

THE SYSTEM OF THE FUTURE

The time has come to fundamentally re-structure human services for individuals with developmental disabilities. After a decade of systems change projects directed at moving control of resources to individuals with disabilities and their close family and allies, enough experience has been accumulated to begin fashioning what human services needs to look like in this century.

This means that at a minimum the Federal Medicaid program and the Social Security income programs need to be changed in ways that will remove irrational prohibitions on living, working and truly being part of one's community.

The current crisis in the Medicaid program along with other crises that are reaching epidemic proportions (see The Perfect Storm below) can be a time of retrenchment and loss of supports and services; or, it can be an opportunity to forge a new and cost effective system based on the principles of self-determination.

The Meaning of Self-Determination

Just about a decade ago a small group of people with disabilities, family members and professionals set out on a new path to reform the system of support for individuals with cognitive and intellectual disabilities. These fundamental changes were predicated on the almost total loss of elementary freedoms experienced by individuals served by the human service system as well as the enforced poverty and consequent deleterious side effects experienced by these same individuals. This movement was named "self-determination" in order to capture both the personal and political dimensions of this effort.

The original principles included:

Freedom: the restoration of those decisions that go to the heart of leading rich and varied lives in the community. These include deciding where and with whom to live, how to create income and establishing important community and personal relationships.

Authority: the ability to personally control (with appropriate assistance) a targeted amount of long-term care dollars.

Support: the arrangement of these resources in ways that are unique and built on the individual preferences of the person with a disability.

Responsibility: the use of these public resources in ways that are wise and cost effective.

Confirmation: the recognition that individuals with disabilities must be part of the public policy changes necessary to implement self-determination and recognition that families and individuals with disabilities must be included in all re-design issues.

The structural reforms necessary to carry out these changes include the development of fiscal intermediaries where public dollars for one's support would be deposited; the creation of highly personal and unique individual budgets that would translate the person with a disability's life goals into line items in an approved budget; and, the availability of truly independent and competent support coordination in order to provide conflict of interest-free assistance to persons with disabilities and family members.

The structural changes have always been viewed as *tools* to carry out the essential foundation of self-determination. What endures as the goal of self-determination from its origins is simply the ability of a person with a disability to craft a meaningful life in the community, overcome the pernicious effects of enforced poverty and experience deep and lasting relationships.

The Perfect Storm

The system of supports and services to individuals with developmental disabilities has been inexorably moving from institution to the community over the past two decades. This must continue since resource re-allocation will become one of the few ways left to finance the supports needed by those who today remain on waiting lists. However, as the demographics cited below illustrate, the time may come when the hard analysis will involve the community system itself. What are the most expensive options, what are the outcomes for individuals served in these options, and can we justify morally and ethically expenditures for certain parts of the system at the high end when tens of thousands remain without support at all? This may become the moral equivalent of the institutional-community argument all over again with much higher stakes this time.

The collection of national waiver expenditure levels using "averages" (Braddock, 2002) masks the real expenditure patterns in the states. Without knowing the *range of spending by type of support or service and by degree of disability*, it is not possible to adequately compare states. Unlike institutional programs, community waiver programs encompass a wide range of supports from family support and respite to group homes and semi-independent living. Only when we have discrete data on each type of support with accompanying numbers and expenditures will we be able to adequately understand waiver expenditures.

The demographics of this population so clearly indicate that what we have witnessed to date with our waiting list or unserved or partially served population is simply the tip of the iceberg. During fiscal year 2000 almost 672,994 individuals with developmental disabilities nationally lived at home with a family caregiver over the age of 60. This same year almost 928,000 individuals nationally lived at home with a family caregiver

between the ages of 41 and 59 years. This represents 35% of all those living at home and means that the states will have an even larger cohort coming behind the 672,000 currently living with an aging care giver at home today. (Braddock, 2002)

When the increased competition for scarce Medicaid resources-especially for a rapidly aging population-is factored in, the crisis will only deepen. The fastest growing segment today among the elderly population are those over the age of 85. As the population of America ages and eventually moves from 12.5% to 20% of the entire population, the cohort of adult children who today account for 80% of their support, only increases by 7% (Nerney, 2001)

Together with a quickly shrinking workforce it is clear that business as usual will no longer suffice. While short-term monetary increases are necessary to keep the current system from collapsing, longer term re-thinking of the system of long-term care is necessary today.

Each of these three storms—increasingly scarce Medicaid resources, the demographics of the developmental disabilities and elderly populations, and the shrinking workforce—will very soon converge to create the perfect storm and rock the entire developmental disability system.

This is not to suggest that self-determination can ever hope to carry this burden. Self-determination is not a magic bullet and it requires careful and thoughtful re-design of the present system. However, it remains one of the few advances in the field of disability to demonstrate cost efficiency as well as increased quality. (Conroy, 2000; Conroy, 2002)

The Federal Medicaid Act and the Social Security SSI/SSDI Program

Currently

The implementation of self-determination has been slowed and sometimes stymied by irrational aspects of both Medicaid and SSI/SSDI. There are prohibitions on room and board charges under Medicaid Waiver programs but in virtually no county in the United States is someone receiving SSI able to afford to live modestly and eat. The eligibility requirements of both programs force those who cannot jeopardize essential benefits to remain totally impoverished on a personal basis. Housing is often prohibitive and transportation unavailable. It is truly difficult to craft a meaningful life based on the principles of self-determination within the strictures of these two programs.

These recommendations for this Freedom Initiative grow out of our work with a small public/private think tank in Washington, DC hosted by the President's Committee on Mental Retardation and The Office on Disability in the Department of Health and Human Services. It is part of an effort to design the "system of the future"—one responsive to individuals and families and more cost effective than the present system.

SSI and SSDI

The intersection of the SSI/SSDI and Medicaid Waiver programs pose substantial problems for individuals with disabilities who rely on both. Supplemental Security Income (Title XVI of the Social Security Act) provides base cash income of \$530 a month. In 32 states eligibility for SSI based on limited income and disability automatically makes one eligible for Medicaid.

Some individuals become eligible for SSDI (Social Security Disability Insurance or Title 11 of the Social Security Act). This generates cash income based on having insured status as a worker or a child of a worker. The benefit under SSDI is an all or nothing proposition. If one becomes eligible then the full cash benefit is calculated and the individual becomes eligible after 24 months for Medicare medical coverage—parts A and B.

The problem for individuals with intellectual or cognitive disabilities historically has been reluctance to "jeopardize" either one of these benefits by working and producing enough income to reduce or eliminate eligibility for these programs. The Social Security Administration has been aware of and attempted to address this problem since 1994.

Under the SSDI program work incentives now include trial work periods, continued eligibility up to “substantial gainful employment”, extended period of eligibility, impairment related work expenses, extended coverage or purchase of Medicare and subsidy allowances.

Under the SSI program work incentives include continued SSI eligibility even when earnings exceed substantial gainful employment, continued Medicaid coverage, impairment related work expenses, PASS plans (plans to achieve self support) and student-earned income exclusions. Under both programs substantial gainful activity is \$740. (\$1240 if you are blind) but the standards for increasing income while reducing or eliminating benefits remain utterly complex for most individuals. This has led once again to the creation of a new job, not for people with disabilities, but for professionals called “benefits counseling”.

By all accounts these modifications are not working. More individuals with disabilities are entering non-work programs today than enter the world of work and competitive or supported employment. Many who are enrolled in supported employment programs still earn below minimum wage and often work in segregated environments. Based on a simple and elementary standard of 20 hours or more per week at minimum wage or higher not much more than 6% of individuals with developmental disabilities “work”.

In virtually all counties and SMSA’s (standard metropolitan statistical areas) throughout the United States SSI income is not enough to purchase food and rent an apartment.

Medicaid Waivers

Medicaid Waiver programs for individuals with disabilities cover support costs associated with living in community settings (though often in human service environments) and attending day, vocational or work programs. Unlike the Medicaid institutional program, to which it is an alternative, Medicaid Waivers are prohibited from covering the cost of room and board. Human service providers and people with disabilities are then forced to use most or all of their SSI or SSDI income for room and board costs.

This frequently leads to congregate living arrangements in order to cover the costs of room and board and great caution in promoting anything that would jeopardize these payments. For those living at home where the family is low income these SSI and SSDI payments become very important for the financial stability of the family and family members will often counsel against the person working.

In addition to the general reluctance to jeopardize one’s own cash income, service providers join the group of those who frequently do not want to risk the steady income associated with monthly SSI and SSDI room and board payments for wages that may fluctuate or not cover the costs of room and board.

Not adequately understanding the complex Social Security rules for working can also put individuals at risk of having to pay back income mistakenly accepted.

Self-Determination

At its heart self-determination has been historically based on a set of principles that included control of the financial resources necessary for one's support. Freedom and responsibility have become the hallmarks of this movement. However, the control of resources has always been viewed as a tool not the goal of self-determination. The goal of self-determination has remained "crafting a meaningful life deeply imbedded in one's community". Understanding that a meaningful life of necessity includes those aspirations that are universal to all human beings, the exercise of ordinary freedom, the chance to earn income and become a productive member of society and engage in deep and personal relationships are now the criteria with which we evaluate the systems change associated with self-determination.

Only by addressing directly the systemic problems in both the SSI/SSDI and Medicaid Waiver programs will the forced impoverishment of individuals be adequately addressed, regular housing opportunities made available and the ordinary freedoms associated with American Citizenship be obtainable for those with developmental disabilities. The following recommendations combine a waiver of some of the current rules under the SSI/SSDI program with an experimental 1115 waiver under the Medicaid program.

The underlying assumption of this approach is the achievement of better economic and housing outcomes for individuals with disabilities with no increase in federal or state payments. These combined waivers simply provide incentives to work and live in ordinary ways—ways experienced by other non-disabled members of the community. They assume that any individual can generate private income based on creative job approaches or the development of a microenterprise that the person may receive assistance in managing. Part of this assumption rests on the acknowledgement that we simply have to find more cost-effective supports without hurting individuals with disabilities. Because so few individuals with disabilities are working we simply don't know the contribution many could make to the costs of long-term care.

Another assumption is that those enrolled in the 1115 Medicaid Waiver will automatically be enrolled in the SSI/SSDI Waiver governing income and asset limitations. *This would position a state on the cusp of true system change by creating an additional SSI/SSDI Waiver that will work seamlessly with the Medicaid 1115 Waiver.*

A final assumption is that with this increased flexibility individuals with disabilities and their close family and friends will achieve "better value" for the dollars available. With proper and unbiased assistance a

new system of long term supports may emerge that removes the disincentives to work, allows for greater flexibility in designing where and how one lives and demonstrates cost effectiveness.

The following recommendations are organized as a planning template for an actual SSI/Medicaid set of Waivers and can be easily re-prioritized and enhanced. Acknowledging the current federal approach to disability policy, this recommendation(s) is titled “The Freedom Initiative”.

THE FREEDOM INITIATIVE

Goals:

- Secure a waiver under Social Security to allow for those enrolled in self-determination to increase their income and assets
- Secure an 1115 Medicaid Waiver that allows waiving those aspects of the Medicaid program that hinder living and working in the community
- Allow individuals to enroll in both the 1115 Medicaid Waiver and the proposed Social Security Waiver in order to encourage creative approaches to housing, work and meaningful lives
- Create a study to determine the cost effectiveness of this increased flexibility and reduction of disincentives to work while increasing opportunities to control transportation and achieve affordable housing
- Create a state-wide training and re-training effort to maximize the effectiveness of using both waivers simultaneously
- Create a model systems re-design for developmental disabilities that will be replicable across the country and prove cost effective

Purpose

The Freedom Initiative is designed to demonstrate first, that when the current ceilings on income and asset limitations are raised, and Medicaid funds can be used more flexibly, individuals will overcome their resistance to earning money privately, take their place as ordinary citizens and resolve housing and transportation problems more efficiently. The second purpose is to demonstrate more cost efficiency in the use of public funds.

Objectives

The overall objective in conducting a project like this is to demonstrate whether providing additional work incentives under the SSI program will remove potential and real barriers to work for recipients of SSI benefits based on ongoing developmental disability. Under this Waiver we can test whether altering certain SSI program rules provides effective work incentives for SSI recipients and concurrent SSI/SSDI beneficiaries to attempt to work for the first time, return to work or increase their work hours and income.

A second objective is to determine whether individuals who might not otherwise work and produce income can contribute to some of the cost of long-term care as well as increase modestly their own wealth.

SSI Waiver

Written under the Social Security Act Section 1110(b)

Written to be utilized only for those participants who enroll in the 1115 Waiver for self-determination

SSI Waiver Provisions

1. \$1 reduction on *earned* income for every \$4 earned
2. \$1 reduction on *unearned* income for every \$4 generated
3. The establishment of *Freedom* accounts of up to \$10,000 per person
4. Continuing Disability Review *suspensions* for two groups participating

Provision 1

- Participants take less of a reduction as earnings increase
- Waiver participants cash benefits are reduced \$1 for every \$4 of earned income
- The current system removes \$1 for every \$2 earned
- Participants keep 25% more of his/her earnings
- No additional cost to state or federal government
- Potential for contribution increases

Provision 2

- Certain types of unearned income receive the same \$1 reduction for every \$4 of unearned income
- Under the current system cash benefits are reduced \$1 for every \$1 of unearned income
- Unearned income can come from workers compensation, unemployment insurance, private disability insurance, state disability payments and private gifts and donations

Provision 3

- Participants can save up to \$10,000 per year of both earned and unearned income in a Freedom Account without affecting benefits

- Interest and dividends are not counted as assets
- Freedom accounts can become Individual Development Accounts or matched savings accounts
- Freedom Accounts can then be targeted for highly desirable personal goals including e.g., microenterprise development and expansion, down payments on homes and transportation, and additional training and educational opportunities
- Types of Freedom Accounts can be checking accounts, savings accounts, certificates of deposit, money market and mutual funds
- Freedom Accounts would be allowed even when the person is enrolled in an employer's retirement plan which would also be exempt from being counted as an asset

Provision 4

- Medical Continuing Disability Reviews would be suspended for two groups enrolled in the dual waivers: Medical Improvement not Expected (MINE) and Medical Improvement Possible (MIP)
- CDR'S are not suspended for those who are classified as Medical Improvement Expected (MIE)
- This provision addresses those who almost never leave the SSI rolls

There are a myriad of issues that would have to be addressed in accepting enrollment into this waiver including the effect on other benefits like food stamps and Section 8 housing certificates as well as anyone with a PASS plan. The proposal would also give those dis-enrolling or when the waiver terminates up to 24 months to "spend down".

It is also possible for fiscal intermediaries to accept the reporting requirements under this waiver as well as the 1115 one. Together with a small research component the results can be tracked and disseminated on a regular basis.

The Second Waiver

The 1115 demonstration waiver authority with the population of individuals with developmental disabilities has rarely been used. This opportunity, now streamlined by CMS under the Independence Plus Waiver template, would allow a state to "waive" existing Medicaid provisions that hinder meaningful lives for individuals with disabilities. As self-determination gets implemented under this waiver the essential "tools" of self-determination are implemented:

Fiscal Intermediaries

Informed and Independent Support Coordination

Individual Budgets

The 1115 waiver can then accent those issues most problematic for individuals with disabilities and complement the Social Security waiver by addressing some of the issues associated with forced impoverishment by featuring the following exemptions:

- Waive the prohibition on room and board in order to make typical housing more available to individuals with developmental disabilities
- Waive the prohibition on purchasing transportation including for those individuals who cannot drive but need to control the means of transportation to live meaningful lives
- Waive any exclusions to paying employers directly for co-worker support, training costs, transportation or temporary wage supplementation
- Waive all prohibitions on qualified Medicaid providers except where appropriate for normal criminal and other background checks. Allow individuals to contract with faith based groups as well
- Waive any real or perceived prohibitions on allowing individuals to capitalize very small microenterprises up to \$1500 annually