

SELF-DIRECTED SUPPORTS POLICY RECOMMENDATIONS

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Report of the Self-Directed Supports Cross Unit Functional Team and the
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Issue: What should be Wisconsin’s policy towards participant self-direction in community-based long-term care?

This paper recommends state policy for participant self-direction in community based long-term care programs serving elders, persons with physical disabilities, and persons with developmental disabilities. It is the result of an intensive policy development process carried out by the Self Directed Supports (SDS) Cross Unit Functional Team and a broad-based SDS Stakeholder Committee.

The paper starts by providing background on self-direction—what it is, what federal Center for Medicare and Medicaid Services (CMS) policy is, and why it is important. It outlines a suggested approach to SDS in Wisconsin. Finally, it identifies key issues and challenges with respect to participant self-direction and recommends next steps for the SDS initiative.

DHFS has recognized the need for a clear policy on participant self-direction. While all Family Care Care Management Organizations (CMOs) and many county Community Options Program Waiver (COP-W) and Community Integration Program (CIP) programs offer some form of SDS, there is not a consistent approach statewide or among the COP-W or CIP waiver counties. SDS currently is not a part of the Wisconsin Partnership model. Furthermore, Wisconsin is embarking on a long-term care reform process that will result in long-term care being delivered by 9-15 regional CMOs. It is anticipated that contracts between CMOs and DHFS will require CMOs to offer SDS to their members; therefore, it is important that DHFS expectations for SDS be clearly defined.

Representatives of Mental Health/Substance Abuse programs and Children’s programs also participated in the policy development process. These programs are working on incorporating SDS into their programs, and the same general principles and approaches developed for long-term care would be applicable. Though there are important programmatic and client differences that may result in some variation in how SDS is applied in these programs, some level of consistency in the application of SDS across long-term care, mental health/substance abuse, and children’s programs would be desirable.

To date this initiative has considered SDS only for long-term care services, not primary and acute medical services. Currently, the Wisconsin Partnership Programs are the only long-term care programs in Wisconsin that integrate long-term care services with medical (primary and acute care) services, though additional programs integrating long-term care with primary and acute care services are under development as part of long-term care reform. This initiative has not to date considered the application of SDS to medical services. However, fully integrated programs could adopt this approach to SDS for the long-term care components of their programs. This paper represents the first phase of the larger effort to improve and expand SDS throughout the state. Upon approval of this policy paper, the initiative will focus on developing specific tools, training and approaches to support implementation of SDS programs.

A complete list of persons who participated in the development of this policy paper is included as Attachment A.

This paper outlines policy for fully operational SDS programs. It is recognized that it will take time for local programs to fully achieve all of the program features outlined in this report. As a next step in this initiative, SDS Cross Unit Functional Team and SDS Stakeholder Committee will be developing a recommended phase-in approach for SDS programs.

Part 1: Background

What are Self-Directed Supports, and why are they important?

“Self-Directed Supports” refers to a wide range of approaches designed to maximize choice and control for people who use long-term care services and supports. People who self-direct are able to hire, supervise, and fire their own direct care workers. But SDS involves many other elements as well, including control of one’s own budget for services, choice of services and supports, and decision-making authority. Though frequently used for in-home care, SDS can be used outside of the home as well, and is particularly promising in supported employment. Elements of SDS will be thoroughly discussed in this paper.

SDS is consistent with the RESPECT values that guide Wisconsin long-term care programs:

- **Relationships.** *Relationships between participants, care managers and providers are based on caring, respect, continuity over time, and a sense of partnership.*¹ By making the option available for participants to select and oversee the persons who provide their care, SDS respects and promotes the participants ability to build on relationships that are meaningful and productive for their lives.
- **Empowerment to make choices.** *Individual choice is the foundation of ethical home and community-based long-term support services.* SDS is grounded in participant choice. Participants choose whether, and what services to self direct. For services that they self direct, they have considerable latitude to choose who is providing the service and how and when it is provided.
- **Services to meet individual need.** *Individuals want prompt and easy access to services that are tailored to their unique circumstances.* Individuals who are self-directing services can tailor them to their specific needs.
- **Physical and mental health services.** *Intended to help people achieve their best level of health and functioning.* SDS recognizes that most people are capable of selecting and directing long-term care services in a way that is consistent with their physical and mental health needs. Involving the participant in a careful care planning process helps ensure that SDS supports the best level of physical and mental functioning.
- **Enhancement of participant reputation.** *Services maintain and enhance participants' sense of self-worth and community recognition of their value in every way possible.* Through SDS, participants have increased control over their own lives and increased ability to interact with the community in ways that they value.
- **Community and family participation.** *Participants are supported to maintain and develop friendships to participate in their families and communities.* SDS promotes the use of community resources and informal supports to meet participant outcomes.
- **Tools for independence.** *People are supported to achieve maximum self-sufficiency and independence.* SDS enables participants to exercise self-sufficiency and independence to the degree that they choose to do so.

¹ The term “care manager” is used throughout this paper to describe a range of similar positions also referred to as “case manager” or “support services coordinator.” Also, while it is recognized that care management is often provided by Inter-Disciplinary Teams (IDT), the paper does not specifically refer to IDTs. For the purpose of this paper, the term IDT can be substituted as appropriate for care manager.

The Recovery Oriented Systems Assessment (ROSA) used by the Bureau of Mental Health and Substance Abuse Services, involves talking with consumers of those services about personal outcomes related to recovery. . Recovery is generally defined as the idea that people can get better and live happy, full, and productive lives with or without a mental illness. The basic tenets of recovery emphasize the importance of recognizing that participants are people and not simply a list of diagnoses or disabilities. People are empowered to take risks and make the decisions they believe will be best for them.

SDS is consistent with the recovery values incorporated in the ROSA tool:

- **Personal Life and Direction.** A person exercises autonomy, courage, and responsibility when making decisions about his or her life and in turn achieves a sense of mastery and purpose.
- **Community, Affiliation, and Connection.** In order to create a sense of belonging, people need supportive, meaningful, and respectful connections with others. People should be free to fulfill social roles and to be as involved in their communities as they prefer.
- **Health, Wellness, and Safety.** The ability to participate fully in life can be impacted by a person's physical, emotional and safety concerns. The person determines when and how these concerns are addressed.
- **Treatment and Services.** Successful treatment is done with – not to people. People should have the opportunity to choose the type of service they believe will best meet their needs, and facilitate their personal recovery.
- **Empowerment and Self-Determination.** In order to make decisions about things that are important to them, people need information about their options and the opportunity to exercise their decision-making power. Having this sense of control encourages people to reach their personal goals and achieve their desired level of recovery.

How is Wisconsin currently using SDS?

Use of SDS varies across local long-term care programs:

- Family Care Program CMOs are required by administrative rule and in their contracts with DHFS to offer self-direction options to members. The nature of self-direction varies with member needs and preferences.
- Many, but not all, of Wisconsin's 1915(c) waiver programs serving Elderly and Physically Disabled populations (COP-W and CIPII) and Developmentally Disabled populations (CIP 1A and 1B) offer SDS to some degree. According to a survey of Wisconsin Counties published in September 2004, 35 out of 66 counties responding to the survey offer some of their participants the option of directly employing their own providers, with the assistance of the county and a fiscal agent. According to this survey 3,197 consumers were utilizing this option in 2004.²

² *Long-Term Support Direct Care Arrangements in Wisconsin Counties; Survey Results, 2004. DHFS/DDES*

Typically, SDS under COP and CIP waiver programs provides consumers or guardians with the ability to hire their own supportive home care worker (using a fiscal agent for related financial transactions.) Counties have varying criteria for determining participant eligibility to self-direct.

The most notable application of SDS among CIP 1A and 1B programs is Dane County's DD program, which has offered SDS to most consumers for 10 years. Consumers are provided with a budget, and work with support brokers to access needed services.

- The Wisconsin Partnership programs (WPP) do not formally use SDS, although WPP provides a consumer-centered planning and service delivery model that results in a generally high degree of consumer input.
- The DHFS Bureau of Mental Health and Substance Abuse Services has submitted an application for a new Community Opportunities and Recovery (COR) waiver to CMS. The COR waiver will fund relocation of nursing home residents with mental illness into the community. SDS would be an important component of the COR waiver. In addition, the Comprehensive Community Services (CCS) program integrates consumer self-direction into its recovery model, and BMHSAS is interested in considering the applicability of SDS to Community Support Program (CSP) services.
- Wisconsin's Children's Long-Term Support (CLTS) Waivers contain provisions for offering SDS as a service option.

What are federal CMS expectations with respect to SDS?

CMS strongly encourages, but does not mandate, expansion of SDS. Its support for SDS is demonstrated in a number of programs and initiatives, including:

- The Cash and Counseling Pilots in three states, co-sponsored by DHHS and the Robert Wood Johnson Foundation;
- The Independence Plus initiative, based on the Cash and Counseling and Self-Determination projects, offers assistance to states to implement programs to support self-direction, either through a 1915(c) or 1115 Waiver;
- CMS requires considerable detail on whether and how the state will provide for participant direction of services in both 1915(c) and 1915(b) Waiver applications;
- CMS audits of waiver programs check for provision of consumer directed services. For example, a 2004 CMS audit of the COP-W and CIP II Waivers expressed concern that the waivers were not including consumer directed services as an approved service.³

³ The DHFS response notes that COP and the COP Waiver require consumer choice as part of the care plan development and throughout the service determination process. The response further notes that consumer direction occurs through the use of fiscal agents or intermediaries, and appears under the supportive home care service category.

Part 2: Recommended SDS policy

This section of the paper recommends a comprehensive policy for Self Directed Supports. The policy primarily addresses SDS for long-term care services for elderly adults and adults with physical or developmental disabilities. However, with certain modifications, these recommendations may also be applicable to mental health/substance abuse programs and programs serving children.

The recommended policy addresses the following key areas:

- A. Who is eligible to self-direct services?
- B. How does SDS apply to residential settings?
- C. What limitations can be placed on participant self-direction?
- D. What is the scope of consumer self-direction?
- E. What are the roles and responsibilities of persons and organizations involved with SDS?
- F. How does care planning take place under SDS?
- G. What training needs are associated with implementation of SDS?

Each of these key areas is discussed below.

A) Eligibility for self-direction

All participants receiving long-term care services would have the opportunity to participate in the self-direction of their supports. No person would be excluded based solely on target group or characteristics such as cognitive deficits or the need for guardianship. Local programs would inform all parties of their right to self-direct.

Persons with guardians are eligible to self-direct. Guardians, parents of minor children, and other alternate decision makers would be considered active partners in the self-direction process. These alternate decision makers would act as the participants' voices, and help the participants navigate the self-direction option. If a participant is not able to select the self-direction option on his or her own, and the decision maker believes it to be in the participant's best interest, the alternate decision maker may choose the self-direction option for the participant.

The policy on paying guardians, parents of minor children, and other legally responsible adults would be consistent with waiver regulations. To avoid a conflict of interest (defined here as existing when a person or any other entity involved in operating any part of the local program has an interest in or the potential to benefit from a particular decision, outcome or expenditure), the local program would have written policies and procedures to ensure decisions can be made without any undue influence.

B) SDS and residential setting

Choice of where and with whom to live and who will provide needed supports and services is fundamental to self-direction.

SDS would be an option for all participants living in private homes. They would have the option of self-directing supports that come into their homes - such as supportive home care workers—as well as services received outside of the home.

SDS for persons residing in substitute care poses more complex issues. First, there is a question of definition. For example, does a 1-2 bed adult family home created especially for a participant constitute substitute care, or is it a private residence? Second, in larger congregate settings, complete participant self-direction may be inconsistent with the staffing and operational requirements. The following principles would apply to self-direction for participants residing in substitute care:

- For all persons living in substitute care, it would be determined that a substitute care setting is truly the least restrictive environment for a participant, and that the residence was chosen by the participant and/or the decision maker.
- At a minimum, participants living in substitute care may self-direct services unrelated to their living arrangements. Under this approach, a person living in a CBRF would not be able to hire or fire residential staff, but would be able to self-direct (hire, supervise, fire) transportation providers, day treatment program, and employment services. The local program would contract with the facility for services directly related to care and supervision of the participant, and the facility would only bill the local program for actual care and supervision costs. Costs related to services that may be self-directed (i.e. transportation, attendant care, day treatment, etc.) would be carved out of the care and supervision rate.
- As an option, local programs may work with interested participants, facilities and the Bureau of Quality Assurance (BQA) to develop options for participant self-direction of residential services in substitute care. Participants could perform limited self-direction in substitute care, consistent with Bureau of Quality Assurance (BQA) regulations and the operational needs of the facility. The concept of choice would be written into local program contracts with facilities. For example, the participant could choose when and what to eat, could direct his or her sleeping schedule, and could participate in hiring direct support staff. Local programs and facilities would work together to ensure that substitute care employees understand the philosophy of self-direction and assist participants to employ these practices.

C) Restrictions on a participant's ability to self-direct

The local program would have written policies and procedures, shared with participants who are self-directing, outlining conditions under which the program may either:

- Forbid a participant from self-directing;
- Restrict the level of self-direction exercised by a participant; or
- Increase the level of involvement of the care management team.

Restrictions on a participant's ability to self-direct would be uniform statewide and across waiver programs. They would be limited to the following circumstances:

- The health and safety of the participant or another person is threatened;

- The participant’s expenditures are inconsistent with the budget and the plan;
- The conflicting interests of another person are taking precedence over the desires and interests of the participant;
- Funds have been used for illegal purposes.

If a local program restricts or terminates a participant’s ability to self direct, it would provide the participant with information about what specific steps he/she would take in order for the restrictions or termination to be withdrawn. The local program would also inform the participant whose level of self-direction is restricted about his or her right to file a grievance, request DHFS review, or request a fair hearing if he or she disagrees with any limit on the level of self-direction. The local program would have written policies and procedures in place as to how it would assist participants in attaining or regaining self-direction authority.

The local program would have written policies and procedures in place related to self-direction that include periodic re-assessment of participants’ competency to exercise their right to self-direct without assistance from an alternative decision maker.

D) Scope of self-direction

The scope of SDS involves a number of components:

1. The participant’s authority to employ workers and manage a budget
2. The services that are available for self-direction
3. Participant’s ability to determine the extent of self-direction
4. Participant’s ability to obtain independent advise and support

Each of these components is described below.

1. Participant authority to employ workers and manage a budget

CMS recognizes two broad categories of self-direction: *Employer Authority* and *Budget Authority*. State SDS programs may offer either or both of these authorities to participants. This policy would provide both employer and budget authority in Wisconsin’s SDS program.

Employer authority

In programs offering employer authority, participants employ their own service providers. Employment entails the full range of employer rights, including the right to recruit and hire service providers, to supervise their work, to set their wages and to terminate their employment.

There are two variants of employer authority: “*employer of record*” or “*co-employment*” (also known as “*agency with choice.*”) Depending on the availability of area resources, local programs would be encouraged to offer both alternatives, but would at least present participants with the “*employer of record*” option. Under each of these variants, the participant functions as the employer of the worker.

- a. Employer of record – When a participant is the employer of record, he or she has the authority to hire, supervise, and fire his or her own workers. The participant is

also responsible for payroll and completing the paperwork required for taxes and social security withholdings. Typically, the local program contracts with a fiscal agent to issue paychecks to workers and handle withholdings. Participants submit necessary information about their employees/service providers, including wage rate and timesheets, to the fiscal agent.

b. Co-employment/agency with choice – Under the co-employment/agency with choice model, the co-employment agency and the individual enter into a dual employment relationship. The agency is typically the common law employer and the participant is the managing employer. Duties of an agency with choice may include invoicing the local program for public funds, conducting human resource activities, managing all aspects of payroll, providing a variety of support services, monitoring workers' performance in conjunction with the managing employer. The participant is responsible for choosing providers from the worker pool available to the agency. Participants may also locate their own workers and request that the co-employment agency hire them.

Budget authority

Participants would also have budget authority. Budget authority is the authority to select the types and amounts of services received, within a given budget, as long as the services relate to the person's long-term care needs.

The local program would be responsible for developing methodologies and standards for budget development to ensure cost effective budgets adequate to meet participant needs.

2. Services available for self-direction

Most services would be eligible for self-direction, with the exception of a few that are carved out and funded separately on an as-needed basis. Services related to health and safety (e.g. acute mental health services) would be provided without penalty to the participant's budget.

Within the budget and the service plan, the participant may purchase any service or support consistent with his or her goals. In order to offer as many service choices as possible for participants, local programs would work to increase provider capacity. Participants would also be encouraged to draw on informal and community supports to provide needed services.

For supportive home care and other supports provided in the home, the participant would typically submit a signed timesheet to the fiscal agent, who would issue payment to the provider. For services provided outside of the home, the participant would typically purchase services and supports by using a voucher supplied by the fiscal agent. By doing this, the participant is actually the person authorizing payment to the vendor.

3. Participant ability to determine extent of self-direction

Subject to any restrictions, the participant may choose which long-term care supports to self-direct, as well as which services and supports would be managed in a traditional

manner by the local agency. A participant may choose to self-direct one service, several services or all services. A participant may also forego self-direction if that is his or her preference.

4. Participant’s ability to obtain independent advice and support

Support brokers are an important component of an SDS program. Support brokers are contracted participant representatives who perform duties similar to those of care managers, but who work independently of the local program, representing participant interests independent of the risk-bearing entity or administrative agency. Support brokers are discussed in more detail in Section E, below, and in Part 3 of this document.

E) Roles and responsibilities of persons and organizations involved with SDS

Successful implementation of SDS programs requires full and knowledgeable involvement from participants, care managers, local program administrators and providers, fiscal agents, and sometimes resource centers and support brokers. This section outlines the primary responsibilities of each of these parties.

Party	Major Responsibilities
Participant	<ul style="list-style-type: none"> • Indicate whether he/she wants to self-direct and what services to self-direct. • Serve as employer of workers. This entails recruitment, supervision, hiring and firing. • Conduct required criminal background checks on potential workers. • Develop clear descriptions of worker responsibilities; assure that workers are adequately trained. • Develop a back-up plan for worker absences or other unexpected occurrences. • Assure that all required state, federal and program paperwork is completed promptly and accurately. This could be done using a fiscal agent, a fiscal intermediary, a co-employment agency, or the participant could do it independently. • Manage self-directed services within the allotted budget.
Resource Center	<ul style="list-style-type: none"> • Where a Resource Center exists, the Resource Center is responsible for educating persons applying for programs about options to self-direct.
Care manager (or service planning team where applicable)	<ul style="list-style-type: none"> • Make sure that all participants are informed of the opportunity to self-direct. • Facilitate person-centered planning meetings and assist the participant with the development of the service plan • Support the participant’s self-direction activities as needed; as appropriate, identify community resources to support the participant in self-direction. • Assure that there are adequate back-up plans to ensure the participant’s health and safety should problems arise with

Party	Major Responsibilities
	<p>self-directed services.</p> <ul style="list-style-type: none"> • Monitor outcomes for self-directing participants. Work with participants to address issues that arise.
Support broker	<ul style="list-style-type: none"> • Support brokers are independent brokers who represent the participant’s interest independent of the risk-bearing entity or the local administrative agency. • Participants would have the option of using a support broker in addition to a care manager. See Part 3 for a discussion of the role of the support broker and its relationship to the care manager. • Depending on the level of broker involvement chosen by the participant, support broker roles could include, but would not be limited to: participating in the service planning process; assisting in identifying and locating services; negotiating with service vendors and providers; advocating for the participant with the local program; serving as a resource about community and neighborhood supports; facilitating team meetings; assisting in the development and monitoring of the participant’s emergency back up plan including arranging for the provision of back up providers; coordinating services with fiscal agents/intermediaries and the local program care managers.
Local program administration	<ul style="list-style-type: none"> • Assure that clear policies on self-direction are in place, and that they are communicated to participants and program staff. • Assure adequate training and support is available to participants and staff on self-direction. • Make sure that training requirements of funding sources are met and documented. • Set budgets for participants who are self-directing. • Take appropriate steps to minimize liability associated with SDS. • Establish and maintain guidelines and procedures for restricting SDS for participants who violate policies or who are otherwise unable to self-direct. Assure appropriate procedures for appeals and reinstatement of SDS authority. • Contract with fiscal agents or intermediaries and co-employment agencies to provide fiscal and/or co-employment services to self-directing participants. • Assure that workers not associated with a provider agency do not have criminal records that would preclude them from providing direct client care.
Fiscal agent or fiscal intermediary	<ul style="list-style-type: none"> • When participants hire workers not affiliated with an agency, fiscal agents or fiscal intermediaries would typically be utilized.

Party	Major Responsibilities
	<ul style="list-style-type: none"> • The distinction between fiscal agent and fiscal intermediary is as follows: The fiscal agent handles employee payroll when the participant is the employer of record. The fiscal intermediary can perform the functions of the fiscal agent, and in addition, can purchase other supplies and services on behalf of the participant. • Specific fiscal agent and intermediary duties include: the payment of service providers; completing fiscal accounting functions and expenditure reports; withholding federal, state, and local taxes from payment to service providers; ensuring compliance with federal state and local tax laws; ensuring compliance with employment and wage laws; verifying that payment is made only for services identified and authorized in the participant’s ISP; maintain an audit trail of disbursement of funds; and develop and maintain service agreements with each provider employed by the participant.
Workers/Providers	<ul style="list-style-type: none"> • Carry out work assignments as specified by the participant/employer. • Record time on timesheets and complete all other required paperwork in a timely manner.

Managing for self-direction differs in a number of respects from managing for traditionally delivered services. Some of the key areas where SDS presents different challenges are described below:

- Advising participants of the right to self-direct. Local programs would be required to have written plans detailing how they will disseminate self-direction information to participants. The plan would include how the local program can ensure that the people participating in the self-directed supports option understand and are agreeing to utilize this option. The information would be presented to the participants both verbally and in a written format in the participant’s primary language.

Local programs, including resource centers, would be required to discuss the self-directed option with all new participants and at six-month reviews with participants already enrolled in the programs. Local programs would be responsible for presenting the self-direction option to school-age participants moving from children’s to adult’s programs.

- Care management. The SDS option may require more front-end time than a traditional care management model, and it may also be time-intensive if the participant requires substantial assistance. That acknowledged, care managers may also utilize other community resources and training opportunities to scale back their involvement and time commitment. Co-employment agencies, independent living centers, or support brokers, for example, may be able to provide some of the necessary assistance that care managers would otherwise provide. In order for self-direction to be successful, it may be necessary for care managers to relinquish some of the control present in traditional care

management models.

Local programs may find it effective to designate certain care managers as “specialists” in SDS. These care managers could receive special training and would become experts in self-direction. They would directly serve as care managers for self-directing participants, and as coaches and advisors to care managers who are not SDS specialists.

- Determining individual budgets. The local program would have a methodology in place for establishing and modifying an individualized budget amount or range available to the participant to pay for the services and supports to be self-directed. Methodologies for creating SDS budgets are being developed as part of the SDS initiative and will be made available to local programs. (See discussion of budgets in Part 3.)
- Supporting participants in self-direction. The local program would be responsible for ensuring a person is able to participate in self-direction if the person expresses a preference to self-direct, notwithstanding his or her capabilities. Regardless of the local program’s level of involvement, there would be a clear distinction between the role of the program as facilitator and that of the participant as primary employer or purchaser of services. Both the participant or representative and the local program would sign a letter of agreement, which clearly delineates the roles and responsibilities of both parties. Local programs would assume the role of “consultant,” helping all involved parties (participants, guardians, care managers, brokers) understand SDS rules and regulations, while clearly sidestepping actual employer duties.

Local programs would have written policies and procedures that include mechanisms for assuring compliance with requirements for the deduction and payment of payroll taxes and for providing legally mandated fringe benefits for individuals employed by the participant. The local program would make assistance available to the participant for all of the following employment-related tasks: recruiting; screening; interviewing; hiring and firing; setting the level of wages; setting workers tasks and hours; authorizing and making payment for services delivered; setting the level of benefits, if any to be provided in addition to requisite state and federal payroll benefits, such as vacation, sick leave or health insurance; assistance in procuring additional optional employee benefits; training workers; assessing participant liability; supervision and disciplining workers; arranging back-up workers or services.

The local program would have in place written policies and procedures under which the participant can make or authorize payments to providers and receive timely information on expenditures and budget status.

- Use of support brokers. Participants choosing to self-direct would have the option of utilizing support brokers in conjunction with care managers. Support brokers are contracted participant representatives who perform duties similar to those of care managers, but who work independently of the local program. Hiring an independent broker compliments the philosophy of self-direction by creating another means for the participant to establish and maintain control over his or her service plan independent of

the local program. See the above table for a summary of support broker responsibilities and Part 3 for a discussion of support brokers.

- Use of a fiscal agent and fiscal intermediary. SDS involves the use of a fiscal agent or intermediary to carry out the payroll and purchasing responsibilities associated with SDS arrangements. (See table above for summary of fiscal agent/intermediary responsibilities.) While presently some local programs directly handle payroll, withholding, etc. for self-directing participants, local programs would be required to contract with a professional fiscal agent. Having a third party fiscal agent is beneficial in that it distances the local program from the SDS relationship. It is also more efficient to have a fiscal agent who specializes in payroll functions and who can devote the time to staying up-to-date on IRS requirements and applicable regulatory changes.

F) Care planning under SDS

While participant centered care planning is an essential component of SDS, it is important to understand that SDS goes beyond just participant centered care planning. SDS allows participants to actually control and direct the services they receive on a daily basis. Through the use of support brokers, SDS also provides independent advocacy and support for participants.

The actual creation of the plan could happen several different ways depending on the structure of the local program and the preferences of the participant. The development of the participant's plan would be person centered and based on the guiding principles of individual and family involvement and participant choice and control. The process would be individualized, interactive and ongoing. The participant would formally review his or her care plan at least every six months. A copy of the participant's plan would be kept in his or her file.

Participants would have the option to use the services of an advocate, independent from the local program to assist with the development of the care plan. The advocate could be a formal or informal support, and would have been chosen by the participant. Participants work with their care planning team to develop plans for self-direction of funding for the supports or services they choose to manage directly. The local program reviews the plans to ensure that the plans do not jeopardize the participants' health and safety, and that expenditures are within the budgets agreed to by the local program. The plans would also meet any other conditions approved by the department. If a participant's service plan is safe and within the stated budget, then the local program should not change the plan without input from the participant.

G) Training and support needs for successful implementation of SDS

Successful implementation of SDS would require ongoing training and support of participants and their guardians, for providers, and for care managers and other local program staff.

Care management organizations would be responsible for providing needed training, either directly or by purchasing training from qualified vendors. DHFS would provide standards and expectations for training, and would make training materials and curriculums available (through a web-based format) to support local training efforts.

Existing county COP and CIP waiver programs would not typically be expected to have the resources to purchase needed training. DHFS would work with these counties to assure access to needed training to support SDS programs.

The following table briefly describes training and support needs for SDS:

Category of persons needing training	Training needs
Participants and guardians	<p>Training would be designed around the needs of individual participants – individuals would not be required to take training that is not relevant to their needs.</p> <p>Training topics for participants could include:</p> <ul style="list-style-type: none"> • Philosophy/guiding principles of the self-direction option • Participant rights and responsibilities • Participation requirements • Budget management • Billing and reporting requirements • Scheduling • How to recruit, interview, hire and fire direct support staff • Liability and reducing risk • Training for guardians to assist them in learning and respecting participants preferences and goals
Workers/Providers	<p>Provider training needs would be based on the needs of the participant. It is expected that in many cases, the participant would directly train the provider. There may also be a need to develop specific skills requiring outside training (for example, transferring skills.) Expectations would be incorporated into provider contracts with participants and local programs. There would be mechanisms developed to assess provider performance, and to assure that the local program and participant are immediately informed of problems with providers.</p>
Care managers	<p>Care manager training needs would focus mainly on the changes to their roles and responsibilities as compared to the traditional care management model. Emphasis would be placed on developing person-centered care plans, understanding personal outcomes, and exploring service and support options.</p>
Support brokers	<p>Because support brokers are not employees of the local program, their levels of familiarity with various programmatic funding sources may vary. They may benefit</p>

Category of persons needing training	Training needs
	<p>from training on balancing the preferences of the participant with the policies of the local program. They would also require orientation to the relationship between their responsibilities and those of the fiscal agent/intermediary, the local program care manager, and the participant.</p> <p>Support brokers would also understand person-centered care planning, use of personal outcomes, and exploring service and support options.</p>
Local program managers	<p>Training needs of local program managers would focus on the development of quality assurance and quality management processes to ensure the successful implementation and delivery of SDS. Additionally, program managers may require training on participant budget determination, cost effectiveness, and provider networks.</p>

Part 3 – Implementation Issues

There are a number of important areas that will require further development as part of SDS system design. While the SDS Initiative has commenced work in these areas, more work is needed to clarify issues and develop policy. These areas include:

- A) Balancing choice and risk
- B) Liability
- C) Incompatibility of funding streams
- D) SDS in a managed care environment
- E) Use of support brokers
- F) Individual budget development, savings, and managing institutional stays
- G) Assessing cost effectiveness of SDS
- H) Assuring quality of SDS
- I) Developing expectations for implementing SDS, both for new CMOs and for existing c-waiver COP and CIP programs
- J) Applicability of SDS to mental health/substance abuse and the children's waivers.

Each of these issues is discussed briefly below.

A) Balancing choice and risk

SDS involves increased participant choice about their services and how they are delivered. Sometimes, participants may make choices that involve a level of risk. At the same time, care plans under home and community based waiver programs must be safe. Concerns have been expressed about balancing choice and risk in SDS situations.

Careful care planning is key to addressing this concern. The care manager needs to work closely with the participant to discuss alternative approaches and their risks. It is within the authority of the local program to deny funds for services or activities that it considers unacceptably risky. However, consistent with the philosophy of SDS, this authority would be exercised only in extreme circumstances. The local program would have a clear policy regarding what is considered acceptable and unacceptable risk, and that policy would be distributed to and discussed with self-directing participants both at the time the initial care plan is created as well as at six-month reviews.

The local program would have a process in place to ensure that the care manager can document the steps taken to evaluate the risk to the participant. Care managers would be trained in this process. At a minimum, the process would include an assessment of the source of risk, what harm may result from it, the level of seriousness, and the likelihood that the risk will result in a negative consequence for the participant.⁴ The care manager would document conversations with the participant or the participant's legal representative regarding the participant's decisional capacity, their reasons for making this choice, how this choice relates to their desired personal outcomes, and whether the participant was aware of all available options.

⁴ Information taken from Ann Pooler, RN, PhD. "Consumer Safety, Risk and Risk-Taking: A Guide for Community Long-Term Care," and La Crosse County Care Management Organization, "Risk Assessment."

Risk assessments can also be used to minimize risk or, at least, minimize harm by creating opportunities for the participant and the care manager to openly discuss all possible options. These discussions would result in the outcome that will best balance the participant's safety and preferences.

All parties involved in the risk assessment process would sign off on the final decision. While the document is a useful mechanism for ensuring participant preferences for care, it cannot override existing State or Federal laws, nor is it established whether a risk assessment will actually protect providers or local agencies from liability claims. The local program would have an appeal process in place, about which the participant would be given information and any needed direction.

B) Liability

While there is potential liability in all forms of long-term care delivery, both local programs and participants may have particular concern about liability in SDS. Several factors contribute to these concerns. First, there is not a corporate provider entity (such as a supportive home care agency) to incur liability. Second, participants are serving directly as employers. Finally, participants are making more independent decisions than under standard service delivery situations. These concerns would need to be proactively addressed for a successful statewide implementation of SDS.

Fundamentally, careful care planning to assure a safe plan, combined with ongoing monitoring, provide the best protection against future liability. Risk for participants (and indirectly for local programs) may also be reduced if workers compensation insurance policies are purchased either for or by the participants. If a participant has such a policy and his/her worker is injured on the job, the policy would pay. This would reduce the chance that the injured worker would sue either the participant or the local program in an injury situation.

However, it is recognized that participants, local programs and providers all need additional information on liability in SDS. This information would be reflective of Wisconsin law, and presented in a manner that is clear and accessible to all parties needing the information. A subcommittee of the SDS Cross Unit Functional Team and Steering Committee is working on researching liability issues and developing appropriate informational materials.

The plan for each participant using self-direction would include a written strategy for how the local agency would ensure and monitor all of the following:

- The health and safety of the participant and other people are not significantly threatened;
- Relevant legal and building code regulations are met.
- The participant's expenditures are consistent with the budget and the service plan;
- Safeguards are in place to ensure that the conflicting interests of other people are not taking precedence over the desires and interests of the participant;
- The plan meets all legal requirements for the applicable waiver program.

C) Incompatibility of programs and funding streams

SDS is sometimes incompatible with the specific requirements of particular funding streams. For example, people participating in this initiative have raised concerns about Medicaid

Personal Care (MAPC), which is very prescriptive about the types of services that MAPC workers can provide. This mix of services is not necessarily consistent with participant preferences for supports. Consideration would be given to a state plan amendment to include a self-directed personal care benefit.

Wisconsin's coming transition to care management organizations as providers of long-term care will be helpful in addressing this concern since there will be a single capitated rate, rather than multiple funding streams as is often the case in fee for service long-term care programs.

D) SDS in a managed care environment

There is relatively little experience nationwide implementing SDS in managed care environments, particularly in managed care programs that combine long-term care with acute and primary care services.

Concern has been expressed that a high degree of participant choice is incompatible with managing within a capitated rate. The MCO is at risk in the managed care environment – this raises the question of how much control the MCO can afford to relinquish. Concern has also been raised that participant choice about long-term care services under SDS could adversely impact their health – and therefore costs – in programs that integrate long-term care and primary and acute care services.

This concern can be addressed through careful planning, development of realistic, cost-conscious budgets for SDS participants, and careful monitoring of costs and budgets. Both Family Care and Michigan's managed care system for persons with developmental disabilities and mental illness, have demonstrated that this is possible.⁵ However, additional work is needed to consider the specific challenges involved with integration of SDS into managed care. The SDS Cross Unit Functional Team proposes to work closely with representatives of Family Care, Partnership and new managed care consortiums to develop workable solutions to SDS issues specific to managed care.

E) Use of support brokers

This policy paper recommends that participants have the option of using support brokers to assist them in self-direction. Support brokers are contracted participant representatives who perform duties similar to those of care managers, but who work independently of the local program. Hiring an independent broker compliments the philosophy of self-direction by

⁵ Michigan provides "specialty services" to persons with mental illness and persons with developmental disabilities through a s.1915(b)(c) managed care waiver. Michigan's program, which began in 2002, makes self-determination available to all participants. Participating programs would assure at a minimum that:

- Within an individual budget based upon needs, participants are able to choose or design their own support and services;
- Participants are not required to utilize network operated or contracted services or programs;
- Participants have access to third-party fiscal intermediaries that participants may select if they choose to employ and direct their own support personnel;
- Participants have the option to select an independent supports broker to serve as personal agent and perform supports coordinator functions.

creating another means for the participant to establish and maintain control over his or her service plan and budget while reducing dependency on the local program.

The SDS Cross Unit Team and Stakeholder Committee have developed a proposed approach for the use of support brokers. However, they recognize that additional research and discussion will be required before policy on support brokers is finalized. The following approach is put forth as an initial discussion draft.

The team/committee's recommendation sets out the following guiding principles:

- The participant would have a choice of using a support broker.
- The participant would choose the broker with whom he or she would work.
- To avoid the duplication of services, the broker's responsibilities and costs are carved out of the duties and costs of the care manager. The roles of the care manager and the support broker could be divided in a number of ways. For example, the care manager could focus on formal services routinely funded by local programs. Brokers, who would not be direct employees of the local program, could help the participant develop informal or community resources not typically offered by the local program.
- Participants could also choose to limit or expand the assistance the broker provides. For example the broker could focus initially on the development of the service plan and getting the services, both formal and informal up and running. As the plan comes together, the participant could choose to reduce the involvement of the broker and work primarily with the care manager. The broker's responsibilities would increase or decrease depending on the preferences and needs of the participant.
- The local program could contract with agencies that provide qualified support brokers. Participants could interview and hire support brokers from these agencies. Alternatively, participants could choose to utilize a broker who is a family member, friend, or another trusted adult with knowledge of the funding program. This could be a paid or unpaid support, however, parents, guardians, payees or other legal representatives of the participant would not be appropriate candidates for a paid broker position.

F) Individual budget development, savings, and managing institutional stays

This paper recommends that participants be offered budget authority for SDS, in addition to employer authority. It is important that the size of the budget the participant manages be sufficient to meet his or her needs, but that it is not excessive.

Typically, approaches for budget development in SDS either use historical data (basing the budget on what services for the participant or similar participants cost under traditional service provision arrangements) or based on needs identified in the assessment (starting with a base of zero, determining what the participant's needs are, and then budgeting an amount of funds sufficient to meet those needs in a cost effective manner.) There may be alternative approaches for budgeting as well. For example, the participant's status as reported on the Long-Term Care Functional Screen could potentially be used to predict costs. The SDS Initiative proposes to continue work on researching and recommending budget development approaches.

Another major issue involves what to do with savings if a participant under-spends the budget. In some programs nationwide, participants have been authorized to maintain at least some of the savings for their use, as an incentive for efficient spending. However, this approach may not be acceptable in a tight fiscal environment. This is another area for ongoing review through the SDS initiative.

Finally, budgeting approaches need to consider how institutional stays are handled in SDS programs. If the participant's workers are not paid during a short-term nursing home or hospital stay, the participant may well lose his or her provider network and thus have difficulty returning to the community. However, paying workers when they are not needed results in duplicative, non-productive program costs. This is similar to "bed-hold" issues faced by nursing homes and substitute care facilities. Efforts are needed to develop cost-effective approaches that comply with waiver standards for addressing this issue.

G) Assessing cost effectiveness of SDS

The use of the self-direction option would not increase service provision costs, nor would it inflate administrative expenses. The cost of services being provided under self-direction would typically be comparable to those provided in a traditional care management model. For example, instead of receiving home delivered meals through a network provider, participants could use a pre-paid credit card loaded with the dollar amount normally spent on a month's worth of home delivered meals. The participants could then use the card to order meals they prefer with the understanding that they need to stay within a budgeted dollar amount per meal. The local program would have spent the same amount of money per month in each option, but by using the credit card, the participants exercise much more autonomy and purchase the meals that they prefer.

Costs can be controlled through careful budget development, utilizing approaches such as the Resource Allocation Decision-making method (RAD) to identify creative, cost-effective approaches to service needs. In addition, programs can be designed to provide participants with incentive to keep costs below budget (for example, some sharing of savings with the participant.)

Systems would be developed for ongoing monitoring of costs to make sure they are staying within budget. Timely identification and response to increasing service utilization and costs can both help bring expenditures under control and ensure that the changing needs of the participant are being adequately addressed.

H) Assuring quality of SDS

Each local program would have a quality management plan that outlines its overall approach to assuring quality of services, including those available for self-direction.

Typically, a local program's quality management plan would involve a number of components, including:

- Participant outcomes measurement, using interviews or another technique
- Satisfaction surveys
- Quality indicators (quantitative measures of program performance)

- Analysis of complaints and grievances
- Analysis of critical incidents

Local programs use information from these discovery techniques as a basis for targeting areas for quality improvement.

These quality management discovery approaches apply equally to self-directing participants and participants receiving standard services. For example, self-directing participants can engage in outcomes interviews and respond to satisfaction surveys, with appropriate follow-up for problems that are identified. However, it may be more challenging for local programs to undertake quality improvement initiatives in response to findings of quality problems in SDS, since the local program may not control all service providers like it does in traditionally delivered services. To the extent that quality problems involve care planning, training or other elements in control of the local program, quality improvement for SDS is more readily achievable.

The SDS Cross Unit Functional Team plans to work closely with the Quality Close to Home (QCTH) Initiative, which is developing an overall quality management strategy for home and community based long-term care services. It will make sure that SDS is an integral part of the QCTH initiative, and that the recommended quality management strategy accounts for the unique characteristics of SDS that could present challenges to quality measurement and improvement efforts.

I) Developing expectations for implementing SDS

Requirements for SDS will be included in the RFP that will be issued for new CMOs as part of the long-term care redesign initiative. It would be expected that new CMOs implement SDS programs.

Recognizing that development of fully functioning SDS programs takes time, and that new CMOs will be simultaneously developing and implementing all aspects of their programs, it is recommended that expectations for SDS programs be phased in over time. For example, it may not be required that CMOs offer SDS budget authority to members during their first year of operation—employer authority may be sufficient. Requirements to offer support brokers also may be phased in.

Counties administering COP-W and CIP programs are expected to offer SDS to participants, however as noted earlier in this paper, the extent to which they are doing this varies substantially. It is very important that waiver counties continue and expand their SDS programs during the period of transition to managed care, to better serve participants, to meet CMS expectations, and to develop their capacity to meet requirements of the managed care environment.

Developing a recommended phase-in for new SDS programs and a recommended approach for expanding existing SDS programs will be an important next step in the SDS initiative.

J) Applicability of SDS to mental health/substance abuse and the children's waivers.

This paper has focused on SDS in long-term care. However, representatives of the mental health/substance abuse and children's systems have also participated in the SDS initiative.

The Bureau of Mental Health and Substance Abuse Services (BMHSAS) supports a recovery-based approach to services. A key component of recovery is consumer ability to make choices about their lives and services. As illustrated in Part I of this paper, this philosophy is compatible with SDS. Work is currently taking place on developing recovery-based CSP and CCS services. Self-direction as outlined in this paper may be appropriate for some clients of these services.

It is particularly appropriate to consider SDS for mental health/substance abuse services along with SDS for long-term care, due to the high level of overlap between the two programs. Many participants in long-term care programs also have mental health or substance abuse issues. Therefore SDS policies need to be crafted to fit both systems.

Children's waivers will likely continue to operate on a fee-for-service basis for the foreseeable future; there are no current plans to migrate them to managed care.

Part 4 – Next Steps

This policy paper begins to define expectations for SDS in Wisconsin Long Term Care programs. However, as noted in the text, there are several areas that need additional investigation and refinement. The SDS Cross Unit Functional Team has identified the following areas for further research and policy development:

- Developing a recommended phase-in for new SDS programs and a recommended approach for expanding existing SDS programs.
- Refining the model for use of support brokers.
- Developing methodology for setting participant budgets in SDS.
- Measuring cost effectiveness of SDS.
- Researching liability issues and developing materials for local programs, participants and workers on this topic.
- Developing models for quality assurance/improvement for SDS, integrated with overall quality management strategies for long-term care programs.

Workgroups involving the SDS Cross Unit Team and the SDS Stakeholder Committee, and staffed by TMG, will be addressing these issues in the coming months. They will be proposing modifications to the proposed SDS policy, as appropriate. They will also be developing resource materials in these areas to support local SDS programs.

In addition, the SDS initiative will be developing specific tools and supports for designing and implementing local SDS programs. The tools and supports will be geared towards participants, care managers, local program administrators, and providers. In developing this material, the initiative will build on the wealth of resources on self-direction that is available nationally. However, all material will be reviewed and edited to ensure that it is compatible with Wisconsin law and policies. The material will be organized to support web-based access.

Representatives of the SDS initiative will work with DDES staff charged with developing contract language for new CMOs to draft contract provisions on consumer self-direction.

Finally, representatives of the SDS initiative will educate county waiver programs, Family Care CMOs, and Wisconsin Partnership programs about the SDS policy, and will familiarize them with resources that have been made available to support design and implementation of local SDS programs.

Attachment A
Description of the policy recommendation development process

The SDS Cross-Unit Team and the Stakeholder Committee developed the policy recommendations in this report. Dan Johnson of the Bureau of Aging and Disability Resources chaired the effort, and TMG provided staffing to the groups.

The SDS Cross-Unit Functional Team meets at least monthly. It is responsible for directing the SDS initiative and for guiding the policy recommendation development process. Its membership includes:

Cecilia Chathas	BLTS – PACE and Partnership
Stuart Gilkison	BADR
Jennifer Gillespie	DDES – Administrator’s Office
Pam Groeschl	BLTS – Children’s Section
Dennis Harkins	Pathways
Chris Hess	Community Care – Milwaukee
Dan Johnson	BADR
Charlie Jones	BLTS – Managed Care Section
Cheryl Lofton	BMHSAS
Jenny Neugart	Pathways
John O’Keefe	BLTS – DD Section
Gail Propsom	BLTS – COP Section
Sharon Ryan	DHFS
Ann Sievert	BADR
Eva Williams	BADR – intern
Deb Wisniewski	Sharing Common Ground

The SDS Stakeholder Committee is a broad-based group including consumers and representatives of county long-term care programs, Family Care CMOs, Independent Living Centers, fiscal agent organizations, and mental health CSPs. The Committee has met 5 times to date (3 phone conference and 2 in-person meetings.) Members of the SDS Cross Unit Functional Team also participated in these meetings. The SDS Stakeholder Committee is for advising and contributing to the SDS expansion effort. Its membership includes:

Nancy Austin	Villa Hope CSP
Joyce Binder	Independent Care
Kathi Cauley	Jefferson County CSP
Dennis Ciesielski	Dunn County DHS
Tiffany Dorst	Waupaca County DHS
Jenny Fasula	Mid-State Independent Living Consultants
Pam Frary	North Central Health Care

Mary Herzog	St. Croix County DHS
Pat Keefer	Milwaukee Center for Independence
Kathie Knoble-Iverson	Independent Living Resources Services
Ron Lockwood	St. Croix County DHS
Karol McKormick	Jefferson County CSP
Mark Morrison	Door County Dept. of Community Programs
Roxanne Price	La Crosse County CMO
Ginger Reimer	Independence First
Dan Rossiter	Dane County DHS
Jean Rumachik	Society's Assets
Tim Sheehan	Center for Independent Living – West Wis.
Naomi Silver	Consumer Advocate
Sally Sprenger	Anew Home Healthcare
Matt Strittmater	La Crosse County DHS
Andrea Summers	North Central Health Care
Chris Thomas-Cramer	WCDD
Dee Truhn	North Country Independent Living
Kari Vinopal	CCP Community Services
Tom Wirth	Eau Claire County DHS
Deanna Yost	Consumer Advocate
Lisa Zaspel	CCP Community Services

The SDS Cross Functional Team and the SDS Stakeholder Committee have had extensive discussions of SDS policy issues, and have jointly contributed towards successive drafts of this policy paper.

The Management Group, Inc. (TMG) provides staffing for this initiative. TMG staff includes Gail Nordheim, Shanna Jensen, Dave Verban and Theresa Hobbs.