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Discussion Paper:

Advancing Self-Sufficiency for Medicaid Beneficiaries: Meeting the Challenges of the Olmstead Integration Mandate

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EXECUTIVE SUMMARY

In 1999, the Supreme Court decision in *Olmstead v. L.C.*[1] provided important clarifications about how states should comply with Title II of the Americans with Disabilities Act.[2] For states that receive federal funding, the *Olmstead* decision confirmed the obligation to serve individuals with disabilities in more integrated community settings rather than provide supports and services in institutional settings. The Supreme Court further explained that states should make "reasonable accommodations" to their long-term care systems and compliance is to be demonstrated through the development and implementation of comprehensive, effective working plans to increase community-based services.

First, with the Clinton Administration and then through the Bush Administration, the federal government (Health Care Financing Administration now Centers for Medicare & Medicaid Services (CMS)) provided states with ongoing policy guidance that encouraged the rebalancing of public resources to improve the availability of community-based options to reduce utilization of nursing homes and other institutions. The *Olmstead "Integration" mandate* accelerated the interest and commitment to nursing home transition and diversion strategies. During the past six years, with the support of CMS funded Real Choice Systems Change[3] and Transformation[4] grants, states have designed and piloted multiple strategies to improve consumer self-direction; increase community-based living options with appropriate needed supports; and, enhance coordination between Medicaid and housing agencies, and family support.

In 2006, with the Deficit Reduction Act of 2005,[5] CMS began to competitively fund states to help shift Medicaid from its historical emphasis on institutional long-term care services to a system that offers individuals with disabilities, across all ages, greater choices of home and community-based services. The Money Follows the Person initiative[6] gives states $1.75 billion over five years to help rebalance their use of Medicaid funds to support expanded community inclusion and participation. Money Follows the Person is part of a comprehensive, coordinated strategy to assist states, in collaboration with stakeholders, to make widespread changes to their long-term care support systems. This initiative assists states in their efforts to reduce their reliance on institutional care while developing community-based long-term care opportunities, enabling the elderly and people with disabilities to fully participate in their communities.

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[1] *Olstead v. L. C.* (98-536) 527 U.S. 581 (1999). Available at: www.usdoj.gov/osg/briefs/1998/3mer/1ami/98-0536.mer.ami.pdf.
[2] U.S. Dept. of Justice. (2008). ADA Home Page. ADA Regulations and Technical Assistance Materials. Provides free materials on the Americans with Disabilities Act. Available at: http://www.ada.gov/publicat.htm.
[3] U.S. Dept. of Health and Human Services. CMS. (2008, March 11). Real Choice Systems Change Grants: http://www.cms.hhs.gov/RealChoice/01_Overview.asp.
[4] U.S. Dept. of Health and Human Services. CMS. (2008, March 5). Medicaid Transformation Grants: http://www.cms.hhs.gov/MedicaidTransGrants/.
[5] U.S. White House. (2006, Feb. 8). Deficit Reduction Act of 2005: http://www.whitehouse.gov/news/releases/2006/02/20060208-9.html.
[6] U.S. Dept. of Health and Human Services. CMS. (2008, Jan. 28). Money Follows the Person Grants: http://www.cms.hhs.gov/DeficitReductionAct/20_MFP.asp.

As states continue to grapple with these challenges—rebalancing funding priorities, the development of community-based infrastructure, and improved coordination of public and private sector resources--to respond to changing expectations of Medicaid beneficiaries to remain at home and/or in community settings to allow maximum independence and choice to meet these challenges, there is a greater need than ever before for state Medicaid agencies, disability-related service providers, and individuals with disabilities and their families to learn about the availability and use of other strategies and tools to advance community inclusion.

What has been learned in recent years from the CMS systems change grants is that Medicaid beneficiaries and other significant stakeholders are challenged by the complexity of the service delivery systems that all have different rules of eligibility and scope of coverage. The complexity of the Medicaid, Social Security, Mental Health, Developmental Disability, and Aging systems is further compounded by the challenges of agency collaboration.

Nationwide, CMS-funded Aging and Disability Resource Centers[7] and the Administration on Aging are beginning to improve the flow of information to beneficiaries and build new levels of coordination of services and supports across systems that impact persons with disabilities and their families. What is still missing, however, is a bridge to connect existing programs to other organized efforts to advance community inclusion and self-sufficiency for individuals who live at or below the poverty level.

Since the early 1990s, organizations have been working together at the community level to implement strategies to encourage income production and preservation and asset-building. Resources from the public and private sectors have created new tools to improve community participation and inclusion. With access to the Earned Income Tax Credit,[8] establishment of Individual Development Accounts,[9] use of Social Security work incentives,[10] and participation in credit counseling and home ownership assistance programs, there is a unique blend of opportunities that can help promote community inclusion and the *Olmstead "Integration" mandate*. This report provides an orientation and introduction to a set of tools and strategies that can have a significant impact on Medicaid beneficiaries in terms of choices of places to live and level of community inclusion.

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[7] U.S. Dept. Health and Human Service. Dept. on Aging. Aging and Disability Resource Centers: http://www.aoa.gov/prof/aging_dis/aging_dis.asp.

[8] Earned Income Tax Credit. Internal Revenue Service: http://www.irs.gov/individuals/article/0,,id=96406,00.html.

[9] Individual Development Accounts (IDAs) are matched savings accounts that enable low-income American families to save, build assets, and enter the financial mainstream. IDAs reward the monthly savings of working-poor families who are building towards purchasing an asset, most commonly buying their first home, paying for post-secondary education, or starting a small business. IDAs make it possible for low-income families to build the financial assets they need to achieve the American Dream. More information is available at: http://www.cfed.org/focus.m?parentid=2&siteid=374&id=374.

[10] Social Security Administration, Work Incentives. Special rules make it possible for people with disabilities receiving Social Security or Supplemental Security Income (SSI) to work and still receive monthly payments and Medicare or Medicaid. Social Security calls these rules "work incentives." Available at: http://www.socialsecurity.gov/disabilityresearch/wi/generalinfo.htm#work.

As states move forward with multiple strategies to support community living for all individuals with disabilities and to promote the principles of person-centered planning, these additional tools and strategies provide complimentary opportunities to accelerate the achievement of inclusive outcomes. With states becoming more advanced with the development of person directed budgets, there are additional opportunities to connect to supports outside of Medicaid funding that provide additional value in the pursuit of an individual's preferences and choices. The blending and braiding of these asset-building opportunities--with the benefits of Money Follows the Person and individual control and direction of person-centered budgets--will bring states closer to the true meaning and intent of the *Olmstead* decision.

To produce this report, interviews were conducted with policymakers at a state and federal level; service providers at a local level; and with individuals with disabilities and their families across the country, who rely on Medicaid to support and advance their health, community participation, and personal freedom. The case studies featured were identified by reviewing reports from CMS Systems Change grants and other federally funded projects from the Social Security Administration and the U.S. Departments of Health and Human Services, Housing and Urban Development, and Treasury.

I. INTRODUCTION

For too long, disability policy has perpetuated an all or nothing dichotomy that continues to view working age individuals with disabilities (18-65 years of age) as unable to work and be self-sufficient. Public assistance is tied to remaining poor. As stated by the President's Committee for Intellectual Disabilities in the 2004 Report to the President,[11] "Historically, public assistance in exchange for enforced poverty and the absence of freedom is a bad deal--one that fails all parties to the arrangement; people with disabilities, their families, and the American people." This report, *Advancing Self-Sufficiency for Medicaid Beneficiaries: Meeting the Challenges of the Olmstead Integration Mandate*, identifies and documents a new framework to align resources and policies that recognize improving economic status and community participation as essential, achievable objectives for individuals and families.

There is no single or simple solution to the multiple challenges faced by Medicaid beneficiaries to improve their personal and economic freedom. However, this report identifies multiple tools and strategies that weave together Medicaid and non-Medicaid opportunities to connect beneficiaries to produce and/or preserve income and to build and/or retain assets. The foundation to build this "Advancing Self-Sufficiency" framework is the principle of self-determination:[12] freedom, authority, support, responsibility, and confirmation. Medicaid beneficiaries must have: the **freedom** to

[11] Presidents Committee for People with Intellectual Disabilities. A Report to the President. (2004). *A Charge We Have To Keep: A Road Map to Personal and Economic Freedom for People with Intellectual Disabilities.*
[12] Center for Self Determination. Principles of Self-Determination: http://www.self-determination.com/principles/index.html.

dream, to make their own decisions and plan their own lives; the **authority** to control how money is spent for their supports; the **support** needed from friends, family, and other people that they choose; the ability to take **responsibility** to do what they say they will do; and, finally, **confirmation**, which represents the recognition that individuals themselves are a major part of the design of their long-term services and supports.

This report provides an orientation to an evolving set of strategies to preserve and build personal freedom and community participation for individuals with significant disabilities. Advancing asset development and economic self-sufficiency is described as an approach to establishing a "third pillar" of social policy intended to complement income support from public benefit programs and social services for low-income individuals and families. For individuals with significant disabilities, Medicaid Home and Community Based-Services (HCBS)[13] has helped tear down the barriers to community participation by providing the supports necessary to learn and develop skills, engage in productive work, choose where to live, and to enjoy personal freedom. This report identifies opportunities that advance self-sufficiency that can be navigated outside the traditional world of Medicaid state plan options and waivers. It is a world that meshes disability-specific and generic policy, public and private sector resources, and individual and community contributions.

With self-determination principles as a guiding framework, there is an evolving new generation of thinking and expectations by both funder and beneficiary to move beyond traditional third party planning, in "the best interests of the individual." Across public agencies and community-based partners, there is a consensus growing that supports or promotes the advantages to person-centered planning that result in the individual with a disability directing resources to reflect individual abilities, preferences, and choices. Although the authority to support self-directed accounts is growing, the challenge for the multiple systems involved with the same recipient of federal financial assistance is to increase their awareness and understanding of the possibilities for coordination and collaboration in the individual planning process. A coordinated process can reduce redundancy and increase efficiency and effectiveness to achieve valued outcomes of personal freedom and advance economic self-sufficiency.

The report begins by providing a framework for increasing an understanding of the importance of income preservation and asset building to make a difference in the lives of people with disabilities. An orientation is provided to eight different types of asset building strategies:

1. Financial Literacy and Access to Financial Services
2. Favorable Tax Provisions Including the Earned Income Tax Credit
3. Individual Development Accounts
4. Home Ownership
5. Work Incentives
6. Microenterprise Development

[13] Dept. of Health and Human Services. CMS. Medicaid Home and Community-Based Services: http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaivers-Section1915(c).asp.

7. Special Needs Trusts
8. Long-Term Care Insurance Options to Preserve Assets

Information will be provided to help increase understanding about the nature and scope of each of these opportunities with the intended target audience to be individuals with disabilities and family members. The appendix provides information that contributes to a greater understanding of the impact of poverty, in general, and more specifically, on the lives of individuals with significant disabilities and their families.

This report represents an important starting point for new dialogue and discussion among public agency leaders, as well as an array of new community partners with the active engagement and full participation of individuals with disabilities and family members. At a local, state, and national level, this report describes new opportunities for collaboration at an individual and systems level. With the fiscal incentives offered to states to help rebalance resources to support community inclusion, such as Money Follows the Person, there is much to be gained by bringing together diverse stakeholders to design a roadmap out of poverty for our nation's most vulnerable citizens.

II. A FOCUS ON ASSET BUILDING

To design a roadmap out of poverty for individuals with disabilities, there will need to be a change in public attitudes, new expectations in the disability community, and new partnerships that support savings strategies and asset building. For there to be change in public attitude, three myths must be overcome about people with disabilities:

> Asset development is an emerging approach to promoting self-sufficiency for low-income workers. Because they promote and reward savings, asset development strategies encourage individuals to set long-term economic goals.
> *Welfare Information Network, 2002*

1. ***People with disabilities are unable to work and produce income***. Without income production, there are limited options to advance self-sufficiency.
2. ***People with disabilities can't be expected to save and build assets***. Focus group research has documented that people with disabilities want to work and build a better economic future. In growing numbers, individuals with disabilities are taking advantage of tools like the Earned Income Tax Credit and matched savings plans to build assets.
3. ***People with disabilities need to be dependent on government assistance to meet their full range of needs.*** People with disabilities, like people without disabilities, value personal freedom and independence. They want choices and control that reduce full dependence on government assistance. Saving and asset building will enhance opportunities for community inclusion and participation. Assets provide greater independence and financial stability.

The question becomes: Can people with disabilities build assets if they receive government benefits? Asset-building programs miss the mark for people with

disabilities, who participate in Social Security entitlement programs through the Social Security Administration (SSA), such as Supplemental Security Income (SSI)[14] and Social Security Disability Insurance (SSDI).[15] As a result, these individuals are often relegated to a life of “living at” or “living beyond” their means. This happens when a person enrolled in one of these programs meets their income or asset limits (defined under each program) and has to choose if they want an uncertain future without health care or monthly cash stipends.

In the case of assets, individuals receiving SSI and Medicaid benefits[16] cannot have more than $2,000 in cash assets; otherwise, they risk losing access to much-needed health care benefits. For people with disabilities, access to health care and services is of paramount concern. Yet for people with disabilities, finding affordable health care and services outside of government programs or group health care plans comes at an exorbitant price; which, in most cases, is even out of reach for most people who do not have disabilities. For people with no “significant” health issues an individual premium costs $4,479 per year according to the latest Kaiser Foundation Survey.[17] Another study by the same group found that people with “significant” health issues could expect their premiums to cost approximately $5,543 per year.[18]

A recent study from Great Britain found that for every dollar a person without a disability needed to maintain an “average” standard of living, a person with a disability needed $1.60.[19] According to this study, a deaf person needs $3.00 for every $1.00 a hearing person needs because of the cost of interpreters. Consensus among the groups of deaf people was that for profoundly deaf people to have access to public, recreational, and commercial services equal to those of hearing people, they would require extensive “on demand” interpreter / communicator services that require approximately 1000 percent of their income from government entitlement programs (which are similar to U.S. entitlement programs).

Because of the extreme expense of maintaining their health, people with disabilities are left with the choice of participating in government entitlement programs such as SSI/SSDI, where the opportunities to improve their standard of living are limited by income and asset ceilings imposed by these programs, or going without health care.

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[14] The Social Security Administration administers the Supplemental Security Income (SSI) program, which is a Federal income supplement program funded by general tax revenues. It is designed to help aged, blind, and disabled people who have little or no income; it provides cash to meet basic needs for food, clothing, and shelter. More information is available at: http://www.ssa.gov/ssi/.

[15] Social Security Disability Insurance pays benefits to individuals and certain members of their family who are "insured" (i.e., for individuals who worked long enough and paid Social Security taxes): http://www.ssa.gov/dibplan/index.htm.

[16] Social Security Online. Understanding Supplemental Security Income: SSI Eligibility Requirements, 2007 Edition. Available at: http://www.ssa.gov/ssi/text-eligibility-ussi.htm.

[17] The Henry J. Kaiser Family Foundation. (2007, Sept. 11). Employer Health Benefits 2007 Annual Survey: http://www.kff.org/insurance/7672/.

[18] The Henry J. Kaiser Family Foundation: http://www.kff.org/.

[19] Smith, N., Middleton, S., Ashton-Brooks, K., Cox, L., & Dobson, B. (October 2004). *Disabled people’s costs of living: More than you would think.* Joseph Rowntree Foundation: www.jrf.org.uk/knowledge/findings/socialpolicy/054.asp.

Asset limits preclude people with disabilities from participating in some mainstream financial products because of the very nature of the way they work.

A. Considering Debt

There are no known studies that address Americans with disabilities and what kind of debts they have, how much debt they carry, what percentage is medical debt, what percentage is for basic living expenses, and what percentage is spent on "wants" vs. "needs." The SSA and vocational rehabilitation (VR) counselors interviewed for this report all said that they do not consider debt when guiding people with disabilities toward employment or other goals, since debt is not a consideration to meet eligibility. A survey conducted by the National Organization on Disability (NOD)[20] found that 58 percent of people with disabilities stated that they did not have enough assets--without income or gifts--to live independently for three months, compared to 36 percent who had no disability.

In 1984, debt was just over 30 percent of total family income for families below the federal poverty level. By 2001, it grew to be almost half of family income. Debt hardship has been described as "total family debt greater than or equal to 40 percent of family income." The study[21] cited above found that debt hardship in the poorest families rose from 42 percent in 1984 to 67 percent in 2001. For families whose incomes are between 50 percent and 200 percent of poverty, their debt hardship rates doubled between 1984 and 2001. While the levels of debt and debt hardship are rising, increases in income are not keeping pace. Families do not have the necessary liquid assets to weather unplanned financial "events." Low-income families have few resources available to them as they attempt to deal with rising levels of debt. Among families with debt, the median amount of liquid assets (assets easily converted into cash, such as bank deposits, money market fund shares, etc.) for families living below the poverty level is less than $200, which is only a slight improvement from 1984 when these families reported no liquid assets. The median amount of liquid assets for a family with income between 100 and 200 percent of federal poverty is only $600, down from $1,000 in the late 1980s and early 1990s.

Low-income families with debt typically have few assets that could be liquidated in a financial crisis, such as a job loss or a layoff. Among these families, more than half of the poorest also lack nonliquid assets--such as real estate investments, cars or major equipment--and they have no home equity that could be tapped into in a time of great need. The median amount of nonliquid assets for a family whose income is between 50 and 100 percent of federal poverty is slightly better, over $2,000 in combined nonliquid assets and home equity, as is the median amount for a family between 100 and 200

[20] National Org. on Disability. *2004 N.O.D./Harris Survey Documents Trends Impacting 54 Million Americans*. Available at: http://www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=1422.

[21] Caner, A. & Wolff, E.N. (2004). *Asset Poverty in the United States: Its Persistence in an Expansionary Economy.* Public Policy Brief: The Levy Economics Institute of Bard College: No. 76. Available at: http://www.levy.org/pubs/ppb/ppb76.pdf.

percent of federal poverty, who have nearly $5,000 in combined nonliquid assets and home equity."

B. Financial Stress and Health

Being financially stressed negatively affects the health of all people--there is no reason to assume that a person with a disability is any different. In fact, there is much to suggest that it is worse for a person with a disability, particularly one with a mental disability. If the goal is to promote self-sufficiency, then it is necessary to understand debt and how programs can address it. The little we do know about income, debt, and assets of people with disabilities comes from the National Organization on Disability (NOD) surveys.[22] The 2004 survey indicated that three times as many people with disabilities live in poverty with annual incomes below $15,000 (26 percent vs. 9 percent) and are twice as likely to drop out of high school (21 percent vs. 10 percent) compared to their peers without disabilities.

Wealth inequity is especially noted among minority families. We have no idea if there are wealth inequities for families headed by a person or persons with a disability; but if they are enrolled in an entitlement program, we can safely assume that they too are wealth poor. Government entitlement programs were not designed to allow for asset accumulation--you cannot get "rich" on government benefits. Many newly disabled individuals will exhaust their personal assets while they prepare to go back to work, or are waiting to go back to work, or waiting to become eligible for disability payments. Many families headed by a person with a disability are low-income and could be considered to be "asset poor." Fifty eight percent of families with a disability said they did not have enough liquid assets to live beyond three months without assistance, which is defined as "asset poor." This is compared to one quarter of all Americans being defined as asset poor.

Contributing factors to the wealth poverty of people with disabilities is the asset and income limits imposed by SSA. Being disabled has been described as "a life of poverty and being disenfranchised, unemployed, and stigmatized, as well as being designated by society as a second-class citizen."[23] As with all asset-building programs for low-income earners, connecting to the economic mainstream is required for success. But people with disabilities are not always connected to the economic mainstream and they make up a larger proportion than low-income people as a whole.

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[22] National Org. on Disability. Available at: www.nod.org.

[23] Swarbrick, M. (2007, March). *Financial Service Model for Individuals Living with Mental Illness.* EQUITY. World Institute on Disability: http://www.wid.org/programs/access-to-assets/equity.

C. What is Asset Development

Asset development is a series of strategies that has the potential to help people with disabilities improve their economic status, expand opportunities for community participation, and impact positively the quality of life experience. Assets are money that is available from the bank, cash on hand, property, owner equity in a home or business, furniture, jewelry, a car, and owed debt. Assets may also be defined by human capital, such as education level or work experience. Assets can expand choices for community participation and independence.

The conceptual framework for long-term supports in a post-*Olmstead* era is to encourage and strengthen opportunities for community participation. For individuals with significant disabilities, HCBS has helped tear down the barriers to community participation by providing the supports necessary to learn and develop skills, engage in productive work, choose where to live, and enjoy personal freedom. In 2002, the Centers for Medicare & Medicaid Services (CMS) unveiled the Independence Plus[24] template to broaden the ability of states to offer individuals the opportunity to maximize choices and control over services in their own homes and communities. The 1915(c) waiver[25] template authorized a comprehensive framework for self-direction, including a person-centered planning process, individualized budgeting, and self-directed supports to enhance independence and community participation. In 2003, twelve states were awarded Systems Change grants to develop Independence Plus programs. In 2007, a growing number of states have included self-directed program options in their section 1915(c) HCBS waiver programs.

With the Deficit Reduction Act enacted into law in February 2006 (PL 109-171),[26] states were offered a new state Medicaid plan option to provide, as medical assistance, payment for part or all of the cost of self-directed personal assistance services (PAS) as medical assistance. Self-direction, according to the proposed rules to implement this new provision (42 CFR Part 441),[27] is "an important component of independence as it promotes quality, access and choice." The proposed rules further emphasize that the person-centered planning process must be "both person-centered and directed" to accurately reflect the participant's abilities, preferences, and choices. The participant must be permitted to exercise choice and control over services and supports discussed in the plan. Person-centered and person-directed plans and individual budgets can be complemented by other federal authorities that have also recognized the importance and impact of self-direction as a key principle of self-determination.

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[24] U.S. Dept. Health and Human Services. CMS. Independence Plus: http://www.cms.hhs.gov/IndependencePlus/.

[25] U.S. Dept. Health and Human Services. CMS. Medicaid 1915(c) Waiver: http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaivers-Section1915(c).asp.

[26] The White House. (2006, Feb. 8). Deficit Reduction Act of 2005: http://www.whitehouse.gov/news/releases/2006/02/20060208-9.html.

[27] Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling); Proposed Rule. 73 Federal Register 13 (January 18, 2008), pp. 3545-3566.

There is an evolving new generation of thinking and expectations by both funder and beneficiary to move beyond traditional third party planning in the "best interests of the individual" to blending or braiding multiple funding authorities to achieve mutually agreeable goals to advance community participation and self-sufficiency. Although the authority to support self-directed accounts is growing, the challenge for the multiple systems involved with the same recipient of federal financial assistance is to increase their awareness and understanding of the possibilities for coordination and collaboration in the individual planning process. A coordinated process can reduce redundancy and increase efficiency and effectiveness to achieve valued outcomes of personal freedom and advancement of economic self-sufficiency.

Blended funding involves more than one public funder authorizing dollars to be included in an individual allocation to respond to identified needs or gaps in services and supports. Allocation refers to the amount of dollars, and individual budget refers to the line-by-line expenditure plan for that allocation. Blended funding can allow systems to finance activities that may be outside specified limits of categorical programs. ***Braided funding*** involves more than one public funder authorizing their dollars to be included in an individual allocation to respond to identified needs. However, with braided funding each public funder maintains control of dollars to track expenditures for agreed to purposes and outcomes to evaluate return on investment.

Whether the approach is blended or braided funding, both require using separate funding streams in more coordinated and flexible ways. Both funding mechanisms could benefit enormously from the concepts of long- and short-term brokering described under structural changes inherent in self-determination. Both require the Medicaid agency and staff from other systems to learn more about each other in terms of overlapping goals, individual planning processes, creation of individual or personal budgets, degree of individual choice and direction, and performance and fiscal accounting requirements.

The multiple systems listed in the following chart have federal authority for individualized plans and variations on the CMS approach to individual person-centered and directed planning and implementation with a personal budget.

Self-Directed Accounts

Agency	Authority	Approach
1. CMS	Title XIX of Social Security Act – Home and Community Based Waivers	Individual Budgets for long term supports
2. SSA	P.L. 106-170 Ticket to Work and Work Incentives Improvement Act of 1999	Ticket to Work Voucher for employment services delivered by Employment Network (EN)
3. Labor	P.L. 105-220 Workforce Investment Act	Individual Training Account (ITAs) Voucher for purchase of skills development
4. SSA	P.L 92-603, Title III Social Security Amendments of 1972	Plan to Achieve Self-Support (PASS) Excludes earned income that would otherwise be counted in determining SSI eligibility to be used to save for vocationally related objectives A person receiving both Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) could use SSDI in PASS and receive a higher amount of SSI. OR An SSDI beneficiary who meets SSI Financial criteria could use SSDI in PASS then qualify for SSI.
5. HHS	P.L. 105-285 Assets for Independence Act	Individual Development Accounts (IDAs) Matched savings plans towards buying a first home, starting a business and continuing post secondary education
6. Education	P.L. 108-446 Individuals with Disabilities Education Improvement Act of 2004 P.L. 105-220 Workforce Investment Act, Title IV	Individual Transition Plan Transition and possible braiding and/or blending of some of these funds Individual Employment Plan Cash advance for employment-related objectives

Agency	Authority	Approach
7. Mental Health	P.L. 102-321 Community Mental Health Services Block Grant	Person-centered recovery plans Rehabilitative services Service coordination Self-directed care
8. Housing	P.L. 101-625 Family Self-Sufficiency Program Housing Choice Vouchers Regulations are found in 24 CFR Part 982.	Promotion of Home Ownership Purchase Transportation Promote Employment Outcomes Promotion of Home Ownership
9. Long-Term Care Insurance	PL 109-171 Deficit Reduction Act of 2005	Purchase private long-term care insurance policies Coordinates with Medicaid No "spend down" of assets
10. Special Needs Trusts	P.L. 103-66 Omnibus Budget Reconciliation Act of 1993 P.L. 106-169 Foster Care Independence Act of 1999	Place money into a trust and become (or remain) eligible for Medicaid and SSI

A braided individual account could bundle public benefits across the domains of long-term supports, housing, personal assistance, employment, social security, transportation, life-long learning, and asset building. Since the common goal across funding authorities is advancement of self-sufficiency, the Medicaid agency in collaboration with the other systems can:

1. explore options to create a unified individual account;
2. simplify the assessment and application process for potential eligible individuals;
3. centralize the collection of and share background information on applicants;
4. pool resources for a collaborative person-centered planning process; and,
5. create a blended or braided account that promotes self-determination.

Multiple agencies are jointly engaged in a person-centered planning process that identifies resources to be committed to respond to individual needs and preferences.

The identification of barriers for income production, saving, and asset building must be a focus of this coordinated approach across systems.

Eligibility requirements for a public benefit(s) that limits income production and asset building must be identified and solutions must be crafted to provide a consistent policy framework that encourages financial stability and security. The challenges of collaboration can be overcome by embracing a consistent policy framework, putting in place an infrastructure that is shared, and leveraging braided public and private supports that respond to individual needs and preferences.

An "Individual Account" workgroup can accelerate the opportunities to advance the knowledge and infrastructure to realign policy and systems that recognize the importance of income preservation and asset building. In Florida, through funding from the State Developmental Disabilities Council, and in Ohio, through funding from their Medicaid Infrastructure Grant, the Medicaid agency has joined with representatives from Mental Health, Developmental Disabilities, Vocational Rehabilitation, Education, and Workforce Investment Systems to examine barriers and facilitators in policies and program design to advance self-sufficiency for individuals with significant disabilities. Other non-disability-specific agencies and systems in the public and private sector have joined these workgroups to explore improved coordination of efforts. The Internal Revenue Service (IRS) and Federal Deposit Insurance Corporation (FDIC) field staff and the State Treasurers Office and United Way have expanded their financial education and promotion of savings and asset building activities for low-income working families to outreach to low-income individuals with disabilities.

The policy barrier that is raised most frequently by individuals with disabilities as creating a disincentive to income production, saving, and asset building is the asset limits for remaining eligible for SSI. There are additional challenges for persons on SSDI. Although there are different rules, the reluctance to jeopardize benefits remains the same against substantial gainful activity rules and loss of SSDI and, in time, Medicare. In order for an individual to be determined eligible or remain eligible for SSI, the individual must not accumulate assets of more than $2,000.[28] A similar barrier exists for eligibility for Medicaid. Unlike the asset limit for eligibility for SSI, which is set at a federal level, the asset and income limits for eligibility for Medicaid allows more flexibility for states to increase the amount. With the SSI asset limit, states have the option to request a waiver from SSA. With the Medicaid asset limit, a growing number of states that have established a Medicaid Buy-In program[29] have significantly increased income and asset limits and allowed eligible individuals to set income aside in an individual retirement account or other types of savings accounts that are not counted as assets.

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[28] Social Security Online. Understanding Supplemental Security Income: SSI Eligibility Requirements, 2007 Edition. Available at: http://www.ssa.gov/ssi/text-eligibility-ussi.htm.

[29] Medicaid Buy-In. Section 201 of the Ticket to Work and Work Incentives Improvement Act of 1999 governs the provision of health care services to workers with severe disabilities by establishing a Medicaid state plan buy-in optional eligibility groups. More information is available at: http://www.cms.hhs.gov/TWWIIA/ and www.migrats.org.

The state of Minnesota has set a higher asset limit for all Medicaid categories. Minnesota is a Section 209 (b)[30] state, and as a result it has the flexibility to not follow SSI rules in determining eligibility. The state of Virginia, with its new Medicaid Buy-In Program, Medicaid Works,[31] allows workers with disabilities to earn higher income, retain more in savings or resources, and still have continued access to health coverage under Medicaid. To enroll in Medicaid Works, the individual with a significant disability (current SSI or SSDI participants) must establish a work incentive (WIN) account at a bank or financial institution. All earned income must be placed in the WIN account and will not be counted against the $2,000 traditional resource limit and will not affect eligibility for Medicaid. Employees in 2008 can have earnings as high as $41,665 and keep resources in the account of up to $29,348. In addition, amounts deposited in the following IRS-approved accounts will not count against the resource limit and will not affect eligibility for the program. These include retirement accounts, education accounts, and individual development accounts. Participants on a sliding scale basis pay a monthly premium to have access to Medicaid supported health care. As a work incentive, Virginia has created a policy framework for its Medicaid Buy-In program that encourages income production, savings, and asset building.

Challenged by budgetary constraints, many states may not have the opportunity to take advantage of the option of higher income and asset limits achieved by Minnesota and Virginia. However, there are still other strategies to be pursued to build a better economic future for Medicaid beneficiaries. From access to financial education to a range of asset building or preservation opportunities, there are options to be explored with traditional and nontraditional partners. The following chart illustrates a layering of strategies to advance economic self-sufficiency.

SELF SUFICIENCY STRATEGIES
Insurance
Special Needs and Pooled Trusts
Microenterprise Development
Home Ownership: Family Self Sufficiency Program
Work Incentives
Individual Development Accounts
Earned Income Tax Credit: Other Tax Provisions
Employment: Income Production
Financial Education
Person-Centered and Directed Service Plan

[30] Minnesota Dept. of Human Services. Health Care Programs Manual. Available at: http://hcopub.dhs.state.mn.us/hcpmstd/.
[31] Virginia Department of Assistance Services. Medicaid Works. Available at: http://www.dmas.virginia.gov/mb-home.htm.

III. BUILDING A BETTER ECONOMIC FUTURE

A better economic future is not just defined by employment status; although, income production is certainly an essential foundation to planning for your future. Rather, building a better economic future relies on person-centered planning across disability-related systems that looks beyond immediate needs and the expenditure of pubic resources to respond to increased expectations about the level of community participation. To plan a better economic future, the person-centered planning process should include a set of objectives that require new thinking that incorporates savings and asset building goals to improve and expand choices that have a direct impact on quality of life in terms of where one lives and the range of community activities to be a part of long-term planning. A person-centered plan should explore options for economic empowerment, which represents the ability to develop and control income and assets.

A. Financial Literacy and Access to Financial Services

Financial education programs improve an individual's understanding and skill to create a budget, manage income, create a savings plan, effectively use credit, and continue to review and refine goals and strategies to advance self-sufficiency. Financial literacy skills help an individual make informed decisions about production, preservation, and growth of financial resources. In those cases where an individual with a disability is not able to directly benefit from financial education programs, their representative or broker can be involved on their behalf. At a community level, there are financial education classes available through banks, credit unions, community colleges, and other nonprofit groups. In 2001, the Federal Deposit Insurance Corporation launched a national financial education program called *Money Smart*. *Money Smart* has ten modules which are available at no cost on the FDIC's website www.fdic.gov/consumers/consumer/moneysmart. Through regional offices, the FDIC staff provides free training and materials to prepare staff and volunteers to become trainers using the *Money Smart* curriculum.

> Financial education fosters financial stability for individuals, families, and entire communities. The more people know about credit and banking services, the more likely they are to increase savings, buy homes, and improve their financial health and well being. The Money Smart curriculum helps individuals build financial knowledge, develop financial confidence, and use banking services effectively.
>
> www.fdic.gov

With states having the option to offer Medicaid beneficiaries the right to self-directed personal budgets under selected state plan and waiver options, there should be an increased focus on building financial literacy knowledge and skills. When third party financial management services are utilized by the state as the alternative to individual control of a personal budget, there are still obvious compelling reasons to improve the understanding of the beneficiary about monthly expenditure statements as compared to approved service budgets. The *Money Smart* curriculum is now being offered to all

jobseekers through One Stop Career Centers[32] as part of free services available from the workforce investment system in Florida, Ohio, Wisconsin, and Michigan. To the Medicaid beneficiary, the knowledge gained could help the individual compare the cost of financial services and benefit from no fee checking and interest bearing savings accounts.

10 *Money Smart* Training Modules

- Bank on It - an introduction to bank services
- Borrowing Basics - an introduction to credit
- Check It Out - how to choose and keep a checking account
- Money Matters - how to keep track of your money
- Pay Yourself First - why you should save, save, save
- Keep It Safe - your rights as a consumer
- To Your Credit - how your credit history will affect your credit future
- Charge It Right - how to make a credit card work for you
- Loan To Own - know what you're borrowing before you buy
- Your Own Home - what home ownership is all about

One of the first targeted customers of the *Money Smart* program were participants in the, then, new Temporary Aid to Needy Families (TANF) program. The *Money Smart* program was to be considered a "work" related activity and could be counted towards the TANF participant's work requirements. Some TANF agencies incorporated *Money Smart* as part of their work readiness-training program. The Illinois TANF agency provided a large start-up grant for the Financial Links for Low-Income People program (FLLIP) and completion is a required activity for receipt of TANF benefits.[33]

The *Money Smart* curriculum is written at a fifth grade reading level, making it accessible to low skilled readers. The ten modules take between one to two hours to complete and instructional materials include a comprehensive, fully scripted guide for instructors, which includes "easy" to follow cues, scripts, and interactive class exercises. The curriculum includes overheads in Microsoft Word and PowerPoint format and take-home guides for participants. There is also an on-line version of *Money Smart* that allows instructors to follow student progress electronically. The curriculum is offered in English, Spanish, Chinese, Korean, and Russian, and as of November 2006, the FDIC announced that the *Money Smart* program was available in Braille[34] and large print formats. The FDIC partners with financial institutions, governments, and other organizations to sponsor no-cost train-the-

[32] The One-Stop Career Center System is coordinated by the Department of Labor's Employment and Training Administration. One-Stop Career Centers are designed to provide a full range of assistance to job seekers under one roof. Established under the Workforce Investment Act, the centers offer training referrals, career counseling, job listings, and similar employment-related services. Customers can visit a center in person or connect to the center's information through PC or kiosk remote access. More information is available at: http://www.dol.gov/dol/topic/training/onestop.htm.

[33] Federal Reserve Bank of Chicago Consumer and Community Affairs Division. (2001, Fall). FLLIP Financial Education and Asset-Building Programs Ready to Launch in Illinois. *Economic Development: News & Views*, 7(2): http://www.chicagofed.org/publications/economicdevnewsandviews/2001/nvfall01.pdf.

[34] Federal Deposit Insurance Corp. (FDIC). (2007, Winter). Best Practices for Teaching People with Visual Impairments. *Money Smart News*: http://www.fdic.gov/consumers/consumer/moneysmart/newsletter/win2007/stories.html. FDIC'S *Money Smart* Financial Education Program now available in Braille and Large Print for Visually Impaired. *Money Smart* Press Releases. November 9, 2006: http://www.fdic.gov/consumers/consumer/moneysmart/press/2006/mspr0506.html.

trainer sessions around the U.S. Since *Money Smart* was launched in July 2001, more than 495,000 consumers have completed a *Money Smart* course and more than 95,000 new banking relationships have been established with *Money Smart* students.

Recognizing that education is not enough, the FDIC is encouraging state non-member banks to offer small-dollar loan products that are affordable. "There is a huge demand for small-dollar, unsecured loans, but there are far too few low-cost options available for consumers," said FDIC Chairman Sheila C. Bair. "It is our obligation as a regulator to encourage those we regulate to create products that are beneficial to both the banks and their customers." A growing number of institutions have found ways to offer these types of loans in a safe and sound manner that is also cost-effective and responsive to customer needs.

> Sheila Glasgow, 45, who works for an office building cleaning contractor, says that before she heard about Cleveland Saves through Olivet Institutional Baptist Church, she had no savings. Now she has cut back on eating at fast-food restaurants, does her hair and nails herself, and puts money in a savings account. Her goal: to go back to school and become a pharmacist.
>
> America Saves
> www.AmericaSaves.org

Another national program that promotes access to the economic mainstream through banking or banking products is the America Saves Campaign (www.AmericaSaves.org). America Saves Campaigns are social marketing campaigns that seek to turn the country back into a nation of savers and help individuals "Build Wealth--Not Debt." The first "Saves" Campaign was kicked off in 1991 in Cleveland, Ohio. The Consumer Federation of America (CFA) chose the Cleveland area because there were already cooperative efforts underway to provide financial education through community development corporations, consumer credit counseling, and financial institutions. It was known early on that in order to get people to the table to learn about financial literacy, there would be an incentive or "payoff" of some sort. It was about this time that the numbers of "unbanked" were counted, and CFA found through studies that Americans were no longer saving, and they lacked the sophistication necessary to make sound financial decisions. A marketing campaign approach was developed because it could take into account the unique programs and partnerships that could develop based on local activities and partners.

Saves Campaigns provide motivation and education about savings through "motivational" workshops provided for free at the workplace, institutions, or in the community. The goal is to sign up "Savers" who will be put into contact with a "Wealth Building Coach"-- a volunteer who has been trained to help the Saver determine saving and/or debt management goals or plans. The Saver is also eligible to sign up for free for low-cost banking services with area banks; thereby providing that "mainstream economy" connection. In collaboration with the Financial Planners Association, a Saver who is further along with their savings goal may also be eligible for a free 30-minute consultation with a Certified Financial Planner. There are currently 49 active and developing Saves Campaigns in the U.S.--from San Diego, California to a statewide campaign in Maryland. As of March 2007, there were 76,743 American Savers.

America Saves also targets its message to various groups through its Black America Saves partnership with Black Entertainment Television, Hispanic America Saves, and Youth Saves programs. There have been discussions between the National Disability Institute (NDI) and CFA to explore an "American with Disabilities Saves" campaign.

There are numerous statewide and local programs that support financial education and access to mainstream financial products and services. One such program, the Collaborative Support Programs of New Jersey, realized early on the benefits of teaching money management and providing access to banking products as a component of rehabilitation services for people with mental illness. Following is this program's story.

> ***Collaborative Support Programs of New Jersey, Inc. (CSP-NJ)***
> http://www.cspnj.org/
> CSP-NJ is a private not-for-profit organization. The agency is directed, managed, and staffed through the collaborative efforts of mental health consumers, survivors and non-consumers. CSP-NJ strives to provide individualized, flexible community-based services that promote responsibility, recovery, and wellness. This is done through the creation and administration of self-help centers, supportive housing, advocacy, and entrepreneurial programs for adults with mental health issues and other special needs.

Case Study -- Collaborative Support Programs of New Jersey

In the early 1990s, Dr. Margaret Swarbrick[35] was collecting "quality of life" data from people with mental illness, along with information on their ability to secure and maintain quality housing. She found that one of the impediments to maintaining a positive "quality of life" was the ability of the individual to make rational choices regarding money management. Basic needs were not being met because rents or utilities were not being paid in full or in a timely fashion, and this could trigger a housing "crisis" or emergency, often causing setbacks in the individual's goal toward becoming more self-supporting. A closer look revealed that for many people with mental illness, the "payee" system was not working because it did not engage the individual in the decision. There was also no guidance provided to the individual on how to make choices that were in their best interest.[36]

Dr. Swarbrick is associated with the consumer-operated agency Collaborative Support Programs of New Jersey (CSP-NJ), which collaborates with the Community Enterprise Corporation (CEC) and has successfully developed a supportive housing model currently serving more than 380 consumers. Started in 1985, CSP-NJ has developed programs based on a philosophy of mutual aid that is not primarily diagnosis-focused and embraces the fact that "there is always hope." CSP-NJ is a consumer-operated

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[35] Dr. Swarbrick is the Director of the Institute for Wellness and Recovery Initiatives, CSP-NJ and a post doctoral fellow, National Institute on Disability and Rehabilitation Research (H133PO50006) Advanced Training and Research fellowship, Department of Psychiatric Rehabilitation, School of Health Related Professions, University of Medicine and Dentistry.

[36] Some mental health services attempt to offer skills building and money-management programs. Generally they offer a payee-type program in which a representative is designated and responsible for managing a recipient's benefit payments when the recipient is judged incapable of managing them on his or her own. Programs generally link the disbursement of funds to treatment adherence or place restrictions on consumers' freedom, both of which consumers find coercive (Swarbrick, 2006).

agency that utilizes a small staff and many volunteer peer advisors. CEC's services are free and "consumer driven." In fact, 70 percent of the board is consumers representing individuals with mental illness from all over New Jersey.

Victor Luna, Director of CEC, took the lead on the project and, with information gathered by Dr. Swarbrick, collaborated with the administrator, Peter Stahl, on a strategy to engage their clients with mental illness in the management of the clients' own finances. They brought in representatives of banks, credit unions, and other local resources to explore what a successful financial wellness strategy might look like for their clients. The program began by providing basic financial education training, and everyone in the program today attends this training. They found financial education training itself was not enough, and that "there must be incentives at all levels," according to Mr. Luna.

> IDAs are matched savings accounts that enable low-income American families to save, build assets, and enter the financial mainstream. IDAs reward the monthly savings of working-poor families who are building towards purchasing an asset -- most commonly buying their first home, paying for post-secondary education, or starting a small business.

The financial services and products offered through the CSP-NJ and CEC program began with education and savings accounts, modeled after "Christmas Clubs." This approach to savings is shorter in duration, offers an incentive to save, and requires the saver to identify a savings goal. Called the Consumer Savings Club, money deposited into these accounts was matched by privately raised funds to help accelerate savings. An early iteration of the Consumer Savings Club was to provide matching money for debt repayment; however, this resulted in individuals taking on higher levels of debt and was quickly abandoned. This program operates much like an Individual Development Account (IDA) program (which will be explored in more detail in a subsequent section), but unlike the IDA program, savings are eligible for any number of purchases. A federally funded IDA limits matched savings to achieve asset goals to three purchases: purchases of a home, starting a business, or continuing post-secondary education. The upper limit on savings in this program is $1,200, to prevent conflict with income or asset limits for their clients who receive SSI benefits, and it offers a one-to-one dollar match. The saver never controls matched monies, and payments are made directly for the good or service purchased. Costs relating to regular daily transportation are the most frequent savings goal for these New Jersey clients. Mr. Luna reports that "If you don't have a car in New Jersey, you don't go very far."

According to Dr. Swarbrick, "Individuals diagnosed with mental illness face the same despair experienced by other people living in poverty. They become dependent and learn that their well-being depends on their being in a dependent client role. They begin to see themselves as people whose needs can be met only by an outsider…they become consumers of services and have no incentive to be productive. They expend vast amounts of creativity and intelligence on surviving. They are generally not supported in any effort to find their way out of poverty."[37]

[37] World Institute on Disability. (2007, March). EQUITY: http://www.wid.org/.

Since the efforts of the CSP-NJ/CEC program are focused on recovery for people with mental illness, the advisors saw that by helping their consumers keep their finances under control they were able to create a sense of well being and prevent relapses. As a way to teach people to make more rational financial choices, the "Representative Payee" program was transformed into the "Client Trust Account" program, modeled after bill-paying programs in the mainstream financial service markets. The Client Trust Account program is a personalized money management service that provides an opportunity for clients to become responsible for their own financial decisions. CSP-NJ works in concert with clients to identify a spending plan to establish when and how bills are paid. Because their mission includes ensuring that their clients remain in housing, those who are in jeopardy of losing their housing due to financial mismanagement may be required to participate in CSP-NJ Housing Services to prevent eviction or homelessness. A proactive approach, rather than a reactive approach, is accomplished through planning, education, and follow-up services.

Another area where very low-income people are disadvantaged in the mainstream financial markets is the lack of availability of short-term loans for an unexpected emergency or crisis situation. For most people, a credit card is useful when a car breaks down away from home or an unexpected medical situation must be purchased out of pocket. However, for individuals with a very low-income who do not have access to credit cards, the alternative is often a payday lender, ubiquitous to low-income neighborhoods. Payday loans can cost up to 1,100 percent for interest expenses[38] and often become "death cycles" for people rolling over their short-term loan. The CSP-NJ program has a no-interest loan of up to $500 for emergency situations or for security deposits for rental housing. This loan program has been quite successful and has a low rate of default.[39]

When these products were being discussed and developed, the Federal Office for Community Services under Assets For Independence (AFI)[40] was releasing its first grant announcements for IDAs. The CSP-NJ program successfully partnered with the New Jersey Department of Community Affairs and other agencies and received funds for an IDA program, which it has been operating successfully for over six years while serving over 40 account holders. IDA savers receive a $2 to $1 match and are saving for homes, small businesses, and education. One IDA saver, Pete Badenhausen, purchased a home in August 2006 by combining his IDA savings and the Section 8 Home Ownership program.[41] Mr. Badenhausen started down the road to home ownership by first saving to buy a bicycle to get to work. After seeing that he could be successful, he was inspired to save for a car and with successful purchase of two assets he was motivated to purchase a home. With the support of the CSP-NJ and his family, Mr. Badenhausen purchased his own home in August 2006.

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[38] Demos: A Network for Ideas & Action: www.demos.org.
[39] Victor Luna interview March 2007.
[40] Assets for Independence (AFI) is a Federal program that provides grants to enable community-based nonprofits and state, local, and tribal government agencies to implement and demonstrate an asset-based approach for offering low-income families help out of poverty: http://www.acf.hhs.gov/programs/ocs/afi/assets.html.
[41] U.S. Department of Housing and Urban Development Home ownership Vouchers: http://www.hud.gov/offices/pih/programs/hcv/home ownership/.

Pete Badenhausen in front of his new home--purchased with Individual Development Account savings and the Section 8 Home ownership program.

The fear of losing health insurance or the fear of losing "everything" was cited by Mr. Luna as the primary reason people with disabilities are skeptical of financial products and services such as those offered through the CSP-NJ programs. New Jersey has one of the highest cost of living indices in the country and the current SSI cash payment is only $545 per month. Many people currently being served have at one time or another lost everything. Because of a strong need for survival, they are reluctant at first to attempt something they may fail at.

This extreme poverty--the kind that holds many people with disabilities in its grip--appears to result in a "short-term planning horizon" and an inability to move from dependency to independence, due in some measure to a lack of confidence and a perception that the "system" can best take care of an individual's needs. One of the most positive changes seen in consumers of these products has been the change in attitude about themselves and the agency that is providing the assistance. Luna and Stahl both remarked that by becoming managers of their own money, their customers are no longer angry at the "institutions" they work with, and they find that they can manage their own financial affairs and make rational choices. They are also finding that consumers who attend the financial education training and participate in Savers Clubs or IDA programs change their attitudes about what constitutes an "emergency," and they are doing a better job at avoiding such emergencies. There are currently 120 people enrolled in the CSP-NJ program, and there is a waiting list of participants.

Mr. Luna related that this agency's staff has adopted the "old style" banking model of years ago in that they treat people with mental illness like "customers," and believe that it is their responsibility to develop a relationship based on trust with their consumers. "I tell people all the time--we are not doing anyone any favors--we get paid to do this." Because it costs approximately $1,500 per year per account, he understands that commercial banks would not see what they offer as being possible, so his agency has stepped in to fill this need. He sees his agency more as a local community bank than a social service agency, and he finds that given the opportunity, even very low-income individuals with mental illness can learn to "pay themselves first."

The scalability of this program has been explored by others, according to Mr. Stahl. The key components to operating a successful financial "wellness" program for people with disabilities include the provision of financial education to all clients and staff, incentives for savings that are realistic goals that can be reached within a reasonable time frame, and there is appropriate monitoring and support of savings account balances and activities.

B. Favorable Tax Provisions Including the Earned Income Tax Credit

The use of favorable tax provisions can be a strategy to preserve income and offer new options for matched savings. In 1975, Congress approved the Earned Income Tax Credit (EITC)[42] to offset the burden of Social Security taxes and to provide an incentive to work for low-income individuals and families. The EITC is a refundable tax credit. In 2006,[43] over 22 million taxpayers received the EITC and received over 44 billion dollars in tax refunds; yet, the IRS estimates that between 20 and 25 percent of taxpayers who are eligible do not claim this credit.

Real Economic Impact Tour
The REI Tour is an unprecedented collaboration of private and public national organizations to bring tax preparation help and financial education to persons with disabilities in 65 cities nationwide. Founding leaders of the initiative are the Office on Disability, U.S. Department of Health and Human Services; the National Cooperative Bank (NCB); National Disability Institute; U.S. Department of Labor; the IRS and the FDIC.

For the past four years, the IRS Stakeholders Partnerships, Education and Communication (SPEC) Division has teamed up with the National Disability Institute, Goodwill, Easter Seal, the ARC, and the National Council on Independent Living to target marketing and outreach activities to individuals with disabilities in over 60 cities nationwide. These entities teamed together to promote a part of a project called the Real Economic Impact Tour (REI Tour),[44] which represents a national, public/private initiative to assist low-income persons with disabilities with asset-building strategies, free tax preparation, and filing assistance. In the 2006 filing season, REI Tour partners prepared 17,223 tax returns in 30 cities. Twelve million dollars in refunds were received by persons with disabilities, $5.7 million alone from the EITC. In the 2007 filing season, REI Tour partners prepared over 36,000 tax returns in 54 cities. A total of $30 million in refunds were received by persons with disabilities--over $10 million from the EITC.[45]

The EITC is not used to determine eligibility for Medicaid, SSI, food stamps, and other public benefits. States have different rules regarding the length of time the EITC refund can remain in a financial account before it is considered an asset and may impact continued eligibility. For the first time during the 2006 tax year, the IRS authorized that tax filers could split their refund to distribute part of their EITC into their own account to encourage savings. In addition, 22 states and the District of Columbia now offer residents an EITC that is most often calculated as a percentage of the federal credit. It varies by state from a low of 3.5 percent to as much as 35 percent.

In communities across the country, EITC is:

- **Reducing the numbers of families living in poverty.** 1 In 2004, over 20 million working families received nearly $38 billion in EITC. EITC lifted 4.7 million people above the poverty line.
- **Promoting work.** The EITC makes wor more attractive than Welfare programs and helps many families make the transition from public assistance into the labor force.
- **Reducing inequality in income.** Has ability to turn a $7 per hour job into an $9 per hour job
- **Helping low-income families build assets.** The potential for significant cas payments to be received, provides a strategic link to introduce various asset-building opportunities

The EITC is only one of several favorable tax provisions that might benefit a Medicaid beneficiary with a disability. Although the EITC is a possibility for individuals with

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[42] ...dit: http://www.irs.gov/individuals/article/0,,id=96406,00.html.
[43] ...s.gov/individuals/article/0,,id=177571,00.html.
[44] ...ct Tour: www.reitour.org.
[45] ...i/.

disabilities who worked part- or full-time at a low-income level (less than $12,250 in 2007) and are between the ages of 25 and 65, other tax provisions may impact individuals favorably outside this age group, such as the credit for the elderly or disabled, impairment-related work expenses, and the scope of coverage under the medical deduction. IRS Publication 907[46] explains these selected provisions in more detail. The IRS Volunteer Income Tax Assistance (VITA) Program[47] offers free tax help to low- to moderate-income (generally, $40,000 and below) people who cannot prepare their own tax returns. Certified volunteers sponsored by various organizations receive training to help prepare basic tax returns in communities across the country. VITA sites are generally located at community and neighborhood centers, libraries, schools, shopping malls, and other convenient locations. To locate the nearest VITA site, call 1-800-829-1040.

In the last ten years, community organizations have formed coalitions and partnerships with the IRS in efforts to help low-income taxpayers claim available refunds and credits. Every state has, or is developing, a coalition and the National EITC Outreach Partnership lists over 300 members on their website.[48] The IRS has sponsored local VITA programs for over 30 years and has utilized this existing volunteer model to expand outreach efforts to reach the estimated 38 percent of people who may be eligible for, but do not claim, tax credits or refunds.

Many low-income earners do not file tax returns because the IRS does not require them to file, or they are not aware of their eligibility for tax refund or tax credit programs. The NOD survey (previously cited) found that people with disabilities were much less likely to file for tax credits. The survey results showed that of those people receiving SSI, 83 percent did not claim tax credits related to work, and fewer than half of homeowners with disabilities took advantage of mortgage interest deductions. The tax credit or refund most under-claimed is the EITC. The credit began as part of a broader effort by Senator Russell Long (D-LA) over twenty years ago. The federal government spends more on the EITC than on TANF,[49] but early studies of the effectiveness of the EITC found that many taxpayers who were eligible were not claiming the credit.

According to John Wancheck, Earned Income Credit Campaign Coordinator for the Center on Budget and Policy Priorities, the EITC is a good example of policies that provide more cash in the hands of low-income or the asset poor. The trouble is that without having the opportunity to manage large financial windfalls (relative to income), many low-income families do not convert these large tax returns into appreciating assets. Studies have shown that tax returns first go to pay bills--utilities being cited most often--food purchases and then clothing. Saving for an asset, such as a car or house, was least often cited.[50]

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[46] IRS Publication 907 (2007). Tax highlights for Persons with Disabilities: http://www.irs.gov/publications/p907/index.html.
[47] IRS Free Tax Return Preparation: http://www.irs.gov/individuals/article/0,,id=107626,00.html.
[48] The National EITC Outreach Partnership: www.cbpp.org/eitc-partnership/index.html.
[49] Earned Income Tax Credit. V. Joseph Hotz University of California, Los Angeles and NBER and John Karl Scholz University of Wisconsin, Madison and NBER, July 15, 2000.
[50] Steve Holt and Associates Milwaukee Asset-building Coalition, 2003.

Coalitions were first focused on reaching out to low-income tax filers and are now shifting strategies to include more asset-building programs or services for their customers. The Milwaukee, Wisconsin Asset-Building Coalition has many banking partners, and in 2007 now has free income tax preparation sites located in over ten bank lobbies where a tax filer can open a free or low-cost account and have their tax refund deposited electronically into their account in as few as ten working days. Many Coalitions are providing seminars or have teamed up with local "Saves" Campaigns, or are providing free credit reports and reviews while customers are waiting to have their tax returns prepared. Tax filers in Madison, Wisconsin are interviewed by volunteers who use a state website to determine if they are eligible for other federal and state programs such as Food Share or Medicaid.

A recent report, *Educating Democracy*,[51] by Dr. Johnette Hartnett of NDI, found that people with disabilities who had tax returns completed for free through an EITC Coalition were predominately low-income, rented more often than owned a home, were more educated, and were older than their non-disabled counterparts. Follow-up focus groups of tax filers with disabilities uncovered a lack of personal confidence in their understanding of taxes and tax filing, and many were afraid they would lose their benefits (SSI, SSDI or Medicaid) if they filed taxes. In fact, it was discovered that some caseworkers were advising them not to file for this reason. These studies were done as part of an outreach program developed specifically to assist persons with disabilities, and are part of the National Strategy for Financial Literacy from the Office of Financial Education.[52]

According to Dr. Hartnett, *Educating Democracy* is a response to the national movement introduced in the 1990s, focused on building savings and increasing wealth for low-income working Americans. Where there is poverty, people of color, unemployment, under employment, and lack of knowledge about tax and financial services, there is disability. Twenty-six percent of 20 million working Americans with a severe disability are living in poverty compared to 9 percent of low-income workers without disabilities. Although disability advocacy groups led the way for civil rights legislation, independent living, integrated education, and the American's with Disability Act, entrance into the formal economy has not occurred for millions of Americans with disabilities. Asset accumulation and tax policy for individuals was not part of the new asset-building frontier for low-income Americans because the concept and potential of work for individuals with a disability was and is not fully realized.

Case study: Wichita Earned Income Tax Credit Coalition

[51] Harnett, J. Educating Democracy*: Tax and Financial Service Needs of Working Americans with Disabilities*. Available at: http://www.ndi-inc.org/resources.html.

[52] U.S. Department of the Treasury, Office of Financial Education: http://www.treas.gov/offices/domestic-finance/financial-institution/fin-education/.

In 2001, the General Accountability Office (GAO) issued a report[53] that saw participation rates in the EITC program for people with no qualifying children were low relative to those with qualifying children--44.7 percent compared to 75 percent for all filers with one or more qualifying child. Judy Stengel, a Taxpayer Education Specialist with the IRS for over twenty years, read that report and thought of people like her son, an adult with a disability who worked in a sheltered workshop and qualified for the EITC. Ms. Stengel wondered if the representative payees or family members who helped low-income adults manage their earnings also helped them file their income taxes and get the federal tax credits they may be eligible for. “A few hundred dollars they may get from EITC might not seem like a lot compared to the thousands filers with children get from EITC, but it might be enough to help someone with the security deposit they need for their own apartment in order to be self-sufficient,” reasoned Ms. Stengel.

In the summer of 2003, Ms. Stengel was invited to spend a “Day with the Director” and present a “best practice” idea to IRS regional managers in Atlanta, Georgia. She developed a presentation using the data from the GAO report and her “theory” that single lower income wage earners who had a disability were not filing federal income tax and consequently not receiving the EITC because they were not required to file. She suggested to the managers that day that the VITA volunteers could be sent to sheltered workshops and other places to assist people with disabilities with their filing for available tax refunds. It just so happened that in that group of IRS managers there was a core team of IRS specialists working to improve access to IRS services and to promote products that were aimed at taxpayers who were low-income, limited English-proficiency, and persons with disabilities. For the 2002 filing season, Ms. Stengel worked with persons with mental disabilities and their representative payees and filed 40 tax returns with the majority claiming EITC. The next year, 86 returns were filed and 69 people filed for the EITC for the first time.

The Wichita EITC Coalition began in 2003 and is championed by the United Way of the Plains. The Coalition consists of members from faith-based organizations and disability organizations, as well as the Kansas State University Extension program. Serving people with disabilities is a core component of its members’ outreach and they have held special events just for tax filers with disabilities. Even though there are literally no funds for this initiative, since it is all volunteer-driven (the IRS does supply the tax preparation software), finding volunteers is not a problem. For the 2007 filing season, the program has gone “mobile” with Ms. Stengel loading the appropriate tax filing software onto the computers at the sheltered workshops, employer sites, or at living centers one day, which enabled volunteers to file tax returns the next day. “We couldn’t do this without the cooperation of the employers and living centers,” said Ms. Stengel, and she credits their enthusiasm and support for the success of this program.

Of the approximately 170 tax returns prepared and filed for people through the Disability Initiative of the Wichita EITC Coalition during the 2007 tax season, a “4506-T” or “Transcript Request” for the current year and the prior year was also filed. IRS rules

[53] General Accounting Office. (2001, December). *Earned Income Tax Credit Eligibility and Participation* (GAO-02-290R).

allow filers who receive refunds to have up to three years to file those claims. Results from this effort at just one employer found that nine low-income adults working at the sheltered workshop collectively received over $1,700 in prior year refunds. "I like to take extra time and explain everything on the tax form when I do these returns. I use the term "reward for working" instead of "refund" when they are getting money back--it shows that there are some good things that happen when you work," says Ms. Stengel. In 2004, the Wichita EITC Coalition was asked to be the flagship site for TAX FACTS, now renamed the Real Economic Impact Tour.

C. Individual Development Accounts

In most states, the EITC refund is only excluded as an asset for a limited period of time, which is usually for less than one year. A third strategy, then, is to consider use of all or part of the tax refund as part of an Individual Development Account.[54] An IDA is excluded from counting as an asset for purposes of determining eligibility for public benefits. In 1998, Congress approved the Asset for Independence (AFI) Act,[55] which created for the first time federal funding for IDAs. Federally funded IDAs are exempt from counting as an asset for purposes of remaining eligible for SSI or Medicaid; therefore, an IDA could actually help preserve eligibility for Social Security benefits by utilizing income produced to be a part of funds placed in the IDA, rather than be counted as assets to determine continued SSI eligibility.

Through the AFI Act projects are funded on a competitive basis, and today there are over 30,000 individuals saving money in IDAs with an estimated 200 IDA projects nationwide. The Office of Community Services is the grantee for the Assets For Independence grants, which fund most IDA programs. The AFI Act provides five-year grants to organizations and agencies that enable low-income individuals and families to achieve economic self-sufficiency by accumulating economic assets. Grantees provide financial literacy training to participants and help them save earned income in IDAs. Eligible grantees include community-based nonprofits and state, local, and tribal government agencies and others, such as community development financial institutions and credit unions. To learn more about future opportunities to apply to become an AFI project, visit www.acf.hhs.gov/assetbuilding.

The AFI program was designed based on a privately funded and highly successful American Dream Demonstration (ADD)[56] in multiple sites nationwide. The ADD demonstration proved that low-income families could be supported with financial

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[54] Individual Development Accounts (IDAs) are matched savings accounts that enable low-income American families to save, build assets, and enter the financial mainstream. IDAs reward the monthly savings of working-poor families that are building towards purchasing an asset, most commonly buying their first home, paying for post-secondary education, or starting a small business. IDAs make it possible for low-income families to build the financial assets they need to achieve the American Dream. More information is available at: http://www.cfed.org/focus.m?parentid=2&siteid=374&id=374.

[55] Assets for Independence: http://www.acf.hhs.gov/programs/ocs/afi/assets.html.

[56] Schreiner, M., Clancy, M. & Sherraden, M. (2002, October). *Saving Performance in the American Dream Demonstration: A National Demonstration of Individual Development Accounts.* Center for Social Development: http://gwbweb.wustl.edu/csd/Publications/2002/ADDreport2002.pdf.

education and a matched saving initiative to put part of their earned income into a special account to purchase an agreed upon asset to advance their self-sufficiency. The report on the ADD found that income is unrelated to saving, but savings programs that are easy and automatic have the most effect on savings levels. Further, according to this report, many IDA participants use their IDA savings as a "checking account," which has the writers recommending an expansion of uses for such savings vehicles to include such things as durable household goods, travel, and health-related emergencies. The study further noted that IDAs were effective at promoting asset acquisition but did not lead to increases in wealth or net worth--income minus liabilities. But what has been found is that among IDA savers, the act of saving was more important than saving itself.

In the statement of findings of AFI, Congress explains, "assets can improve economic stability and independence, connect individuals with a viable and hopeful future, and stimulate development of human and other capital." With federally funded IDAs, an eligible wage earner can target one of three asset goals for a matched savings plan:

a. purchasing a home;
b. starting a business; or,
c. continuing a post-secondary education.

As part of the savings agreement the individual identifies the asset objective, sets a goal of the total amount to be saved and matched, sets a savings schedule of the specific amount to be deposited at regular intervals, and reaches agreement with the program manager on a matched rate. Earned income is matched at various rates depending on the IDA program manager. Nationwide, there is a diversity of IDA program managers, including state and local government agencies, United Way affiliates, community action programs, community development organizations, and community and faith-based groups. To identify IDA program managers in your state, please visit www.IDANetwork.org. Rates may vary from one dollar for one dollar to as much as eight dollars for each saved dollar. The maximum federal matched dollars per individual account is two thousand dollars, which is then further supplemented by public and/or private dollars raised by the IDA program.

Congress created IDAs more generally for low-income wage earners and families. Since IDAs were not specifically created for individuals with disabilities, they have been an underutilized strategy used by them to save and build assets. However, in recent years individuals with disabilities have become more aware of this asset building strategy and have begun to connect to IDA programs in New Hampshire, Florida, Mississippi, and Illinois.

The introduction of asset-building strategies through IDA legislation for low-income adults in the late 1990s brought with it a new way of thinking about poverty and strategies to alleviate poverty. Michael Sherraden, Professor of Social Development and founding director of the Center for Social Development (CSD) of Washington University in St. Louis, is credited with this breakthrough anti-poverty strategy. In 1997,

he testified before the U.S. Congress stating the acquisition of assets would be the ticket out of poverty for low-income citizens and families who were willing to save some of their earnings each month, develop a savings goal that would be tied to an appreciating asset (home purchase, post-secondary education or the creation of a small business), and to learn financial literacy.[57] The idea was to accelerate the savings in order to make the goals more attainable by providing a matched amount to the saver. IDA program participants throughout the U.S. tell stories of how peoples' lives were changed by getting the support, education, and capital needed to fulfill their dream of home or business ownership or education beyond high school.

Published in 1991, Dr. Sherraden's groundbreaking book, Assets and the Poor: A New American Welfare Policy, made the claim that, "Social welfare policy in the U.S. is not working."[58] To the 101st Congress, which was debating welfare reform at the time, Sherraden made a challenge to, "Invent a progressive social policy that goes beyond simple income maintenance to foster individual initiative and self-sufficiency."[59] He added, "We should create a system of incentives that offers low-income citizens the same opportunities that middle- and upper-income Americans have to plan ahead, set aside savings, and invest in a more secure future. Such a policy would stimulate economic growth while giving more citizens a chance to share the rewards of democratic capitalism." He reasoned that people with assets were more economically secure, had more opportunities and options in life, and had the ability to pass it on to future generations through "step-up" assets such as paying a larger share of college costs or down payment assistance for their children. Dr. Sherraden also reasoned that assets have positive social, civic, and psychological effects that are independent of income. He then went on to introduce IDAs.

A survey conducted by NDI on "Asset-Building Strategies for Ohio"[60] found that when asking IDA and other asset-building program practitioners about their efforts to include people with disabilities in their programs, most responded that they worked with whoever made it to their door, but they did not actively market or recruit their programs to people with disabilities. A minority of respondents was influenced by "bad facts"--believing that people with a disability who received Social Security disability benefits were ineligible for programs because they did not or could not work and, therefore, had no "earned income" required for eligibility. Ohio asset-building program practitioners were all supportive of learning more about connecting with advocates and others who assist persons with disabilities, and expressly wanted to better understand how an individual's benefits from Social Security would be affected by participating in their programs--especially once the asset has been obtained. In fact, as can be seen in the case study below, that some states are taking aggressive steps to make IDAs more accessible for persons with disabilities.

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[57] Sherraden, M. (October 18, 2001). *Assets and the Poor: Implications for Individual Accounts and Social Security.* Invited Testimony to the President's Commission on Social Security. Washington, DC: http://www.csss.gov/meetings/Sherraden_Testimony.pdf.
[58] Sherraden, M. (1991). *Assets and the Poor: A New American Welfare Policy*. Armonk, NY: M.E. Sharpe.
[59] Sherraden, M. (1990, January). *Stakeholding: A New Direction in Social Policy*. Democratic Leadership Council: http://www.ndol.org/documents/ACFNYV8Gi4Tc.pdf.
[60] National Disability Institute: www.ndi-inc.org.

There are approximately 540 IDA programs in the U.S. and no two are alike. Eligibility is generally based on a maximum household level of income--often relying on the federal poverty level as a guideline--typically 100 percent to 200 percent of federal poverty, or on the area median income, which is likely between 65 percent and 85 percent. Earned income is most often defined as income from a paycheck--but other sources of income that are sometimes considered are welfare, disability, social security, and unemployment checks. Money that an IDA saver receives through a gift is not considered earnings, and therefore, is not eligible to be matched. Most of these variations are due to requirements of the IDA funders. Debt is often an issue for many IDA savers. Often a poor credit history or an inability to open an account with a bank or credit union needs to be addressed prior to opening an account. An IDA program may make a referral to a credit counseling agency before an IDA can be opened.

The amount of time provided to the saver varies from program to program, with most programs allowing for one to three years for the IDA participant to save the required dollars for matching. A person must be 18 years of age to participate in an IDA program; however, there are youth IDA programs available in limited markets.

Program sponsors are generally non-profit organizations or collaborations that include a financial partner. The non-profit or the collaboration manages the IDA program components--recruiting qualified candidates, providing financial literacy education classes, and offering assistance setting up and monitoring the IDA savings account. One-on-one counseling either provides entrepreneurship or home ownership education and counseling, or provides it through a collaborating agency. IDA participants are required to attend financial literacy education classes, and many programs offer the opportunity to take entrepreneurship and home ownership courses. There are numerous financial literacy education curricula that an IDA program may use. Some IDA programs, like one in Tennessee, are utilizing technology and are offering classes on-line through webinars.

The financial institution agrees to hold the accounts of the IDA participants. If an IDA program participant had a banking account closed for mismanagement or other non-fraud related circumstances, the participating financial institution will waive a ChexSystems[61] "hold" on an account. This is important. Many low-wage earners choose not to have a bank account because they "messed up" at one time and had their accounts forcibly closed, or believe that managing a bank account, especially a checking account, is too difficult.

IDA programs must find a donor to match the dollars saved by the account holder. Most programs will match each dollar saved with two dollars. Money must be deposited into a specific IDA account and the IDA program manager will audit the savings. Savings

[61] The ChexSystems, Inc. network is comprised of member Financial Institutions that regularly contribute information on mishandled checking and savings accounts to a central location. ChexSystems[SM] shares this information among member institutions to help them assess the risk of opening new accounts. ChexSystems[SM] only shares information with the member institutions and does not decide on new account openings.

cannot be withdrawn without permission of the IDA program manager, but withdrawals are allowed for "emergency" situations. Participants receive a statement of their account and matched money is generally paid to the vendor from the IDA program or donor, so the IDA participant never retains "ownership" of the cash.

The Corporation For Enterprise Development (CFED)[62] is the recognized leader in providing information, support, and policy thinking in the field of IDAs. In 2005, CFED received almost 400 surveys from 540 IDA programs throughout the U.S., which represented a 30 percent growth rate from the prior year. They found that each program is serving an average of 56 account holders and has graduated an average of 64 account holders, who have made their asset purchase. CFED concludes that there are over 30,000 IDAs currently open, and even more who have made purchases. Twenty two percent of IDA participants are African-American or Black, followed by 20 percent White, and 17 percent Hispanic or Latino. Half have incomes between $1,000 and $2,000 per month with 33 percent earning less than $1,000 per month.

Account holders in AFI-funded IDA programs have saved an average of $533 towards their asset purchase or put another way, 54 percent of AFI projects reported average balances of less than $400, while 28 percent reported average balances of over $6,000. The total saved by over 30,000 AFI participants is $145.6 million. Home purchase continues to be the most frequent asset purchased, accounting for 24 percent of all purchases, followed by small business and post-secondary education at 16 percent. (Because CFED collects AFI figures only, it also reports asset purchases for Refugee and Youth IDA programs that allow for purchasing such things as job training, computers, and automobiles.)

Given the complexities of how IDA programs are funded, they are quite stable. Over 70 percent of programs surveyed in 2004 had been offering accounts for four or more years. Sixty-two percent represent urban/suburban markets and 38 percent represent rural markets. A great many IDA programs offer more than just matched savings accounts and 21 percent offered free tax preparation assistance. Most IDA programs receive AFI grants to run their programs and these grants still fund the largest portion of the public sources for operating expenses and the matching sources (50 percent), followed by TANF (10 percent) and HUD (11 percent). Of non-governmental sources, foundations, banks, and the United Way make up almost two-thirds of funding sources. It is always much easier to raise funding to provide the savings "match" than it is to raise operating capital.

IDAs have proven to be one way for some households to acquire an asset that holds promise to grow in value. By expanding IDAs, government can also help America's working-poor families save, acquire assets, and participate more fully in the economy.

[62] The Corporation for Enterprise Development (CFED) is a nonprofit organization that expands economic opportunity. Established in 1979, CFED works to ensure that every person can participate in, contribute to, and benefit from the economy by bringing together community practice, public policy, and private markets. We identify promising ideas, test and refine them in communities to find out what works, craft policies and products to help good ideas reach scale, and foster new markets to achieve greater economic impact: http://www.cfed.org/.

Case study: Oregon Individual Development Account Program

There are just over 3.5 million people living in Oregon, with most people living in the western half of the state. There are slightly more women than men (50.6 percent to 49.4 percent) and 86.6 percent describe themselves as "white." There are just over six times as many who describe themselves as Hispanic than African American (9.9 percent compared to 1.6 percent). Among people at least five years old in 2005, 16 percent reported a disability. The likelihood of having a disability varied by age, from 7 percent of people 5 to 20 years old, to 14 percent of people 21 to 64 years old, and 42 percent of those 65 and older. In 2005, for the employed population 16 years and older the leading industries in Oregon were educational services, health care and social assistance (19 percent), and manufacturing (13 percent). The median family income was less than the national average at $42,944, yet median home values were 20 percent higher than the national average at $201,200 and 37 percent of families earn less than $25,000 per year.[63]

In the early 1990s, a children's IDA program was legislated, but unfunded.[64] The discussions leading up to this legislation sparked the interest of legislators who saw promise in the concept of the IDA program as a strategy for moving people from dependence to self-sufficiency, but they were unable to pass an IDA initiative when it was proposed in 1997. At the same time, the Enterprise Foundation (EF) was developing a network of IDA programs throughout the state--seeking to capitalize on existing infrastructure and reduce the start-up costs associated with these new IDA programs. By 1998, the EF had eleven organizations in the planning/development or implementation phase of an IDA program. Because the EF was in the unique position of already having begun developing a statewide IDA network when a meeting of legislators, business leaders, and government cabinet members was convened, the foundation was able to influence the discussion that led to, among other things, further efforts to support IDA legislation and policy that would not become a strain on already tight budgets, yet would try to reach as many low-income Oregonians as possible.

IDA programs were largely untested in the late 1990s and were considered to be expensive programs due to the intensive management and oversight of participants and funds. The use of tax credits to fund a statewide IDA program was politically acceptable to politicians on both sides of the aisle, because they were not seen as an "entitlement" and funding for IDAs would not add to the state budget. The Oregon Housing and Community Services department was chosen as the lead administrative agency once this bi-partisan legislation was passed in 1999. Funds through tax credits could not be raised until the following year and it was quickly determined that the 25 percent tax credit would need to be increased if they were to raise enough money to fund a statewide initiative. In 2000, the tax credits were increased to 75 percent--for every dollar of tax credit purchased, the taxpayer could receive a credit on their taxes due of

[63] US Census Bureau: www.factfinder.census.gov.
[64] For a more complete history of Oregon's IDA Tax Credit Legislation go to: http://gwbweb.wustl.edu/csd/Publications/2003/PolicyReport-TaxCredit.pdf.

75 cents--for a maximum of $500,000 loss of revenue to the state and at least $666,000 to fund the Oregon IDA Initiative at start-up.

Cindy Winters, Director of IDA programs for the Neighborhood Partnership Fund,[65] who now administers the IDA program for the state, said that at first the strategy was to have the local fiduciary organizations that manage the IDA programs market the tax credits locally. This strategy was not "as successful as we had hoped," she said and now they market the tax credits primarily through accountants, financial advisors, estate planners, and others. Tax credit purchases on average range between $20,000 and $50,000, and in the 2006 tax season over $3,500,000 (out of $4,000,000 available) was raised through cash contributions, or contributions of stocks. Ms. Winters reported that they receive a lot of "repeat" customers who purchase tax credits, because "they like the idea that they are giving a hand up, not a hand out," and cites that charitable giving is becoming more of a "personal experience" and donors want to know exactly how their donation is to be used.

New to the 2007 tax filing season is the ability of IDA savers to claim a tax credit for the money they put into savings, as well as any interest earned in their account. Their savings are not considered taxable when spent to buy a house, pay for post-secondary education, or start-up expenses for a business.

The Neighborhood Partnership Fund began in 1990 and provides oversight for IDA programs that have the potential to reach almost three-quarters of the state's IDA eligible population. IDA programs are currently available in 18 counties and are managed by five community development corporations, and five of Oregon's nine federally recognized American Indian tribes have been approved as fiduciary organizations. These five agencies and Tribes partner with over 40 other agencies that provide the necessary services to recruit, educate, and provide support for savers as they prepare to purchase their asset. These 40 organizations are made up of public housing authorities, community development corporations, banks, credit unions, and others who provide the financial literacy, home ownership or entrepreneurship training required of Oregon IDA participants.

[65] The Neighborhood Partnership Fund. As a first step to supporting asset building among low-income Oregonians, NPF partners with the state of Oregon and local partners to manage the IDA tax credit program. Through this program funds are raised to match qualified individual savings accounts. These savings accounts can be used to buy a first home, start a small business, or pay for education or skill training: www.tnpf.org/programs/assets_idas/.

Meet a Recent IDA Grad

Dawna is a single mom with two teenage kids. Several years ago Dawna, who was receiving subsidized housing assistance, signed up with the Family Self Sufficiency program through her local Housing Authority. She set a goal to become a homeowner and was introduced to the Dream$avers IDA Initiative at Umpqua CDC in Roseburg. Through a series of classes on Home Buying and Financial Management, she learned how to plan and save to meet her goal. Because of the Oregon IDA Tax Credits, Dawna received match funds for every dollar she saved. These funds would be used for her down payment when it came time to purchase her new home.

Dawna was close to the end of her savings goal for Dream$avers, and was fast approaching the end of her Self-Sufficiency goal plan when the rental she lived in, along with all of her belongings, burned to the ground. Suddenly, Dawna found herself and her family homeless. Most people would have pulled their money out of their IDA account for an emergency like this, but not Dawna. She refused to give up and rather than find a new rental, she pushed herself to find her dream home. Today her family has more than just a place to live; they have a place to call home.

There are 400 active IDAs open at the writing of this report. However, because home values are rising so fast in many of Oregon's most populous areas, home ownership for many low-income families is becoming out of reach and instead IDA savers are saving for college or other educational expenses.

It was recognized early on that IDAs could be a powerful tool in helping people with disabilities to purchase items that would help them attain or maintain self-sufficiency--but many of them needed to be able to save in order to purchase technology, equipment, or purchase necessary accommodations for their dwelling. Ms. Winter is hopeful that proposed legislation to include the purchase of these items for people with disabilities will be passed when it comes up for a vote this fall.

What was not addressed was the requirement that only earned income is eligible for the matched savings program. Some states, like Ohio for example, apply a very liberal definition of income, but Oregon decided on a strict interpretation of income. However, in Ohio only the income devoted to the IDA must be earned, so a person could still be receiving Social Security disability benefits and participate in the IDA program.

As the Oregon IDA program grows there is a commitment on the part of the state, through legislative efforts, and others to see that the program becomes more accessible for people with disabilities. "In the meantime," according to David Foster, "consumers, advocates, and Oregon's IDA initiative representatives will continue striving to provide

those working with persons with disabilities an improved tool for keeping consumers on their path to greater self-reliance. With the two proposed statutory amendments, all involved in Oregon's IDA initiative anticipate better serving persons with disabilities in the near future."[66] The following represents excerpts from the proposed legislation:

> "*As specified in the account holder's personal plan for becoming more self-reliant, the purchase of specialized training, equipment or other technology required to become competitive in obtaining or maintaining employment or for starting and maintaining a business.*"
>
> "*Improvements, repairs, or modifications necessary to make or keep the account holder's primary dwelling habitable, accessible, or visitable for the account holder or a household member. This paragraph does not apply to improvements, repairs, or modifications made to a rented primary dwelling to achieve or maintain a habitable condition for which ORS 90.320 (1) places responsibility on the landlord. As used in this paragraph, "accessible" and "visitable" have the meanings given those terms in ORS 456.508.*"

D. Home Ownership

One of the greatest challenges for Medicaid beneficiaries with disabilities is to identify and secure affordable and accessible housing due to the restrictions on reimbursement for housing under Medicaid policy. Access to rental assistance through Public Housing Agencies (PHAs) remains difficult, if not impossible, for most low-income individuals with disabilities. Long waiting lists to access rental subsidies remain the norm nationwide. However, through the CMS-funded Real Choice Systems Change grants,[67] new partnerships have emerged between Medicaid and Housing Finance Agencies at a state level in Maryland, Florida, Massachusetts, and Iowa. The collaboration activities have moved from access to affordable rental housing to a focus on opportunities for home ownership.

It is well documented that home ownership is a stabilizing force for many people and the source of most U.S. household wealth. According to the most recent Federal Reserve Survey of Consumer Finances,[68] the median net wealth of a renter household is $4,800, while the median net wealth of a homeowner household is $171,700. According to data from the U.S. Census Bureau, owners do not move as frequently as renters, providing more neighborhood stability. In turn, involvement in community quality of life issues

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[66] David B. Foster, Policy Strategist, Oregon Housing & Community Services.
[67] U.S. Dept. of Health and Human Services. CMS. Real Choice Systems Change Grants: http://www.cms.hhs.gov/RealChoice/01_Overview.asp.
[68] Federal Reserve Board. Survey of Consumer Finances: http://www.federalreserve.gov/pubs/oss/oss2/scfindex.html.

helps prevent crime, improves childhood education, and supports neighborhood upkeep.

For people with disabilities who rely upon SSA or other programs with asset limits, it is impossible to purchase a home with a traditional 30-year fixed interest rate mortgage. These "traditional" mortgage products comprise approximately 75 percent of all home mortgages[69] and require a down payment equal to 20 percent of the mortgage total. A 20 percent down payment on a home mortgage for the median home in the U.S. is $33,500 (20 percent of $167,500), which is well above the asset limit for someone participating in some Social Security or Medicaid programs.[70]

The federal government, through tax policy and other activities, has been promoting home ownership for decades. Interest expense paid on home loans was retained as a tax deduction when deductions for other types of interest were eliminated from the tax code in the 1980s. The U.S. Department of Housing and Urban Development (HUD) has been promoting home ownership for low-income families for many years as well. This, coupled with loosening standards in the credit underwriting and the subprime mortgage products "boom" (unseen since just before the Great Depression of 1929),[71] has made home ownership within reach for more and more individuals and families.

Changes in how government and others approach solutions to poverty through the development of IDAs have also made the "American Dream" a reality for many people. These special savings account programs will "match" the down-payment savings of a low-income homebuyer and provide them with the necessary education to prepare them for the home purchase process and home ownership. Many IDA savers also qualify for other government or locally sponsored home ownership programs that may pay for closing costs, waive mortgage insurance, or provide other assistance to make buying a home affordable. In an effort to provide education to IDA program managers and staff, the Office of Community Service is collaborating with the Administration on Developmental Disabilities to offer the Assets for Independence AFI Family Support 360 IDA Initiative.[72] The goal of this initiative is to coordinate home ownership efforts with long-term care and other supportive programs for people with disabilities.

For people with disabilities who are trying to retain health care benefits, yet want to work, there are two programs offered by HUD through local Public Housing Authorities

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[69] See: www.RealtyTrac.com.

[70] There are many different types of mortgage and sub prime mortgage loans and a discussion of them is beyond the scope of this paper, but for a look at how they work please go to the Center on Responsible Lending website and read their articles on sub prime lending and other mortgage loan products. http://www.responsiblelending.org

[71] Calder & Lendol. *Financing the American Dream: A Cultural History of Consumer Credit 2001*

[72] Family Support 360 IDA Initiative. There is a growing awareness among Assets for Independence program grantees and their partner organizations that some people with disabilities and their families have a difficult time accessing and using IDA services. In response to this need, the Office of Community Services is collaborating with the Administration on Developmental Disabilities to sponsor the Assets for Independence Family Support 360 IDA Initiative. Through the initiative, the AFI Resource Center provides AFI grantees and their partner organizations with training and technical assistance for providing IDA services to this important population: http://www.acf.hhs.gov/assetbuilding.

(PHAs). These two programs are available to participants in the Housing Choice Voucher (Section 8) program[73] and provide an opportunity for people with disabilities to build assets and self-sufficiency through home ownership. In 1999, HUD began allowing Section 8 vouchers to be used by very low-income people, including people with disabilities, to buy their first home. There are over 2,600 PHAs managed by state, regional, or local governments or their agents, and HUD allows each to determine the number of vouchers that will be available to eligible participants for the purchase of a home or home-related expenses. There are approximately 2.1 million vouchers for the approximately 8.4 million who apply, and half of those who did not receive a voucher were considered "worst case," meaning they were spending half or more of their income on housing.[74]

Participants with disabilities receiving a voucher must have an annual income equal to the federal SSI benefit amount ($623 for 2007) for persons living independently in the community multiplied by twelve or an annual income of at least $7,479.50.[75] For households with a member who has a disability, welfare and other sources of public assistance may be included as part of the income examination to determine eligibility. They are not required to meet employment eligibility criteria. The requirement that households be first time homebuyers can be waived on a case-by-case basis by the PHA. All must attend home ownership education and training prior to purchasing a home. If the borrower defaults on the mortgage, PHAs may allow the household to convert the home ownership assistance back to rental assistance.

1. Section 8 Home ownership

The Section 8 Home ownership Program allows first-time home buyers to use their subsidy, or Housing Choice Voucher, to pay their mortgage and costs associated with owning a home, such as mortgage insurance, maintenance, homeowners insurance, utilities, etc., instead of paying rent to a private landlord or living in government housing. Mortgage lenders consider the Section 8 subsidy portion to be part of the participant's income, and therefore, the participant is often able to qualify for a loan or in some cases a larger loan. Participants who have a disability are able to maintain their Housing Choice Vouchers for 30 years; the entire life of the traditional 30-year, fixed rate mortgage.

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[73] U.S. Department of Housing and Urban Development. Office of Housing Choice Vouchers: http://www.hud.gov/offices/pih/programs/hcv/.

[74] The need for housing assistance is very great. A HUD analysis of Census data shows that in 1999 (the last year for which this analysis is available) nearly five million low-income households who did not receive housing assistance had "worst case housing needs," which means they either paid more than half of their income for rent and utilities or lived in severely substandard rental housing. Most of the low-income families with "worst case" housing needs are *working* families. In addition, since housing costs have increased faster than incomes since 1999, the housing affordability problem is likely to be even more severe today: http://www.tacinc.org.

[75] A PHA may establish a minimum income requirement higher than the federal standard, but if a disabled household meets HUD's national minimum income standard and can demonstrate that it has been pre-approved or pre-qualified for homebuyer financing, then the PHA must consider this family eligible for Section 8 home ownership assistance: http://www.hud.gov.

In order to be able to purchase a home through this program, the prospective homeowner needs to contribute 1 percent of the purchase price of the home as part of a 3 percent down payment (the other 2 percent can come from outside sources, gifts or other government programs such as IDAs and local home purchase programs). Where home values are low, this is not a problem for a person participating in Social Security disability programs because one percent of the purchase price does not exceed the total asset allowance of $2,000 ($3,000 for a couple). But, in areas such as New York City, where the median home value is $500,000,[76] a one percent down payment of $5,000 exceeds the asset allowance. In addition, the participant must also be able to afford their portion of the monthly housing expenses, which, according to HUD, are generally between 30 and 40 percent of total income. For many people with disabilities, this is a fiscal impossibility due to a combination of high housing values, lack of employment opportunities, or an inability to maintain steady employment due to health or disability and the generally long waiting lists for Section 8 Housing Choice Vouchers.

Case Study: Opening Doors and More Doors to Open

In 1984, Maryland received approval to waive certain Medicaid statutory requirements under Section 1915(c) of the Social Security Act. The Maryland Department of Health and Mental Health Hygiene's Developmental Disabilities Administration (DDA) began offering HCBS as an alternative to institutionalization for persons with disabilities, and many new independent living options were encouraged. In 1996, the Maryland Home of Your Own Coalition (HOYO) was formed to develop affordable, accessible home ownership opportunities for people with disabilities. HOYO was one of the first groups in the country to focus on increasing home ownership opportunities by promoting Fannie Mae's HomeChoice mortgage[77] product. HOYO also was instrumental in developing the Maryland Department of Housing and Community Development's (DHCD) Home ownership for Individuals with Disabilities Program, a mortgage product offsetting down payment and closing costs in partnership with private lenders.

The Arc of Anne Arundel County[78] was actively involved in the HOYO Coalition, and in 1999 initiated a pilot project called Opening Doors – A Home of Your Own Project. This project received funding from the Joseph P. Kennedy Jr. Foundation to support coalition activities in Anne Arundel and Montgomery county, and Baltimore City, with additional support from the Fannie Mae Foundation for Baltimore City. The Arc provided counseling and education to individuals with disabilities who were interested in living independently. The Arc worked closely with Homes for America[79] in finding potential residents with disabilities interested in living at Homes at the Glen, a new multi-family housing development making use of a lease-to-own model of home ownership. The Arc

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[76] U.S. Census Bureau: www.factfinder.gov.

[77] Fannie Mae: http://www.fanniemae.com/.

[78] In 2007, The Arc of Anne Arundel County formally changed its name to The Arc of the Central Chesapeake Region. More information about The Arc is available at: http://www.thearcccr.org/.

[79] Homes for America, Inc. is a 501(c)(3) nonprofit housing corporation which specializes in developing and preserving housing for low and moderate income households and special needs populations. Homes for America carries out its mission in a variety of ways, including as a developer of affordable housing, providing development services to nonprofit organizations, and providing technical assistance to government agencies to develop and implement housing programs. More information is available at: http://www.homesforamerica.org/.

of Anne Arundel County assisted Homes for America in identifying four residents who were interested in this lease-to-own model, and two residents interested in renting other apartments in the community. The Arc also assisted individuals in securing both Section 8 vouchers through the Anne Arundel County Housing Commission and community supported living arrangement supports through the DDA's Medicaid waiver program.

The *Opening Doors* program produced materials, including a guide to Developing Housing Coalitions at the Local and State Level and a booklet for consumers, parents and advocates on How to Be a Responsible Tenant. The *Opening Doors* project also developed the "designated representative" role, which allows an adult with a disability to identify an individual to speak and act on his or her behalf in housing-related transactions. In response to the needs of adults with developmental disabilities who preferred to rent, The Arc of Anne Arundel County was also successful in persuading the HOYO Coalition to endorse and include self-determined rental as an additional housing option in the state's plan.

The Arc of Anne Arundel County continued its work in developing supportive affordable home ownership and rental options through a successor project called *More Doors to Open*, receiving initial funding from the Developmental Disabilities Council and Developmental Disabilities Administration (DDA) in 2003, with renewal funding received in 2005. In addition to ongoing counseling and education for individuals with developmental disabilities interested in self-determined housing, the organization is developing a financial literacy program, implementing a replication plan to assist other communities in developing housing options, increasing participation of communities of color, and carrying out a divestiture plan that transfers or sells its owned housing stock while maintaining a financially stable balance sheet.

Role of the Medicaid Program and Other Agencies that Provide Long-Term Supports

HCBS waivers are available for individuals who are certified for the waiver's specific institutional level of care. These waivers serve as an alternative to institutionalization and cost Medicaid no more to fund these individuals in the community under the waiver than it would have cost Medicaid to fund them in an institution. Individuals are financially eligible based on their income and assets. The most common waiver used by individuals with disabilities served by the *More Doors to Open* program is the DDA's Community Pathways waiver. In addition, individuals with developmental disabilities can receive services through other waiver programs including: Traumatic Brain Injury, Autism Spectrum Disorder, and the Living at Home Community Choices waiver for individuals with physical disabilities under age 65.

Individuals receiving services through the Community Pathways waiver may choose to do so through a Community Supported Living Arrangement (CSLA). CSLAs provide individuals with the support necessary to enable them to live in their own homes, apartments, family homes, or rental units. CSLAs provide a full range of community-based support through a network of licensed community service providers and/or through friends and neighbors. These supports may include employment services,

personal care, services coordination, environmental modifications, assistive technology, and adaptive equipment.

In July 2005, the DDA initiated New Directions, a pilot Medicaid waiver program in which 100 eligible individuals per year may self-direct their services for 3 years. The individual develops his or her own Individual Plan with assistance from a Resource Coordinator. In addition, everyone in New Directions has an Individual Budget. With assistance from a Fiscal Management Service (FMS) and a Support Broker, the individual manages a budget, hires and supervises staff, and makes decisions about how services are provided. The FMS pays bills, takes care of tax paperwork, and provides monthly budget statements. The Support Broker is someone the person trusts to help them navigate the system, help with staff, and act as an advocate. Persons such as friends and family members may provide approved services based on the Individual Plan. The DDA has identified New Directions waiver contacts in each of its four regional offices. The Arc of Anne Arundel County and MedSource have been selected as the two statewide FMS.

Role of Housing Organizations and Agencies

Homes at the Glen is a fifty-six unit development with a unique component: each resident is sincerely committed to home ownership and makes a monthly rent payment that includes a $15 contribution to an escrow account to be used for purchase and settlement costs at the end of the fifteen year lease period. Residents also agree to maintain their homes, volunteer in the community, and participate in self-governance activities through the Homeowners Association. Homes for America provides a community center and offers “supportive property management” services funded through rents and subsidies to all residents. In addition to the mandatory home ownership preparation classes offered by Homes for America, 4-H offers computer training and Boys and Girls Clubs hold their programs onsite. Movie nights, after-school homework help, and drop-in recreational activities are offered. Off-site services such as family counseling, parenting classes, and employment services are used by many residents.

The incomes of individuals who live at Homes at the Glen are restricted to 50 percent of area median income, which ranges from $23,250 for one person to $38,500 for a family of six. Rents range from $490 to $560 for one and two bedroom units, and from $630 to $950 for townhomes, at least $400-600 below prevailing market rents for new townhomes in the area. Financing for Homes at the Glen totaled $8 million in the form of a $1.853 million first mortgage from Sun Trust structured with an interest rate swap (the lenders’ cost of funds were 3.5 percent and Homes for America is paying 8 percent, and Sun Trust credited the project with the spread to accumulate a credit toward paying off the loan).

The Maryland Department of Housing and Community Development (DHCD) provided a second mortgage of $1.3 million structured under two notes: the first note for $100,000 at 4 percent has an 18 year term and 30 year amortization. The second note for the remaining $1.2 million is structured as a soft second payable out of available surplus

cash at 4 percent. DHCD also awarded Homes at the Glen an annual allocation of $501,447 in 9 percent credits, which generated $4.038 million in equity, or slightly more than 80 cents per tax credit dollar. The tax credits were syndicated by the Enterprise Social Investment Corporation and provided by Bank of America Housing Fund.

The Maryland DHCD requires tax credit applicants to document local support and contributions, and this project was generously supported: the Anne Arundel County Housing Commission made a $700,000 home loan at 2 percent for 18 years, amortized over 30 years; and both the City of Annapolis and the County governments approved very low payments in lieu of real estate taxes ($100 per unit for 15 years to the city, $150 per unit for 15 years to the county), making rents more affordable. Overall, 75 percent of the surplus cash will provide a deferred development fee of $104,000.

Homes for America partnered with Humphrey Development as co-developer and property manager. Homes at the Glen made use of a valuable but under-used feature of the Tax Credit program: home ownership conversion. At the end of fifteen years, Homes for America will sell units at market prices to avoid depressing the local housing market. Buyers will receive thirty-year mortgages with monthly payments set at an amount they can afford at the time of purchase. Homes for America will provide a soft second mortgage between the affordable price and the purchase price, which will be forgiven after five years. Nine Homes at the Glen residents in total have Section 8 subsidies, including the six residents with disabilities identified by *More Doors to Open.* The Anne Arundel County Housing Commission was willing to make Mainstream Section 8 vouchers available for use in home ownership by individuals with disabilities living at Homes at the Glen.

Resources to Develop and Implement the Model

The Arc of Anne Arundel County created the coalition that supported this successful model with grant funding from foundations and the state Developmental Disabilities Council. Another important resource for this project, beginning in 2002, was DHCD's amendment of the Qualified Allocation Plan, which provides bonus points in the competition for federal Low-income Housing Tax Credits and agency-controlled gap financing to applicants committing to target-market units to individuals with disabilities. To receive the bonus points, applicants must commit to set aside and market up to 10 percent of the project's units to individuals with disabilities for at least thirty days commencing at 80 percent construction completion. In addition, upon vacancy the unit must again be marketed for thirty days solely to individuals with disabilities. The result is increased availability of independent housing units dispersed throughout the state offering individuals with disabilities quality housing of choice at affordable rents.

Coordination of Services and Housing

To date, twenty-one individuals have participated in *Opening Doors* or *More Doors to Open*. All of these individuals have received service coordination from an organization called Service Coordination, Inc., which is independent of The Arc of Anne Arundel County. Service Coordination, Inc. is also funded by the DDA and has responsibility for providing case management and quality assurance.

The Arc of Anne Arundel County has been the direct service provider for most individuals living at Homes at the Glen. This role will shift, however, if individuals served by The Arc decide to participate in the New Directions waiver. To avoid a conflict of interest, individuals participating in the New Directions waiver program will identify another direct service provider.

Although there has not been a formal outcome study conducted with the participants of *Opening Doors* or *More Doors to Open*, informal results are very positive. Participants are hopeful about the future and pleased to be living independently in settings of their own choosing. Individuals volunteer in the community and participate in church and neighborhood activities. Employment and health stability appear to be improved.

Replication and Success Factors

The Maryland case study provides valuable lessons that could help other states improve their long-term supports with affordable and accessible housing. Although the target population was persons with developmental disabilities, the strategies utilized to coordinate and leverage resources could be used with other Medicaid beneficiaries. There are eleven key findings from the Maryland case study that should guide planning, development, and implementation of new and improved policy and program practices:

1. Developers of multi-family affordable housing can benefit from partnerships with community-based service agencies. The service agencies can identify qualified applicants for available units and connect to or provide needed support services on an individualized basis.
2. The parties that collaborated were both state and local agencies and involved public and private sector interests.
3. Both the state housing finance agency and the local county housing agency contributed resources that are a one-time benefit for capital development and longer term for rental assistance with subsidies.
4. Points were added to the Qualified Allocation Plan by the State Housing Agency to encourage development of integrated housing with 10 percent of units dedicated to individuals with disabilities. This change in the competitive process to secure low-income housing tax credits provides new reasons for developers to reach out to service agencies that support the needs of individuals with disabilities.
5. For persons with developmental disabilities there is an interest in separating the housing and the support service provision. The separation provides more choices to the consumer and more independence to individualize supports based upon their preferences and needs.
6. There is no single financing stream or approach for community living options that will provide a universal solution to the diverse needs of Medicaid eligible individuals with disabilities. The Maryland case study documents the possibilities to expand options when multiple financial streams are coordinated on both the service and housing sides.

7. Medicaid is paying for support service costs through community-based groups working closely with the developer.
8. Four different housing finance sources were used in Maryland:
    a. Low-income Housing Tax Credits
    b. Section 8 rental subsidies
    c. Community Development Block Grant
    d. Private Lenders
9. The highlighted multifamily development also offered a unique feature that allows individuals to set aside $15 a month in an escrow account to be used for purchase and settlement costs at the end of the 15-year lease period. The rent to purchase option could be replicated in other states.
10. Other states could also replicate the collaboration among state agencies: Medicaid, Housing Finance, and Developmental Disabilities Administration to target use of low-income housing tax credits to add affordable independent community living choices coupled with rental assistance.
11. The Maryland state representatives also noted their need for development of a statewide housing registry that connects supply with demand to individuals with disabilities searching for accessible and affordable units. Developers are having difficulty finding the applicant with a disability in search of an accessible unit. A registry could help connect individuals with disabilities with the developer.

Participants in *More Doors to Open* believe that their success is due to collaborative planning among all the entities: the Arc, Homes for America, the Anne Arundel County Housing Commission, and DDA. Trudy McFall of Homes for America noted how valuable it was to have the Arc identifying, counseling, and pre-qualifying individuals with disabilities interested in the new housing project. Kate Rollason of The Arc spoke very positively about the Anne Arundel County Housing Commission's use of HUD Community Development Block Grant[80] funds for bridge funding until Section 8 subsidies become available for individuals with disabilities with Social Security income.

Every member of the Coalition recognized the significance of the *More Doors to Open* project funding made available by the Maryland Developmental Disabilities Council and the Maryland DDA. In addition, the funding for services for individuals living in Homes at the Glen was provided through the Community Pathways waiver (Community Supported Living Arrangement CSLA).

The availability of Section 8 vouchers is essential to every effort aimed at helping low-income people with disabilities move into self-determined housing. The Maryland Governor's Commission on Housing Policy recommended creating a Bridge Subsidy Demonstration Project (similar to the Anne Arundel County's Housing Commission's project), which will provide up to three years of rental assistance to individuals with disabilities at SSI and SSDI level of income. This rental assistance will "bridge the gap" until Section 8 vouchers or other long-term rental assistance funds are available.

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[80] Community Development Block Grant Program: http://www.hud.gov/offices/cpd/communitydevelopment/programs/.

Funding has been made available by reallocating a portion of existing resources from the Maryland DHCD and other state agencies.

2. Family Self-Sufficiency Program

When people who are receiving SSI earn income, their SSI benefits along with their Housing Choice Voucher can be reduced until they become, according to the SSI formula, "self-sufficient." For many the fear of losing this benefit, as well as health insurance/Medicaid, creates a powerful disincentive to working. However, through the Family Self-Sufficiency Program (FSS)[81] additional income earned through working can be set-aside and not counted as income until an eligible employment goal is met.

Many articles written about the FSS program refer to it as HUD's "Best Kept Secret." The FSS program is an employment and savings program for low-income families that receive Section 8 vouchers. It consists of both case management services that help participants pursue employment and other goals and of escrow accounts into which the PHA deposits the increased rental charges that a family pays as its earnings rise. Families that complete the program may withdraw funds from these accounts for any purpose after five years. The cost of the program to the local PHA is minimal because HUD supports the funding of the escrow accounts.

For participants, according to the Center on Budget, Policy and Priorities,[82] the primary benefit of FSS participation appears to be asset accumulation. As of November 2000, about 48 percent of FSS participants who had been enrolled for 12 months or more had positive escrow balances. These families had an average escrow balance of about $2,400 and were adding to their accounts at the average rate of about $300 per month. Forty-five percent of the families that were considered to have successfully completed the FSS program between the fall of 1999 and November 2000 received escrow funds averaging nearly $5,000 per family.

Jeff Lubell, Director of the FSS Partnership Program, reports that the FSS program appears to increase family earnings. As an example, he cites an evaluation of the Portland, Oregon FSS program in mid-2000 and found that the average annual earnings of its graduates increased from $4,000 at the beginning of the program to $17,500 at graduation. Forty percent of the participants in this program used their escrow savings to purchase a home (the average overall is 36 percent).

There are two unique components of the FSS program that support the opportunity to acquire and accumulate appreciating assets for low-income families: the escrow accounts and the intensive oversight of employment goals over a five-year period. Any increases in rent due to increased earned income is set aside into an interest bearing escrow account at a bank or credit union that is set up by the PHA for this purpose. It is of no cost to the PHA because the amount of the voucher paid to the PHA by HUD

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[81] U.S. Department of Housing and Urban Development. Family Self-Sufficiency Program.: http://www.hud.gov/offices/pih/programs/hcv/fss.cfm.

[82] Sard, B. (2001). *The Family Self-Sufficiency Program: HUD's Best Kept Secret for Promoting Employment and Asset Growth*. Center on Budget and Policy Priorities: http://www.cbpp.org/4-12-01hous.htm.

remains the same and the additional portion is funneled into the escrow account.[83] During the course of the five-year employment plan withdrawals may be made on a case-by-case basis when needed to help meet the goals of a FSS participant's career development plan.

When the FSS program has been successfully completed, the funds in the escrow account and any interest earned are given to the participant for them to spend on whatever they wish. While there is no restriction on these funds, it is reported that many families use the funds for home ownership, transportation, education, and to capitalize a small business start-up.

Through the FSS program, case management services are provided to assist the participant to develop individual employment goals. Participants may take up to five years to complete their goals, but most complete them within three years. The kinds of services provided by case managers depend on the local program. Some programs partner with local welfare agencies to provide resume and employment search services, general education degree programs, financial literacy education, childcare, transportation and English as a Second Language. The FSS Partnership provides assistance to PHAs that are interested in starting a FSS program and helps facilitate local partnerships. The reason why there are not more people enrolled in FSS programs is due to PHAs' lack of staff to manage the program and to provide the intensive case management services necessary to provide a quality experience for families. For people with disabilities, finding employment is a major obstacle to participating in the FSS program, but there have been success stories:

[83] This is generally how the program works and it becomes more complicated if a voucher recipient is participating in the public housing earned income disregard program.

Samantha's Story
Overcoming Multiple Barriers to Work*

"Samantha," a 37-year-old single woman, entered the FSS program in April 1996. She had been diagnosed with Chronic Fatigue Syndrome and Multiple Chemical Sensitivity Disorder and was receiving disability benefits. Due to her medical symptoms, she believed she had limited employment options. She had a Bachelor's degree in communications but had only been employed for two of the previous 10 years. When Samantha began participating in FSS she was not working, had difficulty leaving her house, and had very few social supports. She was always clear about wanting to be self-sufficient. Working as a consultant from her home on a computer was a tentative employment goal.

Initially, Samantha worked eagerly with the case manager to complete the assessment and contract of participation. Shortly thereafter, her concern that her medical limitations would prevent her from keeping her FSS commitments led her to cancel scheduled meetings. The case manager met with Samantha in her apartment and developed a plan that would enable her to gradually increase her participation as well as her supports in the community. When the plan for self-sufficiency was broken down to achievable, incremental steps, Samantha was able to begin to experience several small successes that eventually overcame her immobilizing fear.

With the help of a local concerned citizen, Samantha renewed her long-lapsed driver's license and obtained a reliable vehicle that had been donated to the FSS program. Soon Samantha signed on with a temporary agency and began working 10-15 hours a week. Maintaining a job helped her build confidence. She soon reached the goal outlined in her FSS contract of working 20-25 hours a week. Because of her demonstrated skills and abilities at her temporary position, Samantha was offered a full-time permanent position at an annual salary of $25,000. Within a year, her increased self-confidence led her to request and receive two raises, bringing her salary to $33,000. She has been off of disability benefits for two years, and her health needs are covered by her employer's health plan. Samantha has accumulated nearly $10,000 in her escrow account and plans to purchase a house. Samantha's personal successes have also made her supportive to others and she has been asked to be a mentor to new FSS participants. *

Source: Laurie S. Goldman, Interview of Joyce Neslusan
FSS Coordinator at the South Middlesex Opportunity Council
Framingham, MA, August, 2000.

Comparisons have been made between IDA and FSS programs. One major benefit to the FSS program is the use of the savings realized at the end of the program. In the FSS program, for instance, there is no restriction on what can be purchased with the funds. However, through the IDA program matched savings can only be used for post-secondary education, home ownership, and start-up costs for a small business. IDAs are generally limited to three years and require that the saver have a bank account--FSS programs can take up to five years and do not require the participant to have a bank account, since the housing authority is responsible for administering the funds.

IDA programs, FSS, and Section 8 Housing Choice Vouchers can all work together and when they do, can be a very powerful tool towards helping low-income households and households with a disability acquire an appreciating asset--a new home. A plan for a better economic future must include opportunities for home ownership. The FSS program and Housing Choice Vouchers create unique opportunities to build assets and

help purchase a home. To learn more about which PHAs in your state have FSS programs and allow Housing Choice Vouchers to be used to purchase a first home, please visit the HUD website at www.HUD.gov.

3. A New Approach

Home ownership is not a feasible option for everyone and owning and maintaining a home is not always affordable for people living on a fixed income, but that does not mean that renters cannot build "equity" and enjoy the benefits of home ownership. The Cornerstone Community Fund Renter's Equity Program in Cincinnati, Ohio is a unique program that, while not developed for people with disabilities in mind, has become a welcome alternative and middle ground between renting and owning.

Case Study: Cornerstone Community Fund

Cornerstone Community Fund
Cornerstone Loan Fund
114 Pendleton Street Suite 2NW
Cincinnati, Ohio 45210
513.369.0114 / www.cornerstoneloanfund.org
Margery Spinney, President

Over-The-Rhine (OTR) contains the largest collection of 19th century Italianate architecture still standing in the United States. The entire 360-acre district of Over-the-Rhine is recognized on the National Historic Register. About 7000 people currently reside in Over-the-Rhine. At one time over 50,000 people lived here.

OTR has over 500 empty buildings, 2500 empty units, and 700 vacant lots available for repopulation and renovation. Many of these require serious renovation. Residential development is a vital business in Over-the-Rhine at this time, and one that the Over-the-Rhine Chamber supports. Six districts of character and personality make up the 360 acres of Over-the-Rhine, a neighborhood rich in its diversity and history.

Over the Rhine is a predominantly low-income neighborhood that is adjacent to Cincinnati Ohio's central business district and listed on the National Register of Historic Places. It has long been a home for poor migrants from Appalachia and the rural south looking for a better way of life, and it has all the characteristics of a poverty-stricken community. High crime rates, high unemployment, and absentee landlords have had a stranglehold on Over the Rhine for years. Its citizens cannot afford to own homes without assistance, but many are hardworking people who desire to better their lives and better their community. Median income for the area is $11,787, and 95 percent of its households earn less than $13,000 per year. Labor force participation is low--only 52 percent of those over 16 years of age are working or are looking for work. Creating jobs is the overarching challenge of city leaders, economic developers, and financial institutions in the area, yet Over the Rhine boasts many architectural "gems" and is close to all of the cultural activities taking place in downtown Cincinnati. [84]

[84] Over the Rhine Chamber of Commerce: www.otrchamber.com.

For many people home ownership is a viable and workable proposition. However, due to lifestyle, educational, and career choices, as well as differing abilities, some people are not attracted to home ownership. For those whose incomes may never be high enough to qualify for a mortgage, a program that allows one to build “equity” where one lives might be a very positive and workable alternative.

It is estimated that over 15 housing or housing advocacy programs serve this community of approximately 7,600 people. Neighborhood revitilization and home ownership programs have been on the City Plan and funded since 1985, yet 3,000 buildings are still vacant. Less than three percent of all housing units are owner occupied because they are unaffordable to local residents.

The Cornerstone Loan Fund has been working in Over the Rhine for twenty years and currently has about $800,000 in loan funds for leveraging rental housing. The challenge was to come up with a program that would provide an equity opportunity for low-income households that would also be self-sustaining over a period of time. Margery Spinney, President of Cornerstone, has worked most of her career in Over the Rhine, and when she saw that renters were once again passed over in the growing housing markets she wanted to develop a program that would provide the benefits of home ownership--asset accumulation, wealth building, a sense of ownership, and responsibility. Ms Spinney also saw that IDAs were not a workable solution to the circumstances experienced by those in her community. Instead, Renters’ Equity was developed because it recognizes that home ownership, entrepreneurship, and higher education are not the only paths to increasing wealth.

Renter’s Equity is “not owning or renting, but membership in an organization with a leasing component.” Cornerstone organizes and trains groups of households to cooperatively take on the care and management of their housing. Members earn "equity credits" each month that rent is paid on time; they participate in the resident organization, and perform routine maintenance responsibilities. The credits can be converted to a cash payment through Cornerstone after five years. Residents develop ownership skills, share a supportive community, and earn financial resources that can be used to purchase other assets, such as a home, an education, a business, or an investment in a retirement fund. Property-owners benefit from reduced operating costs and turnover, plus higher long-term property value. The community becomes more stable as residents take greater interest in their housing and neighborhood.[85]

Ms. Spinney developed the idea of Renter’s Equity as a way for non-homeowners to participate in equity building and other benefits homeowners enjoy, as well as to participate in the responsibilities carried by homeowners. Prospective tenants sign a contract agreeing to pay rent on time, attend resident’s meetings and financial literacy education classes, and to participate in whatever way they can in the management of the property, from keeping the lobby clean to reminding tenants of upcoming meetings. Equity is built by depositing that portion of what would normally pay for property maintenance into an investment account. Once they become eligible, renters building

[85] Cornerstone Loan Fund: http://www.cornerstoneloanfund.org.

equity are allowed to borrow against their "equity" just like a homeowner can tap their equity through a home equity loan or line of credit for life's financial emergencies. After ten years, all equity and interest earned can be returned to the renter and used to start a business, purchase a home, or invest in the market.

Renters receive quarterly statements on their investment and are taught about financial education and investing. Renter's Equity properties do not experience the "churn" found in many low-income neighborhoods, and renters are encouraged to take ownership and to maintain the property they are renting. If property maintenance expenses are low, additional funds can be reinvested in property improvements.

St. Anthony's was launched as the first Renter's Equity property five years ago. There are 22 families living at St. Anthony's and they average $17,000 in salary a year. Not all residents are low-income; some live there because of the "community" created by the structure of the program, others because it is safe, and still others because they do not want to leave their neighborhood. Renter's Equity properties could be developed to be truly mixed income communities, which would make them attractive to housing organizations.

"I always tell everybody I'm living in heaven," says resident John Clark. He loves St. Anthony's Village's ceiling fans and air conditioning, its laundry facilities and especially its locking gates. Security is a big issue for Clark, 60, who is retired after a career with the city of Cincinnati's Public Services Department. Clark says he feels safer here, largely because the neighbors behave themselves and he knows who's coming in and out. "Although things go on around here, they don't bother inside this gate," he says.

Residents not only take good care of the unit they rent, but also the common areas such as hallways, laundry areas, and the outdoor grounds. In five years, the St. Anthony's property has only re-rented four apartments, and currently there is a waiting list for residency. A second building has recently opened and it too has a wait list.

Renters are required to attend financial education classes and receive assistance creating a personal balance sheet and an equity statement. Renters receive a quarterly statement on the performance of their equity that mirrors the experience of many investors. The quarterly statement contains an amortized schedule of their rent and equity holdings. Just as homeowners are able to borrow against their equity, so are these renters. They are made aware of the repayment terms and consequences of borrowing against their equity, similar to a homeowner. The Renter's Equity program addresses wealth creation as funds increase to at least $10,000 at the end of ten years. For many residents, it will be the first investment they have ever held. Cornerstone will be providing financial planning services to their residents, and the hope is to start investment clubs in order to get equity earners into the habit of saving and investing at any amount they can.

Ms. Spinney does not ask residents about their disability status, but does know that many of the residents are on fixed incomes such as Social Security disability. She reports that a majority of tenants have developmental and physical disabilities. Ms.

Spinney also reports that assistance providing accessibility accommodations would make these properties more attractive to people with disabilities. The Renter's Equity program could be replicated in other cities, and in addition to low-income individuals, could consider the needs of people with disabilities. Asset limits, however, as it pertains to the equity distribution at the end of 10 years would need to be evaluated.

E. Work Incentives

1. Social Security Work Incentives

Like many of the other programs highlighted in this report, work incentives are underutilized. Over 10 million individuals with significant disabilities are on the Social Security disability rolls on a monthly basis, i.e., receive Social Security disability benefits. To be eligible to receive SSI[86] and/or SSDI,[87] an individual has to have a significant disability that prevents them from engaging in substantial gainful activity (SGA).[88]

Failure to manage these benefits can lead to a loss of cash benefits and access to health care through Medicaid. For some individuals there is such fear of loss of public benefits that they choose to limit income production and stay poor. However, SSA provides more than just cash benefits; it also offers a variety of strategies and supports to encourage work, income production, and to advance self-sufficiency. There are over a dozen work incentives,[89] which can be considered as part of a strategy to advance economic self-sufficiency for individuals with significant disabilities.

Work incentives represent special rules that make it possible for people with disabilities receiving SSI and/or SSDI to work and still receive monthly payments and Medicare or Medicaid. Eligibility for a work incentive may be dependent on a beneficiary's disability status. Certain work incentives, such as Plan to Achieve Self-Support (PASS), which will be highlighted in more detail, and Property Essential for Self-Support (PESS), are available only to SSI recipients. The Trial Work Period and Extended Period of Eligibility is available only to SSDI beneficiaries. The Impairment Related Work

[86] The Social Security Administration administers the Supplemental Security Income (SSI) program, which is a Federal income supplement program funded by general tax revenues. It is designed to help aged, blind, and disabled people who have little or no income, and it provides cash to meet basic needs for food, clothing, and shelter. More information is available at: http://www.ssa.gov/ssi/.

[87] Social Security Disability Insurance pays benefits to individuals and certain members of their family who are "insured," i.e., for individuals who worked long enough and paid Social Security taxes: http://www.ssa.gov/dibplan/index.htm.

[88] To be eligible for disability benefits, a person must be unable to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount (net of impairment-related work expenses) is ordinarily considered to be engaging in SGA. The amount of monthly earnings considered as SGA depends on the nature of a person's disability. The Social Security Act specifies a higher SGA amount for statutorily blind individuals; Federal regulations specify a lower SGA amount for non-blind individuals. Both SGA amounts increase with increases in the national average wage index. More information can be found at: http://www.ssa.gov/OACT/COLA/sga.html.

[89] Social Security Administration, Work Incentives. Special rules make it possible for people with disabilities receiving Social Security or Supplemental Security Income (SSI) to work and still receive monthly payments and Medicare or Medicaid. Social Security calls these rules "work incentives." Available at: http://www.socialsecurity.gov/disabilityresearch/wi/generalinfo.htm#work.

Expense, an option to reduce gross income due to out of pocket disability-related expenses that allow an individual to work, is available to support both SSI and SSDI recipients. The Section 1619(a) and 1619(b) work incentives are only available to SSI recipients. Section 1619(a) enables a person who continues to be disabled to increase earnings beyond the SGA level, allowing continued eligibility for Medicaid even though there is a reduced SSI monthly cash payment. Section 1619(b) allows a beneficiary to earn enough income to no longer receive a SSI monthly cash payment but still maintain eligibility for SSI and Medicaid.

There are three primary reasons why work incentives are underutilized. First, there is a limited awareness of the opportunities that are possible with the use of one or more work incentives. Second, the complexity of the rules makes the use of work incentives difficult for beneficiaries. Third, there remains significant fear by beneficiaries of the possible loss of eligibility, which in turn eliminates automatic eligibility for Medicaid.

It is not necessary for Medicaid-funded support coordinators, brokers or peer mentors, or individuals with disabilities and their families to become experts on the use of work incentives. It is important, however, that awareness of work incentive options is increased and use of work incentives is considered as part of a comprehensive strategy to advance economic security and self-sufficiency. In October 2006, the Social Security Administration established the Work Incentives Planning and Assistance (WIPA) Program to better enable SSA's beneficiaries with disabilities to make informed decisions about work and improved economic status. WIPA grantees have been funded nationwide to directly assist the target population with disabilities to plan for a better economic future, increase the use of work incentives, and produce and preserve income. To identify WIPA grantees in your state, please visit: http://www.socialsecurity.gov/work/ServiceProviders/WIPADirectory.html.

Work Incentive: Plan to Achieve Self-Support

Because this particular work incentive can help individuals with disabilities build their assets and income through work, it will be described in more detail. PASS was introduced as part of the original 1972 SSI legislation. It is a work incentive established to help SSI beneficiaries who are blind or disabled to become self-supporting. A PASS plan allows a beneficiary to exclude income and resources from countable assets that are set aside to reach a specific occupational goal, such as education or starting a business. Under a PASS, funds can be set aside for such things as education, vocational training, and the purchase of a vehicle or equipment related to the work or career goal. The income and resources set aside are excluded under the SSI income and resources tests.

PASS plans were slow to catch on and in 1987 there were fewer than 800 cases nationally. However, after disability advocates, SSA, and vocational rehabilitation agencies made efforts to provide more information on PASS programs, the usage increased to over 10,000 plans. During the 1990s, changes occurred to ensure that PASS plans were being used to pursue achievable work or career goals.

According to the SSA Program Operations Manual System on PASS, there are several factors that make it an "effective tool for someone wanting to work under the SSI program." It reflects individual choice by allowing individuals to choose their own work goal. It is also self-financed since individuals use their own funds, which is often SSDI benefits, to pursue the plan. "The receipt of, or an increase in SSI benefits up to the amount of the Federal Benefit Rate, and any applicable state supplement, replaces some or all of the funds that the individual uses for the PASS." Finally, PASS is basically self-directed because individuals are the ones that decide the goods and services needed to reach the work goal.[90] The PASS program started as a loosely structured program guided by a Congress that "desire[d] to provide every opportunity and encouragement to the blind and disabled to return to gainful employment" and intended that the PASS provision "be liberally construed if necessary to accomplish these objectives."[91]

The PASS Cadre system (i.e., SSA employees who are experts in processing PASS applications) is currently in transition, but as of March 2007 there were 10 regional PASS Cadres. Six of the PASS Cadres have only one Cadre office location per service delivery area and the other four have more than one office. With the exception of California, it does not appear that having a greater presence in field offices increases the utilization of PASS plans by SSA recipients. For example, the Texas PASS Cadre has offices in six locations but has next to the least number of active PASS cases.

A PASS plan must be approved by the SSA PASS specialist (through PASS Cadres) and be reviewed periodically to assure compliance. PASS specialists are looking for plans that include a job title or the type of small business, a reasonable ability to attain the work goal (might use a vocational assessment from the state vocational rehabilitation system), the applicants age, work or volunteer experience, educational levels attained and any additional training, current earnings and an estimate of earnings once the employment goal has been reached. A PASS plan will be approved, not approved, or sent back for more information or revision. PASS specialists maintain all data on how many PASS applications are submitted and how many are approved. It is not the responsibility of a local SSA field office.

In the mid-1990s, SSA adopted a 14-page PASS plan application in response to a concern expressed by Congress that the plans might be used for things other than employment goals. This change to "protect" the plans had a reverse effect and reduced the amount of PASS plans from a high of over 10,000 to current levels. The number of PASS plans in the U.S. has remained stable over the last eight years, resulting in an increase of between 1,000 and 1,700 PASS plans per year.

Because of what is seen as the complexity of the PASS plan and the timing involved if the plan is not approved the first time it is submitted, vocational rehabilitation agencies are allowed to purchase PASS writing services from a professional PASS writer. It is

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[90] POMS Section SI 00870.001 Plans to Achieve Self-Support: https://s044a90.ssa.gov/apps10/poms.nsf/lnx/0500870001.
[91] Ibid.

estimated that there are around 40 PASS plan writers in the U.S. Several PASS writers interviewed for this report have been able to successfully use the PASS to establish self-employment opportunities. Well-written PASS applications have been known to be approved in less than 24 hours. One such PASS application will be featured in the case study.

> PASS can allow some people to double their available money. They can work, save money, have assets, and move toward more meaningful work or starting a business.
>
> *Barbara Knowlen*
> *Professional PASS Writer and Advocate*

There are various scenarios for potential PASS plan participants and how they interact with SSI (cash benefits and Medicaid). PASS plans are intended to help a person reach an occupational objective and to be a "flexible tool to allow individuals to either raise their SSI amount or become eligible for SSI." In certain circumstances, PASS plans are used to provide a mechanism for a person to become eligible for a cash payment of SSI and/or Medicaid by setting aside income or assets that preclude them from the SSI program.

Professional PASS writers concur with Social Security PASS specialists on the distribution of the PASS expenditures. They were, however, willing to state that many PASS plans that they submit are not approved and are denied for "vague" reasons. They believe that due to under-funding and changes occurring in the PASS Cadre system, applications are not being given the scrutiny they once were, and they expressed frustration at not being able to get more plans approved.

From the SSA website we can see why one professional PASS writer described the PASS program[92] from the participant's point of view as "making sausage." What follows is a description of how SSI payments are determined under a PASS:

> *"The SSI amount is increased (or individuals are made eligible for SSI when they would not be under the regular SSI rules) by excluding certain income or assets (also called resources), which would have to be counted under the regular SSI rules. Income and resources, which normally would reduce SSI or prevent eligibility, can be excluded if they are listed in the PASS and used towards an occupational objective. The income and/or resources set aside in a PASS are not counted in determining eligibility for SSI or in calculating the amount of the SSI benefit that individuals will receive. In determining SSI eligibility, individuals must meet an income and resources test. If their income and/or resources are too high they will not be eligible for SSI. However, by excluding this income and/or resources in a PASS, individuals could meet the income and resources test, thus potentially qualifying for SSI. Likewise, individuals already receiving SSI can maintain or increase their SSI cash benefit by excluding income/resources in a Pass to be used in reaching their*

[92] SSA Plan to Achieve Self-Support: http://www.socialsecurity.gov/disabilityresearch/wi/pass.htm.

employment goal. Individuals who have both earned and unearned income can set aside either or both of these incomes to establish or increase SSI cash benefits."

PASS plans can be used to purchase a wide array of goods and services that are determined necessary to support the attainment of a vocational goal. Some examples of PASS expenditures include: child care; tuition/books; attendant care; equipment or tools specific to the condition or general use; transportation expenses; building or vehicle modifications to accommodate disability; licenses; and, equipment, supplies, and operating capital required to establish a business. Anecdotally, we know that PASS plans are most often written for transportation needs. PASS applicants, if they are to be successful, are encouraged to apply for the least costly transportation alternative but all modes of transportation are considered--from the purchase of a new vehicle accommodated for a person's disability to bus passes for local public transportation. The next most popular PASS expenditure is related to educational expenses followed by start-up/capitalization costs for establishing a micro-enterprise.

Counselors and others offering services to SSI recipients working on a PASS plan report that personal debt is often a barrier to a successful PASS and eventually a successful employment outcome. Due to income and asset limits, difficulty finding affordable housing, increases in cash benefits that do not equal or exceed inflation, and living within one's means is difficult for people with disabilities. In recent years, a loosening of credit underwriting criteria and the proliferation of alternative financial services, such as payday lenders, car title lenders, and Internet financial products, have made getting into debt easier and more expensive. According to the Center for Responsible Lending, payday loans charge up to 1100 percent interest on small loan amounts. [93]

A PASS savings program for the purchase of a vehicle, education expenses, transportation expenses, or other goods and services is fairly straightforward and uncomplicated. A PASS savings program for a business start-up is generally more complex and often requires additional financing. Self-employment is a popular employment goal for many using the PASS plan. Personal debt of any size is very often a barrier to operating a successful business and is often the reason why so many small businesses are never given the opportunity to start.[94]

SSA has developed "business plan" guidelines for PASS applicants (a business plan is a requirement for PASS plans) and business specialists with experience with the PASS business plan agree that it is a very valuable tool. If done thoughtfully, it is as good as or better than any number of business plan templates available for small business start-ups. Most PASS Cadre specialists and professional PASS writers felt that small

[93] Payday lenders will argue that "100 percent" of their customers are working and borrow against a "paycheck." However, provisions regarding access to financial services requires that payday lenders not discriminate against borrowers whose income derives from government entitlement benefits such as TANF or SSI/SSDI or Social Security: http://www.centerforresponsiblelending.org.
[94] U.S. Small Business Administration: http://www.sba.gov.

business was an option that more SSI beneficiaries should seek; however, the fourteen page application and/or the business plan work as a detriment to obtaining a PASS.

The PASS plan is one of the better "asset-building" tools Social Security offers that enables a person to achieve self-sufficiency at a much higher rate, according to those in the field, professional PASS plan writers, SSA employees, vocational rehabilitation specialists, and clients themselves. Because of asset and income limitations, none felt that the current program would help someone build assets. As Clark Pickett of SSA said, "Asset-building is not allowed under public dollars." PASS plans are meant to provide the opportunity for the individual to go to work; they are not meant to build assets. If we look at the effect of income and asset limits on a person with disabilities working toward self-sufficiency using a PASS plan, it becomes clear that in an effort to maintain current levels of health care coverage, persons with disabilities are destined to live at their means or beyond their means.

Those that were interviewed for this report that work with PASS were overwhelmingly supportive of any program that would assist a person on SSI (or SSDI) to obtain and keep employment. Those that reviewed PASS plans found that PASS programs were not well known or understood by people with disabilities, or very often the local programs and agencies that exist to assist them.

The local SSA field offices do not collect information that would be helpful in determining the extent of success PASS participants have in this program. However, based on information from the 2006 SSA Annual Statistical Supplement, in December 2005, at least 37 percent of SSI recipients (1.5 million) between 18-64 years of age had wages or SSDI available to set aside in a PASS.[95] The significant use of PASS in the early 1990s clearly demonstrated a high interest and need for PASS. It would be helpful to know if and how much income and assets are increased by having a PASS or how many PASS applications are accepted.

Case Study: Idaho PASS Loan Program

In a Boise, Idaho coffee shop approximately two years ago sat a group of people from all walks of life discussing how the financial lives of people with disabilities could be improved. The discussion was close to the heart and livelihood of Steve Rodoletz, one of approximately 40 professional PASS plan writers. Mr. Rodoletz utilized his own PASS to create the Employment Development Institute where the mission is, succinctly stated, "To help persons with disabilities use the Work Incentives."

The group comprised of: Mr. Rodoletz, a retired State Supreme Court Judge; a former assistant to the Governor of Idaho; and, a retired professor of Entrepreneurship, were discussing the lack of access to capital, particularly for businesses started by people with disabilities. They were interrupted by a customer that came in to buy a cup of coffee, and who was curious about their conversation and asked to join them. That customer happened to be David Player, Senior Vice President of Commercial Lending at Mountain West Bank, a state chartered bank serving Idaho and surrounding states.

[95] SSA Annual Statistical Supplement, 2006--Other income Sources of SSI Recipients (7.D) for December 2005.

Mr. Player, driven by a desire for Mountain West Bank to be a good community partner and the opportunity for the bank to find new customers, returned to work with Mr. Rodoletz and others to create the PASS Loan Program.

The PASS Loan Program uses the savings as the owner equity portion of a loan for goods needed to assist the owner of the PASS become more self-sufficient through work. One problem with the current PASS process is that there is no institutionalized directive to discuss how to save by budgeting, reducing debt, or by any other means. The PASS program, or system, as it currently stands does not require that someone saving in a PASS receives financial education: helping them to understand the process of saving, the product options available (e.g., regular savings account versus Certificate of Deposit, or bank versus credit union), or understanding how to address personal debt issues such as a debt management plan, how to select a credit counselor, debt settlement, equity loans, etc.

Early in the process, the team contacted SSA to ask if there was any policy, legal, or ethical barriers to lending against the PASS for an asset that was identified in the PASS. SSA gave enthusiastic support for the PASS Loan Program, although they stressed that any product could not be used to the detriment, financial or otherwise, of a person seeking rehabilitation. A program should aim to prevent the consumer from going into debt. Norris Krueger, Associate Professor of Entrepreneurial Studies at Boise State University said, "disadvantaged populations have proven to engage and are successful at employment but the population in general requires a customized work environment."

> Idaho Vocational Rehabilitation loves this program--comparable benefits, less expenditures, more cases that might be closed at lower expense of immediate Idaho dollars. At the highest levels, up to the Governor's office, nobody is against NOT spending Idaho money while still serving the vocational needs of Idahoans with this alternative funding stream.
> Steve Rodoletz

The PASS Loan Program requires no additional costs or policy changes to SSA. It is a benefit to the vocational rehabilitation agency because the VR client will be in the workforce sooner and has a better chance of achieving their goals, instead of not participating in the workforce while trying to put savings in the PASS account. This has the effect of freeing up dollars to provide services to other clients. Mr. Player was unequivocal that Mountain West Bank was assuming the greatest risk by participating in this program. Banks are notoriously risk averse; however, by having Mr. Player as an integral part of the project planning team, the bank's interest was fully vetted and the Board of Directors of Mountain West Bank enthusiastically supported the project.

One of the requirements of the PASS Loan Program is that the PASS plan is approved by SSA and is supported by vocational rehabilitation, if it is a VR client. The loan applicant must also work with a non-connected third party or intermediary to prepare the PASS application. This helps to mitigate the risk to the bank by ensuring that the PASS Loan is indeed the best option, and there is no interest expediting the closure of a

"rehabilitation case." The job of the intermediary is to evaluate the PASS plan and determine that the PASS will enable the borrower to repay the loan at the agreed upon terms.

Underwriting standards for a PASS Loan are expanded to include the potential success of the employment outcome stated in the PASS, the feasibility of the employment goal, and the ability of the borrower to repay the loan; although, past credit behavior may have less influence if the borrower is participating in financial education prior to applying for the loan. If the borrower does not have experience with mainstream financial products and/or has issues with past or current debt, they are required to participate in financial education prior to applying for the loan. This is provided by Mountain West Bank and includes creating a debt management plan, a savings plan and a spending plan. The associated risks to the borrower are also fully explained if the loan is not repaid according to terms. In addition, income or monies used to repay the PASS Loan are required to be electronically deposited into the lenders bank, and loan payments are required to be made automatically from the account directly after deposits are made. This mitigates the bank's risk that the funds will not be in the account the day the loan payment is due. This "entrepreneurial" approach to vocational rehabilitation was developed over fourteen months.

The First Loan

Boise, Idaho is located in Ada County in the state capitol, which represents the largest regional center for government, industry, and education. It is the most populous county in Idaho, with over 344,000 citizens, which represents an "astounding" 34 percent growth from 1995. According to the Ada County Workforce Trends,[96] "Ada county's economic vitality, concentration of high-tech industry, outdoor lifestyle and relatively mild climate continue to attract an increasing number of both young adults and retirees."

Unemployment rates for Ada County are consistently below state and national trends[97] and its labor force participation rate in 2005 was 73.1 percent compared to 65.9 percent for the nation.[98] According to John Panter, Regional Economist, "Nearly every person who wants to be working is."[99] That may come as "news" to the approximately 1,500 persons with disabilities who are seeking employment-related services in the Division of Vocational Rehabilitation.

One such person is Alonzo Statham. Mr. Statham became disabled several years ago and requires the use of a motorized wheelchair to get from home to work. Mr. Statham had the ability to become more self-sufficient through employment in a higher paying job and to increase his income if he could travel further than the 12 mile round trip his motorized wheel chair could take him. It was decided that writing a PASS plan would enable him to purchase a truck that was modified to accommodate his disability and his

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[96] Idaho Dept. pf Labor: http://lmi.idaho.gov.
[97] Ada Unemployment 2.6%, Idaho Unemployment 3.4% and US Unemployment 4.5% for 2006.
[98] U.S. Census Bureau: http://www.factfinder.census.gov.
[99] Idaho Dept. pf Labor: http://lmi.idaho.gov.

wheelchair. Mr. Statham had considerable consumer debt and would not have been able to get an affordable prime loan on his own given his income limitations.

The option open to Mr. Statham was to write a PASS plan to save an established amount per month toward the $35,000 purchase of the vehicle. At a current passbook savings rate of 2 percent, Mr. Statham would need to save $563 per month for five years. By the time Mr. Statham met his savings goal, the vehicle he needed to go to work would undoubtedly cost much more than he had been able to save. Also, if he were not working, how *would* he be able to save $563 a month from his SSI, since he needs the vehicle to go to work (which would require daily travel around the Boise area)?

Mr. Statham was chosen as the first recipient for the PASS Loan because he had a feasible employment goal, and it was reasonable to assume that if he were able to secure adequate transportation, he would be able to be employed and reduce his dependency on SSI. Because he had prior consumer debt and no experience with such a large loan, Mr. Statham participated in financial education training. "I never had a loan before--just saving and checking accounts and one credit card that had a balance. I didn't know about saving." After the financial education experience, Mr. Statham could see the value of working to accelerate paying off his debts and making timely payments.

Although the 14-page application stops many from accessing the PASS program, Mr. Statham's PASS plan was approved the day it was submitted to Social Security. The PASS plan was written to include the PASS Loan. According to Mr. Statham, "What I thought would be the hardest thing to do--getting the loan--turned out to be the easiest thing to do." The PASS Loan allows for the interest expense and other loan fees to be included. Mr. Statham signed the promissory note to repay the loan, the vehicle was purchased, and Mr. Statham went to work within days of his PASS plan being approved. It would have been very difficult for Mr. Statham to save what he needed under the traditional PASS path; however, by being able to purchase his asset sooner, he reduced his dependency on benefits sooner.

The PASS Loan Program appears to be successful from the standpoint of its ability to put people to work faster by providing access to capital that allows them to purchase their asset well before saving up for the asset through the PASS plan. It is well known that the sooner a person is able to achieve their employment goal and get back to work, the more successful they will be at remaining in the workforce and achieving their goal of becoming more self-sufficient.

The PASS Loan Program has the potential to be scalable to other areas or even on a national level. Those involved with this program see three elements as key to its success: 1) An intermediary works with the PASS Loan applicant to write the PASS plan and develop feasible outcomes; 2) The borrower obtains financial education and credit/debt counseling prior to the loan application; and, 3) The financial institution designates funds and staff who are knowledgeable about the program and its participants.

2. Medicaid Buy-In Work Incentive

The Medicaid Buy-In program[100] may be a work incentive option for individuals with disabilities in some states. It was developed under the Balanced Budget Act of 1997 and the Ticket to Work and Work Incentives Improvement Act of 1999. Federal legislation for this program left it up to each state to decide if it wanted to offer this work incentive. As a work incentive, the Medicaid Buy-In provides eligible people with disabilities the opportunity to earn above the stated maximum and retain their Medicaid coverage, in some cases by paying an "insurance premium" on their Medicaid benefits.

One of the arguments used to persuade states to sponsor a Medicaid Buy-In program is an unintended consequence of our current Social Security policies as they relate to people with disabilities who work or desire to work. The consequence, known as the "cliff effect," results in wages below substantial gainful activity (SGA) so that a worker does not lose access to affordable health care and disability benefit payments.[101] The thought of not having access to even basic health care coverage is a powerful disincentive to increase earnings or assets or to go to work entirely.

The ability of all Americans, not just those with disabling pre-existing conditions, to purchase health insurance on the open market is becoming more and more unaffordable. Relative to individuals in excellent health, for those with major health problems the premiums are approximately 50 percent higher for non-group insurance. For those who are working and for their employers it is no better. According to a recent employer survey conducted by Towers Perrin,[102] in flat-dollar terms 2008's gross health care expenditure is expected to rise by an average of $518 per employee to an average total cost of $8,748. Employers are expecting to subsidize 78 percent of next year's premium costs while employees will have to cover the remaining 22 percent, in addition to incurring the costs of usage-based co-pays, deductibles, and co-insurance. While the projected growth rate of 6 percent for 2007 marks the fourth year of slower increases, the cumulative effect of rising costs has produced record highs for employer-sponsored health plans, and consequently, employee contributions. In fact, health care costs have increased by over 60 percent in just the past five years.

Clearly, employees with relatively low salaries are particularly vulnerable to the high cost of health care. As an example, for an individual working 40 hours per week at minimum wage, the 2008 average total health care premium (including both employer and employee share) will represent 80 percent of that individual's total annual earnings. Meanwhile, retirees will contribute well over half (56 percent) of the total cost of their coverage, with retirees age 65 and over paying an average of $119 a month ($1,428 annually) for retiree-only coverage. Retirees under 65 will be hardest hit by cost

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[100] Medicaid Buy-In. Section 201 of the Ticket to Work and Work Incentives Improvement Act of 1999 governs the provision of health care services to workers with severe disabilities by establishing a Medicaid state plan buy-in optional eligibility groups. More information is available at: http://www.cms.hhs.gov/TWWIIA/.

[101] Stapleton, D. and A. Tucker (2000). *Will Expanding Health Care Coverage for People with Disabilities Increase Their Employment and Earnings? Evidence from an Analysis of the SSI Work Incentive Program.* Research in Human Capital and Development, Vol. 13, 133-180. Stamford, CT: JAI Press.

[102] Towers Perrin: http://www.towersperrin.com/tp/lobby.jsp?country=global.

increases in 2007 and will pay an average of $298 a month ($3,576 annually) for retiree-only coverage. While many companies are taking steps to help their employees manage the growing costs the fact remains that year after year employee contribution increases are taking their toll on employees. As a result, employers are becoming increasingly concerned about growing numbers of active employees who are opting out of coverage entirely.

"At present, low-wage workers and retirees under age 65 are the ones being hardest hit by the cost increases, but the mere fact that working people are getting priced out of the health care system entirely is a trend with tremendous import for the nation as a whole and one that must be addressed by public and private sectors alike," said Dave Guilmette, Managing Director of the Towers Perrin Health and Welfare practice. "Contrary to conventional wisdom, having uninsured employees is not a good thing for employers and can lead to significant losses in productivity."

There are currently 38 states providing services to over 70,000 people with disabilities through the Medicaid Buy-In program.[103] There are three caveats to any Buy-In program and four basic options to provide these services to people with disabilities who are working. All Medicaid Buy-In or waiver programs that are part of a state plan must provide statewide coverage, and all who are eligible must receive all services available in the plan. Three of the four options create new eligibility groups and the fourth is considered a "waiver" option: the 1115 Waiver. Only three states have chosen the 1115 Waiver option. With the three "eligibility" options, states now determine eligibility for their Medicaid Buy-In program and define income and asset limits, the definition of "income" and the methodology for determining income, as well as what constitutes "work" and how "work" will be documented. Further, states are allowed to recover up to 7.5 percent of income as insurance "premium."

NDI recently compiled national data as part of a study of state Medicaid Buy-In programs to assist the state of Florida, which is considering the start of a Medicaid Buy-In program.[104] NDI found that nationally there were slightly more women than men (51 percent versus 49 percent), and 77 percent of Medicaid Buy-In participants were white versus 23 percent non-white. Both of these numbers mirror the demographics for the U.S. as a whole.[105] Further, 69 percent enrolled in the Buy-In received SSDI and 26 percent receive neither SSI nor SSDI.

Because states structured their programs to purposely include those who were experienced with their state Medicaid program, 85 percent had prior connections to Medicaid or would have been eligible for their state plan. Forty four percent were paying a premium for their health care. For the 19 states that required premiums, the average monthly premium was $64 with the highest premium of $342 per month for 82

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[103] Liu, S. & Ireys, H.T. (2006, May). *Participation in the Medicaid Buy-In Program: A Statistical Profile from Integrated Data.* Washingtion. DC: Mathematica Policy Research, Inc.
[104] Ibid.
[105] U.S. Census Bureau. 2005 American Community Survey: http://www.census.gov/acs/www/index.html.

percent of Utahans in the program, which had 324 enrolled as of March of 2006. Maine required 16 percent of its recipients to pay just an average of $12 per month and had 8,829 enrolled in the Medicaid Buy-In program.

Findings by this and other studies suggest that the presence, not just the cost of the premium, depresses participation in the program. This could be because it is not perceived that increases in net income exceed premium payments, or there still remains a fear of losing all benefits by earning over the Social Security disability limits, even though these programs are designed to mitigate that risk.[106]

It has been noted that there are three characteristics of the premium calculation that may affect program enrollment: the income level below which the participant does not pay any premiums, the treatment of earned and unearned income, and the amount of the premium.[107]

Like its counterpart for employer provided health care, many states have instituted a "grace period" to help an individual who suffers a job loss to remain in the program if their job loss is due to medical issues or layoff. Unlike the COBRA law for all other employees, states can determine the length of this grace period and these can run from one month to 24 months. COBRA provisions[108] allow a worker no less than 18 months, and under special circumstances 36 months for continued coverage. While the grace period of many programs is not as robust as COBRA, it is viewed as a very important feature for the success of the participant, particularly if they experience intermittent relapses in their medical condition. In fact, this is so important that SSA developed an "E-Z Back-On" feature for SSI and/or SSDI beneficiaries who have tried to work but have not been successful due to medical circumstances.

A look at Medicaid Buy-In participants in 2004[109] found that most experienced low wages. Unemployment Insurance (UI) data for that year found that 43 percent of Buy-In participants were included in UI data for the fourth quarter of 2004. Sixty-eight percent of them had earnings below the substantial gainful activity level ($810 in 2004). This may be because some people with disabilities purposely keep their wages low in order to maintain SSDI cash benefits. For participants with UI earnings, 32 percent had monthly earnings above the SGA level in 2004, and 10 percent of those participants had earnings over $1,600.

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[106] Andrews, K., Liu, S., & Weathers, B. (2007, December). *How Do Medicaid Buy-In Participants Who Collect Social Security Disability Insurance Benefits Use SSA Work Incentive Programs?* Washington DC: Mathematica Policy Research, Inc.

[107] Goodman, N., & Livermore, G.A. (2004, July). *The Effectiveness of Medicaid Buy-In Programs in Promoting the Employment of People with Disabilities.* Briefing paper prepared for the Ticket to Work and Work Incentives Advisory Panel. Washington, DC.

[108] U.S. Dept. of Labor. Continuation of Health Benefits-Cobra: http://www.dol.gov/dol/topic/health-plans/cobra.htm.

[109] Andrews, K., Liu, S., & Weathers, B. (2007, December). *How Do Medicaid Buy-In Participants Who Collect Social Security Disability Insurance Benefits Use SSA Work Incentive Programs?* Washington DC: Mathematica Policy Research, Inc.

The share of people with increased earnings differs substantially across states from 58 percent in Nebraska to 20 percent in New Mexico. These differences may be partially attributable to state-specific program features such as asset and income limits.[110] For individuals who did experience earnings increases, the median increase was $2,582, which is substantial relative to the average pre-enrollment earnings of $4,844.

In order for any program to be as successful as one that promotes asset-building, it must allow for the opportunity to acquire and accumulate appreciating assets. Because government programs are not intended to "make anyone rich," the Medicaid Buy-In program as it currently exists does not allow its participants to earn without limits and disregard accumulated assets.

In spite of this, eligibility appears to be quite generous for many of these programs. Maine, which has a 1115 Waiver program, has no earned or unearned income limit for eligibility. Premiums for Maine's program are assessed if income is at or above 200 percent of the federal poverty level. As of the first quarter of 2006, Maine had the third highest Buy-In participants and the lowest average premium at $12. Wyoming appears to have the lowest income test at 100 percent of the federal poverty level of $10,210 for 2007. Median household income for Wyoming is $46,202, which is just $40 less than the national median household income.[111] Wyoming does not charge a premium and it had seven people enrolled in its program for the same time period.

Case Study: Wisconsin Medical Assistance Purchase Program

In 1989, Wisconsin was part of a pilot to explore different strategies that had the potential to increase the availability of health care coverage. One of the goals of the State Health Insurance Pilot Project (SHIPP) was a "Buy-In" program for Medicaid, which was administered over two and one-half years in Milwaukee County, Wisconsin's largest population center. At the time there were many census tracts in the City of Milwaukee, where unemployment was over 80 percent[112] for some populations, and there was growing political will to make changes. The express goal of the program was to "increase the number and proportion of persons with a disability who work, to make available to persons for whom insurance is not feasible or appropriate comprehensive health benefits (including such services as durable medical equipment and personal care attendants for persons with disabilities), and to replace government assistance payments with earned income."

Then Governor Tommy Thompson elected not to continue funding the program. However, it was the 1990s and as we have seen elsewhere in this paper, opinions and policies relating to the treatment by government of the poor were changing to reflect a "Work not Welfare" ideology. In fact, it was because of a failed political maneuver that Wisconsin ended "welfare as we know it" and developed its "Wisconsin Works" program that became the model for welfare reform across the nation.

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[110] Ibid.

[111] US Census Factfinder 2005 American Community Survey.

[112] U.S. Census Bureau: http://factfinder.census.gov/home/saff/main.html?_lang=en.

Out of that pilot project grew the Pathways to Independence program that was started in 1993 and continues today.[113] The Pathways Program is essentially the same as the SHIPP program in its intent (i.e., to provide comprehensive employment and work attachment services to people with disabilities). Pathways identified four disability categories (severe mental illness, AIDS/HIV infection, physical disability, and developmental disability) for beneficiaries of these services and programs.

The Department of Health and Family Services (DHFS) and the Department of Workforce Development, along with 20 partner agencies, make up a network of service providers that provide the support and "navigational" assistance necessary for participants to achieve their employment goals. The 20 partner agencies are made up of: employment, health, and vocational rehabilitation counselors; mental health professionals; care service providers; representatives of transportation and housing; as well as employers.

One very important aspect of the Pathways Program is its Medicaid Buy-In component, the Medical Assistance Purchase Program (MAPP). Two studies done in 1985 and 1986[114] exposed the issue of appropriate health care coverage as an obstacle to working. The fear of losing benefits was seen to be so great among people who wanted to work that it kept many people unemployed or working at levels where income would not exceed eligibility requirements for social security and/or health care benefits. People with disabilities who go back to work also experience declines in cash benefits as earnings rise. A paycheck is sometimes not as reliable as a cash benefit, and if a person experiences a setback in return to work efforts, there is the possibility of not having enough or not having any income. The Medicaid Purchase Plan, approved under the Balanced Budget Act, offers people with disabilities who are working or interested in working, the opportunity to buy health care coverage through the Wisconsin Medicaid Program. Depending on an individual's income, a premium payment may be required for this health care coverage.

Features of the Wisconsin Medical Assistance Purchase Plan

- Utilized a Health and Employment counseling approach.
- Buy-In allowed a 9-month period of time to "get working."
- Coordinated through traditional partners in the not-for-profit community.
- Required premiums.
- 250% FPL, calculated at net before taxes.
- 85% had prior attachment to Medicaid--the highest in the US.
- $130,000 is collected in premiums.
- 7% MAPP participants pay premiums.

To be eligible for MAPP, one must be a resident of Wisconsin and be over 18 years of age. Additionally, they must have been determined to have a disability by the DHFS' Disability Determination Bureau. Net income for applicant and spouse must not exceed 250 percent of the federal poverty level (based on family size) and there must be individual or spousal countable assets of less than $15,000. Countable assets include

[113] The story of the beginning s of the Pathways to Independence Program can be read here: http://www.uiowa.edu/~lhpdc/work/IVleadership/Robert_Wood_Johnson_Project.pdf.

[114] Wisconsin Survey of Working Age Persons with Disabilities and the 1986 Harris Poll.

savings, life insurance policies, stocks, or bonds. A home or one vehicle is not considered a countable asset. Health care is provided for the individual only in this program: no family care is provided.

Eligible participants must also be employed in a paid position or be enrolled in a certified Health and Employment Counseling Program (HEC). HEC is a nine-month pre-employment program that allows people with disabilities who are not yet employed but looking for employment an opportunity to receive the same health benefits offered through the Wisconsin Medicaid Program. Through the HEC process a great deal of coordination, counseling, and assistance is provided. Before applying for MAPP, job seekers are expected to develop an employment plan and submit it to the HEC screener. The screener will review the plan, and if approved it is submitted to DHFS for further approval. Once the applicant receives an approval letter from DHFS they can apply for MAPP.

It is expected that the employment readiness and job search process will take nine months. Extensions may be made but must be requested in the seventh month and the extended time is only for three months. MAPP participants are limited to two extensions in a five-year period, and the MAPP eligibility ends if at the end of nine months (or all extensions have been exhausted) the individual is not working. Income eligibility is based on a formula and allows for deductions that are similar to SSI disregards, consideration of the work incentive impairment related work expenses (IRWE), and a standard deduction. This must not exceed 250 percent of the federal poverty level for the family size.

For the self-employed, any activity that generates some compensation at least once in the calendar month, even if the business endeavor is not profitable, is considered to be work. There are exceptions to this requirement that take into consideration the needs of the people they serve--namely that if serious illness or hospitalization causes one to be unable to work, the work requirement can be suspended for up to six months and the participant remains enrolled in MAPP. The individual must be enrolled in MAPP and have paid premiums for up to six months prior to the need for consideration and cannot have more than two exemptions to the work requirement policy within a three-year time period.

For some, a premium must be paid to DHFS to offset the cost of the health care coverage, although premiums are not large in comparison to what would need to be paid to purchase one on the open market. The “Premium Income” is calculated using the following formula: if an individual has gross income of over 150 percent of the federal poverty level for their family size, a premium must be calculated. Deductions from unearned income include a living allowance of $706, and IRWE and any Medical Remedial Expenses. This is then multiplied by 3 percent and countable earned and unearned incomes are added. If an individual’s Premium Income is greater than $1,225, a premium must be paid. For a couple, the income limit is currently $1,650. Seven percent of the individuals participating in the MAPP pay a premium, and approximately $130,000 dollars a month is collected from individuals in the Buy-In

program. If the employer or spouse's employer provides health insurance, the MAPP premium may be paid directly from Medicaid to the employer. This is known as the Health Insurance Premium Payment or HIPP program.

A report released in March 2007[115] shows that MAPP enrollment has grown steady since it began. Aggregate enrollment reached over 17,000 individuals as of December 2006. However, the program has also seen a decline in growth over the last year. December of 2006 saw a net increase of 537 participants compared to 1,803 for 2005. It is felt that this is due to a declining economy and possibly the introduction of prescription coverage for Medicare. According to the report, the majority of participants (60 percent) is between the ages of 45 and 64 and was divided evenly between men and women. The percentage of African American recipients has increased more than three times (1.6 percent to 5.2 percent) from 2001 to 2006, respectively. During the same period of time the percentage of Caucasian enrollees has remained steady, hovering around 90 percent. In December 2006, MAPP participants had earned income ranging from $0 to $5,362 per month with an average of $194, and a median of $40. The 2006 figures represent a continued decline in average earnings: in 2005, the average was $203 and the median was $45. About 63 percent of MAPP participants had an earned income of $100 or less, explaining why the median earned income is significantly less than the average.

The report also found that HIPP participation was growing up until 2006, when it started to decline. Several reasons were given as possibilities for this decline, including that employers do not offer health care coverage where most MAPP participants work, or county workers who do the initial intake are not familiar with HIPP.

Having the ability to work and maintain health insurance is a useful tool in the effort to build assets through increasing income. So is the ability to work and become eligible for retirement benefits. Many employers do offer retirement benefits, and Wisconsin wanted to create a program that would provide an additional incentive to working. The MAPP Independence Account allows a worker the opportunity to participate in retirement savings by exempting retirement or pension accounts accrued through their work experience while enrolled in MAPP. The Independence Account must be a new account in a depository institution, bank, or credit union, and the participant must be the sole owner of the account. Contributions may not exceed 50 percent of gross income from earnings in a 12-month review period.

This feature allows the worker to plan for retirement and not lose valuable health benefits. The down side is that if work ends and they are no longer eligible for MAPP, they risk losing their benefits or must quickly spend down their accounts. Additionally, these accounts are not portable from one state to another, which can serve to limit career mobility. According to John Reiser, director of the Office of Independence and Employment, Pathways Projects in DHFS, few people actually have Independence

[115] Department of Health and Family Services. Office of Independence and Employment. Pathways Medicaid Purchase Plan Evaluation Annual Report--2006. Medicaid Purchase Plan: http://dhfs.wisconsin.gov/WIpathways/MAPP.htm.

Accounts because, as he put it, “people in the MAPP are poor.” Mr. Reiser explains that when developing this program, the overarching idea was to reward work and monies earned through work, and there are stiff penalties for unearned income. An unintended consequence of this policy is that funds in the Independence Account are counted as assets/unearned income and not earned income when employment ends. When that happens, the individual will either need to spend down what is in these accounts or try to transfer to another Medicaid program. “The reason why we are so successful in Wisconsin,” according to Mr. Reiser, is because “when we create programs like MAPP, we use a comprehensive approach and employment is always the focus.”

Because MAPP participants would likely transfer accounts to other Medicaid programs upon retirement, a “vesting” program that is thought to be neutral in terms of cost to Medicaid is being considered by the Wisconsin Pathways project leaders. It can be argued that money in the accounts was earned income at one time and it should remain earned income after a person has participated in the MAPP for a “reasonable” period of time. A MAPP Retirement category could be available for those who worked while participating in MAPP or another long-term support benefit, and earned at or above the SGA limit for 24 consecutive months. This vesting of funds would more accurately mirror what happens to retirement programs in general.

States continue to adjust to income and asset limits for participation in their Medicaid Buy-In programs and the exclusion of individual retirement accounts to be counted as part of resource limits. For more information on the status of Medicaid Buy-In programs, please visit: www.medicaidbuyin.org.

F. Microenterprise Development

Similar to home ownership, owning a business offers another complementary strategy to advance economic status. A microenterprise is a business with five or fewer employees. There are 23 million microenterprises in the United States representing 18 percent of all private employment nationwide. In the past ten years, there has been growing interest in exploration of microenterprise development in the disability community.

For individuals with disabilities, a microenterprise may offer freedom of flexible hours and match interests with the production of income. A home-based microenterprise may also eliminate challenges of the lack of availability of accessible transportation. Person-centered and directed plans could provide some of the needed supports to establish an income producing enterprise that advances community participation and inclusion. The work incentive, Property Essential to Self-Support, does not count resources that an individual needs to be self-supporting, such as tools or equipment that are used for work; or, for a trade or business, SSA will not count property such as inventory. Use of this work incentive may allow some individuals to hold onto more of their assets. For more information on the PESS program access: http://www.socialsecurity.gov/disabilityresearch/wi/detailedinfo.htm - PESS. In addition,

as previously described an IDA offers matched savings to start a small business or microenterprise.

Nationwide, there are over 300 microenterprise development organizations providing training and technical assistance as well as access to capital. For more information, visit the Association for Enterprise Opportunity's website at: www.microenterpriseworks.org. There is also a three-year federally funded national technical assistance center to assist individuals with disabilities to develop microenterprises. For more information, visit: www.start-up-usa.biz.

Case Study: "A Wheelchair and an Ice Cream Cart—Winning Combination"[116]

In the state of Washington, individuals who receive state support must be working or on a pathway to employment. With her parent's help, Lacey Jean Davis of Montesano, Washington has become not just a valuable member of the workforce: she is an entrepreneur! Lacey Jean is considered to be someone with significant disabilities. She has cerebral palsy, which affects her ability to speak and walk; she relies on body language to communicate. She uses a wheelchair to move from one place to another. But the 23-year-old, who weighs in at around 70 pounds, also has an infectiously optimistic attitude.

Lacey Jean's mother "totally freaked out" when she learned the state wanted her daughter to develop a plan to enter the workforce. "She shows me every day that she is a lot more capable than I thought," said Lacey Jean's mom.

Lacey Jean owns an Italian Ice pushcart business: a very successful one. Beginning July 2007, and in her first 3 months of operation working only on weekends, she grossed $12,000. "We learned a lot, fast," states Larry Garman, her step-dad. "We'll do a lot better next year, but we even paid our employees a few bonuses this summer." Lacey Jean's goal is to be debt-free by the end of her second season.

From her wheelchair, Lacey Jean works hard at fairs and events, offering free samples. Using a simple color cue--red Mylar balloons on her sample tray, and red Mylar balloons at her Italian ice cart--she directs customers to her cart. At the cart, employees scoop the super popular frozen treat, which she purchases from Little Jimmy's Italian Ices (www.italianice.net) in New Jersey. After a taste, the Italian Ice product sells itself--it's non-fat, non-dairy, and has no high fructose corn syrup. "The flavor's intense, and this is something you can't get in stores," says Garman. "It's the kind of treat people look for next year, when they come to the fair again."

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[116] The information for this case study was provided by Griffin-Hammis Associates, LLC. Griffin-Hammis Associates, LLC is a full service consultancy specializing in developing communities of economic cooperation. Griffin-Hammis Associates addresses this mission by providing: High Quality Training and Technical Consultation, Project Development and Management Services, and Inventive Service Delivery. It specializes in community rehabilitation improvement, job creation and job site training, employer development, Social Security benefits analysis and work incentives, self-employment feasibility and refinement, management-leadership mentoring, and civic entrepreneurship. More information is available at: http://www.griffinhammis.com/.

In the van she's purchased to transport her business, Lacey Jean has room for a therapy table where she can stretch out every few hours. As her budget permits, she's adding her own branding to the van, labeling it boldly with the Lacey Jean Enterprises logo.

How did Lacey Jean find the pushcart business? "There was an ad in Entrepreneur's Home Business edition, and I had been looking for something that would connect our daughter with a lot of people," Larry Garman recalls. This very real successful business is a perfect fit for Lacey Jean, who is friendly and outgoing, and she plans to hire others who have a disability as her business grows. She's joined the local Chamber of Commerce and plans to sell Italian Ice year-round now, at openings, festivals, and concerts. "Little Jimmy's is a great partner," says Garman. "They make suggestions about ways to market, they send us lists of shows, and they're always there for us when we have questions."

Lacy Jean's first real signs of success came this summer at a Fourth of July fair. For two hours Lacy Jean Enterprises was swamped with a solid line of customers. Total sales went over $1,700, for 5-6 hours work. At the Surf and Sun Festival in Ocean Shores, the crowd was so large that Lacey Jean ran out of ice and the crew had to run for more! The company has two high school seniors, Britta and Kaila, who work for $8.50 per hour scooping and taking cash.

To help her fledgling business, the State of Washington connected Lacey Jean with a nonprofit training and technical assistance organization, WISE (Washington Initiative for Supported Employment). James Corey of WISE says the innovative partnership has won national recognition from the U.S. Equal Employment Opportunity Commission as a leader in employment of people with disabilities. The organization is part of a network of training and support, both public and private, across the country.

Lacey Jean Enterprises, and other businesses owned by people with disabilities, is part of the microenterprise movement. Self-employment is growing over 20 percent annually across America with an estimated 20 million Americans owning home-based businesses. Between 1990 and 1994 microenterprise generated 43 percent of all new jobs in the United States, and in the past decade 60 percent of microenterprises were founded by women. In fact, these businesses created more jobs than all the companies listed in the Fortune 500 combined. Cary Griffin, Senior partner at Griffin-Hammis Associates, (www.griffinhammis.com) a consultancy for networking business opportunity, says, "There is a cultural and economic shift of taking individual responsibility, and turning it into individual opportunity, and it appears to be largely unaffected by swings in the larger economy."

Self-employment offers the only substantial options available under Social Security and Medicaid/Medicare systems to accumulate personal wealth and manage income in a way that is predictable and personally adjustable. (Through self-employment) a small business owner can accumulate operating cash and other business capital resources and thus, unlimited net worth in the business. This circumstance also creates the possibility of eventually selling the enterprise and using the proceeds to purchase a home, for instance. Self-employment creates an avenue for increasing individual wealth; wage employment has no comparable options.

Making Self-Employment Work for People with Disabilities
Cary Griffin and David Hammis, 2003 Paul

Companies such as Griffin Hammis offer training and support programs for people with disabilities seeking to start a business or get into the workforce. The company networks clients with government agencies and private specialists to find ways to make entrepreneurship possible. Their experience working in this field has taught them that there are no tests or professional evaluations that can identify who will succeed in business; rather, personal commitment and a strong support group can be the best indicators that a person will succeed as an entrepreneur.

Shaw Seaman, of the Washington State Department of Social and Health Services, remarks that Lacey Jean is outstanding, and she has an outstanding family. "Not everyone who comes to us for help goes this far. Our goal is to put people with disabilities on a path to employment, getting them out of sheltered workshops and integrated into the community. Lacey Jean is someone everyone should meet."

G. Special Needs Trust

A mechanism for families to preserve assets to benefit a family member with a disability and still protect eligibility for public assistance with long-term care needs is a special needs trust.[117] [118] [119] A pooled trust is a form of special needs trust that allows families to pool resources with other families in one trust. The operating organization manages and invests the trust as a single fund and beneficiaries receive earnings based on their share of the principal. Pooled trusts allow families with smaller amounts of money to use the trust vehicle to access better quality investments that pay a higher rate of return than what would be available for a small individual trust. Pooled trusts are especially beneficial to people with disabilities receiving services through SSI and Medicaid.

Because SSI and Medicaid are means-tested, they require the individual to contribute toward their cost of care with the proceeds from their earnings, leaving many individuals with only a small personal care allowance for things such as clothing, toiletries, and related items. While money from pooled trusts can not pay for food, clothing, shelter, and basic health care costs, they are set up to provide services and items that do not

[117] The Arc of the Untied States. (2002). *Pooled Trust Programs for People with Disabilities: A Guide for Families.*
[118] Elias, S. (2007). *Special Needs Trust: Protect Your Child's Financial Future.* Berkeley, CA: Nolo.
[119] Davis, S., (Ed.) (2003). *A Family Handbook on Future Planning*. The Arc of the United States and the RRTC on Aging with Developmental Disabilities.

jeopardize means-tested benefits. A beneficiary of a pooled trust program can start to receive or continue receiving public benefits for meeting essential needs and still have resources available for their special or supplemental needs.

Pooled trusts usually do not impact the individual's SSI and Medicaid benefits since the trust restricts distributions to certain limits or usage. In addition, pooled trusts can offer other beneficial future planning services, including information about guardianship and other alternatives, referral to professionals, information on services, and other legal and non-legal assistance. According to a directory of pooled trusts from the Academy of Special Needs Planners, there are currently forty-one states plus the District of Columbia that have pooled trust programs: (http://www.specialneedsanswers.com/resources/directory_of_pooled_trusts.asp).

Pooled trusts are a challenging option to be followed that still meets the full intent of the principles of self-determination. Pooled trusts cannot allow an individual with a disability to control expenditures from these accounts.

Example: Shared Horizons, Inc. Trust and Fiduciary Services for People with Disabilities

Shared Horizons[120] is a 501(c)(3) nonprofit created by the Quality Trust for Individuals with Disabilities, Inc., in conjunction with University Legal Services and the District of Columbia Government. The goal of Shared Horizons is to improve the quality of life for people in the District of Columbia and Maryland with disabilities through the Wesley Vinner Memorial Trust, a pooled special needs trust.

The purpose of Shared Horizons is to assist individuals and their community support teams to develop a quality of life financial plan without jeopardizing the beneficiaries' eligibility for government benefits, such as Medicaid and Supplemental Security Income.

The philosophy of Shared Horizons encompasses the following principles:

- Beneficiaries and their families should have the opportunity to develop individualized financial plans for the future.
- Development of Quality of Life Plans will involve the beneficiary to the greatest extent possible.
- Each Quality of Life Plan will be individualized to best meet the supplemental needs of the beneficiary.
- Quality of Life Plans will take into account the strengths and limitations of service providers, communities, and the beneficiaries.
- Efforts will be directed toward giving every enrolled beneficiary an opportunity to fully participate and be integrated into his or her community, while providing appropriate support and protection.
- Flexibility is important when providing services in order to meet the changing needs of beneficiaries over time while respecting the intent of the grantor. When changes in service delivery are necessary, Shared Horizons will respond within the confines of the policies.

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[120] Shared Horizons, Inc.: http://shared-horizons.org/.

- Beneficiaries of Shared Horizons should be provided services, protection, and advocacy through means that intrude as little as possible on the individual's freedom to direct his or her affairs.
- Shared Horizons will create opportunities for all beneficiaries with all necessary supports and assistance to make choices to the fullest extent possible, including situations where mistakes could be made in the course of their selection of alternatives. Shared Horizons shall balance the safety and protection of the individual against the dignity inherent in their being able to take risks.

H. Long-Term Care Insurance Options to Preserve Assets

Currently, only about 10 percent of Americans over the age of 55 have private insurance protection for long-term costs. Medicaid does pay for long-term care; however, it pays only for those who have exhausted nearly all of their own resources first. In order to receive Medicaid coverage, an individual must "spend down" their assets.

The Robert Wood Johnson Foundation funded a demonstration project, the *Program to Promote Long-Term Care Insurance for the Elderly* (originally called the Partnership for Long-Term Care) [121] [122] to provide states with resources to plan and implement private/public partnerships (Partnership programs). The original demonstration model has been underway since 1992 in California, Connecticut, Indiana, and New York. The Partnership programs joined private long-term care insurance with Medicaid to offer high-quality insurance protection against impoverishment from the costs of long-term care, including both nursing home care and/or home care.

Consumers who purchase such policies are insured for long-term care up to a pre-set dollar level through the private insurer. Once the private insurance is exhausted, they can continue their long-term care under Medicaid without spending their assets, which is usually required to meet the criteria for Medicaid eligibility. In this program, Medicaid covers long-term care costs incurred beyond the terms of the private coverage, and assets protected by the private long-term care policies also are exempt from the Medicaid asset test.

Example: Indiana's Long-Term Care Insurance Program

In Indiana, the Partnership program is referred to as Indiana's Long-Term Care Insurance Program (ILTCIP)[123] and provides incentives for the purchase of private long-term care insurance through a partnership between the Medicaid program and private long-term care insurance companies. The ILTCIP originally used a dollar-for-dollar model to ensure asset protection. However, in 1998 it switched to a hybrid model whereby consumers could choose between dollar-for-dollar or total asset protections.

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[121] Program to Promote Long-Term Care Insurance for the Elderly. Robert Wood Johnson Foundation. Available at: http://www.rwjf.org/reports/npreports/elderlye.htm.
[122] Long-Term Care Partnership Expansion: A New Opportunity for States. Robert Wood Johnson Foundation. May 2007.
[123] Indiana Long-Term Care Insurance Program. Available at: http://www.in.gov/fssa/iltcp/.

In the total asset protection model consumers are required to buy a more comprehensive benefit package. This type of policy allows consumers to protect all of their assets when applying for Medicaid.

The ILTCIP assists the state with containing the growth of Medicaid long-term care expenditures by encouraging persons to purchase private insurance. The ILTCIP seeks to improve the quality of long-term care insurance policies, make long-term care insurance more affordable, and increase public understanding of long-term care risks, costs, and financing options. As of December 2006, there were eight insurance companies approved to participate in the ILTCIP. Through December 2006, 39,774 policies had been purchased. The average age of an ILTCIP purchaser was 61 years. Four hundred and nineteen policyholders accessed their policy benefits, and of those there were 22 policyholders that exhausted their ILTCIP policy benefits and were accessing Indiana Medicaid assistance while preserving assets.

In 1993, citing concerns about the appropriateness of using Medicaid funds for this purpose, Congress imposed a moratorium on new states entering the Robert Wood Johnson Foundation demonstration project in the Omnibus Budget Reconciliation Act of 1993. However, with the passage of the *Deficit Reduction Act of 2005*[124] in February 2006, the technical barriers have been lifted, now allowing for the expansion of the Partnership to other states. This new legislation authorizes changes in state law to allow individuals to purchase private long-term care insurance that coordinates with Medicaid. For states that adopt this approach, individuals will be able to purchase private long-term care insurance policies with the assurance that Medicaid will cover long-term care costs that may be incurred beyond the terms of the private coverage. Individuals with this private insurance will not be required to “spend down” their remaining assets to qualify for Medicaid.[125] Please note, individuals with disabilities with pre-existing conditions may find it very difficult to qualify for these long-term care insurance policies.

IV. CONCLUSION: BRINGING MULTIPLE STRATEGIES TOGETHER

Research used to prepare this report unveiled an evolving world of policy change, emerging systems collaboration, and new pathways to self-determination in pursuit of economic advancement. The complexity of the tools and strategies identified is daunting for both human service professionals, as well as individuals with disabilities and family members. As the demographics of this country change, the competition for scarce resources, especially under the Medicaid program, is going to increase dramatically and will impact individuals that rely on public dollars to support long-term care. The purpose of public funding and the current way that Medicaid funds are

[124] Deficit Reduction Act of 2005: http://www.whitehouse.gov/news/releases/2006/02/20060208-9.html.
[125] *Long-Term Care Insurance Partnerships: New Choices for Consumers--Potential Savings for Federal and State Government*. (January 2007). America’s Health Insurance Plans.

distributed, both across and within states, will have to be adjusted to assist individuals that need support.

Self-Determination is a reform movement committed to moving control of the resources for long-term support directly to individuals with disabilities, their families, and allies. The ultimate goal is not control of the resources but the achievement of meaningful lives rich in relationship and community, sharing with all citizens the opportunity to contribute as equal members of American society.[126] The new assumptions of self-determination are that every person with a disability:

- will have their own place to live,
- generate income,
- be connected to one's community, and,
- facilitate relationships.

One of the foundations of self-determination rests on responsibility for the wise use of public dollars through control of an individual budget that focuses on universal human needs. Individual budgets are individually created, provide for flexibility and authority over personnel, and allow for the promise of freedom and acceptance of responsibility. A key to self-determination is that the budget process includes involvement of the individual and also recognizes that everyone is unique, and this should be reflected in the individual budget.[127]

The individual budget must be developed during the person-centered planning process, which includes the individual and his/her circle of support. An individual should have the option to develop a budget that is as detailed as needed, based on preferences and needs. Some elements of the budget are designed to provide broad general support, while others describe specific services covered through various funding streams. An individual budget translates the person-centered plan into dollars, looking at money as an investment in an individual's life.

The challenge for service providers, individuals with disabilities, and families that are dependent on Medicaid for enhanced community participation is to become more aware and skilled in using other non-Medicaid tools and strategies to advance their self-sufficiency. It will require an alignment of self-determination principles with policy and program implementation across generic and disability specific systems.

This report introduced tools and strategies that recognize the importance of building and preserving choices, community participation, and general quality of life. Operationalizing the principles of self-determination requires a new level of coordination and collaboration among disability-specific and generic systems. Public and private

[126] Nerney, T. (2001). *Filthy Lucre: Creating Better Value in Long Term Supports*. Ann Arbor, MI: Center for Self-Determination.
[127] Nerney, T. (2004). *Guaranteeing the Promise of Freedom: Creative Individual Budgeting*. An Arbor, MI: Center for Self Determination.

sector resources must be aligned to expand the circle of support for an individual with a significant disability.[128]

For the Medicaid agency, there must be:

1. A shared mission with other disability service systems (Mental Health, Developmental Disabilities, Vocational Rehabilitation) to promote community participation and advance economic self-sufficiency;
2. A coordinated approach to providing resources to respond to the needs and preferences of a person-centered and person-directed planning process;
3. A new level of outreach and receptiveness to engage nontraditional partners (asset building community) to be a part of a circle of support on an individual and systems level to encourage income production, savings, and asset building; and,
4. An alignment of service definitions that encourage and promote flexible use of Medicaid-specific and other public and private resources blended and braided to value increased personal freedom and economic self-sufficiency.

Systems of support across funding authorities agree and align polices, benefits, and performance to reject poverty as an acceptable outcome for recipients of public assistance and decouple eligibility requirements that demand beneficiaries have no incentive to produce income, save, build, and preserve assets.

Key Findings

There are six key findings that were identified from the review and analysis of federal and state generic and disability-specific public policies, reports from CMS and other federally funded grantees, and information and data collected from diverse stakeholders at a local, state, and national level.

1. Individuals with disabilities and their families are routinely denied opportunities available to others without disabilities to save and build assets. Research and analysis reveal that this is because of the low ceiling that exists for allowable income and assets to be and remain eligible for Medicaid and many other public benefits.
2. Low-income individuals with disabilities and their families do not benefit from many existing savings and asset building tools and strategies. Research and analysis reveals that this is because of a lack of awareness and understanding of their possibilities without adversely impacting other necessary public benefits.
3. There is no single or simple strategy to the layering of multiple strategies to advance self-sufficiency and community participation for individuals with disabilities and their families. With differing rules of eligibility for beneficial tax provisions, utilization of work incentives, participation in Medicaid Buy-In, and access to matched savings plans (e.g., IDAs), there is a need for cross-agency coordinated and customized outreach to the target audience that communicates the needed information in a way that is understandable and relevant.

[128] Nerney, T. (2004).

4. The identified strategies to advance self-sufficiency for Medicaid beneficiaries is a blending of public and private sector resources that engage nontraditional partners with the more traditional disability community. The common platform is a commitment to self-determination with more individual choice and control of a self-directed account with the overarching goal to achieve a better economic future.
5. Coordination among public agencies at a local, state, and national level can be improved through cross-agency work groups that seek to identify barriers to savings and asset building for the target population and work together to align policy, processes, and programs to consistently support improvement in economic status and increased community participation.
6. Best practice examples continue to be identified, documented, and disseminated across the relevant stakeholders groups. Self-directed accounts and the blending and braiding of public and private sector resources is in the early stages of implementation, requiring further analysis and evaluation of short- and long-term impact at an individual and systems level.

For the future, systems to be adopted include:

- Broad service definitions in both Medicaid and state/county programs that encourage flexibility and promote the use of other public funds generic to the wider community.
- Expansive definitions of "qualified Medicaid Providers" that encourage family, friends, neighbors, and allies to provide support. Include the speedy policy adoption of microboards and other innovative strategies for families and allies to receive public dollars comparable to provider agencies. A microboard helps a single Medicaid beneficiary manage an individual budget as a legally established not-for-profit corporation.
- Full acceptance of informal caregivers including any family member as a legitimate provider.
- Acceptance of one-time purchases that allow for communications and mobility technology, down payments for homes, and equipment and/or inventory for microenterprise development.
- Encourage direct contracting (through fiscal intermediaries if necessary) with employers for co-worker support, training, transportation, and short term wage subsidies.
- Adopt new quality assurance systems that emphasize universal human needs and aspirations, thereby holding human services accountable to outcome measures that are similar to the expectations that all Americans expect.

No single public agency can achieve a better economic future for individuals with disabilities. New levels of collaboration across public agencies and private sector involvement must work together to meet the challenges of the Olmstead mandate with renewed focus on economic achievement.

Appendix A

THE CHALLENGE OF POVERTY

Chronic poverty promotes exclusion and diminishes opportunity to participate in the mainstream of American life. Historically, the tax code's consideration of the extra costs associated with living with a disability focused on these expenses as part of the medical deduction. As a result, little has been done from an individual or family perspective to promote opportunity to become more self-sufficient without a dependence on an array of public benefits. Eligibility for the Social Security Administration's (SSA) Supplemental Security Income (SSI) and Medicaid programs[129] offers assistance of income support and long-term care; however, conditioned on remaining poor both in terms of income and assets.

Working age adults with disabilities with a need for continued access to Medicaid for health care, personal assistance services, assistive technology, and other long-term supports have to meet the perverse dual prongs of eligibility related to inability to participate in substantial gainful activity (SGA) and staying poor.[130] This continues to create a life sentence of impoverishment.

Seniors who have a disability have spend-down requirements for Medicaid eligibility to access skilled nursing or assisted living and home care. Eligibility for long-term supports is conditioned on becoming and remaining impoverished.

A dependence on public benefits for income (SSI), health care (Medicaid), food, and housing rental assistance becomes a trap that requires remaining poor to be eligible. Research has documented that enduring poverty and lack of economic empowerment will diminish choices and quality of life within communities and singularly diminish freedom, opportunity, and self-determination.

Individuals with disabilities are poor. In 2006, the poverty rate of working age Americans with disabilities between the ages of 21 and 64 was 25.3 percent: more than double the rate of individuals without disabilities in this age group.[131] Out of adults 65 years of age and older, 15 percent with a severe disability and 8.2 percent with a non-severe disability live in poverty compared to 5.9 percent of individuals with no disability.[132]

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[129] The Social Security Administration administers the Supplemental Security Income (SSI) program, which is a Federal income supplement program funded by general tax revenues. It is designed to help aged, blind, and disabled people, who have little or no income, and it provides cash to meet basic needs for food, clothing, and shelter. More information is available at: http://www.ssa.gov/ssi/.
[130] Social Security Online. Understanding Supplemental Security Income: SSI Eligibility Requirements, 2007 Edition. Available at: http://www.ssa.gov/ssi/text-eligibility-ussi.htm.
[131] *Rehabilitation Research and Training Center on Disability Demographics and Statistics*. (2007). 2006 Disability Status Report. Ithaca, NY: Cornell University.
[132] U.S. Department of Justice Civil Rights Division. *Access for All: Five Years of Progress.* A Report from the Department of Justice on Enforcement of the Americans with Disabilities Act.

Lack of money is a serious problem among people with disabilities. A national Harris Survey for the National Organization on Disability (NOD) indicated that lack of financial resources is the most serious problem they face. Three times as many live in poverty with annual household incomes below $15,000. The same survey revealed that public assistance represents 59 percent of the total income of people with significant disabilities and only 8 percent of the total income of people without disabilities.[133]

In a 2007 Benchmark Study of the Internal Revenue Service[134] that studied characteristics of taxpayers with disabilities, 51 percent of the sample group with disabilities had an adjusted gross income of less than $20,000 as compared to 32 percent of non-disabled taxpayers. Just over half (51 percent) of surveyed taxpayers with disabilities indicated they were working full-time as compared to 75 percent of the non-disabled taxpayers. The percentage of retired/non working respondents ages 18 to 59 was higher for individuals with disabilities at 28 percent compared to only 9 percent of those surveyed without disabilities.

In the promotion of the goals of self-determination, increased community participation, and personal freedom, the challenge for Medicaid agencies is to recognize and focus on the cause and effect of limiting opportunities to achieve these valued outcomes.

Poverty reduces choices about: where one lives; the ability to travel; and, to take advantage of community activities that are educational, social, or recreational in nature. Poverty impacts individual self-respect, mental and physical health, and adversely challenges individual status and expectations of others including neighbors, co-workers, and the general public.

In order to determine what a roadmap out of poverty might look like, it is first necessary to have a better understanding of the difference between a focus on work and advancing self-sufficiency. In a special report published in 2005 by the Fannie Mae Foundation, entitled "Promoting Economic Security for Working Families: State Asset Building Initiatives,"[135] that examined state asset-building initiatives, author Heather McCulloch observed that, "Today, more than ever, America's families need more than a regular paycheck to achieve financial security. They need the capacity to acquire and preserve assets. They need a pathway to self-sufficiency." The report suggests the conversational focus move away from "preventing a negative (poverty) to advancing a positive (expanding economic opportunity and financial security)" as a way to capture the attention of a variety of stakeholders, including some who had never weighed in on the question "what to do about poverty."

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[133] National Organization on Disability. *2004 N.O.D./Harris Survey Documents Trends Impacting 54 Million Americans.* Available at: http://www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=1422.
[134] Disabilities Research Report. *Characteristics of Disabled Taxpayers Ages 18 to 59: Study of Filing Patterns and Preferences for Receiving Tax Information & Services*. Internal Revenue Service Wage & Investment Research. Prepared for Stakeholder Partnerships, Education & Communication, May 4, 2007.
[135] McCulloch, H.. (July 2005). *Promoting Economic Security for Working Families: State Asset Building Initiatives.* Fannie Mae Foundation: http://www.fanniemaefoundation.org/.

With the inclusion of a new and expanding set of stakeholders, the discussion can cross partisan borders as both sides embrace the idea of moving beyond lifting someone "out of poverty" and into "self-sufficiency." Unheard of just a few years ago, business leaders, community leaders, financial institutions, and others are now joining social service governments to build consensus and develop regional solutions to poverty.

In order to determine what the pathway to self-sufficiency might look like, however, it is first necessary to get a clear idea of where Americans with and without disabilities stand in terms of their current economic standing.

Americans and Their Money

The 1990s brought about a feeling among people that wealth and income were markedly improving due to an increasingly "bullish" stock market performance, particularly among technology stocks. This idea was supported by declines in the traditional income-based measures of poverty. But this approach quickly falls apart when the focus is on wealth distribution and asset ownership. A person or a household is "asset poor" if they do not have sufficient access to assets to meet their basic needs over a short period of time. Some variables used to measure asset poverty include: home ownership, educational attainment, bank assets, credit worthiness, insurance/asset protection, and personal net worth.

A report, entitled Asset Poverty in the United States: Its Persistence in an Expansionary Economy,[136] found that asset poverty increased during a time of great economic expansion (1984 to 1999) for those at the bottom of the economic scale. The median net worth (50th percentile) increased from $43,000 to $56,500, or 31.5 percent. The 25th percentile increased slightly (from $1,600 to $2,000), but the 95th percentile increased from $483,100 to $799,000, or 61.2 percent. The lower tail of the net worth distribution did not increase as fast as the upper tail, so there was a skewed progression in favor of the upper percentiles. In contrast, the poorest 10 percent of the American population was in debt in 1984, and their debt continued to increase between 1984 and 1999. The rise in liquid assets was also highly skewed in favor of the upper tail of the wealth distribution. The median debt increased from $5,600 in 1984 to $9,000 in 1994, before declining to $6,000 in 1999 (a 7.0 percent increase over the period). In contrast, debt in the 95th percentile increased 76.7 percent.

Rising debt levels also help explain the difficulties faced by low-income households that are trying to become self-sufficient. Average debt in low-income families doubled between 1984 and 2001. The median debt in the poorest families rose from just over $1,700 in 1984 to nearly $4,000 in 1994, before falling back to $3,000 in 2001. Debt has also grown much faster than family income, creating a serious impediment to self-sufficiency. In 1984, total family debt for families living between 100 percent and 200 percent of the federal poverty level was just over 7.5 percent of total family income. By 2001, the debt to income ratio had doubled to 15.5 percent.

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[136] Caner, A. & Wolff, E.N. (2004). *Asset Poverty in the United States: Its Persistence in an Expansionary Economy*. Public Policy Brief: The Levy Economics Institute of Bard College: No. 76. Available at: http://www.levy.org/pubs/ppb/ppb76.pdf.

Debt hardship, total family debt greater than or equal to 40 percent of total family income, has risen from 42 percent of families with debt in 1984 to over 67 percent in 2001. It can be anticipated with the cooling of many housing markets, and adjustable rate mortgages set to increase for approximately one-third of all mortgage holders, that these numbers will continue to increase. Families whose incomes are between 50 and 100 percent of federal poverty debt hardship have nearly doubled from just over 25 percent in 1984 to nearly 48 percent.

In response to the inadequacy of the current method for describing poverty, The Family Economic Self-Sufficiency Project has generated Self-Sufficiency Standards for 34 states and the District of Columbia.[137] The Self-Sufficiency Standard relies on published data regarding the cost of housing, health care, transportation, childcare, and other expenses to determine a "Self-Sufficiency Wage."[138] This makes the Self-Sufficiency Wages more meaningful because they take into account the wide fluctuations found between regional housing markets, childcare costs, and health care costs. However, the Self-Sufficiency Standard does not consider the scenario where a person with a disability is part of the household and the additional costs associated with that person or persons.

For example, a Self-Sufficiency Wage for a single parent with two young children living in Milwaukee, Wisconsin would be $22.62 per month, the lowest wage at which the parent would not be eligible for any government sponsored work supports or entitlements like food stamps, Medicaid/Medicare, childcare, or even child support. This does not include birthday or other holiday presents, any meals eaten outside the home, or debt in the budget. If that single parent with two young children received work supports subsidized by government entitlement programs, the Self-Sufficiency Wage is $8.56 per hour, which is more than the minimum wage but up to $3.00 per hour less than starting wages for entry level jobs in the Milwaukee area that do not require post secondary education or certification.[139]

Disparities in wealth have been increasing at much larger rates than disparities in income, although those have been increasing as well.[140] When looking at household income of those at the bottom 20 percent, only 10 percent own tax favored retirement accounts compared to 85 percent ownership of tax favored retirement accounts at the top 20 percent of income. Further, those in the top 10 percent own 50 percent of total assets. It will be interesting to see how new laws that make employer sponsored investing programs "opt out" instead of "opt in" will affect these gaps as more and more employers are eliminating investment programs altogether. Clearly, employees will require more information about investing in the near future.

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[137] Six Strategies for Family Economic Self-Sufficiency: http://www.sixstrategies.org/about/about.cfm.
[138] Pearce, D. & Brooks, J. (April 2004). *The Self-Sufficiency Standard for Wisconsin 2004*. Prepared for the Wisconsin Women's Network: http://www.wiwomensnetwork.org/selfsufftoc2004.pdf.
[139] Wisconsin's Worknet: http://www.worknet.gov.
[140] Wolf, E.N. ACORN: www.acorn.org.

People with Disabilities and Their Money

Most of the challenges faced by moderate-income families are likely as great or greater for people with disabilities. People with disabilities have fewer bank accounts, lower graduation rates, and are less likely to own their own home or other financial assets than persons without disabilities.[141] Those with disabilities who have been on government assistance relative to their disability have been conditioned to be cautious of overstepping their income limits or asset limits, for if they do, they will likely be "cut off" from health care, housing, employment, or supportive living assistance. One should therefore expect greater disparities in asset accumulation for a person with a disability than in the general population.

Fifty-eight percent of people with disabilities stated they did not have enough assets, without income or gifts, to live independently for three months, compared to 36 percent who had no disability. The NOD/Harris Poll Survey of Americans with Disabilities[142] reported only 35 percent of people with disabilities as being employed full-time or part-time, compared to 78 percent of those without a disability. Three times as many people with disabilities live in poverty with annual incomes below $15,000 (26 percent versus 9 percent) and are twice as likely to drop out of high school (21 percent vs. 10 percent).

Research uncovered no data that separately examines people with disabilities and their reliance on predatory lending or alternative financial services, but we know from recent surveys that 30 percent of people with disabilities do not have a savings or checking account compared to 22 percent of all people surveyed nationally.

NOD Harris Survey	***Disability***	***No Disability***
Savings w/bank	46%	65%
W/credit union	28%	37%
IDAs	6%	13%
Corporate Stocks /Bonds	21%	34%
Gov't Savings Bonds	21%	21%
Checking w/bank	69%	76%
W/credit union	22%	24%
Loan w/bank	26%	36%

[141] National Organization on Disability. *2004 N.O.D./Harris Survey Documents Trends Impacting 54 Million Americans.* Available at: http://www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=1422.
[142] Ibid.

Appendix B

ADDITIONAL RESOURCES

1. **Favorable Tax Provisions**
    - Real Economic Impact Tour – www.reitour.org
    - The Internal Revenue Service – www.irs.gov
        - Earned Income Tax Credit
            - www.irs.gov/eitc
            - www.irs-eitc.info/SPEC
        - IRS Publication 907, Tax highlights for Persons with Disabilities - http://www.irs.gov/publications/p907/index.html .

2. **Financial Education**
    - FDIC's Money Smart - www.fdic.gov/consumers/consumer/moneysmart/
    - FDIC Community Affairs Program - www.fdic.gov/consumers/community/
    - U.S. Financial Literacy and Education Commission - www.mymoney.gov/

3. **Individual Development Accounts**
    - The Corporation for Economic Development – www.cfed.org
        - CFED's IDA Network – www.idanetwork.org
        - Assets and Opportunity Scorecard - www.cfed.org/focus.m?parentid=31&siteid=2471&id=2476
    - Assets for Independence (AFI) Program - www.acf.hhs.gov/assetbuilding/

4. **Work Incentives**
    - Social Security – http://www.socialsecurity.gov/disabilityresearch/wi/generalinfo.htm
        - Plan to Achieve Self-Support - www.socialsecurity.gov/disabilityresearch/wi/pass.htm
        - The Red Book - www.socialsecurity.gov/redbook/eng/main.htm
        - Work Incentives Planning and Assistance Projects - http://www.socialsecurity.gov/work/ServiceProviders/WIPADirectory.html
    - Medicaid Buy-In - www.medicaidbuyin.org
    - Go Direct Campaign - http://godirect.org/

5. **Home Ownership**
    - HUD – www.hud.gov
        - Housing Choice Vouchers - www.hud.gov/offices/pih/programs/hcv/
        - Family Self-Sufficiency Program - www.hud.gov/offices/pih/programs/hcv/fss.cfm

6. **Microenterprise Development**
    - Association for Enterprise Opportunity - www.microenterpriseworks.org
    - Start-Up USA - www.start-up-usa.biz

7. Insurance Options to Preserve Assets

- Robert Wood Johnson Foundation - www.rwjf.org/reports/npreports/elderlye.htm

8. Special Needs and Pooled Trusts

- Academy of Special Needs Planners - www.specialneedsanswers.com/resources/directory_of_pooled_trusts.asp

9. Asset Building

- The World Institute on Disability – www.wid.org
  - Equity e-Newsletter -- www.wid.org/publications/?page=equity
- New America Foundation - www.newamerica.net/
- Asset Building - http://assetbuilding.org/
- National Disability Institute - http://www.ndi-inc.org/

10. Self-Determination

- Center for Self-Determination - www.self-determination.com/
  - Principles of Self – Determination – http://www.self-determination.com/principles/index.html

11. Medicaid

- Centers for Medicare & Medicaid Services - http://www.cms.hhs.gov/MedicaidGenInfo/
  - Medicaid Infrastructure Grants - http://www.cms.hhs.gov/TWWIIA/03_MIG.asp#TopOfPage

12. Mathematica Policy Research (MPR)

- http://www.mathematica-mpr.com/disability/medicaidbuy-in.asp

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