

UIC Solutions Suite Webinar Series

Transcript for the Self-Directed Care Implementation Manual: A Comprehensive Mental Health Program Guide

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Slide 1:

Thank you for visiting the University of Illinois at Chicago's Health & Recovery Solutions Suite. The following recording comes to you from the UIC Center on Integrated Health Care and Self-Directed Recovery. Visit our online Solutions Suite to obtain free tools that promote health, self-direction, and employment for the behavioral health field.

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Hello. My name is Judith Cook. I direct the University of Illinois at Chicago's Center on Integrated Health Care and Self-Directed Recovery. Our Center offers an online Solutions Suite, containing free tools for the behavioral health field. These tools promote wellness, self-direction, and employment for people who are recovering from mental illnesses. You can visit our Solutions Suite on the web site where you found this webinar, at www.center4healthandsdc.org. Today, I'll be discussing how to use one of the tools found in our Solutions Suite, called the Self-Directed Care Implementation Manual: A Comprehensive Mental Health Program Guide.

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The Self-Directed Care Implementation Manual and the Solutions Suite are jointly funded by the National Institute on Disability, Independent Living, and Rehabilitation Research of the U.S. Department of Health and Human Services' Administration on Community Living; and by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration. The grant number is 90RT5038. Contents do not necessarily represent the policy of any agency or endorsement by the federal government.

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This webinar has a number of learning objectives. One is to understand what the self-directed care approach is and how it works. Another objective is to learn about the research evidence for self-directed care. I'll discuss the structure and content of the self-directed care manual, which shows people how to design a mental health self-directed care program from the ground up. Finally, you'll learn about different ways to use the manual to establish and run a high-quality self-directed care program.

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Let's begin by learning about the basics of Self-Directed Care, called SDC for short.

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Imagine the following scenarios. In the first one, Roberto is unhappy with the services of his therapist who speaks only English. He talks to his SDC staff 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.

In the second scenario, Darcel benefits from participating in online support groups. She has made friends in these groups and finds them helpful for her well-being. But she can only access the Internet at her local library. 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.

While Roberto and Darcel's choices would be difficult in many mental health systems, they would be very feasible in a self-directed care program. Let's find out why.

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In SDC, public funds that usually go directly to service provider organizations are controlled instead by service recipients. In order to make this happen, SDC program members, called participants, first develop person-centered recovery plans. They also create individual budgets that specify the goods and services they plan to buy to achieve their recovery goals.

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Once their budgets are approved, SDC program staff called support brokers help participants purchase the services and goods named in their budgets. An organization called a fiscal intermediary provides financial management services such as provider billing and withholding of payroll taxes. So to summarize, there are 4 elements that the participant uses to guide the self-directed care process: the person-centered plan, individual budget, support broker, and fiscal intermediary.

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Person-centered plans help participants identify how they see themselves and how they feel about the way they're currently living. Plans also include goals that relate to the kind of life people want to have in the future. Another feature of person-centered plans is that they describe the strengths that participants bring to goal achievement. Strengths might include persistence, creativity, or having a college degree. Also identified is the participant's circle of support, which consists of people who are aware of participants' goals and are willing to help them achieve the lives they aspire to.

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In addition, person-centered plans also identify any barriers to accomplishing desired goals. For example, people who want a job might not have proper clothing for job interviews. Or, people who want to move into a safer apartment might not have enough money for the security deposit. The plan then goes on to describe the supports and services people can access to overcome these barriers to success. For example, the person who wants a job can identify a store that sells affordable business suits. The person who needs money for a security deposit might find a relative from their circle of support who can help with that expense. Person-centered plans also include action steps and timelines for different phases of the goal attainment process. The idea here is that people will more easily achieve their goals if they specify what to do and by when.

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Many people are curious about the personal budget in SDC because it's an unusual feature of the model. Like a budget you and I might make for reaching a life goal, there's a line item for each purchase with a dollar amount attached. In SDC, budget items must relate directly to person-centered plan goals by connecting the steps for goal achievement to the planned purchases. For instance, in order to purchase walking shoes, a participant must have a clearly articulated goal related to the shoes, such as improving their physical health. In order to purchase a laptop, a participant must have a goal related to the computer, such as being in online support groups or taking an online course. Working together, the participant and broker regularly monitor the budget to make sure the purchases are appropriate and connected to goals in the person-centered plan

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The support broker is an SDC expert who helps participants develop their person-centered plans and budgets. The broker also helps participants identify and navigate community resources. Many participants are unaware of natural supports, businesses, and other community services they can use to recover because they haven't had the funds to use resources outside of the public mental health system. A good broker is aware of a wide variety of services and goods that people can purchase to support their recovery goals. If requested by the participant, the broker also can help recruit, negotiate rates, hire, and discharge providers. For example, a person might decide to hire a private trauma therapist, but not know how to find one or how to understand the therapist's rates. Brokers are trained to help participants manage these unfamiliar tasks.

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Brokers also sit down with participants on a regular basis to review budgets and make needed revisions. Budget changes commonly occur when participants find they no longer need a service or if they make a one-time purchase. During the budget review, participants also plan for future line items. Brokers may assist with provider billing by working through the Fiscal Intermediary, especially when providers are unfamiliar with the documentation required by a Fiscal Intermediary. Brokers also help participants make purchases of material goods, such as office supplies for a small business, a smart phone, or business clothes, using a debit card, check, or some other means. However they work with participants, brokers always act in a co-pilot role. By this we mean that they never direct the person's recovery journey. Instead, they act as coaches and helpers.

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Since use of the SDC model with people in mental health recovery is very rare, you may be wondering what kinds of organizations can host an SDC program. Sometimes, a program is hosted by a mental health advocacy organization. An example of this is when the Mental Health Association of Southeast Pennsylvania hosted a program called the Consumer Recovery Investment Fund Program. Another example is the National Alliance on Mental Illness of Collier County, which runs a program called FloridaSDC. In other cases an SDC program can be hosted by an organization that oversees community mental health programs but doesn't provide direct services itself. This occurred when an organization called the North Texas Behavioral Health Authority ran the Texas SDC Program. In still other instances, a service provider organization will host a program. This is the case for the SDC program operated by an agency called Aging True in Jacksonville, Florida. However, if a service provider hosts SDC, the agency must prove that it will act in good faith to avoid conflicts of interest. This is necessary so that participants feel free to purchase services from any community provider, not just the one hosting their SDC program. Finally, peer-run organizations have hosted SDC programs, which occurred when a program called Empowerment Initiatives in Oregon ran one.

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You may be interested to learn that SDC can be a replacement for usual mental health services or an add-on to usual services. What I mean by this is that in some SDC programs, participants replace all traditional outpatient services with services purchased through their SDC budgets. This was the case for programs run in Florida, Pennsylvania, and Texas. In other SDC programs, SDC budgets are used to purchase additional recovery services or buy material goods, while participants' original mental health services remain intact. This was the case for programs in Maryland, Iowa, and Oregon.

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The principle of service substitution is an important feature of SDC programs because it allows for greater freedom of choice. This important principle lets participants acquire less restrictive, more flexible, and more natural services or goods than would be available in usual service systems. Let's look at the various ways that service substitution works.

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There are a number of ways that participants can make service substitutions. One is to replace formal services with informal ones. An example of this is to replace travel in a mental health program van with travel in a neighbor's car, paid for out of the individual's budget. A second type of substitution involves replacing a regular mental health service with a normative community activity. An example of this would be purchasing a gym membership instead of attending an exercise class run at a person's community mental health center. A third kind of substitution is to replace public services with private ones. In this case, participants might decide to hire a private psychiatrist who speaks their native language rather than struggling to talk to a mental health center psychiatrist who doesn't speak their preferred language. A fourth type of substitution involves replacing services with goods. An example here is replacing a vocational group for job seeking with purchasing professional clothes to wear to job interviews. In all of these cases, the greater flexibility of the self-directed care approach allows participants to buy what they really need, rather than choosing from what is available to everyone in traditional mental health programs.

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You may be wondering what funding sources can be used to pay for mental health self-directed care programs. Usually these programs operate using one or all of the following sources: Medicaid, state general revenue, specialized grants, and other local funds.

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Many SDC programs use a braided funding approach. Braiding refers to combining different funding sources in a manner that allows the individual sources to be followed, much like being able to see the different strands of hair that make up a braid. Often, state general revenue funds are combined with Medicaid funding in some manner. Sometimes this is as an add-on to Medicaid, in which Medicaid beneficiaries receive additional funds through either state general revenue or a specialized grant. In a total cash-out approach, Medicaid funding is pooled with other funds such as state general revenue, community reinvestment dollars, a grant, a private foundation, or some other source.

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The ultimate goal for most SDC programs is cost neutrality, which means that SDC costs no more than traditional services.

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Let's turn now to the research on self-directed care. While there's plenty of evidence that the model works for people with physical and developmental disabilities and the elderly, there's much less known about how well it works for people with psychiatric disabilities.

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Our Center conducted an evaluation of one of the first mental health SDC programs located in Jacksonville Florida, called FloridaSDC. We looked at participants' outcomes in the 12 months prior to joining the program, and then during their first 12-months of program membership. We found that, compared to the year before entering the program, participants spent a significantly higher number of days in the community in the year after joining. In other words, they spent fewer days in restrictive settings like jails or hospitals. They also had significantly better functioning in the year after program entry compared to the year before.

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They also achieved some noteworthy outcomes. For example, a third held paid employment, and many were receiving job skills training, volunteering, or taking classes in secondary or post-secondary settings.

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We also looked at how participants spent the funds that were available from their individual budgets. Over a 19-month period, 47% of participants' budgets was spent on traditional psychiatric services such as medication management appointments and therapy sessions. Thirteen percent of people's budgets was spent on service substitutions for traditional care. Twenty-nine percent of their budgets was spent on tangible goods such as books for classes, or tools for an apprenticeship program. Eight per cent was spent on medical care not covered elsewhere, such as for dentures or glasses. Finally, 3% was spent on transportation such as bus passes or taxis.

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In 2006 through 2010, our Center collaborated with the state of Texas to start and study a program called Texas SDC, located in Dallas, TX. We used a randomized controlled trial design and randomly assigned 102 people with serious mental illnesses to the SDC program, and assigned 114 people to the control condition where they continued to receive usual services. Study subjects were interviewed at baseline, one year later, and two years later.

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We looked at outcomes over a 2-year period and found that compared to those in the control group, SDC participants had significantly lower somatic symptoms. Somatic symptoms are feelings of emotional distress related to a person's physical functioning. SDC participants also had higher coping mastery, better self-esteem, higher levels of self-perceived recovery, greater ability to ask for help, greater reliance on social support from others, greater willingness to pursue recovery goals, greater perception of the service system as client-driven, greater likelihood of employment, and greater likelihood of attending school.

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At the same time, these better outcomes did not come at a higher monetary cost. The average per participant total service costs for year 1, year 2, and the 2 years combined showed budget neutrality. For example, while year one costs for SDC participants averaged \$2,998, they average \$3,189 for controls. Year 2 costs averaged \$2,241 for SDC and \$2,303 for controls. Over the 2 year study period, SDC costs averaged \$5,240 per participant and \$5,493 for controls. This was the first mental health SDC program in the country to demonstrate budget neutrality in comparison with a control group.

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We also looked at whether SDC participants were satisfied with the assistance they received from the program. We found that 87% were very or somewhat satisfied with their brokers. These staff were crucial because they helped participants learn about the program, develop plans and budgets, and purchase goods and services. We asked SDC members to compare the services they purchased with their individual budgets to the services they were getting before the program, and almost three-quarters said their new services were better than what they had been getting from the traditional system. Finally, we asked whether the rules for making purchases with their budgets were fair or not, and 90% felt that the program's purchasing policy and procedures were fair.

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Next, let's turn to the SDC implementation manual itself, including its content, how it's organized, and the resources it provides.

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Because mental health SDC programs are so rare, we developed the manual in order to show you how to design these programs from the ground up, as well as how to run them in a manner that is of high quality. The manual describes how to mobilize your local community or State by developing a planning committee, and educating people about the model and how it works. It also discusses how to adapt SDC to your local area's unique strengths, as well as its specific needs and funding availability. It goes into detail about different ways to staff and implement an SDC program. It describes how you can assess fidelity to SDC principles and practices, and make corrections if the program starts drifting back to running like a traditional service delivery program. Finally, it discusses different ways to evaluate your program's impact on participants' lives, as well as monitor how much it costs to operate the program and what people spend their money on.

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Chapter 1 is entitled What is Self-Directed Care? It addresses topics such as what self-directed care is and does, the need for SDC, and the benefits of SDC for program participants. It covers much of the information I provided earlier in this webinar.

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Throughout the manual, there are quotes from actual SDC participants. Here's one example in which a participant explains that, "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."

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Chapter 1 also describes SDC as a business approach that is effective, cost neutral, and an excellent fit with our country's current health care policies. This chapter also describes the benefits of SDC from a system perspective, as well as from the point of view of service providers. Finally, Chapter 1 describes the origins of SDC, and its beginnings in the disability self-determination movement.

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Chapter 2 is entitled Getting Started. It familiarizes the reader with the different values that ground SDC as an approach to helping people recover. These values include freedom of choice, having authority over your life and the services you receive, getting the support you need, and the personal responsibility participants assume when they're entrusted with financial resources and empowered to spend money on their own behalf. The chapter also helps readers decide what they want to do to move an SDC initiative forward. This includes doing research on what others have done in the local area, and whether there is legislation already on the books that would support development of mental health SDC programming. Local research can also determine whether there are possible partners to work with in establishing SDC.

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Chapter 2 also discusses how to get organized. This involves bringing together different stakeholders including service users, providers, advocates, funders, and policymakers. It highlights the importance of including people in recovery, as well as getting support from influential people in positions of power who can make things happen. At the same time, it helps readers anticipate detractors, deal with misunderstandings, and handle the fears that sometimes arise in the change process.

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Chapter 2 also helps readers prepare to address common concerns that arise when planning and implementing the SDC approach. It provides answers to questions that often arise when people are skeptical, or feel threatened, or are simply struggling to figure out how the model works. The questions include the following. Will SDC erode the current system? Doesn't the system already offer choices? Won't SDC cost more than traditional services? And finally, doesn't SDC demand skills and competencies that people in recovery lack? The answer to all of these questions is no, and explanations are provided to help you counter myths and misperceptions about SDC.

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Here's one of my favorite quotes from an SDC participant. "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."

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Chapter 3 is entitled Being Participant-Driven. It discusses the importance of involving people in mental health recovery in planning and developing SDC initiatives. In many cases, consumer involvement in organizing SDC demonstrates the competency and capacity of people with lived experience. People in recovery can often make the best case for the importance of enhancing choice in the selection and use of services and supports for building a meaningful life.

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Chapter 3 also helps the reader understand the notion of competency as it applies to a person with mental illness using self-direction to recover. It explains the differences between concerns about people's skills versus concerns about their choices. It distinguishes between short-term crises that might require a brief hospitalization versus long-term incompetency such as caused by being in a coma. It also points out the difference between concerns SDC participants might have about their ability to make good choices versus concerns others may raise about their decision-making capacity.

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When you involve a variety of stakeholders in an SDC initiative, you can expect things to get messy sometimes. That's why Chapter 3 teaches you how to plan for conflict, learn to manage disagreements constructively, and help everyone feel comfortable in their roles for SDC planning and implementation.

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The title of Chapter 4 is Program Structure. This chapter addresses the key structural elements involved in an SDC program. One is a Steering Committee that includes people with lived experience to work with other stakeholders in guiding the process. Also needed is a program director and support brokers who help participants exercise self-direction by promoting choice and self-determination. A fiscal intermediary is another important part of SDC as are the funding agencies with whom the fiscal intermediary works to accomplish the financial transactions that are integral to the operation of SDC.

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Another important component of SDC is the program's service provider and vendor network. A wider range of providers offers greater access to a richer and more diverse set of services and supports. Vendors supply the material goods that people need in order to reach their recovery goals. Also important is creating an effective public relations program to attract high-quality providers and vendors to work with your program. PR also is useful for enhancing the general public's support for your mission.

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Chapter 5 is entitled Self-Directed Life Planning. It describes the development of person-centered plans that are the cornerstone of self-directed care. When the plan is being developed it's important to ensure that the participant is in charge, rather than some other entity such as providers, programs, or service systems.

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Participants begin by identifying the strengths they bring to the recovery process, along with the challenges and barriers that will have to be overcome. They also develop a list of available social supports such as family and friends, along with practical resources such as living near a bus stop or having access to a computer and the Internet. Development of the plan involves gaining an understanding of how all of these factors relate to the person's ability to achieve the goals that are part of their plan. The planning process also involves reviewing with participants their past service utilization, including what types of services they've tried and how much of each type they've used. An important discussion here concerns which services have helped and which have not helped. This is done to decide which services and supports are likely to help people reach their goals so these can be added to the budget. It's also important to do some advance crisis planning by anticipating unforeseen circumstances that might impede goal attainment.

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Chapter 5 shows you how to help participants set goals using the SMART framework. The S in SMART stands for specific which means that the goal should be clearly and completely stated. An example of a specific goal is, "I will learn to write a business plan for the dog-walking business I want to start." The M stands for measurable, meaning that it should be possible to tell whether the goal has or has not been achieved. In the case of the dog-walking business, the goal is measurable because it will result in a written business plan. The A stands for attainable, which means that the goal should be something that can be accomplished in a brief period of time. To continue our example, by accessing the right supports, most people can prepare a business plan within 1 to 3 months. The R stands for relevant, which means that the goal needs to be personally meaningful to the participant and his or her vision of a good life.

The participant in my example loves animals and always wanted to be a veterinarian. She decided to start a dog-walking business as a way to stay connected with animals while earning income. The T stands for time-based, which means that a time frame should be specified for actions related to goal achievement. In our example, the goal would need to include the specific dates by which the participant would identify and access help for writing a business plan, write the first draft, and get feedback for revisions. This chapter also discusses the best way to monitor participants' progress toward their goals and what to do when set-backs are encountered.

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Chapter 6 is entitled Budgeting and Purchasing. In this chapter, readers learn about two fundamental aspects of the economics of SDC. The first is the Purchasing Policy, which is comprised of specific guidelines about what can and cannot be purchased, as well as the procedures that need to be followed in order to make purchases of goods and services. Past SDC participants found it valuable to know upfront the kinds of purchases they were not allowed to make with SDC funds, such as cosmetic dentistry, herbal supplements, or monthly rent payments. Typically, these restrictions reflect State regulations for the use of public funds. The second key concept covered in Chapter 6 is setting the amount that participants can spend in their individual budgets over a 12-month period. This is an important number because in order to be cost-neutral, the cost of the individual budgets should not exceed what would have been spent on participants in the traditional service system.

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Chapter 6 also describes how to help participants create their individual budgets and get them approved by whatever approval process the program follows. Also discussed is how brokers and the program director can monitor participants' budgets and expenditures to make sure that they adhere to the program's Purchasing Policy and accurately reflect what was approved. Part of this involves setting up a system to pay service providers and vendors and this is covered as well.

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Chapter 7 is entitled Eligibility, Recruitment, and Enrollment. It helps the reader decide what eligibility criteria will be established to define who can join the SDC program. Once these criteria are chosen, they must be communicated to potential participants as part of an advertising strategy designed to encourage interest and applications. Also discussed in this chapter is how to orient new SDC participants and other procedures necessary for a smooth intake into the program. This chapter provides examples of intake forms and procedures used by other mental health SDC programs to stimulate the reader's thinking. It also discusses the need to develop procedures that can be followed should participants wish to withdraw from the program or they need to be discharged for whatever reason.

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Chapter 8 delves into the critical role of the SDC Support Broker and what functions it involves. Perhaps one of the most important of these is to recruit participants into SDC and then orient them about how to use the program. Brokers need to do this in a manner that makes new members feel welcome and empowered to try new ways of working toward their recovery. Brokers also help with development of the person-centered plan and corresponding individual budget, along with helping to get the budget approved. Once approval is obtained, brokers help participants spend money from their budgets. They also help participants monitor their expenditures so they get the most out of what they purchase. Through these processes, brokers provide social and emotional support, coaching, and mentoring that help the participant grow and learn as they use the program.

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Also in this chapter, the role of the support broker is compared and contrasted with that of a case manager. You'll learn that some of the duties do overlap, such as helping people to find and coordinate behavioral health services. However, the major difference is that SDC brokers do not provide behavioral health services as case managers do. Instead, brokers help connect participants to these services. They also help with creating budgets and spending money from the person's budget. But they act as coaches and advisors, not as clinicians. That's a very important distinction and it's critical to the successful operation of an SDC program.

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Also discussed in Chapter 8 are the skills and qualifications needed by support brokers, along with the importance of the broker's commitment to fostering self-direction and maximal choice among participants. In addition, the challenges and rewards of developing effective working relationships with participants is covered. Finally, the nature of training and orientation needed by brokers is described, along with the importance of refresher training and ongoing professional development activities.

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Chapter 9 of the manual covers evaluation and quality assurance, along with how to measure and maintain fidelity to the SDC program model's principles, structure, and practices. Included in this chapter is a section on the importance of evaluating participant outcomes and their level of satisfaction with SDC services. Another section covers the importance of monitoring expenditures at both the individual participant levels as well as the program level to ensure either budget neutrality or awareness of whether the program is operating within budget. Another section discusses the importance of monitoring fidelity on a regular basis and what to do when fidelity drift from the ideal SDC program model is encountered.

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The manual's Appendix contains a host of valuable resources for building a program. This includes legislation from the State of Florida that established SDC programs there, and job descriptions for the positions of support broker and program director. It also includes examples of forms used in other mental health SDC programs for enrollment, person-centered plan development, creation of individual budgets, quarterly budget reviews, and provider invoicing. Also included are example program documents such as purchasing policies, statements of SDC participants' rights and responsibilities, and guidelines for debit card use. Finally, an SDC participant satisfaction survey is included for those interested in program evaluation, along with a fidelity assessment to measure the program's conformity to the SDC model.

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We have some tips for how to use the manual to best advantage. We suggest that you read the manual all the way through before you take any action. This will allow you to understand the full dynamics of what you're undertaking. Another suggestion is to be ready and able to address common concerns that arise when planning and operating an SDC program. You'll find many useful facts and figures in the manual to help you make your case. We've also designed Chapter 1 of the manual around a series of handouts that you can share with others as you move forward. Another suggestion is to take the time to build a supportive SDC community of stakeholders by identifying and nurturing allies in your cause while being as inclusive as possible of different viewpoints and perspectives.

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One way to inspire people in your local community as well as members of your planning committee, is to use testimonials from SDC participants. These personal stories of recovery can be used to explain what SDC is and show how it operates. Some examples of testimonials include stories by Texas SDC participants named Genoveva, Chelsea, Cleveland, and Guisepe, which you can access at <http://www.texasdc.org/>.

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As I mentioned earlier, mental health SDC programs are rare. Right now, only a few states have them. If you are interested in starting a self-directed care initiative in your state or community, or want to develop and operate an SDC program, free, time-limited technical assistance is available. You can visit the web site where you accessed this webinar to learn more, or call us on our toll-free number at 312-355-1696.

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