



The Florida Self-Directed Care Program

A Practical Path to Self-Determination

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Self-Determination & Self-Directed Care

Underlying the goal of recovery for people living with psychiatric disabilities is the fundamental concept of self-determination. Achieving this is often a slow process of taking back control of lives which have been overwhelmed by both the debilitating nature of our illnesses and the loss of control resulting from reliance on a system of services and supports that engender dependence. Self-determination relates “to a person having a purposeful life, having the ability to seek the same goals that all others have related to personal relationships, membership in the community, and establishing an economic future”. Nerney, T., (2004). The overarching principles of self determination are:

- **“Freedom** to decide how a person wants to live his life.
- **Authority** over a targeted amount of dollars.
- **Support** to organize resources in ways that are life enhancing and meaningful to the individual.
- **Responsibility** for the wise use of public dollars and recognition of the contribution that individuals with disabilities can make in their communities.
- **Confirmation** of the important role that individuals with disabilities must play in a redesigned system.” Center for Self-Determination, (2005)

It encompasses concepts such as free will, civil rights and human rights, freedom of choice, independence, personal agency, self-direction, and individual responsibility.

The challenge to the mental health service system is to develop a driving philosophy that places the individual receiving services at the center of the system and specific programs that deliver on that philosophy. In Florida tremendous gains towards these goals have been achieved through the creation of the Florida Self-Directed Care (FloridaSDC) program. FloridaSDC provides an opportunity for individuals who have been diagnosed with a severe and persistent mental illness to assess their own needs, determine how and by whom those needs should be met, and manage the funds to purchase those services. In this way the individual assumes control of their own path to recovery. “Self-direction is a concept in the recovery process which treats individuals as capable of determining their own purposes and achieving their own goals.” FloridaSDC Operational Policies & Procedures, (2007).

FloridaSDC adheres to the principles of self-determination, the Center for Medicare and Medicaid self-direction requirements and the Florida model as determined by legislation. Essential elements include:

- Person centered planning
- Individual budgets
- Availability of independently brokered services from life/recovery coaches and quality advocates
- Access to the program by all that are eligible to enroll
- Participant safety and program incident management planning
- Independent mediated grievance process

“The FloridaSDC program hinges on the belief that individuals are capable of choosing services and making purchases that will help them begin or remain on the road to recovery and to develop or regain a life of meaningful, productive activity.” FloridaSDC Operational Policies & Procedures (2007).

The FloridaSDC “model creates a market-based system, which is demand driven as opposed to supply driven, like the traditional public mental health system in Florida. Supply driven systems favor providers in that the customers do not have as many options and, therefore, must patronize providers that receive funding from the State to serve them.” Haine, S. & Spauding-Givens, J., (2007). Participants in FloridaSDC purchase services they want from both the public and private mental health care system, which provides a wider array of choices. Individuals using Medicaid have always been severely limited in the choices available to them because of the shortage of practitioners accepting the low rates paid for by the program and because of the amount of paper work involved. In SDC a participant who receives Medicaid can choose to use their budgets to purchase services outside the Medicaid system, thereby increasing the choices available to them.

History

The FloridaSDC program grew out of a response by local consumers and advocates to a lawsuit against the State of Florida addressing the lack of funding, proper treatment and medications for people with mental illnesses. Over a period of two years these dedicated individuals worked to develop a concept based on “money following the client” that was drawn from the developmental disabilities field. This initial concept grew to fruition as the FloridaSDC program which was funded by the legislature and the Florida Department of Children & Families, Substance Abuse & Mental Health Program Office as a pilot program. The tireless work of the Self-Directed Care steering committee eventually resulted in the ongoing program that now serves approximately 250 individuals in two areas of the state. Perennial budget shortages have restricted the program from being implemented throughout the state. Negotiations are currently underway to fund additional participants through a contract with a Medicaid managed care organization in one of the two existing programs.

The funds for the self-directed care program come from state general revenue which allows the state to define the program without the restrictions inherent in the Medicaid system. The program, in both locations where it is provided, is contracted through the Florida Department of Children & Families, Substance Abuse and Mental Health Program Office. One of the most important components of the model is that the fiscal entity, that manages the participant’s budgets and provides funding for the program, must be an independent agent that does not provide paid mental health services other than the management of the program. This provides opportunities for peer run organizations to eventually contract to manage the FloridaSDC program in other areas of the state. The current Southwest Florida program is run by NAMI of Collier County who does not provide any paid mental health services. Advocacy organizations are an excellent match to the model.

The cost of a FloridaSDC program for 100 people is approximately \$550,000. This compares to the average cost of a person receiving a full array of outpatient mental health services. Crisis services, inpatient treatment and residential treatment are not paid for by the FloridaSDC program. These services are covered by the traditional mental health system for participants who may need them. A person who experiences a crisis while enrolled in the program would access the services needed and then return to the program upon discharge.

When the FloridaSDC model was initiated it faced a number of areas of resistance. Provider agencies were used to funds being tied to the array of services they provided. Because community mental health centers traditionally provide services to a defined geographic area, there was little choice for individuals in the public mental health system. Providers were reluctant to embrace self-direction because it was perceived as taking funds away from their budgets. “Prior to gaining an understanding of this model, there was some fear that providers would lose business.” Experience has shown that if individuals are satisfied with the services they receive they are likely to continue obtaining services where they are comfortable. “The burden is upon the agency to provide quality services.” Haines, S., Spaulding-Givens, J. (2007).

Another area of resistance was the lack of self-confidence on the part of individuals enrolling in the program. The traditional mental health system engenders dependence on having others make decisions for you and about you. The idea of taking control of your own treatment decision making process is a daunting concept to many people. But as participants begin to make their own choices, both good and bad, they gain in self-confidence and self-esteem and become more comfortable. They also learn that their coaches can provide needed support without coercion and control. Haines, S., Spaulding-Givens, J. (2007).

The Program

Eligibility

The FloridaSDC program is open to anyone who meets the eligibility requirements and desires to take control of their personal path to recovery. There is an erroneous assumption often made by people not familiar with the program that self-direction is only for people who already doing “well”. To the contrary, many people enrolling in the program continue to have active symptoms of their illnesses and come from nearly every level of the recovery continuum. Nor is education a barrier to self-direction. By working closely with a life/recovery coach nearly anyone can navigate the forms and requirements of the program. Even issues of literacy have been addressed and overcome. Motivated people with a strong desire to broaden their lives can overcome most barriers to recovery. Formal eligibility requirements are as follow:

- An individual who is age 18 or older and who has a diagnosis or diagnostic impression of an Axis I or Axis II mental disorder; AND
- Receives supplemental security income (SSI), social security disability income (SSDI), disabled veterans benefits or any other type of disability income due to psychiatric disability; OR
- Receives social security income for reasons other than psychiatric disability and meets the definition of SPMI as described in DCF Pamphlet 155-22; OR
- Does not receive disability income due to psychiatric disability, but has an application in process or has received such income within the last 5 years; AND
- Is legally competent to direct his or her own affairs; AND
- Lives in the department’s district in which the program they participate is located; AND
- Applies for Medicaid and other income support programs for which he or she may qualify AND
- Relies on public funds to cover costs for mental health services.

FloridaSDC Operational Policies & Procedures (2007)

Life/Recovery Coaches

Life Coaches (also called Recovery Coaches) orient the individual to the process involved in the program, provide referral information, advocate for the participant and promote self-advocacy, help them to explore their personal recovery goals and to prioritize and plan for the use of their budgets. The coaches assist participants in learning to broaden their world views and open their

minds to the myriad of choices available to them. People who have lived much of their lives economically dependent on public benefits that provide for only the most basic of needs often have difficulty expanding their goals and taking advantage of new options. “Coaches act in a number of different roles including modeling behaviors, providing hope, providing access to resources, cheerleading, brainstorming, and assisting with paperwork.” Haine, S., Spauding-Givens, J., (2007).

Participants have the opportunity to interview the coaches available to them and to choose the person they feel most comfortable with. The coach/participant relationship is a critical part of the self-direction process as people learn to navigate the requirements of the program. Many individuals quickly learn to complete their own Life Action Plans and budgets and primarily utilize coaches for payments for services and supports. Coaches are responsible for providing participants with reimbursements for approved expenditures on a timely basis and assisting them with major purchases and payments. For instance, if a participant budgets to purchase a computer as part of their recovery plans, the Life Coach might meet them at the store to make the payment or arrange to reimburse them for the purchase at a later time.

Life Analysis

Upon enrollment in the program, participants complete a comprehensive self assessment called a Life Analysis. This is a process that helps the person plan their life activities and to determine how they can get where they want to be in life. The Life Analysis asks the person to:

- Look at their life
- Assess the state of their personal health, including physical health, recovery from mental illness and symptom management skills, substance use factors as they relate to their health, and their level of meaningful activity, including work.
- Identify their goals.
- Complete an action plan to meet their goals.

FloridaSDC Life Analysis (2007)

The purpose of this Life Analysis is to give the person a worksheet to figure out what they have and what they need each year in order to achieve whatever state of mental wellness and productivity they desire. It is the responsibility of the participant to complete a new Life Analysis each year. The Analysis helps the individual to build on strengths, identify needs, set goals, and understand the complex interactions of the facets of their lives. It is somewhat similar to an assessment that a mental health professional would do in traditional services.

Life Action Plan

Upon completion of the Life Analysis each participant proceeds to complete a Life Action Plan which includes their budget. The Action Plan details how a person will address the needs and goals identified in the Life Analysis. The person lists the services or goods they will need to achieve their goals, where they will purchase them, how much they will pay, how they will pay for them (Medicaid, Medicare, VA, self, FloridaSDC, or other source) and the expected outcome

of meeting the goal (how progress will be measured). The Life Action Plan is similar to a treatment plan in traditional mental health services with the inclusion of a comprehensive budget. Life Action Plans and budgets are done on a quarterly basis. Funds may be saved on rolled over within a calendar year. This allows a person to save towards larger expenditures like tuition or the purchase of a computer.

Financial Guidelines

The FloridaSDC program gives each participant control of the public financial resources to access mental health services that are normally directly contracted to a public community mental health provider. Participants in FloridaSDC are eligible to purchase services for the purpose of accessing **Clinical Recovery Services** (traditional mental health services), **Recovery Support Services** (services that are alternative to traditional mental health services, but likely to produce the same outcomes), and **Recovery Enhancements** (these are typically tangible items such as clothes, art supplies, equipment (computers, printers, etc.), office supplies, and personal hygiene products. They may also include things like car repairs, rental assistance and tuition). FloridaSDC Purchasing Policy & Guidelines, (2006).

The amount each person has available in their budget depends on what type of benefits (if any) they receive. Budgets are based on the average cost of traditional mental health services in the local service system. People without benefits have access to the largest budget available since they will have to pay for the full cost of their traditional mental health services while people with Medicaid, VA, or Medicare will continue to pay for those services through that process. People without benefits must allocate 42% of their budgets to traditional services. That money cannot be used to purchase Recovery Support Services or Recovery Enhancements but the remaining amount can be used for any type of service or purchase including traditional services. For instance an individual may choose to spend more of their money on traditional mental health services. People who receive Medicaid or VA benefits do not receive any of the monies dedicated to traditional services since that is covered by their benefits. A person who receives Medicaid or VA may use their remaining budget to purchase traditional services outside the Medicaid or VA system. This allows people a wider range of choices than those provided by their benefits. Participants receiving Medicare are allotted some of the funds available for traditional services. This is due to the significant co-pays built into the Medicare system.

Budgets are also based upon a sliding scale of income compared to Federal Poverty Guidelines. A participant can earn up to \$18,400 in income and still qualify for the full award.

Examples of purchases that will be authorized:

Clinical Recovery Services

- Psychological Assessment
- Medical Services (i.e., Psychiatric Evaluation, Medication Management)
- Individual and Group Therapy provided by a licensed mental health professional
- Supported Employment
- Co-pays for Clinical Recovery Services purchased with Medicaid or Medicare funds

Recovery Supports and Recovery Enhancements

- Transportation
- Massage Therapy as a form of touch therapy to assist an individual overcome issues documented by a licensed mental health professional
- Forms of Art Therapy
- Occupational, speech, and physical therapy when recommended by a licensed mental health professional
- Services related to developing employability and/or productivity that will lead to employability
- Smoking cessation activities under the supervision of a medical doctor
- Non-cosmetic dental work
- Hearing aids
- Non-cosmetic eye glasses and non-disposable contacts once per year, unless otherwise noted by a licensed eye care professional
- Hair cuts from a professional not to exceed once every 3 months
- Make-up lessons
- Facial cosmetic and make-up products for the purposes of camouflaging medical conditions, such as facial scars, burns, etc. and for the purposes of seeking or participating in employment and/or other productive activities
- Tutoring
- Face-to-face and distance learning educational classes
- Pet ownership, initial costs only (a maintenance plan must be submitted with action plan that details the ability to have the pet in the current place of residence, food and health upkeep, and care for the animal in the event of the individual's absence)
- Time-limited assistance to secure or maintain a more independent living arrangement (a maintenance plan must be submitted with action plan that details long-term financial ability to maintain the living arrangement, i.e., rent, utilities, living needs, groceries). It is the participant's responsibility to ensure that payments are made on time.
- Time-limited assistance with vehicle repair for purposes of employment and/or transportation to access Clinical Recovery Services
- Entertainment items (i.e., movie tickets) and restaurant dinners if recommended by a licensed mental health professional

General Guidelines for Participants to Follow for Approval of Purchases

1. Does the purchase provide for the diagnosis, prevention, or treatment of a condition defined in the DSM-IVTR?
2. Is the purchase within standards of good and generally accepted practice, as reflected by scientific and peer literature, best practices, and recognized within the organized behavioral healthcare community?
3. Is the purchase within the standards of good common sense?
4. Does the purchase directly relate to self-identified needs outlined in the life analysis?
5. Is the purchase the most efficient level of service or supply, which can be provided safely and effectively?

6. Does the purchase promote independence?
 7. Is the purchase a good use of public tax money?
 8. Have all other options and pay or sources been explored and exhausted prior to requesting the purchase be made with FloridaSDC funds?
 9. Will the purchase enhance employability or result in productive activity for the individual?
 10. Is this a recurring purchase that ultimately could be purchased through earned income?
- FloridaSDC Purchasing Policy & Guidelines (2006)

Discharge

Discharge from the FloridaSDC program may occur due to a number of situations, voluntary or involuntary. Often a person wishes to be discharged because they have accomplished their recovery goals and is ready to move on with their life. Other times they may wish to return to more intensive services not provided by SDC, such as case management, to further their recovery. A participant may increase their income through employment or other means and no longer qualify for enrollment in the program. If a person fails to complete a Life Action Plan within the allotted time they may be discharged after formal notification. In all cases the person is offered assistance by their Life Coach to assure a continuum of needed services.

Advisory Council

It is the responsibility of the managing entity to maintain an Advisory Council composed primarily of participants in the program and family members. The Council's function is to serve in an advisory capacity to the program. FloridaSDC is an evolving concept and needs ongoing input from the participants in order to grow. The Advisory Council also responds to grievances that cannot be resolved by other means. The Council meets at regularly established times, and in public session to provide input and recommendations to the managing entity.

Outcome Evaluation

In 2006 and early 2007 a study, **A Report on the Effectiveness of the Self-Directed Care Community Mental Health Program**, was conducted to analyze the effectiveness of the FloridaSDC program. This evaluation, mandated by the authorizing legislation for the program looked at the following areas of interest:

- Re-hospitalization rates
- Levels of satisfaction
- Service utilization rates
- Residential stability
- Levels of community integration and interaction

“The evaluation compared participants in self-directed care in Districts 4 and 8 to two different control groups. The first group included all customers in Districts 4 and 8 who were not participating in self-directed care. The second group was a randomly selected subset of non-self-

directed care participants matched to each individual self-directed care participant on three variables: gender, educational level, and minority status. The comparison period was the 2005-2006 fiscal year.

The evaluation revealed positive outcomes for self-directed care participants in terms of community integration and residential stability, both strong indicators of recovery and community functioning. Compared to non-participants, self-directed care participants also used significantly less crisis stabilization unit and other crisis support services. Self-directed care participants had significantly higher numbers of assessments, medical services including psychiatry, outpatient psychotherapy services, and supported employment.” Hall, R. Ph.D. (2007).

Re-hospitalization rates were not significantly different from the matched control group, but this is likely due to the low number of people in the two groups who experienced hospitalization during the study period. FloridaSDC participants experienced one hospitalization versus three in the control group.

Survey data collected from self-directed care consumers by personnel certified to administer the Personal Outcome Measures questionnaire, developed by The Council of Quality and Leadership, on participants assessed presence or absence of conditions conducive to positive outcomes in 25 quality of life domains. Overall, 75 percent of the ratings indicated the presence of these conditions, with relative strengths in areas such as working toward personal goals, satisfied expectations, daily routine, interaction in the community, choice of service options, and exercising rights. Hall, R. Ph.D (2007).

The report indicated that participants in the FloridaSDC program were less likely to be of minority status, were more likely to have a high school education, and were more likely to be female than the non-matched control group.

Because of the lack of reliable data on SDC participants a more comprehensive analysis was not feasible. Both programs have begun to collect in-depth information on participants and outcomes. It is anticipated that a full independent evaluation of the program will be conducted by the Florida Mental Health Institute.

The Future of FloridaSDC

Florida, like many other states, is undergoing serious shortfalls in funding for public mental health services. The Department of Children & Families has requested additional funds from the legislature to expand the FloridaSDC program throughout the state, but it is not expected that these funds will be allocated at this time. It is more likely that additional areas of the state will choose to implement SDC programs through the use of existing mental health dollars. As more information is collected on the benefits of the program, and as Florida continues to work towards

transformation of its' mental health care system, local administrators are likely turn to self-direction as a primary method for delivering services. Front end services like FloridaSDC are highly effective at keeping people out of more intensive services like crisis management and in-patient care.

Negotiations are currently underway with one of the Medicaid managed care organizations, providing services in the state, to buy into the SDC program. The logic of keeping people out of more intensive services through the provision of recovery based supports appeals to the financial managers of these organizations. Pilot managed care self-directed programs have already been enacted in other states.

Self-direction is the logical progression of a person-centered mental health care system. Proponents of the FloridaSDC program believe that eventually it will be the primary method of delivering mental health services in the state. It represents a more effective way of spending a severely limited budget and provides access to a wider array of choices for services. Self-direction offers feelings of self-esteem and hope and promotes recovery for our most vulnerable citizens.

References

Alakeson, V., (2006/7) The Contribution of Self-Direction to Improving the Quality of Mental Health Services. Department of Health and Human Services.

Center for Self-Determination, (2005) Crafting the Instruments of Freedom: Tools of Self-Determination.

FloridaSDC Financial Policies & Guidelines, (2006) Florida Department of Children & Families, Substance Abuse & Mental Health Program Office.

FloridaSDC Life Analysis, (2007) Florida Department of Children & Families, Substance Abuse & Mental Health Program Office.

FloridaSDC Operational Policies & Procedures. (2007) Florida Department of Children & Families, Substance Abuse & Mental Health Program Office.

Haines, S. LMHC, Spaulding-Givens, J. MSW (2007) The Philosophy, Principles, and Practice of Florida Self-Directed Care and Recovery Coaches. Florida Department of Children & Families, Substance Abuse & Mental Health Program Office.

Hall, R. Ph.D. (2007) Report on the Effectiveness of the Self-Directed Care Community Mental Health Treatment Program. Florida Department of Children & Families, Substance Abuse & Mental Health Program Office.

Nerney, T. (2004) Quality Issues in Consumer/Family Direction. Center for Self-Determination.