

After a decade of demonstrations, policy

## Self-Determination After A Decade

BY TOM NERNEY

debates and implementation, it may be useful to reflect on how self-determination as a movement has evolved, where it appears to be going and why it needs to be speeded. In truth, self-determination is suffering from both confusion and compromise. It is difficult to implement in very complex systems that are organized to easily resist the structural changes required. It is labor intensive at the personal and family level.

There are, however, hopeful signs of increased understanding that self-determination is not about tinkering with the present system. It is, in fact, a vital restructuring of what we euphemistically call "long term care" in this country.

We are on the brink of a fundamental reordering of the Medicaid program by others. We are witness to the potential collapse of the community system as it has slowly evolved. We look helplessly at the growing lists of those without supports.

The central questions of the next decade will be how the system of long term supports will be organized, who will be served, and finally, what value base will under gird it. For us, today, the issue of just who will determine the answers to these questions remains an open one.

In the face of this unprecedented crisis, the anemic responses of the traditional provider and professional groups are organized around protecting the existing system and praying for increased appropriations. There is no counter offer to governors and federal officials that rests on deeply held values but acknowledges that the present system is besieged by high costs and few positive outcomes. The time has come for a more robust public policy analysis.



The ultimate goal of self-determination has endured: public dollars should be used to enable individuals with disabilities to craft a meaningful life in the community, engage in long-term relationships, and overcome the consequences of enforced poverty. It has not been easy.

### HISTORY

Self-Determination was organized since its inception not as another "program," but a reform of supports to individuals with disabilities that was based on both a set of principles and a set of new tools to change the structure of human services organizations. Self-Determination challenged everything from typical human service environments to the almost universal acceptance of enforced impoverishment.

From the first demonstration in New Hampshire, self-determination as a movement was committed to obtain "better value" for the public dollars that are raised, and then expended in the name of individuals with disabilities. The ultimate goal of self-determination has endured: public dollars should be used to enable individuals with disabilities to craft a meaningful life in the community, engage in long term relationships and overcome the consequences of enforced poverty. It has not been easy.

### THE GOOD, THE BAD AND THE UGLY

Four competing strategies overlap and have added to both the confusion and the compromises that we have seen in the past decade:

- provider choice
- person centered planning
- self directed services, and
- self-determination

The process of implementing self-determination begins with the creation of three essential "tools" or new structures: individual budgets, independent brokering

and independent fiscal management. The initial confusion in many states rested on individual budgets. A budget is a line-by-line expenditure pattern that reflects the purchases the person with a disability intends to make in order to achieve certain life goals.

When some individuals received their allocation (i.e., their amount of dollars), many states called that an individual budget. Simply assigning your budget to a provider is nothing more than provider choice, which is already a Medicaid requirement. Many simply bought back traditional services — a far cry from self-determination.

Some states decided to substitute self directed services for self-determination. That is, individuals were allowed to hire and fire key personnel to provide various supports. This approach, while surely an advance, ignored all of the deep dimensions associated with the necessity of belonging both to the community and to loved ones, as well as the necessity of addressing the personal and social consequences of poverty. It is entirely possible to "direct your own supports" and remain friendless and impoverished.

Some have substituted person centered planning for self-determination. This interpretation relies on a very paternalistic view of individuals with disabilities. Without control of the resources the goals of person centered plans remain entirely at the discretion of those who typically provide services and supports. "Power sharing" has become the mantra of some. Unfortunately, in these arrangements the "power" can

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always be withdrawn. We have high sounding language and soaring rhetoric that so often compromises the very lives of individuals with disabilities. Others, still, have simply changed the name of case management to independent support brokering, never addressing the inherent conflicts of interest and the necessity for a whole new set of skills.

Self-determination requires a new look at what passes for quality today. Human service systems gather no data on those who are forced to live in unsafe housing; those who live without long term relationships and are entirely dependent on human service personnel; or on the personal and social consequences of personal impoverishment. In fact, by concentrating on health and safety states compromise them deeply by failing to realize that health and safety for any vulnerable population depends to a great degree on the presence of long term committed relationships. So we continue to pretend at quality when we really mean liability.

The struggles to get these issues right is taking place in communities like Midland and Allegan Counties in Michigan as well as parts of Wayne County and all of Madison, Wisconsin and Dane County (to name just a few). What marks the character of the leaders in these communities is the willingness to continually revisit all of these issues and methodically re-think and re-configure. Almost all individuals in these communities have individual allocations and many have true individual budgets. But good leaders don't stop at half measures. They continually push and set very high expectations for all individuals served in these systems. These are the true leaders of tomorrow still largely unknown to the rest of the field.

### A NEW LEGISLATIVE AGENDA

The Medicaid program is broken and beset with archaic and irrational rules and regulations. Individuals with significant disabilities served by the Medicaid program are inextricably tied to the rising costs of health care and

the drag on Medicaid expenditures from institutional arrangements in every state budget. In fact, it can be argued that middle class individuals who protected their assets in order to become Medicaid-eligible for nursing homes are the largest single user group of long term care under Medicaid.

The time is now to advance a legislative agenda that recognizes that defense of the old system will no longer hold. The consequences of failure here will be the constriction of Medicaid eligibility, a huge increase in the waiting lists for those who need support and, finally, a future of significant cutbacks that will do great harm to what will soon become a minority of those who need support and currently receive it. And, we will see those unserved remain unserved.

This new agenda would include at minimum:

- Reduction of the number of nursing home beds by 50% in the next decade
- An end to institutional living for individuals with developmental disabilities and mental illness
- An end to the expensive ICF-MR program
- Support for the dollars being assigned to individuals, with the authority to creatively develop a personal support budget with unbiased assistance
- Change to the Medicaid program to allow for and create financial incentives for self-determination at both the state and the personal level
- Streamline or redo entirely the Medicaid Waiver Program
- Reduce by one half the Medicaid bureaucracy, and give states the opportunity to experiment based on the values of self-determination with the proviso that eligibility not be arbitrarily limited
- Change the Social Security Program to allow for income and asset development that

reaches a meaningful level before any reduction formula kicks in for SSI, SSDI and Medicaid

- Create a unified funding source to match savings accounts so that individuals with disabilities can utilize both earned and unearned income to purchase housing, transportation, technology
- Encourage the use of family and private dollars in the system without jeopardizing benefits

What is remarkable about properly implemented self-determination is that it holds out the promise of real freedom, the promise of better value for the dollars (more cost efficient), and the promise of a new policy partnership which recognizes that the primary stakeholders are people with disabilities and their families and allies.

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## Self-Determination: Principles for Evaluating Your System

www.self-determination.com

Principle	Individuals with Disabilities	Families	System
People have the freedom to plan their own life and to pursue the things that are important to them with the support of independent planning and support coordination	I have the freedom to plan my life and do the things important to me. I can get help from people who are not MRDD or paid workers to make my plan work.	We can receive unbiased assistance of our own choosing when we develop a plan for our child with a disability	Unbiased, competent and independent support coordination of an individual's or family's choice is always available for both planning purposes and for assistance with ongoing monitoring, evaluation and implementation.
People have the freedom to experience the same life opportunities as other people their age, connected with others in their communities.	I have the freedom to have life experiences the same as everyone else, and be a part of my community.	We can choose those opportunities typical for all children with the assistance of resources from the system	Individuals with disabilities and families are encouraged and supported to seek personal and community connections that are age appropriate with the support of our resources. There is no fixed menu.
Each person has authority over his own individual support budget.	I have the freedom to use my individual budget to help me get the things that I need. I know everything about my budget, and I decide how it is spent.	We have the freedom to control a targeted amount of resources and to exercise creativity in purchasing supports.	Once a fair and equitable amount of resources is identified individuals and families can exercise freedom and creativity in making support purchases that assist the person with a disability to lead a meaningful life.
All those involved demonstrate confirmation of the critical role people with disabilities and their families must play in making decisions in their own lives and in designing and operating the system they rely on	Everyone understands and shows that self-advocates and their families are the most important decision-makers when:  1. I make plans for my own future, and  2. Decide about how the service system will operate.	We have the authority to implement responsible planning choices for loved ones who are minors and are an integral part of all rule making and system changes. Our adult children are listened to objectively and considered as "adults" by the human service system.	We encourage and support both responsible individual and family control over resources and enter into equal partnerships with both in all system re-design issues.
People have the freedom to choose and set up the support they need to pursue the life they envision	I have the freedom to choose the people I want to help me reach my goals.	We have the authority to select all personnel and supports to further the life goals of our loved ones.	We delegate the authority for selecting both personnel and supports to individuals with disabilities and families.
People enjoy the freedom of economic independence and security, with opportunities to earn adequate income.	I have the freedom to work and make enough money so I can support myself and have a better life.	We are encouraged and supported to assist our loved ones in planning an economic future through real work at minimum wage or above and/or microenterprise development (very tiny businesses). We are supported in planning these goals while our children are minors. Our targeted amount of resources can be used at various stages to assist in developing these opportunities.	We establish policies together with individuals and families that both encourage economic futures and provide resources to make this a reality.
People take responsibility for decisions in their lives and for the support money allocated to them with the assistance of an independent fiscal intermediary	I take responsibility for decisions I make and for how I spend my individual budget, with help from someone I choose.	We exercise great responsibility for the wise use of public dollars and receive the assistance of an independent fiscal agent.	We provide for the establishment of fiscal intermediaries and jointly with individuals with disabilities and families establish guidelines and principles for the wise and cost-effective use of public dollars.

BY TOM NERNEY and VICKIE VINING

This article addresses the Section 1915 (c) Medicaid home and community based services (HCBS) waiver program, and a recent initiative called Independence Plus. The Initiative authorizes people who participate in Medicaid HCBS programs to have choice and control over their planning, services, and a budget. The article will examine background, current trends, state examples, and future directions. This transformative undertaking within the Medicaid program aims to maximize an individual's qualities of life through greater flexibility and choice over long term supports and services.



For additional information, we invite you to visit the following CMS (Centers for Medicare & Medicaid Services) web sites: [www.cms.hhs.gov/independenceplus](http://www.cms.hhs.gov/independenceplus) (information about Independence Plus, including Sections 1915 (c) & 1115 templates and mailboxes to send questions electronically) and [www.cms.hhs.gov/medicaid/waivers](http://www.cms.hhs.gov/medicaid/waivers) (information about individual states' Independence Plus applications/programs)

### Background

*"Discrimination is a hellhound that gnaws at [people with disabilities] in every waking moment of their lives to remind them that the lie of their inferiority is accepted as truth in the society dominating them." Martin Luther King*

One need not go far back in history to find examples of segregation and incarceration of people with disabilities (Gould, 1989; Rothman & Rothman, 1984; Wolfensberger, 1975). Widespread historical practices of isolation, sterilization, and charity reflect our previously accepted social understanding of disabilities (Gould, 1989; Guess, Helmstetter, Turnbull, & Knowlton, 1987; Katz, 1983; Reilly, 1991; Wolfensberger, 1989, 1984).

In the movie, *The Grass Harp*, Walter Mathau said, "...a man who doesn't dream is like a man who doesn't sweat; he stores up a lot of poison." Despite the best intentions of professionals, our service systems of the past, and even some of the present, have

unintentionally thwarted and poisoned the dreams of the very individuals they were intended to support, depriving many of basic freedoms their fellow citizens take for granted (Wolfensberger, 1987).

In the 1990s, an emerging shift in social norms relating to people with disabilities gained momentum — the widespread recognition of the full inclusion and integration of people with disabilities proceeding from the civil and disabilities rights movements. With passage of The Americans With Disabilities Act (the ADA) and its later affirmation by the Supreme Court in the *Olmstead* decision ([www.hhs.gov/ocr/mis.htm](http://www.hhs.gov/ocr/mis.htm)), for the first time in the United States people with disabilities had some leverage to demand full assimilation. Moreover, as a result of this legislation, governments, communities and businesses were concurrently expected to assure access and provide choices (particularly with regard to community-based, long term care service options).

Also in the 1990s, on the tail of the ADA, two national disabilities pilot programs sponsored by the Robert Wood Johnson Foundation and others contributed further to revolutionizing and forever changing the long term care service delivery system in this country. Better known respectively as the Cash and Counseling (<http://www.cashandcounseling.org>) and the Self-Determination (<http://www.rwjf.org/reports/npreports/sdpdd.htm>) National Projects, these pilot efforts laid the operational foundation for service delivery

models that afforded people maximum levels of choice and control over their Medicaid long term supports and services.

For more detailed information on the research results of the grants, see the respective research organization web sites: Mathematica, <http://www.mathematica-mpr.com/disability/cashcounseling.asp>; The Center for Outcome Analysis (COA), [www.outcomeanalysis.com/DL/pubs/RWJ-SD-Final-Report.PDF](http://www.outcomeanalysis.com/DL/pubs/RWJ-SD-Final-Report.PDF); and Human Services Research Institute (HSRI), [http://](http://www.hsn.org/docs/67bRWJFEvalAb.DOC)

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### The New Freedom Initiative

In February, 2001, in his first term in office, President Bush announced the New Freedom Initiative (<http://www.hhs.gov/newfreedom/>). It was and continues to be his vision for people with disabilities in our country. The New Freedom Initiative is intended to further the goals of the ADA by promoting increased access to education and employment opportunities, to assistive and universally designed technologies, and full access to community life for people with disabilities.

On March 25, 2002, in response to the New Freedom Initiative, HHS Secretary Tommy G. Thompson presented President Bush with *Delivering on the Promise: A Compilation of Individual Federal Agency Report of Actions to Eliminate Barriers and Promote Community Integration* (<http://www.hhs.gov/newfreedom/final/>). In that report and a follow-up report entitled *Progress on the Promise*, the Department of Health and Human Services detailed 55 specific actions the Agency committed to can out or seriously consider.

Most notably, one of the HHS Agencies, The Centers for Medicare & Medicaid Services (CMS), specifically, the Center for Medicaid and State Operations (CMSO), provided a multifaceted response to the New Freedom Initiative through the following (not an exhaustive list):

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- The **Independence Plus Initiative**, which includes templates, or easy-to-follow applications, for use in preparing self-directed Waiver requests and sets forth self-directed service options,
- **Real Choice Systems Change grants**, that provide money and assistance to states to engage in meaningful systems change to address the Olmstead decision and rebalance long term care services,
- **Direct service worker grants**, providing resources to address the shortage of direct care workers, and
- **Ticket to Work activities**, including resources to remove barriers preventing people from engaging in meaningful employment.

While there has been a multifaceted response by CMS to the New Freedom Initiative, the scope of this article is exclusively focused on the Independence Plus Initiative and its influence on long term support services in the United States.

### The Independence Plus Initiative

The Independence Plus Initiative was a direct response to the challenge of President Bush's vision, and also the outcomes from states that pioneered self-directed programs through the national Robert Wood Johnson grants. The Initiative offers increased flexibility in Medicaid home and community based long term care services — most notably, through individual control over hired staff workers and a specified amount of benefit dollars over which the individual can make decisions regarding expenditures for long term supports.

CMS first introduced the Independence Plus Initiative via the publication of a Template, or application, in the Federal Register on May 9, 2002. The purpose of the Template was to enable states to design programs that afforded participants a higher degree of choice, control and supports within the

parameters of Medicaid statute and regulations, in a more efficient and user-friendly format.

Currently, an Independence Plus Program request may be submitted to CMS by a state Medicaid Agency under one of two program authorities in the Social Security Act -- either as a Section 1915 (c) Waiver or a Section 1115 Demonstration. CMS provides technical assistance to states wishing to design a

program under either authority. More specific information may be obtained on the CMS web site at <http://www.cms.hhs.gov/independenceplus/>.

A brief description of some of the program differences in the two authorities is in the Table below. For purposes of this article, only the Section 1915 (c) Waiver will be discussed because by far, the majority of state waivers fall under this category.

Table of Differences Between the §1915(c) Waivers & the §1115 Demonstrations

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Issue	PAGE 7 Section 1915(c) HCBS Waiver Authority	Section 1115 Demonstration Authority
<i>Medicaid Requirements that may be Waived</i>	Statewide Comparability of services Community income and resource rules for the medically needy	The Secretary may waive provisions of Section 1902 of the Social Security Act, if it is likely to assist in promoting the objectives of the Medicaid program
<i>Cash Allowance</i>	Participant does NOT manage the cash allowance directly	Participant MAY manage the cash allowance directly
<i>Hiring Legally Responsible Individuals (Spouse, parents of minor children, legal guardians)</i>	Participant May NOT hire legally responsible individuals unless certain requirements are met.	Participant MAY hire legally responsible individuals.
<i>Provider Agreements with State Medicaid Agency</i>	Provider Agreements MUST be executed .	Provider Agreements not necessary
<i>Direct Payment to Providers</i>	Direct Payment by the Medicaid agency (or eligible entity) to providers is REQUIRED (delegation to a provider agency IS permitted).	Not required
<i>Payment Review</i>	Pre/post payment review of claims required	Prepayment review not required
<i>Payment for Services</i>	Reimbursement occurs after service delivery	Funds available prior to service delivery
<i>Level of Care</i>	Limited to Individuals meeting institutional level of care (hospital, nursing facility or ICF/MR)	Institutional level of care not required
<i>Combining Eligible Populations</i>	Combining populations is LIMITED TO: 1) Aged/Disabled 2) Mentally Retarded or Developmentally Disabled 3) Mentally Ill 4) Any subgroup thereof	States MAY combine populations or include new or expanded populations
<i>Review Process</i>	Application/Amendment MUST be approved by CMS.	Application/Amendment MUST be approved by CMS and an External Federal Review Team. CMS generally conducts a readiness review site visit.
<i>Length of Approval</i>	Waivers are approved for 3 years and renewed in 5-year increments.	Demonstrations are approved for 5 years and renewed in 5-year increments.
<i>Financial Reporting</i>	Waiver must be COST NEUTRAL (Waiver costs may not exceed institutional costs – may be per individual or aggregated).	Demonstration must be BUDGET NEUTRAL (Demonstration costs may not exceed what CMS would have paid without the Demonstration - calculations based on Per Member/Per Month)
<i>External Program Evaluation</i>	NOT required	Required

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When a state submits an Independence Plus program application under the Section 1915(c) Waiver authority, it must comply with applicable statutory and policy requirements. Beyond these, CMS has more specific requirements for an Independence Plus program such that a state may assure the health and welfare of the participants. While all Section 1915(c) programs have health and welfare mandates, the Independence Plus programs have a unique person centered approach that vests additional control and responsibility with the individual participant, thus the additional requirements for Independence Plus programs. The added requirements are designed to emphasize the need for continuous oversight of the program's quality.

Accordingly, on March 4, 2003, CMS asked states to assure that HCBS Waiver programs having the Independence Plus "seal of approval" are comprehensive in both their scope and protections. In other words, while enabling program participants maximum choice and control in an Independence Plus program, states are likewise expected to offer necessary supports to participants to assist them in the management of their services. The requirements include:

- ? Person centered planning, where the participant directs the planning process;
- ? Individual budgets, where the participant directs how some of his or her Medicaid benefit dollar is spent;
- ? Self-directed supports, where the participant is afforded access to information and assistance with financial management and supports services to assist in the management of the self-directed process; and
- Quality management, whereby States follow the quality framework (see State Medicaid Director's letter, August, 2002), including operations intended to foster the development of systems that ensure the states' responsibility for the health and welfare of participants in the Waiver. Specifically, this includes, among others, an

incident management system, an effective emergency back up procedure, and criminal background checks.

As of January, 2005, there are 11 Independence Plus programs in 10 states, and an additional twenty three are under development - CMS awarded 12 Independence Plus grants in September, 2003, and the Robert Wood Johnson Foundation awarded 11 Cash and Counseling grants in October, 2004. These state grantees are creating Independence Plus programs as a condition of their grant awards.

INDEPENDENCE PLUS PROGRAMS	CMS INDEPENDENCE PLUS GRANTEEES	RWJ CASH & COUNSELING GRANTEEES
New Hampshire	Connecticut	Alabama
South Carolina	Colorado	Iowa
Louisiana	Florida	Kentucky
North Carolina	Georgia	Michigan
Maryland	Idaho	Minnesota
Delaware	Louisiana	New Mexico
Connecticut	Massachusetts	Pennsylvania
Florida	Maine	Rhode Island
California	Michigan	Vermont
New Jersey	Missouri	Washington
	Montana	West Virginia
	Ohio	

Of the 11 current Independence Plus programs, eight operate within the Section 1915(c) authority. These initial Independence Plus programs have given rise to a number of preliminary innovations, approaches, and trends. Because some of the program design details influence the level of choice and control participants may experience, a sampling of operational features is summarized in this article, with a state example, and a description of the flexibilities and choices the approach affords individuals within the Waiver. But first, in order to frame the discussion on program approaches, a notable clarification on the limitations of the Waiver Program is warranted.

### Differences Between A Self Direction Program and a Self-Determined Life

The Independence Plus Initiative is an effort to address increased flexibility within the parameters of Medicaid home and community based services. And while a Medicaid Independence Plus program is merely a tool

for individuals to realize greater levels of choice and control over their paid supports, self-determination is an end; it is an approach to living. In fact, a self-determined life is an end most of us with or without disabilities would endeavor to achieve. Yet for people who need long term services and supports on a daily basis, leading a self-determined life has been difficult at best. As a result of Independence Plus programs, some barriers may be removed that would otherwise significantly impede a person from realizing basic freedoms such as choice over who assists them with physical needs.

A self-determined life reaches far beyond choices associated with services and supports. Life goals and fundamental freedoms related to economic access and social justice surpass in scope the ability to have choice and control over paid supports in a Medicaid program. Suffice it to say that an Independence Plus Program is one step on the road to a self-determined life. It is a means to an end, but a "program" cannot and should not be confused with a self-determined life.

### Trends Within the Section 1915 (c) HCBS Programs that Afford Greater Degrees of Choice and Control

#### *Staff and Budget Control*

The choice to manage staff activities and benefit expenditures is an essential component of an Independence Plus program. For this reason it is necessary to understand the

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range of the term, "self-direction" in a Section 1915(c) Waiver, and to distinguish levels of choice that are permissible within the Waiver. The distinction is essential because program participants may not always wish to have control of both the staffing process and benefit expenditures, or these options may not be built into the program. Further, if a person has the opportunity to control how benefit dollars are spent, he or she may not have control over the expenditures of all benefit dollars but only a portion thereof.

### *Staffing Control: What It Is and What It Affords*

Staffing control means simply that an individual has control over staffing decisions related to the workers hired to support him or her. Many participants in waiver programs prefer not to control dollars, but prefer only to hire whom they want, decide on the hours, and direct the activities of the hired workers. This level of choice can be referred to as staffing control. In some waiver services the array of staffing control varies depending on the service. For example, a participant may not direct the funds associated with professional therapy services, but would have choice over which individual therapist to hire. Further, the participant may not have supervisory authority over the detailed activities of the therapist even though they choose who to hire. Professional services, by their very nature, rely on expertise of the provider. Thus, controlling the activities of a paid therapist may not be a reasonable thing to do.

On the other hand, for paraprofessional services such as personal assistance, a participant may desire to exercise the entire range of choices - that is, deciding on the individual staff worker, defining the specific staff activities, and supervising the staff in the performance of those activities. Personal assistance is one of the key services offered under self-directed programs, and it is by far the most frequent service that states choose

to offer through a self-directed service delivery model.

One final note on staff control - a participant in a waiver program may be provided the option to act as employer of record for their staff workers. This means the person becomes the entity ultimately responsible for the employment of the individual worker. In this situation, CMS requires the state to provide self-directed support services to help the person with such employment activities as assistance with payroll, worker taxes and insurance.

All of the choice options described above are premised on the design of the HCBS Waiver program in which the individual participates. CMS encourages states to allow maximum choice and control through the Independence Plus program, because it is most likely that an individual will obtain the full array of choice options within such a program.

### *Agency- With- Choice*

The concept of Agency-With-Choice in a self-directed program means that the "Agency is the common law employer of the worker. The individual is the managing employer of his/her worker and actively participates in recruiting, training, supervising & discharging workers. The Agency also may provide supports to individuals and workers (e.g., skills training). (Flanagan, 2004)."

In an Agency-Widi-Choice model the individual, as the above definition denotes, is usually *not the* employer of record but does have staffing control, as in the recruiting and hiring of workers, and overseeing many day to day activities of the worker. The primary distinction here is with the employer-of-record responsibilities. In the Agency-With-Choice model the Agency acts as the responsible part}', while the individual maintains many of the benefits associated with being an employer. Further, the individual may not have an individual self-directing budget. Controlling how the Waiver benefit dollars are spent is not a level of choice that necessarily accompanies the Agency-With-Choice model; the two are mutually exclusive. Again, specific choices offered to an individual within the Waiver are ultimately found in the states' design of the Waiver.

Kansas: Kansas has several Section 1915(c) Waivers. Four of the Waivers contain the option for participants to have staffing control of personal assistance services within an Agency-With-Choice model. In all cases, the agency acts as the employer of record and provides financial management of payroll, taxes and insurance. The individual has say over hiring and some supervisory activities. Often, the Agency provides additional support services, including assistance with recruiting and training staff. For more information, the CMS promising practices web site will soon have a write up on the Kansas Agency-Widi-Choice model. The web site is located at:  
<http://www.cms.lilis.gov/promisingpractices/selfdir.asp>

### *Individual Budgets: What they Are and What they Afford*

In addition to offering choice in the hiring and supervision of staff workers, HCBS Waiver programs may allow participants to direct how a specified portion of benefit dollars are spent. As one of the foundations and defining criteria of an Independence Plus program, the individual self-directed budget (or benefit dollars over which a participant has control) is a critical component in a comprehensive self-directed program. The CMS definition of an individual budget is "the value of services and supports under the control & direction of the participant."

Simply, an individual budget affords program participants the ability to decide how their benefit dollars are spent. This decision-making begins at the planning process and culminates in the implementation of the individual plan. That is, control over benefit dollars begins with an individual having the flexibility to decide what supports will best meet his or her needs, and then the ability to make changes when necessary. The individual budget in concert with a person centered planning process allows for this.

The array of choice and control an individual may have with regard to spending the waiver benefit dollars in a Section 1915(c) Waiver program includes: establishing rates for service workers, deciding on how much of

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the total benefit is spent on various approved Waiver services, and the ability to move benefit dollars among specified Waiver services. However, it is necessary to distinguish between an individual's self-directed budget and the total Waiver benefit allocated to the person. The self-directed budget is only the portion of the benefit that an individual may direct - often a subset of the total Waiver benefit the person receives. The distinction exists because some Waiver services may be delivered in accordance with an agency based service delivery model. In those cases, the individual does not direct the expenditures because in agency-delivered services, the agency determines the rate and the staff wages and charges a flat fee accordingly.

Similar to staffing control, the array of choices an individual has over a self-directed budget (or the Waiver expenditures) is premised on the state incorporating the self-directed service delivery model within the Waiver design. In other words, for participants to have a self-directed budget, there are layers of design and operational detail a state must address in the Waiver application. Primarily, a state must follow all applicable federal and state laws that relate to the use of those dollars, including at minimum, the statutory and regulatory requirements relevant to the program. For example, in a Section 1915(c) Waiver, the state must assure alignment between the individual plan and the individual's self-directed budget expenditures. Services must be delivered pursuant to a plan of care and based upon assessed needs. An individual budget must correlate with the assessed needed services.

Furthermore, when a participant is given choice over worker pay rates, a state must be able to assure that individuals do not expend all their resources on worker rates at the expense of other needed services (a potential health and welfare issue). There may also exist state laws such as licensing, and perhaps other federal statutes that apply such as

Labor laws. And ultimately, states are challenged to meet the needs of program participants in the waiver within the bottom line allocation from their state legislature. In short, the expenditure of government dollars in a Waiver program involves a variety of legal factors that must be taken into consideration when designing a Waiver program. These are only a few of the many considerations and competing priorities states must balance in the Waiver program design in order to maximize flexibility, choice and control in a Waiver, and meet their collective obligations to individual program participants, funders and regulators.

There are two very general methods states use to determine self directed individual budgets - retrospective and prospective (though there are a variety of iterations on these concepts). Essentially, this difference involves whether the individual benefit amount is determined in advance of the person centered planning process or in direct response to it. Some characteristics of the respective methods are below.

### Prospective Budgeting Method

- v Benefit amount is determined in advance of Person Centered Plan;
- v Objective assessment of need determines IB amount;
- \* Participant determines spending plan, services, supports & implementation strategy.

### Retrospective Budgeting Method

- Benefit amount is determined in response to Person Centered Plan;
- \* Participant identifies needs within Person Centered Plan;
- Participant or Agency (alone or in concert with participant) determines benefit amount, services & supports;
- Participant determines spending plan, & implementation strategy.

*Retrospective Individual Budgeting.* A retrospective budget is one that reflects the needs identified in a person centered plan; a dollar amount is usually calculated by multiplying the number of units of allowable needed services by the respective rates established for each service. The aggregated total of the

New Hampshire: In New Hampshire's developmental disabilities waiver, a process is used whereby the individual identifies his/her needs within the person centered planning process. Based on those needs, the planning team works together to establish a budget reflective of the person's individual needs. The process is based on these principles (Boggis & VanVoorhis 2004):

- Frugality of public funds
- ? Payer of Last Resort, in that other generic resources must be utilized first.
- ? Compliance with the program's standards and expectations.

calculation of these two factors - units and rates - results in an individual budget. Prospective Individual Budgeting. An increasing number of states use a budget methodology that estimates the individual Waiver benefit prior to the person centered planning process. This is often done using needs based assessment tool and calculating an associated dollar amount in response to the assessed need (usually with a statistical formula).

Wyoming: In Wyoming, a prospective budgeting process is used based on an objective assessment of individual characteristics and needs, and the subsequent application of a statistical model called regression. The process calculates an individual benefit in response to the person's characteristics and needs (Fortun 2004).

There are four principles Wyoming uses in this process, better known as the four "P"s:

- ? Personal - the model comes from individual characteristics, not the other way;
- ? Portable - the person has the funding, and it moves with him/her;
- ? Prioritized - people with the greatest need get the most; and
- ? Predictable - both the individual and system know and plan within their limits.

In either retrospective or prospective budgeting methods, a state must decide in the design phase of the Waiver which services are available for a participant to self-direct. As such, the state must have administrative procedures in place so the individual may direct services with ease, with maximum flexibility, and without administrative burden. Ultimately, in many

## Medicaid Program Innovations That Support Individual Autonomy

*Continued from page 10*

waivers, the individual decides from an array which services they wish to direct and which they prefer to have delivered through an agency based model.

The varying degrees of available control over staffing and budgeting occur at different levels in the life of a Waiver program. On the one hand, a state must decide to incorporate a range of options that offer participant control in the design of his/her Waiver. Once the Waiver is approved with these options, the individual participant must decide the level of choice and control he/she desires, and the support he/she needs in carrying out the staffing and budgeting activities.

Accordingly, there is a wide assortment of detailed features both in the program design and the individuals' situations that influence the degree of choice and control a person has over his or her long term services and supports. The Medicaid Section 1915(c) program allows for that variety, and encourages states within the Independence Plus program to offer individuals the full range of choices and supports.

### Organized Health Care Delivery Systems (OHCDS)

CMS defines an Organized Health Care Delivery System (OHCDS) as "...a public or private organization for delivering health services. It includes...a clinic, a group practice prepaid capitation plan, and a health maintenance organization." In a State Medicaid Director's Letter dated December 20, 1993, CMS recognized that states may use the concept of the OHCDS in their Section 1915(c) Waivers, however, certain conditions apply: The OHCDS must be a system that has at least one component organized for the purposes of delivering health care, and must furnish at least one Medicaid covered waiver or state plan service. The entity may contract with qualified individuals or entities to furnish other Medicaid covered services.

A state can use an OHCDS for several purposes:

- a. to consolidate some individual, non-traditional providers (for example, of personal care services) into a network;
- b. to facilitate the ability of non-traditional, individual providers to do business with the state's Medicaid Agency (making provider payments and holding a single provider agreement on behalf of all its subcontractors);
- c. to decentralize some administrative activities away from state government and closer, more accessible to participants in the waiver if problems arise, and
- d. to conduct individual financial management activities for program participants (for example, making purchases and providing expenditure reports).

As such, the OHCDS serves a crucial, enabling role for individuals, providers, and state governments in the provision of self-directed services in a Section 1915(c) Waiver. However, the OHCDS is always first and foremost, a provider in the eyes of Medicaid, and thus is necessarily one of many. Because Section 1902(a)(23) of the Act requires that an individual have free choice of all qualified providers, the state must assure that other qualified providers, if desired, may contract directly with the Medicaid Agency to furnish services under the Waiver. In other words, the OHCDS and its subcontractors may not limit providers outside their network from contracting with the Medicaid Agency.

**Maryland:** Maryland uses the organized health care deliver)' system approach for financial management in their New Directions waiver for individuals with developmental disabilities (see <http://www.ddmaryland.org/waiver.htm>). Each OHCDS handles some of the local administrative functions associated with non-traditional subcontractors or individual providers, including making payments. Every OHCDS holds one provider agreement with the State's Medicaid Agency. The OHCDS acts as an agent or "super contractor" of the individual providers, easing the administrative load for the Medicaid Agency', its subcontractors, and importantly, the participants in the program who use the OHCDS to handle the financial management functions.

### Abbreviated Provider Agreements

Section 1902(a)(27) requires that every provider in a Section 1915(c) waiver program have an agreement with the state's Medicaid Agency. The usual Medicaid provider agreement is not reasonable for small or occasional purchases. The abbreviated provider agreement, on the other hand, is a very short and concise compilation of all the Medicaid requirements to which a provider in the Section 1915(c) home and community based waiver must agree.

An abbreviated provider agreement allows the use of Medicaid dollars to purchase medically necessary supplies (for example, diapers, materials to build a ramp, and so on) from a discount or drug store in an easy and efficient way, so long as it is an approved service category in the waiver. The abbreviated provider agreement can be incorporated into the purchasing process so that purchases such as this are accomplished easily, reducing unnecessary bureaucratic time and expenditure. Ultimately this enables a more efficient use of waiver dollars so the individual may stretch his or her budget for other medically necessary services.

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**South Carolina:** South Carolina pioneered the abbreviated provider agreement in their Independence Plus waiver, working in conjunction with CMS. The Agreement is illustrated on page 12. It is printed on the back of a check, and is used primarily for one time allowable waiver purchases.

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### Innovations and Future Directions

Other trends that have great promise but less application within the scope of the Section 1915 (c) Waiver program include self-directed support corporations and provider co-ops. While these innovations are currently being piloted, CMS is working to understand their place within the statutory and policy environment of the applicable Medicaid program authorities.

*Self-Directed Support Corporation.* The self-directed support corporations (SDSC, aka, the Microboard concept) is a legally design-

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## Medicaid Program Innovations That Support Individual Autonomy

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nated corporation that has a board of

<http://www.tnmicroboards.org/What%20is%20a%20Microboard.htm>

*Provider Cooperatives.* Cooperatives exist all over the world through such diverse applications as insurance, agriculture, food,

A Human Services Cooperative (HSC) is being piloted in Arizona with the award of 2003 CMS Real Choice Systems Change grant for Consumer Directed Personal Assistance Support Services (C-PASS). It was implemented within the State's Section 1115 Medicaid Demonstration program.

In this model the program participants own the Medicaid provider and subcontract with professionals to administer the services. Program participants also direct their benefit expenditures and act as employer of record for their direct care workers. One of the goals of the HSC is to realize cost savings through collective purchase of insurance, equipment and the use of technology, (see the following web site for a more detailed description of the grant:

<http://www.hcbs.org/files/36/1799/azcpass.htm>

### Conclusion and Next Steps

The degree of innovation as a result of tilt New Freedom Initiative and the resultant CMS Systems Change grants is profound, and program trends continue to evolve. The latest examples of the innovations can be found on the CMS Promising Practices web site:

<http://www.cms.hhs.gov/promisingpractices/selfdir.asp>

One noteworthy change at CMS is the formulation of a new and comprehensive Section 1915(c) Waiver application, to be released for comment in Spring, 2005. The draft application will enable states to easily incorporate self-direction within the standard Section 1915(c) electronic application. The draft application will allow the incorporation of varying degrees of self-direction in a clear, easy to complete format.

While use of the application will be voluntary, it accomplishes many of the same outcomes the Independence Plus Template did — providing a straightforward set of program requirements that can be completed without difficulty in an electronic format by states submitting Section 1915(c) Waiver applications. Furthermore, the integration self-direction options within the standard Program application is evidence of the approach

### Abbreviated Provider Agreement from South Carolina

Date: \_\_\_\_\_

**Agreement between the South Carolina Department of Health & Human Services (DHHS), Community Long Term Care and**

Provider \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

The provider agrees to accept check(s) for item(s) or service(s) purchased for individuals served through Community Long Term Care. Financial management, for these purchases, is provided by \_\_\_\_\_ which is not a South Carolina government agency. Acceptance and endorsement of the check(s) will signify that the provider agrees to the following terms and conditions:

1. Accept payment, in form of check(s), from \_\_\_\_\_ doing business in \_\_\_\_\_
2. Agree to keep records of the service(s) or purchase(s).
3. Provide only the service(s) or item(s) authorized on the check(s).
4. Accept the check(s) as payment in full for the service(s) or item(s) purchased.
5. No additional charges will be made or accepted from clients.
6. Upon request, provide DHHS or its designee information regarding the service(s) or purchase(s) for which payment was made.

\_\_\_\_\_ DHHS Representative                      \_\_\_\_\_ Provider Representative

directors whose primary purpose is to manage the waiver services in partnership with a participant. Because the Board consists of the individual's unpaid support network, the end result is a provider who acts totally in the best interest of the person (Golden, 2004). In many cases the SDSC conducts the financial management of the individual's services, and in some cases acts as the employer of record for staff workers. The SDSC had its origins in the Microboard concept piloted in British Columbia in 1989 (see their web site for more information: <http://www.microboard.org/whatis.html>)

For more information on SDSC applications within the United States see the following web sites: [http://www.ucp.org/ucp\\_generaldoc.cfm/1/8/11210/11210-11210/2614](http://www.ucp.org/ucp_generaldoc.cfm/1/8/11210/11210-11210/2614)

housing, and banking. In recent years, both human service providers and advocates have investigated the applicability of cooperatives within the human service domain, specifically in response to self-direction. From the authoritative website on cooperatives, the International Cooperative Alliance (1996) defines a cooperative as: "...an autonomous association of persons united voluntarily to meet their common economic, social, and cultural needs and aspirations through a jointly-owned and democratically-controlled enterprise....Cooperatives are based on the values of self-help, self-responsibility, democracy, equality, equity, and solidarity. In the tradition of their founders, co-operative members believe in the ethical values of honesty, openness, social responsibility, and caring for others (The International Cooperative Alliance, 1996) <http://www.wisc.edu/uwcc/icic/issues/prin/21-cent/identity.html>

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## Medicaid Program Innovations That Support Individual Autonomy

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has gained a foothold into mainstream Medicaid program practices, a critical source of assistance for individuals with long term support needs in the United States.

The advances taking place affect millions of people in our country who participate in the Medicaid program. Cumulatively, these developments are indication of a genuine focus on solving administrative barriers so people who need long term support services need not give up fundamental freedoms to enjoy improved qualities of life.

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Are you looking for a way to communicate with other TASH members from across the country and around the world?

**Consider joining TASHUpdate!**

TASHUpdate is an internet discussion group that covers all aspects of progressive disability policy, practice and thought. It is a vehicle for seeing what others are doing, getting ideas and information, and bouncing your thoughts off of others who share your values and concerns.

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<p style="text-align: center;"><b>Report to President Bush</b></p> <p style="text-align: center;"><b>A CHARGE WE HAVE TO KEEP</b></p> <p style="text-align: center;"><b>A Road Map to Personal and Economic Freedom for Persons with Intellectual Disabilities in the 21st Century '04</b></p> <p style="text-align: center;"><b>[President's Committee on People with Intellectual Disability Endorse Self-Determination and Income and Asset Development]</b></p>	<p style="text-align: center;"><b>England Moves to Individual Budgets</b></p> <p><b>Prime Minister's Strategy Unit report to transform the life chances of disabled people</b></p>
<p>It will take time to change the decades-old policies of the 20th Century that have created unnecessary barriers to opportunities for Americans with disabilities. The recommendations contained in this document are for the 21st Century and are not expected to be addressed simultaneously or within a short time-frame, but to be carried out judiciously over a period of time to allow for effective implementation. We are determined to bring about the recommendations for the changes contained in this Report and have committed ourselves to this effort. Mr. President, this is in keeping with your New Freedom Initiative, which you issued shortly after you were sworn into office in 2001.</p>	<p>The Government has today published a radical strategy for transforming the life chances of disabled people. The final report "Improving the Life Chances of Disabled People" states that, by 2025, disabled people should have full opportunities and choices to improve their quality of life and be respected and included as equal members of society.</p>
<p><b>A Small Sample of Recommendations from the Report</b></p> <ul style="list-style-type: none"> <li>• The President's Committee supports new emerging opportunities for students with intellectual disabilities to become involved in various transitional programs located at two year colleges or four year universities, or to participate in vocational education and training programs in integrated community-based settings. Additionally, continuing education and training should be made available to people with intellectual disabilities, as it exists for other people in our society. To implement such options, there is a need for funding support from a variety of sources, such as IDEA, vocational rehabilitation, Medicaid waivers, and other appropriate sources.</li> <li>• Dual enrollment, a relatively new development for students with intellectual and other disabilities, allows them to complete high school while attending a two or four year college with same-age peers, pursue an academic or vocational curriculum, or a combination of both, in an inclusive setting. Such opportunity permits students with disabilities to remain eligible for services under IDEA, if deemed appropriate by the IEP.</li> <li>• Mr. President, in your State of the Union Address on January 20, 2004,— you announced the Jobs for the 21st Century initiative.— This initiative should include students with intellectual disabilities in all of its facets. Those facets encompass improvement in reading instructions, acquisition of reading skills, improvement in post-secondary education outcomes, and improvements in postsecondary employment opportunities for all individuals with intellectual disabilities. Grants under this initiative should be considered on a pilot basis to provide incentives to educate and serve people with intellectual disabilities. Grants should also foster community-based initiatives that lead to improved employment and post-secondary outcomes for students with intellectual disabilities.</li> <li>• Persons with intellectual disabilities can work, and want</li> </ul>	<p><b>Prime Minister's Strategy Unit report to transform the life chances of disabled people</b></p> <p>The joint DWP, DH, DfES, ODPM and PM's Strategy Unit report - which has been agreed as Government policy - makes recommendations across four key areas:</p> <p><b>Independent living</b> - increasing disabled people's ability to live independently at home, at work and in the community with support based on personal need, choice and empowerment through a major expansion of Direct Payments in the form of individual budgets. (EMPHASIS ADDED)</p> <p><b>Early years and family support</b> - family-focused support, childcare and early education that enables families with young disabled children to achieve 'ordinary lives' and remain economically and socially included.</p> <p><b>Transition to adulthood</b> - planning focused on the individual needs of disabled young people, based on smooth provision of support and services during transition and leading to appropriate opportunities and choices in adulthood.</p> <p><b>Employment</b> - early intervention supporting disabled people to stay in touch with the labour market; improving the employment prospects of disabled people through ongoing personalised support, with employers supported in a key role, while providing security for those unable to work.</p> <p>A new Office for Disability Issues will also be established. It will be a strategic unit responsible for coordinating Government work on disability and ensuring that this fits with the wider equalities agenda.</p> <p>The Prime Minister welcomed the report and said:</p> <p><i>"The ideas outlined in this report will mean increased choice and control, personalised services and ultimately a better quality of life for disabled people. As a Government we remain totally committed to improving the opportunities for disabled people and I really believe that working together we can achieve this goal."</i></p>

- to work. Research has shown that for many of these persons, there is a perception that employment is not a realistic option. The internalized belief that one cannot work is well founded in the current policies and practices that require persons with disabilities to document inability to work as a pathway to accessing financial and health benefits.
- The presumption of an interest and ability to work by people with intellectual disabilities needs to exist among all educators and prospective employers. For this reason, meaningful work experience needs to be provided at both the secondary and post-secondary school level for the benefit of youth and young adults who are preparing for employment. This work experience should coincide with the needs of the open job market. Employers need to recruit workers with readily usable work experience.

At the federal level, initiatives must allow for the blending of resources; at the state level, agencies must consider how mandates for comprehensive services leading to employment are structured; and at the local level, resources must be brought to the table so that persons with intellectual disabilities can enter and remain in employment.

It is evident that:

*"To create a new system will require a re-design that relies on the creation of new tools and structures. They [tools and structures] include fiscal intermediaries, where a blended and targeted amount of dollars is deposited and assistance provided in complying with all applicable federal and state laws, as well as reporting requirements; independent assistance that is conflict of interest-free to help with planning and implementation; and, finally, creative and personal individual budgets that accurately reflect and help purchase hopes and ambitions for achieving the American dream that individuals with disabilities possess."*

- Thomas Nerney  
President, Center for Self-Determination

One exciting new development based on the waiver authority of the Social Security Administration (SSA) was announced in the Federal Register on February 5, 2004. It will allow individuals who enter employment to set aside some of their earnings in a savings account.

In these instances, the individual will be able to retain earnings, gradually reduce cash benefits, and preserve some of these earnings in an asset development account as a form of support in retirement years. For the Centers for Medicare and Medicaid Services (CMS), the development of comprehensive employment options, as presented under their Medicaid Infrastructure Grants, will allow continued access to health care until the individual is able to secure such benefits through the workplace. Flexibility in the use of the waivers will allow states to design a system that recognizes the economic environment in the state, the general labor force needs and the support of the individual with intellectual disabilities when entering employment. The dual waiver would be managed collaboratively, but streamlined in the application and approval process by both CMS and SSA.<sup>31</sup> The dual waiver holds great promise for

improving community-based services for people with intellectual disabilities and should be promoted nationwide.

Maria Eagle, the Minister for Disabled People, said

*"This report builds on the considerable achievements of this Government in combating disability discrimination and in delivering civil rights for disabled people through the Disability Discrimination Bill, which is currently going through Parliament. This report is the next step which sets out a radical vision for delivering choices and opportunities for disabled people over the next 20 years. It sets out a full programme of action to support disabled people in leading independent lives. This will lead to significantly greater participation and inclusion of disabled people in the economy and in society."*

Stephen Ladyman, Community Minister at the Department of Health said,

*"I welcome the Strategy Unit report as an important step towards ensuring greater independence for disabled people. Measures such as individualised budgets will give people more control by allowing them to purchase the services they need when they need them. The Government is committed to promoting independence. Later this year I will publish a green paper on adult social care - our plans to reform health and social care services to support and empower the people who use them."*

The report is also welcomed by Lord Filkin at the Department of Education and Skills:

*"I commend the Strategy Unit on this report which powerfully describes the situation facing many disabled children and young people and contains important policy recommendations which we at DfES are committed to taking forward in conjunction with our existing Change for Children Programme, and our work on the implementation of the Children's National Service Framework. The publication of this report gives us renewed momentum to improving the life chances of disabled children, young people and their families."*

Minister at the Office of the Deputy Prime Minister Yvette Cooper, praised the report's focus on housing for disabled people and said:

*'This report is a valuable contribution to improving disabled people's lives. It will help address the barriers they face in achieving independent living by increasing the accessibility of current and future homes.'*

**PURPOSE OF THE HUMAN SERVICE SYSTEM:  
to provide assistance and support so that people with disabilities can enjoy the same basic life quality expectations as other human beings**

**People live in their own homes which are safe and decent**

Adults live in homes they choose and control (determining who lives with them and what happens within the home;)

Children live with their natural family and where that is not possible with an alternative family,

**People have enduring relationships and community connections that enrich their lives and support them to pursue their life goals and to be healthy and safe**

People have connections in the community and are valued members of organizations—playing, learning, worshipping, contributing and using community resources just as other community members do

People have friendships, romantic relationships and family connections, where they have people they care about and who care about them

**Adults have the means to control their own financial security and stability**

Adults earn enough income through jobs or operating small businesses to meet their needs

People's jobs or businesses are personally satisfying to them

**People are healthy and safe**

People enjoy good health.  
People have access to adequate health care resources.  
People live safe lives but have the opportunity to take reasonable risks.

**Children receive a useful and complete education**

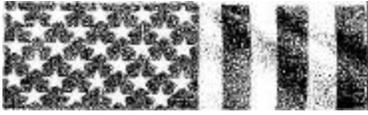
Children attend neighborhood schools, learning along side other children their age

Children receive any extra support they need to be successful in learning and participating in activities

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BY TOMNERNEY and VICKIE VINING



# System of the Future

## The Florida Freedom Initiative

**C**urrent disability benefits, employment and welfare programs interact in complex ways that often discourage consumers from seeking employment and increased wages.

Eligibility and benefit levels are often tied to earning levels. Housing/rent supplements, SSI, Medicaid, Medicare, food stamps and TANF all have the effect of reducing or disappearing when the consumer has an increase in earned income.

Nearly all individuals with disabilities could work if support and environmental changes are provided. The unemployment rate for persons with disabilities is approximately 70%. Nationally, the unemployment rate for all working adults is just over 5%.

Self determination is dependent on five basic principles

**Freedom** to develop a personal life plan

**Authority** to control a targeted sum of resources

**Support** to obtain personal goals

**Responsibility** for contributing to one's community and using public dollars wisely

**Confirmation** of the important role that self advocates must play in a newly redesigned system and support for the self-advocacy movement.

Self-determination establishes that individuals with disabilities are the planner and decision-makers in all daily living. It means working, and taking financial control of services, resources and personal income.

Florida participated in the most comprehensive demonstration of Consumer Directed Care Plus to enable participants to control and accumulate financial resources in a separate (approved) account for special purchases.

The Florida Freedom Initiative is the next giant leap for those participants in the CDC+ program to expand flexibility, control, and modest resources to obtain the freedom every citizen enjoys.

The Florida Freedom Initiative enables participants to exercise the principles of self determination following additional waivers to Medicaid and special Social Security rules to allow:

- Room and board to make typical housing more available
- Purchasing transportation (even for those who do not drive, but need to control the means of transportation)
- The ability to pay employers directly for co-worker support, training costs, transportation or temporary wage supplements.
- Flexibility in determining qualified Medicaid providers (except normal background and criminal checks)
- Allowing capitalization of very small micro enterprises up to \$1500 annually.
- Social security will not count the first \$280 plus half of anything over \$280
- The ability to establish (approved) individual development accounts (IDA). Accruing interest that will not count as income or resource. The dollars from earnings deposited will be matched privately, and the total amount that can be saved each year is \$10,000 without affecting benefits.
- The right to submit a plan for achieving self support (PASS) to SSA for secondary

education as long as the last six month of course work relates to a work goal

- Exemption from continuing disability review (CDR) while participating in the Florida Freedom Initiative

Training becomes key to ensuring that individuals, families, and consultants will have the tools to achieve goals in the self-determination effort. The training will range from public policy considerations to the most basic elements of creating a budget.

The training modules will accent:

- High expectations for lives
- Modest economic futures
- Expectation that community connections, deep personal relationships and a degree of economic security is achieved
- Responsibility of attaining better value for the public dollar expenditure
- Person Centered Planning
- Individual budgeting
- Financial Management Services
- Supports Brokerage and
- Participant protection.

Targeted participants in five regional areas will convene to structure changes that must take place to make self-determination a reality. Florida Freedom Initiative training will overlap with existing training with special attention to developing expertise on a deeper level than has been exhibited in traditional approaches. The new approaches to work and income development, better understanding of communities and more creative spending and expenditure patterns that maximize quality of persons' lives while conserving public resources are the ultimate goal-

**Real Choice Systems Change Grant for Community Living is administered by HHS and is a co-operative effort by:**

Agency for Persons with Disabilities  
 Florida Developmental Disabilities Council  
 Agency for Health Care Administration  
 Florida Department of Elder Affairs and  
 Florida Self Advocacy Groups

