

Self-Directed Care Implementation Manual:

A Comprehensive Mental Health Program Guide

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About This Manual

Why And How We Created This Manual

This manual was created for people who are interested in alternative ways to help people recover their wellness following a diagnosis of mental illness. Staff at the University of Illinois at Chicago's Center for Mental Health Services Research and Policy created the manual. They worked with staff and administrators of SDC programs across the country to gather information and make it available to you. The manual's production and distribution are funded by a grant from two federal agencies. The first is the National Institute on Disability, Independent Living, and Rehabilitation Research of the U.S. Department of Health and Human Service's Administration on Community Living. The second is the Center for Mental Health Services, which is part of the Substance Abuse and Mental Health Services Administration.

Who Is This Manual For?

This manual is for anyone who is interested in designing, implementing, evaluating, or maintaining a self-directed care program for people with mental health conditions. Our intent is to make it accessible to a wide range of readers and to provide practical information about various aspects of SDC program development and operations. Throughout the manual, we provide links and resources so that you can follow up on specific areas of interest. To keep the text easy to read, we also have included a list of References and a Resources section containing helpful information.

How Can this Manual Help Me?

Self-directed care in behavioral health care is a relatively new and promising model, but has not yet been shown to be an evidence-based practice. This manual offers information about what has worked for others, and provides practical tools you can use or adapt to your unique situation. We also hope to stimulate your thinking about what you can do to start an SDC program in your area. Finally, we want to inspire you to believe you can make a difference!

SDC has a strong evidence base in the disability, aging, and social service fields, where there are an increasing number of ways that it is being organized and delivered. Different States approach SDC somewhat differently, with varying legislative mandates, Medicaid/Medicare contract stipulations, and local resources. Even within programs, people have different ideas and opinions about how to organize SDC. However, contained in this diversity is a common denominator: the participant is in the driver's seat.

A Word about Language

Language is important because the words we use communicate many subtle things about our attitudes and values. They carry more meaning than just what is understood on the surface. We strongly believe that individuals have the right to determine how they and their experiences are described. However, we are also aware that there is currently no consensus about appropriate or respectful terms that describe groups of people with experiences in the mental health system. In this manual we will use different terms to refer to these individuals, depending on the context, such as people with psychiatric disabilities, serious mental illness, or lived experience of mental health disorders. Generally, we use person-first language or refer to SDC participants.



What is Self-Directed Care?

Imagine...

Roberto is unhappy with the services of his therapist who speaks only English. He talks to his SDC support broker about Spanish-speaking therapists in the community and makes a decision to find a bilingual service provider. After talking to a few, he selects the one he feels most comfortable with and makes the switch.

Darcel benefits from getting online support. She has made friends online and has found virtual support groups to be helpful for her well-being. She would like to have an Internet connection at home so she can go online in the evenings. She looks at her personal SDC budget and decides to purchase Internet service as part of her recovery plan.

Denise hates being overweight. Her medications only seem to make it worse. Her neighbor has had success going to the self-help weight loss program Weight Watchers[™]. Denise wonders if it would work for her, too. With her support broker, she revises her SDC budget to cover the weekly fees and arranges to attend with her neighbor. In 6 months, she has lost weight and has developed new friendships within the group.

Shawn has always been interested in creative writing. He wonders whether he might have a hidden talent in this area. He submits an application and is accepted into a course on writing stories and articles for publication. His support broker encourages him to plan and budget for enrollment. Shawn earns four college credits, has authored an article for publication, and views writing as a future source of earned income.

In Self-Directed Care programs, these stories are not fantasies. They are real accounts about new ways services are being made available to people with mental illnesses. You can read other success stories by visiting the Texas Self-Directed Care web site: http://www.texassdc.org/.

This manual is designed to help people understand self-directed mental health care and to provide practical information and resources for promoting, developing, and operating an SDC program.

The main sections of Chapter 1 are:

- What is Self-Directed Care?
- Why is SDC Needed?
- Benefits for SDC Program Participants
- SDC as a Business Approach
- Benefits of SDC as a Service Delivery Approach
- Where does SDC Come From?

What is Self-Directed Care?

Self-directed care involves 4 basic components (Cook, Russell et al., 2007). First, participants develop recovery plans that specify life goals they have identified through a person-centered planning process, along with goods and services needed to promote goal attainment. Second, participants create budgets allocating dollar amounts for each purchase related to their life goals. Third, SDC program staff (called support brokers) are available to help participants develop their plans and budgets and to support them in purchasing the goods and services specified in their plans. Finally, an organization called a fiscal intermediary provides financial management services such as provider billing and withholding of money for payroll taxes. The SDC model is founded on principles of self-determination (Cook & Jonikas, 2002). Self-determination emerged as a service delivery concept in the 1990s. Rooted in a human rights movement, as well as concerns about rising costs and limited choice of services, disability advocates promoted the idea that people should directly purchase their own care and services.

In itself, the idea of giving people purchasing power in health care is not new or unique. The innovative elements are: (1) the purchasers are individuals with disabilities who are receiving publicly funded services; (2) a portion of public resources typically directed toward communitybased agencies are shifted to the control of individuals; and (3) participants can choose to purchase services outside of the public service system, within the parameters of State and federal regulations.

SDC is a model of health care financing in which individuals have the power, resources, and authority to choose the services and supports they feel will help them achieve their personal recovery goals. Individuals in SDC programs have a large say in how the funds used for their outpatient care are spent.

In mental health SDC programs, funds that are ordinarily paid to a community-based mental health service provider agency are made available, through a fiscal agent, to participants based on various formulas. Individuals can then:

- assess their personal needs for care and support;
- develop individualized recovery plans that will help them to achieve their goals;
- design, implement, and monitor individual budgets based on their recovery plans.

This way of choosing and paying for services is different from traditional mental health care. To navigate recovery plan and budget development, participants receive support and help as needed from SDC program staff, often called "support brokers," "life coaches," or "recovery coaches." These staff members work on behalf of SDC participants and not a particular service delivery agency. Brokers provide information and education and help to coordinate services. They also monitor quality and effectiveness of services and purchases. They can further assist participants to:

- assess their needs;
- identify and research service options;
- establish personal recovery plans and budgets;
- make decisions about how and by whom their needs will be met;
- manage the person's individual budget;
- trouble-shoot problems as they arise.

The service brokers are not case managers. Their allegiance is to the individual participant and his/her goals, not to the needs or interests of a specific service agency or program.

SDC programs use financial agents, called fiscal intermediaries, to handle administrative tasks such as enrolling providers, billing, payroll, tax withholding, and accounting. Preferably, the fiscal intermediary is independent of any traditional service provider agency.





Why is SDC needed?

For me, it's been a life changing process that helped me discover who I am, my needs, my dreams, and the future of my choosing.

~SDC Program Participant

SDC offers people more choices, greater control, and enhanced personal responsibility for their care and support services. It can increase options for individual recovery pathways, improve quality of life, and control costs for the funder.

SDC has been used for a number of years as a viable approach to services for older adults, persons with long-term medical conditions, and those with physical and developmental disabilities. However, it has been slower to emerge in the mental health field (Alakeson, 2008; Cook et al., 2010).

Nonetheless, there has been increasing interest in SDC in mental health. This interest is being driven by a number of factors:

- Service users' personal involvement in decision-making about their care is increasingly recognized as critical for effective service delivery and positive recovery outcomes
- Many States have implemented national and local policy initiatives to transform their mental health care system to promote recovery through increased participant self-direction
- The complex array of public mental health services often lacks mechanisms to keep the system responsive to the needs and desires of people with psychiatric disabilities
- Growing evidence links individuals' recovery success to the exercise of personal choice and the availability of acceptable options
- Rigorous evaluations of SDC programs show that they improve quality of life, achieve superior health outcomes, and have high user satisfaction at no greater cost than traditional services

Success of SDC initiatives for other groups raises the question of "why not in mental health?" In 2003, the President's New Freedom Commission on Mental Health included self-directed care as part of its system transformation vision.

"Consumers and families will play a larger role in managing the funding for their services, treatments, and supports. Placing financial support increasingly under the management of consumers and families will enhance their choices. By allowing funding to follow consumers, incentives will shift toward a system of learning, self-monitoring, and accountability" (U.S. DHHS, SAMHSA, 2005a).

For many years, there had been a presiding belief in the traditional mental health system that people with mental illnesses cannot and should not take significant responsibility for making decisions about their care. The consequences of this assumption have been disempowerment and dependency for many people.

Over the past decades, there has been growing emphasis on a recovery-oriented system. Reflecting this trend, the Commission's report challenged the service system to transform itself by implementing consumer-direction in every aspect of service delivery. SDC is a significant approach for increasing self-direction with the potential to transform the service system profoundly.

Benefits for SDC Program Participants

The program made a huge impact on my life. The financial aspect helped. But the effects were emotional and mental more than anything. I feel like people care, like I am needed and wanted.

~SDC Program Participant

People with psychiatric disabilities typically have little control over the services they receive. As "patients," "clients," "or "users" of services they are often on the receiving end of decisions made by other people that are driven by needs or interests other than their own. They have rarely had the power of being a "purchaser" of services. This dynamic sets up the potential for disempowerment, learned-helplessness, and dependency.

In free-market economies, the suppliers of goods and services compete with one another to earn the business of the purchaser. As such, suppliers are accountable to purchasers who control the dollars. If purchasers are not satisfied, they take their business elsewhere.



The Four Basic Rights and Responsibilities of Self-Determination

Freedom

To choose supports and services that match individuals' lifestyles and expectations.

Authority

To direct providers and control an individual budget by purchasing the supports and services outlined in a plan.

Responsibility

To give back to the community in beneficial ways.

Support

Through interdependence that fosters participation in the community.

Source: Cook, J.A., Terrell, S., & Jonikas, J.A., 2004

However, the business model in mental health services does not operate as a free-market economy. More often, it is a monopoly in which the supplier (the providers and their funders) decide what will be available, where, and at what price. Usually, the purchaser can only "take it or leave it."

In SDC programs, participants have the "power of the purse" as purchasers of their own services. SDC is a concrete example of putting recovery values into action. Through SDC programs, people with psychiatric disabilities are able to select specific services, supports, and other resources that meet their individual needs and preferences. Options are expanded by not being limited to what is available from traditional mental health service providers. Satisfaction is higher because if a participant is not satisfied, he or she can change vendors. The burden is on the vendor to ensure service quality and customer satisfaction.

The Substance Abuse and Mental Health Services Administration (SAMHSA) reports that SDC can facilitate "personal responsibility, create an economic interest in obtaining and sustaining recovery, and promote learning, self-monitoring, and accountability. Most important, choice and control can lead to recovery and improved quality of life" (U.S. DHHS, SAMHSA, 2005b).

People who are motivated are more likely to be successful. People who have choice and control of decisions pertaining to their lives and services are more likely to be motivated. When this occurs, everyone benefits in the following ways:

- Individuals feel better and can point to their own efforts and say, "I did it!"
- Service providers can take pride in high rates of consumer satisfaction and positive outcomes for their clients
- Funders can ensure the effective use of financial resources and take pride in the fact that value is high for the outlay of public funds



SDC as a Business Approach

Publicly funded mental health services involve business and economic decisions, as well as clinical and social justice decisions. Service funders such as States and the federal Centers for Medicare and Medicaid Services (CMS) have found that SDC programs can provide "more bang for the buck." Importantly, this costs no more than services provided in the traditional way.

SDC is Effective

Evaluations of SDC programs show that self-direction is both efficacious and cost effective. As discussed later in this chapter, research has found that participants make good choices that maintain their health and safety, while they improve their outcomes, satisfaction, and quality of life (Cook, Russell et al., 2008; Dale et al., 2003).

There is logic in this. If people are able to choose and purchase what they think will be most helpful to them, they are more likely to use and benefit from these expenditures. Further, some of the support and care services desired by individuals on the open market are less restrictive and less costly than those purchased from traditional providers. Research on the original Florida mental health SDC program found that participants chose wellness services they preferred, and subsequently, used fewer high-cost crisis stabilization services than non-participants (Teague & Boaz, 2003). This win-win is beneficial to individuals' personal recovery, and also creates a favorable cost-benefit ratio for the service system.

Cost Neutrality

In some models of SDC, services are "cashed out," meaning that a proportion of the public funds (e.g. Medicaid/Medicare, State Block Grants) that would have been spent on an individual's outpatient care is controlled by that person to directly purchase services and supports (Cook et al., 2004). Studies of SDC programs show that, over time, participants chose services that effectively reduced the need for and use of more intensive, restrictive, and expensive services such as nursing home or other institutional services. In effect, SDC programs were "cost neutral," meaning that they did not cost any more than traditional funding approaches (U.S. DHHS, SAMHSA/CMHS, 2010). In some instances, SDC went beyond cost neutrality and generated savings for certain costs related to long-term care (Dale & Brown, 2007). This was in addition to the added benefit of higher user satisfaction.

Policy Support for SDC

Increasingly, SDC is being used by both private enterprise and publicly funded health care. Some managed care companies are exploring ways to establish effective SDC Plans for their members. For example, in 2014 Magellan Health Services partnered with the Mental Health Association of Southeastern Pennsylvania, Temple University, and Delaware County on a mental health self-directed care program.¹

Federal policy makers are fostering interest in selfdirected care in mental health services. The New Freedom Commission on Mental Health Final Report states that services should be consumer-driven (U.S. DHHS, SAMHSA, 2005a). SAMHSA offers articles and resources on recovery and self-determination strategies that support system transformation, most of which may be downloaded from the Internet at no cost.² The UIC National Research and Training Center's web site, One-Stop Source for Self-Directed Care, also provides free resources including: 1) Free to Choose: Transforming Behavioral Healthcare to Self-Direction; 2) Promoting Self-Determination for Individuals with Psychiatric Disabilities Through Self-Directed Services: A Look at Federal, State, and Public Systems as Sources of Cash-Outs and Other Fiscal Expansion Opportunities, and 3) In the Driver's Seat: A Guide to Self-Directed Mental Health Care.3

CMS is increasingly recognizing the need for service delivery models that promote personal recovery, consumer choice, and self-determination in mental health care. Based on their positive experience with "Cash and Counseling" demonstration programs in numerous States, CMS supports SDC initiatives for vulnerable groups such as people with physical and developmental disability, the elderly, and at-risk youth.





Benefits of SDC as a Service Delivery Approach

SDC has advantages for service providers as well as participants. It enables providers to unbundle services by pricing and selling them separately, depending on what SDC participants wish to purchase. It also creates a motivated cadre of service users, since SDC participants have freely chosen where to purchase their services.

SDC can offer opportunities for participants that cannot be funded through traditional service funding mechanisms, such as Medicaid. SDC does not replace some services, such as inpatient, crisis, or residential care. Instead, SDC is one point on a continuum of care for people pursuing specific recovery goals. Provider agencies are often limited to providing services that are billable and that meet specific funding requirements. Often these services are expensive, as well as constraining for both providers and clients. SDC can help providers focus on developing excellence in their clinical array, expand available options, and offer chances for participants to meet their recovery goals in more creative ways. As a service delivery approach, SDC can offer opportunities for participant recovery that other models cannot, as described in the box on the right.

SDC can assist providers with quality assurance and improvement. While some SDC participants select non-traditional goods and supports, others choose to purchase more familiar, traditional services. If a participant is not happy with one vendor, he or she can research and select another. This offers providers an opportunity to explore why SDC participants choose their services and why they do not. This knowledge about the value of one's services on the open market can be invaluable to providers as they look toward changing health care business environments.

Opportunities For Participant Recovery Through SDC

- 1 Restoration of the whole person: mind, body and spirit
- 2 Escape the cycle of dependency
- **3** Learning to accept change as a challenge instead of a fear
- 4 Obtaining services that focus on quality not just immediate satisfaction
- 5 Embracing consequences of choices as opportunities
- 6 Embracing success
- 7 Learning to monitor progress through self- evaluation along the way
- 8 Learning to advocate for personal needs
- 9 Learning the importance of person-centered language





Where Does SDC Come From?

Civil Rights, Liberties, and Responsibilities

Democratic societies are grounded in freedom of choice, independence, and personal responsibility. We presume these rights for all people, limiting or removing them only under certain circumstances. Opportunities for choice and self-determination – with their attendant personal responsibility – are part of full citizenship for persons with disabilities.

Lived Experience

Mental health advocates believe that self-determination is a core element in recovery-oriented service systems. Individual stories of recovery always contain elements of personal decision-making, risk-taking, learning from mistakes, growth in understanding, and developing skills.

Self-Determination Theory and Motivation Research

The importance of choice and self-determination is supported by considerable theory, research, and practice in a variety of fields. Studies show that there is a positive connection between self-determination and better physical health and mental health outcomes. For example, research has found that self-determination is associated with higher levels of involvement and attendance in treatment programs, better adherence to medication regimens, attaining glucose control in persons with diabetes, and maintaining weight loss.⁴

Self-determination enhances motivation, which in turn increases participation in positive activities. This ultimately leads to improved recovery outcomes.

The well-known "stages of change" model, developed by Prochaska and DiClemente (1983), also supports the concept of self-determination. This model looks at motivation and change as a process that incorporates five stages: pre-contemplation (not yet thinking seriously about changing), contemplation (beginning to desire change), preparation (planning for change), action (taking necessary steps to realize change), and maintenance (sustaining change over time). This approach also recognizes that people need to internalize the need for change before they feel ready to move forward.

In applying this model to SDC, it is important to remember that eligible and enrolled participants may be at different stages of change. This is true between different people and within the same person, because stages of change can fluctuate over time and with various goals.



SDC Pilot Programs and Research

As mentioned earlier, pilot SDC programs in the early 1990s gave elderly participants and those with disabilities the opportunity to control financial resources, in order to direct their own personal attendant care. The Robert Wood Johnson Foundation (RWJ), in conjunction with CMS, established the Self-Determination for People with Developmental Disabilities Program. The program's goal was to help States implement a more cost-effective system for serving persons with developmental disabilities and simultaneously give those persons and their families more choice of services.

The RWJ evaluation of this program found that participants did assume more responsibility for decision-making regarding their services and that their quality of life improved.⁵

In 1997, CMS launched the "Cash and Counseling" demonstration program in which cash allowances were given to people with disabilities, the elderly, and parents/guardians of children with special needs to purchase their own personal assistance services (Cook, Russell, et al., 2008). These services included personal care attendants and other service providers, and disability-related goods and services such as home modifications, assistive devices, and supplies. Evaluations of this program in Arkansas, New Jersey, and Florida found that participants were more satisfied with their services, more likely to receive evening and weekend support, and had fewer perceived unmet needs. In addition, participants chose home services rather than more costly nursing care services, resulting in cost neutrality (Dale et al., 2003). Overall outcomes were as good as or better than comparison groups in traditional services (Lepidus-Carlson, et al., 2007).6

In 2001, a group of Florida mental health service users, family members, and other advocates formed a taskforce to consider whether and how SDC could be made available to people with psychiatric disabilities. Their work resulted in the Florida Self-Directed Care Program (FloridaSDC). These visionaries demonstrated that, when given an opportunity, people with psychiatric disabilities could make their own choices and successfully attain individual recovery goals. One evaluation (Cook et al., 2008) showed that FloridaSDC participants spent a significantly higher number of days in the community after joining the program than they did in the year prior to program enrollment. Additionally, participants scored significantly higher on global functioning in the year following program participation than the year prior. Notable proportions engaged in

productive activity including paid employment (34%), vocational skills training (19%), volunteer activities (16%), and post-secondary education (7%).

In 2003, the Oregon Technical Assistance Corporation received a Real Choice systems grant through the State of Oregon Department of Human Services to pilot an SDC program for people with psychiatric disabilities. With the ability to serve 25 participants, the Empowerment Initiatives Brokerage (EIB) was the first 100% mental health consumer-run SDC program in the nation. An evaluation of the program found high levels of satisfaction, perception of empowerment, and goal attainment among participants (Sullivan, 2003). The evaluation included appraisals by the staff about community outcomes of the participants. Participants increased their involvement in competitive jobs from 23% to 47%; increased independent living from 88% to 95%; and increased their enrollment in formal education from 8% to 44%.

In 2008, with funding from NIDILRR and CMHS, the UIC Center on Mental Health Services Research and Policy, in concert with collaborators in the State of Texas, conducted a randomized controlled trial study of mental health self-directed care (Cook et al., 2010). Consenting adults were randomly assigned to an SDC program or a services as usual control condition, and followed for 2 years. Results revealed that, compared to controls, SDC participants had significantly lower severity of symptoms, higher self-esteem, greater coping mastery, and higher levels of self-perceived recovery. Over the two-year period, costs for the SDC group were roughly equal to the control group (\$5,240 versus \$5,493, respectively). Costs for some services were less, for example inpatient costs, which averaged \$295 per person for SDC participants versus \$613 for controls (Cook et al., 2015).

In 2008, the Mental Health Association of Southeastern Pennsylvania, partnering with the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities and Magellan Health Services, launched a mental health SDC program with State funding in Delaware County, Pennsylvania. This group also conducted a randomized controlled trial study to determine the effect of SDC on participants' mental health recovery, empowerment, community integration, and costs of care.





Take-Home Messages

SDC has many benefits for participants, providers, and the overall system. Federal agencies also are increasingly recognizing the need for human service systems to promote personal recovery, choice, and self-determination. Research also demonstrates that SDC participants generally choose services that increase their well-being and quality of life without costing more than traditionally-financed community services.







This chapter provides information and tips for developing an SDC program in your area. It emphasizes the importance of understanding the values underpinning SDC, getting grassroots support, and working with people who have the power to implement the larger system changes needed to operate the program. It addresses the common concerns that people have about SDC, and offers guidance for dealing with them as you plan your new SDC initiative.

The main sections of this chapter are:

- Understand the Values that Ground SDC
- Decide What You Want To Do
- Get Others Interested & Build Grassroots Support
- Organize!
- Common Concerns about SDC
- Planning Your Program

Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; where he works...Unless these rights have meaning there, they have little meaning anywhere.

~Eleanor Roosevelt

Understand the Values that Ground SDC

The concepts of recovery, self-determination, and self-directed care are intertwined and often synergistic. While SDC is an alternative mechanism for funding individual services, it is also based on certain values. There are four primary values that ground SDC initiatives (Cook, Terrell et al., 2004; Nerney & Shumway, 1996).

Stakeholders need to be familiar and comfortable with these values and their implications for SDC, the service system, potential participants, and others. In your initiative, there will be times you will need to educate others about these values. There may even be times when it will be necessary to fight for or defend them.

Freedom

Most traditional systems of care are able to offer people limited choices and little individual control over their mental health services and caregivers. Paradoxically, this kind of system can increase dependency in the name of "treatment" rather than fostering independence. A fundamental aspect of freedom is the ability to choose how to live and the capacity to obtain the means to develop and achieve our goals.

Authority

Authority in self-determination refers to the fact that people have control over the dollars spent on their own care. Giving people purchasing power promotes a wider range of service choices, and enhances both consumer outcomes and satisfaction. SDC affords people with a mental illness the opportunity to exercise authority over who provides services and supports, as well as decision-making power about the kinds of services and supports they need. Authority also has the intrinsic value of increasing one's sense of responsibility and self-efficacy, consistent with the recovery approach. This is accomplished in an atmosphere of partnership and negotiated risk.

Support

A prerequisite for successful SDC initiatives is a range of service options available to people in a public mental health system. These can include services from traditional systems, services from other agencies and organizations, or goods and resources in the community at large. It can be difficult for people who have long been dependent on public systems to suddenly assert themselves as independent agents, capable of making well-informed choices. Participants in SDC may need individualized support to learn how to exercise the kinds of decisionmaking and personal responsibility inherent in SDC. Further, they may require additional support for decision-making when symptoms of the illness are overwhelming, in order to ensure health and safety. Making an Advance Directive or a Crisis Plan (such as is found in a Wellness Recovery Action Plan[™]) can help determine in advance who will make decisions for and support the SDC participant in times of acute crisis and post-crisis.



Responsibility

Often people in the public mental health system lose skills related to taking responsibility for their lives. Part of the process of recovery is reclaiming the personal responsibility for control over one's life. Responsibility in SDC is a "two-way street." Professionals have responsibility for fostering individual recovery in ways that promote personal dignity, while also allowing for risk-taking and learning from mistakes (Deegan, 1996). Individuals have the responsibility for setting goals and deciding how to achieve those goals, even in the face of setbacks. They also have responsibility for developing and adhering to a budget to purchase services and supports for goal attainment.

Taken together, these values constitute empowerment, and challenge both providers and individuals to take on different roles and responsibilities. They also represent a fundamental shift in power within the mental health service system based on "who decides" and who holds the dollars or "power of the purse."

These values and their implications can be difficult for some to accept. There can be significant barriers that make it difficult to shift the status quo, especially when it challenges long-held opinions and ways of operating. When starting an SDC initiative, you should anticipate that there may be objections from many directions as people deepen their understanding of its full meaning and implications. This push-back may continue as you establish and operate the program. As SDC becomes more familiar to all parties and tested by time, the resistance will typically diminish.

Decide What You Want To Do

The first step in getting started is learning everything you can about SDC. Do not limit your research to just programs for persons with psychiatric disabilities. Look at the materials and programs developed for other people: persons with physical disabilities, children and families, and elders. These programs offer experience and wisdom on which to draw.

Questions to consider in your research

- What have others done in your State or elsewhere?
- Are there already programs in your area that you can build on, such as SDC for older persons, children, or people with other disabilities?
- Is there legislation in your State that would support an SDC initiative for people with psychiatric disabilities?
- Are there other people interested in establishing an SDC program in your area? How can you connect with them?

This manual provides you with some places to start with your research. The Resources section and End Notes include web links for information and resources about SDC, many of them downloadable for free. Remember to also web-search keywords such as "self-directed care," "self-determination," and "Cash and Counseling." You will find many more resources than could be included in this manual. Additionally, the References section contains citations for all of the articles cited in this manual.

But, do not limit your research to this manual or the Internet. If there are people or groups in your area that are already operating SDC programs of any kind, talk to them. Find out as much as you can about how they operate, whom they serve, and how they are financed and structured.



Questions to ask of other SDC programs

- What were their experiences in getting started?
- What assets and allies did they have for getting started?
- What kinds of challenges did they have and how did they overcome them?
- Do they have any outcome data that support the success of their program?
- What guidance do they have for your initiative?

As you do your research, you will get not only information, but also ideas for what an SDC program in your area could look like, what resources might be available, what barriers you may anticipate, and how to address various challenges.



Get Others Interested & Build Grassroots Support

To begin an SDC initiative, you need to get others interested and involved. It may take a few passionate people to get things rolling, but you also need to build grassroots support for both the idea and the commitment to persevere in creating something new. Initially, creating interest in SDC is not difficult. It is a new opportunity. Reach out to anyone you think might be interested. Talk to stakeholders who may not be enthusiastic as well, in order to understand their concerns.

Tailor Your Message

Ideally, you want support from potential program participants, family members, service providers, policy makers, and advocates. Individuals and organizations may be interested for very different reasons that reflect their stake or investment in the service system. For example, potential participants are interested in the opportunity to have more control, options, and resources for accessing personalized services and supports. The mental health system may be grappling with the federal call for transformation, and might be amenable to considering ways to provide more recovery-oriented services. Disability advocates often want to promote individual autonomy, rights, and citizenship. Family members may see an opportunity to help loved ones get services, resources, and supports that are not currently available. In building interest, the challenge is to help each stakeholder understand how SDC may be advantageous to him/her, as well as to others.

Share Information

You will need to educate others about what SDC is and what it is not. How you present the idea will have an impact on how others receive it. Be clear and concise in your communication with others. Talk about the program's integrity, intent, and values. Chapter 1 of this manual can be used as a handout. Copy it and share it with others who already are interested, as well as with those you think may come to support SDC over time. If your State or region already has SDC programs, get copies of their brochures and hand them out. This communicates that SDC has been tried, tested, and is successful for persons with disabilities in your State or region.



Listen for Concerns

Anticipate that some people will have worries and concerns. Some may not be interested at all or may react negatively to the idea. Listen to what people have to say, even the negative comments. Be respectful, courteous, and determined, even when others disagree with you. Avoid emotional responses which can sabotage your efforts. Negative responses are an opportunity for you to understand how people perceive the idea and what challenges and barriers must be overcome. Respond carefully and thoughtfully. If you don't know something you are asked, simply say, "Great question. Give me some time and I'll see what I can find out." Then, make sure you follow up on the issue. These attributes model the positive outcomes of the SDC initiative you are presenting.

With information about worries and concerns in-hand, you can go back and do more research. How have other SDC initiatives addressed these issues? How could these challenges be overcome in your area? Create a plan for addressing them.

Keep It Transparent

Aim for transparency. Avoid lots of private conversations and emails. Keep people informed, and make sure everyone has the same information. Having discussions in public forums can often be difficult and timeconsuming, especially when people have a wide range of opinions or ideas. However, they are important so that everyone feels involved and knows what is happening.

Involve Potential Participants

Make sure to get many potential participants involved right at the beginning and in every way. As a grassroots effort, SDC should not be "done to" people. You are creating a new opportunity with them and for them. People who are potential participants will be some of the strongest proponents, and their passion can propel the initiative forward. However, do not force people to be involved if they are not interested or ready. Some people are content with the services they get from traditional agencies. Like others, they may fear that SDC will mean losing things that they are familiar with and depend upon. Listen to these concerns, and provide information about SDC to clarify or correct any misconceptions.

Organize!

Come Together

Find a place and time to bring interested people together. Try to find a place which communicates that SDC is an independent initiative – not another mental health treatment program. It helps to use natural settings, such as a community center or town hall. Try to keep the same meeting site and time throughout the planning process to help people anticipate it and attend.



Preliminary Meeting

Invite interested people you've talked with during your research to come to a preliminary meeting. You may want to consider advertising it more broadly in the community as well. At this stage, however, you want to avoid inviting people who are against the idea. You will need to address their concerns in the near future, but first you need to get organized.

Create an agenda that includes a presentation by people knowledgeable about SDC and leaves time for discussion. The purpose of the preliminary meeting is to get people excited about SDC and moving it forward. Ideally, you can end the meeting by forming a planning committee comprised of a small group of stakeholders who are willing to put time and effort into taking the next steps.

Create a Planning Committee

The planning committee is your primary vehicle for moving forward. Ideally, you want people serving on the committee to support SDC, represent various stakeholders who may be affected by the program, and at least some who have real power to make change. The people in power vary from community to community, so you'll need to determine this for your own initiative. It's important to ensure that people in mental health recovery are well-represented on the planning committee as well.



Getting people on board is just the beginning. The productive use of meeting time is an important consideration. Unfocused or unproductive meetings are often a "turn-off" for participants who want to feel their contribution is meaningful and valued. There should be clarity about the purpose of each meeting. Make an agenda either in advance of the meeting or as the first activity, and stick to it! Make a list of tasks and activities that need to be addressed or completed, along with a timeline for completion. Refer back to it regularly to make sure that momentum is maintained.

Not everyone knows how to effectively serve on a committee. For some, it is a learning process. Often people with psychiatric disabilities have been excluded from this kind of activity, so they may not have developed these skills. They probably aren't the only ones! There are a number of resources that can help to support committee members who are not familiar with what is expected of them.⁷ An online search of "non-profit board member training" will turn up resources. Without a doubt, however, the best support for people new to committee work is mentoring and personal support by people with more experience. This helps build relationships and also provides accommodations for people who have difficulty with reading, writing, or participating.

The planning committee needs lots of information. This is where your earlier research pays off. You also may want to get committee members involved in doing research themselves on particular topics and sharing results with the rest of the group. It can be useful to learn together by bringing in experts on a specific issue, such as current State or local legislation and rules pertinent to SDC.

Many groups find it useful to write a mission statement that spells out clearly what the group wants to achieve. As an organizing tool, a mission statement establishes a clear, shared, and positive vision and creates a common rallying point for the group. It also provides a foundation you can return to if people begin to lose focus or become discouraged. The process of writing the statement helps illuminate the places where the group has consensus and where the points of difference may lie. The initial goal is to write a mission statement that establishes common ground for everyone.



Build Relationships and Nurture Allies

Get to know people personally and develop positive relationships with them. Actively nurture these relationships over time; they are your greatest asset. When there are differences of opinion, do your best to work through the issues respectfully and find common ground. It is in everyone's best interest to make compromises along the way or "agree to disagree" on some points in order to pursue a larger, shared goal. You can find allies in many places, and may be surprised at some of the people who are interested. People who are not fully onboard initially may become some of your strongest supporters over time. Take care to avoid alienating anyone along the way! You may need them down the line.

The original Florida SDC initiative was fortunate to have a knowledgeable, persistent, and compassionate advocate who never accepted "no" for an answer. Her name is Jo, but she later became known as the "Hat Pin Lady." The purpose of a hat pin, of course, is to secure a hat to a person's head, and similarly, Jo was committed to securing resources for participants in SDC. She wouldn't allow anyone to dispute the fact that people with mental illnesses deserve opportunity and choice in their recovery journeys. Those who resisted change undoubtedly felt the "hat pin" prick of her persistent advocacy. People like Jo motivate interest, commitment, education, and inspiration. We are not advocating that you go around provoking or pricking people. The point is to look for stakeholders in your community who could be your "hat pins," in terms of commitment in the face of opposition. They are invaluable to the process.



Get Support from High Places

There are other important people who you may want to involve in the process, including on the planning committee if possible. These are:

• Administrators of the State or local agencies. By including these authorities, you have opportunities to discuss how changes can be made in contracts and other mechanisms that drive service financing and delivery in your State or region.

• State legislators and other elected officials. These people often care what their constituents are thinking about. Further, you will need them as allies if you decide to advocate for changes in your State legislation to enable SDC for persons with psychiatric disabilities. Get them onboard as early as you can.

Potential supporters may require lots of information and personal contacts before getting interested or involved. You may need to reach out to them directly and spend considerable time talking with them personally to educate them about SDC. Many will not have the time to participate as members of a planning committee, especially in the early stages, but they may appreciate being invited as speakers or as guests. Keep them in the loop by sharing copies of minutes, materials reviewed, or reports created by the planning committee. Your effort may recruit powerful allies to your cause.

Anticipate Detractors

Show me someone who has done something worthwhile, and I'll show you someone who has overcome adversity.

~Lou Holtz

Anticipate and accept that there will be people who do not understand or like what you are proposing. Dealing with detractors can be difficult and frustrating. But it comes along with building a new program, especially one that is different. Work publicly as much as you can. Addressing detractors is certainly difficult in public settings, but it helps ensure that everyone hears the same thing and provides opportunities to clarify misinterpretations.

Detractors come in different forms and have different motivations. Some might be openly opposed to your initiative, while others might be more subtle. Some may work actively against you, while others may be more like a stone wall that you cannot get around. There are different ways to strategically address detractors. Sometimes, you have to use multiple approaches simultaneously! The following list outlines some different kinds of detractors and some suggestions for how to proceed.

• Those who need better understanding about mental illness and recovery.

Stigma is pervasive in service systems as well as among the general public. Many people do not understand or fully appreciate the wealth of abilities and potential of people with psychiatric problems. Stories of individual recovery journeys can help instill the notion that people can and do recover.

- Those who need education and information about SDC. There are a number of misconceptions and myths about SDC. Some people need information that is objective and factual to help them sort out the myths from the reality.
- Those who fear loss of control.

Because SDC involves reorganizing service financing streams, it can be threatening to those who benefit from the current system. Use common sense in dealing with powerful actors and organizations.

Using common sense means that you should:

- Understand the situation from their perspectives
- Address their specific concerns
- Avoid adversarial actions
- Work towards a "win-win" for all



• Those who say yes, but mean no.

This is more difficult to manage because it is so common, and because so much happens behind the scenes that these people can be hard to confront directly. Avoid retaliating in the same manner; it can make things worse. Acknowledge the problem and raise difficult issues for discussion. Do your best to model open, honest, and direct communication.

• Those who work actively against you.

Think strategically. Why are they working against you? What can you safely ignore and what requires direct response or action? How can you or someone else change the situation? Is there room for negotiation? What assets and allies do you have that can be brought to bear on the situation? Be willing to make trade-offs in details, but not values.

• Those who refuse to budge.

Yes, there will be those who will refuse to give an inch, no matter what you do. This is especially problematic when those who will not budge are also those who control the fiscal policies and funding streams. These are situations when you may need to call in higher authorities to support your cause. Your relationships with State legislators, other elected officials, and various powerful authorities become critical in this circumstance. You've built allies and you may need to call on them.

Stay focused on your values and long range objectives. Try not to "sweat the small stuff." You will have hurdles and set-backs, but these are part of the process of systems change. Patience and perseverance should pay off.



Common Concerns about SDC

Below are some common fears and worries about SDC. It is not an exhaustive list, but provides some guidance for addressing these issues when they surface during your organizing and planning work.

Will SDC initiatives erode the mental health system?

No. SDC is a way to expand a comprehensive system of care for people with psychiatric disabilities. For most people, SDC is a complement to the traditional system rather than an alternative to it. SDC provides defined resources to people who cannot get their needs met through traditional avenues. Many necessary services such as hospitalization, emergency response, and other acute services - remain with the traditional service system. Providers continue to offer counseling, case management, psychiatric rehabilitation, supported employment, and other services. SDC participants have greater ability to choose from and purchase such services to best meet their preferences and recovery goals. With SDC, the intention is to offer participants the opportunity to choose from a broader group of providers in an SDC Network or from alternative sources, including private providers. It doesn't mean that people won't want or need services from public mental health providers anymore.

In Florida, the publicly-funded community mental health centers were reluctant to endorse the project because of concerns about their budgets being reduced by the cash-out. To deal with this equitably, budget reductions were spread over 10 centers. Their contracts were reduced proportionally, using a per capita formula by catchment area and proportion of clients served, so that no one center experienced large funding reductions.

Doesn't the public mental health system already provide people with choices?

Yes and no. In some service areas, there are multiple behavioral health care providers and, as a result, individuals have some degree of choice among vendors and the array of services offered by those vendors.



Don't people with mental illness lack the ability to make decisions about their services?

Certainly not. It is important to remember that all adults have rights to make personal decisions in a democratic society, as long as those decisions do not jeopardize or impinge on the basic rights of others. Only in limited and carefully defined circumstances are these fundamental rights removed from an individual through a legal proceeding. Unless a person is adjudicated as not competent to make decisions, and is assigned a guardian or other agent to make decisions for him or her, then that person retains full legal decision-making authority.

Research on SDC programs to date shows that participants make good decisions about purchases that support their personal recovery goals. Further, there are mechanisms in place to ensure safety in decision-making, such as the SDC program's Purchasing Policy which specifies limitations on spending choices.

Stefan (2004) suggests that many issues concerning competency are more effectively framed as program issues than as individual ability issues. Under this line of thinking, a different set of questions, framed programmatically, can be asked:

- Should there be any prerequisites to participation in a self-directed care program for people with psychiatric disabilities?
- What limitations on choice should the program impose, and on what basis?
- How will the program manage crises?
- How will the program deal with different perspectives on symptomatology and functioning?
- How will the program intersect with Federal and State statutory programs and requirements? For example, if an individual in a self-directed care program funded by Medicaid is involuntarily committed under a State commitment statute, how does the Medicaid Institutions for Mental Disease (IMD) exclusion, which bars the use of Medicaid funds for treatment in a psychiatric hospital, affect the person's participation in the SDC program?

Regardless of where people live, even this level of choice is often limited if only one mental health vendor is easily available. In other systems, the philosophy or type of services available may be exclusively medically-focused or solely office-based, with few options for people who prefer different or additional approaches such as peer and home-based support.

Available vocational services may offer low-paid, entry-level jobs, rather than job training or education that can lead to higher-paid, competitive employment. Wellness-focused recovery tools (like exercise or nutrition counseling) and peer-delivered services may not be available within the existing mental health service array.

Part of the challenge inherent in public services is that they are often funder- or provider-driven, with a focus on what can be offered given current resources. SDC is participant-driven, with a focus on what is actually wanted and needed.

Won't SDC cost more?

Most SDC programs are set up to be cost neutral. That means they are designed not to cost the system more or less than it is already paying for services for a given individual. Additionally, the focus on helping people access a broader array of preventative services/supports means that they might avoid more costly encounters such as the hospital, emergency department, or jail.

All that said, your program will incur administrative costs that must be considered when mounting an SDC program. Such costs may include salaries and fringe benefits for the program director and support brokers, computer equipment, a photocopier, telecommunications, office supplies, meeting costs, and other similar expenses. In some SDC programs, participants pay for time with their support brokers out of their personal budgets. This helps to offset salary costs. Even if you go this route, you'll need to factor in other general administrative costs when seeking external funding, as discussed in a later section of this chapter.



Aren't professionals better at knowing what is best for people?

There are very caring, skilled, and understanding mental health professionals who have dedicated their careers to helping people with psychiatric disabilities. There are also those with limited awareness, training, skills, or inclination, who have narrow perceptions and lower expectations about the potential of people with psychiatric disabilities.

The idea that professionals know best has been challenged as the field learns more about the process of recovery and the trauma and re-traumatization of individuals using public service systems. The "provider knows best" perspective also has been debunked by established evidence-based practices that emphasize the importance of consumer involvement, shared decision-making, and collaborative approaches to care and treatment (Cook, 2005; Institute of Medicine, 2001).

Professionals have knowledge and expertise in many clinical and technical areas, while the individuals they serve are experts on their own needs, experiences, and what works for them. The goal is a mutual and constructive dialogue that leads to shared decision-making based on shared knowledge and reflection. However, this is not the experience of many mental health service users. Some of them feel that their opinions and preferences bear no weight against expert opinions or paternalistic practices. Others feel worried that providers are too pressed for time to listen to their concerns and engage in mutual problem-solving. Still others believe that the provider should be the expert and lead the process, and thus, don't wish to share equally in medical or health decisions (Jonikas et al., 2013).

SDC programs promote and support individuals in regaining the confidence to make decisions based on their carefully considered needs, cultural beliefs, preferences, and recovery goals. SDC staff work side-by-side with participants in a collaborative rather than a directive way.

Doesn't SDC demand budgeting and other skills people do not have?

Budgeting can be difficult for anyone, and the less money you have the harder it is to cover the necessities of daily living. People with psychiatric disabilities typically live on very restricted incomes. Some are quite proficient at stretching their limited dollars. Others have had little opportunity to develop financial management skills because they have few resources to manage, or a guardian or payee has handled these matters. However, financial planning and budgeting skills can be taught, learned, and developed through practice over time.

Often public systems are organized to manage the needs of people with long-term conditions within an acute care framework. One unintended consequence of this arrangement is that clients develop learned helplessness and dependency on the system and its providers. Additionally, due to limited funding, systems often are set up to respond to the needs of the group rather than each individual. In this context, choice has meant that people have to "go along or go alone," and skills for autonomous decision-making erode. Depending on the length of time an individual has been in this situation, it can be frightening to be asked to make meaningful choices, take on responsibility, and assume risk for the choices made. Additionally, the "pent up" demand caused by a scarcity-oriented system can complicate choice. As a result, people become overwhelmed in deciding what to address first after living with many unmet needs and desires for so long (SHADAC, 2005).

SDC is an option for individuals who are ready to take a significant step forward in their recovery journey. Opportunities for meaningful choices, skill building, assumption of risk, and personal responsibility are fundamental aspects. But so are social support and coaching. There is a built-in system to help protect against unsafe or frivolous choices; this includes proactive planning, budgeting assistance, a wellarticulated Purchasing Policy, pre-approval of purchases by an independent agent intermediary, and accounting oversight.



What if someone needs the hospital and doesn't have SDC funding to cover the cost?

Anyone who needs emergency or crisis services, including hospitalization, will receive it. Funding and eligibility for these services do not change for SDC participants. Individuals do not need to budget for emergency or inpatient care in their SDC Plans.

Planning Your Program

Once you're ready to start planning your SDC program, you'll need to address a number of organizational and operational issues in some detail.

Some of the questions you'll be considering include:

- Exactly what kind of program do you have in mind?
- How will it be structured?
- Who will run and staff it?
- What kind of governing board will it have?
- How will it be funded?
- How will you recruit participants?
- What kind of records and documentation will you keep?
- Who will be eligible?

Get Started with a Pilot or Demonstration Project

In most cases, you will be focusing on securing approval and funding for a pilot or demonstration project. You are seeking a chance to prove that SDC will work for persons with psychiatric disabilities in your area. People need to see it work on a smaller scale before making significant changes in the service system or launching it more broadly. To this end, you'll need to build in data collection and evaluation right from the start (see Chapter 9). Success stories and testimonials are very helpful, but people also need to see the numbers.

Remember that pilot projects are learning projects and they entail risk – for everyone. There is always risk in trying something different or putting money into a new venture. Personal credibility is as valuable as public resources. If things do not go as planned, potential harm is minimized by keeping the program small at first. SDC is a very different way of doing business in public mental health. It will require taking some risks, learning to trust, and making adjustments on many levels. Starting a program from scratch also entails a lot of detail-oriented work. Such tasks include: creating program policies and forms, developing training for staff, figuring out how to hire support brokers, creating personnel policies, deciding what to document and how, entering into contracts with service providers, and developing the procedures for pre-authorization of participant purchases, among many other decisions.

Pilot projects provide the latitude to develop new infrastructure and policies, figure out what works and doesn't, and make the necessary changes. In pilot projects, there is an expectation right from the beginning that you will need to make modifications along the way.

Identify Funding Opportunities

Perhaps the most daunting part of planning an SDC initiative is finding the resources to capitalize it. There are several different options to consider for funding your initiative, both in the start-up and maintenance phases.

Medicaid State Plans and Waivers

States that wish to fund self-directed care with Medicaid dollars can use their State Plan or waivers to fund selfdirected care in four different ways (CMS, 2015). Under the Home and Community-Based Services (HCBS) State Plan Option-1915(i), States can offer a variety of services under a HCBS benefit and allow individuals to self-direct any or all of those services. Under the Community First Choice-1915(k) option established by the Affordable Care Act of 2010, States can use their State Plan to allow Medicaid beneficiaries to self-direct their personal attendant services and supports. Under the Self-Directed Personal Assistance Services State Plan Option- 1915(j), States can allow beneficiaries to self-direct the personal care and related services provided under the Medicaid State Plan and/or section 1915(c) waivers the State already has in place. Finally, under the Home and Community-Based Services Waiver Programs- 1915(c), States can develop HCBS Services Waivers to allow people to self-direct long-term care services and supports in their home or community, rather than in an institutional setting. While these four mechanisms currently exist, to date, no States have used them to fund the kind of comprehensive mental health SDC programs described in this manual.



Center For Medicaid and Medicare Services Definition of a Self-Directed Care Program

A state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget.

The CMS requirements for a comprehensive selfdirected care program generally include the following:

- **Person-centered planning -** A process, directed by the participant, intended to identify the strengths, capacities, preferences, needs, and desired outcomes of the participant.
- **Individual budgeting** The total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant.
- Self-directed services and supports A system of activities that assist the participant to develop, implement, and manage the support services identified in his/her individual budget.
- Quality assurance and quality improvement A process of ongoing review, remediation, and continuous improvement.

State General Revenue

Some States such as Florida have exclusively used State general revenue funds (i.e., tax dollars) to capitalize self-directed care. With this approach the State has greater leeway to permit the spending of public funds on a broad array of services, supports, and material goods than might be permissible under more traditional Medicaid State Plans. Using this option, the same SDC program structures are in place (described in Chapter 4) but there is no need for the amendment of existing State Medicaid Plans or applications for new waivers.

Managed Care Organizations

Still other States have used existing managed care waivers to fund self-directed care programs. The value of this approach lies in the fact that under managed care waiver authority, public dollars can be spent with greater flexibility to allow participants to purchase non-traditional services and material goods along with traditional mental health services. As one example, provisions in some public behavioral health managed care contracts mandate that cost savings above a certain percentage or dollar amount must be re-invested by the managed care organization (MCO) for the good of the community under a State-approved plan (Sabin & Daniels, 2000). These so-called "community reinvestment dollars" can be combined with Medicaid funds by MCOs to fund a full array of options in mental health SDC programs including traditional and non-traditional services and service substitutions. Another example is the State of Texas, which located its SDC pilot program in a community where an existing managed care behavioral health carve-out already combined Medicaid and State general revenue dollars to serve a mixed Medicaid and medically indigent clientele (Cook, Shore et al., 2010). This allowed the SDC pilot to serve both Medicaid and non-Medicaid beneficiaries and allowed a larger amount of flexibility for funding allocation.

Grants

Finally, some States have funded mental health SDC programs using time-limited grants. As one example, the State of Texas used a SAMHSA Mental Health Transformation State Incentive grant (designed to help States transform their mental health programs into better-integrated, more recovery- and resiliency-oriented systems of care) as well as a local private foundation grant to fund the administrative costs of its mental health SDC pilot program. Oregon used a CMS Real Choice Systems Change grant (designed to help States transform their long-term care system to rely less heavily on institutions and more heavily on community-based care) to capitalize its mental health SDC pilot program called the Empowerment Initiatives Brokerage.



Legislative Support

Building connections with State legislators and elected officials is especially important. State legislators must authorize the required State share of Medicaid and Medicare financing. People with psychiatric disabilities often represent a large portion of State spending in this area and legislators may be willing to consider SDC as an alternative financing mechanism. Many States already have legislation that supports forms of SDC for public service recipients from other populations such as the elderly and those with physical and developmental disabilities. Why not for people with psychiatric disabilities, too?

SDC initiatives may require supportive legislation in some States, and pilot programs may require legislative approval. To date the Florida SDC legislation is the only legislation geared specifically to promote SDC initiatives for adults with psychiatric disabilities and children with severe emotional disturbances and their families.⁸

Submit Proposals for Grant Funding

There are resources available to help you with the technical aspects of writing a proposal.⁹ Solicited proposals go by several names such as "Request for Proposals" or "RFP." The entity releasing a request for proposal has specific requirements about who can apply for funding, for what the funds can be used, and precise rules on exactly how to organize, write, and submit the proposal. If you are submitting a proposal for a grant, you need to get the submission application package, read it thoroughly, and follow the instructions carefully and precisely. Writing a grant is a big undertaking, so be sure to share the work and writing with allies.

Take-Home Messages

Getting an SDC initiative started is a serious undertaking. Expect it to take time and considerable effort. In getting started, it's important to have a clear vision of what you are trying to achieve. You will also need to identify allies with the passion and willingness to contribute time, energy, and resources to the initiative. Finally, the tenacity and commitment to follow through on your plans even as you encounter resistance and roadblocks are essential to making SDC possible for people with psychiatric disabilities.



3 Being Participant-Driven

Self-directed care is a participant-driven initiative. The statement, "Nothing about us without us," is more than a slogan or a request for inclusion at meetings. It is a critical factor in successful SDC initiatives. SDC cannot be planned, developed, implemented, or evaluated without leadership from those who will be self-directing their care – the program participants.

This chapter will address two forms of participant involvement. The first is participants as planners and implementers of an SDC initiative. The second is at the level of program participants making personal decisions about their own services and resources. The main sections of this chapter are:

- Consumer Involvement in Planning SDC Initiatives
- Competency, Capacity, and Choice in Personal Decision-Making
- Choices of Experience: Ellen Talks about the Role of Providers and the System

Customer Involvement in Planning Initiatives

Satisfaction surveys are not enough

Customer involvement and input are powerful forces in the marketplace. Think about the services and products you use every day, and you'll see what we mean. For example, even after spending millions of dollars to create them, movies and commercials are not released without extensive audience testing. The candy manufacturer, Mars, Incorporated, had many focus groups with children and adults before deciding to add blue M&Ms® to its standard colors. "New and improved" products and services are usually based on solicited and unsolicited input from customers. When given more than one purchasing option within their price range, people make choices based on their preferences and how well a product meets their unique needs or desires. Therefore, companies that understand and fulfill customer demands for particular goods or services remain viable in the marketplace. Those that ignore or misinterpret their customers' preferences lose market-share when people decide to purchase their competitors' goods or services instead.

In some service sectors, including mental health, service choices are limited, and the option to purchase recovery-promoting goods or products is nearly non-existent. The people who use services have limited opportunity to provide input into the design, delivery, or direction of their services. Many mental health systems and providers do survey their clients about satisfaction with services. While this is an important aspect of quality assurance, being participant-driven requires more than just surveying people. There are a number of reasons for this.

Satisfaction surveys are periodic.

Many satisfaction surveys are conducted annually or less often. Because of this, the results may not be available on a timely basis, which may impede making expedient changes.





Satisfaction may be difficult to interpret.

If survey respondents have received limited types of services, they will have little basis on which to make comparisons. It is difficult to distinguish between the full meaning of "satisfied" and "good enough" without having known much else.

Clients may find it difficult to say negative things.

Sometimes, clients rate a program positively because they fear that saying negative things will result in recriminations or loss of the services they depend upon.

Surveys require reading and writing skills.

Some people have limited literacy skills or cognitive challenges that make responding to questionnaires difficult. For others, English is a second language and questionnaires are not translated into their preferred languages. Administering surveys in-person can help address these needs, but add cost and time to the survey initiative.

Surveys may be administered by agency employees.

Surveys conducted by peer researchers often yield different results from those administered by agency employees. When responding to their peers, people may be more candid with their complaints or concerns than they would be to their providers.

Surveys may over-sample satisfied clients.

Often, surveys capture only those people who are actively receiving services and attending a program regularly. Those who attend less frequently or who have "dropped out" of a program are seldom included in satisfaction surveys. Their concerns are not captured in the survey results, so the reasons they had for withdrawing cannot be addressed.

Survey feedback seldom results in program change.

It is common for satisfaction survey results to reinforce the status quo. Sometimes, identified changes cannot be made because of fiscal or personnel restrictions. Often, findings simply languish without real action.

Customer-conscious companies are motivated to obtain an accurate appraisal of how customers evaluate their products. Accuracy is necessary so that companies can tailor their products in ways that keep customers coming back to them rather than to a competitor. Take this lesson to heart as you organize an SDC initiative because the same principle applies. You want to make sure you know what your SDC "customers" want from their program. You also want to keep asking whether the program is meeting participant needs or should be changed to better accommodate them.

Find meaningful roles for everyone

When organizing your SDC initiative, you'll want to offer people a number of different ways to get involved. Some people like attending meetings; others prefer to work in the background. Some people want to be active in organizing meetings and making proposals directly to the group; others prefer to offer their opinions "off the cuff" or in writing. You need all of these contributions.

There are many different tasks that can foster a sense of involvement such as:

- planning the meetings
- setting up meeting venues
- preparing agendas and other documents
- facilitating the meetings
- taking minutes and preparing them for distribution afterwards
- designing brochures and fact sheets
- contacting potential allies to garner support
- writing funding proposals
- sharing personal experiences
- making public presentations
- participating in rallies or forums

Try to find a meaningful way for every interested person to help out, even if it is not in a public way.

Expect things to be "messy"

Involving people in change initiatives is rarely tidy, especially when there are many different opinions about what should happen or how it should happen. Things can get "messy." Think about what happens when a referee at a sporting event makes an unpopular call. Uproar! While referees rarely change their calls based on the crowd's response, there will be times when you'll want to adjust your process or change your course in response to input from the group.



Keep in mind that one or two vocal people do not necessarily express the will of the larger group. Nonetheless, if a sizeable portion of the group is in favor of a specific direction, you should try to take heed. Also, consider whether more vocal individuals might be stating the opinions of quieter group members. It can be helpful to draw out the opinions and ideas of these quieter folks. Make sure they have an opportunity to express themselves, even if you have to take the time to talk to them individually, outside of the group forum, or solicit their ideas in writing.

The issues involved in planning and launching an SDC initiative can be emotional for some people. The bottom line is one of control – who has it, who wants it, how to get it, how to keep it. Deciding who will control money can be an acrimonious process. Control over important decisions in the lives of people with mental illnesses can also be contentious.

Anticipate that people will have a full range of reactions from "It's about time," to "People with mental illness can't do this," to "It's scary and overwhelming," and even, "My case manager will be mad at me if I do this." Some participants may suddenly realize what little choice they have had over services and be angry as a result of this insight. When people begin to grasp the potential of SDC, they may become territorial and protective of what they already know or have. This applies to providers and policymakers as well as to participants!

Establish Expectations

Unfocused or unproductive meetings can be a turn-off for everyone. It can be helpful to establish some upfront expectations and guidelines about how the group will conduct business and communicate respectfully. It is best if these rules and guidelines are decided by the group itself. They should apply to everyone equally.

Basic Guidelines For Group Communication

- One person speaks at a time.
- Each person has an agreed upon length of time to speak.
- Each person is allowed to speak at his or her own pace.
- All communication is respectful.
- Everyone accepts that the group won't always agree. Having strong feelings or beliefs is okay, but not a reason to shut others down when they do not feel the same way.
- Each person is given an opportunity to participate in a way that is most comfortable for him or her.

You may also want to consider under what conditions and how you would ask someone to leave the meeting. This might occur, for example, if a person repeatedly interrupts others and disregards requests to allow others to finish speaking. Another condition is when a person becomes disruptive and prevents the group from attending to its business.

The criteria for being asked to leave a meeting should be clear, concise, and apply to everyone. It should not be solely based on symptoms associated with mental illness. People should be allowed to return to the meeting when they are able to respect the group's guidelines.





Make Conflict Constructive

Conflict is inevitable in every change or advocacy initiative. It is not necessarily a sign that things are going wrong. In fact, without conflict, it can be difficult to foster change. Without some constructive conflict, there would be no challenge to the status quo and nothing to force us to think in new ways. We might not learn as much about each other or ourselves. When handled productively, conflict can be a major source of creativity, and "creative tension" can give projects their shape and vitality. Given people's different life experiences, beliefs, needs, and desires, differences of opinion are to be expected. The trick is to deal with conflict so that it yields positive results, rather than becoming a force that destroys, alienates, or interferes with goal achievement. How you handle conflict can make or break your initiative. The tip box below provides guidelines for managing creative tension in ways that leave everyone feeling heard and able to move forward.

There are excellent resources for learning how to manage conflict in an organization.¹⁰ Some of the key factors for successful conflict resolution include one's attitude and approach to it, interpersonal communication skills, problem-solving ability, and knowing when to get an outside mediator to help.

Tips for Managing Conflict

- Reframe conflict positively. Remind those involved that conflict is evidence that everyone cares deeply about the issues at hand.
- Deal with conflict immediately. Do not wait to address it later. Do not think it will just go away.
- Use conflict to demonstrate that constructive outcomes are possible when people express themselves and are heard by others. Conflict can also be constructive when it leads people to listen to one another with mutual respect and intention to learn from each other, even if a resolution is not found.
- Foster conversation. Encourage the parties involved to talk with each other. Conflict can become divisive if conflicting individuals talk to others rather than to each other.
- Encourage people to use "I" statements and to avoid use of aggressive language.
- Clarify the issues. Separate the content from the process. Clarify what is being said and what the concern is. Separate issues from personalities.
- Use the group's guiding principles and values to direct its interaction. Remind conflicting parties of their commitment to the larger project.
- Determine the needs of each party. Give each person an opportunity to speak without interruption about what the issue is for him or her, and what he or she feels and wants.
- Look for common ground and creative solutions. Affirm that there is a way to find a solution to this conflict and a willingness to seek a way for each conflicting party to find what will work for him or her.
- Consider an outside mediator with skills in conflict resolution. Consider organizational training in conflict resolution.

In National Empowerment Center (2007) Voices of Transformation: Developing Recovery-Based Statewide Consumer/ Survivor Organizations as adapted from: Rosenberg, Marshal B. (2005)



Help People Feel Comfortable

Some people have little or no experience as participants in structured meetings or planning initiatives. This can be intimidating. Strategies to encourage and support involvement of people who are new to the process include the following:

Personal outreach

Talk to people beforehand about what the meeting will entail. If possible, review the agenda in advance. Talk about the kinds of things that will be discussed and help people form their ideas and opinions ahead of time. Going into a meeting knowing what to expect helps people to prepare and reduces anxiety. Having a chance to think about things in advance can help people formulate their ideas more clearly and positively. A great way to involve new people is to encourage a more experienced person to take a "newbie" under his/her wing.

Attend to logistics

Travelling to meeting locations can be difficult, especially for people without cars or financial resources for public transportation. Set up a carpooling system to ensure that everyone can attend. Hold meetings in locations that are accessible and in settings that are conducive to the work of the group.

Follow up

Check in with people after a meeting. Did they have something to say that didn't get said? Do they have questions about what happened or need clarification? It is especially good to follow up with people who stop attending to find out why. Again, when delivered and used constructively, negative feedback can ultimately be more useful to the success of your initiative than hearing only nice things.

Communicate strategically

Sometimes, you will find yourself personally triggered by something that is being said or done. The previously outlined guidelines for respectful communication should help. Below are some additional tips for dealing with these difficult situations.

Think strategically

Will your response help or hurt your cause? You may need to say what you are feeling or thinking. However, you also need to consider the impact of how you say it, not just on you, but on others and your ultimate cause. Are you furthering SDC or trying to make yourself feel or look better in some way? If it is the latter, can you find someone else to share your feelings with, so you can resolve them without shutting others down or creating barriers to progress?

Write it down

Sometimes taking the time to jot a few notes on a piece of paper will help you organize your thoughts before you respond. You can also use your notes as a private place to "vent" your negative reactions. You can be as negative or aggressive as you need to be...but only on paper and only for yourself! Speaking outright in this manner almost always does more harm than good. Consider destroying your venting notes so that they remain truly private and don't do needless damage.

Confide in a trusted person

It is easy to hear things differently from what a speaker intended or jump to conclusions about the speaker's attitude. It helps to have a trusted person to check in with about what you believe you heard. Your trusted person can be helpful by providing feedback about your behavior. Did you come across as confident or as rigid? Did you talk too much or not enough? Did you go off on tangents rather than state your point clearly? Ask and take any feedback you receive seriously. The better you become at public speaking, the better you can promote your cause.

Use "hot" language carefully

Getting outwardly angry may be useful in very rare situations that call for a strong emotional response. However, it is also likely to create a contentious environment in which you discourage people from taking you seriously. In many ways, how people conduct themselves can go a long way to reassure policymakers and others that the control and responsibilities inherent in SDC are viable for people with psychiatric disabilities.

Agree to disagree

There are some conflicts that are not easily resolved. If they become barriers to moving ahead, it can be strategic to simply agree to disagree. If you cannot come to a win-win resolution of the situation, set the conflict aside respectfully. Find your common ground – something you can both agree on – and move on.



Competency, Capacity, and Choice in Personal Decision-Making

When applying concepts of SDC to people with psychiatric disabilities, there is often concern about whether individuals have the competency (understanding) and the capacity (skill) to make informed decisions about critical aspects of their care. Traditionally, the mental health service system has been full of assumptions about the capacity and competency of people with mental illnesses to make these kinds of decisions. Further, some people experience fluctuations in their mental wellness, resulting in shifting interest in and ability to participate in SDC advocacy. Mechanisms such as outpatient commitment, guardianship, and representative payees are common. Each one puts significant constraints on individuals' rights to make decisions, and also limits responsibility for the consequences of personal decisions. Many people find it difficult to extract themselves from these constraints once they have been implemented. We discussed some of these issues briefly in Chapter 2, "Getting Started," but we'll deal with them in more depth here.

Competency

First, keep in mind that all individuals in our country, including those diagnosed with mental illnesses, are presumed competent to make medical and mental health treatment decisions. This principle of self-determination is so fundamental to U.S. society that it can only be limited through carefully defined legal mechanisms. Unless a person has been adjudicated by a judge or court as unable to make specific decisions, we must operate on the assumption that each and every adult is competent to make decisions pertaining to his/her life and treatment. Yet, in practice, there are widespread assumptions about the incompetence of people with mental illnesses. This puts them in the unfair position of having to "prove" their competency, even when they have not demonstrated any lack thereof. I know there are many concerns about capacity or competency, and whether or not people are capable of directing their own care. The real issue isn't about whether or not a person needs assistance, but that he or she has a voice and choice, and access to services based on individual needs at all levels of care. Every opportunity of choice is a seed that will grow into a healthy, empowered, self-directed life. It's about eliminating dependency in individuals who are capable of moving forward with their lives. It is unfortunate that the majority of people in our systems have never been encouraged to do so.

~Nancy Sweatland, Florida SDC Participant

Because of the value placed on self-determination in the U.S., the law has established mechanisms that must be used to proactively plan and direct decision-making in the event that an individual is legally determined to be incompetent. These mechanisms include advance directives, durable powers of attorney, and health care proxies (Stefan, no date).

Determination of competence is not a judgment made about a broad range of life areas, but is considered in the context of specific decisions or abilities, such as the competency to enter into contracts, make medical decisions, execute a will, manage finances, or vote in an election. Furthermore, it is recognized that for some people, competence can vary over time with age, illness, or other impinging factors. Judgments about individual competence are value-laden, discretionary, and culturally bound, affected by differences in gender, culture, and economic status (Stefan, no date).

Susan Stephan, an expert in mental disability law, has carefully examined the issue of capacity and competency of persons with psychiatric disabilities in relation to SDC.¹¹ As she notes, competence is an abstract concept that serves as an unhelpful proxy for actual, concrete problems that need to be addressed in order for self-directed care to work. Real issues associated with adapting self-directed care for people with psychiatric disabilities include how to deal with acute or short-term crises, and how to adapt self-directed care for people who are ambivalent or forgetful or who change their minds frequently. The concept of competence simply may not be the best way to either frame or solve these problems.



Rather than frame concerns around the general competency of individuals, Stefan suggests that pragmatic consideration be given to specific issues as they pertain to an individual and his or her circumstances, including:

- Concerns about an individual's skills versus concerns about the choices the individual makes (as long as they are safe)
- Short-term crises which may cause temporary fluctuations in competence, such as increased symptoms due to a medication change versus longer-term incompetence resulting from chronic and unvarying circumstances, such as being in a coma
- Concerns raised by an individual about his or her ability to participate in an SDC program versus concerns raised by third parties

Within this framework, the specific circumstances and needs of each individual should be considered and addressed.

Need for Accommodation Versus Lack of Competency: Joe's SDC Story

Joe has always had difficulty with numbers. He just couldn't wrap his head around the difference between 1's and 10's on all those green bills that looked alike. So, Joe would pay for something with a \$10 bill and walk away without his change, or he would get angry at a clerk who wanted more than the \$1 he gave her for his purchase. To help him manage his finances and ensure that he had food, shelter, and clothing, Joe was assigned a representative payee. "Not competent to handle money" was listed in his chart, and the label (with its overt assertion of his incompetence) followed him everywhere. Joe felt embarrassed about having to ask his payee for spending money. Every one of his requests was closely scrutinized. To get more money, he had to account in detail for how he had spent his previous allotment no matter how small. He felt like a child and he hated it. He believed that, as an adult, he should be responsible for managing his own money.

Joe began working with an SDC staff member, Dawn, who believed that he could learn to manage his own money. Dawn convinced Joe's payee to let her help him in a different way. Every month, Joe cashed his Social Security check and requested the total amount in \$1 bills. Then, they sat down together to make lists of his "have to's" for that month (rent, utilities, food) and his "want to's" (cell phone plan to stay socially connected, meeting a friend for coffee). Joe knew the difference between his needs versus wants, and understood that he had only a limited amount to spend each month.

Together with Dawn, Joe divided his \$1 bills into piles for each of his "have to" expenses. He either paid his bills directly with the piles of \$1 bills, or Dawn helped him get money orders that he learned were equal to the amount of each pile. Next, he looked at his "want to" list and made decisions about what was most important to him that month. Based on those decisions, he made piles of bills for each discretionary purchase. Dawn helped him develop an envelope system into which he put his dollars for cell phone payments, dollars for coffee out, etc. Joe learned exactly how much money he had, where it went, and what he had available to spend on items each week.

This system worked well and Joe was in control of his money, making decisions that were important to him. Joe had good judgment about finances. He had both competence and ability to make his own financial decisions. But, to demonstrate his competence, he needed support, accommodation, and a system that he understood and that made sense to him. He also needed someone to give him a chance. To the surprise of many, Joe was successful in his efforts to be his own payee again.



Capacity

Joe's story demonstrates the importance of differentiating judgment in choice-making from ability to manage a budget. They are two separate things, and each can be learned. As Stefan notes, "A number of different skills or abilities may be involved in self-directed care. Skills may, for example, include entering into contracts, choosing providers, hiring caretakers, directing care, and authorizing payment...it is simply assumed that people may need some assistance in carrying out their programs, and the assistance is provided in the form of 'cash counseling' or 'fiscal intermediaries.' People are, to the extent possible, taught these skills, but the lack of skills does not preclude them from participation in [an SDC] program."

Choice

A larger concern, often subsumed in the debate about the competency and capacity of people with psychiatric disabilities, is that of choice. Given the flexibility and latitude available in SDC Plans, some people wonder whether participants will make choices that truly support their personal recovery, or whether they'll squander public funds.

It's important to understand that, even in SDC programs, people's choices are circumscribed and finite. It's not a program where "anything goes" based on what the participant chooses. This is because public dollars can only be spent on certain kinds of purchases, and they must be used in accordance with federal laws and State statutes. However, in SDC programs, participants are told in advance what is and what is not an allowable purchase, and they submit their personal budgets for prior approval before they begin spending money.

As Stefan notes, "…limitations are carefully considered and articulated at the outset of the program, and within those limitations, the individual's choice [is] respected and supported. The limitations should not narrow the possibilities available to the individual to such an extent that they effectively replicate the existing mental health program. A core value of self-determination programs must be that they expand the options available for recovery, allowing the individual to design and choose the services needed to the maximum extent possible."



I no longer allow others to validate who I am, or define me by my illness. My failures are detours not road blocks, lessons not judgments of competency. My budgeting, time management, and prioritizing skills have become fine-tuned. Change is no longer a fear but a welcomed challenge!

~Florida SDC Participant

Stefan offers the following programmatic strategies to promote individual choice-making for recovery:

- The participant should have access to information from a wide variety of sources.
- Everyone should be clear about what the participant's vision of recovery looks like what kind of living arrangement, job situation, and personal relationships are desired. The focus should then turn to the individual selecting services and supports to accomplish those goals.
- It is helpful if the participant has trusted friends, family, or peers to serve as sounding boards and help with crafting a recovery plan and individual budget.

A successful SDC program is run with flexibility, patience, humor, humility, and common sense.

Program administrators understand that participant decisions demonstrating a lack of good judgment do not necessarily signal an incompetent decision-maker. We've all made decisions that didn't turn out the way we had hoped. We often learn more from decisions that don't work out, than we do from those that do.

Nancy Talks about Transformation and SDC

I will share with you some of my recovery experiences as a participant in an SDC program, along with my personal perspectives on what I feel are essential components for a recovery-oriented system. It won't be a sad story of "suffering" but rather an insightful view of successfully living with a mental illness.

As a service provider, are you having difficulty reaching your goals? Are your projected outcomes unrealistic? Do you feel frustrated by funding issues? Do you feel like you can't be creative because of inflexible contracts, policies, regulations, or other barriers? Do you feel like you are trying to accomplish "Mission Impossible?" If so, then you and I share similarities. Over the years, it's been difficult for me to develop meaningful goals because my vision of myself focused on my recovery. Until recently, though, the vision for mental health focused on compliance and stabilization. I've also been frustrated with funding issues that didn't allow me to choose more cost effective and meaningful choices for recovery. My ability to be creative was entangled in eligibility criteria and lack of choice. For years, recovery from where I stood was "Mission Impossible."

In 1999, I was one of five advocates in Northeast Florida that met to discuss alternatives to a mental health class action law suit. With Florida ranking 47th in the nation per capita for mental health funding, service choices were limited, difficult to access, inflexible, untimely, and mired with endless criteria. People hopelessly cycled between crisis and minimal stabilization. With the knowledge that the State's Developmental Services office had already begun implementing Cash and Counseling pilot projects, we mounted a grass roots campaign to establish a similar pilot for people with psychiatric disabilities.

Florida Self Directed Care (SDC) was created by the Florida Legislature in 2001 as a fiscal program which allowed flexibility of service choice and delivery. The fiscal management is based on self-determination and the clinical foundation is recovery-oriented. Individual needs are met through choice, responsibility, accountability, and self-direction which maximize the principles of self-determination. I became a participant in 2002. Two things were very clear to me during our process of developing FloridaSDC: (1) a lack of belief that people with psychiatric illnesses had the potential to direct their lives or make healthy decisions concerning their care; and (2) the acceptance of a system design where the supply created the demand, instead of the demand creating the supply.

Transforming the System

Why is mental health system transformation needed? Because recovery is no longer wishful thinking...it's a reality for many people and it's happening all over the country. The role of the provider is changing from managing people's care to providing choice and assistance so people can manage their own care. Webster's dictionary defines transformation as, "the act of completely changing or altering in nature, form or function." How do we apply this to a system that provides mental health services? While this seems like an overwhelming question, it simply requires creating a system of care that is recovery-oriented (nature), person-centered (form), and person-driven (function). Equally important is the assurance that dignity, respect, trust, safety, and quality are not compromised in the process. One thing I've noticed over the years is that change is the one thing that is constant, and yet it's met with the most resistance. One main difficulty in making changes within the present system is that we continue to layer positive changes and effective initiatives on top of an infrastructure that doesn't support them. Allowing what hasn't worked to be a part of any change is like spreading a computer virus...your system will crash. So, I guess you might say that transformation is an opportunity to "defrag," "delete" and "reboot." It gives us the opportunity to work together to download a new system of care that will promote a recovery-oriented system.

What Is Recovery?

People who are ready to move forward with their lives will define and seek recovery in ways specific to their needs and aspirations. The important thing to remember is that recovery is a life process. People with psychiatric disorders want the same things anyone else desires in their lives. Safe housing, food, meaningful employment, education, health care, social activities, and transportation are realistic and basic necessities that support quality of life.

SDC allowed me to create a budget specific to my recovery needs, and to obtain services in a fully integrated way in the community. Taking control of my life through self-determination, choice, and self-direction allowed me to see myself as a whole person...mentally, physically, and spiritually. The ability to control the dollars for my care allowed me to practice cost effectiveness, focus on my abilities, discover my responsible limits, and eliminate the blame game by being personally accountable for the consequences and successes of my choices. The long-term goals I set when I became a participant were met in my first quarter.

What I discovered was a new way of challenging my potential by setting goals that moved me beyond mere "survival" to actually creating a healthy and successful life. It included services that addressed my abilities not just my disability. I learned the valuable connection between physical, spiritual, and mental health, and I chose services with a holistic approach. Even the Neuroscience Institute supports non- traditional services such as tai chi, yoga, and massage as therapies to improve energy, as well as emotional and spiritual well-being. For me, recovery meant freedom -- freedom to control my own destiny.





Take-Home Messages

From the outset, an SDC initiative must include people with lived experience of psychiatric disabilities in program planning, implementation, and evaluation. Stakeholders in your State or local area may need education and support to understand the skills and abilities that people in recovery bring to the table. Testimonials and success stories from SDC participants go a long way in showcasing the benefits of self-direction initiatives to promote recovery.





4

SDC Program Structure

Self-directed care is not a clinical approach to treatment, nor is it a service option that is offered by a particular provider. It is an alternative mechanism for funding services and supports chosen by participants to help them achieve their personal recovery goals.

One of the easiest ways to understand the basic structure of an SDC program is to think about how managed care plans work. In managed care, an administrative entity oversees a pool of funds allocated by a funding authority. These funds are distributed to qualified service providers based on individual client needs, as outlined in specific treatment or rehabilitation plans. There are negotiated parameters specifying what the funds may and may not be used for, a process for authorization of expenses that fall outside the established parameters, procedures providers are required to follow, and a review of how the funds are being spent to ensure compliance with various policies and regulations. As you'll learn over the next several chapters of this manual, many of these managed care elements also are found in the structure of a successful SDC program.

That said, SDC shares some of the structural elements of traditional mental health service entities as well. These include a steering committee (or board of directors), a program director or manager, staff to support program participants, a funder and fiscal administrator, and a network of traditional and non-traditional service providers.

This chapter will address the basic infrastructure of an SDC program:

- Steering committee
- Project director or program manager
- SDC support brokers
- Program funder and fiscal intermediary
- Provider network

Steering Committee

After accomplishing initial planning and securing funding, you're ready to tackle the creation and implementation of the administrative procedures of your program. Structural design might best be accomplished by your initial planning committee, or a subset of it that has the expertise, time, and resources to help build the operational backbone of your program. It is critically important that the Steering Committee include people in mental health recovery and family members. In addition, you may want to include relevant State government officials (such as from the Department of Mental Health, Vocational Rehabilitation, and the Medicaid Office), local service provider agency leadership and staff, consumer self-direction experts (including from the intellectual and developmental disability community, if they have implemented self-direction in your area), and members of your larger community. Steering committee members must be willing to make a commitment to meet regularly at an established time and location.

How Does a Steering Committee Function?

The primary responsibility of the steering committee is to ensure that program participants have meaningful choices and rights within the boundaries of State and funding regulations. In order to promote choice, the Steering Committee must clearly define policies for the SDC Program that balance funding and regulatory requirements, needs and viewpoints of the participants, and program outcome expectations. Fiscal and operational policies and procedures should reflect the values of the participants, but also ensure fairness and accountability. It is critically important that all program policies are informed by the participants, not just by members of an oversight body, provider agency, or managed care company. You want to be careful not to replicate a paternalistic dynamic, in which someone other than the participant is authorized to make treatment or purchasing decisions.



The responsibilities of the steering committee usually include the following:

- Developing the operational policies and procedures for the program
- Creating a fair and sound purchasing policy
- Identifying and recruiting SDC program staff and participating in the interviewing and hiring processes
- Maintaining active oversight of all aspects of program operation
- Addressing grievances or problems as they arise
- Ensuring that the program is accountable to funders for use of resources
- Conducting participant satisfaction surveys and participating in quality/fidelity audits
- Assisting the program with public relations and educational activities
- Developing strategic plans for future development



In considering the structure and expected role of your Steering Committee, it is important to determine whether and how its members will assume fiduciary responsibility. Another decision is whether the Steering Committee will serve in the role of a board of directors, and if so, whether it will act solely in an advisory capacity or whether it will have direct responsibility for governance (e.g., hiring and firing staff; managing overall program operations). Yet another decision is whether the Steering Committee will operate as a voluntary body or whether its members will be paid.

Examples of SDC Steering Committees

In the original FloridaSDC program, governance structure included a twenty-member advisory board whose membership included ten program participants, an individual in recovery who was not participating in the program, and nine participant relatives including spouses, parents, siblings, and adult offspring. To preserve the independence of the program and to avoid any conflicts of interest, members of the FloridaSDC Provider Network were prohibited from serving on its board of directors.

FloridaSDC Board members interviewed all staff and independent contractors, provided input into hiring decisions, and designed the program's fiscal and purchasing policies. This body was responsible for reviewing and approving any major changes to program structure and procedures, reviewing staff performance evaluations, addressing participant grievances, and engaging in public relations activities representing the program to outsiders. However, the Board did not control the program's budget or its daily operations, which were the ultimate responsibility of the state mental health authority.

In contrast, in Oregon, the Empowerment Initiatives Brokerage (EIB) pilot program was established as an independent, peer-run, nonprofit organization. In this program, governance was directly provided by the organization's board of directors, which was comprised entirely of people in recovery.¹² In the Texas Self-Directed Care Program, an Advisory Committee – comprised of participants, family members, service providers, State and program administrators, and researchers – was convened to represent the viewpoints of people in recovery, provide a safe avenue for other participants to raise grievances or problems, and ensure a forum to discuss and debate programmatic decisions.

However your steering committee functions, a key to success is ensuring good decisions about the use of public dollars in a self-direction initiative. The general rule is to make the best possible use of funds within the boundaries of participants' choices, funding requirements, and state regulations. Public outcry about how SDC funds are authorized and spent can put your program in serious jeopardy. The same is true for your program's method of determining who is eligible or ineligible. You need to have fair policies with good documentation to back them up. A steering committee can serve either to make these policies directly or to provide oversight to ensure that they are fair and transparent.



Program Director or Manager

Another key role in an SDC program is that of program director or program manager. This individual supervises the staff and oversees all aspects of program operation to ensure its integrity and effectiveness. This person also will represent the program to the public. Different entities or stakeholders can assume responsibility for recruiting and selecting the program director. However, if they don't do the actual interviewing, the Steering Committee should have direct input into the recruitment and hiring of this individual.

Program Director Qualifications

- A Bachelor's degree or, in lieu of a college degree, demonstrated experience working in or managing a self-directed care program
- A minimum of one year of experience managing or providing self-direction or brokerage services
- A minimum of one year of supervisory or leadership experience
- Experience planning and administering program budgets, claims data, and financial reports
- Advanced computer skills and ability to use data to manage a program
- In-depth knowledge of community resources and support services
- Demonstrated cultural competency, flexibility, and compassion
- Personal or lived experience of psychiatric disability

The SDC program director's salary should reflect the demands of the job and the standards for similar managerial positions within your region. Minimally, the salary should be high enough to attract qualified applicants who meet necessary certification and licensure requirements. We have included a detailed program director job description in the Resources section.

SDC Staff

SDC staff members, known more formally as support brokers, are a unique and critical component of a successful SDC program. Support brokers help program participants with designing and managing their SDC Plans and related budgets. Their tasks typically include recruiting eligible participants into the program, assisting participants as they explore personal values and goals, helping participants to identify and access services and supports, coaching participants as they develop SDC Plans and individual budgets, providing operational assistance in making purchases, and troubleshooting problems and difficulties that arise in implementing SDC Plans and budgets. Within the parameters of the purchasing and other policies, support brokers defer to participants' choices regarding service selection and goal setting, providing whatever support and assistance participants request (Haine & Spaulding-Givens, 2006). We have included a detailed support broker job description in the Resources section.

A support broker is not a case manager. Case managers are clinical service providers who help individuals address their psychiatric and rehabilitation needs. They conduct assessments, develop and review treatment plans, provide supportive counseling, make referrals for external services, monitor progress.

SDC Support Broker Qualifications

- A Bachelor's degree or, in lieu of a college degree, demonstrated experience working in a self-directed care program
- Three years of professional experience in mental health, counseling, social work, or rehabilitation services
- Experience teaching financial management skills and creation of personal budgets
- In-depth knowledge of community resources and support services
- Demonstrated cultural competency, flexibility, and compassion
- Personal or lived experience of psychiatric disability
- Completion of a standard number of hours of training



Titles such as "coach" or "advisor" capture the essence of what is different about support brokers. They do not "manage," which implies a certain amount of control over another person. Instead, they coach and advise, which implies offering special expertise and guidance, but with participants themselves "playing the game." Coaches have a variety of roles that can include offering hope and encouragement, teaching skills, modeling attitudes and behaviors, helping obtain resources and accessing services, providing options to repair mistakes or problems, and helping with paperwork.

Organizing Your Brokerage Services

In terms of program infrastructure, there are several ways to organize brokerage services that your program will want to consider. One option is for SDC participants to select and hire their own support brokers, paying for this service out of their individual budgets. In this case, the program's managing entity or fiscal intermediary establishes a pool of contracted people who will provide brokerage services to participants. As a contracted service to participants, the fiscal intermediary pays the broker's salary and manages his/her payroll taxes. In this arrangement, brokers are considered self-employed professionals or independent contractors under federal tax laws, rather than program employees.¹³

Self-employed brokers are compensated based on the number of participants they serve. Their contract with the fiscal intermediary or managing entity should delineate the maximum number of participants that may be served by one support broker. Because brokers are selected and hired by SDC participants, they may be discharged if the participant is not satisfied with their services. Thus, for self-employed brokers to maintain a reasonable salary, they need to provide services that participants find valuable. The original FloridaSDC participants who were dissatisfied with a broker under contract with the program could make personnel changes at the beginning of the month, similar to an open enrollment process with a health insurance company. FloridaSDC also held the right to terminate a contracted support broker for any breach of contract.

Another option is for your program to cover the operating and administrative costs of making support brokers available, much like case managers are made available without clients directly paying for the service. This can be a good option for individuals who are new to SDC and need considerable support and guidance in developing an SDC Plan and budget. It also allows participants to spend more of their budget on other recovery-oriented services, supports, and goods, since they do not have to pay for brokerage themselves. It also gives the program more control over the training, supervision, and performance evaluations of its SDC brokers.

The roles and responsibilities of support brokers are discussed more fully in Chapter 8.

Program Funder

The primary funding for self-direction programs typically comes from CMS (when participants are Medicaid beneficiaries), State General Revenue, or both in a braided approach. Braiding funding from Medicaid and other State or federal sources can increase the flexibility and usefulness of SDC, but each source must be accounted for separately.

When considering your program infrastructure, the type of funding source is important. The funder will define legal parameters to ensure compliance with State and federal regulations and State Medicaid Plans. The funder's parameters also will have direct or indirect bearing on your budget allocation and restrictions, accountability and documentation requirements, enrollment eligibility, Purchasing Policy parameters, and provider qualifications.

Fiscal Intermediary

A hallmark of the self-directed care model is the fiscal intermediary, which is an organization that serves as the "banker," drawing money from the program's funding sources and making it available to be used by SDC participants. In most cases, you will select the organization that serves as your program's fiscal intermediary.

The fiscal intermediary (FI) generally receives its authority from a contract with a State or federal funding agency (such as Medicaid). This contract spells out the roles and responsibilities of the FI, along with expectations regarding financial and program accountability, documentation and quality. Therefore, the contract also determines the structure and operation of the fiscal component of your program.

The FI's primary responsibility is to ensure that participants in your program have access to funds and spend them in compliance with contracted agreements. The intermediary also handles billing and contracting with the program's network of service providers and submits claims for Medicaid-billable services. It is important that the intermediary be readily available to program participants and network providers as they seek information about the program, resolve invoicing issues, and request problem-solving assistance.



The FI also can provide participants with account statements similar to those provided by banks or credit unions. That said, while the FI may provide some banking services, it does not offer amenities like unscheduled or unbudgeted withdrawals. The FI may assume the following responsibilities (Haine & Spaulding-Givens, 2006), many of which would be performed in concert with the program director.

Fiscal Intermediary Duties

- Establish a pool of contracted support brokers to serve participants and to ensure a wide range of options
- Maintain and expand the SDC Provider Network to maximize participant choice in mental and physical health care, as well as in non-traditional services and goods
- Provide information to prospective participants, SDC network providers, and community members about the SDC model and program
- Collaborate with the funding authority, Steering Committee, and other stakeholders to address emerging issues and refine program policies and procedures
- Maintain, analyze, and report data for state audits and quality assurance
- Create a website providing easily accessible information for participants, providers, and others about the program, support brokers, the provider network, community resources, and other issues¹⁴
- Provide a "warm-line," staffed by people in recovery to assist participants with non-emergency distress or difficulties
- Offer access to a 24-hour crisis or emergency support service provider
- Distribute a newsletter (via mail and electronically) for participants and network providers regarding changes in plan benefits, the addition or departure of providers in the network, mental and physical health care tips, and coupons for services and goods
- Develop and distribute public relations and educational materials

Choosing a Fiscal Intermediary

There are several options to consider for who will perform this fiscal role for your program, depending on your region, resources, and the experience of local organizations interested in consumer direction. One primary source is the growing industry of organizations and entities that specialize in fiscal intermediary and other financial management services for consumer-directed staff and programs. These organizations are knowledgeable about SDC laws and regulations, and have established mechanisms to make fiscal administration efficient and cost effective.¹⁵

Managed care organizations or insurance groups often have the administrative apparatus and interest in providing FI services, such as Magellan Behavioral Health Services for the Pennsylvania SDC Program and Value Options for the Texas SDC Program. Advocacy organizations and other non-profits in your community also might function as your FI, as is the case for the FloridaSDC Circuit 20 Program, in which the National Alliance on Mental Illness of Collier County serves as the intermediary.¹⁶ Another example is the Oregon Technical Assistance Corporation, a non-profit disability organization that provided FI services to the Oregon Empowerment Initiatives Program. Universities also may have the infrastructure to provide fiscal accounting and oversight services, as was the case for the original FloridaSDC Program that used Florida State University as its fiscal intermediary.

Standards for Fiscal Intermediaries

When choosing an FI, it is important to remember that the entity should be free from conflicts of interest, and should not be a provider of mental health services. The intermediary should have no vested interest in what participants choose to purchase, beyond the parameters established by contract with the funding authority. This "firewall" helps to ensure that the intermediary does not pressure or influence participants to purchase a particular set of services or engage a specific vendor. It is not the FI's responsibility to scrutinize purchase requests to determine whether a participant is making the "right" choices or is "ready" for a particular option. These decisions are made by the participant, with support from SDC staff and in accordance with the program's Purchasing Policy. The ultimate responsibility, and therefore risk, for budget and service decisions rests with the SDC program, not the fiscal intermediary.



What to Look for in a Fiscal Intermediary

- Knowledge and experience with consumer-directed or self-directed care
- Established mechanisms for receiving, holding, authorizing, distributing, and accounting for SDC funds and managing individual accounts
- Clean audit records, which are available as public record in each state
- Free from complaints through the Better Business Bureau or other consumer complaint entities in your state
- Desire to understand your needs and able to "talk your language" by communicating in clear and understandable terms
- Willingness to be available and in direct communication with the Steering Committee, as well as with participants and network providers
- Ability to offer a contract that is cost-effective and within the parameters of your SDC operations budget
- Willingness to work closely with the Steering Committee regarding disposition of any unused monies at the end of the fiscal year

Long-time advocates for self-determination, Thomas Nerney and Donald Shumay, describe the following three minimum standards for fiscal intermediaries (Nerney & Shumway, 1996):

1. Individual Budget Isolation

Each person's individual budget is isolated from any other budget, and from traditional provider contracts. The money is available upon receipt of an approved budget and is accounted for by the FI to both the public funding authority and the person with a disability.

2. Conflict-of-Interest Free

FIs must have no other duties that conflict with their role in SDC. This means that they are independent of service provision or treatment. If the FI is a government or quasi-government agency, it has specific rules that prohibit the use of this money for any other purpose.

3. Close to the Person and the Community

To the degree possible, FIs should be neighborhood or community organizations that enable people with disabilities to create relationships with others in their natural, community settings. The closer this function is to that of a neighborhood bank, the better it is for the participants.



SDC Provider Network

Let's go back to the managed care framework for a moment. Managed care firms develop networks of providers meeting certain eligibility, practice, and quality standards. Qualified individuals or agencies provide services under specific contract parameters. Providers submit invoices to the managed care company for services rendered, which the managed care company reviews and reimburses. Clients who want to use providers outside of the managed care network need special authorization for their purchases, must comply with additional rules, and usually pay money out of pocket. For example, they may need to demonstrate that the needed service is not available within the network, or they may need to assume a higher co-payment for the out-of-network service.

Many SDC programs create a similar provider network, consisting of individuals and organizations that meet the program's requirements for quality services and willingness to comply with reimbursement regulations. The SDC provider network consists of both traditional and non-traditional service providers. Traditional providers include psychiatrists, psychologists, therapists, rehabilitation counselors, and peer specialists. These may be individual providers such as therapists in private practice, or small collections of providers such as medical groups, or larger organizations such as mental health or psychiatric rehabilitation centers. Other professional providers include primary care physicians, dentists, ophthalmologists, nutritionists, and testing laboratories.

Non-traditional providers include physical therapists, fitness facilities, weight loss programs, local community colleges, certificate programs, educational tutors, and barbers or cosmetologists (to prepare participants for a job interview or professional audition related to an employment goal). Also included in the network are vendors who provide needed goods related to participants' SDC goals, including cell phones (related to making social connections or conducting job searches), office supplies or computer equipment (to outfit a microenterprise related to an employment goal), workout clothes (for a fitness goal), or eye glasses or hearing aids (for a physical health goal). Ensuring access to non-traditional providers and vendors is a critical (if sometimes controversial) component of the SDC approach. The model is designed to promote meaningful choice among a wide variety of services, supports, and goods to foster recovery. For this to happen, people need access to more than what one mental health center, even an excellent one, can offer. It's like being allowed to order "off-menu" when a restaurant doesn't have what you want or can safely eat, having the option to choose another restaurant entirely, or buying your entrée at one restaurant and your dessert at another. Equally important, SDC fosters community integration by encouraging access to services, supports, and goods used by anyone living in the area, not just those with a mental illness.

Qualifications and Enrollment of SDC Network Providers

SDC participants may wish to retain some or all of their service providers and this will be possible if providers are willing to join the program's network. Regardless, additional providers will be needed to enhance choices. There are a number of ways to build your program's provider network. Your program director and staff can identify and build relationships with providers and vendors interested in joining the network. Participants also can help to build the network as they identify and contract with new providers and vendors who are willing to serve other SDC participants. Every effort is made to be inclusive when building a provider network. If applicants meet minimum requirements, they are included in the network and remain members unless there is a contravention of regulation, such as a loss of licensure or an ethical violation. It is important to note that endorsement of an SDC philosophy is one of the minimum requirements.

Potential network members are given information about the program, required qualifications or certifications, procedures for invoicing and payment, and how to enroll in the network. Minimum enrollment eligibility expectations for professional providers include any State regulations regarding licensure and certification. While these are not guarantees of service quality, they do provide a minimum threshold for eligibility. Asking providers to sign a code of ethics also can help ensure integrity and high quality of care.¹⁷ Sample provider enrollment forms from the TX SDC Program can be found in the Resources section.





Basic requirements for non-traditional providers can include a valid occupational or business license within your State, or certification or training appropriate to the service being offered. Documentation is needed to show that the vendor complies with general industry standards for minimum quality or competency, and is registered in some manner with the State. Your State's Better Business Bureau, or other quality assurance entities, can provide information about whether complaints have been lodged against a particular vendor. In cases of peer providers who are certified but not working under the supervision of a peer or non-peer program, you will need to ensure that supervision is being provided by a qualified professional. This is an excellent role for your program's Steering Committee with input from your fiscal intermediary.

If interested in joining the network, an individual or agency completes and submits an enrollment application. The Texas Self-Directed Care Program provider enrollment forms are a useful guide for creating your own forms and procedures.¹⁸ The program director and fiscal intermediary then review the application and screen for the requisite credentialing, insurance, or licensure requirements, as well any for ethical or legal violations.

Once a provider or vendor is admitted to the network, it begins billing the FI for pre-approved services authorized within the participant's SDC Plan and budget. After ensuring that the service was authorized in the participant's individual budget, and that the billed amount is accurate, the intermediary makes the payment to the provider or vendor. The Texas Self-Directed Care Program provider enrollment forms are a useful guide for creating your own forms and procedures.

SDC Provider Network Directory

You will want to create a directory of all network providers and vendors for your program participants.¹⁹ A directory helps participants to consider their needs and choices, as they review the range of traditional and non-traditional options available to them. It is important to include a list of specific services or goods being offered and all associated fees, so that participants can plan and budget accordingly. Because information in a directory is subject to frequent changes, it is wise to augment a printed version with an online resource that can be updated more easily. If a web site isn't feasible, you can provide participants with a toll-free number, staffed by an SDC broker who can verify the accuracy of services and costs. Participants may require support in navigating the directory and understanding various fees, as they construct their Plans and budgets.





SDC Program Forms and Policies

When considering infrastructure, the Steering Committee and other leadership will need to be prepared to develop multiple program policies pertaining to participant eligibility, enrollment, personnel qualifications and hiring, staff training and education, participant grievances, contracting, provider network development and management, and public relations. These issues are discussed more in later chapters, but it's important to remember to allocate the time and resources needed to create various SDC program policies.

Standard Program Forms

Many program policies will create the need for program forms, such as those related to participant enrollment, SDC Plans, personal budgets, funding requisition requests, expenditure reviews, accounting, satisfaction surveys, quality assurance, fidelity, and so forth. Forms can be burdensome, but they are a critical aspect of program accountability and transparency.

All forms should be written in clear and accessible language, so avoid jargon and clinical terms when possible. Participants should be offered copies of all of their forms and paperwork. Some people may decline the forms, preferring that confidential information not be accessible to others in their household or residential setting. Either way, people should have the option to review and keep all forms that pertain to their personal situation, SDC Plan, and personal budget.

Below is a list of standard forms that will need to be developed, in addition to others that are unique to your program:

- Enrollment Agreement specifying participants' responsibilities in the program
- Personal Life History Form to collect and document participant's demographic characteristics, income level and sources, degree of physical wellness, any substance use or abuse, composition of circle of support, education and training, employment and volunteer experience, mental health history, and view of mental wellness
- Forms for Life Plan development, setting goals, and creating a combined SDC Plan and Budget
- Eligibility Form to establish eligibility and periodically review it
- Informed Consent upon enrollment to outline the benefits, responsibilities, and program evaluation expectations of being an SDC participant
- Quarterly review of SDC goals and budget
- Documentation of reasons for purchase denial and forms to file a grievance related to budgets or purchasing
- Service Vouchers or Guaranteed Payment Memorandums for traditional service providers
- Invoice forms to be completed by non-traditional service providers and submitted for payment
- Program evaluation and fidelity assessment forms

Examples of many of these forms can be found in the Resources section of the manual.





Confidentiality Policy

When working with network providers and vendors, particularly non-traditional ones, confidentiality concerns can arise. Mechanisms such as purchase orders or vouchers may single out people or disclose confidential information about their mental health status that is unrelated to their purchases. As one example, if a check from the fiscal intermediary includes a memo such as, "Mental Health SDC Fund," then the vendor will learn that the purchaser has a mental health problem or qualifies for a special program. Most vendors (such as a clothing or computer store) don't need this information.

Many non-traditional vendors are not regulated by federal or State confidentiality guidelines, such as the Health Insurance Portability and Accountability Act (HIPAA). HIPAA has strict rules about disclosure of any personal information, including enrollment in mental health or substance abuse treatment programs. Traditional service providers are familiar with these confidentially regulations, but non-traditional providers may not be. Therefore, it is important to be thoughtful about how your fiscal intermediary and your staff communicate with outside providers and vendors, particularly when invoicing and reimbursing for services rendered. Your FI may suggest workable solutions to protect people's confidentiality in these situations. Additionally, as discussed in the next chapter, use of a participant debit card also can alleviate some of these confidentiality concerns.

Grievance Policy

Policies pertaining to grievances take on unique dimensions in an SDC program. In traditional programs, clients are (or should be) allowed to bring grievances regarding rights violations or poor treatment to the attention of the proper authorities. This is certainly the case in SDC as well. The program's grievance policy should outline how a participant goes about filing a grievance. Typically, grievances will be handled directly by the program director, and if not resolved at that level, by its managing entity. However, grievances that cannot be resolved at these levels can be addressed by the Steering Committee or by an independent mediator.



Public Relations

Public perception is important for any mental health provider, but it takes on added dimensions for an SDC program, especially when the model is unfamiliar to the surrounding community. Some community members might find objectionable the idea that people with disabilities are being given authority over their service dollars and access to non-traditional services or goods. For example, some people may object to the idea that purchase of a yoga class might yield better personal benefit and cost savings than would attendance at a day program's stress management group. This is why public relations are especially important to the long-term success of an SDC program. When considering your infrastructure, be sure to include public relations experts on your Steering Committee or identify members who can tap public relations experts.

The media in particular (TV, newspapers, online blogs) can be pivotal to the public acceptance of your program. Thus, it's important for the Steering Committee and program leadership to work on building positive relationships with the media. Keep the following points in mind:

• Stay ahead of public opinion

Share good news! Success stories about people with psychiatric disabilities are rare in the media, so get the word out when good things happen. Also point the media to your program's web site, if it contains testimonials.²⁰

• Designate one primary spokesperson

Select one reliable individual to be the spokesperson for media relations. This will ensure consistency in messaging, and minimize confusion or appearance of dissention within your initiative.

• Emphasize participant rights and responsibilities While the focus on choice and a meaningful life are key aspects of your mission, you also want to highlight the personal responsibility that goes along with selfdirection. SDC does not promote an "anything goes" attitude. Underscore your program's commitment to accountability for public tax dollars, as well as its ability to monitor and control purchases.



Take-Home Messages

There are key structural elements to consider as you build your SDC program. These include a Steering Committee comprised of a significant proportion of people with lived experience given its key role in program development and governance. The backbone of your program will be its director and support brokers and their ability to promote choice and selfdetermination. Your fiscal intermediary and funding agencies must establish an efficient working relationship given the importance of financial transactions in this model. Your provider and vendor network are the life blood of the program, providing greater access to a wider range of needed goods and services. Finally, an effective public relations program can advertise your successes and enhance public support for your mission.



5

Self-Directed Life Planning

Self-directed life planning is the cornerstone of selfdirected care and each Plan's building blocks are its goals. There are various ways to create and monitor progress towards these goals. Whatever the process, the person must be in charge, rather than a provider, program, or system. Generally, the participant begins with a Life Plan, which involves identifying personal strengths and challenges, available social and practical resources, and how all of these relate to their dreams and goals. The Life Plan can be created with or without help from a support broker or other supporter. In many cultures, this process is completed within the family, with the participant at its core.

The Life Plan is cross-walked with participants' current mental health service use, in view of what they believe is working and not working for them, as well as what they'd like to do differently to achieve their goals. Discussion then turns to which goals can be partially or fully supported by the SDC personal budget. Emphasis is placed on understanding that the SDC budget will not support all of a person's life goals, but will provide a springboard toward attaining some of them, and thus, provide a foundation for fulfilling others.

In this chapter, we'll review various procedures participants can use to complete a Life Plan, explore current and desired service use, identify traditional and non-traditional resources to support personal goals, and create and monitor an SDC Plan consisting of achievable goals. The next chapter will address how to create the personal budget to realize these goals.

The major sections of this chapter are:

- Participants Decide
- Self-Directed Life Planning
- Reviewing Past Service Utilization and Costs
- What's My Goal?
- The SDC Plan
- Monitoring Progress and Set-Backs
- Planning for Crises that may Disrupt Goal Attainment

Participants Decide

In this approach, the person who is seeking services and supports decides what is needed, based explicitly on their goals. It can be empowering to identify a new direction in life, one's personal needs and preferences, and how to allocate a limited pool of resources to realize one's dreams. In the process, people assume personal responsibility for their life direction and decisions. In many cultures, of course, the family is the key decision-making unit, and the idea of a person making decisions outside of the family or community is unfamiliar or uncomfortable. If a person chooses to make SDC-related decisions in concert with family (or other supporters), that is honored. The point is that the participant decides whom to involve in the planning and decision-making. The emphasis is on helping participants to think about their lives, envision what they'd like to achieve, and identify the resources, services, and supports that will help along the way.

It is expected that participants will go through a learning process as they develop a Life Plan that incorporates SDC goals. Most people in human service systems haven't been asked to self-direct their life by setting and working toward goals. Thus, they may require specific skills training in order to create a workable Plan. As long as they remain in the driver's seat, provision of support and training are not seen as counter to self-direction. Instead, they are seen as valuable ways to help people grow and take personal responsibility for their recovery.

This process assumes that the choices people make most likely will range from carefully considered and achievable to ill-informed and unrealistic. That's okay. Few decisions are truly permanent. Part of SDC is learning to recognize when a bad decision was made, extraditing oneself from it as gracefully as possible, and shifting to a more positive or productive direction. Additionally, the program's Purchasing Policy is designed to protect people from unsafe or significantly unhealthy choices. SDC is not "anything goes," but the person also should be granted the dignity of taking some risks as part of learning what does and doesn't work on the road to recovery (Deegan, 1995).



Self-Directed Life Planning

For many people, suddenly having access to funds for personal goals can be overwhelming or confusing. When living on a limited income, people often experience "pent-up demand" as a result of doing without on a daily basis. Having authority over a budget can open the floodgates to feeling a need for many things that people have wanted to purchase but couldn't. As a public resource, their personal SDC budget is limited, so it won't be adequate to cover all of their unmet needs. Therefore, participants often benefit from using a structured process to set goals that can be realized within the parameters of their personal SDC budgets.

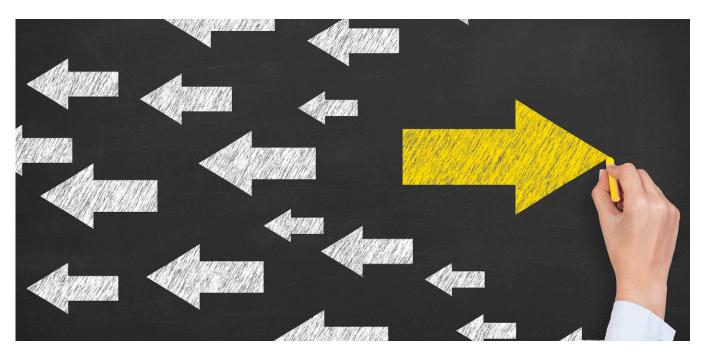
The first step in this process is a Life Plan. It is distinguished from a treatment or service plan, which might very well be a part of the Life Plan. The Life Plan is a more global, self-directed assessment of what someone wants out of life and the steps (i.e., goals) needed to achieve it. In the beginning, most SDC participants say that their lives aren't what they would wish. Yet, many aren't able to articulate, in concrete or measurable ways, what would lead to a better life. As we'll see, life planning based on the Stages of Change model can help participants learn to set achievable goals.²¹

A Life Plan can be as simple or complicated as the participant would like. Some people don't have the wherewithal to complete a detailed analysis of their lives, dreams, and goals. Others find the process empowering, and benefit from taking the time to contemplate what they most want out of life.

Life change is a process, not a one-time event. Making lasting change involves small steps made over time.

Therefore, it's important to have life planning procedures (and forms) that meet people where they are, allowing them to choose either a simplified or complex process, as suits their needs and readiness for change.

The self-directed life planning process involves stepping back and viewing one's life as a whole, not just as a service user or as someone with a particular set of challenges. But, it's important to recognize that people are at different stages of readiness to make life and behavior changes. We've all set health or life goals that we weren't able to meet. There are varying reasons for why this happens, such as not being ready for change, being overwhelmed or distracted by other things that take the focus off of our goals, trying to do too much too fast, getting discouraged by set-backs, and not taking care of ourselves along the way. After failing to reach our goals, we tend to feel worse about ourselves and a vicious cycle begins. When helping SDC participants with self-directed life planning, it's important to recognize and be prepared for these dynamics. It helps to remind participants that life change is a process, not a one-time event, and that making lasting change involves small steps made over time (Jonikas & Cook, 2004).





Let's walk through the UIC Self-Directed Life Plan,²¹ which is based on the Stages of Change to help participants set measurable and action-oriented goals.²² It is just one way that you can help SDC participants to make a Life Plan.²³ UIC Self-Directed Life Planning workshoets to accomplish

worksheets to accomplish these steps are found in the Resources section of this manual.

As a first step, participants are oriented to what a Self-Directed Life Plan means, as shown on the right.

What is a Self-Directed Life Plan?

A Life Plan is basically just that – a Plan for what you would like to do in your life. It helps you look at areas where things are going well and other areas where you want to make some changes by setting new goals. Some of these areas are:

- where you live,
- who you spend time with,
- how you spend your time,
- where you get services and supports for your needs or problems, and
- where you work or go to school.

It may seem hard to think about all of these things at once. Most people pick one or two areas to work on at a time. This will increase your chances of success.

It also helps to remember that most people, with and without mental health challenges, reach goals every day. Think about it like this. Most days, you probably do a lot of things like shower, eat breakfast, read the paper, go to work/school/a program, watch a favorite TV show, and so on. We don't usually think about these things as goals, but they can be. So, you already have a history of achieving goals! Remember most people's Life Plans are built on small goals to reach a larger goal.



Next, participants learn the steps they can expect to go through when making a goal-oriented Life Plan.

This step helps people see that there are defined phases in making a self-directed Life Plan. Their support brokers and others will help them to consider and take these steps.

Some of the steps will be re-visited or may change over time. For example, the people they include today in their circle of support may grow and change as they take advantage of SDC. Also, they are likely to consider many changes during their tenure in the program that will require re-visiting the planning, action, and maintenance phases.

Making Your Self-Directed Life Plan

There are many ways to go about making a Life Plan, but we have found that having some steps to follow makes it easier to manage. Steps that others have found useful are:

Step One:	Maintaining the Goals You've Already Achieved	
Step Two:	Where Am I in the Change Process?	
Step Three:	Getting Ready to Make and Use a Life Plan	
Step Four:	Creating your Circle of Support	
Step Five:	Considering Change and Choosing a Life Goal	
Step Six:	Planning for a New Goal or Life Change	
Step Seven:	Acting on a New Goal or Life Change	
Step Eight:	Maintaining Success	
Step Nine:	A Look to the Future	

Each of these steps helps you to make a Self-Directed Life Plan.



Participants now assess where they are in the change process.

This is very important information for participants, their brokers, and other supporters to have. Expecting someone to act on large goals when she's in the preparation stage, for example, can be an exercise in frustration for everyone.

The goal-setting process that grows out of life planning involves helping people break their goals down into small, manageable action steps that lead to specific purchases. Small actions can be accomplished even while they remain in the contemplation or preparation stage for their larger goals. Learning how to take small action steps, even when in the pre-acting stages, takes time and practice for both participants and brokers.

Where Am I in the Change Process?

For your life change, you may want to make a friend, get better control of your mental health problems, lose or gain weight, get a job or earn some money, go to school, take up a hobby, or do something else. Whatever change you are hoping to make, you will go through a process to get to your ultimate goal. For most of us, this process involves moving from being unaware or uninterested in the need for change, to considering the pros and cons of change, to making actual plans for change, to acting on and maintaining change over time.

Uninterested » Considering » Planning » Acting » Maintaining

James Prochaska and his colleagues call this idea the "Stages of Change Model." This model has been used to understand how life change works in many different areas, like smoking or dieting for health reasons. The basic idea is that when we are faced with changing our lives in some way, we need to first figure out the stage of change we are in. This will help us decide whether we're ready to make change, and what we need to do to succeed, if we are ready.

To help you figure out what stage of change you are in, ask yourself these questions:

1. Do you feel that you would like to change something in your life, to make it better, happier, or easier?

🔘 Yes 🔵 No 🔵 Don't Know

2. Have you been thinking lately about a **specific** thing in your life you either don't like or would like to change?

🔘 Yes 🔵 No 🔵 Don't Know

3. Do you intend to start planning **within the next few weeks** exactly what you need to do to make a life change (it doesn't matter right now what the change is)?

🔘 Yes 🔵 No 🔵 Don't Know

4. Have you **already started** to make changes in your life to make it better, happier, or easier?

🔘 Yes 🔵 No



For the next phases of life planning, participants go through a series of steps to identify their emotional strengths, their mental health challenges, their current coping skills and wellness tools, and a circle of supporters who they can count on to help them reach their goals.

This process leads up to two key questions in the self-directed life planning process:

• What do I like about my life?

• What would I like to change about my life?

The answers to these two questions give participants a new direction to pursue in the SDC program. What they record will be referred to throughout the process of goal-setting, to make sure that any new goals reflect what the person most wants to change about his/her life. As participants experiment with new goals and related purchases, they may find that what they wanted to change about their lives also changes. This is common, and they are encouraged to update their answers to the above two questions as their SDC journey progresses.

Reviewing Past Service Utilization and Costs

Next, participants are asked to review a summary of their past service utilization. This exercise can be accomplished in different ways, but the main point is to have participants review the services and supports they have been receiving over a set period of time (the past 1 or 2 years is standard), how much those services cost, which of the outpatient services are helpful and worth keeping, and which they would like to discontinue or replace with a different service. As one example, in Pennsylvania's SDC Program, participants and brokers received a summary of the person's past service use from the partnering managed care company.²⁴ Typically, the list reflects utilization of case management, a psychiatrist, a peer counselor, education or skills training groups, vocational preparation, and so forth. Also included in the review is how much each of these services costs to help participants conduct an informal cost-benefit analysis for each outpatient service.

Participants can either write on the service summary or they create a new list of traditional services they would like to continue (plus associated costs), and those they would like to discontinue or replace with non-traditional resources. This list should reflect the life planning process they have completed, and what they are hoping to change about their lives while participating in SDC. This example below illustrates how SDC participants are encouraged to identify resources from a variety of businesses and individuals in the community. These resources are referred to as non-traditional services. Using public mental health services can be a key aspect of recovery, but there also are natural supports and community resources to foster goal attainment in a more natural, and often more affordable, way.

In reviewing her past service use, Julia sees that in the past 12 months she used case management, medication management, and emergency services. Some of these were costly. One thing she wants to change about her life is the fact that she doesn't feel emotionally stable, in spite of the services she uses. Julia tells her support broker that trauma-informed counseling would help her to feel better emotionally, but it's also a service that's been unavailable to her in the past. She doesn't want to discontinue her case management, but would like to complement it with trauma counseling. She feels this combination would help her avoid using the ER for panic attacks. She puts on her list the exact amount of case management and trauma counseling she would like to use (and can afford) for her first quarter in the SDC program. She then considers other services she has used in the past, such as a nutrition group at her mental health program. Since her Life Plan revealed a desire to eat healthier, they decide that she might get more direct benefit from a healthy cooking class at the local community center. This service and its cost are researched, and then, added to her list as well.

Reviewing past service use also helps to control SDC costs via budget neutrality (ensuring that SDC doesn't cost the system more than traditional services). Typically, participants choose to reduce or substitute services that they have not found to be beneficial or have been over-utilizing for lack of alternatives. Other times they decide to substitute goods for services. For example, one participant purchased a bicycle to use instead of taking the agency van to his therapy appointments. This is explained more fully in the next chapter on financing.



Setting Life and Recovery Goals for the SDC Plan

With a Life Plan and list of desired goods and services in mind, participants are ready to set their SDC goals.

For many, jumpstarting the process with a list of possible goals helps them think more broadly and creatively. Even people who can name their goals benefit from seeing this list to be sure they've considered the ones that are most relevant and realistic.

What's My Goal?

Here are some goals to help you think about your own recovery and life goals.













Mental & Emotional Wellness

- Reduce stress by attending yoga or stretching classes
- Reduce unwanted feelings or behaviors (when I feel down, worried, or angry) by seeing a counselor or better managing my medications

Health and Fitness

- Eat healthier by adding fruits and vegetables to my diet
- Increase physical activity by walking each day
- Engage in diabetes self-management with regular A1c checks and healthier eating habits

Education and Learning

- Take a class at the community college or university
- Finish my GED
- Learn a skill to develop my career (cooking, photography, computers)

Work and Employment

- Learn new skills for job searching and interviewing
- Get a job
- Raise my salary or get a promotion
- Change my job or job goals

Relationship and Social Network

- Make a new friend
- · Join an online dating service to meet someone new
- Improve my parenting skills by engaging in positive activities with my kids

Financial Wellness

- Take a budgeting class and purchase budgeting software
- Find free resources to support my recovery and health
- Get out of debt
- Save money each month to reach a larger life goal

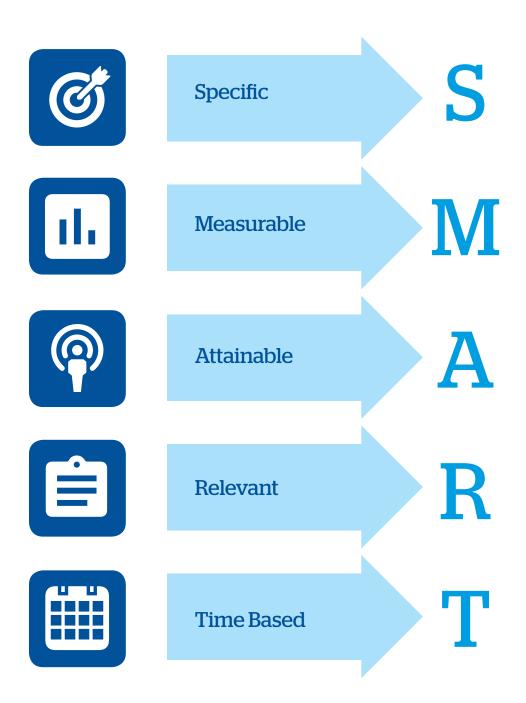
Content adapted from: http://www.smart-goals-guide.com/Example_Of_Goals.html



Setting SMART Goals

Participants are now ready to set "SMART" goals for their SDC Plan (and budget).

SMART goals are characterized by five attributes.



What is a SMART Goal?



Setting SMART goals is facilitated by the use of motivational interviewing techniques. First, participants are encouraged to name and record a specific goal on a SMART Goals Worksheet, shown to the right.²⁵ For example, rather than writing, "I want to feel better by being healthier," participants are taught to write, "I want to feel less stressed and feel more physically fit by walking each week." They are encouraged to consider how this goal can be measured, so they know when they've met it. This includes naming specific purchases they will make to reach their goal. So, in our example, they would write, "I will know I'm working on this goal when I sign up for the local YMCA, buy better walking shoes, buy a water bottle, buy a pedometer, and text my peer counselor each time I go to the Y to walk. I will know that my goal has been met when I am walking three times each week, and I start to feel less irritable and less out-of-breath." Based on motivational interviewing, participants would next rate how important the goal is to them on a scale of 1 to 10. If they rate 6 or lower, they are asked to consider modifying their goal to something that is more important and more personally motivating to them.

Next, participants are asked to consider whether the goal is realistic and attainable for them, especially given where they are starting from. To help them do this, they are asked to rate on a scale of 1 to 10 how likely they are to meet their goal. If they rate 6 or lower, they are encouraged to either change the goal entirely or reduce the goal in some way to make it more reachable.

Finally, participants are asked to set a due date either for the goal-related tasks or by when they will achieve their larger goal. Setting a due date for each task is the ideal to encourage progress and self-assessment of set-backs (Jonikas & Cook, 2004). When monitoring and rating their progress each quarter (as discussed later in this chapter), if participants haven't met their goal by the set due date, they will modify their goal to make it more attainable, choose a new goal, or change what they are doing to reach their goal.

- 1. Here's my **SPECIFIC GOAL**. This is what I'm changing or adding to my life.
- 2. Here's the main way to **MEASURE** this goal. This is how I'll know I've met it.

Write exactly how you'll know when you've met your goal. How will others know it, too?

I'll know I've met my goal when....

3. This goal is **RELEVANT** and matters to me.

On a scale of 1 to 10, how important is this goal to you? If you can't say 7 or higher, think about choosing a different goal.

Once at 7 or above in importance, write the benefits this goal has for you. How will it improve your life or mental wellness?

4. This goal is realistic for me. Is it **ATTAINABLE?**

Think about your current health, feelings, living situation, and skills. On a scale of 1 to 10, how confident are you that you can reach it? If you say 6 or below, try changing your goal until you can say 7-10.

If you need to change it, what is your new **SPECIFIC** goal? Be sure it matters to you personally.

- 5. By when will you finish this goal? Setting a **DATE** is important, so you can monitor your progress.
- 6. To finish, go through the S.M.A.R.T goal checklist:
 - a. Is the goal RELEVANT for you? Is it important to you?
 - b. Is it ATTAINABLE? Are you confident it's within your control and skills to achieve it?
 - c. Is it MEASUREABLE? How will you (and others) know when you've met it?
 - d. Is it TIME-BASED? Have you said exactly by when you'll meet your goal?

You must answer "yes" to all of these questions. Go back and work on questions 2-5, if needed.

Congratulations! - You have set a SMART GOAL!

Content from: www.Smart-Goals-Guide.com and Suzanne Mitchell, MD, MS: http://www.medscape.org/viewarticle/757625



Common Pitfalls

As participants contemplate their SMART goals, it helps to review common mistakes that people make when setting goals, such as the "10 Common Mistakes in Setting and Reaching Self-Directed Goals" shown on the right.

Chances are that the participants also will experience these common challenges when goalsetting. Discussing them in advance can help participants in their quest to set specific, relevant, achievable, and timeoriented goals.

10 Mistakes in Setting & Reaching Self-Directed Goals

People often make goals that they can't achieve. This is common. Goal setting is a skill that few of us are taught. Here are 10 common goal-setting mistakes that it helps to avoid.

- 1. Thinking goals are something you only do once a year, like at the New Year.
- 2. Not taking the time to think about what you really want.
- 3. Setting a goal you can never achieve, leading you to believe that you're not good at meeting goals.
- 4. Setting a goal that is too big or too general. Not breaking it down into smaller more manageable steps.
- 5. Setting a goal that can't be achieved in a specific amount of time.
- 6. Setting a goal that's too difficult given your current circumstances, skills, or needs.
- 7. Setting a "should" goal instead of a "want" goal.
- 8. Having too many goals.
- 9. Not having a written plan to reach your goal.
- 10. Not thinking about or finding the resources you need to achieve your goal. Not knowing where to look or who can help.

Adapted from Smart Goals: http://www.smart-goals-guide.com/setting-goals-and-achieving-them.html



Tips to Create Motivation in Goal-Setting

For people in the contemplation or preparation stages of change related to their goals, it is important for the broker to help them break the goal down into smaller steps that they can act upon, even if they're not ready to make full-scale change in their chosen goal area. Otherwise, the broker should help the participant choose a different goal on which he or she is ready to act. This is a balancing act, since goal-setting should be participant- driven. At the same time, you want participants to take advantage of their personal budgets to further their recovery, which can happen only if they set action- oriented goals. Motivational interviewing skills can be useful in helping people figure out what they are ready to do and what they will gain from doing it, while resolving any natural ambivalence.²⁶ In particular, supportive, open-ended questions can help to resolve ambivalence by helping participants to contemplate what needs to change.²⁷

Participant seems to shut down, and doesn't want to talk about goals. I'd like to understand how you feel. I'm not going to lecture you. I just want to hear what you think.

Participant knows she wants to work on smoking but has no idea how to proceed.

Tell me how smoking affects your life. We might find something there to work on.

Participant says he can't see himself succeeding. Tell me about a time in your life when you made a positive change, even a small one. How did that happen?







The SDC Plan

Once the SMART goals worksheet has been completed, the goal from it is transferred to the participant's SDC plan. The SDC plan is designed to link each person's goal to specific purchase requests as outlined in their personal budget. In this way, funds are directly linked to the goal of each participant. Thus, the SDC plan also serves as an accountability tool for programs to document that purchases directly reflect recovery goals. Moreover, the plan ultimately serves as a mechanism for releasing SDC funds for each participant's authorized purchases.

There are different forms that can be used to document the SDC plan. Typically these forms also contain the person's individual budget. One form used by the Texas Self-Directed Care Program, entitled "SDC Recovery Plan and Budget," provides space for the participant to record his/her name and the specific goal.28 Also included are the goal number (since most people set more than one), the date the goal was added to the plan, and the date it was removed from the plan, as relevant. The form also includes the specific resources or purchases the person has identified in the personal budget to support the goal (as described more fully in the next chapter). Space also is provided for relevant signatures. A more detailed form was used for new participants, entitled "Person-Centered Plan and Budget." This form directed them to think about how their goal, regardless of its nature, would specifically impact their mental health. It also led them to list the resources they would need to reach their goal and exactly how the purchase of those resources would lead to goal attainment. Finally, it showed them how the new purchase would affect their ending budget balance. Examples of SDC forms can be found in the resources section.

Monitoring Progress and Set-Backs

For most participants, self-directed goal planning and achievement will be a relatively new experience. Thus, as discussed previously, it is expected that the process will encompass mistakes and set-backs, along with successes. As such, it is important to monitor participant progress on a regular schedule. We suggest using quarterly reviews, in order to give participants ample opportunities to adjust goals to stay the course toward recovery. This is discussed in the following chapter.

The review process can be handled in different ways, but it must involve an in-person meeting between the support broker and participant. Having a meeting dedicated to reviewing what is and isn't working, in a safe and non-judgmental atmosphere, is a crucial component of SDC. In the Texas SDC Program quarterly review process, brokers and participants answered a series of questions about whether participants made progress toward their goals, what might have prevented the goals from being met, and specific modifications to the Plan that could increase likelihood of goal attainment.29 This is shown in the Quarterly Review Form in the Resources section. This was also a time when participants could decide that a goal was no longer relevant or attainable, and either scale it back or set a new one using the SMART goals worksheet. This sometimes required them to use the network provider directory and other information to choose options that would facilitate attainment of their existing or new goals.

As discussed in the next chapter, the budget is amended quarterly as well, in order to document purchase requests to support goals.

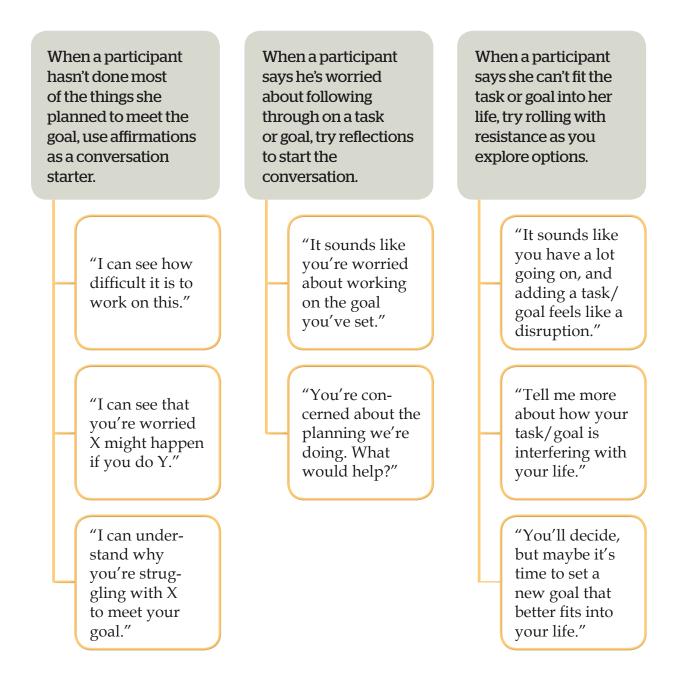
The SDC Plan links each person's personal needs and preferences to specific purchase requests.





Addressing Set-Backs or Ambivalence

It's important to note that, when people are struggling to meet their goals, simply changing goals may not be sufficient. Support brokers may need to use motivational interviewing techniques to help participants move forward. This starts with the broker recognizing that most people are ambivalent about making changes, even when they know they should and have extra money in-hand. Brokers can help to resolve this ambivalence by finding out how participants are feeling, what barriers they are facing, and what motivation they have for making a change. As Dr. Suzanne Mitchell (2012) notes, by helping people "deliberate" we help them to gain self-knowledge. This knowledge includes what skills or mindset might be shifted to support behavior change. By tying goals to participants' needs, values, and perspectives, the process becomes both recovery-oriented and more likely to lead to lasting change.





Planning for Crises that may Disrupt Goal Attainment

An important aspect of SDC is helping participants to anticipate difficulties or crises that may derail their SDC goal attainment. Additionally, because support brokers are not therapists or case managers, participants need to make sure they have specific plans and procedures in place for managing a crisis should one occur.

Of course, most people would prefer to avoid crisis situations, especially those that result in psychiatric hospitalization or disruptions in home or work life. Going through difficult times is painful, and it takes energy away from desired activities. Many people who receive public mental health services find it difficult to talk about their past crises, or to think in advance about how they would prefer a crisis to be managed. However, many crises can be avoided through thoughtful and proactive planning. If caught early enough, mental health problems can be addressed before they become serious enough to require hospitalization.

Advance crisis management entails taking an honest look at one's challenges and circumstances, identifying patterns of wellness and difficulties, and recognizing positive and negative influences on well-being. Some useful crisis management tools include crisis plans, post- crisis plans, and psychiatric advance directives.

Crisis Plans

Crisis plans are simple, written documents that participants create to delineate what they want to do, and what they want others to do, when they experience an emotional crisis. Crisis plans work best when they are limited to simple and clear actions that the person and others in his/her circle of support will take to de-escalate the situation. See the Resources section for a Relapse Prevention Plan used by the TX SDC Program.

There are a number of models and approaches for crisis planning. One of the best tools comes from WRAPTM (Wellness Recovery Action Planning, co-developed by Mary Ellen Copeland) and is well-regarded for the way it combines crisis planning with wellness planning.³⁰ Crisis plans offer participants a structured way to tell others important information including:

- What tough times look like
- Preferred medications, services, treatments, and facilities
- Undesired medications, services, treatments, and facilities
- The signs that things are headed towards a full-blown crisis, and what others should or should not do

The most effective crisis plans are developed by the participants, rather than by a provider, professional, or someone else. That said, participants often choose to consult with others while developing their crisis plans, including family, friends, providers, physicians, and lawyers/advocates.

In the Texas SDC Program, participants worked with their brokers to develop crisis plans upon entry into the program. They also were offered the chance to participate in WRAP classes as a proactive strategy for managing their own wellness.

Post-Crisis Plans

Post-crisis plans specify how an individual wishes to manage the often sensitive and challenging time after a crisis has occurred. A post-crisis plan focuses on what the person and his/her supporters should and should not do following a period of crisis. It includes information such as:

- Concrete signs that the crisis is over
- What the first few hours at home will look like, if relevant
- Things that need to be done right away, things that others can do, things that can wait until the person is feeling better
- Things and people to avoid while recovering from the crisis
- Daily activities and strategies while recovering from the crisis
- What to do to prevent further problems arising from the crisis
- People to thank and apologize to
- A time table for resuming personal responsibilities



Psychiatric Advance Directives

A psychiatric advance directive can take many forms, but typically it is a legal document that is similar to a crisis plan. As a legal document, a psychiatric advance directive is signed by an attorney who also maintains a copy. Each State has its own regulations and language to ensure the legality of an advance directive, so it's important to be sure your SDC program leadership and staff are well- versed in this or have access to a consultant with this expertise.³¹

Typically, an advance directive includes the designation of a person with Durable Power of Attorney (also known as an agent, proxy, or surrogate), who is selected by the participant to take over when the person temporarily lacks competency to make decisions about treatment, finances, or other personal matters. The duty of the Durable Power of Attorney is to ensure that the participant's wishes, as specified in the psychiatric advance directive, are known and honored. Like a crisis plan, the process of creating a psychiatric advance directive also can improve communication between a participant and her/his medical team, providers, and personal supporters.

Take-Home Messages

Person-directed goal planning is the cornerstone of self-directed care. It begins with the creation of a life plan to assess what aspects of participants' lives are going well and should be maintained, and what parts they would most like to change. Along with a review of past service utilization, this planning process informs the goals that are documented in the SDC Plan. Such plans typically include the use of traditional mental health services to address needs and meet goals, such as therapy, medication management, peer support, and case management. Additionally, SDC Plans also include non-traditional services, supports, and material goods needed to create a meaningful life. These may include fitness classes, education/instructional fees, transportation, vision or dental care, massage therapy, job interviewing clothes, or a computer. When given this level of personal responsibility, along with the skills for allocating a pool of limited resources, many people become more satisfied with and engaged in the services and supports they choose for recovery.





6 Budgeting and Purchasing

A central feature of SDC programs is their fiscal operation. In Chapter 4, we discussed the important role of fiscal intermediaries. In this chapter, we offer a more in-depth look at the technical aspects of budgeting and purchasing in self-directed care, which many people believe are at the heart of the approach.

The major sections of this chapter are:

- Developing a Purchasing Policy
- Determining the Amount of the Personal Budget
- Creating Personal Budgets
- Monitoring Personal Budgets
- Payments and Reimbursements

Developing a Purchasing Policy

The main purpose of the purchasing policy is to clarify for participants what goods and services may be purchased with funds from their individual budgets. A secondary purpose is to establish accountability for the use of public funds in your SDC program. This policy documents what is allowed and disallowed for purchase with program funds. You will find that one of the primary concerns about SDC among various officials, service providers, family members, and community stakeholders is that the participants will misuse the funds over which they have been given authority. Simultaneously, a major concern of many participants is that they will not be given meaningful control over how they spend their SDC budgets to facilitate recovery. When well-crafted, an SDC purchasing policy addresses the dual priorities of good stewardship of public funds and the maximization of participant choice. As is true for any service program, participants do not have unlimited options, but the purchasing policy should be flexible enough to allow as much choice as is possible within State and local regulations.

Ideally, purchasing policies are developed by the steering committee. They also require review and approval by funders or other regulatory entities. The fiscal intermediary also must be sure that your policy meets all of the legal and regulatory statutes for which it is responsible. Additionally, the program director and the SDC brokers will need to be sure that participants are budgeting for allowable purchases or, when an emergency arises, are adhering to the established policy for purchasing crisis-related supports or goods. The SDC purchasing policy addresses the dual priorities of good stewardship of public funds and the maximization of participant choice.

Maximize Flexibility Within and Across Funding Sources

One of the first elements you will consider when developing a purchasing policy are the rules and regulations governing the public funds that finance your program. Funders will have different regulations regarding allowable and non-allowable purchases, along with varying service eligibility criteria. If you draw upon multiple sources of funding (e.g., Medicaid waivers, State general revenue, federal grants, etc.), you must attend to the restrictions and opportunities available through each source as you develop your policy. As a general rule, you want to ensure that each participant receives all of the benefits and entitlements for which he or she is eligible, while demonstrating that funds were not spent by individuals who were not eligible to receive them. Your fiscal intermediary will need to stay current on all relevant State and federal regulations as they tend to change frequently.



One advantage of having multiple funding sources is the ability to maximize the strengths of each funding stream while minimizing its limitations. For example, medical necessity regulations under Medicaid may allow attending a weight management group, but disallow the purchase of workout shoes to facilitate weight loss goals. However, your State general revenue fund might allow purchase of the shoes, as long as acquiring them is clearly linked to a participant's program goal.

Elements of the Purchasing Policy

When creating the Purchasing Policy, it is useful to group purchases into broader categories. FloridaSDC's policy used the following three categories (Haine & Spaulding-Givens, 2006):

1. Clinical Recovery Services

These include traditional mental health services such as psychiatric evaluation, medication management, and therapy. Also included are certain medication purchases and co-pays. The Purchasing Policy dictates that purchase of clinical recovery services takes priority over other types of purchases.

2. Recovery Support Services

These alternatives to traditional mental health services can yield similar or better outcomes for participants. Examples include occupational, speech, and physical therapy, massage therapy, art therapy, fitness programs, optometry and dental services, and employment or education services.

3. Recovery Enhancements

These include tangible items that contribute to a participant's ability to engage in productive activities such as paid or volunteer work, education or training programs, or therapeutic groups or activities. Included are professional clothing, hygiene products, art or office supplies, text books, computers, and so forth. Also in this category are hair care services or transportation related to employment or other goals.

Consider these elements when creating your SDC Purchasing Policy

- 1. Which purchases are allowed and disallowed, including emergency purchases, sales tax, tips, or shipping costs
- 2. The process for seeking approval to use a provider or vendor outside of the SDC Provider Network
- 3. Whether and how development of new allowable purchases will be accounted for in the purchasing policy
- 4. The guidelines (if any) for allocating a portion of the personal budget to traditional services and a portion to non-traditional resources (one recommended split is approximately 60% on traditional and 40% on non- traditional purchases)
- 5. The process for personal budget approval and monitoring, including the expectation that purchases are made with SDC funds only after prior authorization
- 6. Whether participants are expected to take responsibility for using other sources of funding for needed resources prior to requesting SDC funds (such as Medicaid funding for oral appliances)
- 7. How goods and non-traditional services will be purchased (via vouchers, checks, debit cards, or other mechanisms) and the documentation that will be needed to process payments
- 8. The effective dates for SDC plans and budgets (when do they go into effect and when do they expire)
- 9. The process for making budget amendments, and when and how often they can be made
- 10. How receipts are to be managed (must be original, itemized, and dated within the budget's effective dates; must be submitted within 5 days of purchase, etc.)
- 11. Any limits on amounts that can be spent within budget line items, or on whether (when and how) participants can shift monies from one budget line to another
- 12. Whether emergency purchases can be made and under what circumstances, along with who will make the determination that they are allowable after the fact
- 13. The person responsible for resolving problems with vendors when the goods or services are dissatisfactory, inoperable, damaged, or otherwise of an unacceptable quality
- 14. Clearly worded sanctions for purchasing policy violations
- 15. Grievance procedures if a participant wants to challenge the denial of a purchase request



Allowable versus Disallowable Purchases

One of the primary purposes of the purchasing policy is to provide clarity about which purchases are allowed and not allowed. This empowers participants with information about what they can and cannot purchase prior to budget development. The policy also provides ideas for goods or services participants might find beneficial in their recovery. It provides brokers with back-up documentation if participants object to the denial of a proposed purchase.

Below are the types of expenses that have been allowed (again, only if they correspond to a documented recovery goal) and disallowed in some SDC programs. It can be helpful to summarize allowed and disallowed purchases in a user-friendly manner. As an example, see the TX SDC Program's participant brochure, *Guidelines for Participants*, summarizing this information in the Resources section.

Allowed purchases

SELF-CARE

Yoga, therapeutic massage, books, acupuncture, arts and crafts supplies

MENTAL HEALTH

Private psychiatrist, individual or group counseling, peer support services, medication management

PHYSICAL HEALTH

Gym memberships, personal trainer, exercise equipment, weight-loss

Disallowed purchases

ACCESSORIES Jewelry, belt, watch

PHYSICAL HEALTH

Over-the-counter medications, non-FDA approved herbal remedies

DENTAL CARE Teeth whitening, dental cosmetic services Sometimes programs find it difficult to establish hard and fast rules about what is allowed and not allowed. It also can be difficult to guard against classifying a purchase as disallowed due to personal bias or traditional notions of what public money should pay for. For example, when learning about one SDC program, a provider became upset that a participant might be able to use funds for a yoga class when the provider herself could not afford to take yoga. These are challenging issues, and it can be difficult to sympathetically point out that denying one person a resource because another person cannot afford it is not a fair policy. Therefore, it can be useful to engage "fresh eyes" to help you navigate bias or misinformation as you develop your purchasing policy. Engaging an attorney knowledgeable in these areas can be a good investment. Another source of guidance may be State agency staff. While they may not have direct expertise in self-direction, they may have access to legal, public policy, or fiscal consultants who can assist you.

Even with such a list, participants may require help in deciding whether a purchase is acceptable, particularly for something that has not been requested previously. The FloridaSDC Program handled this issue by including guidelines in its purchasing policy to help participants determine the suitability of requested purchases.

Participants are asked to consider:

- Does the purchase directly relate to the needs you described in your recovery plan? Specifically, does the purchase promote your mental health self-management, recovery, and/or independence?
- Will the purchase enhance your employability or result in productive activity for you?
- Is the purchase the most efficient level of service or supply that can be provided safely and effectively to you?
- Is the purchase a good use of public tax money?
- Have you explored other options of pay or resources prior to requesting this purchase be made with SDC funds?
- Is this a recurring purchase that ultimately could be purchased through earned income (as a future goal)?



Cost versus Value

When considering allowable and disallowable purchases, bear in mind that the least costly option does not always produce the best value. Therefore, it is important to balance positive value and personal outcomes for the money spent. For example, buying an outfit at a thrift store for a job interview (linked to an employment goal) might be the least costly option, but used clothing also may make the person appear less professional, thereby compromising the impression he or she can make. Or, a participant whose goal is to exercise for improved mental and physical health might be deterred by sore feet when purchasing the cheapest walking shoes. It is important that the Purchasing Policy does not unreasonably promote cost over value.



Determining the Amount of the Personal Budget

As a public resource, the amount of the personal budget must be determined in a fair and transparent way. Although participants are likely to have many unmet needs, the SDC budget is not an inexhaustible resource. Careful fiscal planning and monitoring by both participants and staff are required to prevent "run-away" program costs. This can be accomplished not only by closely adhering to the Purchasing Policy, but also by pre-defining the parameters of the personal budget.

One way to pre-determine the budget is to limit it to the average per capita cost of outpatient publicly-funded services in a State's system from the previous year (Cook et al., 2004). Excluded from these calculations would be the costs of inpatient and emergency treatment, and potentially pharmacy and substance abuse treatment, thereby guaranteeing the continued availability of these services to participants. For both the Florida and Texas SDC programs, this per capita amount ranged from \$3,000-4,000 per year (Cook et al., 2008), which is what each SDC participant was authorized to spend annually on outpatient traditional and non-traditional services via a personal budget. Another way to set the budget amount is to tie it to an individual participant's service utilization costs in the previous year or two years. In this way, each participant has a different amount of money to spend and the program's budget neutrality is determined on an individual participant basis.

Whatever calculation method is used, the personal budget should not exceed the average amount already being spent for outpatient behavioral health services for the target population. This is the primary way that SDC programs remain budget neutral. As discussed in Chapter 2, the size of the individual budget does not include infrastructure costs of an SDC program, which will need to be supported with State, federal, foundation, or other sources of funding.

> As a public resource, the amount of the personal budget must be determined in a fair and transparent way.



Creating Personal Budgets

The purpose of the personal budget is to specify purchases that will help participants to reach their SDC goals, while adhering to the program's Purchasing Policy. The personal budget is the cornerstone of an effective SDC program. It makes the model unique and powerful. It also can make SDC too costly, if budgets are not carefully constructed and managed by participants and brokers. Indeed, participants are encouraged to monitor their own spending and account balances for the same reasons as anyone else:

- It is a normative adult responsibility to keep track of income and spending
- Monitoring spending helps people make responsible purchasing decisions and use limited resources wisely
- Budget monitoring provides an important check for mistakes made by providers or the fiscal intermediary in invoicing or payments

In the public system, most people choose services or supports from a pre-defined set of options. They are not provided with information on service costs, or ways to obtain the same quality of service more affordably elsewhere. This lack of transparency can deprive people of the opportunity to learn and practice personal accountability in service utilization. As one SDC participant put it,

"The ability to control the dollars for my care allowed me to practice cost effectiveness, focus on my abilities, discover my responsible limits, and eliminate the 'blame game' by being personally accountable for the consequences and successes of my choices."

As participants come to understand not only that they are drawing from limited resources, but how much each option costs, they are more likely to make choices that will have the greatest impact on their goal attainment. When learning to be cost efficient in this way, they also have the opportunity for low-risk experiments to determine whether a new service or good does or does not promote recovery, and if not, what to substitute moving forward. Additionally, this process allows the participant and broker to identify sources of free or low-cost resources that will result in goal attainment with the least financial impact.

Let's consider an example budget, using one of the SDC goals discussed in the previous chapter.

Recall that our sample participant stated, "I want to feel less stressed and feel more physically fit by walking each week." For this goal, the participant noted,

"I will know I'm working on this goal when I sign up for the local YMCA, buy walking shoes, buy a water bottle, buy a pedometer, and text my peer counselor each time I go to the Y to walk."

Let's assume that this person is authorized to spend approximately \$4,000 annually on outpatient services and resources. In the first quarter of the year, the participant would have around \$1,000 to budget. After researching costs with the broker's help, the participant determines that walking shoes will cost \$40, the water bottle \$5, the pedometer \$10, and an unlimited data plan to text her peer counselor will cost \$270 for the quarter (at \$90/ month). The YMCA membership for an adult is \$300/ year, or \$75/quarter. Altogether, this goal will cost \$400 for the quarter.

Let's say that this participant also has a goal to maintain her mental wellness by taking her daily medications, and receiving monthly cognitive behavioral therapy (CBT). Related to this goal, she would budget for monthly medication management (\$50/visit x 3 visits for the quarter = \$150), and monthly CBT sessions (\$100/hour x 3 visits = \$300), totaling \$450 for the quarter.

Finally, let's say she also has a goal to eat 3 low-sodium dinners each week to help reduce her blood pressure, and thus, improve her emotional and physical wellbeing. She would budget for 4 sessions of a cooking class designed to teach people how to prepare nutritious low-cost meals at \$20 per session, totaling \$80 for this goal for the quarter.

Altogether, the participant has budgeted \$930 for the quarter, leaving her with \$70 a "cushion" to use towards unanticipated needs related to her current goals, or for purchases related to a new goal during the current or future quarter.



Example SDC Plan Costs for Quarter

Goal	Items	Funds
Exercise	Walking shoes	\$40
	Water bottle	\$10
	Pedometer	\$5
	Data plan	\$270 (\$90/month x 3 months)
	YMCA membership	\$75
	Goal Total	\$ 400
Medication Management with Psychiatrist	Psychiatrist visits	\$150 (\$50 per monthly visit)
Cognitive Behavioral Therapy	CBT sessions	\$300 (\$100 per monthly visit)
	Goal Total	\$ 450
Healthy Eating	Cooking class	\$80 (\$20 per session x 4 sessions)
	Goal Total	\$ 80
Total		\$ 930



In order to create a budget, participants draw from multiple sources, including: the Purchasing Policy; a review of their past service costs; and the SDC provider directory that contains negotiated service costs. If a service or resource has not been pre-negotiated by the SDC program, the participant and broker can research potential vendors and costs.

One hallmark of the personal budget is the opportunity for participants to purchase non-traditional services that they believe will help them achieve a goal better than traditional services. However, it would not be good stewardship if individuals repeatedly select non-traditional resources that do not measurably help them to achieve personal recovery goals. For example, prioritizing continued purchase of self-help books over a medically-necessary service could be of concern, especially if the participant becomes unwell and is unable to continue participating fully in SDC as a result. The participant and the broker will weigh these choices together as the budget is created. Indeed, since clients of public systems have not created personal budgets to foster their recovery, they typically require financial skills training and support, especially when they first enter the program.

As part of financial skills development, teaching participants to create and monitor their budgets using computer software is ideal. Many people use Microsoft Excel[™] to monitor income and expenses, and SDC participants need not be an exception. Moreover, an electronic budget is easier to share with SDC program staff, and participants can run personalized reports on their spending needs or habits. However, many people on limited incomes do not have regular access to a computer, which would rule out online expense monitoring. Other people aren't comfortable entering expense and income data into a computer. In these cases, printed budgeting forms will do the job just as well.³²

Once the broker verifies that each purchase is directly tied to a participant's SDC goal, the personal budget must be approved. Typically this is done by the program director, but it can be done by any objective party that embraces recovery and understands how the self-directed care model works. If the program leader determines that a requested purchase falls outside of the Purchasing Policy, this is documented in writing and the budget is returned to the participant and broker for modification. Once approved, the fiscal intermediary translates the individual's budget into standardized fiscal centers, cost categories, and activity codes, thereby encumbering the money for the planned purchases. As discussed in more detail below, the fiscal intermediary will not render payment for goods or services that are not pre-approved as a participant's budget.

Monitoring Personal Budgets

At any point during the quarter, participants can request from their support brokers up-to-date account balances and payment status for any provider. This is a good way for participants to closely monitor their finances, and to ensure that providers and vendors are being paid in a timely fashion.

In most SDC programs, the SDC Plan and budget are reviewed and updated on a quarterly basis. This means that participants complete new Plans and budgets on a regular schedule, allowing staff to regularly review Plans and budgets for completeness, adequate fund balances, and compatibility with the SDC Purchasing Policy prior to final approval and payment authorization. Limiting changes to the SDC Plan and budget to a quarterly schedule reduces the challenges that come along with frequent Plan and budget changes. These challenges include lost documentation or receipts, missed payments to vendors, or excess paperwork. In some programs, exceptions to this policy include times when participants need additional clinical services because of an unanticipated change in their mental health. In these cases, a need for an amendment to the SDC Plan and budget is discussed with the program staff and leadership prior to authorization.

Quarterly reviews typically involve the participant and broker candidly discussing the former's progress toward each goal. It is helpful to have both parties independently rate the level of progress using pre-specified rating anchors (e.g., no progress, some progress, goal achieved). The ratings are compared and any discrepancies are examined to determine a fair and objective rating that would bear scrutiny in a case review. If both parties agree that a goal has been attained, discussion ensues about whether any purchases are required in order to maintain the goal. If not, the person considers whether he or she wants to develop a new goal and accompanying budget. On the other hand, if little progress has been made, brokers suggest that participants consider one of three options. First, they can revise their goal to make it more attainable. Second, they can decide to abandon the goal and potentially replace it with a new one.



Third, they may consider different or additional purchases that are more likely to result in goal attainment. It is not uncommon for brokers and participants to see things differently. Often honest discussion can bring them closer in how they see things. If not, their opinions of both are noted on the Quarterly Review Form. Also clearly noted are changes to either the Plan or budget in response to little or no progress. This is important because the program needs to show that it is having a positive impact on people's mental health and recovery, given the dollars that have been spent.

After reviewing whether the person has met or needs to set new goals, discussion turns to the next quarter's budget. This includes clarifying the amount the person will be authorized to spend in the coming quarter, taking into consideration whether the person spent more or less than was anticipated for the last quarter. The participant and broker must conduct an analysis to ensure that current spending patterns won't result in the person being far over or under-budget at the end of the fiscal year. If it appears that the projected expenditure patterns will exceed or fall short of the annual amount, plans are made to change spending accordingly. The broker and participant may also decide that they need to touch base more frequently to ensure that spending stays on-track.



As mentioned earlier, mid-quarter budget changes are discouraged in order to prevent errors and reduce paperwork. However, the budget may be amended mid-quarter in some circumstances, as delineated in the Purchasing Policy. When amendments are requested, the participant and broker must determine how the unanticipated expense is tied to an existing SDC goal. They also need to assess how the new expense affects the available fund balance for both current and future quarters. In order to stay cost neutral, the participant may have to reduce other planned expenses, but also must consider how reductions will affect attainment of their related goals. In these situations, guidance from the broker can be very valuable. For example, the broker might help a participant find free or low-cost sources for a purchase, or suggest putting less essential purchases "on hold" in order to accommodate a mid-quarter budget change.

Sometimes, the quarterly review also includes reconciling the last quarter's purchases. This involves going through the quarter's receipts and invoices, and reviewing what services were utilized during the quarter. The Purchasing Policy serves as a guide for how to handle lost receipts and missed payments to vendors.

Payments and Reimbursements

Payments for Traditional Services

For traditional service providers, payments are typically processed as they would be by any health care insurer, especially if the fiscal intermediary is a managed care organization. Providers enrolled in the SDC network submit claims to the fiscal intermediary for services rendered to a participant. The fiscal intermediary reviews the claim against the participant's budget. Once approved, the claim is paid either by check or electronic transfer of funds.

Timeliness in submitting claims for services rendered is needed if participants are to effectively track and manage their budgets. Typically, providers take several months to invoice for a service. Thus, its cost is not reflected in the fiscal intermediary's records. For this reason, participants and brokers must keep track of each service used and deduct it from the person's real-time budget. Another way of handling this is to encumber projected service delivery dollars by removing them from the available balance at the time of budget approval. This can help prevent the earmarked funds from being spent in any other way without discussion and documentation.

Payments for Non-Traditional Services

Payments to non-traditional service providers and the purchase of material goods can be handled in several ways. First, a check can be issued whenever a participant produces an invoice for a pre-approved good or service.

Typically, these checks would be mailed directly to the provider or vendor. Examples include invoices for a tuition payment to a local college or private fitness training.



If this option is used, it is important that the checks do not include notation that they are from a mental health or social service program. Additionally, return of any material goods results in a cash outlay that could put participants at risk for misuse of program funds. Another option is for participants to pay in advance for nontraditional services or goods, submitting receipts afterwards for reimbursement. This option is difficult for individuals with limited incomes. Another option involves directly disbursing cash to participants, so that they can pay for pre-approved services or goods themselves. While this option has the appeal of protecting people's confidentiality and reducing some paperwork, it again puts people at risk for spending money on non-approved purchases. Given these issues, some SDC programs have opted to provide participants with a regulated debit card for authorized purchases.

SDC Debit Card

Use of debit cards can effectively promote choice and access to non-traditional vendors. Debit cards can help to ensure accountability for the SDC program and their use can develop important money management skills among SDC participants. This was the case in both the Texas and Pennsylvania SDC programs. The card should look like any other debit card, avoiding the stigma of being identified as a service recipient. When debit cards are used, monitoring by the broker and processing by the fiscal intermediary ensures that the funds go where they are supposed to.

To protect the participant and the program, restrictions are placed on the debit card, such as where it can be used, how much can be charged, and for what kinds of purchases. Participants are informed of debit card restrictions upon joining the SDC program (see Guidelines for SDC Debit Card Purchases in the Resources section),³³ and the Purchasing Policy delineates how misuse of the card will be handled. For example, a participant might be allowed two violations of the Purchasing Policy before the card is revoked. Or, instead of revoking it, the card might be suspended for a period of time following minor misuse. Or, as a result of misuse, the program might decide to use a combination of checks and limited access to a debit card for a given participant. There are several feasible ways to provide debit cards to encourage fiscal responsibility, while avoiding shaming participants for financial mistakes that most everyone makes at one time or another.

Many fiscal intermediaries prefer that the SDC program establish and manage its own debit card system. In this case, the fiscal intermediary may transfer a block of funds to the program, after which program staff load the debit cards with funds electronically at the time participants are scheduled to make purchases. If fees are associated with debit card activation and use, these are typically paid for from a participant's budget as would be the case for any card user.

Take-Home Messages

Sound fiscal management is a critical component of a successful self-directed care program. The program's Purchasing Policy is an extremely important tool for ensuring that the fiscal intermediary, program leadership, program staff, and participants use SDC funds in an accountable and transparent manner. Creating and monitoring a personal budget will be a new experience for many participants. Yet, it can be one of the most empowering aspects of the program. Providing comprehensive information and financial skills training are invaluable as participants learn to maximize their budgets to meet their SDC goals.







Eligibility, Recruitment, & Enrollment

Let's assume you are ready to open for business. Your funding, governance structure, policies, and procedures are in place. Now you need people who are willing to try something different by enrolling in your SDC program. Some people will be excited to give it a try, anticipating that the enhanced options and flexibility are just what they need for their recovery. Others will be wary, with concerns about how this new program will affect their current services. Some may worry about losing access to needed benefits or have fears of alienating providers whom they wish to retain. Some may be attracted to the flexibility of SDC, but unsure about whether they can assume the level of personal responsibility required by the model. Some simply may not be interested. Your task is to attract eligible participants who believe they can benefit from the program and are ready to give something new a try. To do this, you'll need a well- articulated marketing plan designed to reach people and fully inform them about the program. You also need to consider what to do when people choose to leave the program.

This chapter addresses participant eligibility, recruitment, and enrollment.

The major sections are:

- Eligibility
- Advertising and Promotion
- Participant Education
- Intake and Orientation
- Withdrawals and Discharge



Eligibility *Who is SDC for?*

The answer to this question has several layers. Primarily, your target population is the same group you used when setting your SDC participants' personal budgets. If you used the average amount spent on outpatients with severe mental illness in the public mental health system, then that is the group from which you will recruit. If you took a subset of outpatients to determine average costs (such as those who are high service utilizers) then that group becomes your primary target for recruitment. This approach helps to ensure budget neutrality because the goal is for SDC to cost no more than what would have been spent in the current system.

Another consideration is how your various funding sources define eligibility. Eligibility criteria typically include diagnostic, disability, economic, and geographic factors. Sometimes they also include age or legal status.

The next layer is defined by participant interest. Here, you will find a range from enthusiastic to indifferent. Most people will fall somewhere in-between, and they will have questions that need to be answered before being ready to sign up. This is why a well-executed promotional campaign is important. You want to be able to educate and excite people about a new way of receiving services and supports.

Finally, if your SDC program is being mounted with State or federal research dollars, your eligibility criteria will be determined by the study's guidelines.

Sample Eligibility Criteria from Two SDC Programs

Florida SDC Eligibility Requirements

- Age 18 or older
- Diagnosis of diagnostic impression of Axis I or Axis II mental disorder
- Willing to apply for any disability income or benefits for which he/she is eligible (such as Veterans benefits, Social Security programs such as SSI/SSDI, food stamps)
- Legally competent to direct personal business
- Lives in district in which program is located

Texas SDC Eligibility Requirements

- Live in the target service county
- *Be currently authorized for Texas' Resiliency and Disease Management adult service package 3, with a specialty provider (SPN)*
- Be 18 years or older
- Not currently in crisis
- If individual has a substance abuse or dependence diagnosis, is willing to engage in treatment or already is engaged in treatment, and is willing to continue treatment or support groups throughout SDC study period
- If homeless, has an adequate support system or plan for housing stability
- Is legally competent to direct his or her own affairs

Your program will need a procedure for verifying the eligibility of each potential participant. The process likely will begin with eligibility verification by your program director. The fiscal intermediary also may need to verify that each person is eligible under one or more of your funding sources. If your program is funded within a research or evaluation project, the investigators also will need to verify that each person meets the eligibility criteria that have been pre-approved by the entity that protects participant rights in research (typically a university or agency Institutional Review Board).







Advertising and Promotion

State governments produce various publications about the services they fund, which also are promoted on their web sites. It is advisable to have your SDC program included in these State-sponsored resources, if possible. In addition, you'll want to execute a larger marketing campaign to reach a wide range of potential participants.

Planning a Promotional Campaign

When you're ready to open your doors, your main goal is getting the word out to as many potential participants as you can. Before you do this, however, you need to make sure that your promotional campaign is as effective as possible. Start by considering what you most want people to know about your SDC program. Who needs to know about it? Do different audiences need to receive different information? For example, do some messages need to be geared specifically to potential participants, their families, and supporters? Should other messages target service providers and referral sources? Where and how can you best reach the people you wish to target? Is your promotional campaign serving different needs besides recruitment, such as public education or fundraising? The answers to these questions will guide the content and approach of your campaign.

You also need to give careful consideration to your promotional materials. You'll want to determine what kinds of materials you need, including brochures, flyers, social media or web site announcements, newsletter articles, public service announcements, or in-person presentations. The Steering Committee can be a resource in creating and approving promotional materials. In your excitement, you want to be careful not to oversell the benefits that participants can receive from SDC. An enthusiastic but balanced approach will serve you well.

Work together to ensure that your promotional campaign is as effective as possible.



Keep It Simple

Each promotional piece should be clear, with language that's easy to understand. Avoid too many words or jargon – keep it simple. Also avoid lecturing people about what "should be" or overloading your materials with philosophical statements. Share your values, yes, but don't alienate potential participants or network members by railing against the current system. Try to position SDC as an alternative that provides opportunities beyond what currently exists.

Engage Participants as Educators

Testimonials and success stories are powerful promotional strategies. Since it will take time for people to demonstrate success in your program, you can draw from the experiences of other SDC participants in the meantime. For example, the Texas SDC Program provides testimonials on its web site: http://www.texassdc.org/.

People currently enrolled in the program also can be effective recruiters or promoters. Encourage participants to talk with their friends and others about SDC and recommend enrolling. As one SDC participant put it, "sharing my experiences with SDC has encouraged others to believe in their potential." Participants also can be helped to prepare formal presentations to give at community meetings or other gatherings attended by potential SDC members.



Reaching Your Community

Create Awareness

SDC promotes community integration by encouraging participants to use a wide variety of services and supports within and outside of the behavioral health care system. It also provides an excellent opportunity to educate the public about recovery and to de- stigmatize mental illness. Thus, your promotional campaign should also include distributing flyers or brochures in public areas around the community, such as libraries, grocery stores, places of worship, community centers, town halls, chambers of commerce, clinics, and so forth. Service groups such as Rotary or Lions Clubs often seek out community speakers to make presentations at their meetings. Engaging community members can help them to consider more broadly how to create healthier, more productive, and more tolerant environments for everyone living in the area.

Use a Speakers Bureau

Try to respond to every opportunity to spread the word about your program and its benefits. Creating a Speakers Bureau that includes SDC participants can help you quickly respond to community requests for education or speakers. Be sensitive to participants' comfort levels in sharing personal information. Some participants may not be interested in "going public" for fear of potential discrimination. Others may have publicly disclosed their experiences with psychiatric disabilities already, and will be comfortable sharing in the community.

Engage the Media

As part of your promotional campaign, it helps to develop a positive relationship with the media. Try to identify at least one journalist who either has a good understanding of mental illness and recovery, or is willing to learn. Public mental health care and service financing are specialized areas. Thus, you cannot assume that journalists will have expertise or get all of the details right. Promotional materials tailored for the media will make a journalist's job easier, increasing the likelihood that she or he will share accurate information.

Reach Out to Programs and Organizations

It's important to engage traditional and peer providers in your promotional campaign. In particular, programs such as clubhouses, drop-in centers, peer-operated programs, and self-help organizations can be excellent allies and serve as sources of client referrals. They also can be invited to join the SDC Provider Network.

Tailor It!

Here again, tailoring promotional materials to the interests and needs of traditional and peer providers is key. Such providers often are cautious about SDC due to legitimate concerns about how SDC will impact their budgets and programs. This is especially the case in fee-for-service environments, where lost clients equal lost revenue. You want to help them see that they might be able to retain revenue streams by becoming members of your SDC Provider Network. It's important to reassure traditional and peer providers that most participants continue to purchase these types of services with their SDC budgets.

Tap Providers

Providers are a wonderful referral source. They often are willing to distribute flyers or brochures. With some training, supportive providers also can help explain the program and encourage potential participants to find out more. You want to tap any SDC champions in the provider community and avoid those who might discourage participants due to personal bias or concerns about lost revenue. Making accurate information available to potential members via different outlets, not only through their current provider system, will help address this concern as well.

Participant Education

Written materials have a role to play in participant education, but personal contact is critical. The SDC program director, support brokers, current participants, and peer supporters are all good candidates for providing this personal contact. When educating potential participants, it is important to directly address their specific worries, rather than downplaying or avoiding them. The opportunity to self-direct care can be overwhelming for people who are accustomed to having decisions made for them. Some people will find it challenging to envision a new way of choosing and managing their services. Some will have lost confidence in their ability to recover and make important life decisions. Others will have limited decision-making or financial management skills. Assuming responsibility for the consequences of one's decisions can feel burdensome. Some people will wonder what would happen if they make a poor decision or don't use their budgets in the most beneficial ways. Others will need information about how enrolling in SDC will affect their public entitlements. Finally, there are those who will be concerned that SDC is a fad, and that they will join the program only to see it discontinued. Your promotional materials and personal contacts will need to directly address these concerns to help people feel comfortable signing on.

Intake and Orientation

As in most programs, participants enroll by completing an intake process and various forms. Intake procedures will be driven by the organization hosting your SDC program. Some of the forms commonly found in an SDC intake packet include:

- Welcome letter
- Program consent form
- Notice of privacy practices
- Statement of participant rights
- Demographic and personal information form
- Release of information form
- Policy for debit card use
- Purchasing policy brochure and agreement form
- Relapse prevention/designation of health care surrogate plan
- SDC enrollment agreement

In some SDC programs, the onus of completing intake paperwork is placed on the participants. The philosophy guiding this approach is that, if people are not able to complete enrollment tasks and submit documents within the required timeframe, they may not be ready to assume the responsibilities associated with SDC. If going this route, it can be helpful for your program to link applicants with active participants who will provide peer support, and share experiences and wisdom. In other SDC programs, support brokers provide direct support to participants as they complete intake forms and orientation. Here, the idea is that most people have not had much experience with self-direction, and need reasonable accommodations and coaching to complete paperwork accurately, especially in the beginning phases of the program.

Program orientation can be handled in various ways. One approach is to conduct group orientation sessions, which is a time-saving way to discuss program regulations while introducing participants to one another for future peer support opportunities. This option also allows people to complete their SDC Plan and personal budgets in a group setting, so that participants can learn from each other while planning goals and purchases. Another approach is to conduct program orientation individually via a meeting between broker and participant. The Texas SDC Program used a combination of group and individual meetings to accomplish orientation and planning.

Don't underestimate the importance of program orientation or the time it takes to help people feel comfortable with SDC. Even if participants are enthusiastic, SDC is a very different way of selecting and receiving services. People need time to adjust and understand the journey on which they are embarking. Some participants will be unfamiliar with recovery and self-determination, and thus, will need a primer on these foundational concepts before they are ready to set goals and create budgets. The more ready people feel to engage in planning and budgeting, the more successful they will be. Some SDC programs offer recovery classes to help orient participants to notions of self-determination and goal attainment. Other programs, such as the one in Texas, offered a monthly Learning Community with guest speakers, specific skills training, discussion of new community resources that participants/brokers have found, participant sharing, and a luncheon. Read more about Learning Community meetings here:

http://www.texassdc.org/pages/participant-flyer.2-21-12.pdf

A participant learning community is a great way to engage, orient, and support SDC participants.



Withdrawal and Discharge

Individuals should be free to withdraw from SDC and return to whatever system of care for which they are qualified. The steering committee can establish policies and procedures regarding withdrawal and discharge from SDC. Typically, advance notice is required. As in most managed care environments, changes in enrollment status may be limited to a specific time period, such as at the end of a budget cycle.

It is the ethical responsibility of the SDC program to ensure a smooth transition back to usual care for participants who wish to resume traditional mental health services. There should be policies and procedures for this transition, and for notifying relevant providers so that a person does not experience a gap in psychiatric medications, medication consults, or other outpatient services. Some people will choose to leave the SDC program because they have met their recovery goals. For example, a person might obtain full-time employment with private health insurance coverage, and no longer need SDC. Others will move out of the area and will no longer be eligible for services.

Your steering committee also will need to develop a policy for whether and how to serve individuals whose eligibility status changes during their tenure in the SDC program. For example, if a participant is incarcerated for an extended period of time, a decision will need to be made regarding whether to withdraw the person from services or suspend participation until the individual's release.

In some cases, your program staff will decide to initiate disenrollment or administrative discharge from SDC. Typically, this occurs when a participant consistently fails to meet the responsibilities of the program. In these cases, it's important for staff to make a concerted effort to re- engage the participant. However, SDC is not for everyone, and sometimes this is discovered only after people are enrolled and given a chance. Re-enrollment may be an option for these individuals, if they and program staff determine that they are now ready to engage.

For audit and quality assurance purposes, it's important to thoroughly document all incidents of withdrawal or discharge, along with the circumstances and related dates. Also documented would be any transition support provided and referrals made. Regardless of how participants exit your program, make sure that their transition is a smooth one whether back to traditional services or a life of independence.

Take Home Messages

Eligibility, recruitment, enrollment, and orientation are critical to the operation of SDC programs. It's important to design workable procedures and user- friendly forms so that brokers and participants can efficiently work together. Giving people adequate support and coaching as they embark on their SDC journeys can set them up for success in meeting their goals and making the best use of their personal budgets. At the same time, thought must be given to the ways participants will exit the program, particularly to ensure that their return to usual services is as smooth as possible.



8 SDC Support Brokers

Support brokers play a critically important role in SDC programs. They recruit and orient participants, and help them with life planning, budget development, documentation, and other tasks. They also provide support, coaching, and mentoring.

You might think that this role sounds a lot like that of a case manager. It's true that some of the duties overlap. However, by definition, SDC brokers do not provide clinical support or services. They act as coaches and advisors who demonstrate needed skills, provide encouragement, and guide people to resources. They do not help participants with their clinical needs or emotional crises. They do help participants identify others who will address clinical needs related to their SDC goals and to budget for them accordingly.

This chapter will address the unique role, relationships, and activities of the SDC support broker.

The major sections of this chapter are:

- Brokers are Not Case Managers
- The Role of the Broker
- What It Takes to be a Broker
- Relationships with Participants
- Training for Brokers

Brokers Are Not Case Managers

One primary feature that distinguishes brokers from case managers is that brokers must be free from conflict of interest. This means that they must not represent the interests of a human services agency. This is because they must remain free to recommend services based on participants' needs and not what their agency has to offer. Case managers may find that their duties to their employers (such as promoting the agency's services or being driven by the need for billable hours) sometimes conflict with their duties to clients (such as supporting client choices in services or helping clients find resources outside of public systems). Case managers are faced with the fiscal realities of their agencies that limit client choices to accepting or refusing only what the agency offers or deems as appropriate. Of course, SDC participants may choose to hire case managers to help them navigate the complexities of human services systems, particularly if they wish to access services across the fragmented mental health, substance abuse, vocational rehabilitation, and public health systems. Brokers, on the other hand, help participants to identify what they want to change about their lives, their goals, the services and supports they need to acquire, and how to budget for these resources. Brokers do not help people to directly navigate public systems.

Another distinguishing feature is that participants select a broker rather than being assigned to one. In some programs, participants also pay for a broker's time out of their personal budgets. If a participant is not happy with a broker's approach or services, then the participant may discharge the broker and select a new one. This provides market-driven quality assurance for the program. Brokers who routinely provide mediocre or unsatisfactory help will not be able to maintain a client base, as participants look elsewhere for their brokerage services. This is not how it usually works with case managers. Unless a supervisor documents professional incompetence, the case manager is not likely to be fired or lack clients to serve.







The Role of the Broker

"You can do it. We can help." This is the motto of the home improvement mega-store, Home Depot.TM Their business approach is to build confidence among homeowners to tackle projects and, of course, to return to the store for future purchases. Home Depot provides access to goods and services that its customers want or need for their various projects. The store also provides workshops and demonstrations. Their personnel are knowledgeable and give information and guidance, so that customers can make good choices about their purchases. However, Home Depot does not tell you that you must purchase a particular shrub for your yard, or come to your house to fix a clogged drain. You choose the shrub you want within your budget. You purchase the solvent or equipment to fix a clogged drain. Similarly, support brokers help people to understand what they want to do, identify and obtain the needed resources, and develop skills to apply to their own "projects" (in this case, their goals for recovery).



What do brokers do?

The primary duties of a broker are provision of personal support, information, coaching, and administrative assistance. Brokers typically perform the following tasks.

- Orient participants to SDC
- Assist participants with completing enrollment paperwork
- Take participants through a structured goal-setting process that leads to an SDC plan and accompanying budget
- Meet with participants at least quarterly to monitor progress, update SDC Plans, reconcile purchases, and create budgets
- Ensure that each participant follows the purchasing policy and makes approved use of the debit card
- Arrange for each SDC Plan and budget to be approved according to program policy
- Teach participants how to research and identify services and goods tied to specific recovery goals
- Offer information, education, and skill building
- Help participants to create and access crisis and post-crisis plans as needed
- Co-facilitate monthly Learning Community or other participant meetings to promote learning opportunities and peer support within the SDC program
- Liaison with the program leadership and fiscal intermediary to ensure proper documentation
- Compile outcome or other information required for reporting to the steering committee, funders, auditors, or evaluators
- Participate in regular supervision by the program director, as well as quality assurance and/or fidelity audits



How are Brokers Hired?

Support brokers can be under contract to a managed care organization, a free-standing SDC program, or the fiscal intermediary (FI). If under contract to an organization, brokers would be managed by the SDC program director, using personnel policies and procedures developed by the host organization and the steering committee. The FI may be called upon to help with human resources responsibilities, such as managing payroll, various benefits, and health insurance options. However, if brokers are under contract to the participant, they are typically considered self-employed, and handled like any other independent provider who wishes to join the SDC provider network.

When working as independent contractors, typically the support brokers can receive only limited support from another organization. Specifically, under federal law, independent contractors must provide their own tools or equipment, decide when and where to do their work, and decide how they will do the work. A FI may be called upon by brokers to provide consultation or problemsolving assistance, but staff of the FI cannot provide direct supervision. This is very different from how case managers are hired, resourced, and supervised.

Of course, just because a broker is under contract does not guarantee that participants will engage his/her services. A broker may be chosen by only one participant, by none, or by several. There may be "waiting lists" for brokers with excellent reputations. In programs where the participants pay for brokerage services from their personal budgets, the brokers will need to serve between 40-50 people to earn a livable wage. In programs where the brokerage services are underwritten by a contract or grant, full-time brokers can limit services to 30-35 people each. Either load is generally manageable, since brokers are not providing case management or clinical care.

What it Takes to be a Broker

Your contracting entity will likely have specific qualifications that the brokers will need to meet. Typically, qualifications include the following:

- A Bachelor's degree or, in lieu of a college degree, demonstrated experience working in a self-directed care program
- Three years of professional experience in mental health, counseling, social work, or rehabilitation services

- Experience teaching financial management skills and creation of personal budgets
- In-depth knowledge of community resources and support services
- Demonstrated cultural competency, flexibility, and empathy

Given its focus on community integration, SDC demands that brokers understand the social and economic fabric of their communities. The more brokers are linked into the community, the more effective they will be. Brokers need to know such things as the days and times that the local recreation center offers computer classes or pick-up basketball, what it takes to adopt a service dog, or where to obtain low-cost eyeglasses or affordable tutoring. Of course, it is unrealistic to expect a broker to know about every resource in the community. The point is that familiarity with the human services system alone isn't sufficient for being a skilled broker.

Cultural competency is a critical quality of support brokers. This requires understanding the different worldviews that SDC participants may hold, and the diversity within ethnic or cultural groups. For example, veterans of any ethnicity share a unique set of experiences arising from active military duty. People with lived experience of mental illness or who have survived traumatic experiences may have a different worldview from those who have not. The experiences of war refugees may be hard to imagine by people who feel relatively secure in their communities, but it impacts every aspect of life for those who have fled their homelands.

People with lived experience of mental health difficulties are an obvious choice for the role of broker. They have dealt with their own mental health difficulties and have negotiated the challenging but rewarding process of recovery. This offers advantages in engaging participants, understanding their perspectives, and having insider knowledge of the service system. They also are likely to encourage participation in self-help and peer support, which have been shown to foster self-determination.

Above all, brokers need to be committed to participant choice and self-direction. They must believe in the capacity of each and every participant to find the pathways that will help them to grow, change, and recover.



Characteristics of Successful Brokers

Haines and Spaulding-Givens (2006) present some of the qualities of successful brokers (called recovery coaches) as described by FloridaSDC participants:

- "Compassion, integrity, dependability, and caring!"
- "I think a recovery coach should be personable and empathetic."
- "Available, patient, accessible, open communicator, good listener."
- "Being well-educated (about the program). Willing to teach. Listening well and helping to set goals. Helping you get there by yourself."
- "Honest and friendly, willing to hold participants accountable for their goals and progress in the program. Gives direct and honest feedback. Able to recognize when a person is ill."
- "A good sense of humor helps to make people feel relaxed and comfortable and not so stressed about the process."
- "Compassion, fairness, and understanding. A nonjudgemental approach, laughter and concern when deemed necessary."
- "Privacy between recovery coaches and participants is important."

Do you believe in the potential of the people you will be working with?

Do you have a work ethic that empowers self-confidence and self-determination in yourself and others?

If so, you will be a positive role model for the people you work with.

Nancy Sweatland, a former FloridaSDC participant, offers top ten qualities of effective SDC brokers:

1. Dedicated

Willing to accept and perform tasks professionally, timely, and sensitively.

2. Respectful

Respect is the first step in creating trust; it's a basic human right.

3. Non-judgmental

Accept participants at each level of their recovery process. Their successes or failures don't depend on your opinion of them.

4. Good Humored

You don't have to be a comedian. A smile or laugh is very healing. It helps create a healthy and happy working environment.

5. Flexible

The ability to be creative is enhanced with the freedom to be flexible.

6. Responsible & Accountable

Accountability is more than organizing records and financial bookkeeping. It's about being answerable to the quality of the services you provide. Are you organized and professional? Do you believe in the potential of the people you will be working with? Do you have a work ethic that empowers self-confidence and self-determination in yourself and others? If so, you will be a positive role model for the people you will work with.

7. Team Player

Discover your place on the team. Are you a cheerleader, team player, or coach? Can you accept constructive criticism? Can you agree to disagree?

8. Honest

Simply put, do you say what you mean and mean what you say?

9. Trustworthy

Follow through with commitments in a timely manner and be responsible for keeping your participants informed when you cannot.

10. Good Communicator

You will provide participants with the information they need to make informed decisions in their own best interests. Also, you need to be aware of all types of communication – verbal, written, and especially, body language. Best guideline: always treat participants in the same manner that you want to be treated.



Relationships with Participants

Brokers and participants meet at times and in places they agree upon together. This could be in participants' homes, libraries, public parks, malls, or restaurants. If both parties prefer it, brokers can meet participants at the office of a service provider or the fiscal intermediary.

The nature and intensity of the relationship between brokers and participants will vary from person-to-person, and over time. The broker is a resource and a supportive partner in each participant's personal recovery journey. This means that there will be times when participants need to spend a lot of time with their brokers (usually when first entering the program or during times of rapid change), and other times when they need only minimal contact.

On an interpersonal level, the broker functions as a role model, a coach, a cheerleader, and sometimes a motivator. Many participants have lived through difficult and painful experiences. Along the way, they have received numerous negative messages about their personal worth, capabilities, and potential. Many people come to believe these messages and their confidence erodes. It is easy for them to become overwhelmed, to give up, or to believe they don't deserve SDC. As a coach, the broker's job is to help participants find their personal strength and develop resiliency to overcome negative messages. A broker can help people "re-story" their lives by giving new meaning to old experiences and by discovering their strengths and abilities. Ultimately, the broker can help a person shift from being "mentally ill" to a "person recovering their wellness." But it's the participant's job to make that shift for himself or herself.

While a broker should be friendly and collaborative, the participant - broker relationship is a professional one. Brokers should not develop friendships or intimate relationships with participants as this violates the ethical codes of all professional certification and licensing entities, and is grounds for termination.

Depending on the relationship between brokers and participants, the broker may offer a range of personal supports including:

- Thoughtful listening and validation
- Modeling of social and problem-solving skills
- Encouragement to dream, to take some risks, and to overcome the "you can't" messages

- Helping participant to believe in their own potential and build on their strengths
- Holding out hope, especially when things are very difficult
- Thinking outside the box considering different ways to view situations and resources
- Celebration of success

Training for Brokers

Formal training for brokers needs to include the workings and policies of the SDC program, as well as how recovery principles and values are operationalized within a brokerage. It is strongly recommended that persons with lived experience of mental illness be full partners in delivering training to the SDC brokers. Training topics could include developing a recoveryorientation, motivational interviewing, stages of change, wellness self- management models (such as Wellness Recovery Action PlanningTM), goal planning and budgeting, boundaries and personal ethics, and crisis planning. Ongoing and refresher training should be offered as frequently as possible, but at least biannually. These topics would emerge from the challenges that brokers are experiencing in the field as they support participants in goal attainment and budget management.

As discussed in the next chapter, training also would be tailored to the results of ongoing fidelity audits. If the program and/or brokers are not meeting SDC fidelity standards, ongoing training and supervision would be geared to correcting drifts from fidelity to ensure the highest quality services possible.

Take Home Messages

SDC support brokers serve a unique role in participants' lives. They are a combination of coach and cheerleader, helping people to direct their own decisions, Plans, and budgets. Brokers may work as an employee of an agency or as an independent contractor; each option will differentially affect how they are identified, trained, supervised, and paid. To be most effective, brokers need to acquire a vast knowledge of the options offered within and outside of human service systems.



9 SDC Program Evaluation & Fidelity

Throughout the process of developing your program, you and your stakeholders may wonder whether SDC really helps people to move on with their lives. How will you know one way or the other? Are participants more satisfied with the services they receive through SDC than those they were getting previously? Does participating in SDC help them attain their goals? Can you demonstrate to funders, the public, and others that SDC is not only feasible, but also produces desirable outcomes?

Your ability to answer these questions may determine whether your program flourishes or languishes. Program evaluation provides you with information about where and how to make program improvements and ensure quality for your participants. It also creates an opportunity to contribute to the body of knowledge about SDC. It's best to implement mechanisms for gathering information to address quality and outcomes right from the start. Evaluation does not need to be complicated, but it does need to be implemented in a consistent and meaningful way.

The major sections of the chapter are:

- Why Evaluate your SDC Program?
- Getting Started
- The Value of Fidelity Assessment in Program
- Measuring Outcomes and Impact
- Participant Satisfaction



Why Evaluate your SDC Program?

Day-to-day program operation includes continually assessing how well your program is fulfilling its mission and helping participants to benefit from SDC. This happens when you talk with participants, meet with network providers, participate in steering committee meetings, and supervise brokers. These informal methods of evaluation are critical to monitoring the ongoing health of your program. But, they aren't enough. Your program also should develop a systematic way to collect program evaluation information, in order to improve its effectiveness and maintain high quality services (U.S. DHHS, CDC, 2011).³⁴

In general, your evaluation will address the following types of questions (CDC, 2011):

- Implementation: Was the SDC program implemented as originally intended?
- Effectiveness: Is your program achieving the goals and objectives it was intended to accomplish?
- Efficiency: Are your program's activities occurring through appropriate use of resources such as budget and staff time?
- Cost-Effectiveness: Does the benefit of achieving your program's goals and objectives exceed the cost of producing them?
- Attribution: Can you show that participant progress toward achieving goals is related to your program, as opposed to other things that are going on in their lives?

Addressing these evaluation questions will enable you to document your program's progress, demonstrate accountability to your funders, and identify ways to make your program better. Given its importance in terms of accountability and quality, some suggest that at least 10% of your overall budget should be allocated to your program evaluation (WHO, 1998).





Getting Started Who Conducts the Evaluation?

If your program is small or your resources are limited, you may have to assign the responsibility for conducting program evaluation to people internal to your organization. For example, members of the steering committee might assume responsibility for this task by forming an evaluation subcommittee. If you have greater resources, then it's advisable to convene an evaluation team consisting of internal staff and participants, steering committee members, external stakeholders (including people in mental health recovery), and consultants with evaluation expertise (CDC, 2011).

The goal of this team is to clarify and reach consensus on the following aspects of your evaluation: 1) its purpose; 2) users of the evaluation findings; 3) approach and methods for the evaluation; 4) resources available for it, including money and time; 5) methods for sharing the results to inform program improvements; and 6) ensuring adequate protection for the participants, the program, and the community as data are collected and results are shared.

Describing Your Program

Your evaluators need to have a very clear sense of the purpose and activities of your program. This description goes beyond your mission statement or policies, although these may be used to develop it. Instead, it is meant to clarify all of the components and intended outcomes of your program, in order to focus your evaluation on the most important questions (CDC, 2011). Many federal agencies recommend the use of a "logic model" to describe programs in a way that informs program evaluation.

A good logic model shows the connection between your planned work and your intended results (Kellogg Foundation, 2004).³⁵

Your planned work describes the resources you need to implement your program and what you intend to do. Planned work is divided into two categories:

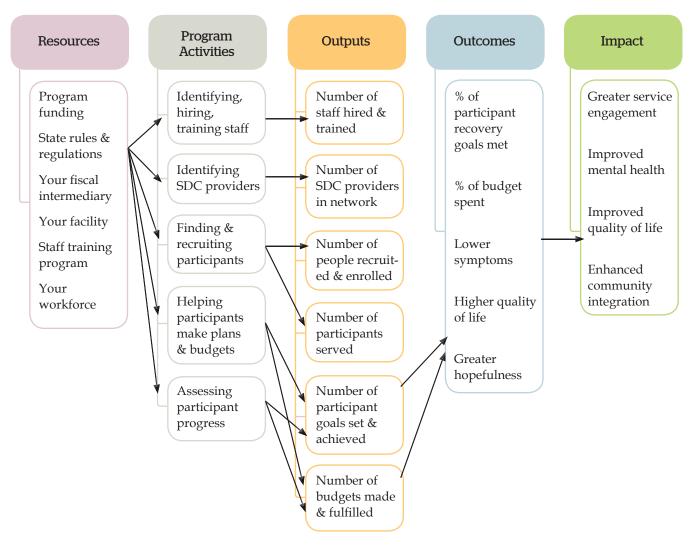
- 1. Resources, which are your program's human, financial, organizational, and community resources. Sometimes this component is referred to as Inputs.
- 2. Program Activities, sometimes referred to as program process, are what your program does with its resources. Activities are the processes, tools, events, technology, and actions that are an intentional part of program implementation. These activities are used to bring about the intended program changes or results.



Your intended results include all of your program's desired results, and are divided into three categories:

- 1. Outputs, which are the direct products of your program activities and may include types, levels, and targets of services to be delivered. Outputs are often confused with outcomes. For example, it may be important to track the number of enrolled participants, the number of hours that brokers spend with participants, or the number of goals that participants achieve as markers of your progress. But, be clear that these are outputs that are intended to lead to results/outcomes, such as participants reporting improved mental or physical health or becoming employed.
- 2. Outcomes are the specific changes in your program participants' behaviors, knowledge, skills, or level of functioning. Short-term outcomes should be attainable within 1 to 3 years, while longer-term outcomes should be achievable within 4 to 6 years.
- 3. Impact is the fundamental change that occurs within organizations, communities, or systems as a result of your program activities within 7 to 10 years.

Example of a Logic Model for SDC





The logic model provides a road map that illustrates the entire sequence of events that powers your program. This includes everything from obtaining resources through intended outcomes and impact (Kellogg Foundation, 2004). Generally, arrows are used to show the progression of program activities through intended results. The exercise of developing a logic model helps you to visualize how the human and financial investments you put into SDC are intended to lead to specific results. The map also can help you see where you might experience barriers or challenges along the way, and how best to resolve them to achieve outcomes and impact.

It is important to be as specific as possible when creating your logic model. The model will provide benchmarks of your progress, and point to what is next for your program. For example, once you have developed job descriptions and job advertisements (Resources) and hired your staff (an Activity), then you have met benchmarks that will help lead to participants creating SDC Plans and budgets (an Output and benchmark). These activities and outputs are intended to result in participants achieving their short-term or long-term recovery goals (An Outcome and benchmark).

Interestingly, some experts suggest that you should use the same SMART goals framework that you encourage SDC participants to use, in order to define your SDC program's outcomes and impacts. This means that for your program, too, intended results should be Specific, Measureable, Action-Oriented, Realistic, and Timed (Kellogg Foundation, 2004).

The Value of Fidelity Assessment in Program Evaluation

One useful strategy for measuring the presence and quality of your Resources, Activities, and Outputs is to institute a biannual or annual fidelity assessment. A fidelity assessment is commonly used in clinical research as a way to ensure that the intervention meets the highest standard of quality as determined in prior research. The assessment tool describes exactly how to measure the Resources, Activities, and Outputs that a program is applying toward its intended results. For example, in SDC, the assessment might specify that the ratio of broker to participants be set at 1:35, that the brokers' demographic characteristics match those of the community being served, or that each broker is trained in motivational interviewing and person-directed goal development. Each of these criteria would be rated on a scale indicating "not met" to "fully met." For criteria that aren't being met, the fidelity assessors would provide

recommendations for how to achieve the standard in time for the next assessment. The notion is that programs strictly adhering to fidelity standards are far more likely to achieve the intended results/outcomes for their clientele than are programs that don't adhere to fidelity standards.

The evaluators associated with the Texas SDC Program have developed a comprehensive SDC Fidelity Assessment tool, which was administered biannually by a team of reviewers.36 We've included the Texas SDC Fidelity Assessment in the Resources Section. Our assessment team included researchers, Texas Department of State Health Services staff, and peers. Components that were assessed for fidelity included: 1) program staffing; 2) organization and management; 3) and services provided. Assessment data were collected via: structured interviews with staff, participants, and SDC network providers; direct observations of supervision, team, and client meetings; and chart and policy documentation reviews. Fidelity reviews were conducted over a 2-3 day period, and results were shared immediately with the SDC program director and staff to inform ongoing program improvements.

Even if your SDC program is not part of a research study as was Texas SDC, you can benefit from conducting regular fidelity audits. These are best conducted by someone external to your program to avoid bias, if possible. Short of that, the Steering Committee or other external stakeholders can be tapped to complete the audit.

Measuring Outcomes and Impact

Both quantitative and qualitative methods can be used to evaluate how well your SDC program was implemented, and the impact of your program on participants' knowledge, attitudes, and behaviors. Detailed surveys or structured interviews can be used to collect quantitative data on whether and how participants' well-being, health, and lives have improved. Typically, these assessments would be administered at the time a participant starts SDC, and then, periodically throughout his/her tenure. Changes in outcomes would be tracked over time to determine whether and how participants are improving. Quantitative assessments can also include data on the number of participants who avoided the emergency department or hospital, experienced an improvement in mental or physical health (reporting fewer symptoms, improved blood panel results, or weight loss), obtained and maintained a competitive job, successfully completed college or vocational classes, obtained relevant certification to support employment goals, and so forth.



Qualitative methods also can be used to gather information on your program's intended results. Focus groups, participatory dialogues, empowerment photography, and open-ended interviews all are methods to help you gain insights into the strengths and weaknesses of your program in the participants' own words (CDC, 2011).

When designing your program evaluation, it is important to consider the confidentially and anonymity of your program participants. They must have a choice about whether to participate in evaluation activities. Additionally, if data regarding their progress will be used in an evaluation, even anonymously, they should be informed of this fact and provide written consent when they enter the program, by signing a consent form.

Participant Satisfaction

Assessment of participant satisfaction is a critical aspect of program evaluation.³⁷ You want to regularly obtain participants' feedback on what they experienced in the public mental health system before SDC, what they currently experience in SDC and its quality (including staffing, services, supports), and their perceptions of whether the processes for budgeting and purchasing are well-executed and fair. We've included the satisfaction survey used in the Texas SDC Program (Texas SDC Participant Satisfaction Survey) in the Resources section.

- Satisfaction with the Purchasing Policy and procedures
- Satisfaction with the quality and integrity of the providers in the SDC network
- Satisfaction with the quality and integrity of the fiscal intermediary (assuming they have contact with the FI)



- What they like and don't like about the program
- Unmet needs
- Overall feelings of hope, empowerment, and recovery

SDC staff and leadership also can be surveyed about their experiences in working with participants, SDC providers, and the FI.

SDC participants should be informed upon entry into the program that they will be periodically surveyed, and encouraged to respond in order to help develop the program. It is important for people in mental health recovery to be hired to conduct the satisfaction surveys whenever possible. People are more likely to share honest appraisals with their peers than they are with non-peers.

Take Home Messages

Program evaluation is a critical component of your overall success. While evaluation takes time and resources, it is important to institute systematic and ongoing strategies to measure whether your intended approach (Resources and Activities) is leading to your intended results (Outputs, Outcomes, and Impacts). Creating a logic model and administering fidelity assessments can help you to measure your intended approach. Quantitative and qualitative interviews can help you to measure your intended results. Participants also should be regularly surveyed about their satisfaction with the program to inform your quality assurance efforts.



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End Notes

- 1. Web search terms: Magellan, Pennsylvania SDC
- 2. Web search terms: SAMHSA Store, Resources
- 3. Web search terms: UIC NRTC Self-determination
- 4. For more self-determination theory and research, see the articles by Deci, Williams, and Ryan in the Resources section of this manual.
- 5. For more information on the Robert Wood Johnson Self-Determination program and its evaluation studies, search those keywords at: http://www.rwjf.org/ en.html. Also see Nerney & Shumway, 1996 in the References section.
- 6. Web search terms: National Resource Center for Participant-Directed Services
- 7. See for example, training materials on board/ committee participation available from the Community Tool Box at http://ctb.ku.edu/ (search "board of directors"). Many local United Way agencies and other groups offer new board member training as well.
- 8. Or go to http://www.flsenate.gov and under "Find Statues" search for "self directed care" for 2016.
- 9. See the Resources section of this manual for online resources and classes about preparing a successful grant application. Doing your own Internet search with the key words "grant writing" will yield additional options.
- 10. You can find many resources on conflict resolution, negotiation, and mediation on the Internet or at a local library. Another helpful resource is, "Managing workplace conflict: A skills training workbook for mental health consumers and supervisors," by S. Shore & L. Curtis, available from the National Research and Training Center on Psychiatric Disability, University of Illinois at Chicago: http://www.psych.uic.edu/ mhsrp/publications.htm.
- 11. Susan Stefan's full report on competency and capacity, "The Application of the Concepts of Patient Centered Care and Self-Directed Care to Individuals with Psychiatric Disabilities: Legal, Policy and Programmatic Considerations" (2006) is available at: http://papers.srn.com/sol3/papers.cfm?abstract_ id=936407.

- Establishing a 501(c)3 non-profit can be an involved process, but help is available from federal and local organizations that provide information and technical assistance, especially during the start-up phase. The Resources section of this manual provides two online resources to get you started.
- 13. You can also go to http://irs.gov and search for "Independent contractor self-employed" in the main search bar.
- 14. For sample SDC web sites, see http://www.texassdc. org/ and http://www.floridasdc4.com/home.htm.
- 15. For one example, see this web site from a Fiscal Intermediary in Massachusetts, which includes information about FI services, sample forms, time sheets, and frequently asked questions: http://www.stavrosfi.org/English-Index.html.
- 16. See the FloridaSDC Circuit 20 Program web site for a description of how the National Alliance on Mental Illness of Collier County serves as their fiscal intermediary: http://www.flsdc.org/.
- 17. See the Resources section for the FloridaSDC Code of Ethics for providers.
- For the Texas SDC provider enrollment paperwork, visit: http://www.texassdc.org/_forms/TXSDC. ProviderEnrollment.pdf.
- 19. Visit the Texas Self-Directed Care web site for a sample SDC Provider Directory: http://www.texass-dc.org/pages/ProviderNetwork.asp.
- 20. See the Texas SDC web site for success stories: http://www.texassdc.org/.
- 21. Web search terms: Stages of Change Model, James Prochaska.
- 22. Web search terms: UIC, "This is Your Life"
- 23. See the Resources section of the manual for sample Life Plans from different SDC programs.
- 24. Personal communication (2015) with Erme Maule, Program Director.
- 25. See the "Your SMART Goals Worksheet" in the Resources section of the manual.



26. To learn more about motivational interviewing, visit http://legacy.nreppadmin.net/ViewIntervention. aspx?id=346 Or at http://nrepp.samhsa.gov click "Find an Inter-

or at http://nrepp.samhsa.gov click "Find an Intervention" and search for "motivational interviewing"

27. A presentation by Moseley et al from 2011 can be found at http://www.integration.samhsa.gov/images/res/Motivational%20Interviewing%20Sangre%20 de%20Cristo%20Presentation%20for%20CIHS_FI-NAL_Final.pdf Or web search "motivational interviewing for better

Or web search "motivational interviewing for better health outcomes SAMHSA"

- 28. See the Resources section of this manual for a copy of the TX SDC Recovery Plan and Budget.
- 29. See the Resources section of this manual for sample Quarterly Review forms.
- 30. Mary Ellen Copeland's My WRAP Crisis Plan and Post-Crisis Plan forms may be downloaded at no cost from www.mentalhealthrecovery.com.
- 31. An overview of psychiatric advance directives and a PAD template can be downloaded from the Bazelon Center by visiting: http://www.bazelon.org/ Where-We-Stand/Self-Determination/Advance-Directives.aspx.

- 32. See the Resources section of the manual for sample personal budgeting forms.
- 33. See the Resources section of the manual for an example agreement that participants sign prior to receiving a debit card from the program.
- 34. The CDC's report "Introduction to Program Evaluation for Public Health Programs: A Self-Study Guide" can be found at https://www.cdc.gov/eval/guide/ dex.htm
- 35. The Kellogg report on logic models can be found here: https://www.epa.gov/evaluate/wk-kellogg-foundation-logic-model-development-guide Web search terms: Kellogg Logic Model Development Guide, EPA
- 36. See the Resources section of the manual for a complete copy of the TX SDC Fidelity Assessment tool.
- 37. See the Resources section of this manual for a sample SDC Satisfaction Survey.



Resources

Websites current as of June 2017.

Research on Self-Determination Theory

Deci, E.L., Ryan, R.M. (1985). Intrinsic motivation and self-determination in human behavior. New York, NY: Plenum.

Ryan, R.M., Deci, E.L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. American Psychologist, 55, 68-78.

Williams G.C., Deci, E.L. (1996). The National Cancer Institute Guidelines for Smoking Cessation: do they motivate quitting? Journal of General Internal Medicine, 11(Suppl. 1), 138.

Williams, G.C., Freedman, Z.R., Deci, E.L. (1998). Supporting autonomy to motivate glucose control in patients with diabetes. Diabetes Care, 21, 1644-1651.

Williams, G.C., Grow, V.M., Freedman, Z.R., Ryan, R.M., Deci, E.L. (1996). Motivational predictors of weight loss and weight-loss maintenance. Journal of Personality & Social Psychology, 70, 115-126.

Williams, G.C., Rodin, G.C., Ryan, R.M., Grolnick, W.S., Deci, E.L. (1998). Autonomous regulation and adherence to long-term medical regimens in adult outpatients. Health Psychology, 17, 269-276.

The Cash and Counseling Demonstration Program, 1996-2005

Information regarding the purpose, procedures, and outcomes of the Cash and Counseling Demonstration Program may be found on the web site of the National Resource Center for Participant-Directed Services.

http://www.bc.edu/schools/gssw/nrcpds/cash_and_ counseling.html/

Information regarding the Cash and Counseling (C&C) Demonstration Program evaluation studies may be found on Mathematica Policy Research's web site. This evaluation assessed the effects of the C&C program on recipients, paid and unpaid caregivers, and costs to Medicaid and Medicare.

http://www.mathematica-mpr.com/our-publications-and-findings/projects/evaluation-of-three-cash-and-counseling-programs

Tips for Writing Grant Proposals

Grant Space provides a number of online courses about writing different kinds of proposals, including those to foundations and the federal government: http://grantspace.org/training

Non-Profit Guides provides an overview of available grant opportunities, contract grant writers to assist you in developing a proposal, and sample grant proposals: http://www.npguides.org/

The National Network of Libraries of Medicine provides an online course on grant writing. Sessions include: documenting the need; identifying the target population; writing measurable objectives; and developing a work plan, an evaluation plan, and a dissemination plan. http://nnlm.gov/class/grants-and-proposal-writing/

Obtaining 501(c)3 non-profit status

The Foundation Group provides free information on how to obtain 501(c)3 status:

http://www.501c3.org/how-to-start-a-501c3-nonprofit/

Charity Net USA also provides free information on steps for becoming a non-profit entity:

http://www.charitynetusa.com/resources/free-startup-guide/

2013 Florida Statutes									
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Job Description for Program Director of the Texas Self-Directed Care Program

Title:

TX SDC Program Director

Supervisor:

(Name designated supervisor)

General Position Description:

The Program Director is responsible for the helping to implement and oversee the Texas Self-Directed Care (TX SDC) program for people with serious mental illnesses in Dallas, Texas. The person acts under the supervision of (name designated supervisor).

Qualifications:

Minimum four-year degree (masters degree preferred) from an accredited college or university and five years of full-time employment in the social service field, at least two of which were related to mental health services and two of which were as a program manager. Car preferred for job-related travel. Must be available on some evenings and weekends to attend meetings/events. One year of experience with a brokerage or self-directed care program is preferred. Must demonstrate excellent written communication skills, advanced computer skills (particularly with spreadsheets), outstanding organizational skills, ability to work independently and in a team, exceptional ability to supervise, motivate, and inspire staff, knowledge of a wide array of social, medical, psychiatric, and commercial services available in the Dallas area, and understanding of contemporary managerial practices.

Salary Range:

Commensurate with Program Director positions in Dallas-area SPNs.

Job Duties:

Help to develop the policies and procedures for the TX SDC program, including the program's policies, forms, personnel handbook, and other processes used to develop and administer the program. Development will occur under the direction of the position's supervisor and in conjunction with other program stakeholders.

Responsible for maintaining proper files, records, and documentation about the program, program staff, and the participants in accordance with state and federal policies. In conjunction with supervisor, responsible for ensuring program compliance with all grant, contract, and state/federal requirements, mandates, and laws.

Help to develop the Provider Network. Conduct quarterly and annual assessments of the Provider Network to ensure quality and ongoing commitment to the TX SDC program and its participants.



Job Description for Program Director of the Texas Self-Directed Care Program (continued)

Oversee the management of program funds according to the approved budget. Approve Support Brokers' requests for leave and time sheets, as well as oversee operational resources and expenses. Liaison with the Fiscal Intermediary as pertains to budgetary and administrative matters, under the direction of supervisor.

Interview, hire, supervise, and evaluate the program's Support Brokers.

Assign SDC participants to the Support Brokers for assessment and ongoing services/supports.

Review and approve (or request modifications to) the recovery plan and independent budget for each participant in accordance with program, grant, and state/federal regulations. Review participants' subsequent expenses/vouchers to ensure that they reflect the recovery plan. Approve or deny purchases accordingly.

Conduct quarterly meetings with a random selection of participants for quality assurance purposes (assess satisfaction; discuss progress on goals; etc.). Work with Support Brokers as needed to creatively identify services/products that meet participants' goals but are traditionally difficult to access.

Monitor the care and support of each participant through weekly supervision of the Support Brokers, and review of Support Brokers' progress notes and documentation. Report findings to supervisor on a weekly basis.

Attend and/or lead team, managerial, and other meetings as indicated to develop and maintain the SDC program.

Provide or arrange for ongoing training personally and for the Support Brokers.

Liaison with advisory committee, state funders, providers, consumer groups, the external evaluators, and other project stakeholders. Ensure that all reports to the supervisor, the advisory committee, state funders, the external evaluators, and other project stakeholders are completed and submitted in a timely fashion.

Provide informational presentations about the TX SDC program to providers, state officials, and other constituents.

Perform other duties related to the administration of the TX SDC program as assigned by the supervisor.



Job Description for SDC Support Broker for SDC Research Study

Supervision:

The person works under the supervision of TX SDC, Value Options, and UIC.

General position description:

The support broker manages mental health and claims data to foster service coordination for adults with serious mental illnesses. This involves helping participants to create and manage self-directed recovery plans, goal statements, and individual budgets. In coordinating care, the broker applies knowledge of a wide array of psychiatric, rehabilitation, and health promotion services in the Dallas area. The broker is independent from any person or organization providing services/supports/products to participants within the SDC Program's Provider Network.

Qualifications:

REQUIRED: 3-5 years of experience in the social service field, with an emphasis on managing mental health data for service coordination. Must demonstrate competency with Microsoft Excel and Access, ability to work with mental health claims data, and skills in preparing and managing budgets with service recipients. Applicant must have excellent ability to interact with adults with mental illnesses, and knowledge of a wide array of services in the Dallas area, including, psychiatric, rehabilitation, recovery, and health promotion services. Applicant must be culturally competent. Research experience preferred. Personal qualities desired include compassion, a sense of humor, good listening skills, and the ability to accept supervision and demonstrate flexibility and creativity in dealing with challenging situations. Reliable car required for job-related travel.

PREFERRED: BA required; advance degree preferred. Bi-lingual English/Spanish. One year experience with a self-determination program. A self-identified consumer of mental health services.

Salary:

Commensurate with experience.

Job duties:

The broker is responsible for recruiting, consenting, and enrolling adults with mental illnesses into the research study. This requires participating in specified training and being certified to protect human subjects in research. The broker also participates in other required initial and continuing education.

The broker orients people to the program and completes initial program paperwork. The broker helps participants to complete their self-directed recovery plan, goal statement, and individual budget, starting with a review of their past 24 months of service utilization and spending. The broker helps participants to complete a Crisis Plan to address afterhour emergencies.



Job Description for SDC Support Broker for SDC Research Study (continued)

Once the recovery plan, goal statement, and budget are approved, the broker helps participants to meet their personal goals by identifying and linking them to natural, community, and multi-system services and supports. The broker helps participants evaluate the quality of services/supports/products they receive from providers in the network. The broker helps participants to secure and to discharge providers as needed.

The broker is well informed about the SDC Program's purchasing policy. The broker is responsible for collecting, verifying, and monitoring participants' purchases/receipts. The broker assists the participants with billing and other purchasing paperwork.

The broker is responsible for the required monthly meetings with participants (although some people may need to meet more frequently, especially initially). At these meetings, the broker reviews and updates goal statements and individual budgets with participants as required. Once each quarter, the broker helps participants to complete their Progress Reports.

The broker is responsible for maintaining proper files, records, and documentation about the program and the participants in accordance with state and federal policies. The broker completes and submits all reports and paperwork in a timely fashion. The broker accepts and responds to supervision regarding program management and research responsibilities. The broker attends team and other meetings to maintain the SDC program.

The broker works with his/her supervisor and UIC to ensure that the SDC program maintains a high level of fidelity to the SDC model, as defined by the project's fidelity scale in accordance with Centers for Medicare and Medicaid Services (CMS). The broker provides all information needed to rate program fidelity to evaluators on an ongoing basis. S/he engages in any corrective actions needed to enhance fidelity to the model.

The broker performs other job duties as assigned by the supervisors.

Due to federal funding limitations, this job may not last more than 2 years.

(Signatures of acknowledgement by supervisor and employee needed)

Code of Ethics



The FloridaSDC Program addresses the rights of individuals to participate in a recovery-based model, which emphasizes an individual's strengths and assets. Recovery can be defined as a process in which the individual makes personal decisions about lifestyle and future direction. Individuals we serve are held responsible for their actions and selections, are given the opportunity to participate in society in a meaningful way and are given the opportunity and tools to develop natural and community supports to assist them in their Life Action Plans should they choose this information. The individual is viewed in a holistic fashion with the emphasis on their current and future strengths, dreams and the restoration of their self-esteem through achieving their personal outcomes. Providers interested in participating in this program have a belief that individuals with mental illnesses are capable of recovery and grow, learn and change.

Adherence to your professional code(s) of ethics, as well as this Code is important to the success of the program. Violation of this Code may be grounds for dismissal from the FloridaSDC Provider Network. This code stands in accordance with the values and vision of the FloridaSDC program.

Although the code of ethics for the FloridaSDC Program outlines many minimum standards for behavior it should not be used as a substitute for not making other ethical decisions when working with individuals. If any question arises as to how to handle an ethical dilemma, you should consult with your supervisor or refer to Florida statute or your professional code.

Criminal behavior will not be tolerated and will be reported to the appropriate agencies and law officials.

FloridaSDC Specific Ethical Guidelines

1. FloridaSDC Provider Network members shall promote individual recovery as defined by the participant to the fullest extent.

<u>Recovery</u>: In its simplest form recovery can be defined as improving, mending, healing and renewal. A more practical definition is told better by individuals who have participated in recovery from mental illnesses such as the following:

"Broadly defined, recovery is the ability to live well irrespective of an individual's experience of mental illness. It means that people are able to minimize or eradicate the distressing symptoms associated with mental illnesses, to make personal decisions about lifestyle and future direction, to find personal meaning in activities of daily living, in relationships, and in spiritual expression....It is about rekindling hope and realizing dreams. It means achieving personal outcomes."

Recovery is about developing individual's strengths and assets and giving individual's the room, support and confidence to do so in the process.

2. FloridaSDC Provider Network members shall promote individual selection of providers and services as identified by the participant to the fullest extent.

Selection: Selection is the ability to choose alternatives, to have a say in selection, and to have options. Selection does not mean that one can have anything they want, but allows one at least two options to choose from which makes one feel more in control and more invested in attaining self determined goals.

3. FloridaSDC Provider Network members shall encourage participant responsibility for meeting personally identified goals and objectives to the fullest extent.

<u>Responsibility</u>: Responsibility is taking accountability for one's actions. In order to have responsibility one must be treated as if they can be responsible.

Responsibility involves accepting that one makes good and sometimes not so good selections. Taking responsibility for mistake does not make one a failure but a true learner. Likewise, taking responsibility for triumphs and other accomplishments serves as positive support especially when shared with others. Learning from anything often requires non-judgmental and honest feedback from others combined with thinking of options for the next time.

4. FloridaSDC Provider Network members shall encourage participant accountability for meeting personally identified goals and objectives to the fullest extent.

<u>Accountability</u>: Accountability is much like responsibility in that one understands they are accountable for the selections they make and for not making selections. Accountable adults accept they are human but do not make excuses when they know they have done something wrong. Accountable adults understand the difference between having limits due to having a diagnosed, serious mental illness symptoms and blaming things they can control and improve upon due to their illness. Recovery is about looking at the holistic picture and especially on focusing on strengths that individuals have as opposed to limits they cannot control.

5. FloridaSDC Provider Network members shall encourage participant control in meeting personally identified goals and objectives to the fullest extent.

Control: Control for our purposes is about helping individuals identify the things they can control, i. e., their goals, hopes and dreams, and things they have no control over, i.e., how other people act or think. Control in recovery is about developing and accomplishing goals which will help one feel more in control while knowing we cannot control everything and really no one but ourselves.

6. FloridaSDC Provider Network members shall encourage and respect participant self-determination for meeting personally identified goals and objectives to the fullest extent.

Self-Determination: Self-determination stems from the ability to think one has control, accountability, selections and responsibility. Self-determination and free will comes from the feelings and practices that one can succeed despite all odds. The more chances a individual is given to succeed through a focus on their strengths and positive feedback about their accomplishments, no matter how small to someone else, the more likely they will develop self-determination.

7. FloridaSDC Provider Network members shall respect and encourage participant self-direction in identifying, setting, and meeting personally identified goals and objectives to the fullest extent. FloridaSDC Provider Network members shall NOT impose objectives, goals, services, providers, or anything else on participants, regardless of the intent behind the imposition.

<u>Self-Directed</u>: Self-directed is a concept in the recovery process which treats individual's as capable of making and determining their purposes and goals. Self-direction is encouraged and supported by people whom work with individuals. Individuals are engaged in discussions regarding their capabilities and strengths therefore helping the individual see hope and possibilities. Individual's can gain a sense of independence by determining their life's direction.

FloridaSDC General Ethical Guidelines

- 1. FloridaSDC Provider Network Members shall represent themselves accurately and fully and not engage in misrepresentation of their position or organization.
- 2. FloridaSDC Provider Network Members shall not disclose information about any individuals they serve to anyone except while under supervision, or in the case of an emergency without the written consent of that individual.
- 3. All records concerning FloridaSDC members shall be stored in a secure, locked area, out of view of others.
- 4. All information pertaining to FloridaSDC member shall be properly disposed of in order to protect confidentiality.

- 5. FloridaSDC Provider Network Members shall use clear language when discussing services and billing with program members.
- 6. FloridaSDC Provider Network Members respect and promote each person's independence and decision-making abilities and discourage making decisions for them.
- 7. FloridaSDC Provider Network Members shall engage natural support and community based services to the greatest extent possible and brainstorm creative solutions to meeting goals and overcoming barriers with participants.
- 8. FloridaSDC Provider Network Members shall provide services within the boundaries of their education, and training. Nonprofessional providers should provide only services for which they have been approved.
- 9. FloridaSDC Provider Network Members shall not engage in any unwanted physical contact with members of the program.
- 10. There shall be no sexual contact between providers and professional network members. Any unwanted sexual contact will be grounds for immediate termination as a provider.
- 11. FloridaSDC Provider Network Members shall not sexually harass others. Sexual harassment includes sexual advances, sexual solicitation, requests for sexual favors, and other verbal or physical conduct of a sexual nature.
- 12. FloridaSDC Provider Network Members shall not communicate with others in a way which is disrespectful, offensive or threatening to others.
- 13. FloridaSDC Provider Network Members shall maintain records which are accurate and describe services performed or observations made. Records should be written in black ball point pen ink.
- 14. FloridaSDC Professional Provider Network Members shall not accept gift, goods, or services from participants under any condition.
- 15. FloridaSDC Provider Network Members and individuals seeking services shall not exchange money, gifts, goods, or services. Funds owed to providers are dispensed through the ASO to avoid conflict of interests.
- 16. FloridaSDC Providers shall bill the program members in a timely manner (within 30 days of services rendered).
- 17. FloridaSDC Provider Network Members shall attempt to resolve disputes in a professional manner with other colleagues, providers or staff members. FloridaSDC Provider Network Members shall not resolve disputes in front of members or attempt to gain favor by discussing disputes with participants.
- 18. FloridaSDC Provider Network Members shall discuss with colleagues their concerns when they have reasonable suspicions that such colleague may have a condition or concern which is interfering with their ability to behave in a professional manner
- 19. No FloridaSDC Provider shall use any type of substance, illegal or otherwise that will impair his/her ability on the job or place a program member in potential harm.
- 20. All program participants shall be able to return to previous providers if available or be returned to services which are satisfactory to the participant wishing to terminate services. Recovery Coaches will help to provide a smooth transition to prior services for participants.



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NOTES:

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Welcome to the Texas SDC Program. We ask all new participants to show their commitment to the program by reading and signing the following information.

1. I agree to participate in the Texas SDC Program.

2. I understand that by signing this document I have agreed to acknowledge the strengths and frustrations of being diagnosed with ________. I also agree to lead the process that will help me manage my mental health and reach my life goals.

3. I will have 60 days to develop a Life Analysis with assistance from Texas SDC Program staff (called SDC Advisors).

4. My Life Analysis will be discussed with me when I enter the program.

5. I agree to use my Personal Crisis Planning process if I start to experience problems or symptoms that stop me from reaching my goals.

6. I understand that I may withdraw from the Texas SDC Program at any time. I will let the Texas SDC Program Director <u>and</u> the researchers at UIC know that I wish to withdraw within 3 days of my decision.

By signing below, I agree that I have read and understand the above statements. I also agree that I am able to direct my own recovery (as I define it) and the attainment of my personal goals.

Signature

Date

Name Printed

Witness Signature

Date

Name Printed



Statement of Participant Rights

As a customer of Texas SDC Program, you are entitled to your rights as an individual and as a customer. The Texas SDC Program will work with you to make sure you get the information and services that you want. If you ever have any questions, or feel you are not satisfied with our services, please let us know.

As a Texas SDC Program customer, you have these rights:

The right to be treated with respect

You have the right to be treated fairly and kindly.

The right of freedom of choice

As a customer and as an individual, you decide how to manage your life.

The right to be protected from abuse

Every individual has the right to be treated with respect and to be free from personal or financial abuse.

The right to select qualified providers

You have the right to choose the providers you work with. Whether it is an agency or an Independent provider, you can choose the person who you feel would provide the best service for you. This provider must:

- Be old enough to work (18 and over)
- Be allowed to work in the United States
- Not live in the same household
- Have a license if needed
- Be able to pass a criminal history check
- Be able to effectively help you get the services you want
- Have a license to do the job if working through an agency

The right to direct the services you receive:

You have the right to direct your own life. When developing your Person-Centered-Plan, you choose which services would be helpful to you. Your Resource Broker will empower you to:

- Decide which services will most benefit you
- Find the providers that you want to work with
- Find activities you choose to be involved with
- Budget your brokerage funds

The right to withdraw from services

If you are not interested in participating in this project you can exit services at any time.

The Texas SDC Program's Individual Rights and Responsibilities Policy have been explained to me in my primary language, or I have read the policy. Any questions I have regarding the policy have been answered. If I have any questions in the future, my Self directed Care (SDC) Advisor has offered to answer any questions I may have.

I understand that Texas SDC Program's Standard Operating Policy and Procedures for Rights of Individuals in Service is available to me if needed.

Name of Participant	Name	of P	artici	ipant
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Date

Signature of Participant Date

Signature of Guardian (if applicable) Date

Signature of Witness

Date

Rights sign off sheet



What is a Self-Directed Life Plan?

A Life Plan is basically just that – a Plan for what you would like to do in your life. It helps you look at areas where things are going well and other areas where you want to make some changes by setting new goals. Some of these areas are:

- where you live,
- who you spend time with,
- how you spend your time,
- where you get services and supports for your needs or problems, and
- where you work or go to school.

It may seem too hard to think about all of these things at once. Most people pick one or two areas to work on at a time. This will increase your chances of success.

It also helps to remember that most people, with and without mental health challenges, reach goals every day. Think about it like this. Most days, you probably do a lot of things like shower, eat breakfast, read the paper, go to work/school/a program, watch a favorite TV show, and so on. We don't usually think about these things as <u>goals</u>, but they can be. So, you already have a history of achieving goals! Remember most people's Life Plans are built on small goals to reach a larger goal.



Making Your Self-Directed Life Plan

There are many ways to go about making a Life Plan, but we have found that having some steps to follow makes it easier to manage. Steps that others have found useful are:

Step One:	Maintaining the Goals You've Already Achieved
Step Two:	Where Am I in the Change Process?
Step Three:	Getting Ready to Make and Use a Life Plan
Step Four:	Creating your Circle of Support
Step Five:	Considering Change and Choosing a Life Goal
Step Six:	Planning for a New Goal or Life Change
Step Seven:	Acting on a New Goal or Life Change
Step Eight:	Maintaining Success
Step Nine:	A Look to the Future

Each of these steps helps you to make a Self-Directed Life Plan.



Step 1: Where Am I in the Change Process?

For your life change, you may want to make a friend, get better control of your mental health problems, lose or gain weight, get a job or earn some money, go to school, take up a hobby, or do something else. Whatever change you are hoping to make, you will go through a process to get to your ultimate goal. For most of us, this process involves moving from being unaware or uninterested in the need for change, to considering the pros and cons of change, to making actual plans for change, to acting on and maintaining change over time.

Uninterested in Change Considering Change Planning Change Acting On & Maintaining Change

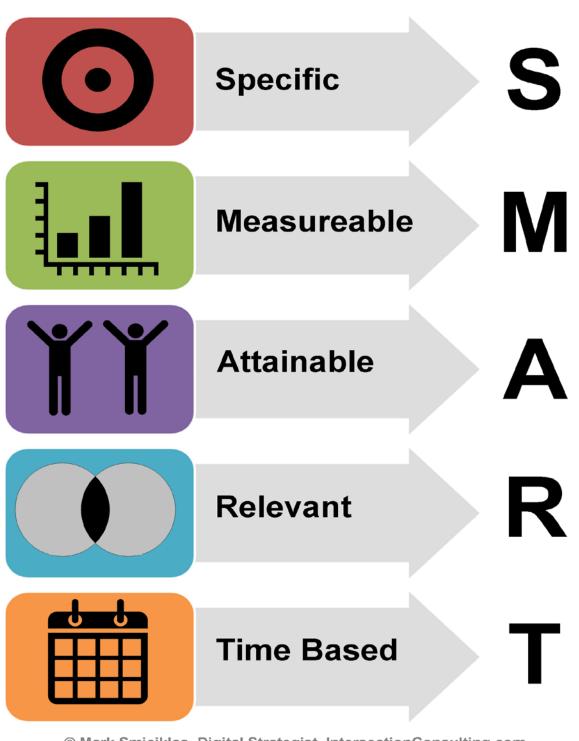
James Prochaska and his colleagues call this idea the "Stages of Change Model." This model has been used to understand how life change works in many different areas, like substance abuse, smoking, or dieting for health reasons. The basic idea is that when we are faced with changing our lives in some way, we need to first figure out the stage of change we are in. This will help us decide whether we're ready to make change, and what we need to do to succeed, if we *are* ready.

To help you figure out what stage of change you are in, ask yourself these questions:

- 1. Do you feel that you would like to change something in your life, to make it better, happier, or easier? Yes No Don't Know
- 2. Have you been thinking lately about a **specific** thing in your life you either don't like or would like to change? Yes No Don't Know
- 3. Do you intend to start planning **within the next few weeks** exactly what you need to do to make a life change (it doesn't matter right now what the change is)?
 - Yes No Don't Know
- 4. Have you **already started** to make changes in your life to make it better, happier, or easier? Yes No



What is a SMART goal?

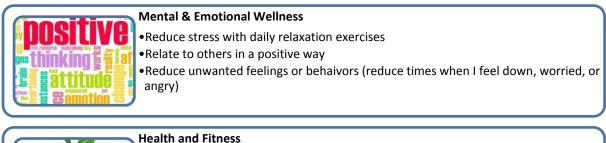


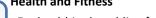
© Mark Smiciklas, Digital Strategist, IntersectionConsulting.com "Bar Graph" icon by Scott Lewis, from the NounProject.com collection "Calendar", "People" and "Target" icons from the NounProject.com collection



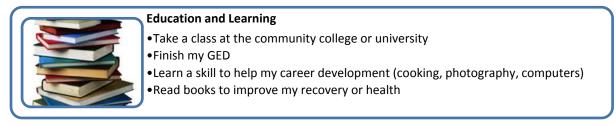
What's My Goal?

Here are some goals to help you think about your own recovery and life goals.





- •Eat healthier by adding fruits and vegetables to my diet
- Increase physical activity by walking each day
- •Reduce cigarettes to a certain number each day or quit altogether
- •Engage in diabetes self-management with regular A1c checks and diet





- •Learn new job searching or interviewing skills
- •Get a job

time

rkers

- Raise my salary or get a promotion
- •Change my job or job goals



company job

cornoration

Relationship and Social Network

- Make a new friend
- Use online chat groups
- •Be in an intimate relationship
- •Improve my parenting skills by spending more positive time with my kids



Financial Wellness

- •Learn to stick to a budget
- •Find affordable resources to support my recovery and health
- •Get out of debt
- •Save \$X each month or quarter to save towards a larger life goal

Content adapted from: http://www.smart-goals-guide.com/Example_Of_Goals.html. Images courtesy of Google Images.



Your SMART Goal Worksheet

Name:

Date:

1. Here's my **SPECIFIC** GOAL. This is what I'm changing or adding to my life.

2. Here's the main way to **MEASURE** this goal. This is how I'll know I've met it. Write exactly how you'll know when you've met your goal. How will others know it, too?

I'll know I've met my goal when....

3. This goal is **RELEVANT** and matters to me.

On a scale of 1 to 10, how important is this goal to you? If you can't say 7 or higher, think about choosing a different goal.

Once at 7 or above in importance, write the benefits this goal has for you. How will it improve your life or mental wellness?

4. This goal is realistic for me. Is it **ATTAINABLE**.

Think about your current health, feelings, living situation, and skills. On a scale of 1 to 10, how confident are you that you can reach it? If you say 6 or below, try changing your goal until you can say 7-10.

If you need to change it, what is your new SPECIFIC goal? Be sure it matters to you personally.

5. By when will you finish this goal? Setting a **DATE** is important, so you can monitor your progress.

6. To finish, go through the S.M.A.R.T goal checklist:

- a. Is the goal RELEVANT for you? Is it important to you?
- b. Is it ATTAINABLE? Are you confident it's within your control and skills to achieve it?
- c. Is it MEASUREABLE? How will you (and others) know when you've met it?
- d. Is it TIME-BASED? Have you said exactly by when you'll meet your goal?

You must answer "yes" to all of these questions. Go back and work on questions 2-5, if needed.

Congratulations! - You have set a SMART GOAL!

Content from: www.Smart-Goals-Guide.com and Suzanne Mitchell, MD, MS: http://www.medscape.org/viewarticle/757625



10 Common Mistakes in Setting and Reaching Self-Directed Goals

People often make goals that they can't achieve. This is common. Goal setting is a skill that few of us are taught. Here are 10 common goal-setting mistakes that we'll help you avoid.

- 1. Thinking goals are something you only do once a year, like at the New Year.
- 2. Not taking the time to think about what you really want.
- 3. Setting a goal you can never achieve, leading you to believe that you're not good at achieving goals.
- 4. Setting a goal that is too big or too general. Not breaking it down into smaller more manageable steps.
- 5. Setting a goal that can't be achieved in a specific amount of time.
- 6. Setting a goal that's too difficult given your current circumstances, skills, or needs.
- 7. Setting a "should" goal instead of a "want" goal.
- 8. Having too many goals.
- 9. Not having a written plan to reach your goal.
- 10. Not thinking about or finding the resources you need to achieve your goal. Not knowing where to look or who can help.



SDC Recovery Plan and Budget

Participant Name	Goal #	Date Added to Plan	Date Removed from Plan
Recovery Goal			

Resource or Purchase	Purchase Start & End Dates	Cost Per Unit or Item	Total # Units	Total Cost	Date Added to Budget	Date Approved
		\$		\$		
		\$		\$		
		\$		\$		
		\$		\$		
		\$		\$		
		\$		\$		
		\$		\$		
		\$		\$		
		\$		\$		
	Total Amoun	t Spent on t	his Goal	\$		

Participant Signature	Date
SDC Advisor Signature	Date
SDC Program Director Signature	Date



PERSON CENTERED PLAN AND BUDGET

Name:	Address, phone number, email address:	TX SDC ID:	NORTHSTAR ID:	DATE:
	recovery, think about your major life goals. So job, going to school, being physically fit, makin			CIRCLE ONE:
good relationship with your spouse/pa		g menus, naving social a	cuvines, or having a	NEW PCP & BUDGET
WHAT IS ONE OF YOUR MAJOR I goals you have right now, if any.)	LIFE GOALS IN RELATION TO RECOVER'	Y: (Use additional sheets	for other major life	CONTINUATION PAGE FOR EXISTING PCP
				REGULAR CHANGE OR UPDATE TO PCP
				EMERGENCY UPDATE TO PCP (STOP & USE AMENDMENT FORM)
	improve when you reach the above goal. In oth lieved? An <u>example</u> is that a goal of being phys			
HOW WILL YOUR GOAL IMPROV	YE YOUR SYMPTOMS, PROBLEMS, OR OT	HER EXPERIENCES R	ELATED TO YOUR MI	ENTAL HEALTH ISSUES?
Make other notes or comments here a	bout your goal or what you hope to improve in	your life.		



3. List the resources you will need AND how each purchase will help you reach your goal in #1. Resources mean social, mental health, or substance abuse services; therapy; products; classes; memberships; or other purchases that will help you meet your goal. Some <u>examples</u> are: a bus pass from transit services to get to school; a suit of clothes for a job interview, a health club membership to get in shape; family therapy to learn coping skills; or dental work to help get ready for a job interview.

LIST THE RESOURCES YOU NEED AND HOW THE PURCHASE WILL HELP YOU MEET YOUR GOAL FROM #1:

Now please budget for the resources you need. Please list each resource or purchase separately, along with the duration of the expense (start and end dates, or ongoing), the cost per unit or item (including tax), the total number of units or items, and the total cost of each purchase. Use an additional sheet if necessary.

i ai ticipant Signature	Date	SDC Auvisor Signature	Dat			Date Date
Participant Signature	Date	SDC Advisor Signature	Dat	· •	gram Director Signatu	ure Date
		is the total amount you will spend on nor				Ψ \$
	4 What is th	e total amount you will spend on tradition				\$
				ending balance	e (B minus A), after e(s):	\$
			balance f	/	(D minus A) often	¢
					arted with (called your	\$
			on this g			
				•	e requesting to spend	\$
5.						
5.						
4.						
3.						
2.						
			Ť			Ť
1.		(START & END DATES)	\$			\$
		(START & END DATES)		cluding tax)	UNITS OR ITEMS	THIS PURCHASE
RESOURCE OR PURCHASE		DURATION OF EXPENSE	E COST PI	ER UNIT OR	TOTAL # OF	TOTAL COST OF

Life Action Plan

					1											
Name:					Unique	Program ID:	Type of I	Public Benefits,	if applicable: Medicaid / Med	dicare / Clinic Card / V	A / Other		_			
Address:				Phone	number:	Diagnosis / ICD-9 (if known) (Axis I): Symptoms related to this diagnosis:						Life Action Plan Page of				
			State: FL	Zip:												
City: Cost		Detailed	•		I		Reso	ources						Actual Cost		
Center	Activity Code (office	(office use		Priority Component (list mental health items first, include	even if	Need Based on Action Plan (See Life Analysis)	1050		Expected Ou	tcomes	Duration		Number		5110	5111
(office use only)	use only)			the item is covered by public bene	fits)		Source	Financing				Cost per unit	of units needed	Regular (\$836.70)	BHC (\$766.70)	ENH (\$830.60)
				(1)												
				(2)												
				(3)												
				(4)												
				(5)												
				(6)												
				(7)												
				(8)												
				(9)												
				(10)												
				I			A	dd each row an	nd enter the total amount you a	are requesting to spend	here (A) →					
Specific th	ings I need to ac	complish before	withdraw from	n the FloridaSDC Program:				Fligibl	F le for Public Benefits Medicaid, M	unds I am eligible to req	uest (B) →					
								Ligibi		arry-over from previous						
									-	Remaining Funds (B +						
							Crisis and YES NO		evention Planning	Date Complete	,					
Participant	Signature					Date		Crisis Plan		Buto complete						
								Post Crisis								
Other Signa	ature (if applicable)	- may include recov	/erv.coach.fami	ly member, friend or other particip	pant	Date		-	revention Plan n of Healthcare Surrogate							
Approved			iong occorr, rann		, and		Comme	nts / Additiona	v							
Certification S purchase mee 1. The 2. Ne 3. Ind 4. Co 5. Re	tatement by Recovery ts all six of the following purchases adhere to the cessary to protect life, to ividualized, specific and nsistent with generally a flective of the level of set	y Coach: The purchase ing conditions: ne requirements outlined ir prevent significant illness consistent with symptoms ccepted medical standards rvice that can be safely fur	the program purchas or significant disability or confirmed diagnosi s as determined by the nished and for which r		ot in excess vestigationa ess costly tr	al; are										
							Space F	For Office Use	Only (BHC)	(ENH)		Date of Entry_		Entoro	d Dv	
Reviewed wi	th Participant by Re	ecovery Coach				Life Action Plan Effective Date						Date of Entry_		Entere	u by	
_	_															



Life Action Plan

Cost Center	Activity Codes	Description of Services	Service Substitutions
12 - Medical Services	90801	Psychiatric Evaluation	
	H2010	Comprehensive Medications Services (per 15 minutes)	Medication Management, IDP, Labs, Pharmacy
	99214	Office or Other Outpatient Services	Dental, Hearing and Vision.
	H0046	Mental Health Services not otherwise specified	Anything not covered above.
14 - Outpatient - Individual	H0004	Behavioral Health Counseling and Therapy	Behavioral health counseling by a clinician to in
	H2017	Psychosocial Rehabilitation Services (including counseling and skills training and development)	Interventions to improve educational, occupatio living skills. E.g. Volunteer work.
	H0031	FARS	
	H2014	Skills Training and Development	Refers to fairly serious services - Restoration of living including appropriate use of community se developing a support network.
	H0046	Mental Health Services not otherwise specified	Anything not otherwise covered under Outpatier not employed), taxi (but not employed) car repa employed), rent, household items, hygiene and
	H0038	Self-Help / Peer Services	Provided by a peer - can include warm lines, ou groups. E.g. Gym membership, art supplies and
25 - Supported Employment	H2025	Ongoing Support to Maintain Employment	Assisting in the implementation of a plan for ass including interventions to assist in task completi
	H0004	Behavioral Health Counseling and Therapy	Behavioral health counseling by a clinician to in
	H2017	Psychosocial Rehabilitation Services (including counseling and skills training and development)	Interventions to improve educational, occupatio living skills. E.g. school, supplies, certification c computer purchase or repair if related to work o
	H0046	Mental Health Services not otherwise specified	Anything not otherwise covered under Supporte employed), car repair (if employed) and haircut
	H0038	Self-Help / Peer Services	Provided by a peer - can include warm lines, ou groups.
25 Outpotiont Crown	H2014	Skille Training and Development	Refers to fairly serious services - Restoration of living including appropriate use of community se
35 - Outpatient - Group	H0004	Skills Training and Development Group Counseling or Therapy	support network.
			Behavioral health counseling by a clinician to in
	H0046	Mental Health Services not otherwise specified	Anything not otherwise covered under Outpatie
	H0038	Self-Help / Peer Services	Provided by a peer - can include warm lines, ou groups.
	H2017	Psychosocial Rehabilitation Services (including counseling and skills training and development)	Interventions to improve educational, occupatio living skills. E.g. school, supplies, certification c

MAINTENANCE PLAN

How many months do you need assistance with your living arrangements, i.e. rent / utility / grocery / hygiene / household items (circle all that apply)?

_____ (Assistance is limited to 6 no more than 9 months.) (How many months?)

If you are asking the Florida Self-Directed Care (FloridaSDC) Program to assist with any of these living expenses, it is required that you submit this maintenance plan that details your long-term financial ability/plan to maintain your living arrangements.



cy, etc.

improve symptoms, etc. ional or social development, including

of skills necessary to independent services, hygiene issues and

ient - Individual. E.g. Utilities, JTA (but pair (but not employed), haircut (but not d grocery assistance.

outreach, advocacy and support nd crafts.

ssuring client income maintenance etion and maintaining concentration.

improve symptoms, etc.

ional or social development, including courses, work or school clothing and or school.

rted Employment. E.g. JTA (if ut (if employed).

outreach, advocacy and support

of skills necessary to independent services, hygiene issues, developing a

improve symptoms, etc. ient - Group.

outreach, advocacy and support

ional or social development, including courses, etc.

Goal Attainment Plan								
Name:		Customer Number:						
Today's date:	Phone #:	Plan Begins:	Plan Ends:					

What is my goal? What personal outcome do I expect as a result of this request?

Specific description of request	Resource analysis List provider here if needed (All the ways to get what I need, include family, friends, community supports)	How will this purchase help me achieve my goals	What it might cost Monthly & Annually	When will we start and end
PLAN TOTAL: \$				

SIGNATURES					
Individual:		Legal Representative:			
	Date:		Date:		
Resource Broker:		Other:			
	Date:		Date:		

Goal Attainment Plan

Name:		Customer Number:			
Today's date:	Phone #:	Plan Begins:	Plan Ends:		

What is my goal? What personal outcome do I expect as a result of this request?

Specific description of request	Resource analysis List provider here if needed (All the ways to get what I need, include family, friends, community supports)	How will this purchase help me achieve my goals	What it might cost Monthly & Annually	When will we start and end

Goal Attainment Plan



Personal Life History Form

Before you begin planning your goals and the budget for your purchases, it is important to think about your life, including your mental and physical health, your family and friends, services you've used and their effect, and your educational and employment histories. Reviewing this information can help you and your SDC Advisor decide what you have and your strengths, along with what you need and your difficulties.

Remember, you are a WHOLE person, with strengths, ideas, and goals. This is true no matter what hard times you've had or are still having. Part of participating in our program is recognizing that while mental health problems may be hard to cope with, you can take an active role in managing your emotional and physical health to help you find and participate in meaningful activities in your community. Indeed, it is widely believed that having a goal or purpose in life is the best thing for your recovery.

In using this form to think about your life, we suggest the following steps:

1. Review the whole form before you start writing anything down. This will help you figure out if you need any other information to complete it (such as the types of services you've used in the past year). When you're ready, please complete all of the sections, and do not leave any questions blank. Use the back or extra sheets if you need more room to write.

2. You may choose to complete this form on your own, and then share it with your SDC Advisor. Or, you may wish to complete the form with your SDC Advisor or another trusted support person. Either way, you should choose a time to work on this form when you are most rested and focused. You also may choose not to complete it all in one session, but we ask that you have it finished within *one week* of having received it. (FILL IN RETURN DATE HERE: _____)

3. Keep a copy of this form for yourself. It will help you to assess your progress and to remember what has worked and not worked for you in the past.

Sometimes forms like these can seem overwhelming or frustrating. People who've received physical or mental health care often feel like they've completed hundreds of forms that aren't reviewed again. However, we encourage you to view this form differently. You can use it to better understand where you've been and your dreams/goals *before* you turn to making a plan and a budget for where you're going on your self-directed care journey.

Remember, life change is a process, not a one-time event.



<u>Mental Wellness</u>

Start by reviewing how your mental health affects your life. Sometimes people would rather avoid thinking about this. But, thinking about the problems you've had, what has helped you to cope with them or made them worse in the past, and the services you've had may reveal patterns that you wish to continue or change when working on your mental health recovery.

I've been diagnosed with the following psychiatric disability or mental illness:

How do you describe yourself when you're feeling well? (How can you or others tell when you're feeling well?)

Please list all of the symptoms you experience because of mental health problems (please list all of them, even if you don't have them all the time):

These mental health symptoms go away or are less bothersome when:



When mental health symptoms really start bothering me, I usually:

The symptoms get worse when:

Do you like the medications you are currently prescribed? YES NO UNSURE Please explain what you like or don't like:

Do you adjust your medications on your own between doctor's appointments? SOMETIMES OFTEN RARELY NEVER Please explain why you might adjust a medication between doctor's appointments:



Please list the mental health or social services you've used in the past 12 months. These can be from a psychiatrist, a therapist, a case manager, a peer counselor, an employment specialist, a self-help group, or any services you've used to help you cope with problems.

NAME OF SERVICE	HOW OFTEN	REASON FOR SERVICE	DID IT HELP YOU?	DO YOU NEED IT
	RECEIVED?			NOW?



What is your overall goal related to improving your mental health symptoms or services as part of the SDC program?

What strengths or resources within yourself can help you reach this goal?

What barriers within yourself may make it hard for you to reach this goal?

What resources (people, places, and things) do you know about already that may help you reach this goal?

What barriers in your everyday life may stop you from reaching your goal?



<u>Physical Wellness</u>

Now think about your physical health, especially as it affects your mental health.

Date of most recent complete physic examination (month and year):	cal								
Are you aware of any current health problems?			Νο	Yes	(ear		Description		
Are you now under medical care or the medicines for a physical health prob	0		No	Yes					
Do any of the following apply to	you?	Please co	onsider any	past history as well.					
Serious illness	No	Yes	Denta	al problem	No	Yes	Headaches	No	Yes
Serious Injury	No	Yes	Visior	n problem	No	Yes	Allergies	No	Yes
Birth defects/inherited disease	No	Yes		ach/bowels/gall er problem	No	Yes	Obesity/weight problem	No	Yes
Surgery	No	Yes		matic Fever	No	Yes	Jaundice, Hepatitis, Liver Disorders	No	Yes
Skin/glands problem	No	Yes	Apper	ndicitis	No	Yes	Kidney/bladder problems	No	Yes
Ears/eyes problem	No	Yes	Cance	er	No	Yes	Anemia or blood disorders	No	Yes
Nose/sinus problem	No	Yes	Sugar	/Diabetes	No	Yes	Thyroid problems	No	Yes
Teeth/tonsils problem	No	Yes	Infect	tion	No	Yes	Heart condition or high blood pressure	No	Yes
Dentures	No	Yes	Bed-v	vetting	No	Yes	Sexual problems	No	Yes
Bridge	No	Yes	Menst	trual problem	No	Yes	Nervous system condition	No	Yes
Chest/Lungs condition	No	Yes	Herni	a (rupture)	No	Yes	Artificial Limbs	No	Yes
Heart Murmur	No	Yes	Back/	'Limbs/Joints problem	No	Yes	Undiagnosed Condition	No	Yes
Hearing problems	No	Yes	Sleep	walking	No	Yes	Other:	No	Yes



Do you have a specific goal related to improving your overall physical health or physical symptoms/problems as part of the SDC program?

YES NOT RIGHT NOW UNSURE

If yes, please briefly describe your goal:

If yes, please answer the following questions.

What strengths or resources within yourself can help you reach this goal?

What barriers within yourself may make it hard for you to reach this goal?

What resources (people, places, and things) do you know about already that may help you reach this goal?

What barriers in your everyday life may stop you from reaching your goal?



Substance Abuse/Dependence

For this part of the form, you will think about whether you abuse or are dependent on substances (alcohol, illegal drugs, or prescription drugs not taken as prescribed). Substance abuse/dependence can affect your mental health recovery and ability to reach your goals. Many people have issues with alcohol and/or drug use, so you aren't alone if this is a problem for you. There are services and supports that can be helpful.

Do you want to cut down on your drinking or use/abuse of drugs?

Do you find that people make comments about how much you drink or how often you use/abuse drugs?

Does your drinking or drug use/abuse interfere with the things you want to do in life?

Do you need a "kick-start" in the morning or afternoon? What about using alcohol or drugs to get to sleep?



Do you have a specific goal related to substances as part of the SDC program?

YES NOT RIGHT NOW UNSURE

If yes, please briefly describe your goal:

If yes, please answer the following questions.

What strengths or resources within yourself can help you reach this goal?

What barriers within yourself may make it hard for you to reach this goal?

What resources (people, places, and things) do you know about already that may help you reach this goal?

What barriers in your everyday life may stop you from reaching your goal?



Circle of Support

Your circle of support is made up of people who care about you, advocate for you when you're not feeling well, stick with you, and believe that you can achieve what you want in life. It's okay if you only have 1-2 people in your circle right now. You may decide to add to your circle of support as part of your goals for this program.

Who are your current supporters? (Examples include: doctor, case manager, mother/father, sibling, friend, spouse/partner.)

Would you like to add to your circle of support as part of the SDC program?

YES NOT RIGHT NOW UNSURE

If yes, please answer the following questions.

Who might you like to add (boyfriend/girlfriend, friend, peer advocate, teacher, etc.)?



What strengths or resources within yourself can help you reach this goal?

What barriers within yourself may make it hard for you to reach this goal?

What resources (people, places, and things) do you know about already that may help you reach this goal?

What barriers in your everyday life may stop you from reaching your goal?



Education/Training

Please list the training or education you've had.

Name of high school:				
	City		State	Attendance Dates:
Did you graduate or receive a certificate of completion?	Yes	No	Year received, if yes:	
Technical/vocational school, if any:				
	City		State	Attendance Dates:
Course of Study				
Did you graduate or receive a certificate of completion?	Yes	No	Year received, if yes:	
College you attended, if any:	_			
	City		State	Attendance Dates:
Course of Study				
Did you graduate or receive a certificate of completion?	Yes	No	Year received, if yes:	
Other training, if any:				
	City		State	Attendance Dates:
Course of Study				
Did you graduate or receive a certificate of completion?	Yes	No	Year received, if yes:	



Do you have a specific goal related to education or training as part of the SDC program?

YES NOT RIGHT NOW UNSURE

If yes, please briefly describe your goal:

If yes, please answer the following questions.

What strengths or resources within yourself can help you reach this goal?

What barriers within yourself may make it hard for you to reach this goal?

What resources (people, places, and things) do you know about already that may help you reach this goal?

What barriers in your everyday life may stop you from reaching your goal?



Employment/Volunteer Work

Please list the jobs or consulting positions you've had or volunteer work you've done. Use the back of this sheet, if needed.

	you worked or voluntee	red:			
Circle one: Full-time	Part-time	Hourly			
			City	State	Work Dates
Job Title/Position:					
Description of your res activities:	ponsibilities and				
	you worked or voluntee	red:			
Circle one: Full-time	Part-time	Hourly			
			City	State	Work Dates
Job Title/Position:					
Description of your res activities:	ponsibilities and				
Company name where	you worked or voluntee	red:			
Circle one: Full-time	Part-time	Hourly			
			City	State	Work Dates
Job Title/Position					
Description of your res activities:	ponsibilities and				



Do you have a specific goal related to employment or volunteer work as part of the SDC program?

YES NOT RIGHT NOW UNSURE

If yes, please briefly describe your goal:

If yes, please answer the following questions.

What strengths or resources within yourself can help you reach this goal?

What barriers within yourself may make it hard for you to reach this goal?

What resources (people, places, and things) do you know about already that may help you reach this goal?

What barriers in your everyday life may stop you from reaching your goal?



QUARTERLY REVIEW FORM

Advisor initials Participant name	Q'ly	Review Date	Date of Review with Program Director	
Goal # State Goal				
Advisor rating: A - NO PROGRESS B - SLIGHT PROGRESS C - ADEQUATE PROGR				
Participant rating: A - NO PROGRESS B - SLIGHT PROGRESS C - ADEQUATE PRO	DGRESS D - SU	BSTANTIAL PROGRESS E - GOAL A	CHIEVED (circle one)	
Participant Comments:				
If rated A or B, did you consider changing this goal? YES NO (circle one) If NC), why not?			
				I
If NO to above, did you add new services/supports/purchases? YES NO (circle on	e) If YES, what	services/supports/purchases did you	u add?	
				I
If NO to above, state why same purchases remain in budget if little progress has be	en made			
Goal # State goal				<u>-</u>
Advisor rating: A - NO PROGRESS B - SLIGHT PROGRESS C - ADEQUATE PROGR	ESS D - SUBS	ANTIAL PROGRESS E - GOAL ACHI	EVED (circle one)	
Participant rating: A - NO PROGRESS B - SLIGHT PROGRESS C - ADEQUATE PRO	OGRESS D - SU	BSTANTIAL PROGRESS E - GOAL A	CHIEVED (circle one)	
Participant Comments:				
If YOU rated A or B, did you suggest that this goal be changed? YES NO (circle	e one) If NO, w	hy not?		
If NO to above, did you suggest new services/supports/purchases? YES NO (circle	e one) If YES, w	hat services/supports/purchases did	you suggest?	
If NO to above, state why same purchase remained even though little progress has				
Advisor Signature	Date	Program Director Signature		Date

Quarterly Recovery Progress Report			
ame:	Date:	Unique Program	ID:
is report is due every three months and should be comp rel of progress toward goals on which you have been wo ing your level of progress, fill in the steps as you have th ellness, Physical Health, etc.) on which you are working.	rking, while the following poem written on your assess	bages can be used to revise your goals of sment or past progress report and fill in t	or set some new ones. In
	RE IF NOTHING HAS		
SELECT YOUR DOMAIN (circle on PHYSICAL HEALTH / SUBSTANC			/
What is your goal associated with y	our domain?		
Rate your progress with this goal:	0 1 2 No progress	3 4 5 6 7 8 Comple	9 10 ted goal on time
How can your Recovery Coach help	you meet your go	al?	
How does your SDC purchasing rel Reduce symptoms Increase prod Other Steps to meet your goal:	luctive activity M	laintain stability Meet basi YED THE SAME 🗌	
1) 2)	-		
How long will it take to meet your g How will you know you have met yo	our goal?		
What are your strong points that we			
What in your environment will help	you get what you r	need?	
What in your environment keeps yo		at you need?	

Quarterly Recovery	Progress Report	Fle	oridaSD
e:	Date:	Unique Program ID:	
DOMAIN	AND GOAL CONNE	CTION	
SELECT YOUR DOMAIN (circle on PHYSICAL HEALTH / SUBSTANC			
What is your goal associated with y	our domain?		
Rate your progress with this goal:	0 1 2 3 4 No progress	5 6 7 8 9 Completed goal on t	10 ime
How can your Recovery Coach help			
Steps to meet your goal: 1)	3)		
1) 2)			
How long will it take to meet your g How will you know you have met yo			
What are your strong points that wo	ould help you meet your g	oal?	
What are your weak points that wou		your goal?	
What in your environment will help	you get what you need?_		

Empowerment Initiatives Brokerage Progress Notes

Customer:

Date	Progress Notes	Initials
Staff Na	me Initials	
~ ~ ~ ~ 1 10		

Empowerment Initiatives Brokerage Progress Notes

Customer:					
Date	Progress	Notes	Initials		
	Progress Describe your progress towards your goals: What are your next steps? When do you want to meet again?	Notes	Initials		
Steff NI		Initiala			
Staff Nat	ne	Initials			
		+			

Texas Self-Directed Care

The Texas SDC Program is **not** a crisis service or even a regular component of your basic mental health services. We will help you add goals, value, and meaning to your life through person-centered planning, but it is your responsibility to maintain your mental health throughout the SDC experience. This exercise(s) will hopefully assist you and the Texas SDC Program staff in understanding how you manage your health.

Making a Crisis Prevention Plan

When things are quiet and calm, it's a good time to plan what to do if a crisis should occur. Having such a plan will make it easier for you to know what to do if you have a problem. It's a good idea to create your crisis plan with the people you plan to call if you need help. You'll get more ideas by making everyone a part of the plan.

1. Which of my early warning symptoms require a quick response?

2. Whom should I call first if I need help?

3. Who will call and stay in touch with my doctor, nurse, or case manager if I can't do it myself?

4. What should I do when I feel out of control?

5. Sometimes, the hospital can't give any information to the people who are helping me. Can we set up a plan ahead of time with my treatment team so information can be given to the people who are helping me? Write your plan here:

Taking Steps to Prevent Crisis:

Avoiding a crisis means taking action in advance to prevent a crisis from occurring.

- Keep track of your early warning symptoms.
- Ask a close family member or friend to help you monitor your symptoms.
- Take your medicine as directed by your doctor.
- Talk to your doctor, nurse, pharmacist, or other member of your treatment team before starting any new medicines (including nonprescription medicines).
- Keep to a regular sleep schedule.
- Ask for help with activities that may cause stress.
- Avoid situations that you feel are too stressful for you.
- **Do not** use alcohol or street drugs.

• Call your doctor, nurse, case manager, or other member of your treatment team right away if you notice early warning symptoms or need their help in avoiding a crisis.



Crisis Situations Don't Have to Happen to You

Keeping stress at an even, comfortable level is one way to keep you from heading toward a crisis. Stressful situations can't be avoided entirely. But knowing how to solve problems before they get too big, and knowing how to communicate the way you feel may help you handle stressful situations more easily. Knowing when to ask for help is also important. Don't be shy about asking family members or friends to be involved in your Crisis Prevention Plan. They may see things that are happening to you before you do—and they can alert you that it's time to take action. Finally, be sure to keep doing the things that will help you feel well—take your medicine every day, visit your doctor regularly, get the right balance of rest and exercise, and watch for early warning symptoms. All of this may not seem necessary, especially if you're feeling well. But as many clients have discovered, these are some of the best ways you can help yourself prevent crisis situations from interfering with your life.

*REMEMBER, YOUR SDC ADVISOR **WILL BE CONTACTED** IN THE EVENT THAT HOSPITALIZATION OCCURS DUE TO A CRISIS.*

PARTICIPANT NAME

DATE

SDC ADVISOR

DATE



Allowable/Not Allowable Purchases

Guidelines for Participants

- This list is a guide to help you develop your plan and budget. There may be things you want to purchase that aren't on the list. Feel free to ask your Advisor.
- All items in your budget must be clearly linked to your recovery goal.
- All plans and budgets must be approved by the SDC Program.
- If a purchase is not approved, you will be sent a letter from the SDC Program explaining why.
- Alternatives to denied purchases can be discussed with your Advisor. Feel free to ask your advisor what other things might be approved.

USUALLY ALLOWABLE IF RELATED TO A RECOVERY GOAL

> CLOTHING/SHOES/ACCESSORIES

- ✓ Job-related
- ✓ Fitness-related
- ✓ Health-related
- DENTAL CARE
 - ✓ Fillings, root canals, cleanings not covered by another payer
 - ✓ Dentures
- VISION CARE
 - ✓ Eye exam (1 per year)
 - ✓ Prescription glasses or contact lenses (not both) (1 per year)
- > SELF-CARE
 - ✓ Yoga
 - ✓ Therapeutic massage (need letter from mental health provider)
 - ✓ Books and tapes
 - ✓ Self-defense class
 - ✓ Acupuncture
 - ✓ Arts and crafts supplies
- ➢ MENTAL HEALTH
 - ✓ Private psychiatrist
 - ✓ Counseling
 - ✓ Peer support services
 - ✓ Case management
 - ✓ Group counseling
 - ✓ Medication management
- PHYSICAL HEALTH
 - ✓ Gym memberships
 - ✓ Personal trainer
 - ✓ Exercise equipment
 - ✓ Weight-loss programs
 - ✓ Quit smoking program
 - ✓ Doctor and prescription co-pays
 - ✓ Hearing aids

> TRANSPORTATION

- ✓ Bus pass
- ✓ Taxi cab (each ride must be listed in Personal Plan and Budget)
- ✓ Peer transport (each ride must be listed in Personal Plan and Budget)
- ✓ Bicycle and accessories (helmet, etc)
- ✓ Bicycle repairs
- ✓ Driver's license fees

EDUCATION/EMPLOYMENT

- ✓ College applications
- ✓ College entrance tests and study guides
- ✓ Classes
- ✓ Computer and accessories (printer, modem, etc)
- ✓ Internet access
- ✓ Cell phone
- ✓ Business cards
- ✓ Membership fees for work-related organizations

> QUALITY OF LIFE

- ✓ Small household appliances (coffee maker, microwave)
- Household items (dishes, bedding, lamps, answering machine, laundry detergent)
- ✓ Hygiene (soap, toothbrush, haircuts, make-up)
- ✓ Pest control
- ✓ Groceries (time limited and with exclusions)
- ✓ Radio
- ✓ Cell phone/landline phone (not both)
- ✓ State ID

USUALLY NOT ALLOWABLE

CLOTHING/SHOES/ACCESSORIES

- × Jewelry
- × Belts
- Watches
- DENTAL CARE
 - × Whitening
 - **×** Cosmetic services
- ➢ VISION CARE
 - * Non-vision correcting color contact lenses
- ➢ MENTAL HEALTH
 - ★ Substance abuse treatment
 - * Prescription co-pays
- > PHYSICAL HEALTH
 - **×** Over the counter medications
 - Non-FDA approved herbal remedies
- > TRANSPORTATION
 - × Car repair
- > LEGAL FEES
 - × Any
- ➢ HOUSEHOLD EXPENSES/UTILITIES
 - × Any



Guidelines for SDC Debit Card Purchases

We are pleased to provide you with a debit card for specified purchases that help you meet the goals in your SDC plan. Like any debit card, this one has certain restrictions. Please read the following guidelines, and discuss any of your questions with the SDC staff. Then, sign the form indicating that you understand the terms. If you don't wish to sign this form, that is your right. However, you cannot receive the debit card without signing the form indicating that you understand and accept these terms.

1. Debit card purchases may be made only for items and services named in your budget that correspond to a specific SDC goal. Any purchase not in your budget and not on the list of allowable expenses must be discussed with the SDC Program <u>before</u> you make it.

2. You will be asked to pay for minimal debit card fees from your personal budget.

3. To help track use and expenses, you and the program staff will receive automated emails whenever the debit card is used. The following restrictions will be placed on your debit card: 1) limitations on the amounts that you can charge at any one time or in total; 2) prohibition on card use in certain stores/venues, including liquor, weapon, and tobacco stores, bars, gas stations, and restaurants; 3) prohibition on certain purchases including liquor, tobacco products, or lottery tickets. Other restrictions may be placed on the card, and you will be informed when this occurs.

4. Within 5 days of a debit card purchase, you must submit to the SDC program receipts that match the purchases you made.

5. As possible and reasonable, you should explore whether you can use other community resources prior to making purchases with your debit card. SDC staff can help you with this.

6. Any loss or theft of the debit card must be reported immediately to the SDC program.

7. Each misuse of the debit card will be reviewed by the SDC Program and other program leadership. Egregious debit card misuse may cause you to be ineligible to continue in the SDC program.

Signature of participant, indicating acceptance of the debit card terms

SDC staff witness

DATE



TEXAS SELF-DIRECTED CARE FIDELITY ASSESSMENT

To complete a Fidelity Assessment for the Texas Self-Directed Care Program, the rater obtains objective information from a variety of sources. These sources include: documents describing program policies and procedures; SDC staffing information; a review of a random sample of case files; interviews with program management, staff and participants; interviews with providers; and analysis of management information systems data regarding service delivery and budgetary expenditures. Individual meetings are recommended to collect this information when necessary.

The Fidelity Assessment outlines the key criteria for self-directed care programs. Raters are instructed to obtain accurate information and avoid leading respondents to answers that may not be reflective of the actual perspectives or activities of staff, participants, or providers. The format for interviewing is conversational and the items listed here are not meant to be used as a structured interview. The rater does not need to obtain ratings information or data in the order listed in this measure.

Data sources:

PP = policies and procedures (the SDC Program's written policies and procedures)

DOC = document review (review of participants' files, contact logs, minutes from meetings, memoranda, etc.)

INT = interviews (interviews with the Program Director, staff, participants, and program partners)

OBS = observation (Fidelity Rater makes direct observations)

MIS = management information system (data obtained from the SDC Program's data systems)



Name of Fidelity Raters:	Date:	Total Score:

After reviewing the relevant data sources, circle one correct answer for each item.

Fidelity Area #1: Staffing

CRITERION	DATA SOURCE	ASSESSMENT
<u>1.1</u> Advisor Peer Make-up: The team of Advisors is comprised of behavioral health peers and non-peers.	PP, DOC, INT	1= 20% or less peers 2= 21%-29% peers 3= 31%-39% peers 4= 41%-49% peers 5= 50% or more peers
Observations:		

1.2 Advisor Diversity:	PP, DOC, INT, OBS	1= <25% representative of clients or community served
		2= 25-49% representative of clients or community served
The team of Advisors is diverse in terms of		3= 50-74% representative of clients or community served
race/ethnicity/culture, gender, age, etc.		4= 75-89% representative of clients or community served
		5= 90-100% representative of clients or community served

Observations:

1.3 Caseload size:	PP, MIS, DOC, INT	1= >50 clients (>36 for ½ time)
		2= 46-50 clients (31-35 for ½ time)
Advisors have individual caseloads. The maximum caseload is		3= 41-45 clients (26-30 for ½ time)
35 for a full-time Advisor and 20 for a part-time Advisor		4= 36-40 clients (21-25 for 1/2 time)
(working 20 or more hours per week).		5=maximum caseload or less (35 for full-time, 20 for part-
		time)
Observations:		

University of Illinois at Chicago NRTC SDC Fidelity Assessment



DATA SOURCE

1.5 Advisor as Support Broker: PP, DOC, INT, MIS 1= evidence of client engagement 2= plus evidence of provision of PCP and budget creation support 3= plus evidence of services/goods identification and linkage, quarterly reviews, follow-along, service utilization and 4= plus evidence of quarterly reviews and follow-along engagement engagement engagement services/goods linkage, quarterly reviews, follow-along, service utilization and engagement engagement service of quarterly reviews and follow-along engagement engagement	 <u>1.4 Role of Advisor</u>: Advisors serve only in the capacity of service broker. They do not directly provide case management, therapy, or mental health or social services. Observations: 	PP, DOC, INT, OBS	1= provide brokerage services <60% of the time 2= provide brokerage services 60-74% of the time 3= provide brokerage services 75-89% of the time 4= provide brokerage services 90-95% of the time 5= provide brokerage services 96-100% of the time
Observations:	1.5 Advisor as Support Broker: Each Advisor carries out all phases of SDC, including engagement, person-centered planning, budgeting, budget reconciliation, services/goods identification, services/goods linkage, quarterly reviews, follow-along, service utilization and recovery progress monitoring.	PP, DOC, INT, MIS	 2= plus evidence of provision of PCP and budget creation support 3= plus evidence of services/goods identification and linkages 4= plus evidence of quarterly reviews and follow-along engagement 5= plus evidence of budget reconciliation, service utilization

TOTAL SCORE, FIDELITY AREA #1: /25

ASSESSMENT



Fidelity Area #2: Organization and Management

CRITERION 2.1 Purchasing Policy:

DATA SOURCE

1= no purchasing policy 3= incomplete purchasing policy 5= purchasing policy includes all stated elements

ASSESSMENT

The Purchasing Policy details allowable and non-allowable expenditures; consequences of exceeding allowable spending; consequences for making unauthorized purchases; allowable service substitutions; allowable durable goods expenditures; and states upper limit on non-traditional expenditures.

Observations:

2.2 Use of Purchasing Policy:	MIS, DOC, INT, OBS	1= There is evidence that the purchasing policy is applied <=20% of the time
The Program Director and each Advisor is aware of and consistently applies the strictures of the Purchasing Policy.		2= There is evidence that the purchasing policy is applied 40% of the time
		3= There is evidence that the purchasing policy is applied60% of the time
		4= There is evidence that the purchasing policy is applied 80% of the time
		5= There is evidence that the purchasing policy is applied 100% of the time
Observations:		

MIS, DOC, INT

2.3 Fiscal Intermediary:

The Fiscal Intermediary facilitates direct payments to all types of SDC providers, supports use of participant debit cards, provides the SDC program with timely accounting of claims payments, and is responsive to payment problems encountered by the SDC staff and participants.

1= FI facilitates direct provider payments 2= Plus provides funds to SDC Program for debit cards 3= Plus is responsive to resolving payment problems 4= Plus provides timely accounting of claims payments 5= Plus provides all monthly reports of service claims to allow tracking



DATA SOURCE ASSESSMENT

Observations:

	2.4 SDC	Provider	Network.
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PP, DOC

PP, DOC, INT

The SDC Provider Network is formalized through written agreement, and includes public providers, private providers, community resources (non social or mental health service providers), and peer providers and supports.

Observations:

1= no network
2= public providers only
3= public and private providers
4= public, private, and community partners
5= public, private, community partners, and peers

2.5 SDC Program Advisory Board.

The SDC program has an Advisory Board. The Board is comprised of 50%+ consumer members, includes current program participants, and includes relevant community partners (e.g., mental health advocacy, service providers) and experts. It meets at least quarterly.

Observations:

2.6 SDC Program Supervision/Management:

The SDC Program Director facilitates weekly staff meetings at which problems and accomplishments brought forth during staff supervision are discussed/resolve. On a weekly basis, Program Director reviews participant milestones and budgets for corrective action. The Program Director uses participant data to manage program outcomes. 1= no board3= board meets quarterly5 =board meets quarterly and includes all stated representation

eetings at during staff s, Program for pant data to	PP, DOC, INT, OBS	 1= Program Director leads weekly staff meeting 2= Plus discusses and resolves problems/crises that have arisen during the week 3= Plus addresses issues from staff supervision and proactively plans for problem management 4= Plus reviews on a weekly basis all participants' milestones and budgets 5= Plus evidence that Program Director uses participant data to manage the program



DATA SOURCE ASSESSMENT

CRITERION

Observations:

2.7 NTBHA Program Manager: The Program Manager provides at least bi-monthly clinical and programmatic supervision to Program Director. The Program	DOC, INT	 1= evidence of liaison activities 3= evidence of liaison activities plus bimonthly meetings with PD 5= evidence of the above plus use of participant and
Manager uses participant and financial data to review program outcomes, and liaisons with the state funders, the FI, and the host organization.		financial data to review program outcomes.
Observations:		
2.8 Advisor Training.	PP, DOC, INT	1= no training
All Advisors receive initial didactic, regular on-the-job, <u>and</u> refresher training on SDC values and practices.	, ,	 2= initial didactic training 3= plus on the job training and observation by program supervisor 4= plus regular refresher trainings 5= plus topic specific training
Observations:		
2.9 Advisor Supervision:	PP, DOC, INT	1= no evidence of supervision 2= no evidence of regular supervision/supervision schedule
All Advisors receive weekly clinical and programmatic supervision.		 is irregular 3= evidence of monthly supervision 4= evidence of biweekly supervision 5= evidence of weekly supervision
Observations:		



Observations:

DATA SOURCE

ASSESSMENT

3= evidence of some listed Q/A activities 4= evidence of most Q/A activities 5= evidence of all listed Q/A activities

PP, MIS, DOC, INT 1= no documented evidence of a grievance procedure 2.11 Grievances. 2= documented evidence the grievance procedure exists, but no evidence of resolution/documentation of resolution 3= documented evidence that some grievances are resolved site. All grievances are addressed in a timely manner and to mutual satisfaction within one month 4= documented evidence that three-guarters of all grievances are resolved to mutual satisfaction within one month 5= documented evidence that all grievances are resolved to mutual satisfaction within one month **Observations:**

> TOTAL SCORE, FIDELITY AREA #2: / 55

Fidelity Area #3: Services

CRITERION

DATA SOURCE ASSESSMENT

There is a written grievance procedure. It is available to participants in their orientation packets and on the program web

resolved to mutual satisfaction, as possible.

The SDC Program surveys participants annually about their

procedure to ensure participant rights and satisfaction.

program/life satisfaction, makes changes to the program based

on guarterly and annual reviews, and fairly applies its grievance

University of Illinois at Chicago NRTC SDC Fidelity Assessment



DATA SOURCE

PP, DOC, INT

1= evidence this occurs <50% of the time 2= evidence this occurs 51-69% of the time 3= evidence this occurs 70-79% of the time 4= evidence this occurs 80-89% of the time 5= evidence this occurs 90-100% of the time

ASSESSMENT

3.1 Participant Orientation.

Information packet is mailed within 48 hours. New participants are contacted within 1 week in person or by phone. Initial contact is followed by a formal orientation to the program, including an overview of policies, procedures, staff, and services.

Observations:

3.2 Person-Centered Plan Development.

The Plan is developed by all participants within 6-8 weeks of beginning the program, is in the person's own words, and includes at least 60% traditional services and goods. Each participant receives support to develop a PCP as needed. Participants' supporters are included in PCP development as requested. Plan is amended upon request by participants.

Observations:

PP, MIS, DOC, INT

1= evidence this occurs <50% of the time 2= evidence this occurs 51-69% of the time 3= evidence this occurs 70-79% of the time 4= evidence this occurs 80-89% of the time 5= evidence this occurs 90-100% of the time

3.3 Budget Approval Process.

Budgets are reviewed and approved by Program Director. Reason for denied expenditures is documented in file and shared with the participant in writing, along with a copy of the appeals process (also documented in file). Alternatives to denied purchases are discussed with participant by Advisor.

Observations:

PP, DOC, INT

1= evidence this occurs <50% of the time 2= evidence this occurs 51-69% of the time 3= evidence this occurs 70-79% of the time 4= evidence this occurs 80-89% of the time 5= evidence this occurs 90-100% of the time



DATA SOURCE

ASSESSMENT

3.4 Person-Centered Plan Monitoring/Amendments.

Participant's PCP is reviewed each quarter with completion of Quarterly Review Form. Plan is amended each quarter as needed, based on progress toward goals.

Observations:

PP, MIS, DOC, INT

1= evidence this occurs <50% of the time 2= evidence this occurs 51-69% of the time 3= evidence this occurs 70-79% of the time 4= evidence this occurs 80-89% of the time 5= evidence this occurs 90-100% of the time

3.5 Individual Budget Development. Budget is developed by	PP, MIS, DOC, INT	1= evidence this occurs <50% of the time
participants within 6-8 weeks of beginning the program, and		2= evidence this occurs 51-69% of the time
adheres to Purchasing Policy. Participants receive budget		3= evidence this occurs 70-79% of the time
development assistance from staff and personal supporters as		4= evidence this occurs 80-89% of the time
desired. Budget is amended upon request by participant.		5= evidence this occurs 90-100% of the time

Observations:

3.6 Budget Monitoring/Amendments.	PP, MIS, DOC, INT	1= evidence this occurs <50% of the time
ū	, , ,	2= evidence this occurs 51-69% of the time
Participant's budget is reviewed each quarter with completion of		3= evidence this occurs 70-79% of the time
Quarterly Review Form. Budget is amended each quarter as		4= evidence this occurs 80-89% of the time
needed, based on progress toward goals.		5= evidence this occurs 90-100% of the time

Observations:

3.7 Expenditures Monitoring.	PP, MIS, DOC, INT	1= evidence this occurs <50% of the time
		2= evidence this occurs 51-69% of the time
Expenditures are tracked by the Advisors with oversight from the		3= evidence this occurs 70-79% of the time
Program Director (to avoid over or under spending), are in		4= evidence this occurs 80-89% of the time
compliance with approved budgets, and are reconciled against receipts/invoices on a monthly basis.		5= evidence this occurs 90-100% of the time

Observations:



DATA SOURCE AS

ASSESSMENT

3.8 SDC Values and Process. SDC participants set their own goals, make their own decisions, freely make choices within program guidelines, control their own expenditures within guidelines, and receive individualized support to identify and make purchases, as needed. Observations:	PP, DOC, INT, OBS	1= evidence this occurs <50% of the time 2= evidence this occurs 51-69% of the time 3= evidence this occurs 70-79% of the time 4= evidence this occurs 80-89% of the time 5= evidence this occurs 90-100% of the time
<u>3.9 Participant Access to Services</u> : Each participant is aware of the SDC Provider Network, and knows how to access a range of mental health, social, and community resources.	PP, DOC, INT, OBS	1= evidence this is true for <50% of participants 2= evidence this is true for 51-69% of participants 3= evidence this is true for 70-80% of participants 4= evidence this is true for 81-89% of participants 5= evidence this is true for 90-100% of participants
Observations:		

TOTAL SCORE, FIDELITY AREA #3:

/ 45

TEXAS SELF-DIRECTED CARE FIDELITY ASSESSMENT

TOTAL SCORE: / 125



<u>Scoring</u>

25 questions, each can be scored from 1-5. Minimum possible score = 25. Maximum possible score = 125.

115-125 = exemplary fidelity 100-114 = good fidelity 74-99 = fair fidelity <74 = not SDC



Texas SDC Participant Satisfaction Survey

Hello, my name is ______ and I'm calling from []. We're conducting a short 10-minute telephone survey of members of the Texas SDC program. We'd like to find out how you feel about the services you've received in the program. It's completely voluntary so you don't have to do it if you don't want to. And we won't use your name when we share the results. To thank you for your time, we'll send you a \$10 money order for completing the survey. Are you interested in doing it?

IF NO, say: OK, no problem. Thank you for your time. Goodbye.

IF YES, say: Great. Is now a good time to do it? It takes about 10 minutes.

If NO, schedule a date and time to complete the survey. If YES, continue below.

OK, then let's get started. When answering these questions, please think about the help you've received from SDC over the <u>past few months</u>. We're interested in your honest opinions, whether they are positive or negative.

1. How would you rate the SDC program? Would you say it's...

□ Poor □ Fair □ Good □ Excellent

2. Are you getting the kind of help you want from the SDC program? Would you say...

- □ No, I'm definitely not getting the help I want
- □ No, I'm not really getting the help I want
- $\hfill\square$ Yes, I'm generally getting the help I want
- □ Yes, I'm definitely getting the help I want
- 3. To what extent is the SDC program meeting your needs? Would you say that...
 - □ None of your needs have been met
 - □ Only a few of your needs have been met
 - $\hfill\square$ Most of your needs have been met
 - □ Almost all of your needs have been met

4. If a friend needed similar help, would you recommend the SDC program? Would you say...

- □ Yes, I'd recommend the program
- □ I'm not sure if I'd recommend the program
- □ No, I would not recommend the program

5. How would you rate your progress in achieving the goals you put in your Person Centered Plan? Would you say you've made...

□ No progress □ A little progress □ A lot of progress



6. How satisfied are you with the SDC Advisor you work with now? Would you say you're...

- □ Very satisfied with your advisor
- □ Somewhat satisfied
- Somewhat dissatisfied
- □ Very dissatisfied

7. In your own words, what are some things you like about working with your SDC Advisor?

8. What are some things you don't like about working with your Advisor? Remember, we won't share this information with your name connected to it.

9. Overall, how do you like the <u>mental health</u> services you are purchasing with your SDC budget? Do you like them...

A lot
A little
Not very much
Not at all

10. Compared to the <u>mental health</u> services you were getting *before* you joined SDC, are the services you're buying *now*...

Better than the services you got before SDC

- □ About the same
- $\hfill\square$ Worse than the services you got before you joined SDC

11. Do you feel the rules about what you can and can't purchase are fair? Probe for why or why not



12. What would you say is the most important purchase you have made with your SDC budget and funds? GET DETAILS, THEN, ask: Are there other important purchases you've made you can tell me about?

13. Do you think that being in the SDC program is helping you get your life back on track? IF YES, ask: Can you give me some examples of how the program has helped you get your life back on track?

14. Do you have any comments or suggestions about the SDC program that you'd like to share with me?

We're now at the end of our survey. Thanks again for sharing your thoughts with us. Good bye and enjoy the rest of your day.

Instructions: Please complete the following evaluation of the quality of the services and assistance provided by your FloridaSDC Recovery Coach. For each item, please circle one number that best describes your level of agreement (Strongly Agree, Agree, Neutral, Disagree or Strongly Disagree) with the statement. Also, please see the back of this form. When finished, please return the evaluation in the stamped envelope provided. <u>Please DO NOT write your name on this form.</u> If you have any questions or require assistance completing this evaluation, call Roxanne Campbell @ 904-743-1883, ext. 7501. <u>PLEASE RETURN AS SOON AS POSSIBLE.</u>

FloridaSDC Recovery Coach Evaluation	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	
Recovery Coach Name: Recovery Coach Name	s ,		2	ā	S	
Planning		1	1	1	1	
My coach helps me to identify possible problems I may encounter.	5	4	3	2	1	
My coach encourages me to use available and natural resources.	5	4	3	2	1	
If I ask for assistance, my coach helps me to define my goals and develop action steps to meet my goal	s. 5	4	3	2	1	
Programming		1	1	r	1	
My coach helps me to brainstorm new ideas.	5	4	3	2	1	
My coach helps me to find needed resources.	5	4	3	2	1	
If I ask for assistance, my coach helps me to set reasonable completion dates for my goals.	5	4	3	2	1	
Organizing			1		1	
My coach has made efforts to develop a good working relationship with me.	5	4	3	2	1	
My coach uses his/her time with me effectively.	5	4	3	2	1	
My coach is available when I ask for help.	5	4	3	2	1	
Leadership			1	1	1	
My coach helps me to focus on my strengths.	5	4	3	2	1	
My coach communicates effectively with me.	5	4	3	2	1	
My coach is willing to work with me even when I am having problems.	5	4	3	2	1	
Operating						
My coach returns calls in a timely manner (48 hour turnaround, excluding weekends and Holidays).	5	4	3	2	1	
My coach does what s/he says s/he will.	5	4	3	2	1	
My coach is on time for our scheduled phone or face-to-face appointments.	5	4	3	2	1	
My coach lets me know if s/he is going to be late or needs to reschedule.	5	4	3	2	1	
My coach makes sure I receive requested funds/services in a timely manner.	5	4	3	2	1	
Effectiveness			1	1	1	
Having a recovery coach is helping me to meet my goals.	5	4	3	2	1	
My coach provides support so that I can solve my problems independently.	5	4	3	2	1	
My coach ensures that I am in charge of my care and that all decisions made are mine.	5	4	3	2	1	
Personal Characteristics			1	1	1	
My coach has a positive attitude.	5	4	3	2	1	
I find it pleasant to work with my coach.	5	4	3	2	1	
My coach is dependable.	5	4	3	2	1	
My coach is responsive to my needs.	5	4	3	2	1	
Potential		1	1	r	1	
I think that my recovery coach does a good job.	5	4	3	2	1	
My coach is a helpful person.	5	4	3	2	1	
My coach does not act or sound annoyed or bothered when I make contact.	5	4	3	2	1	
I think that my coach genuinely enjoys helping others.	5	4	3	2	1	

Comments					
What particular strengths does your Recovery Coach possess?					
Are there any weaknesses that your Recovery Coach has that need to be addressed?					
List any suggestions to improve the SDC Program:					
General Comments:					

Thank You! Please return your completed evaluation in the self-addressed, stamped envelope provided.

Empowerment Initiatives Brokerage Service Quality and Outcome Evaluation of <u>Current Mental Health Services</u> TO BE COMPLETED BY EIB CUSTOMERS

Name: _____

(This is optional.)

Date: _____

Current or Traditional Mental Health Services

For each of the below items, please indicate by making a (4) or (\mathbf{x}) under the corresponding column, whether you Strongly Agree, Somewhat Agree, Somewhat Disagree, or Strongly Disagree on each of the following aspects of the current or traditional mental health services you receive:

Item	Strongly	Somewhat	Somewhat	Strongly
	Agree	Agree	Disagree	Disagree
1. The current mental health service(s) provides				
me with access to the information and resources				
I need.				
2. The current mental health service(s) provides				
me with a range of options from which to make				
decisions.				
3. Staff at the current mental health service(s)				
are available when I need them - either I can				
immediately reach them or they return my phone				
call promptly.				
4. Staff at the current mental health service(s)				
understand my needs and wants.				
5. Staff at the current mental health service(s)				
treat me as an equal.				
6. Staff at the current mental health service(s)				
are sensitive to my cultural needs and				
preferences.				
7. Staff at the current mental health service(s)				
encourage me.				
8. Staff at the current mental health service(s)				
try to help and support me as best they can.				
9. I feel comfortable speaking with the current				
mental health service(s) staff.				
11. I received the education and training I need				
to reach my goals.				
10. Staff at the current mental health service(s)				
have helped me, or are helping me, to meet my				
goals.				

11. What are some of the goals the current mental health service(s) is helping you to achieve? Is there anything you would like to share about this goal, working to achieve the goal, or how the current mental health service(s) has helped you with this goal?

Goal Attainment Planning and Service Budgets

For each of the below items, please indicate by making a (4) or (\mathbf{x}) under the corresponding column, whether you Strongly Agree, Somewhat Agree, Somewhat Disagree, or Strongly Disagree on each of the following aspects of goal attainment planning and current mental health service(s) budgets:

Item	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. I felt in charge of the planning process.			2.0081.00	21549100
2. My plan reflects what is important to me.				
3. My plan reflects my decisions				
4. I have a copy of my plan.				
5. The planning process was helpful in providing				
direction or setting priorities.				
6. My current mental health service(s) budget				
process was explained to me in a way I understand.				
7. My current mental health service(s) budget				
reflects my choices.				
8. My current mental health service(s) budget meets				
my needs.				
9. I have a copy of my current mental health				
service(s) budget.				

#

#

10. How many people are in your Circle of Support?

11. How many people attended your last planning meeting?

Individual Empowerment.

For each of the below items, please indicate by making a (4) or (\mathbf{x}) under the corresponding column if you Strongly Agree, Somewhat Agree, Somewhat Disagree or Strongly Disagree with each statement regarding your individual level of empowerment.

Item	Strongly	Somewhat	Somewhat	Strongly Disagree
	Agree	Agree	Disagree	Disagree
1. I make my own decisions.				
2. I am able to assert my will.				
3. I know I am an equal member of my community.				
4. I feel comfortable speaking up for my rights and				
myself.				
5. I am able to manage my supports.				
6. I am confident as an individual.				
7. I am confident in my independence.				
8. I feel in control of my own life.				

9. Has the current mental health service(s) made a difference in your life? If so, in what ways has your life changed since working with the current mental health service(s)?

10. What effect do you feel the current mental health service(s) has had on your life?