

A Blueprint for Self-Determination in Florida

Executive Summary

Center for Self-Determination

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Purpose

Over the past several months the Center for Self-Determination has been looking at Florida's system of support and services through the lens of self-determination. The purpose of this review has been to create a blueprint that would enable Floridians with disabilities to obtain the support they need to craft meaningful lives in their communities. This Executive Summary of *A Blueprint for Self-Determination in Florida* highlights the main points of that review, and presents recommendations for further implementation of self-determination in Florida.

The Executive Summary follows the outline of the main report. It presents a brief discussion of the current situation, barriers to, and opportunities for self-determination within key features of Florida's developmental disabilities services system, as well as suggestions for systems change.

Introduction and Background

The basic analysis begins with re-thinking what is meant 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 highlighted within key systems components of quality assurance and improvement; housing; school transition; supported employment and vocational rehabilitation; transportation; and Medicaid waivers. The context of Florida's growing fiscal crisis is noted throughout this analysis.

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. This movement was named "self-determination" in order to capture both the personal and political dimensions of this effort.

The structural reforms necessary to carry out these changes include the development of fiscal intermediaries where public dollars for one's

support would be deposited; the creation of highly personal and unique individual budgets that would translate the person with a disability's life goals into line items in an approved budget; and, the availability of truly independent and competent support coordination in order to provide conflict-of-interest free assistance to persons with disabilities and family members.

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 the ability of a person with a disability to craft a meaningful life in the community, overcome the pernicious effects of enforced poverty and experience deep and lasting relationships.

Recent Florida History

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.

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 waiver that puts state and federal resources under the control of individuals and families.

Additionally, through a contract with the Mercer Corporation, Florida is in the process of re-evaluating how dollars are now allocated under its Medicaid community care 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.

The Perfect Storm

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.

The demographics clearly indicate that what Florida and other states have witnessed to date with waiting list or partially served populations is simply the tip of the iceberg. The crisis will only deepen as the increased competition for scarce Medicaid resources by our aging population is factored in. Add a quickly 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 it requires careful and thoughtful redesign of the present system. The following summary highlights critical components of Florida's system that impact the lives of persons with disabilities and their families, with recommendations 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.

Maintaining and Improving Quality

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 best elements of this system represent an important step away from past facility-based quality assurance systems. The focus on personal outcomes is to be commended. Florida is certainly contributing to the rapid and cumulative learning occurring today across the country in developing ways to better measure and support quality in the lives of people with disabilities.

There are several recommendations that arise in looking at Florida's current quality assurance system through the lens of self-determination:

- 1) In the domains of Safeguards and Health and Wellness the average scores are 77% and 74% respectively on a recent survey. An analysis by the Center indicates that these scores may reflect reporting errors.

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 individual outcomes that are not present range from 83% (people perform different social roles) to 66% (people have friends) for these categories. This means that provider agency standards and personal outcome measures need to be made more congruent.

- 2) While Florida's quality assurance system has features that could potentially support self-determination efforts in the future, a new set of standards needs to be adopted that would be consistent across all individuals served and provider agencies.

Aside from concerns about the application and results of the evaluations, and the respective roles of provider agencies and support coordinators, the outcome measures developed by The Council on Quality and Leadership may very well contribute to this problem, particularly as they relate to self-determination. These concerns relate primarily to the inherent contradictions that can and do arise by measuring outcomes simply as "present or not present;" the inherent shortcomings in the current focus on "satisfaction" as an outcome measure; and the previously described disconnect between measuring personal outcomes and having a way of assigning system accountability for whether or not those outcomes are met.

Recommendations

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.

Our system of human services has traditionally been based on provider agencies creating 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.

Given current concerns, Florida should reach an agreement on 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. These could be outcome-based measures that Delmarva can quickly implement. In addition to continuing to address health and safety, add several outcome measures scaled on a simple 1 to 5 or 1 to 10 scale, that address domains such as the following within a 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

These standards 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” or change, 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 how and what they are doing that increases the likelihood such aspirations will be met.

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 DD Council's previous reports. 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.

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.

Recommendations

The full report presents several examples from Ohio that are relevant for how Florida can build upon its current efforts to expand housing for people with developmental disabilities. 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.

Both recommendations would appear to be doable in the near future through applying learning from Ohio and elsewhere to the infrastructure Florida already has in place. The obvious “wild card” that would enable Florida to leap frog the efforts of other states is the possibility of amending the current Medicaid 1115 Consumer-Directed Care waiver to allow funding of rent subsidies, offering enormous potential as a needed funding source for housing.

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., as well as discussions with this project’s advisory committee indicate that employment barriers for Florida citizens with disabilities are similar to those faced by people with disabilities across the country. Transition from school to work is woefully inadequate; most funding resources are invested in day programs and sheltered workshops; professional decision-making dominates the field; and opportunities for people with disabilities and their families to exercise choice to create employment and income-producing opportunities is in its infancy.

Summary of current challenges

- Current transition practices are marked by inconsistent application across the state. What is most consistent is the general lack of coordination among school districts, the Division of Vocational Rehabilitation (DVR), and

Developmental Services Medicaid waivers. Particular concerns relate to policies and/or policy interpretations that in practice limit DVR time-limited intensive funding to find, develop and obtain employment or related services (Phase I) to only those individuals for whom Medicaid waiver funding has been committed for extended ongoing support (Phase II).

Interagency Cooperative Agreements drafted to respond to the transition crisis have understandably emphasized coordination among state agencies and local school districts, but have essentially overlooked the role of individuals and families in creating meaningful transition to employment and other income-producing opportunities. 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 are graduated or leave the schools. This will dramatically increase the Florida waiting list.

- 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.
- 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.
- Vocational services are time limited. 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 waiver there are greater opportunities for choice and control, but processes are incomplete and work never became a central goal of this waiver.
- Individuals and families who have never experienced opportunities to have real control and influence over the services they receive. They do not understand these opportunities nor do they have the experience or knowledge to take advantage of them when they arise.

Recommendations

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.

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:

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 (1115) waiver. The experience of these individuals will identify barriers to implementation of vocational services under this waiver.

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.

The training will include current options under the Independence Plus waiver as well as new options described below.

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 individuals and their families.

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

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 by developing a microenterprise.

Action Steps:

1. Identify a state level administrative agent. Ideally it should be an organization with excellent communication systems that reach individuals with disabilities, their families and support coordinators.
2. Define standards for employment agent commissions and microenterprise grants.
3. Create informational material and conduct project introduction seminars.
4. Conduct targeted training for microenterprise teams (two-days) at the end of which individuals will have the foundation of their business plans.
5. 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 of the Blueprint, “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 person 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.

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 low-income, elderly and disabled individuals, and children in FY 2002. 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. 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. The overall number of total trips decreased by 6%, with trips for the purpose of employment and education and training decreasing substantially more.

For fiscal year 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. The average one-way trip cost \$6.61 but these costs ranged from a low of \$2.18 to a high of \$34.87.

Of all individuals considered “transportation disadvantaged” in Florida, only 9.9% were actually served in fiscal year 2002. 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 Commission for the Transportation Disadvantaged 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.

People with disabilities in fixed route transportation arrangements frequently spend an inordinate 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 for every constituency for this report, transportation was universally regarded as a serious problem.

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 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.

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 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 they 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. 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 that cannot meet the needs of so many, enabling the Commission to support increased freedom and mobility for individuals with disabilities in Florida.

The Tools of Self-Determination: Individual Support Coordination, Fiscal Intermediaries and Individual Budgets

The Consumer-Directed Care (CDC) Waiver

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 waiver under the three-state "Cash and Counseling" initiatives 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 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 1915c 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.

The Cash and Counseling 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.

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 grounded in and 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.

Recommendations

The following discussion is organized around the three primary “tools” of Self-Determination: individual budgets, independent support coordination or brokering; and fiscal intermediaries. The recommendation for each area is essentially to take the learning from Florida’s self-determination experience, particularly as it applies to the Consumer-Directed Care

waiver, and expand the breadth and depth of that learning to encompass serving people with developmental disabilities.

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.

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 1915c 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 these new 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. 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 in Florida.

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.

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.

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.

Creating New Opportunities: The Freedom Initiative

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.

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 Freedom Initiative would combine a waiver of some of the current rules. Those enrolled in the current 1115 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 (1915c) to move into the 1115 waiver. 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.

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 waiver. A template for doing so is included in the *Blueprint* report from which this Executive Summary is excerpted.

Learning to Re-Tool the Florida System

All stakeholders need to secure a 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 *Blueprint* report presents a core curriculum that can be adapted for each of the following stakeholder groups:

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 be 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.

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. The key is to understand that the depth of change required by self-determination applies to all elements of the system.