



# **A Blueprint for Self-Determination in Florida**

# **A Blueprint for Self-Determination in Florida**

## **Center for Self-Determination**

**May, 2003**

Thomas Nerney  
Center for Self-Determination

Patricia Carver  
Center for Self-Determination

Pat Rafter, Director  
Creative Housing Inc.  
Columbus, Ohio

Bob Morgan, Superintendent  
Delaware County Board of Developmental Disabilities  
Delaware, County Ohio

Edited by Dennis Harkins  
A Simpler Way  
Madison, Wisconsin

Sponsored by United States Department of Health and Human Services, Administration on  
Developmental Disabilities and the Florida Developmental Disabilities Council, Inc.



**FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL, INC.**

124 Marriott Drive, Suite 203, Tallahassee, Florida 32301-2981

Phone (850) 488-4180/ (800) 580-7801 ♦ Fax (850) 922-6702 ♦ TDD (850) 488-0956/ (888) 488-8633

Web page [fdcc.org](http://fdcc.org)

## Florida Advisory Team for Self-Determination Assessment Project

The following advisory team was constituted to oversee implementation of this project:

---

Janet Adams  
Bureau of Instructional Support and  
Community Services  
Florida Department of Education  
Turlington Building, Room 601  
325 West Gaines St.  
Tallahassee, FL 32399-0400  
850-245-0478  
850-922-7088 fax  
janet.adams@fldoe.org

Shelly Brantley  
DCF/ Developmental Disabilities Program  
1317 Winewood Blvd.  
Building 3, Room 325  
Tallahassee, Florida 32399-0700  
850-488-4877 x121  
850-922-6456 fax  
shelly\_brantley@dcf.state.fl.us

Chris Drummond  
960 Alberto Street  
Longwood, FL 32750  
407-332-9937  
chrisfieldd@worldnet.att.net

Bradley Hunt  
Florida Association for Support Coordinators  
4290 Hwy 90,  
Pace, FL 32571.  
850-994-7664  
bradhunt@netzero.net

Jo Ann Hutchinson  
Commission for the Transportation  
Disadvantaged  
605 Suwannee Street, MS-49  
Tallahassee, FL 32399  
850 410-5715  
joann.hutchinson@dot.state.fl.us

John Satterwhite  
Southern Movement for Independence  
PO Box 385550  
Tallahassee, FL 323115  
850-386-2022  
850-386-2312 fax  
jsatterw@tampabay.rr.com

Gladys Schneider  
Habitat for Humanity of Lee County, Inc  
1288 N. Tamiami Trail  
N. Ft. Myers, FL 33908  
239-652-0434  
gladysschneider@comcast.net

Kathy Burton  
Florida Developmental Disabilities Council,  
Inc.  
124 Marriott Drive, Suite 203  
Tallahassee, Florida 32301-2981  
850-488-4180  
Toll Free: 800-580-7801  
TDD Toll Free: 888-488-8633  
850-922-6702 fax  
kathyb.fddc@nettally.com

Sandi Smith  
Florida Developmental Disabilities Council,  
Inc.  
124 Marriott Drive, Suite 203  
Tallahassee, Florida 32301-2981  
850-488-4180  
TDD Toll Free: 888-488-8633  
850-922-6702 fax  
SandiS.fddc@nettally.com

Tom Nerney  
Center for Self-Determination  
52 Lake Dr. N (home office)  
New Fairfield, CT 06812  
cell: 734- 751-1682  
office: 203-746-0502  
tomnerney@earthlink.net

Pat Carver  
Center for self-Determination  
401 East Stadium Blvd.  
Ann Arbor, MI 48104  
810-231-6364  
810-231-6369 fax  
pcarver@chartermi.net

# TABLE OF CONTENTS

## Introduction 1

<b>Section 1 Background .....</b>	<b>2</b>
The Meaning of Self-Determination .....	2
Recent Florida History .....	3
The Perfect Storm.....	6
<b>Section 2 Maintaining and Improving Quality .....</b>	<b>8</b>
Current Situation .....	8
Discussion .....	10
<i>Re-Thinking What We Mean by Quality and New Planning Assumptions.....</i>	<i>12</i>
Recommendations.....	14
<b>Section 3 Housing .....</b>	<b>17</b>
Current Situation .....	17
HUD and Public Housing Authorities.....	17
Discussion .....	18
<i>Promising Beginnings: Private and Non Profit Sector .....</i>	<i>18</i>
Recommendations.....	19
<i>Rent Subsidy Expansion.....</i>	<i>19</i>
<i>Breaking into Section 8 (Special Accommodations).....</i>	<i>19</i>
<i>Creating a Subsidy Program in Florida.....</i>	<i>21</i>
<b>Section 4 Employment and Income .....</b>	<b>26</b>
Current Situation.....	26
<i>Transition from school to work.....</i>	<i>26</i>
Discussion .....	28
<i>Relationship of funding and income.....</i>	<i>28</i>
<i>Who helps get people jobs?.....</i>	<i>29</i>
<i>Summary.....</i>	<i>30</i>
Recommendations.....	33
<b>Section 5 Transportation .....</b>	<b>38</b>
Current Situation.....	38
Discussion .....	39
Recommendations.....	41
<i>A New Role for Florida's Commission for the Transportation Disadvantaged.....</i>	<i>42</i>
<b>Section 6 The Tools of Self-Determination Individual Support Coordination, Fiscal Intermediaries and Individual Budgets .....</b>	<b>44</b>
The Consumer-Directed Care Waiver .....	44
<i>Characteristics .....</i>	<i>44</i>
<b>Section 7 Creating New Opportunities: The Freedom Initiative .....</b>	<b>51</b>
The Federal Medicaid Act and Social Security SSI/SSDI Program .....	51
Current Disincentives and New Opportunities.....	51
<i>SSI and SSDI.....</i>	<i>51</i>
The Response of Self-Determination .....	53
The Freedom Initiative .....	55
<i>SSI Waiver Objectives .....</i>	<i>56</i>
<b>Section 8 Learning to Re-Tool the Florida System .....</b>	<b>60</b>
Training and Technical Assistance Guide .....	61
<b>Appendix i</b>	
Short bios on contributors to A Blueprint for Self-Determination in Florida.....	i

## Introduction

This report summarizes the Center for Self-Determination's analysis of Florida's system of supports to individuals with developmental disabilities, and provides a series of recommendations designed to create a blueprint for the implementation of self-determination in Florida. Key systems components reviewed in this analysis include: quality assurance, housing, school transition, supported employment and vocational rehabilitation, transportation, and Medicaid waivers.

The lens used to both highlight the current system and frame the recommendations is the lens that has been crafted over the last decade by the thousands of families and persons with disabilities who have set out to create a new human service system based on the principles of self-determination. Florida has been a leader in this movement.

The basic analysis begins with re-thinking what we mean by quality and the policy implication that emanates from that: the need to create high expectations for the lives of individuals with intellectual/physical and or cognitive disabilities. The practical fiscal and important personal reasons for fundamentally reforming what we call human services are also highlighted. Individuals with significant disabilities can no longer "wait" for incremental change in order to experience life to its fullest and take their place as citizens and contributing members of our society. Florida's growing fiscal crisis makes the search for more cost-effective supports a priority.

## Section 1 Background

### The Meaning of Self-Determination

Ten years 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. The fundamental changes they initiated 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. The 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 which important community and personal relationships to maintain or establish.
- **Authority:** the ability to personally control (with appropriate assistance) a targeted amount of long-term care dollars.
- **Support:** the arrangement of these resources in unique ways, built upon the individual preferences of the person with a disability.
- **Responsibility:** the use of these public resources in ways that are wise and cost effective.

Finally, it became apparent that a fifth principle needed to be included:

- **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

assistance free of conflict of interest to persons with disabilities and family members.

**What endures as the goal of self-determination from its origins is simply to support each 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.**

These 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 to support each 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.

## Recent Florida History

At the beginning of federal fiscal year 2000 the percentage of persons in need of service in Florida who actually received services was one of the lowest in the country.<sup>1</sup> Medicaid waiver expenditures of \$134.7 million dollars for home and community-based services were exceeded by expenditures of \$159.0 million in public and private Intermediate Care Facilities for People with Mental Retardation (ICFs-MR). Florida was ranked 38<sup>th</sup> in the country for serving individuals in smaller community settings (6 or fewer), with 50% (6,303) of individuals with developmental disabilities in residential services living in these settings.

By federal fiscal year 2000 there were 3,734 individuals served in supported employment in Florida, while 13,188 individuals received services in typical day/work programs. Supported employment spending has risen and fallen since FY 1993, with modest expenditures of \$9.2 million in FY 2000. In that same period spending for supported living and personal assistance increased to \$16.3 million from just over \$2 million, with more than 2,800 people receiving supported living services by FY

---

<sup>1</sup> All data in this section drawn from [Disability at the Dawn of the 21st Century and the State of the States](#). David Braddock, PhD Editor. American Association on Mental Retardation, Washington, DC 20002

2000. Support for families has risen dramatically from approximately \$2 million in FY 93 to \$64.4 million in FY 2000.

In the last few years Florida's entire system, including its under-funded community services system, has been under a series of class action lawsuits. Virtually every issue experienced by other states, including the issue of community vs. institution, large waiting lists, arbitrary payment systems, and under-funded programs, has arisen to throw Florida's system into the national limelight. No other state has had to deal with such massive litigation.

In response to these issues positive change has occurred and is on the horizon for Florida.

Under the leadership of Florida's Governor Jeb Bush, with the assistance of state legislative leaders and members of the executive branch, Florida has recently made a massive commitment to increase spending in the community, reform its community system and pilot truly innovative ways to serve individuals and families. Two things stand out: a huge commitment of new dollars unprecedented in the country, and the inclusion of individuals with developmental disabilities in an innovative "cash and counseling" Medicaid 1115 demonstration waiver that puts state and federal resources under the control of individuals and families. No other state in the union has pioneered this innovation for persons with developmental disabilities.

Additionally, through a contract with the Mercer Corporation, Florida is in the process of re-evaluating how dollars are now allocated under its 1915(c) Medicaid home and community-based services waiver, with a view to bringing objectivity and fairness to this endeavor. An individual amount of money will be determined for each person and that person and/or family will be informed of the amount. Completing that process will set the stage for self-determination. Florida also plans to continue its experimental Consumer-Directed Care (CDC) 1115 Medicaid waiver and give every individual served under the 1915(c) Medicaid home and community-based services (HCBS) waiver the option of choosing a self-determined life.

That said the Florida community system remains in crisis. Current discussions of potential funding shortfalls only highlight the crisis. A central question likely to emerge is whether the massive infusions of

dollars will be used to address the systemic problems described below, or used simply to bolster an old and inefficient system.

Traditional responses may not suffice. It is clear that Florida has a Governor who champions community living for individuals with disabilities. His leadership in providing the infusion of new dollars has certainly resulted in more individuals receiving services than before. It is important, however, as the short-term crises hopefully get resolved, to look at the bigger picture. Within that context, Connecticut and California offer interesting comparisons and provide potential lessons for approaching the future.

The State of Connecticut spends nearly three times the average amount in its community waiver program compared to Florida. In fiscal year 2000 Connecticut spent an average of \$72,000 per participant for 4,783 individuals in the waiver program (Braddock, 2002), while Florida spent \$28,000 per waiver participant.<sup>2</sup> Cost of living differences alone cannot account for this difference. In Connecticut the one remaining large institution serves about 650 people but consumes well over 20% of the entire state MR/DD budget. The fiscal crisis that is sweeping the nation has also affected Connecticut, which is the wealthiest state in the country. In January of 2003, more than 2,200 state employees were let go with more to be laid off soon if the budget deficit is not rectified. The provider community is desperate for a new infusion of funding. They cannot keep, let alone hire, direct support staff and have received very little (comparatively speaking) in the way of increases in recent years.

Connecticut maintains an extensive waiting list and is currently in litigation over that as well as its institution. The state projects a continuing deficit. The community system feels that it is in a tremendous crisis.

In California average spending per participant under the Medicaid waiver program has remained under \$20,000 through fiscal year 2000. California is a state that has created an "entitlement" to receive service. It is apparent to all observers that this "entitlement" is often less than a person might need. The fiscal crisis facing the State of California dwarfs those crises facing both Connecticut and Florida. Human services in California may well experience a real reduction in funding.

---

<sup>2</sup> Ibid

What do we learn from comparisons among these three states? When average daily expenditures vary so much across states for very similarly disabled populations, it clearly cannot solely be the amount of money expended per person that has resulted in the crisis. The first stage of analysis must then be at the particular models or arrangements that dominate the community system. Which ones are more expensive? Can the system be reconstituted to favor more cost efficient arrangements without hurting people?

Long term, each state will first be faced with reallocating existing dollars from its institutional programs to its community programs. The vast majority of individuals who need supports reside in the community and the vast number of those unserved live at home. Institutional investments represent the first major expenditure that will need to be reinvested. Ideological debates over the continuation of more costly and unnecessary institutional services will soon come to an end as the overwhelming community demographics of this population make the case for increased fairness and equity in the distribution of public funds.

## The Perfect Storm

As the demographics cited below illustrate, the time has come when the hard analysis involves the community system itself. What are the most expensive options, what are the outcomes for individuals served in these options, and can we morally and ethically justify 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 demographics clearly indicate that what we have witnessed to date with our waiting lists of unserved or partially served individuals and families 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. The Florida estimate for this population is 55,000. That 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 Florida will have an even larger cohort coming behind the 55,000 currently living with an aging caregiver at home today.<sup>3</sup>

---

<sup>3</sup> Ibid

The crisis will only deepen as the increased competition for scarce Medicaid resources by our aging population is factored in. The fastest growing segment today among the elderly population is 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 female adult children who today account for 80% of support to aging family members, only increases by 7%.<sup>4</sup>

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

Self-determination alone cannot hope to be the sole solution to this crisis. Self-determination is not a magic bullet and requires careful and thoughtful redesign 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.<sup>5</sup>

The following discussion is based upon an evaluation of critical components of Florida's system that impact the lives of persons with disabilities and their families. The recommendation in each section is designed to create a comprehensive blueprint for Florida to implement self-determination. Reforming the system based upon such a blueprint offers *one* critical response to both managing current crises and creating a better future as the storm clouds gather.

---

<sup>4</sup> Tom Nerney, *Filthy Lucre*, Center for Self-Determination, 2001

<sup>5</sup> Jim Conroy, Center for Outcome Analysis, Ardmore, PA., has documented the cost-efficiency stemming from self-determination in New Hampshire, Michigan, New Jersey and California.

## Section 2 Maintaining and Improving Quality

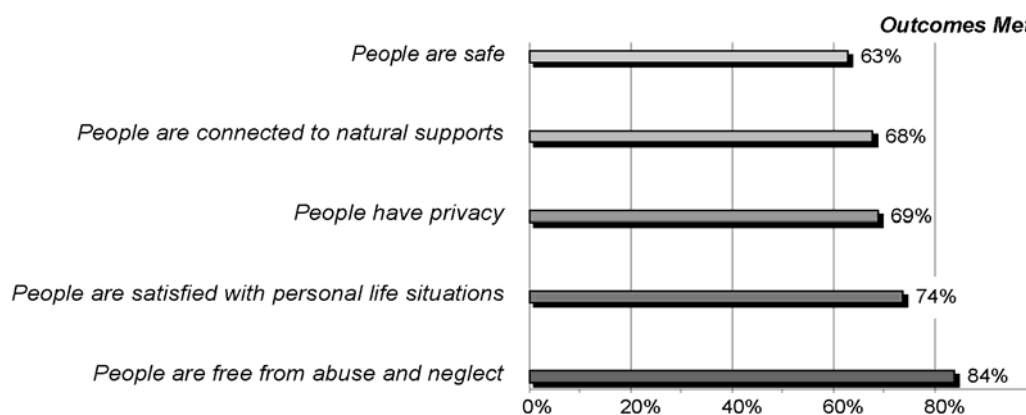
A system that will create a better future for people with disabilities, their families, and the public and private agencies that support them must be of high quality. What does that mean for Florida’s system?

### Current Situation

Florida has embarked on a complex quality assurance system carried out under contract to the Delmarva Foundation. There are two broad aspects to this evaluation system: 1) evaluating personal outcome measurement data by interviewing individuals served by the Florida developmental service system, and 2) evaluating provider agencies with performance measurements. The basic standards used are those developed by The Council on Quality and Leadership, and training in these standards takes place with The Council’s assistance.

Most agency reviews, called On-site Provider Performance Reviews, are of “core” services including Support Coordination, Supported Living Coaching, Supported Employment, Adult Day Training, Residential Habilitation, and Non-Residential Support Services. Delmarva also conducts “desk” reviews in which agency documents are simply forwarded to Delmarva staff for review.

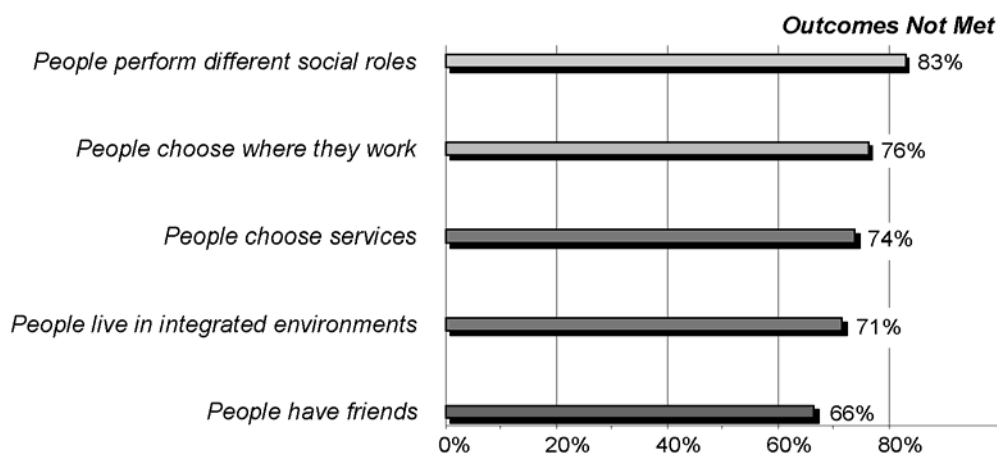
The basic results from the Delmarva sample for years one and two are consistent with regard to personal outcome measures. Outcome measures that address Safeguards and Health and Wellness are met much more frequently than others:



Delmarva also evaluates whether supports are present for each area. There appears, as one might expect, a high correlation between “supports present” and “outcome met.”

The personal outcome measures include important areas concerning the roles individuals can assume in their communities, the relative freedoms they experience, their degree of integration and the presence of friends. The data that Delmarva has generated here are consistent with the results of personal outcome measures in other parts of the county.

The individual outcomes that are not present look like this from a recent report prepared by Delmarva:<sup>6</sup>



Additionally, in the four domains of Attainment, Affiliation, Rights and Identity, 65% to 53% of individuals served do not meet these outcomes.

In other words, based on core values adopted by the State of Florida, the vast majority of individuals could benefit from increased outcomes that are all related to self-determination and the principles of self-determination.

The Delmarva evaluations of provider agencies, including support coordination, resulted in an average statewide score for performance outcomes met by all provider agencies of 87%. The differences in provider versus individual outcome scores is an important finding, particularly as it relates to the outcomes noted above. As it relates to self-determination, a stronger correlation between personal outcomes and provider outcomes might result from utilizing a single set of principles across the board, and by better identifying the locus of

<sup>6</sup> Florida Statewide Quality Assurance Program Delmarva Foundation July - September, 2002

responsibility and accountability for ensuring successful personal outcomes.

Delmarva has created a highly sophisticated quality assurance system with the built-in ability to track outcome measures for individuals by agency, type of agency and district. They can and do immediately send an alert when a major problem surfaces in their reviews and they do require plans of correction. As Florida moves forward in creating a system based upon the principles of self-determination, a single set of quality standards that determine whether individuals with disabilities are creating meaningful lives needs to be developed. Based on their work to date, Delmarva may be in a good position to create these needed changes.

## Discussion

Florida's quality assurance system has features that could potentially support self-determination efforts in the future. First, individuals in the 1915 Medicaid waiver program have assistance from support coordinators in developing their own desired "personal outcome measures." These should form the basis for a person's individual services plan. Provider agencies also develop "goals" for the individual. These are supposed to be "implementation" goals, based upon Medicaid waiver services requirements. It is entirely possible for a person with a disability to have a personal outcome measure plan, and multiple service provider plans. Currently, the desired personal outcomes and the provider-defined implementation goals are not necessarily congruent. If the latter goals were based more concretely on personal outcome measures, provider agencies might be better able to help individuals with disabilities realize their desired personal outcomes.

The Council on Quality and Leadership process, and other attempts to improve quality assurance, have responded to a need to counteract the past prevalence of quality standards that related more to services and programs rather than to individuals. This has been a positive step in the evolution of quality standards and measures, and more needs to be done based on what we have been learning through the implementation of self-determination.

In The Council on Quality's introduction to Personal Outcome Measures,<sup>7</sup> the sections on "principles" and "choice and decision making" set out a

---

<sup>7</sup> Personal Outcome Measures. The Council on Quality and Leadership in Supports for People with Disabilities, 1997, page 115.

fundamental challenge for self-determination. In the introductory section on these principles one of the first sentences reads: “There is no standard definition of any outcome that applies to a group of people.” This is highly problematic if funding systems are to set high expectations for individuals and if responsibility for attaining outcomes is to be addressed in a meaningful way. Setting high expectations based on universal human needs means at the very least that there needs to be some agreement on the standards for whether these needs are being met.

The potential contradiction in how a personal outcome measure gets “measured” is illustrated in the following quote from the next section of the manual on choice:

*For example, an outcome measure may indicate that people participate in the life of the community. However, in instances where a person chooses not to participate in the life of the community, the measure would be considered to be present based on how the person defined the outcome.*

A person could then participate in the community by **not** participating at all. A quality standard on community participation could be considered “met” for an individual with a pathological fear of leaving the house. The focus on “how the person defined the outcome” is an admirable break from past quality assurance efforts that virtually ignored the wishes of individuals receiving services. However, the notion of *choice* that this standard represents may inadvertently support an incomplete understanding of self-determination, and has the potential to leave individuals vulnerable.

In several sections of the outcomes developed by The Council on Quality the distinct possibility exists that the standard or outcome will be “met” even if it does not exist for the person solely because the person did not *choose* it. This applies even to “*People Have Intimate Relationships.*” That is, one of the very things that make us human can be voluntarily surrendered by a person with a disability.

Similar problems are found within the outcome, “*People Have the Best Possible Health.*” These outcomes are met if the person with a disability sees health care professionals, has his/her best possible health situation identified, and the health services have been selected in consultation with the health care professional. The instructions for evaluating this

outcome call for it to be listed as "present" if the person chooses to ignore all of the above. Emphasizing personal choice over individual responsibility and need for support contradicts basic core principles of self-determination and again creates the potential to increase vulnerability.<sup>8</sup>

When personal outcomes are established based upon high expectations for individuals with disabilities, the attainment of these goals or outcomes needs to be measured with more precision than allowed by The Council on Quality. Attainment of important and complex personal outcomes is frequently partial and can run the gamut from “not attained” to “partially attained” to “fully attained.” A more complete approach, which would better enable policy makers and others to know if progress (or even regression) is happening, could *scale* each goal or outcome on a simple 1 to 5 or 1 to 10 scale of attainment.

### ***Re-Thinking What We Mean by Quality and New Planning Assumptions***

Virtually all of our approaches to ascertaining individual “quality” in contemporary human services revolve around some notion of *satisfaction*. While no one would suggest that some degree of happiness and/or contentment not be measured, there are some fundamental weaknesses to this approach. Satisfaction based standards for quality assurance may unintentionally set a standard well below that commonly associated with meaningful quality of life in this society.

Defining satisfaction as an outcome for the provision of human services presupposes that the individual has clear and broad experience in order to evaluate the degree of “satisfaction” with what is now received. All of the literature on satisfaction surveys done in the last twenty years reach very similar conclusions: virtually all or the great majority of individuals with cognitive or intellectual disabilities are “satisfied.” This research shows that measures of satisfaction are not related to where a person lives, under what circumstances, or whether a person works or doesn’t work. In addition, satisfaction is the norm whether the person with a disability has important personal relationships or not. One can quibble over the methodological questions surrounding traditional quality assurance surveys but the end result is the same: they are inadequate for measuring outcomes that reflect universal human aspirations.

---

<sup>8</sup> Ibid, page 115

The Delmarva data support this analysis. Over 70% of individuals interviewed expressed satisfaction with their lives. However, the same data reveal that the majority of these individuals do not attain important personal outcome measures that they set for themselves or that appear to be basic requirements for ordinary citizenship in America.

Satisfaction has become the lowest common denominator and falls short of measuring outcomes that funding authorities should be adopting as quality measures for the receipt of public funds. The foundation for re-thinking quality based upon self-determination rests on two assumptions. One, that the human service system has high expectations for individuals with disabilities; and, two, that quality itself is definable based on meeting “needs” that are universal to all human beings. This certainly includes health and safety issues, but is not limited to them.

The implications of this kind of analysis are enormous for human service agencies. Public funding authorities and the citizens they represent will not be content with “satisfaction” regardless of whether or not a person has elementary freedoms to choose where and with whom one lives; whether a person works or not (especially if it is clear that the person can work and wants to work); or whether a person with a disability has friends and deep human relationships or not. The list goes on. While the current human service system has not yet created quality improvement and quality assurance models to address these issues in a meaningful way, the transformation of our systems based upon self-determination principles is leading us in that direction.

We are moving towards redefining quality in two important ways. First, quality needs to be normed on the common human aspirations that all human beings share, shaped by their particular culture and the American society at large. Second, quality does need to be grounded in what individuals with disabilities, and those in committed relationships with them, tell us constitutes quality. However, this does not include allowing people with disabilities to be placed at risk for health and safety. While these two aspects of defining quality may not always be congruent, this inherent and natural tension can be negotiated when conflict arises.

There is also an inherent contradiction in using personal outcome measures in typical congregate human service settings. Our system of human services has traditionally been based on provider agencies being funded to create congregate day and residential programs that offer “slots” to individuals with disabilities. It should be readily apparent that

these situations do not lend themselves to individuals exercising the freedom to determine where they live and with whom, as well as where they work. The time has come to stop measuring ***the adequacy of human service environments and interventions*** and move decisively to measuring ***the quality of the person's life—quality normed on universal human aspirations.***

## Recommendations

Given current concerns, Florida should re-evaluate the current process for evaluating personal outcomes and the role of providers in supporting people to achieve those outcomes. It would seem important to begin this re-evaluation with the current Medicaid home and community-based services waiver, but at the very least these issues need to be addressed as changes are made to support self-determination. A simple and elegant solution for those who engage in self-determination would be to create a set of outcome measures that reflect as nearly as possible what all Americans desire in their lives. In addition to continuing to address health and safety, add several outcome measures *such as* those below, scaled on a simple 1 to 5 or 1 to 10 scale, that address the following domains of any person's life:

### *Home*

---

The degree to which the person lives in typical housing

The degree to which the person chooses that home

The degree to which the person chooses who lives with them

### *Community*

---

The degree to which a person “belongs” in their community measured by

The number of organizational affiliations

Regular attendance at a place of worship if desired

The amount of shopping at typical neighborhood stores

The use of community and generic recreation resources

Attendance at cultural, social and political events

### *Relationships*

---

The degree to which the person is involved in reciprocal relationships measured by

The number of visits from and to friends

The number of visits from and to family

The number of invitations from friends

The interest in and the facilitation of romantic relationships

### *Transportation*

---

The degree to which the person can in a planned and spontaneous way

Decide to “go out”

Plan an evening or weekend trip

Get to work on a regular basis

Decide to provide transportation for a friend

### *The World of Business and Commerce*

---

The degree to which a person generates private income by

Working at a job of his/her choosing

Operating a micro enterprise

Having disposable income for private purposes

Contributing to one's own long-term costs

Standards and outcomes such as those above are based on universal human aspirations and ambitions. They are exceedingly concrete, unlike many of the current standards that lend themselves to tremendous interpretation and frequently do not result in the achievement of a meaningful life. They also lend themselves to the scientific meaning of “outcome” which means a result, typically positive or negative. Many individuals supported through self-determination may not initially have these outcomes rated very positively. But that is the purpose of measuring and re-evaluating, so that individuals with disabilities can achieve these human aspirations, and the systems that support them can know what they are doing that increases the likelihood such aspirations will be met.

## Section 3 Housing

### Current Situation

Florida finds itself in a similar position to most states as it moves from a congregate care residential system for people with disabilities to one in which people with disabilities choose where they live and the necessary supports follow them. In the congregate system housing subsidies were embedded in the fees paid to providers. As support services and housing have been de-coupled, housing subsidies have evaporated as we have relied on Medicaid waiver programs that have traditionally not provided for housing subsidies. The question that currently begs asking is, “Where are we going to find safe, accessible and affordable housing for individuals whose main income is a Social Security check?”

The Housing Crisis for individuals with significant disabilities is well documented in the Florida Housing Coalition/Florida Developmental Disabilities Council’s previous reports.<sup>9</sup> Individuals with significant disabilities are basically frozen out of the housing market, and the gap between their ability to pay and the cost of housing is widening rather than diminishing. Furthermore, even when housing subsidies are available, fully accessible rental properties often are not.

### HUD and Public Housing Authorities

Florida Developmental Disabilities Council and Housing Coalition reports have provided information about existing federal low income housing programs and the important politics of making the disability constituency’s needs known to Public Housing Authorities (PHAs). In some parts of the state inroads have been made and PHAs have provided increased housing options for individuals with disabilities. However, there has not yet been a systemic response to the demand for housing created by recently added or planned Medicaid waiver slots. This is not surprising, given that 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.

---

<sup>9</sup> Three separate housing documents sponsored by the Florida Developmental Disabilities Council, Inc., and authored by Gladys Cook Schneider, Florida Housing Coalition.

Assuming that existing HUD programs represent, at best, a partial answer to the housing needs for individuals with significant disabilities, what can the disabilities community in Florida propose as a supplemental program to meet the articulated needs of people with disabilities? If we do not develop a supplement to HUD programs, do we believe ten 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 congregate care facilities or remaining home with aging parents?

## Discussion

### ***Promising Beginnings: Private and Non Profit Sector***

Florida has the groundwork in place within existing funding streams to develop a strong response to the unmet housing needs of individuals with disabilities. Several regional centers have established rent subsidy programs for very low income individuals with disabilities. With additional funding and a statewide commitment, rent subsidies can enable very low-income individuals to live in existing market rate rental units. This approach provides a wide array of housing options and bypasses what is often a multiyear development process. The recommendation in Section 7 of this report to amend the current Medicaid 1115(c) waiver to allow funding of rent subsidies has enormous potential as a needed funding source for housing.

Rent subsidies utilized in the private market will not be the sole solution to the housing shortage. The existing Coalition to Assist Supported Living (CASL) program offers an example of a non-profit housing corporation offering housing at below market rates with a special sensitivity to the needs of people with disabilities. The CASL approach, with its separation of housing and support systems, also empowers people with disabilities to hire their own support providers.

While the State Housing Initiatives Partnership (SHIP) program may see future cuts in funding, it currently represents an excellent conduit for funding existing non-profit housing corporations or for developing new non-profit housing infrastructures. National experience has shown that the development of housing for individuals with disabilities requires deep subsidies and the avoidance of debt service. SHIP funds have potential to address those requirements for non-profit housing corporations that focus on serving very low-income individuals with disabilities.

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 significant disabilities.

### ***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 significant disabilities the application process itself represents a significant barrier. After the Public Housing Authority's (PHA) 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.

Local ARC chapters in Anne Arundel County, Maryland, and Hennepin County, Minnesota, aided by a grant from the Joseph P. Kennedy Foundation, have also established partnerships with their local PHA. They have successfully paired up Section 8 rent subsidies with individuals receiving Medicaid home and community-based services waivers.

### *Supporting and Informing PHAs*

Getting a local PHA to focus on providing housing for individuals with significant 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 Florida*

Some regions in Florida have taken the initiative to develop their own rent subsidy programs. The strategy proposed in Section 7 of this report regarding the use of 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 we recommend building 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 supports and Section 8 funding become simultaneously available to an individual. Regional 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 individuals have 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.

The use of fiscal intermediaries under self-determination can be a viable solution to address the needs for short-term flexible funding to help individuals maintain their housing.

### *Growing a Non-Profit Housing Infrastructure*

In *Priced Out in 2000: The Crisis Continues*, 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. Working in partnership with the Technical Assistance Collaborative (TAC), CCD has created the “*Opening Doors*” web site,<sup>10</sup> which provides a useful and ongoing analysis of federal housing programs for disability organizations. Used in tandem with Florida’s Housing Coalition/Florida Developmental Disabilities Council reports, 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 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.

It is important to realize that in the words of TAC/CCD Congressional testimony, “most Public Housing Authorities do not see people with disabilities as an important constituency.” As it currently stands, the ingredients of disability groups inexperienced in the creation of housing and inattentive PHAs are a recipe for, at best, maintaining the status quo that is the current housing crisis for people with disabilities.

---

<sup>10</sup> <http://www.c-c-d.org/tf-housing.htm>

## *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 supported living coaches 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. Successful non-profit housing corporations have several common characteristics, which we recommend Florida adopt:

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. Staff salaries for the non-profit housing corporation are primarily supported by management fees from rental properties. 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 mental health issues and the elderly.
3. ***Work in Tandem with Support System:*** Housing is separated from services and support, empowering people with disabilities to select and maintain service providers. 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.

4. **Accessibility Expertise:** Apartments that meet basic American with Disability Act (ADA) requirements still may not allow an individual in a motorized wheelchair to enter a bathroom and transfer to a shower chair. Successful housing corporations have in-house expertise to meet extraordinary accessibility needs. These can run the gamut from bathroom lift systems to smoke detectors for the hearing impaired. The development of this housing reduces the cost of support care and provides an opportunity for individuals with disabilities to move out of congregate settings. Often individuals are left in congregate settings for no other reason than lack of accessible housing.

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 conversions currently being exercised by for-profit developers are one of the main factors in reducing the existing stock of affordable housing.

Listed below are three non-profit housing corporations worth contacting. All are from Ohio, where the state has made capital funding available to non-profits for supported housing acquisitions:

**Preferred Properties (Toledo) [www.preferred-properties.org](http://www.preferred-properties.org)**

---

This organization has been extremely successful in developing HUD Section 811 projects. Preferred Properties has two projects operational, with three more in development. New developments have involved the use of low-income tax credits made available through the Ohio Housing Finance Agency.

**Northcoast Community Homes (Cleveland) [www.ncch.org](http://www.ncch.org)**

Northcoast Community Homes provides housing to more than 800 individuals in over 200 locations in a four-county area. The housing serves individuals with developmental disabilities as well as with mental health issues. The organization has a strong fund-raising arm.

Northcoast is completing a textbook to assist families in developing properties for adults with disabilities, with or without the assistance of a non-profit housing corporation.

**Creative Housing Inc. (Columbus) [www.creativehousing.org](http://www.creativehousing.org)**

Creative Housing provides housing to more than 900 individuals in over 450 locations including over 300 Creative Housing-owned properties.

Creative Housing also has an extensive renovation for accessibility program, renovating homes for people with disabilities and the elderly in a seven- county area in central Ohio. This organization has grown its renovation expertise into an income stream, which helps to subsidize renovations for low-income individuals.

## Section 4 Employment and Income

### Current Situation

The report prepared for the Florida Developmental Disabilities Council's Employment Task Force in March 2002 by Wilson Resources, Inc.<sup>11</sup>, as well as discussions with this project's advisory council indicate that employment opportunities for Florida citizens with disabilities are similar to those faced by people with disabilities across the country. Florida has invested most of its resources in day programs and sheltered workshops that do not provide adequate income or benefits for people with disabilities.

In 2001, the Department of Education published a training curriculum titled "Supported Employment and Natural Support." The manual provides an excellent guide to Florida's system of employment training; however, its focus and the actual practice within the vocational system continue to vest control of resources and decision-making almost entirely with professionals and agencies. Florida does have professionals and agencies that have the knowledge and experience needed to provide support to individuals to find community-based employment. Yet, except for the Cash and Counseling waiver (1115 Consumer Directed Care waiver), individuals and their families have no real control of financial resources or decision-making.

### *Transition from school to work*

The Florida Department of Education does not specifically fund employment training of students with disabilities. School districts may use local funds for this purpose, including IDEA Part B allocations, but there is not a consistent practice across the state and many districts do not offer these services. Policies of the Division of Vocational Rehabilitation (DVR) require that post-transition funding for extended ongoing support (Phase II) must be in place before time-limited intensive services and supports can be provided. The general understanding of this policy is that only those with Medicaid waivers can thus receive funding from the Division to find, develop and obtain employment or related services (Phase I). This policy has created bureaucratic barriers that prevent individuals from receiving services that could help them to secure community employment, and may very well be a violation of the Americans with Disabilities Act. The Wilson Report concluded that

---

<sup>11</sup> March 2002, "Survey of the Employment Needs and Goals of Individuals with Developmental Disabilities."

employment for persons with developmental disabilities transitioning from school is not a priority when overall resources are allocated.

Under the current system, school districts, Division of Vocational Rehabilitation, and Developmental Services Medicaid waivers all can fund Phase I services and do provide these services independent of the other's systems. Often, each of the funding sources have different providers for Phase I service. Also, one provider may provide the Phase I service and a different provider would provide Phase II supports. Many individuals are denied services when they do not have a Medicaid waiver to provide ongoing support. The problems of fragmentation and lack of coordination of school to work transition led to developing Interagency Cooperative Agreements.

The Interagency Cooperative Agreements focus only on solutions for managing the state-level bureaucracy. The November 1, 2002, draft agreement defines no active role for individuals with a disability or their family. They are not mentioned in any role except as passive recipients of services. For example, on page 12 the agreement reads, *“Likewise, this collaboration will seek to ensure that students, adults, their families and/or representatives understand the roles, services and supports provided by each agency.”* There is no similar emphasis for agencies to understand and respond to the individual and their family.

This agency-based focus is stated even stronger on page 14 under Referral, which reads, *“If the individual decides not to seek services from the Second Agency, and such decision will or may affect the provision of services from the Initial Agency, the Initial Agency shall inform the individual about the consequences or possible consequences of the individual's decision.”* While not the intent, such language could easily be read to imply the threat that if individuals make choices that are “disruptive” to the state system, then choice will be limited. The current draft of the Interagency Cooperative Agreement shows little commitment to the principles and practices of self-determination.

Bureau of Instructional Support and Community Services (BISCS) funds two major statewide projects for the purpose of improving transition outcomes for students with disabilities.

- The Career Development and Transition Project (CDT), housed at the University of Florida, focuses on service (information and technical assistance), education (in-service and preservice training for families, students, educators, agency representatives), and research (development and assessment of best practices). Project CONNECT is a special project within CDT that implements a variety of activities to strengthen interagency collaboration (including family involvement) at the local level. (web site at <http://www.thetransitioncenter.org/>)
- The Transition to Independence Process (TIP) Project, housed at the University of South Florida, focuses on addressing the transition needs of students with emotional and behavioral difficulties. TIP Project staff provide information, technical assistance and support in the implementation of the TIP system in project sites and throughout the state. (web site at <http://tip/fmhi/usf/edu/>)

## Discussion

### *Relationship of funding and income*

The Wilson Report stated that based on surveys conducted between February and April 2001, the average earnings per week for individuals in day programs and workshops was \$10.39 (\$540.28 annually). Those in supported or competitive employment averaged \$100.62 per week (\$5,234.24 annually). The combined cost of General Revenue and Medicaid waiver funding for FY 2000-01 was \$4,655 annually per person in Adult Day Training (ADT) workshops and day programs, while the annual cost for Supported Employment was \$1,996 per person.

The report stated that over 7,000 more people were in ADT than supported employment, two-thirds more people than in supported employment. Yet Florida spends seven times more money on ADT services than it does for supported employment. When evaluated on their effectiveness for generating income for individuals compared to the operational cost, ADT services generated just under 12 cents for every dollar spent, while supported employment generated \$2.62 of income for every dollar spent.

There still appears to be a significant number of individuals and families as well as providers who do not see the work potential of those with significant disabilities.

### ***Who helps get people jobs?***

The Wilson Report summarized the results of a survey of 522 individuals from across the state. When asked, “*Who helped you get a job immediately after you graduated from high school?*” 30% responded “*No One,*” 18% said “*family member or friends,*” and 11% stated “*other persons.*” The remainder of the responses was paid staff such as teachers, support coordinators, provider agencies and VR counselors. This means that 59% of the jobs were developed by someone other than paid professionals. Yet these primary agents of employment for people with disabilities are not recognized for their effectiveness, generally not considered as a provider option, and are not compensated for their efforts and success.

Unlike paid providers these natural supports, particularly family and friends, do not experience high rates of turnover. They stay involved during budget cuts and after funding ends. However, when paid providers are involved natural supporters tend to assume a passive role, deferring to the judgment, priorities and schedules of the providers. Natural supporters have a high level of commitment to the individual and are often willing to provide both intensive short-term effort and ongoing monitoring and support, when their knowledge, skills and commitment to the individual are respected, and when they are not expected to assume the administrative burdens associated with managing services or to simply replace needed services.

A common problem for human service systems is how to effectively work with natural supports. Professionals can too often push families away while assuming total responsibility for an individual’s care and training. Systems may introduce intensive activity and involvement of numerous professionals, and then cut off assistance after an arbitrary period of time or completion of a specific function. Public agencies feel constrained in using natural supports by policies of comparability of services and standards of care.

The variability of natural supports and family assets that each individual has available does make it difficult to have policies and practices that offer consistent services and supports to everyone. However, by incorporating the principles of self-determination within individual plans

and budgets, professionals have a means for maximizing all of an individual's personal assets and providing support with fewer public dollars than past approaches. These efforts not only cost less than traditional options, they may produce better results for the individual.

### *Summary*

- Florida has a significant investment in facility-based day programs and sheltered workshops that produce very low wages. These options offer few or no benefits such as health insurance and paid leave. The cost of these programs cannot be justified by the income they produce for individuals with disabilities.
- Vocational services, especially for school-age transitional service, are not effectively coordinated between the three funding and administration agencies. Services are inconsistent and overlapping. Schools need to make a greater commitment to realize the promise of transition for individuals with the most significant disabilities. This problem is of enormous consequence to the State of Florida and to the costs associated with long-term care. The greater the failure in helping students transition to real employment, the greater the millions of dollars that will be needed to help support thousands of individuals after they have graduated or leave the schools. This will dramatically increase the Florida waiting list.
- Work incentives and employment programs are not effective for individuals with the most significant disabilities. The criteria of these programs generally exclude individuals with the most significant disabilities. Current incentives are not adequate for these individuals.
- Services do not make effective use of families and other natural supports that could not only be a key to the success of employment but could also provide cost efficient alternatives to current options.

- Traditional vocational services are time limited under the Division of Vocational Rehabilitation but not under the home and community based waiver. The lack of consistent and committed support contributes to vocational failure. As a result, less than one-third of individuals with disabilities work in competitive or supported employment, while 75% of those who were not in paid community jobs stated they would like to have community employment.
- Individuals and families do not have real control and influence over the services they receive as a result of such factors as:
  - Their lack of real choice of providers;
  - Funding made to the provider and not to the individual;
  - Reimbursement based on services provided and not related to wages received by the individual or other major outcomes;
  - Many providers that do not want individuals to have increased control and are resistant to allowing such control. When systems begin to change, providers who are vested in the traditional service models can create fear and resistance on the part of individuals, families and staff.
  - Under the Cash and Counseling/Consumer Directed Care waiver there are greater opportunities for choice and control, but processes are incomplete and work never became a central goal of this waiver.
  - Most individuals and families have never experienced opportunities to have real control and influence over the services they receive. Many do not understand these opportunities nor do they have the experience or knowledge to take advantage of them when they arise.

Utilizing new quality standards for producing income will focus on the need for all aspects of these systems to change the degree to which a person generates private income by:

*Working at a job of his/her choosing;*

*Operating a microenterprise;*

*Having disposable income for private purposes;*

*Eventually contributing to one's own support.*

## Recommendations

The objectives of the following recommendations are to

1. provide individuals and their families with greater control of the decision making process and of the public resources spent on their behalf;
2. improve Florida's vocational services product, specifically by:
  - Creating more timely options;
  - Obtaining greater results for dollars spent;
  - Addressing waiting lists for services;
  - Diverting individuals from the traditional long-term care systems;
  - Broadening the pool of providers and natural supports; and
  - Creating opportunities for private dollars to match public dollars; and
3. address the individual and statewide economic consequences of the massive and growing crisis in transition.

*Objective 1 – Improve the effectiveness and efficiency of Florida's current vocational services through the application of the principles of self-determination.*

The primary vehicle to implement this recommendation is Florida's Independence Plus waiver. If services provided by local schools and Vocational Rehabilitation services do not meet an individual's needs, then individuals on the Independence Plus waiver will have the opportunity to direct new options for employment-related services.

To accomplish this, individuals with disabilities, their families and support coordinators will need training on how to make self-determination work, how to manage individual budgets and how to develop and manage self-directed vocational services.

**Action Steps:**

1. Select a pilot group of individuals with their families and support coordinators in several regions of the state to receive individualized training and assistance on creating individual employment plans and budgets as part of their Independence Plus waiver. The experience of these individuals will identify barriers to implementation of vocational services under the waiver.
2. Representatives from the pilot group and those who help to modify the training curriculum will conduct expanded training that will need to be carried to all the schools so that they can replicate the outcomes under IDEA during the transition years.
3. The training will include current options under the Independence Plus waiver as well as new options described below.
4. Representatives from the above group and representatives from the Interagency Work Group who wrote and edited *“Supported Employment and Natural Supports - A Florida Training Curriculum”* will revise the current edition to create a version targeted to strengthening the roles and authority of individuals and their families.

***Objective 2 – Create New Options for Obtaining Employment and Creating Personal Income*****Funding Employment Outcomes**

This recommendation would create a small experimental pool of funds that would be available to individuals, their families and non-traditional providers. Instead of a traditional fee for service model this option would commit payment for the results of employment, wages paid to an individual with a disability, or the opportunity for an individual with a disability to own a business.

This option greatly increases the involvement and resources of the individual, their families, local businesses, service groups and faith-based organizations. It requires very little infrastructure and can be implemented quickly. It provides a fair and efficient option for individuals on waiting lists for service.

The concept of Employment Outcome has operated in Ohio since 1997 and has produced excellent results for a small group of individuals at

**Family, friends and personal care attendants can be actively involved in the business as well. Most important, it gives individuals the opportunity to have greater control over their lives and income.**

very modest cost for both the program and fees paid for commissions and business startup grants. Some of the benefits realized in Ohio are:

- Active involvement of families and non-traditional providers in employment opportunities;
- Employment agents include

parents, residential providers, and employers in addition to traditional vocational providers;

- Sustained support of employment over many years at modest cost; and
- Significant cost-to-benefit results. In traditional sheltered workshops, the cost of services is \$10 for every dollar earned by a worker with a disability. The cost of Vocational Rehabilitation Services is \$1.60 for every dollar earned. Based on agent commission the ratio is at minimum \$.50 in cost for every dollar earned. Results from the project showed as much as \$20 in earnings for an individual with a disability for every dollar spent.

#### **Developing Microenterprises**

Microenterprises are very small business enterprises owned in whole or part by individuals with disabilities. They are carefully built around each individual's interests and desires. They not only accommodate the individual's disability but they may actually incorporate an individual's disability and resources to help start and operate the business.

Microenterprises are not to be confused with small businesses. By definition a small business has an annual operating budget in excess of \$500,000. Business plans for small businesses require sophisticated proposals and high standards of experience and knowledge to gain approval from lenders. Microenterprises can be started for less than \$5,000 and many times for just a few hundred dollars. Individuals do need assistance and training as well as a simple business plan.

Starting a microenterprise is a vocational goal that is new and not yet typically encouraged by Vocational Rehabilitation counselors. It may take a long time to develop and may be difficult to justify in case reports.

However, it can be a better vocational option than sheltered employment or adult day care. Typically it provides for more community inclusion and generates more income than sheltered employment. Family, friends and personal care attendants can be actively involved in the business as well. Most important, it gives individuals the opportunity to have greater control over their lives and income.

**Action Steps:**

Identify a state level administrative agent that is in a position to create change with excellent communication systems that reach individuals with disabilities, their families and support coordinators. The administrative agency will administer both options; employment agents and microenterprise. It could be an advocacy organization, protective services or a progressive professional agency that will administer access to the funding and track progress and barriers.

1. Define standards for employment agent commissions and microenterprise grants.
2. Create informational material and conduct project introduction seminars.
3. Conduct targeted training for microenterprise teams (two-days) at the end of which individuals will have the foundation of their business plans.
4. Re-evaluate and change the project as necessary.

*Objective 3 – Immediately Address the Problems with Transition Planning and Practice in the Schools throughout Florida.*

In Section 2 “The Perfect Storm” is described. It is a resource problem of unimaginable proportions. An immediate strategy to address and at least diminish the power of this storm is quick implementation of real transition planning and practice in Florida. As individuals benefit from good transitioning, they can bypass the adult service system, come to it later at less cost, or come to it immediately from school with the experience and the ability to lead more productive lives and even contribute to their support in some instances. The alternative is an ever-growing waiting list, higher costs and increased human misery.

The Florida Developmental Disabilities Council is taking a leadership role in focusing on planning for persons with disabilities who are transitioning from school. The Partners in Transition project provides for a systematic statewide approach to address the needs of Florida's students with disabilities. It will bring together state agencies and community organizations to develop Florida's first unified four-year strategic plan. We commend this approach and urge all stakeholders to support it as well.

## Section 5 Transportation

### Current Situation

The Florida Commission for the Transportation Disadvantaged is a unique program in Florida that organized and/or monitored transportation services to 615,091 individuals in FY 2002. The Commission noted a 6% decrease in the number of individuals utilizing services from the previous fiscal year. The 48,176,142 passenger trips recorded were also a reduction of 6% from the previous fiscal year. Florida's 67 counties are served through a network of 49 regional or county based transportation "systems." Each of these has a Community Transportation Coordinator responsible for ensuring both efficiency and quality. Operating revenue increased from \$271 million to \$292.9 million in the fiscal years between 2001 and 2002—an 8% increase. Operating expenses jumped at the same time from \$246.6 million to \$286.6 million—a 16% increase.<sup>12</sup> Clearly, rising gasoline costs and insurance premiums will continue to play havoc with these expenditures.

The target populations for the Transportation Disadvantaged Fund are low-income individuals, elderly and disabled individuals, and children. About 40% of total revenues are generated at the local level. The state Medicaid agency contributes 26% in reimbursement and the Department of Children and Families 11% of the total. The majority of all one-way passenger trips were provided via fixed routes comprising 57% of all trips. Between fiscal years 2001 and 2002 the number of trips for medical reasons increased 25% from 14,681,180 to 18,359,937. On the other hand, during those same fiscal years, trips recorded for purposes of employment fell 41% from 8,257,662 to 4,876,886. Trips for reason of "nutrition" increased 203% from 2,420,633 in fiscal year 2001 to 7,342,518 in fiscal year 2002. At the same time trips for education and training decreased 8%.

As the overall number of total trips decreased by 6%, trips for the purpose of employment and education and training decreased substantially more. During these two fiscal years, medical and nutritional trips rose from 33% of total trips to 53% of all trips sponsored by the Transportation Disadvantaged Fund, helping move the fund from a balanced medical and non-medical system to one skewed in favor of medically-related transportation.

---

<sup>12</sup> Data are from the Commission's Annual Performance Report, 2002.

The Commission for the Transportation Disadvantaged was able to identify 1,568,328 one way trips specifically for persons labeled developmentally disabled. The total cost for these trips was \$10,368,138 in fiscal year 2002. The average one-way trip cost \$6.61 but these costs ranged from a low of \$2.18 to a high of \$34.87.<sup>13</sup>

What is most unnerving in reviewing the excellent data gathered by The Florida Commission for the Transportation Disadvantaged is that of all individuals considered “transportation disadvantaged” in Florida, only 9.9% were actually served in fiscal year 2002. With rising costs and increased revenues this is down from 10.8% the previous fiscal year. In fiscal year 2002 the Commission was able to document 1,065,528 unmet need requests. In many ways these figures mirror the coming crisis about the excruciating competition for scarce public resources among populations who may be equally deserving.

## Discussion

It is clear that the Transportation Disadvantaged Commission with its 49 Community Transportation Coordinators does not represent a fully coordinated transportation system. This is particularly evident for people with developmental disabilities. Many of those included in the numbers above are served by typical provider agencies that receive reimbursement within their rate structure from the state Medicaid agency or bill Medicaid separately. Their data goes into the system as if they were an integral part of it. Others may be served by the county system.

The Florida Commission for the Transportation Disadvantaged has of necessity pieced together a patchwork quilt. There are too many disparate populations; too much competition for scarce resources; and as data from the past two fiscal years suggest, the possibility for major priority changes in transportation policy that are not necessarily widely discussed nor agreed upon in advance. Transportation data is coordinated. Transportation itself is not, at least for some populations.

The Commission focuses many activities on quality and safety; however, it appears from the data that *system efficiency* is the highest priority. A much greater focus on quality would result from adding analyses of “wait times” for transportation, “length of time” en route, and number of rides that were scheduled but did not occur. People with disabilities in fixed route transportation arrangements frequently spend an inordinate

---

<sup>13</sup> This data was generated privately by The Commission from a request by the Center for Self-Determination.

amount of time traveling from home to “place” and home again. When arranging for a “ride” for an individual purpose, waiting times are often so long, should the ride materialize at all, that spontaneity is lost as well as the original purpose for the ride. In interviews of every constituency for this report, transportation was universally regarded as a serious problem.

In *An Affirmation of Community*,<sup>14</sup> the first monograph on self-determination, transportation was identified as “The Final Frontier:”

*“We believe that transportation is the final frontier. While physical accessibility is often seen as access to buildings, transportation is also a dimension of accessibility. For people with mobility problems, transportation is a critical issue, if not the most critical. Each person’s individual budget should have sufficient funding allocated to insure control of personal transportation needs including the purchase of a personal vehicle if necessary.”*

As we move to new standards of quality we have to ensure that eventually individuals with disabilities can in a planned or spontaneous way:

*Decide to “go out;”*

*Plan an evening or weekend trip;*

*Get to work on a regular basis;*

*Decide to provide transportation for a friend.*

The key policy issue then becomes: Is this even possible, especially in a time of constricted public resources? Wouldn’t this be too expensive? For a human service system which is used to routinely congregating people with disabilities onto vans, it may appear unrealistic. This kind of transportation dependency is a direct result of the forced impoverishment of individuals with disabilities.

---

<sup>14</sup> Nerney, T. & Crowley, R., 1993, University of New Hampshire monograph

## Recommendations

Control over personnel, flexibility over a targeted amount of money, and creative, competent and independent support coordination can lead to a number of potential solutions, including:

### *Changing job descriptions*

With the authority to set working conditions under self-determination, individuals and families can re-structure job descriptions for individuals who provide personal support. Simply requiring that a driver's license, a vehicle in good working order and insurance be part of what an individual must bring to the job of supporting individuals with disabilities is the first

**New types of compensation packages are necessary in any case if those most important to the person with a disability will stay in committed relationships for longer periods of time.**

and most cost effective way to begin to solve this problem.

Individuals in direct support positions frequently don't have access to all of the above or own vehicles in poor condition, reflecting their own status in the human service hierarchy. Creative approaches within the self-determination movement are now fashioning compensation packages that reflect this need. Adding the cost

of additional insurance or paying outright for part of a worker's insurance is one example of how both parties can benefit. New types of compensation packages are necessary in any case if those most important to the person with a disability will stay in committed relationships for longer periods of time. These arrangements are much more cost effective than current transportation systems and provide flexibility and control individuals will expect under self-determination.

### *Leasing and Purchasing*

Outright leasing or purchasing of cars or vans, sometimes by more than one individual with a disability, can also be cost effective and will lead to greater control over transportation, even when the person with a disability does not drive.

### *Bartering*

When the individual with a disability owns or leases the vehicle, bartering with direct support workers can become an important element in both new forms of compensation packages for direct support workers and greater control of the means of transportation for the individual with a disability.

The cost effectiveness of leasing, owning and bartering is not intuitive for many in human services. Consider the data from The Florida Commission for the Transportation Disadvantaged. The average one-way trip expenditure for a person with a developmental disability is \$6.61, or \$13.22 daily, to attend a human service program. If the person attends only 20 days a month, that cost is \$264.40 a month. Not including insurance, that amount is adequate to pay a monthly lease or even a monthly car payment for any number of modest vehicles now on the market. If this approach could be combined with that offered below in the "Freedom Initiative," both public and private dollars could be used to defray these costs.

### ***A New Role for Florida's Commission for the Transportation Disadvantaged***

At either the state level or county level, the Commission and its 49 transportation regions could begin to pilot assistance to individuals who want to control the means of transportation in order to participate meaningfully in their communities and in work. This could be done by:

- Buying insurance as part of a "group" policy;
- Subsidizing that insurance;
- Providing the initial capital for purchasing or leasing;
- Holding title of the vehicles while giving control to the person with a disability;
- Making the purchases or leases part of a larger more cost-effective arrangement with car dealers (bulk purchasing);
- Arranging maintenance or upkeep on vehicles through their existing systems;
- Inspecting and monitoring the condition of the vehicles; and

- Assisting with the purchase or lease and the amortization costs associated with accessible vans.

In other words, more cost effective ways may very well emerge that give a new role to a Commission for the Transportation Disadvantaged that cannot meet the needs of so many, enabling the Commission to support increased freedom and mobility for individuals with disabilities in Florida.

## Section 6      The Tools of Self-Determination Individual Support Coordination, Fiscal Intermediaries and Individual Budgets

### The Consumer-Directed Care Waiver

#### *Characteristics*

Florida is one of three states participating in a national project, funded in part by the Robert Wood Johnson Foundation, to demonstrate the ability of consumers to direct their own care. Florida's 1115 Consumer-Directed Care (CDC) waiver under the three-state "Cash and Counseling" initiative is a Medicaid waiver that gives beneficiaries a chance to receive a monthly budget amount instead of traditional services. Participants can then design their own expenditure plan. In its formative stage Florida included a similar group to those enrolled in the 1115 CDC waiver as a "control" group in order to study the differences between those who could exercise freedom in hiring and creating an expenditure plan that was unique to them (with many traditional restrictions removed) and those who continued in the traditional Medicaid 1915(c) waiver with established human service agencies receiving the dollars.

Florida was unique in this national three-state demonstration because, in addition to frail elderly adults and non-elderly adults with physical disabilities, Florida included both children and adults with developmental disabilities. Some features and outcomes of the CDC waiver included:

- The budget amount available to each person or family was discounted 8% below typical service cost, building in a cost efficiency measure;
  - Participants were free to hire family, friends and neighbors for personal care assistance; to pay for equipment or devices to increase their independence; and to save for purchases, as well as purchase all typical waiver services;
- "Consultants" to assist individuals and families in the developmental disabilities services system were drawn from existing independent support coordinators;
- A single fiscal intermediary was hired to provide basic check writing services for the majority of those enrolled (individuals were free in the initial demonstration to provide their own bookkeeping services). Participants paid \$5 per check up to a maximum of \$25 a month.

- Mathematica Policy Research, Inc. was chosen as the evaluator of all three Cash and Counseling demonstrations including Florida. Their preliminary Florida results indicate more positive outcomes for people receiving services funded through the CDC waiver than found by Delmarva for people whose services are funded through the Medicaid home and community-based services waiver. They also noted an extraordinary number who chose family and friends to provide support and services. For all participants the order of hiring ranged from over 55% who chose family members; almost 30% who chose friends, neighbors or church members; and over 21% who chose former agency workers.<sup>15</sup>
- On the negative side, most adults did not engage in using funds to procure employment despite many indicating they would have preferred this choice. This may have been a function of inadequate attention and training for the consultants in the CDC waiver.

---

<sup>15</sup> Totals exceed 100% as many individuals hired support from more than one category.

### *Differences between “Cash and Counseling” and Self-Determination*

The Cash and Counseling CDC waiver is built on a personal care assistance model. The main categories in the consumer purchase plan are those related to directly hiring workers or home health care agencies; equipment; personal care supplies; and modifications to homes and vehicles. The “counseling” component is designed both to help individuals plan their purchases and to address the relative competence of the person to manage their financial affairs with assistance when necessary. It is an entirely appropriate model for individuals with physical disabilities, but poses some challenges for those with intellectual and cognitive disabilities, especially those with significant disabilities. A broader training and technical assistance endeavor will be necessary for this approach to be expanded.

Many of the structural requirements are similar to self-determination. The counseling resembles independent support coordination. Fiscal intermediaries are similar in most respects in both approaches, but individual budgets are frequently much more complex under self-determination. While the assistance needed by those with intellectual and cognitive disabilities usually far surpasses what is provided through typical personal care waivers, many families and individuals with developmental disabilities can benefit completely from the current CDC waiver. Others would find it difficult. That said, Cash and Counseling and the structural aspects of self-determination are simply slightly different trains on the same track with similar destinations.

The differences are mostly in the degree and depth of planning and support that many individuals with significant cognitive or intellectual disabilities may need. The structural “tools” of self-determination have been developed to address several problems that are important to this population:

- Many individuals do not have close friends or close relationships;
- Many remain in enforced personal poverty for a lifetime, and only a minority work;
- Many live in very restrictive congregate environments; and

- Many need unbiased and knowledgeable assistance to articulate their desires and make appropriate decisions.

### *Discussion and Recommendations*

The following discussion is organized around the three primary “tools” of self-determination: individual budgets, independent support coordination or brokering; and fiscal intermediaries.

#### **Individual Budgets**

Based on current best practice individual budgets meet requirements for self-determination when the budget is actually controlled by the person and freely chosen allies. Public dollars are then seen as an ongoing investment in the person’s life. The obligation to be responsible as well as contribute to one’s community becomes part of the budget development process.

Individual budgets are *ideally* organized around holistic plans that include three assumptions. First, everyone will have a place to call home. That is, individuals will live in typical homes and apartments with freely chosen friends or companions. This part of the budget will include ordinary household expenses as well as expenses associated with support needs. Second, every individual will have the opportunity to create a financial future either through regular employment, creative job development or starting a microenterprise. When individuals with no initial interest in these options are given information and provided the opportunity to imagine them, creative responses often emerge. Third, individuals with developmental disabilities will be part of their communities in important ways and be able to establish enduring relationships.

All of the above require good allies, well-trained and unbiased assistance, fairly complex budgets, and sometimes fiscal intermediaries that perform more than simple check writing. In many demonstrations these ideal standards are only partially reached, but this represents an important step in the right direction. Adopting self-determination principles leads to embracing the following standards for individual budgets:

#### ***Individually created***

The person with a disability and freely chosen family and friends create individual budgets. This includes the creation of unique line

items that reflect the distinct dreams and ambitions of the person with a disability.

***Authority over Personnel***

Any person who works for the individual with a disability is hired and can be fired as well. In fact all employees and consultants work for the person and that person's social support network. Even if another organization assumes some legal responsibility to become the employer of record, all personnel and consultants work for the person with a disability.

***Flexible***

Within approved amounts, dollars can be reasonably moved from line item to line item as long as the essential supports are maintained. New line items may also be created as well as old ones erased.

These principles and practices closely resemble those adopted by the Consumer-Directed Care waiver. They are readily adaptable for use within Florida's 1915(c) Medicaid waiver as well.

***Independent Support Coordination***

The linchpin to the success of creative, highly individual budgets and life plans is the function that is variously referred to as independent support coordination, personal agents, or independent brokering. This is a function that may help with plan development, assist in organizing the unique resources that a person needs and even assist with ongoing evaluation of these supports. This set of responsibilities and commitment to the individual being served is significantly greater than currently required of typical case managers or support coordinators.

The most important characteristics of an independent brokering function include:

**Independence from Service Provision**

It is important to keep this function separate from service provision and create a way for this person or agency to truly represent the individual and not the public or provider system.

**Real Public Authority**

Whether the person is an independent contractor or an independent agency is used, this function has to carry some state, county or publicly

sanctioned authority if this person is going to adequately represent the person with a disability.

### **Responsibility to the Individual**

It must be clear that the person who carries out this function works for the person with a disability. It is always the individual with a disability who chooses the independent broker.

Florida has already created support coordination that is independent of all services. However, the training and the grounding in self-determination principles and competencies are not yet in place in Florida. There are many ways that this function can be carried out, from family members doing it to case managers assuming new roles. One creative project allows the person with a disability to select anyone they know and trust and pays them separately if necessary. Sometimes ongoing and regular “brokering” is also required and some individuals are actually including this in their individual budget since it meets the test of a “service” when it does not duplicate the role of the support coordinator. In Florida most support brokers who became counselors received only a modicum of training on the issues and competencies required to carry out this function under the Consumer-Directed Care waiver. The depth and breadth of this training must be expanded as self-determination moves forward.

### *Fiscal Intermediaries*

Fiscal intermediaries are simply organizations, places really, where an individual budget gets parked or banked. The functions carried out by a fiscal intermediary include, but are not limited to, check writing for all bills and personnel costs; tax withholding; and paying worker’s compensation, health insurance and other taxes and benefits that might be appropriate depending on the individual’s budget. The fiscal intermediary works for the individual and remains accountable for ensuring compliance with all federal and state laws. Some states, like Connecticut, have sanctioned many fiscal intermediaries and the competition has proved beneficial to individuals and families. Other states, like Michigan, allow individuals with accounting credentials to perform this function, as well as advocacy groups.

Minimum standards include:

**Individual Budget Isolation**

This means that every person's individual budget is isolated from any other and certainly from traditional provider contracts. The money is available upon receipt of an approved budget and is accounted for by the fiscal intermediary to the public funding authority as well as to the person with a disability.

**Conflict of Interest Free**

Fiscal intermediaries have no other duties that conflict with their role. This means that they are independent of service provision. If the fiscal intermediary is a government or quasi-government agency, it has specific rules that prohibit the use of this money for any other purpose.

**Close to the Person and the Community**

Fiscal intermediaries, to the extent possible, are generic, neighborhood, community agencies or organizations that enable the person with a disability to create relationships with personnel who work there in regular community settings. The closer this function moves to a "neighborhood bank" the better for the person with a disability.

These are ideal standards. Some human service systems can move quickly to implement them. Others may take much longer. Florida already has experience with one type of fiscal intermediary. It is entirely possible that a fiscal intermediary could be created or sanctioned that would also become the "employer of record" for those who want to control hiring and firing but not assume the risk of an employer. Under certain circumstances provider agencies can also become the employer of record but delegate the real authority to the person with a disability and that person's support circle.

## Section 7      Creating New Opportunities: The Freedom Initiative

### The Federal Medicaid Act and 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. The cost of 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.

The recommendations for this *Freedom Initiative* grow out of the Center for Self-Determination's work with a small public/private think tank in Washington, D.C., 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.

### Current Disincentives and New Opportunities

#### *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 Social Security Disability Insurance (SSDI).<sup>16</sup> 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 has 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; and 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 about 6% of individuals with developmental disabilities in the United States “work.” In virtually nowhere in this country is SSI income enough to purchase food and rent an apartment.

---

<sup>16</sup> To be eligible for SSDI benefits, an applicant must (1) have worked and paid Social Security taxes for enough years to be covered under Social Security, (2) be considered medically disabled, and (3) not be working or working but earning less than the “substantial gainful activity” (SGA) level. Family members can also get benefits.

### *Medicaid Waivers and SSI/SSDI*

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 they were originally created as an alternative, Medicaid waivers are prohibited from covering the cost of room and board. 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 people living in congregate living arrangements simply 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 in low-income families, SSI and SSDI payments become very important for the financial stability of the family and family members will often counsel against the person working. Residential services providers may also join the group of those who do not want to trade 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.

### The Response of Self-Determination

At its heart self-determination has been based on a set of principles that include control of the financial resources necessary for one's support. Freedom and responsibility have become the hallmarks of this movement, while 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."

**Only by directly addressing 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.**

If we believe a meaningful life includes those aspirations that

are universal to all human beings, then the exercise of ordinary freedom, the chance to earn income and become a productive member of society, and the opportunity to engage in deep and personal relationships are the criteria with which we will evaluate the systems change associated with self-determination. Only by directly addressing 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 would combine a waiver of some of the current rules under the SSI/SSDI program with modifications to Florida's current 1115 CDC waiver. 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. In part this assumption rests on acknowledging that we simply have to find more cost-effective supports without hurting individuals with disabilities. These combined waivers would simply and elegantly provide incentives to enable people to work and live in ordinary ways—ways experienced by other non-disabled members of the community.

This approach would enable any individual to generate private income based on creative job approaches or the development of a microenterprise that the person may receive assistance in managing. Because so few individuals with disabilities are working we simply don't yet know the contribution many could make to reducing the costs of long-term care.

A key element of this approach is that those enrolled in the current 1115 CDC Medicaid waiver will automatically be enrolled in the SSI/SSDI waiver governing income and asset limitations. Florida already intends to allow anyone served by the regular Home and Community-Based Developmental Services waiver program 1915(c) to move into the 1115 CDC Waiver. ***These steps would position Florida on the cusp of true system change by creating an SSI/SSDI waiver that will work seamlessly with the Medicaid 1115 Home and Community-based Developmental Services waiver.***

We can expect that individuals with disabilities and their close family and friends will use this increased flexibility to 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 changed. Acknowledging the current federal approach to disability policy, this set of recommendations is titled “The Freedom Initiative.”

## The Freedom Initiative

### *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.

### *Core Components*

- Secure a waiver under Social Security to allow for those enrolled in self-determination to increase their income and assets;
- Allow individuals to enroll in both the Florida CDC 1115 Medicaid waiver and the proposed Social Security waiver in order to encourage creative approaches to housing, work and creating meaningful lives;
- Create a state-wide training and re-training effort to maximize the effectiveness of using both waivers simultaneously;
- Create a Florida 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 model, cost-effective systems re-design for developmental disabilities that will be replicable across the country.

### *SSI Waiver Objectives*

The overall objective is to demonstrate that providing additional work incentives under the SSI program will remove potential and real barriers to work for individuals who receive 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 modestly increase their own wealth.

### *SSI Waiver Conditions*

This waiver would be written under the Social Security Act Section 1110(b), and would be utilized only for those participants who enroll in the Consumer-Directed Care1115 waiver.

### *SSI Waiver Provisions*

**Provision 1:** A \$1 reduction on *earned* income for every \$4 earned:

- Participants take less of a reduction as earnings increase;
- Waiver participants cash benefits are reduced \$1 for every \$4 of earned income, compared to the current system, which removes \$1 for every \$2 earned;
- Participants keep 25% more of their earnings;
- No additional cost to state or federal government;
- Potential for contribution increases.

**Provision 2:** A \$1 reduction on *unearned* income for every \$4 generated:

- Certain types of unearned income receive the same \$1 reduction for every \$4 of unearned income, compared to the current system in which 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:** The establishment of *Freedom Accounts* of up to \$10,000 per person:

- 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 be targeted for highly desirable personal goals including 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;
- Families with the means to do so would be encouraged to contribute to these accounts without fear of jeopardizing their child's benefits, thereby assisting them in the same ways they may do for their children without disabilities.

**Provision 4:** Continuing Disability Review *suspensions* for the two groups participating:

- Medical Continuing Disability Reviews (CDRs) would be suspended for two groups enrolled in the dual waivers: Medical Improvement Not Expected and Medical Improvement Possible;
- CDRs are not suspended for those who are classified as Medical Improvement Expected;
- 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 the impact on PASS plans. The proposal would also give those disenrolling or when the waiver terminates up to 24 months to “spend down.”

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

#### **A Modified 1115 Waiver**

Through its participation in the Cash and Counseling project, Florida is the only state with experience in using the Consumer-Directed Care 1115 demonstration waiver authority with the population of individuals with developmental disabilities. As individuals with developmental disabilities receive support and services under this waiver, experience is gained in implementing the essential “tools” of self-determination:

- Individual Budgets
- Informed and Independent Support Coordination
- Fiscal Intermediaries

Modifications to the current CDC 1115 waiver can accent those issues most problematic for individuals with disabilities and complement the Social Security waiver. The amended CDC 1115 waiver would add provisions to:

- 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 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; and
- Waive any real or perceived prohibitions on allowing individuals to capitalize very small microenterprises up to \$1500 annually.

The careful melding of these two waivers would seamlessly allow individuals with disabilities to create meaningful lives in Florida's communities, supported by their families, friends, and a trained and re-trained workforce.

## Section 8 Learning to Re-Tool the Florida System

All stakeholders need to secure grounding in the basic concepts and assumptions that are both explicit and implicit in preparing to create the systems change necessary to implement self-determination. The elements discussed below are those that have been found to be critical in creating the needed systems changes to implement self-determination. They can be created by stakeholders themselves, or obtained through those who have experience in implementing them elsewhere. The following training and technical assistance guide has been created by the Center for Self-Determination. It is one example of a comprehensive curriculum that can be tailored to deal specifically with issues that are germane to each of the following stakeholder constituencies:

### **Individuals with disabilities and families**

These are the two major constituencies that must not only understand and be able to take advantage of the system of the future but also be offered leadership roles in its creation. The Southern Movement for Independence, a self-advocacy movement funded by the Florida Developmental Disabilities Council, provides a fine foundation for individuals with disabilities to rise to a leadership role in the implementation of policy and practice as Florida moves to implement self-determination.

### **State and Regional Officials**

It is imperative that those individuals legally responsible for both the funding and the administration of services are well grounded and serve as resources as well as “problem solvers” for implementing this kind of fundamental systems change.

### **Provider Agencies**

Provider agencies have much at stake in this transformation of human services. Across the country providers are rising to the occasion and volunteering to work together with families and individuals in order to assist in this historic shift in power. In the new system providers will be necessary but their roles will change substantially.

### **Independent Support Coordinators**

Individuals and agencies that provide this role are the linchpin of systems change. The initial work is labor intensive. A new knowledge base needs

to be mastered, and these “brokers” of a future system need to move their primary allegiance to individuals with disabilities and families.

## Training and Technical Assistance Guide

The following core curriculum can be adapted for each stakeholder group. Particular themes may be reinforced for particular groups. The state or regional authority can select, combine or sequence particular core training and technical assistance strategies depending upon the needs and experience of those involved. To achieve the goals of self-determination for a significant number of individuals with disabilities will require a commitment to the training, retraining and technical assistance so necessary in attempting to restructure so large a system.

### *Public Funding and Self-Determination; A Review of the Principles of Self-Determination within the Context of the Purpose of Public Dollars:*

From time to time confusion arises around the ultimate goal of self-determination: enabling individuals with disabilities to achieve a meaningful life deeply embedded in our communities. Some of the confusion arises from substituting the means to self-determination with the ultimate goal. For example, hiring one’s own staff, controlling expenditures, etc., are *means*. If these means do not result in the person “achieving a meaningful life” then self-determination essentially becomes another program that does nothing to elevate the status of individuals with disabilities within our community.

It is entirely possible for individuals with disabilities to use all of the new, structural “means” (having a fiscal intermediary, independent support coordination and control of an individual budget) without changing their status or creating high expectations for their own lives. It is also entirely possible for those with fairly intense clinical needs to see a meaningful life suborned to meeting these clinical needs.

The very purpose of public funding then needs to be addressed anew. From the perspective of self-determination public funding is inextricably related to individuals with disabilities creating futures for themselves that reflect those adopted by the wider society; cultural and personal goals that are grounded in common aspirations for all citizens; and expectations that are elevated in spite of any particular disability. This reflection on the purpose of public funding becomes an introduction to all of the training and technical assistance that follows.

1. ***The Origin and History of Self-Determination:*** A multi-hour module tracing the ten years of self-determination efforts across the country.
2. ***Public Policy and Self-Determination:*** A multi-hour training on the role of public dollars and the new public policy issues that need to be addressed. Includes issues of workforce development and retention as well as changes in public policy.
3. ***The Tools of Self-Determination:*** An “overview” module that can be extended in depth on the structural reforms needed to implement self-determination. This module feeds into number 5 below.
4. ***Fiscal Intermediaries, Independent Brokering, and Individual Budgets:*** Three related modules that can be scheduled separately or together, depending upon the audiences for whom they are tailored. The fiscal intermediary training module reviews the typical qualifications and skills of people and entities that act as fiscal intermediaries in other states, and the steps necessary to overcome systems barriers toward independent fiscal intermediary access. Independent brokering (or support coordination) training is typically tailored directly to a particular audience, with a different emphasis for potential support brokers, provider agencies, county administrators, and people with disabilities and their families.

Training and technical assistance on individual budgets provides grounding and develops competency at all levels: state, county, provider and individual. The initial two-day training module assists participants and their circles of friends to develop draft plans and budgets, and to learn the process for helping others do so as well. Building on the training received, final plans and budgets would be the end product of subsequent meetings focused on determining the wants and needs of the person with a disability based on this new view of quality and the possibility of building an economic future. Circles and others will learn strategies to identify paid and unpaid community resources that are available to the person with a disability as a part of this process. A template and guide are created for each individual as part of a workbook. This training and technical assistance approach builds into budget development everything we have learned to date about being cost effective. It addresses the

tendency to solve every difficulty with more money and the tendency to see the amount of money as the benefit rather than the freedom and flexibility with new assumptions that self-determination provides.

5. **Organizational Planning for Implementing Self-Determination:** Multi-day consulting and technical assistance for funding and provider agencies. This training is tailored specifically to match the experience and scope of responsibilities of each particular type of agency or organization.
6. **New Leadership Approaches:** One-day module that explores emerging notions of leadership and is especially important for the new and important roles that individuals with disabilities and family members as well as ordinary community members must play in a “revised” system of support.
7. **Generating Income** is a two-day course that involves people with disabilities, direct support staff, support coordinators, and other people close to the individual who are interested in non-traditional approaches to generating income. The first approach is creative job development, expanding the pool of job developers beyond the usual vocational counselor or job developer. The second is microenterprise development.

This is a very interactive session with “hands-on” work in small groups developing the plan for the business with individuals with disabilities and those who are close to them.

8. **Circles of Friends:** A proven, demonstrated strategy for implementation of a person-centered plan is the development and maintenance of a circle of friends. Circles are networks of friends, relationships and community connections. In this instance, it is bringing together people who care about one another with the common bond being the person who is planning. This training melds creating circles of support with developing a working personal budget.
9. **Re-Thinking What We Mean by Quality:** A one-day session that reviews the shortcomings of contemporary quality assurance systems, particularly as they relate to self-determination, and describes an approach to quality that is normed on universal human aspirations.

10. ***Re-Thinking Guardianship:*** A one-day session that explores alternatives to providing assistance to individuals without stripping them of constitutionally guaranteed rights. Moving from “incompetence” to “assisted competence” is the goal of this session. Florida already has a very progressive approach in this area.
11. ***Getting Connected to One’s Community and Generating and Sustaining Relationships:*** Two related three-hour training and learning opportunities to explore the importance of both and strategies to accomplish them. Best completed as a single-day training.
12. ***Focusing on New and Clear Assumptions for Planning with Individuals:*** The promise of self-determination, just like the promise of person-centered planning, can be lost when it is time to develop an individual budget. The self-determination movement is poised to posit at least the following when planning with an individual commences: everyone will have his or her own home—a place to call home; and, everyone can produce income. Having a place of one’s own, whether living with a friend with a disability or a companion without a disability is central to the meaning of self-determination. The production of some private revenue is increasingly being seen as necessary for all the reasons mentioned above not the least of which that it gives new meaning to freedom and responsibility. This session particularly addresses the forced impoverishment of individuals with disabilities in the present human service system.

### Short bios on contributors to **A Blueprint for Self-Determination in Florida**

**Thomas Nerney** is the Director and one of the founders of the Center for Self-Determination. The Center is a national effort working in an equal partnership with individuals who have disabilities, family members and professionals to create a training and technical assistance capacity to implement the principles of self-determination nationwide. Tom previously served as Co-Director of the Robert Wood Johnson Foundation's Program entitled "Self-Determination for Persons with Developmental Disabilities." In this role he managed grants and provided technical assistance to states, policymakers, families, and individuals with disabilities. Prior to this, Mr. Nerney was director of the Robert Wood Johnson Foundation's funded pilot on Self-Determination for Monadnock Developmental Services in Keene, New Hampshire. Mr. Nerney has been an independent consultant and lecturer on human services reform. He has consulted with a wide variety of public and private groups in the United States, including numerous disability, parent, and advocacy groups. He is a former Kennedy Fellow in Public Policy and a Mary Switzer Distinguished Fellow, U.S. Department of Education.

**Patricia Carver** coordinates communications and training for the Center for Self-Determination. Previously, she directed the Robert Wood Johnson Self-Determination project in Ann Arbor, Michigan and for 12 years served as an advocate for inclusive education, equal housing opportunities and just public policy for the Association for Community Advocacy. Ms. Carver has directed state and local disability organizations and coordinated numerous training opportunities for families, professionals, children and adults with disabilities.

**Patrick Rafter** is the founding President/CEO of Creative Housing Inc, Columbus, Ohio. He has over 25 years experience in programs for individuals with disabilities and has held several senior management positions in state government. Prior to Creative Housing, Mr. Rafter served as Assistant Director of the Ohio Department of Mental Retardation and Developmental

Disabilities. Mr. Rafter holds Bachelor and Masters degrees from the University of Notre Dame as well as a Masters degree from the University of Toledo. He has also studied at the Kennedy School of Government at Harvard University. Mr. Rafter has also consulted with community agencies as well as state and local governments in housing development in a number of states.

**Bob Morgan** is Superintendent of Delaware County Board of Developmental Disabilities in Delaware, Ohio and has worked in the field of community disability services since 1974. Delaware County was one of the four Ohio pilot counties selected for the Robert Wood Johnson Foundation grant on Self-Determination in 1997. Today there are over 411 individuals in Delaware County who have the services managed through a self-directed individual budget. In June 2000, the Ohio Developmental Disabilities Council granted three years of project funding for "Self-Determination in Employment." The project makes available challenge grants to individual consumers in order to pay their employment agents a commission based on the wages the consumer earns. The project also provides the opportunity for people with disabilities to own their own business.

**Dennis Harkins** is a former state director of services to people with developmental disabilities in Wisconsin who now works on transforming state and local systems based on the principles of self-determination and new leadership. Mr. Harkins wrote the successfully funded and implemented Robert Woods Johnson Self-Determination grant for the State of Wisconsin in 1996, facilitated the self-determination planning effort in Dane County from 1997 through 2002, and has provided training on self-determination and systems change across the country over the past five years. He has 25 years experience as a trainer, with the management issues within a complex state and county system of services.