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Estate and Gift Taxes	Estate and gift taxes apply as in Section 529 of the Code.	Estate and gift taxes apply as in Section 529 of the Code.		The Dodd bill does not specify whether estate and gift taxes apply.
Medicaid Payback	n/a	n/a	At death or disqualification, funds are paid to the state from the DSA up to the equivalent amount paid by a State Medicaid plan for total assistance.	The Dodd bill includes a Medicaid Payback, where as the Crenshaw and Casey bills do not.
Tax Treatment of Distributions	Any amount paid or distributed out of this FSA is included as gross income by the beneficiary only to the extent that the payment is not used for qualified expenses of the beneficiary. Where a beneficiary's qualified expenses for a given year exceed the amount of distributions, no amount of the distributions will be includible in gross income. On the other hand, where a beneficiary's qualified expenses for a given year are less than the amount of distributions, the difference between the amount of distributions and the qualified expenses will be includible in gross income (and subject to a penalty, as below).	Any amount paid or distributed out of this FSA is included as gross income by the beneficiary only to the extent that the payment is not used for qualified expenses of the beneficiary. Where a beneficiary's qualified expenses for a given year exceed the amount of distributions, no amount of the distributions will be includible in gross income. On the other hand, where a beneficiary's qualified expenses for a given year are less than the amount of distributions, the difference between the amount of distributions and the qualified expenses will be includible in gross income (and subject to a penalty, as below).	Any distribution from a DSA is included as gross income to the extent it is not distributed for a qualified service or product or not paid directly to the provider of a qualified service or product (see above for definition of qualified service or product). The taxpayer may not claim any other deduction, credit, or exclusion for amounts excluded from gross income under this section. Distributions will not be gross income where they are made within 90 days of an equivalent contribution, regardless of whether they are spent on qualified services or products.	Payments and distributions, according to all three bills, are not treated as gross income to the extent that they are attributable to qualified expenses.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Additional Taxes	A 10% penalty is imposed on distributions that are not attributable to qualified expenses, unless the distribution is made to the beneficiary on or after the death of the beneficiary. This penalty does not apply if the distribution is made to return an excess contribution before the 1st day of the sixth month of the following tax year if the distribution is accompanied by the amount of net income attributable to the excess contribution. The net income accompanying the return of the excess contribution will be includible in income for the taxable year in which the excess contribution was made.	A 10% penalty is imposed on distributions that are not attributable to qualified expenses, unless the distribution is made to the beneficiary on or after the death of the beneficiary. This penalty does not apply if the distribution is made to return an excess contribution before the 1st day of the sixth month of the following tax year if the distribution is accompanied by the amount of net income attributable to the excess contribution. The net income accompanying the return of the excess contribution will be includible in income for the taxable year in which the excess contribution was made.	There is a 10% penalty imposed on distributions not used for qualified services or products.	The Dodd bill does not provide exceptions to the 10% penalty.

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Rollovers and Changes in Beneficiaries	An FSA to FSA transfer (rollover) completed within 60 days does not give rise to a taxable event. Only one such rollover is allowed tax-free within a 12-month period. Any change in the beneficiary of an FSA does not give rise to a taxable event as long as the new beneficiary is disabled and is a member of the family as defined in Code Section 529(e)(2).	An FSA to FSA transfer (rollover) completed within 60 days does not give rise to a taxable event. Only one such rollover is allowed tax-free within a 12-month period. Any change in the beneficiary of an FSA does not give rise to a taxable event as long as the new beneficiary is disabled and is a member of the family as defined in Code Section 529(e)(2). Amends section 223(f)(5) by treating payments from health savings accounts into an FSA as a rollover. Amends section 408(d)(3) by treating payments from IRAs as rollover provided the entire amount received is transferred into an FSA for a child or grandchild within 60 days of receipt of payment.	A DSA to DSA transfer (rollover) completed within 60 days does not give rise to a taxable event where the transferee DSA is for the benefit of the same qualified beneficiary, another qualified beneficiary, the spouse of a beneficiary or other person bearing a relationship to the original beneficiary described in Section 152(d)(2). The same rule applies to transfers from DSAs to trusts described in Section 1917(d)(4) subparagraphs (A) and (C) where the trust is for the benefit of an individual described above. Only one rollover is allowed tax-free within a 12-month period. Any change in the beneficiary of a DSA does not give rise to a taxable event if the new beneficiary is another qualified beneficiary, the spouse of a beneficiary or other person bearing a relationship to the original beneficiary described in Section 152(d)(2). If the beneficiary or a qualified individual (spouse or other related person described in Section 152(d)(2), legal guardian, individual providing over one half of beneficiary's support, or appointed representative) engages in any transaction prohibited under Section 4975, the account will lose its status as a DSA as of the first day of the taxable year in which the transaction is entered into. If the account is pledged as security, the amount pledged will be treated as having been distributed to the beneficiary. No qualified beneficiary may have more than one DSA.	In all three bills, rollovers and changes in beneficiaries are not treated as taxable events. The Dodd bill contains a more detailed designation of persons qualified to be beneficiaries of the recipient account in rollover transactions. These more detailed designations carry over to beneficiary changes. The Dodd bill has additional anti-abuse provisions that may be worth adding to a final bill. The Dodd bill explicitly limits beneficiaries to one DSA each.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Tax Treatment of Accounts	Rules similar to paragraphs (2) and (4) of section 408(e) of the Internal Revenue Code apply. The FSA is treated like an individual retirement account. NOTE: Section 408(e) describes the tax treatment of accounts and annuities in individual retirement accounts (IRAs). Paragraph 2 provides that if the beneficiary of an IRA performs certain prohibited acts, the account ceases to be an IRA and the assets in the account are deemed to have been distributed to the beneficiary as taxable income. Paragraph 4 states that if a beneficiary uses a portion of an IRA as security for a loan, the amount of the security is deemed to have been distributed as taxable income.	Rules similar to paragraphs (2) and (4) of section 408(e) of the Internal Revenue Code apply. The FSA is treated like an individual retirement account. See note, left. This FSA is treated as a Medicaid Excepted Trust under paragraph (4) of section 1917(d) of the Social Security Act. (42 U.S.C. 1396p(d)(4)) DSAs with a value of $250,000 or less are exempt from taxation.	DSAs over $250,000 are taxed as qualified disability trusts. The value of the DSA is determined by measuring whether the daily value exceeds $250,000 for the majority of the days during the taxable year.	While the Crenshaw and Casey bills consider the FSA similar to an IRA, the Dodd version qualifies the account as a trust once it exceeds $250,000.
Community Property Laws	Community Property Laws do not apply.	Community Property Laws do not apply.	The Dodd bill has no community property law provision.	**Custodial Accounts**
The custodial account is defined as a trust if the assets are held by a bank or person who acts in the same manner, or the amount paid out of the FSA is	included as gross income by the payee of distributee. The custodian is treated as a trustee.	The custodial account is defined as a trust if the assets are held by a bank or person who acts in the same manner, or the amount paid out of the FSA is included as gross income by the payee of distributee. The custodian is treated as a trustee.		Custodial is different from the other accounts in that it may be rolled over. Therefore, it is treated differently.

Side-by-side Analysis of the Crenshaw, Casey/Hatch & Dodd Financial Security Accounts Bills: Working Draft (continued)

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Reports	Timely reports must be issued to the Secretary and the beneficiary, and must include details of contributions, distributions, and other required matters. If a person required to file a report according to Section 6693 of the Internal Revenue Code of 1986, and fails to file such report at the time and in the manner required by such provisions, a person must pay a penalty of $50 for each failure unless it is shown that such failure is due to reasonable cause.	Timely reports must be issued to the Secretary and the beneficiary, and must include details of contributions, distributions, and other required matters. If a person required to file a report according to Section 6693 of the Internal Revenue Code of 1986, and fails to file such report at the time and in the manner required by such provisions, a person must pay a penalty of $50 for each failure unless it is shown that such failure is due to reasonable cause.	Timely reports must be issued to the Secretary and the beneficiary, and must include details of contributions, distributions, and other required matters. The Secretary of the Treasury, in consultation with HHS, will make an annual report to Congress on the usage of DSAs.	Reporting is the same in all three bills. Only the Dodd bill mandates Congressional reporting on the usage of these savings accounts. The Dodd bill does not have a penalty for failure to report.

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Tax Benefits for Contributions		The taxpayer may claim up to a $2,000 (plus cost-of-living adjustments rounded to the next lowest multiple of $200) deduction for amounts paid in cash for the taxable year by or on behalf of the taxpayer to an FSA. Cost-of-living adjustments to the deduction begin after 2008. The deduction is phased out under the same tables that apply to retirement savings accounts (I.R.C. 219(g)), which begin the phase-out for individuals with adjusted gross income of more than $50,000 and for joint returns reporting adjusted gross income of more than $80,000. Extended only to specific family members: individual's child, grandchild, brother, or sister.	Qualified individuals receive a tax credit equal to 50% of qualified contributions to a DSA in a year, not exceeding $2,000. The credit is phased out for individuals with more than $30,000 adjusted gross income, heads of household with more than $45,000 of adjusted gross income, and joint returns with more than $60,000 of adjusted gross income. The phase-out is adjusted for inflation. The credit may not exceed the taxpayer's earned income. Where another taxpayer receives a deduction under Section 151 with respect to the DSA beneficiary, no credit is allowed to the beneficiary and any DSA contributions by the dependent beneficiary are treated as being made by the taxpayer claiming the dependent beneficiary. Overpayments attributable to the credit are transferred to the DSA to which the taxpayer made a qualified contribution. If contributions were made to more than one account, the overpayment will be divided among the accounts in the same ratio as the contribution to each account bears to total contributions. These amounts (overpayments attributable to the credit) are recaptured and taxed upon distribution, but the rules for recapture are taxpayer-favorable.	The Dodd bill allows a tax credit for 50% of the contributions for a DSA with a means-tested phase-out. The Casey bill provides for a deduction for contributions up to a $2000 maximum. The Crenshaw bill does not provide any tax benefits for contributions.

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Tax Free Rollover from Education Savings Accounts	Section 529 of the Code would be amended to allow tax free rollovers from ESAs into DSAs. Similarly, rollovers from Coverdell accounts within 60 days would not be taxable events. [Coverdell education savings accounts are exempt from taxation aside from Section 511 (relating to imposition of tax on unrelated business income of charitable organizations).]	Section 529 of the Code would be amended to allow tax free rollovers from ESAs into DSAs. Similarly, rollovers from Coverdell accounts within 60 days would not be taxable events. [Coverdell education savings accounts are exempt from taxation aside from Section 511 (relating to imposition of tax on unrelated business income of charitable organizations).] .	Section 529 of the Code would be amended to allow tax free rollovers from ESAs into DSAs.	
Credit to Institutions for Maintaining Disability Savings Accounts			Eligible entities maintaining DSAs receive a DSA investment credit equal to $50 per DSA for each of the first 7 years the DSA remains open and where such DSA has a balance of not less than $100. The credit is treated as a business credit. There is a denial of double benefits. No deduction or credit is allowed for any maintenance expense associated with the DSA.	The Dodd version provides a tax incentive to entities maintaining DSAs. This is intended to promote the establishment and use of DSAs by offsetting the high cost to financial institutions of managing small accounts with high transaction activity levels.

Section	H.R. 2370 Crenshaw	S. 2743 Casey/Hatch	S. 2741 Dodd	Analysis
Additional Regulations			The Secretary, along with the Secretary of HHS, may issue regulations to carry out provisions and prevent abuses of this section. There is a marketing, outreach and education program provision authorizing appropriations for the HHS Secretary to enact such programs. They may contract with non-profit entities.	The Crenshaw and Casey bills do not leave administration and regulation open-ended and subject to change
Additional Definitions and Special Rules	Crenshaw's new draft limits the individual contributions to all accounts to $500,000. Provisions in the bill with Section 4975 of the Internal Revenue Code of 1986 to prevent abuses.	Casey/Hatch limits the individual to having one account. Provisions in the bill coordinate with Section 4975 of the Internal Revenue Code of 1986 to prevent abuses.	A qualified individual is the beneficiary, a spouse or family member, provides over 1/2 of the beneficiary's support, legal guardian, or an appointee if the beneficiary is in the custody of a State or any agency. Provisions in the bill coordinate with Section 4975 of the Internal Revenue Code of 1986 to prevent abuses. The account may not used to secure a loan. No individual may have more than 1 DSA.	Dodd and Casey / Hatch bills limit individual to having one account. Crenshaw just caps overall contributions for an individual to $500,000.

1 Income or resources in excess of the Medicaid resource limit in a child's name would cause financial disqualification from Medicaid.
2 Centers for Medicare and Medicaid Services. (2004), pp. 22-24.

LIFE

Remember the old song—

What's TOUGH
LIFE
What's **LIFE**
A magazine
Well how much does it cost
It costs twenty cents
But I only got a nickel (a nickel)
Woah oh well that's **LIFE**

That's **LIFE!**