

Breaking the Cycle of Poverty: Asset Accumulation by People with Disabilities.

Abstract

In this article the authors argue that equality for people with disabilities is contingent on economic equality and financial independence. They discuss the use of asset accumulation strategies, such as Individual Development Accounts ("IDAs"), by people with disabilities who utilize Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Temporary Assistance to Needy Families (TANF) and Medicaid. The major federal IDA programs, Assets for Independence (AFIA) IDAs and TANF IDAs, are compared in their use by people with disabilities. Further, the authors examine the income and resource limitations of SSI, SSDI, TANF and Medicaid and show how these often operate as barriers to asset accumulation by people with disabilities. Work incentives that operate within these programs are discussed in relation to asset development. Finally, the article concludes with proposals to encourage asset accumulation by people with disabilities.

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Introduction

The purpose of this article is to discuss how asset accumulation strategies such as Individual Development Accounts (IDAs) may be used to alleviate the poverty faced by many people with disabilities in light of some of the barriers posed by the programs on which people with disabilities often rely. Section I proposes that the current disability framework alone, based in the civil rights model, will be ineffective unless more is done to assist people with disabilities out of poverty. Section II is divided into two parts: part A examines the linkage between poverty and disability; part B discusses how asset accumulation and IDAs operate to alleviate poverty. Part B then further

examines the operation of IDAs connected to the Temporary Assistance to Needy Families (TANF) program versus the operation of IDAs funded through the Assets for Independence Act (1998). Section III discusses the programmatic barriers to asset accumulation and IDA participation faced by people with disabilities who receive benefits through Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), TANF and Medicaid. Finally, Section IV proposes some programmatic changes that may help people with disabilities earn and accumulate wealth and achieve greater economic independence.

I. Background

In 1988, then Vice President George H.W. Bush said, "The statistics consistently demonstrate that disabled people are the poorest, least educated and largest minority in America." Although the positive societal changes brought about by the Americans with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act are undeniable (see Blanck, Hill, Siegal & Waterstone 2003, 2005), these seminal policy initiatives will be Pyrrhic victories unless people with disabilities achieve a measure of economic equality. President Lyndon B. Johnson expressed this idea forty years ago when he spoke in the context of racial equality:

You do not take a man who for years has been hobbled by chains, liberate him, bring him to the starting line of a race, saying, 'you are free to compete with all the others,' and still justly believe you have been completely fair...This is the next and more profound stage of the battle for civil rights. We seek not just freedom but opportunity—not just legal equity but human ability—not just equality as a right and a theory, but equality as a fact and as a result. (Johnson, 1965).

It is evident to policy makers from across the political spectrum that creating a level playing field is not enough to assist people out of entrenched poverty, and that rising above poverty is a key to equality. As Ray Boshara and Dr. Reid Cramer of the New

America Foundation pointed out in testimony before the Subcommittee on Social Security and Family Policy, an offshoot of the Senate Finance Committee, chaired by Sen. Rick Santorum (R-Pennsylvania), "Asset-based policy is intended to enable individuals to exert greater control over their lives and expand their capacity to take advantage of the diverse opportunities afforded by American society." (Boshara and Cramer, 2005, 18). Yet, existing income-maintenance programs put food on the table for millions of families, but do nothing to enable and empower the families and individuals who rely on them to participate fully in the economic and civic life of America.

Asset development, often in the form of IDAs, is seen by many as a key to bringing individuals, families, and communities out of poverty. Asset development strategies are a centerpiece of the George W. Bush Administration's concept of an "ownership society" and proposals such as the Savings for Working Families Act of 2005, which would expand IDA opportunities, have garnered bipartisan support. (S. 922, 109th Cong. 2005). This article addresses the application of the principles of asset development and IDAs to people with disabilities living in poverty, particularly in light of the various government programs that people with disabilities rely on to provide income, healthcare, food and shelter.

II. Poverty, Disability and Asset Accumulation Strategies

A. Prevalence of Poverty among People with Disabilities

Unfortunately, many initiatives in the disability policy arena have not reduced poverty among people with disabilities (Blanck, 2004; 42 U.S.C. § 12101(a)(8), 2000). Despite significant advances people with disabilities have achieved in terms of civil rights, the 2005 Harris Poll from the National Organization on Disability (N.O.D.) reveals that 34% of people with disabilities live in households with annual incomes of \$15,000 or less, almost three-fold compared to non-disabled peers (34% versus 12%, respectively). In addition to limited household

income, the N.O.D./Harris poll data reveals that people with disabilities are asset poor.

As Schmeling and colleagues point out in this issue, 59% of people with disabilities reported that they had insufficient resources to live at the poverty level for three months without another means of support. By contrast, 37% of people without disabilities report being asset poor. The link between poverty and disability has a profound impact on children. Thirty-one percent of low-income, unemployed parents report that an illness or disability prevents them from working (NCCP, 2004).

Poverty is a complex problem in any population; poverty among people with disabilities is especially complex in its causes or possible solutions (Schmeling, Scharz, Morris, Blanck, this issue). There is strong evidence that the conditions of poverty--malnutrition, poor prenatal care, insufficient general medical care, increased rates of drug and alcohol abuse in poor communities, unhealthy levels of lead paint and other toxic environmental exposures, and high rates of sexually transmitted disease, including HIV and AIDS--give rise to an increased incidence of disability in poor communities (LaPlante, Kaye, et.al, 1996; Seelman, 1995). In addition, there are a number of ways in which disability may cause or exacerbate poverty. For example, single mothers who have one or more children with disabilities face an increased risk of living in poverty compared to single mothers who do not have children with disabilities (LaPlante, Kaye, et al.). The vast numbers of people with disabilities who are beneficiaries of government aid programs is an indication of the level of poverty among people with disabilities. It is estimated that 44% of TANF recipients have a disability, and approximately 38% of TANF recipients have a severe disability (Lee, Oh, Hartmann, & Gault, 2004). More than 10 million people with disabilities receive SSI, SSDI or a combination of the two programs (GAO, 2005). Although programs such as SSI, SSDI and TANF are intended to alleviate the impact of poverty by providing

income and other vital services, this article examines ways these programs serve to trap many of the recipients in poverty (see also Giliberti, this issue).

B. Asset Development and People with Disabilities

Tax relief programs designed to encourage saving, such as the Roth-IRA and 401(k) plans have been in place since the 1970s. These programs are used widely by middle and upper-income people to save money and accumulate wealth (Leydorf & Kaplan, 2001). As Sherraden (1991) puts it:

[a]ssets are the key to economic development. Individual and family development is not built on receiving and spending a certain amount of monthly income. Rather, development is built on planning for the future, accumulating savings, investing, using financial assets to support life goals, and passing along assets to offspring (p. 231).

Sherraden proposed government-sponsored matching funds programs or Individual Development Accounts to encourage individuals and families to accumulate assets and move out of poverty. In the mid-1990s, IDAs began to receive bipartisan support from the Congress and the President and were included as part of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (Leydorf & Kaplan, 2001).

IDAs provide enrolled members the opportunity to save money that is then matched when the funds are used as specified by the particular IDA program. Presently, there are two federally funded IDAs--those funded under the Assets for Independence Act (AFIA) and those funded under TANF. AFIA and TANF IDAs may be used for the limited purposes of buying a house, starting a business or for educational expenditures. In addition to these sources of IDA matching funds, a number of smaller state and privately funded programs have sprung up around the country. For example, Iowa incorporated an IDA program into its welfare reform efforts as early as 1999 (Palmer 2005). A number of states provide tax

deductions to encourage private entities to provide matching funds to IDAs. Although the elements of IDA programs vary widely and from state to state, they typically include income eligibility, permissible expenditures, education components, savings thresholds, match rates, accumulation periods, account ownership and withdrawal processes.

1. TANF IDAs

Section 404(h) of the Social Security Act authorizes the use of TANF funds for IDAs. The law limits the uses of these funds in several ways. First, the IDA participant must be eligible for assistance. If the family meets the state eligibility criteria but does not receive TANF benefits other than the IDA matching funds, or would be eligible for assistance but can no longer receive benefits because of the five-year limit on receipt of benefits, they are still eligible to participate in a TANF IDA (42 U.S.C.A. § 609(a)(7)(B)(i)(IV), 2004; U.S. HHS, n.d.). Alien families legally residing in the United States who meet general eligibility requirements under TANF are eligible for IDA participation, although they are excluded from TANF under Title IV of PROWRA (U.S. HHS, n.d.).

The second limitation on a state's use of federal funding for IDAs is that the money may only be used for a "qualified purpose." Qualified purchases include postsecondary educational expenses, a first home purchase, and expenditures towards starting a business (42 U.S.C.A. § 604(h)(2)(B)(i—iii), 2004; U.S. HHS, n.d.). The states have flexibility with regard to the "qualified purpose" requirement. The DHHS policy guidance regarding TANF IDAs specifies that states can use TANF money, "in any manner that is reasonably calculated to accomplish the purpose..." (42 U.S.C.A. § 604(a)(1)) under the TANF statute. According to DHHS guidance, this means that states may establish IDA programs using TANF money that are not governed by the "qualified purpose" limitations of §404(h) of the Social Security Act (codified at 42 U.S.C. § 604(h)) (see also U.S. HHS). A number of states have exercised this option, and DHHS Annual Report highlights

that numerous states allow withdrawals from TANF IDAs for purposes ranging from medical expenses to education of a dependent. (U.S. HHS, n.d.a). Additionally, states may use Maintenance of Effort money (the state's TANF contribution--MOE) to supplement funds in an IDA established under §404(h), supplement funds in an AFIA IDA, or fund a state designated program (U.S. HHS, n.d.b).

The final limitation on TANF IDAs--note "TANF IDAs" refers only to IDAs established under 42 U.S.C. §604(h)--is that the participant's contribution must be in an amount derived from earned income. In other words, the money does not have to come from earned income, but it must not exceed his or her earned income. For example, an individual could contribute money to an IDA that was received as a gift or that is derived from an Earned Income Tax Credit refund (42 U.S.C.A. § 604(h)(2)(C), 2004). However, the amount of money contributed must be an amount that could have been derived from the individual's earned income.

2.AFIA IDAs

The Assets for Independence Act (AFIA) (1998) provides another savings opportunity for people with disabilities. AFIA is similar to the TANF IDA program; the major difference is that individuals may be eligible to participate without being eligible for TANF. Eligible participants are described in Section 408 of the Act, which is codified as a note to 42 U.S.C. §604, the TANF IDA provision. An individual is eligible if they are eligible for TANF or if the adjusted gross income of the household is equal to or less than 200 percent of the poverty line and the net worth of the household does not exceed \$10,000. One motor vehicle and the value of the primary dwelling are excluded from consideration of the net worth of the household (AFIA, § 408(a)(1)—(2)).

TANF and AFIA IDAs differ in the way emergency withdrawals are handled. Both TANF and AFIA IDAs allow for the withdrawal of the eligible individual's

contribution to an IDA account under limited circumstances. AFIA IDAs do not allow any withdrawals within the first six months of the program; emergency withdrawals are allowed after the initial six months for medical care, prevention of foreclosure or eviction, and living expenses due to loss of employment. Participants do not receive matching funds for emergency withdrawals and must replace the funds within twelve months or be dropped from the program (AFIA, 1998, § 404). TANF IDAs allow emergency withdrawals of participant funds on a case-by-case basis as determined by state policy. (45 CFR §263.23).

Like TANF IDA funds, AFIA funds do not go directly to individuals who are eligible to participate. Instead, the funding goes to a private organization or a state agency operating a program. The federal money is then used to match contributions to individual development accounts by eligible individuals. There are AFIA IDA programs in every state.

III. Programmatic Barriers to IDA Participation by People with Disabilities

Means-tested benefits programs by definition limit the ability of participants to accumulate wealth. Households receiving means-tested benefits are required to hold liquid assets below the federal or state mandated limits. Some analysts have suggested that raising these resource limits would encourage saving among populations receiving these benefits (Hubbard, Skinner, & Zeldes, 1995). Others postulate that, "[p]ublic welfare remains the primary obstacle to alleviating poverty through asset building. For more than a half-century, poor families were denied capital because of restrictions on assets as part of the means test attached to public assistance benefits." (Stoesz & Saunders, 1999, p. 389).

However, evidence from the TANF program indicates that raising the resource limits for these programs would not, in and of itself, promote saving on the part of most recipients. In a recent study, researchers compared the savings rates of families identified as being "at risk" for receiving welfare in states that raised the asset limits

allowed under TANF and those that left the asset limits at the level allowed under Aid to Families with Dependent Children. That study revealed that raising the asset limits did not significantly alter the savings behavior of those families. Although changes to asset limits alone may not be enough to promote saving, it is true that asset limits do pose significant barriers to saving that would ultimately need to be removed to encourage a broader asset accumulation initiative for people with disabilities.

A. Asset Limitations in Programs Used by People with Disabilities

1. Social Security

The Social Security Administration has two major programs used by people with disabilities. Although people with disabilities may be Social Security beneficiaries by virtue of a parent's death or disability, the vast majority of non-elderly people with disabilities who benefit from Social Security do so through SSI or SSDI. SSI is an income maintenance program in which a person with a disability who is unable to work can access a minimal income without regard to their work history. SSDI, by contrast, is a social insurance program that provides people with disabilities who are unable to work with an income that is based on their previous work history.

a. Supplemental Security Income (SSI)

The purpose of the SSI program is to provide people with disabilities who are of limited means and unable to work with a minimum level of income (SSA 2005c). To receive a cash benefit through SSI beneficiaries must be unable to engage in "substantial gainful activity" from a medically determinable impairment that is expected to result in death or last for a period of not less than one year (20 C.F.R. § 416.905, 2004). Substantial gainful activity is defined as income earned from work of more than \$1,350 per month for blind individuals and \$810 for other individuals with disabilities (Workworld, 2005a). Single individuals are limited to \$2,000 in resources, married

individuals to \$3,000 in combined resources with his or her spouse (20 C.F.R. § 416.1205, 2004).

Earned income includes gross wages, net earnings from self-employment, income tax refunds, payments received for participation in a sheltered workshop, and certain types of royalties and honoraria (20 C.F.R. § 416.1110(a)—(e)). Unearned income includes cash or "in kind" support. Until recently, gifts of clothing were regarded as unearned income to be counted against eligibility or reduce the amount of SSI benefit. The former rule requiring the reporting of gifts of clothing was administratively burdensome and viewed as "harsh and demeaning" by beneficiaries (SSA 2005c).

Resources are defined by the Administration as cash or other "liquid resources" that could be converted to cash for the individual's support (20 C.F.R. § 416.1201(a), 2004). Income received by an individual becomes a resource if retained in the month following the one in which it was received (SSA, 1998, SI 00810.010). Recently, some of the restrictions on resources were modified including eliminating the dollar value limit on the exclusion of household items and one car, as long as the vehicle is used to meet the transportation needs of the beneficiary. Items that are held for their value are still considered resources and must, in aggregate, fall below the \$2,000 resource limit. For example, jewelry and collectables that are not worn or kept as family remembrances would count as resources (20 C.F.R. §§ 416.1216—1247, 2004).

Social Security excludes an extensive of items from being counted as resources. These exclusions apply to the recipient and their spouse, whose resources are considered to belong to the recipient and therefore can affect eligibility. One car, one house, and, as noted above, some household goods and personal effects are not considered within the resource limitation. Other specific exclusions include the beneficiary's medical equipment, wedding rings and engagement rings, Earned Income Tax Credit (EITC) refunds, funds in a dedicated account (meaning a bank account in which only SSI benefits are deposited and not commingled with other funds), the value of assistance paid through other federal benefits programs such as

housing and food stamp assistance, a burial plot and certain money set aside for burial expenses, and cash paid to reimburse the recipient for the loss of an excluded resource (i.e., an insurance payment to replace a car which was excluded from resources) (20 C.F.R. §§ 416.1216—416.1247, 2004).

An individual's receipt of SSI may be conditioned on their agreement to dispose of resources. The money that one receives as a result of the sale of such property is then counted as a resource and the person will not be eligible until that amount, combined with all their other resources, is less than \$2,000 (20 C.F.R. §§ 416.1242, 2004). If an individual gives away or sells property for less than its fair market value for the purpose of establishing SSI (or Medicaid) eligibility, they will be charged with the "uncompensated value" of the resource transferred. To determine eligibility, the Social Security Administration (SSA) divides the total value of the property transferred (the amount received by the individual in the transfer and the uncompensated value) by the amount of the maximum monthly SSI benefit. The resulting figure is the number of months the individual will be ineligible for SSI from the date of the transfer onward, up to 36 months (SSA, 1998, SI 01150.110). Under this rule, Social Security looks at transfers occurring within the six months prior to the individual's application for SSI.

If an individual sells a piece of property that would count as a resource and the sale is for \$10,000 less than its worth, the individual's resources will be said to include the \$10,000 "uncompensated value" of the property (20 C.F.R. § 416.1246(a)(1), 2004). However, if counting the uncompensated value of the property would cause the individual undue hardship then this rule may be waived by Social Security. An undue hardship would occur where a person's ineligibility resulting from the imputation of the uncompensated value of the invalid transfer would result in their being deprived of food or shelter and the federal benefit rate combined with any federally administered state supplement would exceed the individual's monthly countable income and monthly countable resources (20 C.F.R. § 416.1246(d)(3)).

According to Social Security regulations, the standard SSI benefit for an unmarried, eligible individual is \$579 per month (20 C.F.R. § 416.410, 2004). If both members of a married couple are eligible, the maximum benefit is \$705 per month (20 C.F.R. § 416.412). In addition to income and resources, the benefit level is determined by living arrangements, marital status, and state supplements. For example, if family members (excluding spouses) or unrelated others who are living with the beneficiary provide food, clothing or shelter for an SSI beneficiary, the benefit will be reduced. This rule does not apply to minor children receiving food, clothing or shelter from a parent (SSA, n.d.a). SSI beneficiaries who reside in institutions receive \$30 from SSI; the remainder of the SSI benefit goes to the institution for the beneficiary's living expenses.

All but six states supplement the basic SSI benefit. Fifteen state programs and the District of Columbia are federally administered; the state supplement is included in the SSI but the beneficiary must meet federal eligibility criteria. Thirty-five states administer these supplemental programs and are free to establish their own eligibility criteria and establish their own payment categories. States may establish their own resource limits and income exclusions regardless of whether the program is administered by the state or the federal government, so long as they do not exceed federal requirements (WorkWorld, 2005b). However, under a state- administered system, certain types of money or assets may be categorically excluded from being counted as a resource. For example, the state may not treat EITC refund money as a resource, even though the federal government does count EITC money as a resource after a grace period has elapsed (Sweeney, 2004b).

Whether administrative duties fall to the state or the federal government, there may be beneficiaries whose income is at least equal to the federal benefit level but is less than the federal and state combined level, in which case the beneficiary may receive a state supplemental payment even if he or she does not receive a federal benefit (SSA, 1998, SI 01401.001).

SSI allows beneficiaries to receive income while continuing to receive benefits. The first twenty dollars of earned or unearned income received in a month is disregarded (SSA, 2005a; 20 C.F.R § 416.1123, 2004). The beneficiary's benefit is reduced by half of the remainder of the unearned income. If a beneficiary graduates from college and receives a gift of \$220 from a relative, the next SSI check based on that month's income would be reduced by half of the \$200 in countable income. In the case of *earned* income, the first \$20 exclusion applies to all income; additionally, a \$65 exclusion for earned income is applied. If an SSI beneficiary earned \$220 their total countable income for that month would be \$135. As is the case with unearned income, the individual's SSI check would subsequently be reduced by half that amount, so \$67.50 would be taken out of their SSI check to offset their earnings. According to SSA regulations, the benefit reduction occurs two months later (20 C.F.R § 416.420; see also SSA, 2005a). Earned income is based on gross pay rather than take-home pay (20 C.F.R § 416.1110).

There are exemptions for EITC or Child Care Tax Credit refunds. These refunds are not considered a resource until nine months after the month in which they were received (42 U.S.C.A § 1382b, 2004). If the individual still has the money, in a bank account for example, and the amount combined with the individual's other resources exceeds the \$2,000 resource cap, it may affect the individual's SSI. To avoid this, the refund money can be used within the nine months exclusion period to purchase items that do not count as resources. An SSI beneficiary who is participating in an IDA that does not count as a resource for SSI (such as a TANF, AFIA or demonstration project IDA) could use their EITC refund as a contribution to their IDA.

The Student Earned Income Exclusion allows students who attend class at least 8 hours a week (12 hours per week for those still in high school) to exclude up to \$1,410 in earned income per month from SSI before triggering a reduction in SSI benefits. This exclusion is applied before the regular exclusions for earned and unearned income. The exclusion is capped at \$5,520 per year and can only be utilized by students who are 22 and younger (SSA, 2005a, p. 41).

i. Program-Wide Incentives

The Plan to Achieve Self-Support (PASS) and the Ticket to Work Programs encourage SSI recipients to work, earn income, and accumulate assets. The PASS program allows an SSI beneficiary to save money for up to 18 months to achieve a work goal under a plan approved by the Administration (20 C.F.R. § 416.1226(d), 2004). Money set aside under the plan does not count as income or resources for purposes of figuring either the amount of the SSI payment or continued eligibility for the program. The money may come from earned or unearned income (20 C.F.R. § 416.1122(c)(13)).

The PASS plan must be in writing, identify a work goal that is achievable by the beneficiary, outline a timeframe for achieving the work goal, and demonstrate how the money set aside under the plan will be kept separate from other resources. These plans may be written by someone with Social Security or by a vocational counselor, benefits specialist, social worker, or even an employer (SSA, 2005a). The Administration periodically reviews the individual's progress to ensure that they are making progress towards the goal they identified in their plan and to verify that the resources set aside are being expended to further that goal (SSA, 2005a). IDAs may be used as a part of a PASS plan. However, the uses of PASS money are limited and may not ultimately further real asset accumulation over the long term because the money must be spent on an approved activity during the limited time that the PASS plan is in force.

ii. Treatment of IDA Funds Under SSI

SSI beneficiaries may take advantage of either TANF or AFIA IDAs depending on whether or not the beneficiary is otherwise eligible under those programs. The IDA program funded by TANF excludes the individual's investment in the IDA as well as the federal match from countable assets:

Notwithstanding any other provision of Federal Law (other than the Internal Revenue Code of 1986) that requires consideration of 1 or more financial circumstances of an individual, for the purpose of determining eligibility to receive, or the amount of, any assistance or benefit authorized by such law to be provided to or for the benefit of such individual, *funds (including interest accruing) in an individual development account under this subsection shall be disregarded* for such purposes with respect to any period which such individual maintains or makes contributions into such accounts. (42 U.S.C. §604(h)(4)).

Social Security assures beneficiaries that, "earnings, the matching money, and the interest that goes into your IDA do not count as your income or resources when we figure your SSI benefit" (SSA, n.d.a).

Although the AFIA legislation excludes the federal matching funds from consideration as income or resources, the Social Security POMS—the internal operating manual used by SSA employees—indicates that: "Any earnings an individual contributes to his/her Demonstration Project [AFIA] IDA are deducted from his/her wages in determining countable income. An individual's contributions that are deposited in a Demonstration Project IDA are excluded from resources." (SSA, 1998, SI 00830.670). Finally, the Administration recently issued final regulations that exclude federal matching funds in an AFIA or TANF IDA and the interest accrued from those funds from the countable income and resources of an individual receiving SSI (SSA, 2005d). This is a codification of existing procedures as outlined above and was done to effectuate the intent of the AFIA and TANF IDA legislation.

SSA treats emergency withdrawals from a TANF-funded IDA as loans; this means that emergency funds are not counted as income and do not reduce the amount of the beneficiary's SSI check (SSA, SI 00830.665). This is also true of emergency withdrawals from an AFIA IDA (SSA, SI 00830.670).

iii. Demonstration Projects

SSA has the authority to approve demonstration projects at the state and local level that waive or alter resource and income limits in order to encourage SSI (20 C.F.R. § 416.250, 2004) and SSDI beneficiaries to work. Although this demonstration authority gives SSA the flexibility to make systematic changes that could enhance the ability of people with disabilities to accumulate wealth, the Government Accountability Office (GAO) (GAO, 2004a) reports this capacity has not been properly leveraged by SSA. The GAO found that SSA has no formal system for identifying the broad range of policy issues that could be addressed by demonstration projects, nor does SSA have a formal system for evaluating the success of past projects. The report concludes, the demonstration authority has failed to address a broad range of policy alternatives and focused instead on a relatively narrow category of programs mostly involving employment services (GAO).

Despite flaws in the development and administration of demonstration projects identified by the GAO, there are a number of these programs that deserve mention. The Cash and Counseling Demonstration Project is one recent program that has generated a fair amount of excitement. This demonstration project began in Arkansas, Florida and New Jersey and has since expanded to 11 additional states. The Cash and Counseling project allows people receiving Medicaid who need personal assistance (PA) to receive the money to pay for those services directly and then use the money to hire the individual(s) of their choice (CPAS). In addition, money that is not spent to purchase PA services may be used towards another qualified purchase, such as assistive technology (SSA, 1998, SI 60010.005). Money received through this program is excluded as income and resources throughout the duration of the demonstration project (SSA, SI 60010.010).

The Florida Freedom Initiative (FFI) is a demonstration project that attempts to build on the successes of the "Cash & Counseling" project in Florida (SSA, 2004a). This initiative allows beneficiaries to save money to pay for assistive technology, durable medical equipment, and social services without having that money counted as income or as a resource. In addition, SSA has agreed to treat money in FFI IDAs the same as

TANF and AFIA IDAs are treated; this means that neither the money deposited into an FFI IDA, nor the matching funds provided by the project, count as income or resources against the receipt of SSI. FFI IDAs are less restrictive in their definition of approved purchases and allow participants to save money for Assistive Technology and other items and services for which TANF and AFIA IDA money cannot be used (SSA). Furthermore, in lieu of the standard \$65 exclusion of earned income, SSA will exclude the first \$280 an FFI participant earns each month regardless of how the individual uses the money. SSA has agreed to a partial waiver of the "work goal" requirement under PASS, and suspension of Continuing Disability Reviews (CDRs) during participation in the FFI.

The Youth Transition Demonstration shares some characteristics with the FFI, but there are differences. The target audience for this demonstration project are people with disabilities aged 14 to 25 who are beneficiaries of SSI, SSDI or Childhood Disability Benefits, and those who are at risk for receiving such benefits. This project raises the income exclusion by increasing the amount excluded to three-fourths instead of the standard one-half after the initial \$65 exclusion has been applied. The waiver also allows participants to remain on benefits even if a CDR at age 18 determines they are no longer eligible. Additionally, the requirement that beneficiaries must be under 22 for the Student Earned Income to apply is waived. This allows participants who are in school to claim the credit up to age 25. Finally, like the FFI, this program allows beneficiaries to develop a PASS plan with post-secondary education as its ultimate goal, with the work-goal being secondary (Sweeney, 2004a).

b. Social Security Disability

SSDI offers replacement income to workers who have paid FICA taxes and are no longer able to work due to a disability. Unlike SSI, the amount of an individual's benefit is based on their work history and past earnings.

Disability determination is the same for SSI and SSDI. However, there is no resource limit for SSDI, and applicants for SSDI must undergo a waiting period of five months before receiving benefits. The waiting period is a time when the applicant is disabled and is insured (has worked the requisite number of months and paid into the Social Security Trust Fund) (20 C.F.R. § 404.315(a)(4), 2004).

Unlike SSI, SSDI benefits are contingent on the applicant or the applicant's deceased parent or spouse having worked a sufficient period of time to be "insured" by SSA (20 C.F.R. § 404.130). Adults who have been disabled since childhood may receive SSDI after having worked fewer quarters than are required for the general population (20 C.F.R. § 404.130(c)(1)). Family members of a person who is eligible for SSDI, or old-age benefits under Social Security, may receive "auxiliary benefits." An individual who became disabled before age 22 may continue to receive benefits based on a parent's work history indefinitely (20 C.F.R. § 404.350(a)(5)).

The benefits payable under SSDI vary because it is based on work history. The average benefit received by SSDI beneficiaries in 2003 was \$833 (About, 2005). SSDI, unlike SSI, provides for a "Trial Work Period" in which a beneficiary can work and earn money for up to nine months within a "rolling 60-month period" without losing benefits (SSA, 2005a, p.36). SSDI beneficiaries can earn an unlimited amount of income for a total of nine months. 1 However, benefits will cease once the trial work period has been exhausted, rather than being reduced on a month-to-month basis as in the SSI program. For 36 months following the last month of the Trial Work Period, the individual remains in an extended period of eligibility (20 C.F.R. § 404.1592a(b)). During the extended period of eligibility, SSDI payments may be reinstated without a new application being filed if the individual's income drops below SGA. The individual should receive their full SSDI benefit for any month that their earnings dropped below SGA.

A work incentive shared by SSI and SSDI is the provision for "Impairment Related Work Expenses" (IRWEs). An IRWE is an expense that a person with a disability

incurs which enables them to work. For example, the cost of attendant care, prosthetics and other medical devices may be deducted from the beneficiary's countable income. This means that an SSI beneficiary who pays \$200 for the attendant care that enables him to get to his part time job has that amount excluded from his countable monthly income. Similarly, an SSDI recipient would have that amount excluded from the determination of whether or not he was earning SGA. If an SSDI beneficiary made \$900 per month (\$90 over SGA) but paid an attendant \$200 per month out of his own pocket, the beneficiary would only have countable income of \$700, well below SGA.

An IRWE must be an expense related to the impairment, but if an expense facilitates daily living it is presumed to facilitate work. The expense is an IRWE if the cost was incurred by the beneficiary. Finally, IRWEs are taken into account in initial eligibility determinations; at one time an IRWE could only be subtracted from countable income once an individual had established eligibility for SSI and SSDI (SSA, 1998, DI 10520.001). A related provision that applies to blind beneficiaries of SSI and SSDI is the Blind Work Expense (BWE). A BWE is similar to an IRWE except that it allows the beneficiary to have 100% of all work expenses, whether impairment related or not, excluded from earned income for purposes of figuring their SSI benefit amount and in determining whether the individual is engaged in SGA (Workworld, 2005c).

2. TANF

TANF is the federal block grant program that replaced the Aid to Families with Dependent Children (see Blanck et al., 2004, 2005). Under this program, the federal government provided states with \$16.5 billion each year (GAO, 2004b p.5). In addition to federal funding, states must contribute "maintenance of effort" funding for TANF. The total cost of the program was \$28.4 billion in FY 2002 (GAO). It is estimated that 44% of TANF households are headed by someone with a disability or by someone providing care for a child with a disability (GAO, 2002b). These families are half as likely as families not affected by disability to be able to exit TANF (GAO). People with

impairments who are able to exit TANF are "less likely to be employed and more likely to receive federal supports than were people without impairments." (GAO, p.3). Not only are families affected by disability less likely to achieve self-sufficiency from all federal supports than others who leave TANF rolls, they also are more likely to report that they have no income from any source (from employment or non-TANF federal and state supports) once they exit TANF (GAO).

A recent GAO (2004b) report on the relationship between TANF and SSI found that almost all county TANF offices encourage recipients with impairments to apply for SSI. Almost two-thirds (61%) of county TANF offices followed up by assisting TANF recipients who were referred to Social Security with filling out the necessary paperwork to apply for SSI. County TANF offices reported that 86% of recipients awaiting an SSI determination are sometimes or always exempted from TANF's Work Requirements (GAO). Although most county TANF offices offer training and support to recipients with impairments even though they are exempted from the work requirements under TANF, a large number of TANF recipients who have filed applications for SSI are unwilling to take advantage of the employment supports and training opportunities available through TANF for fear of jeopardizing their chances of receiving SSI (GAO, 2004b).

3. Medicaid

Medicaid is a federal grant to the states to provide medical assistance to pregnant women, the elderly, families with dependent children, and people who are blind or disabled. The program is administered by the state and subject to broad Federal rules. "Each State decides eligible groups, types and range of services, payment levels for services, and administrative and operating procedures. Payments for services are made directly by the State to the individuals or entities that furnish the services." (42 C.F.R. § 430.0, 2004). Although Medicaid does not provide people with disabilities with direct payments like the other programs described in this article, Medicaid benefits extend beyond the fee-for-service health insurance model. Medicaid covers

institutional care, but also covers community and in home services and supports to eligible people with disabilities. Therefore, an individual's eligibility for Medicaid can impact not only their access to health services, but other services that are vital to maintaining independence. The restrictive resource and income limits a beneficiary is required to adhere to qualify for and retain this important benefit create a profound disincentive to earning and saving money.

To be eligible for Medicaid benefits, an individual must first fit into one of 25 general eligibility categories identified in the federal law. These generally fall under the rubrics of: pregnant women, children and teenagers, and the blind, aged and disabled (CMS, 2004a). Within these groups, the income and resource limits may be different from category to category and from state to state.

Under Medicaid, income is anything a person receives which may be used to purchase food, clothing, shelter or resources. Resources are anything an individual owns that can be converted to purchase food, clothing or shelter. To determine eligibility, Medicaid specific methodologies are used in applying exemptions and deductions; what remains is the individual's countable income and resources that are compared to the income and resource standards. Once the process is complete, if the categorically eligible individual has countable income and resources less than or equal to the Medicaid standards for the relevant Medicaid program, they are deemed eligible for medical assistance (NASMD).

To be eligible for federal funds, states must provide Medicaid coverage to most recipients of federally assisted income maintenance, as well as related groups that do not receive such payments. Examples of these mandatory groups include: low income families with children who meet eligibility requirements in the state's AFDC plan in effect on July 16, 1996; infants born to Medicaid-eligible women; children under age six and pregnant women whose family income is less than 133% of federal poverty level (in some states the income limit may be higher); some Medicare beneficiaries, known as dual eligibles and special protected groups, such as those no longer

receiving cash payments from SSI due to earnings from work (42 U.S.C. § 1396a(a)(10)(A)(i), 2000; CMS, 2004b).

Eleven states do not automatically enroll SSI recipients in Medicaid. These states are referred to as 209(b) states after the original section number of the Medicaid law (Social Security Act Amendments of 1972) that gives states the option of limiting Medicaid eligibility to people who would have been eligible prior to the passage of SSI in 1972 (42 U.S.C. § 1396a(f), 42 C.F.R. § 435.121). Section 209(b) is the provision that states use to require a "spend down" to establish Medicaid eligibility, and occurs when an SSI recipient fails to qualify for Medicaid because their non-SSI income or resources exceed the asset or income rates in place in the state in 1972 (Melady, 1993). To qualify for Medicaid, the individual must generally incur and be responsible for medical bills equal to the difference between the non-SSI income they have and the 1972 income cap in that state (Melady). People with disabilities may qualify for Medicaid under the medically needy program, even if their income exceeds the established income for Medicaid. States participating in the medically needy program must cover certain children and pregnant women who would qualify as categorically needy except for earnings and resources. In addition, states may opt to cover people with disabilities and others under a medically needy program (CMS, 2004b).

Thirty-five states and the District of Columbia operate medically needy programs, all of which, except Texas, include people with disabilities in their medically needy programs (Kaiser Family Foundation, 2005). A person with a disability becomes eligible for Medicaid under the medically needy program when their medical bills are equal to or exceed the difference between the individual's income and the maximum income allowed under Medicaid (CMS, 2004b).

Finally, the Medicaid Buy-In program is a way for people with disabilities to earn a significant income and accumulate wealth while receiving the benefits provided by Medicaid. The Balanced Budget Act of 1997 (BBA) and the Ticket to Work and Work Incentives Improvement Act (TWWIA) authorize states to establish Medicaid Buy-In

programs. If the Medicaid Buy-In is authorized under BBA, states can charge premiums and surcharges on a sliding scale to provide Medicaid coverage to people with disabilities who cannot qualify for Medicaid because of their earnings, but only within strict federal guidelines. Section 4733 of the BBA creates an optional categorically needy category which authorizes states to allow people with disabilities to buy-in to Medicaid if they have a net family income of no greater than 250% of the Federal poverty level after all the SSI income disregards have been applied, and meet SSI eligibility criteria except for the income limit, including the limits on unearned income and resources (CMS, 2004c). In addition, states can use more liberal income and resource methodologies than are used by SSI, but not more restrictive methodologies (42 U.S.C.A § 1396(a)(r)(2)(A), 2004).

The Ticket to Work and Work Incentives Improvement Act (TWWIA) created two new eligibility groups that could access the Medicaid Buy-In, the Basic Coverage Group and the Medical Improvement Group. Both groups require the beneficiary to be between the ages of 16 and 64 and allow states to set income and resource limits (or not to set such limits) as they see fit. As with the BBA, if a state chooses to set income and resource limits, SSI methodologies for determining the individual's income and resources are used to determine whether the individual is within those limits (CMS, 2004c).

Massachusetts has a unique Medicaid Buy-In program that was fashioned out of Section 1115(b) waivers. These waivers allow states to operate demonstration projects within their Medicaid systems that cover services not normally covered under Medicaid and allow people to qualify for Medicaid who would not ordinarily be eligible. The demonstration projects are subject to approval by CMS and are operated in five year cycles. The main criteria for the waivers is that they must be budget neutral over the whole of the program, although an individual is not precluded from participation in a waiver program because services provided under the waiver will cost more on an individual basis than the Medicaid services that person would otherwise be entitled to receive (CMS, 2004d).

Medicaid Buy-In is a potential avenue for a large number of people with disabilities who would like to work but are afraid of losing their Medicaid benefits. Over half the states (26) have active Medicaid Buy-In programs (SSA, 2004b). A number of the remaining states have plans pending approval with CMS or have legislation pending in the state house to begin the process of implementing a Medicaid Buy-In program in their state (SSA, 2004b). As mentioned, Medicaid Buy-In programs vary, especially in income and resource limits on eligibility. For example, the Medicaid Buy-In program in Michigan has no income limit for participation and beneficiaries who buy into the system can accumulate up to \$75,000 in assets before losing their Medicaid benefits (State of Michigan, 2003). On the other hand, to be eligible for the Medicaid Buy-In in Iowa, an individual's income cannot exceed 250% of the poverty level and their resources must be less than \$12,000 (Jensen, 2003).

Some people with disabilities access health coverage while earning income and accumulating assets if they meet the criteria for the Qualified Disabled and Working Individuals "dual eligibility" category for Medicaid and Medicare. This applies to people with disabilities who have lost their Medicare due to earnings from work, but have income that is less than 200% of the federal poverty level and resources of less than twice the resources allowed under SSI. There are a number of dual eligibility categories which have a variety of income and resource limits that are alternatively more or less restrictive than the limits in effect under SSI (CMS, 2005a). The benefits afforded through dual eligibility range from full Medicaid coverage to Medicaid paying the premiums and/or co-payments for Medicare Part A or B.

Section 1619(b) of the Social Security Act allows SSI beneficiaries who return to work to continue to receive Medicaid if they have been eligible in the past for a cash payment through SSI, meet the disability requirement, need Medicaid benefits to continue working, and have gross earnings that are insufficient to replace SSI, Medicaid and publicly funded attendant care services. These criteria remain a barrier to people with disabilities earning more than a threshold amount of income and affect their ability to accumulate wealth. However, a person with a disability might be able to

make a fairly significant amount of money while maintaining eligibility under 1619(b) if they can exclude some of their income through one of the following provisions: an IRWE, a blind work expense, a PASS plan, a publicly funded personal care attendant, or above average medical expenses (SSA, n.d.b). The threshold amount an individual can earn and remain eligible for 1619(b) coverage under Medicaid varies from state to state depending on the amount of earnings which would cause SSI cash benefits to stop in that state and the average Medicaid costs in that state (SSA).

IV. Programmatic Changes

The confusing eligibility rules and asset limits imposed by the programs discussed herein need to be simplified and redesigned to encourage, rather than discourage, asset building by people with disabilities. Few solutions are obvious or easy to implement without impacting the system in ways that are difficult to predict, and may cause problems that need to be remedied later on.

However, there are several changes to SSI, SSDI, TANF and Medicaid that further the joint goals of economic independence and real equality for people with disabilities. Additional ways that asset accumulation strategies may be available to people with disabilities are likely to present themselves as policymakers use asset development rather than just income maintenance strategies to alleviate poverty. Loosening the knots in the safety net that prevent people with disabilities from accumulating the assets they need to escape poverty is a daunting task. However, it is a task that policy-makers cannot shy away from if people with disabilities are to achieve meaningful equality. The following are a few of the programmatic changes that might be made to encourage asset accumulation by people with disabilities.

A. Social Security

The Social Security administration has made significant efforts to promote self-sufficiency among SSI and SSDI beneficiaries. However, many of the programs that

facilitate employment, training and asset accumulation are underused. The PASS program was being utilized by 1,598 beneficiaries in December 2004 (SSA, 2005b). This is striking in light of the fact that every individual on SSI or SSDI who needs to accumulate assets to obtain an education or start a business to achieve an employment goal is eligible to participate in the PASS program.

Similarly, the Ticket to Work program has not been used widely to enable people with disabilities to access the training and supports they need to work and earn enough income to become self-sufficient. According to a report by the Adequacy of Incentives (AOI) Advisory Group, which included representatives from SSA and from the Ticket to Work and Work Incentives Advisory Panel, too few employment networks exist to offer the kinds of diverse employment and training opportunities envisioned by the program (CSADP, 2003). This is due, in part, to the fact that the payment system under the ticket does not cover costs up-front; employment networks get paid only once the ticket holder has worked for a period of time (CSADP, 2003). Given the low percentage of people on SSI and SSDI who are able to exit the benefit system currently, offering an up-front incentive to employment networks to expand training and employment supports would be a worthwhile investment.

B. TANF

There are a number of reasons that a person with a disability may remain on TANF beyond the time limits that normally apply to recipients of TANF benefits (see Blanck et al., 2005 for a review). An SSI or SSDI eligible parent of a child or children who are receiving TANF funds has no time limit on the receipt of TANF funds. TANF gives states flexibility to establish a definition of "hardship"; states are allowed to use 20% of the TANF grant they receive to provide extensions for families which meet this definition. In 46 states, a parent with a disability meets the "hardship" criteria and may stay on TANF past the 60 month time limit (GAO, 2002a, p.7). States must continue to provide 75—80% of the level of funding to welfare prior to the passage of the legislation that replaced Aid to Families with Dependent Children with TANF. These

funds can be separated and used to provide for families beyond the 60 month time limit (GAO).

Although most of the separate state funded programs have a work-requirement, half of these provide exemptions for people with significant barriers to work, such as disability or the disability of a dependent (GAO). Most states have programs designed to assist TANF recipients with disabilities in applying for Social Security benefits (GAO, 2001). The fact that the work requirements and time limits are waived for TANF recipients and their families where disability is a factor is a recognition that the application of these rules is unfair where disability makes self-support far more difficult. However, in practice, this means that families dealing with disability tend to stay on welfare and in poverty longer than other families that receive TANF. The federal government should encourage states to implement work incentives for people in the TANF program with disabilities that mirror those that have been created for the SSI and SSDI programs. This could be achieved through grants and waivers in a fashion similar to Social Security Work incentives. These programs might be more effective in the context of TANF than they have been in the context of SSI and SSDI, because the "welfare-to-work" approach is more conducive to these types of programs and incentives.

C. Medicaid

Medicaid is currently under the Congressional microscope; the program is being examined for ways that savings can be achieved to ensure long-term sustainability (CMS, 2005b). One of the Medicaid Commission's recommendations is to increase the "look-back" period during which transfers of assets to determine Medicaid eligibility are examined from three to five years (CMS, 2005b). This change is aimed at limiting the ability of older people who anticipate needing long-term care from forcing the federal government to pay the costs of that care rather than watching their savings be depleted to pay for long-term health care needs. Nonetheless, this points out a fundamental issue with Medicaid, which is that it discourages saving to establish and maintain eligibility and actually encourages individuals to "spend down" their assets.

Changes need to be made to Medicaid to ensure long-term sustainability to be sure; however, it is important to be mindful that Medicaid has a profound impact on the lives of working-age people in need of long term services and supports. Programs like the Medicaid Buy-In and Medicaid for the medically needy should be expanded and income and resource limits for those programs raised so that people with disabilities can be sure that they will not lose access to medical care as well as other necessary services paid for by Medicaid if they choose to work and accumulate assets. Additionally, "money-follows-the-person" policies such as the Cash and Counseling programs described in this article should be employed to help people with disabilities access the services they need to work, earn money and achieve a higher degree of economic independence and stability.

Conclusion

The benefits programs that people with disabilities use to access an income, health care, food, and shelter, have the potential to both sustain and economically trap individuals. This is evident in statistics revealing how few individuals are able to attain economic independence from SSI and SSDI. While there have been a number of work incentives put in place, it is unlikely these incentives alone will meet with long-term success unless people with disabilities are able to accumulate assets that replace the benefit safety net when they earn too much to continue to receive medical or cash benefits.

In addition to suggestions for programmatic changes outlined above, there are steps policymakers may take at a federal level to rethink the relationship between public benefits and current means testing to establish or continue eligibility for individuals with disabilities. First, a federal interagency group may be tasked by an Executive Order to identify policy barriers and facilitators to asset development for beneficiaries with disabilities. Second, work group members (Social Security, Labor, CMS, Education, Administration on Children, Youth and Families at HHS, and the Treasury) could identify opportunities similar to the Florida Freedom Initiative to provide states

under demonstration authority to test strategies to promote individual saving and asset development without loss of benefits such as Medicaid, Social Security and housing assistance. These demonstration activities should include IDA matched savings plans, financial literacy and credit counseling and blend work incentive options with waivers of existing asset tests. This could help increase the current state of knowledge on variables that support asset development behavior for persons with disabilities.

Third, current benefit counseling activities supported by SSA though the BPAO need to expand their framework to assist current and potential beneficiaries with disabilities to explore longer-term objectives beyond employment to include the importance and value of asset development.

Fifteen years after the passage of the ADA, policymakers have an opportunity to compliment previous thinking about civil rights to encompass economic advancement as a means toward fuller community participation (Blanck, 2005). The means testing elements of current public policy need to be updated and rethought to embrace the notion of access to economic equality.

While Roosevelt's words at the signing of the Social Security Act that, "We can never insure 100 percent of the population against 100 percent of the hazards and vicissitudes of life..." still ring true, it is apparent that Social Security, TANF and Medicaid may be helpful in the short term but are insufficient means to address disability issues over the long term (Singletary, August 14, 2005). If we lack the political will to re-evaluate, redesign and simplify these programs to foster the economic growth, development and integration of the disability community into the broader economy, we are consigning another generation of people with disabilities to wait on the sidelines of the "level playing field" created by the ADA.

The lead author spent almost twelve years on the asset sidelines, and was finally able to use a PASS plan and work incentives programs to finish graduate school and enter the world of work. But, from personal experience, she knows how difficult, complex

and frightening the prospect of leaving the benefit system can be. "Leaving that system is a leap of faith I'm glad I took, a leap I might have taken sooner if I had known and understood that there was a net to catch me if I fell" (Ball).

Asset accumulation strategies such as IDAs provide people with disabilities the means to create a safety net of their own. This empowerment may provide people with disabilities the incentive and courage to untangle themselves from the safety net created for them by society.

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Endnotes

1. A month counts towards the Trial Work Period when an individual earns in excess of \$580 (SSA, 2003).

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