KEEPING THE CHARGE

PERSONAL AND ECONOMIC FREEDOM FOR PEOPLE WITH INTELLECTUAL DISABILITIES

An Exploration of Asset Development

2006

President's Committee for People with
Intellectual Disabilities

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PERSONAL AND ECONOMIC FREEDOM FOR PEOPLE WITH INTELLECTUAL DISABILITIES:

An Exploration of Asset Development for People with Intellectual Disabilities

2006
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The President
The White House
Washington, D.C. 20500

Dear Mr. President:

The President's Committee for People with Intellectual Disabilities (PCPID), which is made up of twenty-one members appointed by the President and the thirteen ex-officio members who represent nine Departments of government and four independent agencies, surveyed the cultural, social and political landscape that exists for persons with intellectual disabilities and their families in the course of preparing a report for you in 2004 and 2005. During these deliberations, the members of the PCPID were struck repeatedly by the lack of personal and economic resources that people with disabilities confront throughout their lives. Indeed, the most disturbing aspect of this poverty is the fact that it is "required" as a consequence of utilizing public benefits. Eligibility for public benefit requires adhering to an income limitation and an asset limitation of $2,000. For too many persons with disabilities whose life circumstances force them into this bad bargain of benefits in exchange for poverty, the bargain leads to a lifelong cycle of poverty from which they are not able to extricate themselves.

In its 2004 report entitled, "A Charge We Have To Keep: A Roadmap to Personal and Economic Freedom for Persons with Intellectual Disabilities in the 21st Century," the President's Committee identified as one of its most important recommendations the creation of a qualified disability savings account for individuals with disabilities and their families as one method of allowing persons with disabilities to accumulate assets for education, assistive technology, employment training, housing and long-term care.

After the publication of its 2004 report to the President, PCPID continued to pursue more targeted and intensive reports on the key recommendations it contained. For example, PCPID sent a report to you, Mr. President in February, 2005, on improving access to dental care, a critical need for persons with intellectual disabilities. Upon completion of the report on dental care, PCPID determined to explore its next topic: asset development and savings instruments for families and individuals with disabilities. In this endeavor, PCPID was very fortunate to find two allies – the Office of Planning and Evaluation (ASPE) and The Office of Community Service (OCS). These two components in the Department of HHS co-sponsored with PCPID a roundtable on Asset Development, which took place on March 22, 2006 and included experts on asset development from within and outside government.

PCPID is pleased to submit this report which we hope will promote further Federal understanding and prompt further Federal action with respect to broadening the reach of existing asset building policies and programs for persons with intellectual disabilities and stimulating the development of new ones. PCPID believes that asset development will prove to be a cornerstone of policy for persons with intellectual disabilities in the 21st century as government and society, in partnership, move these persons toward personal and economic freedom.

Sincerely,

Madeleine Will
Chair

Asset Development for People with Intellectual Disabilities

Introduction

It is estimated that some six million Americans of all ages, or three percent of the general population of the United States have an intellectual disability (mental retardation). Nearly 30 million, or one in ten families, are directly affected by a person with intellectual disabilities at some point in their lifetime. Intellectual disabilities present a major challenge to social, educational, health and economic systems in the United States.

The President's Committee for People with Intellectual Disabilities was first established in 1966 by Executive Order to focus on this critical subject of national concern. The Committee's primary function is to provide advice and assistance to the President of the United States and the Secretary of Health and Human Services on a broad range of matters relating to programs, services, supports, and policies that impact the lives of people with intellectual disabilities and their families.

In February, 2001 President George W. Bush declared his commitment to tearing down the barriers to equality that challenge millions of Americans with disabilities when he announced his New Freedom Initiative, established to improve the lives of Americans with disabilities by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of people with disabilities to integrate into the workforce, and promoting increased access into daily community life.

In order to continue to provide improved opportunities for people with intellectual disabilities, it is imperative that policy makers, advocacy groups and the disability community stay at the forefront of new programs and cutting edge technologies with the potential to improve the lives of people with intellectual disabilities. Asset development represents a tremendous opportunity to create greater independence, foster self-determination, and ensure people with intellectual disabilities greater access to full citizenship rights. It is the intention of the following report to heighten awareness of the challenges and opportunities of asset development for people with intellectual disabilities.

Statement of the Problem…The Issue of Asset Development

Asset development policies have the potential to create greater independence, foster self-determination, and ensure people with disabilities greater access to full citizenship rights. Many individuals with intellectual disabilities and their families struggle financially, and most people with intellectual disabilities receive a large share of their personal income through public income transfer programs (Medicaid, Supplemental Security Income, etc.).

Issues of asset development for people with intellectual disabilities reside within several larger societal trends that must be considered as part of the larger context of asset development for people with disabilities. These include the aging of individuals with disabilities and their parents and guardians, rising health care costs, and fluctuations in private and public insurance coverage.

Asset development for the poor, as originally conceived by Dr. Michael Sherraden, is inclusive for all individuals.[1] However, most asset development programs have not specifically targeted people with disabilities, and significant barriers exist for those who wish to participate while receiving publicly funded benefits.

Case Studies in Asset Development for People with Disabilities

The following case studies illustrate some of the barriers to economic self-sufficiency that people with disabilities and their families face throughout their lifespan. A barrier may result from a restrictive program rule or from the complexity of rules that are designed to promote self-sufficiency but are difficult to understand. When benefits under more than one program are involved, a barrier may result from the lack of coordination among those programs on how earnings affect the totality of benefits. And although programs and policies exist that can enable people with disabilities to become more economically self-sufficient, they often are not well publicized in the disability community.

Janice & Paul

Janice and Paul live in a Midwestern city with their families. Both have an intellectual disability and receive Supplemental Security Income (SSI) from the Social Security Administration (SSA). Both recently graduated from high school, where they received special education services, and are preparing for life as adults.

Paul is on a waiting list for support under his state Medicaid program should he ever

[1] Sherraden, M. (1991). *Assets and the Poor: A New American Welfare Policy*. Armonk, NY: M.E. Sharpe.

leave the family home. He and Janice are on a waiting list for a HUD Section 8 voucher but it will be many years before their names get to the top of the list. They have been sweethearts since Junior high school and want to get married.

While in school, Janice was referred to her state vocational rehabilitation agency. They determined that she would benefit most from a sheltered workshop, which she now attends under the state Medicaid Waiver. She earns less than minimum wage for the few hours of work available each day and wants to obtain a real job. While Paul was in school, his brother helped him find employment at the local supermarket. He has held that job for three years and now works 18 hours a week earning $8.00 an hour.

At a meeting of the two families, the issues facing these two young adults were discussed once again. One concern is that, with their current income, it would be difficult for Janice and Paul to live independently (to pay rent and utilities and buy food) even if they remained single. But if they marry, their SSI benefits will be based on a couple rate, which is 1.5 times the individual rate. In addition, the exclusions that now apply separately to their individual earnings will apply only once, to their combined earnings, so more of their earnings will be used to reduce their SSI.

Another concern is the effect of Paul's earnings on benefits. Paul now earns $576 a month. He can earn up to $1,291 a month in 2006 before his earnings zero out his SSI benefits and he then can remain eligible for Medicaid under the Medicaid While Working provisions of the Social Security Act. However, if he were receiving housing assistance and food stamps, his earnings would be offset, dollar for dollar, by the simultaneous reduction of his SSI, housing assistance and food stamps. He would be no better off, financially, than if he were not working at all.

Virginia

Virginia is a 44-year-old woman with Down syndrome who receives Social Security Disability Insurance (SSDI) benefits. She is fiercely independent and has lived for 10 years in her own apartment in a New England state. She works 15 hours a week packaging supplies at a medical company and earns slightly more than $800 a month, which does not reduce her SSDI benefits.

The cost of living is high in the area where Virginia lives and she receives no housing subsidy (the Section 8 list has long been closed) and very little in food stamps. Her monthly expenses sometimes exceed her income and she has built up a large amount of credit card debt. She has no money to save. And even if she could save enough for the home she longs to buy, her credit history would prevent a lender from granting her a mortgage.

Virginia could earn more but she understands that if she earns $860 or more a month, her SSDI benefits will stop. In 2006, earnings of $860 or more a month constitute substantial gainful activity, or SGA. SGA is a basis for terminating SSDI (but not SSI) benefits. Virginia cannot afford the loss of that income and cannot earn enough to replace it. She wants to be more self-sufficient, but does not see how she can be given these limitations.

Richard

Richard is in his early 60's. He lives in a group home in a western state and receives SSI. He has many disabilities, but he has tried to work for the last 15 years. When he works, Medicaid rules require that he turn over most of his earnings to the group home to help pay for the cost of his care. He has no opportunity to benefit financially from work. As Richard ages and the cost of his care continues to increase, Richard will have no real personal income and no assets.

As the case studies illustrate, people with intellectual disabilities and their families face significant barriers to becoming economically self-sufficient throughout their life span. These barriers cannot be traced to a single source and are not the result of the actions of any one agency, law or policy. Instead, they stem from systemic cultural and political realities that have resulted in a variety of disability and non-disability specific programs and policies that are significantly outdated and difficult to navigate due to program fragmentation and misinformation. In response to these barriers, government, advocacy groups and the disability community are encouraging dialogue to identify areas of concern and opportunities for change.

Definition of Asset Development

The following definition of "asset development" is a product of the March 22nd, 2006 Roundtable on Personal and Economic Freedom for People with Intellectual Disabilities…An Exploration of Asset Development. Roundtable participants, following considerable discussion, developed and accepted this working definition around which their small group deliberations and reports were centered. The President's Committee for People with Intellectual Disabilities offers this definition of "asset development" to the Administration as a practical way of defining resources that support and facilitate personal and economic freedom for people with intellectual disabilities.

Assets are capacities, including public and private resources that enable individuals to identify, build and manage financial, personal and social capital, and make and implement decisions that sustain and enhance the family and individual quality of life experiences.

Examples of assets include:
1) Individual assets: money, savings, stocks, real and personal property;
2) Income asset such as a job;
3) Human capital assets: skills, knowledge, and experience gained from education and training;
4) Gateway assets: community assets that consist of the value of access to family and social contacts, education, transportation, communications, health care and expert advice (such as tax and financial advice).

All citizens benefit from public services and programs that help build and sustain our society. Asset building is a complimentary policy tool. It does not replace income transfers, support services, or other public programs, but adds new capacity for reducing poverty and promoting community integration for persons with disabilities. Asset ownership empowers persons with disabilities to economically control, manage, and grow their assets over the life span ensuring they will have a valued social role in society – owner.

Asset development represents a new pillar of support for people with intellectual disabilities to ensure full citizenship rights.
Pillar 1: Income supports
Pillar 2: Service supports
Pillar 3: Asset development supports

Findings of the Committee - Research and Data

Research on Asset Development for People with Disabilities

Currently there is limited scholarship on asset accumulation and savings patterns of people with disabilities. Known barriers to asset building for people with disabilities include asset capitations and income limits for participation in certain public programs, negative stereotypes about the capabilities of people with disabilities, and lack of accessible environments and accommodations to promote participation. Known facilitators include asset building mechanisms such as individual development accounts (IDAs), financial education, and policies and programs that build individual capacity, reduce environmental barriers, and promote community integration and inclusion.

Much more information is needed to understand how to best address the asset development needs of people with disabilities. These include developing a better understanding of: 1) current asset holdings of people with disabilities and the long-term implications of asset accumulation; 2) the relationship between the mix of policies for people with disabilities including income, employment, health and tax policies, and the ability of people with disabilities to accumulate assets; 3) the capacity of current asset building programs to effectively meet needs of people with disabilities; 4) how people with disabilities believe asset development facilitates economic empowerment and community integration and inclusion; and 5) if asset development can mitigate the disability experience by developing individual capacity and lowering social and environmental barriers.[2]

Developing a stronger understanding of what is unique to the experience of living with disability and how it effects asset development over the life span is important. Existing research suggests variances in asset building needs and experiences that can inform research and policy for persons with disabilities. Specifically, savings outcomes vary by age,[3] and it is recommended that long-term independence and care planning be included in the financial education curriculum of asset building programs.[4] These findings suggest that asset building programs may tailor program options to specific audiences and that both short and long-term individual savings goals may be important for persons with disabilities.

Training and education programs are also important. Future efforts should include the development and evaluation of training curricula for consumers and asset building

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[2] Putnam, M., Sherraden, M., Edwards, K., Porterfield, S., Wittenberg, D., & Welch, P. (2005). Building financial bridges to economic development and community integration: Recommendations for a research agenda on asset development for people with disabilities. *Journal of Social Work in Disability & Rehabilitation, 4*(3), 61-86.
[3] Putnam, M., Sherraden, M., Zhang, L., & Morrow-Howell, N. Age differences in IDA savings outcomes: Findings from the American Dream Demonstration. *Journal of Aging & Social Policy (forthcoming).*
[4] Putnam, M. & Tang, F. Future planning and financial education needs for asset building among persons with multiple sclerosis in rural areas. *Journal of Social Work in Disability & Rehabilitation*, (forthcoming).

program professionals about the bundling and braiding of public and private resources, including how receipt of various tax credits interact or affect receipt of public benefits. Developing consumer, family, and professional knowledge of and commitment to asset building programs may also contribute to successful asset development.

As asset development policies for people with disabilities move forward, more research is required to generate successful asset development strategies. Additionally, increased training and education will help ensure individuals with disabilities are able to successfully participate in asset building programs.

Findings of the Committee - Asset Based Policies and Development Vehicles

Asset Development in the Supplemental Security Income Program

The Social Security Administration (SSA) believes that one of the most powerful incentives to work that it can offer its disability beneficiaries is the opportunity to leverage their earnings to acquire assets. Asset-development strategies play an important role in SSA's efforts to promote greater self-sufficiency among its disability beneficiaries, particularly those who receive Supplemental Security Income (SSI).

Eligibility for SSI is based, in part, on having limited income and resources. The SSI resources limit is $2,000 for an individual and $3,000 for an eligible couple. However, this limit (which does not apply to the home, a car, and various other property and money) appears to have little effect on the actual savings of SSI beneficiaries, which average less than $500.

The greater barrier to asset development for most SSI disability beneficiaries may be that they cannot afford to divert what little income they have from living expenses and debt maintenance to savings. It appears to be a lesson of SSA's recently concluded State Partnership Initiative demonstration that this remains true even when the resources limit is waived and earnings produce a modest increase in net income.

Social Security Research Demonstrations That Have an Asset-Development Component – Currently Available on a Limited Basis

The Youth Transition Demonstration (YTD) includes seven projects in six states: one each in California, Colorado, Iowa, Maryland, and Mississippi, and two in New York. The projects focus on young people between the ages of 14 and 25 who receive disability benefits or are at heightened risk of becoming eligible for them. The projects are designed to show how agencies and communities can integrate services and resources in ways that focus on the needs of individuals and enable them and their families to share in defining those needs and deciding how they will be met. Each project is different, but all have the same goal: to improve educational and work outcomes for young people with disabilities.

To encourage young people to take part in the YTD and to reward their efforts to work, SSA modified some of its program rules for demonstration participants. The modified rules will treat any IDA program established for YTD participants as if it were a TANF or AFIA program **– s**ubject to SSA approval of the IDA program's rules. The IDA program may allow funds to be used for assistive technology, transportation, or other purposes that support the efforts of participants to maximize their self-sufficiency.

The Florida Freedom Initiative (FFI) is a demonstration that Florida's Agency for Persons with Disabilities is conducting with a grant from the Centers for Medicare and Medicaid Services (CMS). The FFI focuses on Medicaid beneficiaries with developmental disabilities who use long-term care supports and services. Instead of agency-furnished services, participants receive a cash allowance that they use to self-direct their long-term care. The demonstration also emphasizes self-sufficiency, especially through the development of micro-enterprises.

SSA modified a number of program rules to enable SSI beneficiaries to take part in the FFI, to support the efforts of CMS and the state of Florida, and to test whether the modified rules promote work and asset building. The modified rules for FFI participants include the same IDA provision created for YTD participants.

The Plan-for-Achieving-Self-Support Program (PASS) can be an extremely effective tool for a person with disabilities to enter the workforce. In a PASS, an individual identifies the job or business that is his or her occupational goal, the steps he or she will take to achieve the goal, and the costs associated with achieving the goal. If SSA approves the PASS, it excludes any income and assets earmarked for plan expenses when determining eligibility for SSI.

In some cases, this exclusion creates eligibility for SSI and Medicaid. In others, it permits a higher SSI payment. As a result, SSI benefits replace funds used for plan expenses (up to $603 a month in 2006). PASS expenses commonly include things like: postsecondary education, training, transportation (including the purchase of a car or van), business start-up costs, assistive technology (including the purchase of a power chair or scooter), child care and personal assistance services.

Individual Development Accounts (IDAs) – Currently Unavailable to People with Intellectual Disabilities without Earned Income

Individual Development Accounts (IDAs) have become the most well-know vehicle for low-income individuals to build and save assets; encouraging and rewarding personal investing and becoming financially literate. For persons with disabilities, IDAs provide an opportunity to save towards a down payment on a home, post secondary education, or invest in a microenterprise. Unfortunately, regulations and restrictions hamper individuals with disabilities' ability to participate. Furthermore, the availability of Federal and state IDA programs is limited, and access is hampered by a lack of understanding of SSI rules and a capacity shortage to provide accommodations.

Assets for Independence Act

The Assets for Independence Act was passed in 1998 to encourage asset accumulation and self-sufficiency for low-income working families. Administered by the Office of Community Services, Assets for Independence is the Federal government's largest program for individual development accounts. There is an appropriation of about 25 million dollars for issuance of grants to promote individual development accounts (Temporary Assistance for Needy Families also has an individual development account subject to the same rules and regulations as Assets for Independence).

Grants are awarded to not-for-profit and faith-based organizations and State, local and Tribal government agencies to assist families out of poverty. This may include Community Development Financial Institutions that partner with a community-based anti-poverty group; Low Income Credit Unions that partner with a community-based anti-poverty group; and consortia of organizations and agencies that target multiple service areas. Every grantee has a financial institution partner. There are currently more than 350 AFI-funded projects throughout the US.

AFI grantees serve individuals and families with limited income and assets. Eligible individuals include: people eligible for Temporary Assistance for Needy Family benefits; people eligible for the Federal Earned Income Tax Credit; or people whose household incomes are less than 200% of the Federal poverty line.

<u>Individual Development Accounts</u> – IDAs are special purpose matched savings accounts. Every dollar an AFI Project participant saves in his or her IDA is matched with Federal grant funds and nonfederal resources. The matching rate ranges from $1 in matched funds for every $1 in savings to a high of $8 in matched funds for every $1 in savings. The IDA mechanism enables participants to acquire a lasting asset after saving for a few years. AFI participants use their IDA savings, including the matched funds, to acquire any of three primary asset types: a first home; capitalization of a small business; or post-secondary education or training.

In addition to helping participants with their IDA savings, AFI grantee organizations provide their project participants with basic training and supportive services related to family finances and financial management. These include, for example: financial education on issues such as owning and managing a bank account, a credit card, or other financial services; credit counseling and credit repair; guidance on accessing refundable tax credits including the Earned Income Tax Credit; specialized asset-specific training regarding asset purchase and ownership.

<u>Assets for Independence and People with Intellectual Disabilities</u> – The Assets for Independence program is limited in its ability to provide IDA services to people who do not have earned income, including many people with intellectual and other disabilities:

- <u>Earned Income</u> – Participants must have earned income to save in an Assets for Independence individual development account. Social Security benefits (SSI or SSDI) are not considered earned income, therefore, people who rely solely on SSI or SSDI may not open and save in Assets for Independence individual development accounts.
    - For those who qualify for an IDA, the regulations exclude matching deposits from being counted as income and the account itself from being counted as a resource when calculating public benefits. Moreover, they provide for deducting from countable income half of any earnings the account holder deposits into the IDA.

- Eligibility –Eligibility for Assets for Independence individual development accounts are based on household income and household net worth. Household income at the time of enrollment may not exceed 200% of the poverty line. Household net worth must be less than $10,000, not counting a home and one automobile. Therefore, people with disabilities who live with their parents or a guardian may be ineligible due to the parent or guardian's household income or their net worth.

- Asset Goals – Participants may use their Assets for Independence individual development account savings to purchase a first home; acquire higher education or training; or support a new or existing small business. They may also transfer their Assets for Independence individual development account to a family member.

- Savings Period – Participants must save in their Assets for Independence individual development account and purchase an asset within the grant period, which is five or six years. They cannot keep the Assets for Independence individual development account for a longer period of time.

- Nonfederal Cash Required – Grantees must provide substantial nonfederal cash to receive an Assets for Independence grant. The project budget must include at least as much nonfederal cash as the Assets for Independence grant amount. Grantees may not use funds from other federal grant programs to meet this requirement.

- Special Needs – Asset for Independence grant funds are used primarily to match participant IDA savings. Only a limited amount of the grant funds are available to support financial education, coaching or other services that participants may need.

Consideration should be given to how to make Assets for Independence more accessible to people with disabilities; particularly to people with intellectual disabilities who have limited incomes. People with intellectual disabilities who are solely receiving government benefits may want to seek employment in order to receive earned income for deposit into Assets for Independence individual development accounts, but under current regulations that limit the amount of assets that a person with disabilities may have in order to qualify for public assistance, participation in an Asset for Independence individual development account risks losing some of their government benefits.

Stepwise progression should be considered whereby people with disabilities may have the opportunities to earn income and contribute to Assets for Independence individual development accounts without losing their government benefits.

Furthermore, people with disabilities need assistance out of poverty in many ways. Opportunities should be considered for broader utilization of individual development account funds for people with disabilities who may need, for example, economic assets, such as: (1) Assistive technology equipment and modifications, (2) special adaptations to their home and work environments, (3) special communication equipment, (4) special transportation adaptations and (5) special adaptations for financial literacy assistance, and financial education and training for people with intellectual disabilities. However, people with disabilities would still need to have opportunities for saving for a first home, college education and capitalizing a business as options.

Medicaid related services and supports that contribute to asset building – Currently Available to People with Intellectual Disabilities

There are several mechanisms that states can use in conjunction with their Medicaid programs that allow for individuals to keep their income and build assets. Asset building is consistent with the President's New Freedom Initiative which encourages individuals to live and work in their community in the most appropriate setting. These mechanisms are:

<u>Medicaid Income and Asset Disregards</u> – The Medicaid program provides medical benefits to low income people who have no medical insurance or inadequate medical insurance. While the federal government establishes general guidelines for the program, the Medicaid program requirements are actually established by each state. Whether or not a person is eligible for Medicaid will depend on the state where that person lives.

To be eligible for Medicaid, an individual must fall into one of the medically needy or categorically needy groups and meet certain income limitations and thresholds. States have the option to disregard certain income and assets to enable persons to continue to receive Medicaid benefits. These assets can be accrued and used for a person's specific needs, including health, education, housing, transportation, and retirement. This option, to allow a person to accrue assets, contributes to their ability to leave an institutional setting or to remain in the community to live and work.

<u>Ticket to Work and Work Incentives Improvement Act</u> - The Act was passed in December, 1999 and includes a significant health related benefit. The Ticket to Work Act gives states flexibility to enable people with disabilities to return to work without fear of losing their health care coverage. Individuals can keep their Medicaid health care coverage even if they are earning amounts that would have exceeded Medicaid income requirements.

This provision – referred to as a Medicaid buy-in – encourages people with disabilities to obtain work, or continue to work, without the disincentive of losing their health care. Currently there are about 125,000 people nation wide who take advantage of the Ticket to Work Medicaid buy-in provisions.

<u>Medical Coverage for Children with Disabilities and their Families</u> – Starting in January, 2007, states have the option to cover children with disabilities and their families who would not have otherwise been covered because their earnings exceeded certain thresholds. This provision enables people up to 300 percent above the poverty

level to purchase Medicaid coverage for their children. In the past, families would sometimes relinquish their children because of the high medical costs associated with treating their conditions.

Health Savings Accounts and the Deficit Reduction Act – Currently Unavailable to People with Intellectual Disabilities

Health Savings Accounts (HSAs) were created by Public Law 108-173, the "Medicare Prescription Drug, Improvement and Modernization Act of 2003," and signed into law December 8, 2003. Health Savings Accounts change the way millions of people meet their health care needs because they are designed to help individuals save for qualified medical and retiree health expenses on a tax-advantaged basis.

Any adult who is covered by a high-deductible health plan (and has no other first-dollar coverage) may establish an HSA. Tax-advantaged contributions can be made in three ways:

1. the individual or family can make tax deductible contributions to the HSA even if they do not itemize deductions;
2. the individual's employer can make tax free contributions; and,
3. employers sponsoring cafeteria plans can allow employees to contribute pre-tax salary through salary reduction.

Health Savings Accounts and Medicare – To encourage saving for health expenses after retirement, individuals age 55 and older are allowed to make additional catch-up contributions to their HSAs. Once an individual enrolls in Medicare they are no longer eligible to contribute to their HSA.

Amounts contributed to an HSA belong to the account holder and are completely portable. Funds in the account can grow tax-free through investment earnings, just like an IRA.

Funds distributed from the HSA are not taxed if they are used to pay qualified medical expenses. Unlike amounts in Flexible Spending Arrangements that are forfeited if not used by the end of the year, unused funds remain available for use in later years.

Health Savings Accounts and Asset Development – Health Savings Accounts (HSA) are not designed as an instrument to encourage and promote assets development for people with intellectual disabilities. It does not assist in building and maintaining control over one's own assets for purchasing a home, starting a business and other non-health related endeavors.

The Deficit Reduction Act of 2005

There is a movement in the direction of asset development through the Deficit Reduction Act of 2005 (DRA). The law, which includes 10 titles, of which only a few address disability related issues, puts some control back into the hands of the individual or families who experience disability. Some of these new policy options include a state's ability to offer home and community based services, without the necessity of an SSA waiver, and the choice of including in its state plan the ability to offer individuals the use of self directed care and personal assistance services. Of some concern, however, are several policy provisions within DRA, including increased co-pays for medical services. The State plan option for self directed care would provide a large degree of self-direction by giving the individual control over the funds due to them. This would allow the individual or family to make their own decisions about the services they need and when they need it. This would be in lieu of giving control over to local government providers, who would be making decisions on behalf of individuals.

<u>Health Savings Accounts in the Deficit Reduction Act</u> – Health Savings Accounts (HSA) were addressed in the DRA, but under another format; Health Opportunities Accounts (HOA). However, HOAs in the DRA are limited to individuals who do not have a disability and are not senior citizens. HOAs are very clear about what populations can be included in Health Savings Accounts, and what populations would be excluded. There were concerns and criticisms that these accounts are not appropriate for people with high medical needs and expenses.

<u>Health Opportunities Accounts</u> – HOAs are reserved for the "moms and kids" population on Medicaid. However, it may be beneficial to show their value at present and where that value may be expanded in the future. Currently, the law states that no more than ten State demonstration projects will be able to offer HOAs, and they could not be extended without review, study and evaluation. However, they represent a step towards greater individual and family control over funds, which is a very promising idea.

<u>Living with Independence, Freedom and Equality</u> – After two years in the President's budget, Medicaid came up with an approach called, "Living with Independence, Freedom and Equality," or LIFE Accounts, which would allow unspent funds to build up over time. LIFE Accounts would be available to individuals and families and would provide the opportunity for self-direction and personal control over funds. The idea behind LIFE Accounts was to provide individuals and families with the ability to build assets that would not be subject to the eligibility rules under either SSI or Medicaid. Unfortunately, SSI and Medicaid did not receive the enthusiastic response that it was hoping for regarding the LIFE Accounts. It did not move legislatively, but the idea has the potential to give people with disabilities greater control over the billions of dollars that are spent on their behalf.

Population Restrictions – DRA took some small steps through HOAs. Currently, they are restricted to only certain populations, but over time, it may grow in acceptance and include other populations. It is about control and freedom for the individual and family.

Assessment Instruments – The transition from one system to another will be based on the success of proven needs assessment instruments being applied by professionals who are independent from the service delivery system. The assessments would need to be done statewide in various localities, including across high, medium and low income counties. The assessments need to be standardized and uniform in procedures and open to the public. Final success would be based on standardized assessment instruments with uniformity in their administration by professionals.

Qualified Savings Accounts (QSAs) – Currently Unavailable to People with Intellectual Disabilities

Qualified Savings Accounts represent an approach to long term planning and savings for parents and family members of people with disabilities. The concept was originally proposed by members of the President's Committee for People with Intellectual Disabilities in its report to the President for 2004.

Qualified Savings Accounts would encourage parents and families with individuals with disabilities to establish a savings account to provide for the future needs of their child or relative with disabilities.

Qualified Savings Accounts would not be tax deductible, however, all account earnings (capital gains, dividends, interest) would be tax free, making the account an attractive savings mechanism.

The earnings would not count as assets against SSI and Medicaid eligibility. The funds would be used to supplement, not supplant government benefits, and distributions would be used to pay a third-party service provider for a number of purposes, including: (1) To supplement special transportation services, (2) to buy additional family support services, (3) to hire a special aide that could offer one-to-one support, (4) to obtain additional or special eye or dental care.

The Committee proposed a limit of $11,000 for a qualified savings account. That amount represents the amount that one can give to a beneficiary without filing a gift tax return, and is consistent with statutory limits on estate taxes.

As the population ages, states have more fiscal challenges than ever before. It is important that families and advocates step up to the plate. People with disabilities are now living longer which leads to higher total medical costs over the life span. Qualified Savings Accounts would provide an opportunity for families to confront the reality that government is not going to have all of the necessary resources to assist people with disabilities. It is up to families to assist in making the life of a loved one with disabilities more meaningful.

Earned Income Tax Credits (EITC) – Currently Available to People with Intellectual Disabilities

The Earned Income Tax Credit is an anti--poverty program administered through the IRS tax code to encourage work. Last year over 21 million working families received over 37 billion dollars in EITC. Studies show that up to 20% of working families do not claim this refundable credit. In working with the TaxFacts campaign, the National Disability Institute (NDI) has found that many low wage working persons with a disability are among those eligible for the credit, but not claiming it. More trusted community organizations are needed – such as those already involved; Goodwill, ARC and Easter Seals – to work directly with the disabled to educate them about EITC. Additionally, more volunteers are needed for NDI's free tax preparation program to provide assistance to people with intellectual disabilities to file their returns. A third strategy of the TaxFacts campaign is to provide asset building strategies to persons with disabilities.

529 College Savings Plans – Currently Available to People with Disabilities, but Counted as an Asset for Calculation of Public Benefits

There is a growing interest among individuals with disabilities in pursuing education and training beyond high school. Thinkcollege.net indicates that there are over 110 post secondary education programs for people with intellectual disabilities in 28 states. One interesting pilot project being conducted across the country is designed to alter the structure of the traditional 529 College Savings plan, providing a match to the individual's savings, in order to more equitably benefit people of low incomes. Unfortunately, many people with disabilities and parents with disabilities, wanting to save for their children's educations, are being categorically excluded from these demonstration programs. This is largely because 529's are considered restricted accounts by SSA and some states' Medicaid plans. Because there is limited access (with heavy penalties), any funds saved in a 529 over the asset limitation negatively affect SSI benefits.

Aspire Act – Children's Savings Accounts – Proposed Legislation – Currently Unavailable to People with Intellectual Disabilities

In the last couple of years, bi-partisan legislation – The America Saving for Personal Investment, Retirement, and Education Act – was introduced in Congress in 2004 and again in 2005 to create a "KIDS Account" for every newborn child in America.

Under the ASPIRE Act, every child born in 2007 and beyond would automatically receive a $500 deposit into a KIDS Account once a Social Security number is issued. Children from households below the national median income would receive a supplemental deposit of up to $500 at birth, and they would also be eligible to receive dollar-for-dollar matching funds up to $500 per year for voluntary contributions. These may come from any source – including, for example, family members, corporations, and charities – but are limited to $1,000 per year from all sources. All funds grow tax-free. Access to the account prior to age 18 would not be permitted, but kids – in conjunction with their parents and financial advisors – would participate in investment decisions and watch their money grow. A KIDS Account Fund and Board would be established within the U.S. Treasury Department to hold and manage the accounts.

Two provisions may be of particular interest to persons with disabilities: there is no "earned income" requirement for contributions – contributions to KIDS Accounts can come from any source; and all amounts in KIDS Accounts are disregarded in determining eligibility for any public assistance program based on need. Funds in the account may be used tax and penalty-free for post-secondary education, buying a first home, or, of course, retained in the account for retirement.

Findings of the Committee…Observations and Ideas for Further Exploration

- EXPLORE making savings instruments available to all Americans, including people with intellectual disabilities.

- EXPLORE spending public dollars to help people with disabilities become economically self-sufficient to reduce their long term dependency on public benefits.
- EXPLORE ways to encourage policy makers to include people with intellectual disabilities and their families in the development of asset building programs and policies.

- EXPLORE ways to facilitate and measure information sharing between state agencies and organizations that serve individuals with disabilities to ensure awareness of current asset building programs and policies.

- EXPLORE ways to measure collaboration among agencies to create strong programs and policies that result in improved quality of life for people with intellectual disabilities.

- EXPLORE ways to inform state legislatures and governors of the many model programs that could benefit people with intellectual disabilities, and encourage them to work proactively to bring those programs to their respective states.

- EXPLORE avenues to educate individuals with disabilities and their families about long term financial planning, asset building and the programs and policies that affect their financial goals.

- EXPLORE the potential to expand savings instruments across the life span of people with intellectual disabilities including; post secondary education, assistive technology, employment, microenterprises, housing and long term care.

- EXPLORE opportunities for People with Intellectual Disabilities to build assets that don't necessarily require earned income (as with IDAs).

- EXPLORE long-term care policies that will not limit long-term savings options for individuals with intellectual disabilities and ensure their continued reliance on government support until death.

- EXPLORE ways to provide incentives to financial institutions to participate in fund matching programs (as with 529 College Savings Plans).

- EXPLORE the impact of current asset building policies on the family – to what extent do families invest their own money in the care of their child over the life.

- EXPLORE the use of benefits in programs such as SSI and Medicaid in asset development as permitted by the Florida Freedom Initiative.

- EXPLORE avenues for promoting the Earned Income Tax Credit and the Plan for Achieving Self Support (PASS Plan) and educating people with disabilities and their families about these underutilized resources.

Conclusion

Members of the President's Committee for People with Intellectual Disabilities sincerely believe that most Americans with intellectual disabilities want jobs in order to earn an income, seek to open savings accounts, and desire to build assets for the purposes of continued education, a first home and/or investment in a microenterprise. Yet, for many people with intellectual disabilities, such opportunities rarely exist.

This report is about American citizens searching for more freedom and opportunities in their lives, while existing concurrently with a government and society that often displays limited understanding. Although citizens with intellectual disabilities desire the same kind of opportunities as all other Americans, most have been trapped into a life of continuing poverty and dependency with no mechanism to make their way on their own. Leadership and assistance from others is required. It begins with understanding. Next comes action.

The report addresses the situation faced by many people with intellectual disabilities of the need for personal and economic survival on one hand, weighed against a desire for achievement of personal and economic freedom, including self-sufficiency, on the other.

This report highlights numerous areas of economic and financial challenges facing adults with intellectual disabilities, but clarification of such complex issues is not always simple. Once presented, barriers may seem almost insurmountable. However, the Federal government has an important role to play to help resolve these issues through legislation and policy development.

In the creation of this report, the Committee consulted with experts in economics, finance, savings instruments and asset development for people with intellectual disabilities. Many of their thoughts and ideas for solutions are included in this report.
The chair, and the members of the Committee trust that this report will be useful to the President and his staff at the White House in assisting our American citizens with intellectual disabilities improve their quality of life through the opportunities provided by asset development.

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Current Efforts to Produce Original Research on Asset Development for People with Disabilities

The Asset Accumulation and Tax Policy Project (AATPP), funded by the National Institute on Disability & Rehabilitation Research and located in the Law, Health Policy and Disability Center, University of Iowa College of Law, is the first center dedicated to asset development for people with disabilities. Working in collaboration with the National Disability Institute, World Institute on Disability, National Federation of Community Development Credit Unions, Southern New Hampshire School of Community Economic Development, and Disability Tax Research, AATPP focuses on examining asset development strategies to advance the economic and personal freedom and full community participation of individuals with disabilities.

National initiatives and outreach of AATPP include a disability course on national Credit Union Institute financial training curriculum, a 20,000 subscriber e-newsletter on asset development for people with disabilities, development of a national disability committee for Community Development Credit Unions, the Reach Up Awards for individuals with disabilities reaching their financial goals in the Wichita, Kansas pilot credit union site, development of the TaxFacts+ Campaign, and on-going research on the relation of tax policy and asset accumulation for individuals with disabilities.

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