

The Promise of Self-Determination for Persons with Psychiatric Disabilities

By Thomas Nerney, Director, Center for Self-Determination

Introduction

Individuals with psychiatric disabilities represent the largest category of persons with disabilities in the United States. No other category of disability is treated so disparately and remains so inadequately funded that it can truly be said that no coherent national finance policy exists for this population. In the last decade public policy for individuals with physical and cognitive or intellectual disabilities has gradually been coalescing around several important themes. These themes all lead toward greater recognition of community participation, income production or work, control over resources and leading meaningful lives that resemble in all-important respects the aspirations and ambitions that all Americans have for themselves. This is not to say that these goals have been realized or that the impetus to achieve them does not vary from state to state.

In order to expand on the work of those with psychiatric disabilities, allied clinicians and committed family and friends, this paper attempts to organize an agenda around the implications of self-determination for those with psychiatric disabilities that:

- Suggests important parallels with the self-determination movement among those with intellectual and cognitive disabilities
- Recognizes that funding streams and public dollar investments differ considerably among various disability populations

- Analyzes these difficulties and more in one state (Michigan) that has developed positive public policy with an invitation to embrace self-determination toward those with significant psychiatric disabilities
- Recommends a formal expansion of quality assurance in mental health to encompass not just treatment and recovery issues but issues of living and working in community
- Recommends several courses of action with regard to both public policy and financing in order to meet the promise of self-determination for individuals with psychiatric disabilities. *These concrete recommendations are meant to build on the general ideas explored and advanced in the President's New Freedom Commission Report.*

This paper then is an exploration of the meaning of self-determination as it moves across all disabilities with an emphasis on the importance of including those with psychiatric disabilities in the growing movement to literally restore citizenship to individuals with these disabilities.

The History and Meaning of Self-Determination

The Promise of Self-Determination

The promise of self-determination from its inception was rooted in increased quality, increased power for individuals with disabilities, increased status within the community for these same individuals and, at the policy and organizational level, a fairer, more equitable distribution of public funds. It was just over a decade ago that the first demonstration on self-determination in New Hampshire began with a grant from the Robert Wood Johnson Foundation. The two populations included in this initial pilot were individuals with developmental disabilities and individuals with acquired brain injury.

The original monograph outlining the general goals of this fundamental shift were spelled out in *An Affirmation of Community* (Nerney, T. and Crowley, R., 1994) This monograph outlined the “harm” that resulted from typical human services for these populations. Self-determination was not some form of rugged individualism but rather recognition of our inter-connectedness and shared vulnerability. This included loneliness, isolation and increased expenditures of public dollars with no concurrent set of positive outcomes.

This fundamental shift in power was predicated on the human service system adopting structural changes that would facilitate and hasten the shift in power necessary for self-determination to become a reality for tens of thousands of individuals presently served and for those tens of thousands currently awaiting public dollars for support. At its heart, self-determination was committed to fiscal conservatism. Better put, the self-determination movement was committed to obtaining better value for the dollars currently expended. Self-Determination then, under this rubric, became organized around a set of principles rather than a set of human service interventions or environments. These principles were not human service categories and tried to capture both the political significance of this change and the implications for individuals at a very personal level. *Beyond Managed Care* (Nerney & Shumway, 1996) outlined these:

Freedom, the opportunity to choose where and with whom one lived as well as how one organized all important aspects of one’s life with freely chosen assistance as needed; **Authority**, the ability to control some targeted amount of public dollars; **Support**, the ability to organize that support in ways that were unique to the individual; **Responsibility**, the obligation to use public dollars wisely and to contribute to one’s community. In 2000 at the request of the national self advocacy movement The Center for Self-Determination added **Confirmation**, the recognition that individuals with disabilities themselves must be a major part of the redesign of the human service system.

Increased Quality

Increased quality as a cornerstone of self-determination emerged from the recognition that quality was importantly related to two dimensions that were inherently lacking in the lives of so many individuals: deep, personal relationships and elementary freedom. It was apparent in the early 1990s that individuals served by the human service system lacked the ordinary freedoms that all Americans take for granted. These included the right to establish where and with whom one lived as well as more mundane freedoms associated with what to eat, what time to go to bed and other decisions that go to personal habits all other individuals in this society take for granted. This included the realization that highly personal goals were so often subjugated to an annual plan that substituted human service and behavioral goals for the very real aspirations of individuals with disabilities.

Equally as important was the perceived lack of personal relationships grounded in friendship, romance and family. The vast majority of those served twenty-four hours each day, seven days a week, lived without both close relationships and elementary freedoms. There was no expectation that the human service system would listen to their dreams or aspirations nor encourage high expectations. What passed for quality was little more than liability assurance for health and safety. The stunning insight of the early days in forging the self-determination movement was the realization that even health and safety could be easily compromised without close personal, committed relationships. And so it became imperative to fashion a new approach to quality that relied on the perspectives of individuals with disabilities and close family and committed friends to determine what constituted quality. This notion of quality became deeply rooted then in the very foundation and promise of self-determination.

Increased Power and Authority

There was no easy way to say it. This new notion of what constituted quality demanded that control of the resources move from those who presently

controlled the human service system directly to individuals with disabilities and their allies. Every attempt at fashioning quality without moving power over resources and decision-making resulted in a continuation of some form of paternalism and resulted very often in compromises that adversely affected the quality sought. This necessitated the creation of highly personal and individual budgets that melded person centered planning with person centered budgeting. One of the hallmarks of a person-centered budget became flexibility. Flexibility in where and with whom one could purchase supports and flexibility in changing and prioritizing line items as a person's experience changed and priorities were reset. The simple and straightforward "tools" of self-determination were spelled out in *Communicating Self-Determination: The Tools of Self-Determination* (Nerney, 1999) These three tools were individual budgets, independent support coordination and fiscal intermediaries. All were necessary in order to deal with the inherent conflicts of interest in the present human service system. The Federal Medicaid Agency, CMS, has virtually adopted these tools as requirements for states submitting Waiver applications under the Medicaid program for self-determination.

Increased Status within our Communities

Central to this new notion of quality was the issue of status or recognition of the individual with a disability as a responsible, contributing member of society. Interview after interview with persons with disabilities revealed a deep desire to work, produce income and contribute or "give back" to the community where the person lived, as well as enter into meaningful relationships. Self-Determination as a movement then began to address the status of persons with disabilities and recognize the implications of enforced poverty and lack of meaningful work for the vast majority of those served by the present system.

The first step in this evaluation of the current status of individuals served by the human service system was the understanding that most of these same individuals did not even engage in culturally appropriate activities during the day

and frequently lived in environments that were perceived as human service environments rather than community environments. The lack of real income as a contributor to personal isolation and lack of reciprocal-based relationships was the next step in understanding just how important this lack of status was for so many people. As a result a new sense of economic justice began to pervade the self-determination movement. Small demonstrations quickly revealed that lack of income was almost solely a residual by-product of the organization of human services not a result of the significance of a person's disability. One of the new, clearly articulated goals then became "the production of private income for everyone". For those without the physical skills or interest in typical jobs, the development of microenterprises became an alternative that greatly enhanced both the community integration of these individuals and made possible the kinds of purchases that went to the heart of reciprocal relationships and true community memberships. This new but important dimension of self-determination was spelled out in a University of New Hampshire monograph, *The Importance of Income*, in an essay entitled *The Poverty of Human Services* (Nerney, 1998)

Policy and Organizational Change

The promise of self-determination then began to rest on the creation of new policy and the institution of structural change. Policy itself may not be determined without those most affected assuming an integral role in policy development. This meant that the self advocacy/consumer movement had to become a priority everywhere and that systems had to commit to support all the dimensions of self advocacy including its political dimension. Support for an enhanced role for families and community members also became imperative.

The structural changes necessary to accomplish this were becoming more and more apparent. The "Tools" were gradually seen as absolutely essential because it became more and more apparent that human service systems were not only incredibly complex but were rife with conflict of interest over both money and power or status. Individuals with disabilities, families and allies had to have

uncompromised or “conflict of interest free” assistance in order to navigate the complexities of the funding authorities, the personal planning and budgeting necessary to craft a meaningful life-plan and the authority to adequately represent the person with a disability. This new function was referred to as independent support coordination and/or independent brokering.

Two other structural changes mentioned above needed to be put in place as well: fiscal intermediary organizations that would protect the integrity of individual budgets and individual budgets that were highly personal and unique. There turned out to be many ways to develop fiscal intermediaries from simple bill paying companies to organizations that would assist in compliance with federal and state regulations regarding tax and labor issues as well as key employment issues. The creation of highly personal and unique individual budgets became central to the implementation of self-determination. They also became the most problematic precisely because individual budgets under self-determination raised all of the conflicts of interest in the present system and represented a stark departure from typical human service contracts. This issue went right to the heart of equity in the allocation of long term care dollars as well.

The present system did not understand well the inherent conflicts of interest in the present case management systems that relied so heavily on paper compliance, huge caseloads and untrained individuals in the elements of self-determination. Even those systems where case management was separate and independent of service provision there was neither the time nor often the inclination to reform the system to make it more responsive. While purists will claim there is only one way to provide this function, in fact, experience has shown that there may be several ways.

The organizational changes that must be in place then include conflict of interest-free support coordination with adequate authority to represent each person with a disability; the removal of the sums allocated to an individual from existing or

future provider contracts and deposited exclusively for each person within a fiscal intermediary organization; and, the creation and support of a highly unique individual budget with maximum flexibility. This later structural change must include the ability to purchase directly from community organizations and individual members of the community as well as from existing provider agencies that enter into contracts with individuals for discrete supports of various kinds. It is entirely possible that the psychiatric disability community will create new forms of these structural changes. For example, in some parts of the country individuals with disabilities can hire virtually anyone they choose to provide independent brokering. This function does not have to be a traditional professional service.

This particular strain of self-determination that we began just over a decade ago has deliberately eschewed psychosocial and pedagogical views of self-determination. There are those who focus on “teaching” self-determination skills (Wehmeyer, 1996) and, while this may be appropriate during school, it contains a very dangerous element. If self-determination ever loses its focus on basic human and civil rights then the hazard will be that professionals will once again determine when individuals with cognitive, physical, intellectual or psychiatric disabilities are “ready” to exercise those freedoms guaranteed by the Constitution and The Bill of Rights.

The actual implementation of real self-determination has been often difficult, fraught with compromises and resisted by many stakeholders. It is important for those with psychiatric disabilities and their allies to understand this history, understand as well the additional barriers they face in an inadequately funded system, in order to create an agenda for change that will make self-determination a real possibility.

Michigan

Michigan Department of Mental Health

July 18, 2003

Persons who rely on the public mental health system for necessary supports and services must have access to meaningful options from which to make choices, and be supported to control the course of their lives. Arrangements that support self-determination must be sponsored by the public mental health system, assuring methods for the person to exert control over how, by whom, and to what ends they are served and supported.

This new 13 page policy directive from the Michigan Department of Mental Health spells out the obligations and the responsibilities of both the Michigan Community Mental Health Boards and the consumers of typical mental health services. Michigan then becomes the first state in the United States to formally offer self-determination to those in the mental health system as well as those with developmental disabilities served by these same mental health authorities.

Michigan in many ways is representative of the difficulties that states encounter when they embrace self-determination. While self-determination has been voluntary up until July of 2003, several mental health authorities made major commitments to implement it for individuals with developmental disabilities. Many ignored it and some took small steps to both learn and to experiment with very small numbers. The fundamental shift in both structure and values indeed proved difficult on a statewide basis. But the difficulties encountered with individuals with developmental disabilities are more manageable than what mental health authorities will encounter for those with psychiatric disabilities.

The actual deployment of resources and the amounts of dollars available for those with psychiatric disabilities differ substantially from those with developmental disabilities. With an average long term care Medicaid expenditure

of about \$55,000 Michigan is above the norm on spending for those with developmental disabilities. Coupled with a managed care waiver that mandates that everyone be served, Michigan is better positioned to reallocate resources for those with developmental disabilities in ways that comply closely with the utilization of fiscal intermediaries, independent support coordination and individual budgets. One of the reasons is that so much of the spending for this population is invested in personnel who provide direct supports of one kind or another. The same cannot be said of those with psychiatric disabilities.

In too many instances resources in this system are targeted to clinical professionals and ignore basic housing needs. When dollars are spent on some aspects of self-direction such as peer clubs the dollars are pooled. Sorting out the public dollars deeply embedded in the current system will be complex.

The dollars for those with psychiatric disabilities tend to get invested into clinical services. The dollars for those with developmental disabilities were invested more heavily in group home and other community settings. In Michigan today three quarters of all those served by the public mental health authority are persons with psychiatric disabilities. However, only about 45% of the Medicaid resources are directed at their support resulting in an average per capita expenditure of about \$6,000. (Estimates vary)

As Michigan attempts to valiantly implement self-determination, people with psychiatric disabilities still fall through the cracks, experience homelessness in great numbers and live in abject poverty in greater numbers than any other population. In fact, in July of 2003 the Governor of Michigan declared that there was a crisis in mental health and vowed to correct it. (Detroit News, 2003)

The sheer numbers of individuals who need support, state budget considerations, low per capita investments and large bureaucracies all contribute to the difficulty of implementing self-determination in a state with a reputation for

at least acknowledging the need to address the problems and having the courage to begin. The same cannot be said for some other states.

Quality and Self-Determination

In the field of developmental disabilities issues of quality have been paramount for some time. Very gradually quality assurance has moved from simply ascertaining the person's health status to asking the person with a disability about various levels of satisfaction and more recently what choices the person is able to make over important program and living and working arrangements. The goals and the implications of self-determination are now beginning to take us much further as we look more closely at the best that contemporary quality assurance systems promote. At the Center for Self-Determination we have become convinced that we must take this notion of quality to another level and move from simple satisfaction with services and supports to control of those supports and a new view of quality.

This means that for self-determination the essential standard for quality will no longer be based on satisfaction with supports and services. Rather, we believe that quality assurance needs to become normed on universal human aspirations. The implications are enormous. Instead of asking the person with a disability if they are "satisfied" or even had some choice about where they live and with whom they live, or "satisfied" with mental health services provided, we recommend that the person be asked if they were able to choose typical housing arrangements, live with another person only by mutual consent, and have authority over who comes in the front door. The same goes for what individuals do during the day. Instead of asking if they are satisfied with a day or vocational program, the new questions turn on the amount of money earned each week, the number of hours worked and the amount of disposable income available to the person. Likewise for being connected to one's community and having enduring

and lasting relationships. *We are distinctly moving from quality of services to quality of life.*

In the psychiatric community notions of recovery and especially taking responsibility for one's own recovery have emerged as a high standard. This important aspect of self-determination needs to be promoted. However, the promotion of recovery and personal responsibility is or should be inseparable from support for living quality lives. If this notion of quality can be adopted and promoted for individuals with psychiatric disabilities then we will need to forge a public policy and financing agenda that will address the forced impoverishment of individuals with psychiatric disabilities, the homelessness of so many, the incarceration of many others and the inability to sacrifice meager federal benefits in the frequently vain hope that employment will eventually sustain the individual. Additionally, we will have to examine the low per capita investment that many states still make for this population.

What follows is a very modest attempt to initiate an agenda for quality lives that focuses on Medicaid, SSI/SSDI, Vocational Rehabilitation and the housing crisis that so many individuals with psychiatric disabilities face constantly. It is intended only as an initial formulation of public policy and financing strategies that hopefully will be generously augmented by the contribution of many others.

Funding a Quality Life

From a public policy perspective it becomes important to articulate the costs of forced impoverishment and homelessness as well as the cost of marginal living arrangements that inhibit the assumption of responsibility for recovery. Studies are now beginning to emerge that demonstrate that it is wiser, e.g., to provide adequate housing for those previously homeless than it is to bear the public costs associated with continued homelessness. A recent seminal report on the difference in costs associated with continuing homelessness versus supported housing with a rich mix of supports in New York (Culhane, Meraux, and Hadley,

2001) revealed that, even after accounting for the costs associated with developing the housing, the increase in public costs was marginal.

The results:

A homeless person in New York City uses an average of \$40,449 of publicly funded services over the course of a year.

Supportive housing—independent housing linked to comprehensive health support and employment services—provides major reductions in costs incurred by homeless mentally ill people across the seven service systems--\$16,282 per person in a housing unit year round.

The reduction in service use pays for 95% of the costs of building, operating and providing services in supportive housing, and 90% of the costs of all types of service-enriched housing in New York City.

Accounting for all costs the marginal increase in total expenditures per person for the most common type of supportive housing was only \$995 annually.

This is not only better public policy it is good public policy. A precursor to a public policy and financing agenda should include a compilation of this type of research and an agenda for further research in order to better inform public policy.

It is in fact fairly intuitive to reason that safe, affordable housing and the potential for jobs and real income will bolster the possibility for successful recovery. What is needed is a cross-department national and state by state agenda that addresses the following issues:

- A comprehensive national and state policy on safe and affordable housing
- A model Social Security waiver that changes the disincentives within the SSI/SSDI program for individuals to work without jeopardizing benefits until income increases over current limits

- A model Medicaid waiver program specifically targeted to those with psychiatric disabilities that allows both services and supports as well as supplements to room and board
- A model vocational rehabilitation (including reform of The Ticket to Work) approach that targets cash grants to be deposited directly into individual accounts for job training and microenterprise development
- A National Public Policy and Financing Agenda

Housing: creating a national set of strategies for safe and affordable housing

HUD and Public Housing Authorities

HUD's only new construction/ Supportive Housing Program for people with disabilities, the Section 811 Program, has not only been drastically reduced in recent years, but also requires significant "up front" investment. Efforts to use the Section 811 program to develop the low-density housing that provides true community integration are particularly problematic.

Assuming that existing HUD programs represent, at best, a partial answer to the housing needs for individuals with significant disabilities, what can the psychiatric disability community propose as a supplemental program to meet the articulated needs of people with these disabilities? If we do not develop a supplement to HUD programs, do we believe 10 years from now we will have moved much further down the road of solving our housing crisis? Or, will most individuals with significant disabilities continue to have no options other than homelessness or marginal and unsafe housing?

If we are to adopt quality standards for housing based on universal human aspirations, then we need to dramatically increase housing assistance for individuals with disabilities in order to increase:

The degree to which the person lives in typical housing;

The degree to which the person chooses that home; and
The degree to which the person chooses who lives with them

Recommendations

These recommendations focus on 1) expanding rent subsidy programs to increase access to market rate rental properties and encourage landlord participation, and 2) developing a non-profit housing corporation infrastructure sensitive to the needs of individuals with psychiatric disabilities. (Rafter, 2003)

Rent Subsidy Expansion

Breaking Into Section 8 (Special Accommodations)

Across the country most communities have lengthy Section 8 rent subsidy waiting lists or are not even accepting new applications because the waiting lists are so extensive. For many individuals with psychiatric disabilities the application process itself represents a significant barrier. After the Public Housing Authority's public notification that it is opening the application process, candidates must get to the Section 8 office, complete an application and have ancillary documentation such as bank statements, pay stubs, and social security cards. Even if the agencies supporting the individual with disabilities are aware of a sign up period, the necessary documents may not be readily available and application windows are missed.

In Columbus Ohio, *Creative Housing Inc.*, a non-profit housing corporation, showed the local PHA how the Section 8 sign up process unintentionally discriminated against individuals with significant disabilities. The local PHA designated Creative Housing as a "partner" and has initially assigned 180 project-based housing choice vouchers to Creative Housing for use for individuals with significant disabilities.

Creative Housing was able to assist the tenants in the application process and coordinate the collection of required documentation. These vouchers enabled

Creative Housing to attach a subsidy stream to 180 property units. Within this project, after the tenants live in the property for a year their voucher becomes portable and they can move and rent from any landlord willing to accept their voucher. In addition, if the tenants choose to leave, the Section 8 subsidy to the property is maintained. Creative Housing provides apartment-finding assistance to those individuals who prefer to use their vouchers to find housing elsewhere. The project enables a non-profit housing corporation to maintain a subsidy to units that have a waiting list of applicants while at the same time giving existing tenants the freedom to move on and rent from other landlords.

Supporting and Informing Public Housing Authorities (PHA's)

Getting a local PHA to focus on providing housing for individuals with psychiatric disabilities is not readily accomplished and often requires a lengthy political and educational process. Partnering with a disability service group offers a PHA an efficient approach to provide housing services to people with significant disabilities. The Columbus, Ohio, PHA notes in its publications that partnering allows the PHA to:

- Target housing to the “neediest of the needy”
- Decrease the number of no-shows for applications and re-certifications
- Reduce the number of terminations for program violations
- Reduce landlord and neighbor complaints

In short, the partnership provides a mechanism for the PHA to target particularly needy individuals and also reduce their administration expenses. For disability organizations the Section 8 revenues represent a solid funding stream to support individuals who wish to reside in private market apartments. Section 8 can be an important funding stream for non-profit organizations that are developing housing, which requires deep subsidies for individuals with significant disabilities.

Creating a Subsidy Program in Each State

Some states have taken the initiative to develop their own rent subsidy programs. Others, like Ohio, make bond dollars available to non profit housing corporations for purchase and renovation in order to create the deep subsidies that individuals on SSI need to obtain affordable housing. The strategy proposed in the Medicaid/SSI/SSDI section of this paper regarding the use of Social Security and Medicaid waiver funds to subsidize housing offers the possibility of expanding existing rent subsidy programs as well as initiating subsidies in those regions where they are non-existent. However as these subsidy programs are implemented it is necessary to build in funding flexibility to allow for the following:

Bridge Subsidies with Section 8: As access to Section 8 rent subsidies increases, it will still be a rare occurrence when waiver or state-only supports and Section 8 funding become simultaneously available to an individual. Regional or state subsidy funds can be used on a short-term basis with the understanding that the individual will apply for Section 8 subsidies, and when those funds are received the regional subsidy dollars will be used to support another individual.

Deposit Assistance: Many of the low-income individuals who will be served will not have enough money to pay the expected security deposits after other move-in expenses are incurred. Building in the flexibility to pay security deposits will be necessary.

Extraordinary Damages: There will be occasions when individuals in a subsidy program damage a property beyond their limited ability to compensate a landlord. Many apartments are under the umbrella of large property management companies, which have hundreds of units. The ability to “step up to the plate” and compensate a landlord for extraordinary damages will go a long way towards establishing successful partnerships with property management companies.

Rent Payment Gap Funding: Inevitably some individuals are either going to choose not to pay their rent or run into financial difficulties that prevents them from doing so. While some landlords may exhibit patience in this situation, others will move quickly to eviction proceedings. Once an individual has an eviction on their record they will typically be screened out of decent apartment communities and often relegated to substandard and unsafe housing. Creating the flexibility to

step into some situations and pay a tenant's portion of the rent can avoid an unwanted eviction.

Growing a Non-Profit Housing Infrastructure

In *Priced Out in 2000: The Crisis Continues*, (Cooper & O'Hara, 2002) the most comprehensive national report of the housing crisis facing people with disabilities, the Consortium for Citizens with Disabilities (CCD) Housing Task Force recommended that efforts be made to strengthen the role and housing capacity of non-profit disability organizations. CCD is a Washington based coalition of approximately 100 consumer and advocacy groups, providers, and professional organizations who advocate with and on behalf of people with disabilities and their families TAC/CCD reports present a comprehensive overview of relevant housing programs that is extremely useful and does not need to be repeated here.

What does need to be stressed is that accessing these federal housing programs in a manner that is sensitive to the needs of the psychiatric disability community requires specialized expertise and up front funding. In short accessing these federal programs is beyond the capabilities of disability organizations that only dabble with housing on the side.

Creating Non-Profit Housing Corporations as a Catalyst for Change

Non-Profit Housing Corporations are playing a central role where disability organizations have moved from a role of passive bystander to the housing crisis to an active participant in creating housing for people with disabilities. Such housing corporations serve as an important resource in assisting to put together a package for private market housing. They take the lead in implementing a housing development plan to serve individuals not readily served by the private market, and they become the center of concentrated housing expertise for serving people with disabilities including people with psychiatric disabilities. Successful non-profit housing corporations have several common characteristics:

1. Start Up Grants: Whether the corporation is founded from scratch or an existing low-income housing provider is persuaded to develop a disability sensitive focus, start up funds are needed. Management fees from rental properties primarily support staff salaries for the non-profit housing corporation. Initial start up grants serve to support the non-profit during an “incubation period” until the organization achieves a critical mass that allows management fees to support needed in house expertise.
2. Multi-Disability Focus: Housing corporations that have confined themselves to serving a restricted niche (e.g., housing for individuals with Down Syndrome) limit their growth potential and have minimal system wide impact. Successful organizations serve a broad cross section of disabilities, and have also included individuals with psychiatric disabilities and the elderly.
3. Work in Tandem with the Support System: Housing is separated from services and support, empowering people with disabilities to select and maintain services or supports separately. Necessary services are in place to support the tenants. Most important, guarantees of tenant-selected support services are in place before any development proceeds.

Housing development functions as a subset of an overall system plan, which is driven by stated customer preference and self-determination. Development of specific numbers of single-family homes, duplexes or apartments buildings occur as a result of an assessed need, with customers informing the system whether to emphasize developing single-family homes for shared living, or apartments for those who want to live alone.

Non-profit housing corporations are best positioned to work within the complex governmental funding and regulatory environment and produce the low rents needed to provide housing to individuals living primarily on Social Security. Moreover, non-profits are not going to convert properties to market rents once use restrictions have expired.

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

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. Typical community support waivers are still not in place for most individuals with psychiatric disabilities.

SSI and SSDI

The intersection of the SSI/SSDI, Medicaid and the 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 any significant 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.

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 \$810 (more 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 not working or 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.

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. People with psychiatric disabilities typically do not enjoy long term care coverage under this program.

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. Many individuals with psychiatric disabilities are forced into nursing homes, the streets or sub-standard housing.

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

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 psychiatric 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. While Medicaid acute care has become more available with earned income, long term care is still unavailable or inadequate. Section 1115 of the Medicaid statute allows prohibitions to be removed under a

controlled study of their effects. Also, it is suggested that a new provision in the Vocational rehabilitation Act (unlike The Ticket to Work) should be invoked to make small amounts of cash (through fiscal intermediaries) available to individuals in order to hire employment agents of their own or capitalize a microenterprise and obtain legislative changes to The Ticket to Work to accomplish the same.

The underlying assumption of this approach is the achievement of better economic and housing outcomes for individuals with psychiatric disabilities. It would require the psychiatric disability community to petition both CMS (Centers for Medicaid and Medicare Services) and the Social Security Administration as well as each individual state government. 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 through self-determination 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 supports and the potential positive impact on recovery.

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.

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 NEW FREEDOM INITIATIVE

Goals:

- Secure a waiver under Social Security to allow for those interested in self-determination to increase their income and assets
- Secure an 1115 Medicaid Waiver that allows waiving some eligibility requirements and waiving those aspects of the Medicaid program that hinder living and working in the community for individuals with psychiatric disabilities
- 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
- Secure a waiver under the Rehabilitation Act including The Ticket to allow for cash grants
- 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 all waivers simultaneously
- Create a model systems re-design for psychiatric 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.

Social Security Waiver

Written under the Social Security Act Section 1110(b)

Written to be utilized for those participants who can also enroll in the Medicaid 1115 Waiver for self-determination but especially as a stand-alone waiver for those with psychiatric disabilities.

Social Security Waiver Provisions

1. \$1 reduction on *earned* income for every \$4-7 earned or a new threshold of \$500 is established *before* Social Security benefits are reduced.
2. \$1 reduction on *unearned* income for every \$4-7 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 participant's cash benefits are reduced \$1 for every \$4-7 of earned income or they are allowed to keep \$500 before the reduction formula kicks in.
- The current system removes \$1 for every \$2 earned after the first \$85 is earned
- Participants keep much more of their earnings
- Participants start contributing to the Social Security Trust Fund

Provision 2

- Certain types of unearned income receive the same \$1 reduction for every \$4-7 of unearned income (see also provision 3)
- 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.
- This also encourages family members to save for their adult children with disabilities.

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 as well as technology.
- 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
- Freedom accounts would allow family members to contribute to their children's future much as they do for their adult children without disabilities

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)
- 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 psychiatric disabilities has rarely if ever been used. This opportunity, now streamlined by CMS under the Independence Plus Waiver Template for all other individuals with disabilities, would allow a state to “waive” existing Medicaid provisions that hinder eligibility and 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 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

The Third Waiver

Vocational Rehabilitation Waiver

Simply allow in each state small cash grants, funneled through a fiscal intermediary, to be available for individuals to hire anyone of their choosing to assist in securing a job or to use the cash to capitalize a microenterprise. This can begin to address the issues outlined above and begin to remedy the serious defects in the present vocational rehabilitation system most especially the Ticket to Work surrender of control after choosing a provider from a limited list and the requirement to abandon Social Security benefits under the Ticket. A legislative reform of the Ticket to work would move the tickets from vouchers to cash deposits with fiscal intermediaries utilizing individually controlled budgets and unbiased assistance in the production of income.

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