Consumer Directed Support: Lessons Learned from Wisconsin's Family Care Program

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Abstract

*This qualitative study examined Family Care managers' and Interdisciplinary Team members' perspectives on various aspects of implementing a self-directed supports service provision in five counties in Wisconsin. Family Care is a program that uses a managed care model for the delivery of community based long-term care services for frail older adults and adults with physical and/or cognitive disabilities.[1] Factors facilitating implementation and barriers to implementation of self-directed supports were the main foci of this research. Findings and **lessons learned/recommendations** presented in this report include initial implementation issues such as member involvement in the early planning stages, legal issues, and intellectual shifts, along with ongoing issues such as member training and choice within the model.*

Introduction

In 2000, the state of Wisconsin instituted Family Care, a managed care program for long-term care for people with disabilities and frail older adults. Family Care, as part of Wisconsin's long-term care re-design effort, sought to improve community-based services to Medicaid eligible people through the elimination of waiting lists. Additionally, this waiver-based initiative uses a managed care model, wherein participating counties receive a capitated rate per enrolled consumer. At the Care Management Organization (CMO), as with many other managed care models, services are determined and delivered to individuals enrolled in the program in the hope that the cost of services among some consumers with high utilization will be offset by those who use fewer services. Eligible individuals are first screened for participation in Family Care by a Resource Center in each of the participating counties. Once found eligible, they are enrolled in the county CMO that administers Family Care. The CMO then works with the consumer/member to identify service/support needs and coordinates the delivery of the services. One important distinction between Family Care and the other community-based long-term managed care models in Wisconsin (PACE and Wisconsin Partnership Program) is that Family Care does not provide medical care. Individuals in Family Care may use whichever healthcare providers they choose.

Each of the five county Care Management Organizations (CMOs) must include a Self-Directed Supports (SDS) option. SDS is a consumer-directed service provision schema in which control over specific services like supportive home care, respite care, and transportation rests with the members and their loved ones, to a much greater extent than with conventional agency-directed services.

Given that there is a trend towards Consumer-Directed Care models across the United States and Europe[2], it is especially useful to examine the SDS program in detail. In the qualitative study presented in this report, the authors examined the perspectives of the CMO managers and

Interdisciplinary Team (IDT) members (including care managers and nurses) regarding SDS implementation in the five Family Care counties. Factors facilitating implementation and barriers to implementation were the main foci of this research.

Methods

This study was based primarily on qualitative group interviews. During September and October of 2004 two interviewers conducted fourteen focus group interviews with groups of managers and Interdisciplinary Team (IDT) staff at each of the five Family Care CMOs.[3] Focus groups were used in order to ellicit the broadest range of staff's perspectives on factors which facilitated or inhibited the use of SDS. Participants were recruited for participation by a contact person on staff at each CMO. The interviewers asked contact people at each CMO to select managers and IDT members to participate in the focus group interviews.[4] Interviewers requested that IDT members with significant SDS experience and limited SDS experience be included in the focus groups. Each focus group was comprised of three to seven participants, and all interviewees were provided with interview questions prior to the group interviews. At each CMO, focus groups were organized as follows: managers and supervisors were interviewed together, followed by one or two groups of IDT members. In larger counties, IDT members were separated into "more experienced" and "less experienced" focus groups. This procedure was as an attempt to elicit honest responses from individuals with the broadest range of perspectives. Each focus group lasted approximately 70-90 minutes, and the interviews were audio recorded. Participants gave written consent for permission as per a protocol approved by the Institutional Review Board of the University of Wisconsin-Madison. (See Appendix A for a list of interview questions.)

The interviewers began each focus group with both a review of the overall purpose of the study and an explanation of what to expect during the interview. With some exceptions, interviewers asked questions in sequential order. However, IDT focus groups less experienced with SDS were not asked to give an historical overview of the CMO's SDS implementation. Interviewers added questions for clarification as appropriate, and took written notes during the interviews.[5]

Following the focus groups, the interviewers transcribed the audiocassette tapes and coded the transcripts by hand. Coding consisted of systematically constructing categories of salient ideas, concepts, and issues seen throughout the SDS interviews. In addition, interviewers compiled a summary of all of the pertinent ideas expressed in the interviews, wrote a summary of the main themes, and recorded qualitative impressions for each interview. Ideas that surfaced across multiple interviews, or that were of central importance to a single interview were included as possible themes for the final report. This coding and analysis allowed the interviewers to thoroughly evaluate the data in order to provide recommendations that reflect the concerns and professional insights of the people responsible for implementing SDS.

Issues Common to CMOs

More often than not, interviewees at the different CMOs reported similar experiences with, and opinions about, SDS.   While no two CMOs have had the same experience with implementation of SDS, general findings cut across CMO lines.   Common findings across CMOs during the *early implementation stage* are presented first, followed by common findings for SDS *as an ongoing service*.   Note that not every interview or every CMO touched upon all of the aspects of SDS discussed below, but that interviewees in at least two or three of the five CMOs commented on the issues presented in this report.

INITIAL IMPLEMENTATION ISSUES
Implementing SDS in the Family Care Counties invariably presented certain challenges across the CMOs.   At the same time, certain factors tended to make implementation more feasible.

In the context of shift to Family Care
CMOs reported that during the shift to Family Care, SDS was often not the highest of priorities. In a context in which an entirely new administrative and programmatic structure was being developed in a challenging environment, SDS was often valued, but not seen as one of the key priorities.   A manager reported: "There were three goals the first year.   SDS wasn't one of them. That nobody got hurt . . .   We pay our providers.   And we survive."   Similarly, another manager recounted, "I think leadership both here . . . and at the state, recognized that while SDS was in the Family Care contract . . . [it] was not the highest priority. . . . We talked about it, and . . . we were starting to implement it a little bit.   But it was never a priority for us, the same as it was a priority to get our claims system operating, so that we could pay our providers.   As it was to get our IT system operating, so that we could figure out where our money was going, so we wouldn't go bankrupt."   Because of the relative unimportance of SDS in relation to other aspects of Family Care implementation, SDS was not always given sufficient attention at the beginning.

SDS as a contract requirement
In some CMOs, it is unlikely that SDS would have been developed when it was, had it not been a contract requirement for Family Care.[6] A manager remarked, "If we wouldn't have had Family Care, we probably wouldn't have done it.   That was our impetus to do self-directed supports." Similarly, another manager said, "I think [SDS] was always important . . . if that is what [the members'] wish was.   But . . . making sure the policies and procedures were developed . . . became much more important the closer the implementation date got . . . so that we were consonant with our contract"

Managers reported that with the implementation of Family Care came the addition of refinements that were essential for SDS to function, even in counties with pre-existing SDS services.   For example, each CMO had to develop a brochure for the Resource Center.[7] Similarly, in some places pool worker systems had to be implemented to provide backup to members who were self-directing. One care manager supervisor noted that since the

implementation of Family Care, "[The CMO has] tried to standardize [SDS]—how [SDS employees] are hired, how they are paid, what the expectation of that worker is. . . . It's become more refined, more governed, more structured."

Reconciling SDS and managed care philosophies
Most CMOs reported that one challenge in implementing SDS was a sense amongst staff that managed care and self-determination are philosophically incompatible. There are two specific areas in which these philosophies were felt to be incompatible by some: from a fiscal perspective and from a control of services perspective. Firstly, increasing cost-effectiveness is probably the most important reason for switching to a managed care model. By contrast, while SDS may at times be cost-effective, members are theoretically allowed to "bank" some of the hours allotted to them under SDS for alternative uses. Thus, some interviewees wondered whether or not services that were going to be banked should have been included in the individualized budget in the first place, from a cost-effectiveness standpoint. In other cases, fiscal eyebrows were raised by the fact that members could set the wages they paid their SDS workers at a higher rate. A manager remarked "In a managed care environment, you're . . . being the most cost effective that you can. We have embraced that people have the right and the ability to hire their own staff [through SDS]. The question then is where is the cost effectiveness if [members] want to pay all of [their] staff $10 an hour?"

Secondly, some interviewees felt that the underpinning value of member control in SDS philosophically requires giving members full power over all aspects of the services they receive. These staff people felt that for program to be consonant with this value, the CMO and care managers should have practically no role in service provision beyond funding members' care. From this perspective, however, the role of CMOs in protecting member health and safety would be called into question. (This issue is discussed in more depth below in the section "Member choice on a continuum".) These tensions between cost-containment and member choice, and between protection of health and safety and member choice, are inherent to an SDS model. SDS philosophically requires ceding some control to members, when more of this control has traditionally resided in state/county agency hands. It may be that at the root, this philosophical shift is the locus of the tensions, rather than the intersection of SDS with a managed care model. (See below: "Intellectual shift from traditional to self-directed model")

Legal issues
According to management level focus group participants in each county, liability was a barrier for initial implementation. The fear was that the CMO would be considered the employer of record and found liable in the case of accidents involving SDS members or employees. Depending on the county, the establishment of a fiscal intermediary, a co-employment agency (or both) helped reduce the liability risk. This helped pave the way for SDS, though legal risk remains a very serious ongoing concern for all CMOs.

Importance of previous experience with SDS-like services
Interviewees at several counties reported that having previous experience with SDS-like services made a noticeable difference in the ease with which SDS was implemented in their county. CMOs that had some experience in member self-direction reported an easier transition to a functional SDS option. For instance, one CMO had the distinction of being a Robert Wood

Johnson Foundation grantee for their self-determination project. As a result, this CMO had worked closely with a consultant on self-direction before Family Care was implemented. As a result, fiscal intermediary and co-employment options were both well established, and the staff seemed to have a clear understanding of the philosophies underpinning SDS. This county also had an ongoing workgroup in which SDS issues are discussed. Other counties that did not have this sort of pre-existing SDS training have had a longer road to travel toward full implementation of SDS.

SDS as part of a larger movement
Interviewees at some CMOs expressed that understanding SDS as part of a national movement facilitated an embrace of SDS philosophy. A manager expressed the importance of understanding the larger context of consumer directed supports: "Maybe the biggest change [in SDS since becoming a Family Care county] is consciousness that this is part of a national movement." This awareness lent implicit support to the SDS philosophy of member choice in hiring workers. Similarly, care managers at another CMO credited the Independent Living and People First movements, along with other agencies in the wider community, with helping create momentum for SDS. When direct-service staff understood that SDS was a cutting-edge innovation, they were more likely to embrace the philosophy and practice of SDS.

Supportive leadership, especially one person who takes a lead on SDS
The existence of one (or more) individuals with a passionate interest in SDS seemed to affect how eagerly SDS was embraced by a county. The impact could be felt especially strongly if the people excited about SDS were in positions of authority. In one CMO county, Interdisciplinary Team members reported that there had originally been a higher level manager in the county who was a strong advocate of SDS. For example, according to one interviewee, because of that person the CMO was, "more likely to at least go through the motions of being interested in SDS." Another person initially served as an outside SDS consultant for care managers pre-Family Care. That person later became a care manager with the CMO, and served as an important informal SDS consultant for other care managers. Finally, in another county, care managers reported that a DD manager and a supervisor both enthusiastically bolstered support for SDS service provision around the time the county became a CMO. Since then these strong advocates have been promoted, and have found they are unable to devote the same time and energy to SDS. The result, according to some of the interviewees, was that SDS, while still supported by management, is not always given the same special attention it once was.

Interviewees from another CMO were also extremely passionate about the potential role of SDS, and have put a lot of energy into the program. The interviewees continue to work toward implementing a number of creative, innovative ideas for offering greater choice to members, whether through debit cards for choice in meals, through cooperative housing for elders, or through self-directed nursing home care.

By contrast, in another CMO, which has struggled to develop SDS fully, one care manager remarked, "I don't think upper management has taken it on passionately. You can't do more then. . . . You have to have the buy-in." When SDS is not a priority for management, implementation faces extra hurdles. Having one, or a few, people to take SDS on passionately can go a long way toward comprehensive implementation.

Intellectual shift from traditional to self-directed model
Traditionally, state agencies that work in long-term care are accustomed to having a certain amount of control over service provision to care recipients. While SDS still falls within the rubric of state-supported services, and control remains largely with the state, under SDS, the CMOs must cede some amount of control to members. This shift requires a reorientation towards agency control, which can be uncomfortable for managers and IDTs alike. Therefore, finding ways to grow more comfortable with less control is essential for effective implementation of SDS.

One manager articulated this dilemma well: "I think the part that people struggle with is the giving up of control, agency control. . . . We just have to let go, as hard as it is, we have to let [members] try [SDS]. . . . It's really hard for people who've been with the agency and have had that control for so long to just say [to a member] 'you know, if you want to do it you can do it, and we'll help you as much or as little as you want.'" A care manager from another CMO remarked that CMO management "couldn't do [SDS] if they didn't believe in [it]. But I think SDS is a thorn in their side, because it's less easy to control, manage, [and] fund." The managers at one CMO reported that at the administrative level, educating the board of directors was also essential, especially because SDS is accompanied by member control of fiscal resources: "It was also important to inform policy makers. Because that's a strange concept for a board member to know that members are controlling resources."

Some care managers are initially equally uncomfortable with SDS, and feel that they lack the power to monitor SDS workers and financial resources appropriately. For care managers, this issue came up not only in discussions of initial implementation, but also in discussions of SDS as an ongoing service, because new interdisciplinary team members are constantly hired and trained by CMOs. One care manager clearly expressed discomfort with the idea of members controlling resources, especially the issue of "banking" hours for use in alternative ways. Another care manager similarly expressed concern about perceived lack of agency control over SDS: "There really isn't any accountability. It's just the member's word against the person who is providing the cares. . . . How do you really know that providers were doing what they said they were doing?" This person later admitted, "I think it's just so much easier to go through an agency. And you've got someone who's actually monitoring the workers, they're accountable, and if they can't make their shift, there's a replacement." The philosophical shift to an SDS model can be a major challenge at all staff levels.

Monthly vs. annual budgets
At the outset of SDS implementation in a CMO, each county struggled with decisions about the format SDS took. One of the key decisions was whether members who choose to self-direct will have a monthly or an annual budget. Although interviews did explicitly solicit information on this issue, there were implicit differences in the interviews depending on CMOs' choice to use monthly or annual budgets. Only one CMO chose to operate SDS with an annual budget for members, and this resulted in some notable differences. Care mangers in this county discussed the issue of hours that are "banked," or left unused by the member, either intentionally in exchange for some other service or good, or unintentionally when actual service usage is less

than what had been expected. This issue did not surface as a major theme in the other CMOs, because monthly budgets do not result in a considerable number of banked hours.

Choosing an annual budget has a number of advantages. Annual budgets offer greater member control over resources for members who want this, as well as a greater flexibility for members to obtain goods and services. Care managers at the CMO that banks hours did note that this practice can be very useful in the event of unforeseen circumstances. For example, if there is an unexpected doctor's appointment, banked hours can be used to provide transportation in a pinch.

Drawbacks to annual budgets also surfaced in the course of interviews. First, annual budgets require ongoing monitoring throughout the year to ensure that use of resources is roughly in the target range. This can be confusing to members and time consuming for care managers. Secondly, care managers find themselves in a quandary when members spend either significantly more or less than their budgeted amounts. They are not sure if the annual budget should be reduced, or if the hours should be saved for other uses in the case of under-spending. In the case of overspending, care managers need to decide whether to increase the budgeted amount, or to let the overspending serve as a learning experience for the member and keep the budgeted amount as is, unless health and safety are at risk.

State workgroup
When Family Care began, a group with 1-2 representatives from each CMO was formed to work on implementing SDS in the five Family Care CMO's. In general, the CMO interviewees reported that the state SDS workgroup for Family Care was extremely useful, especially during the implementation phase. The CMOs found that the SDS workgroup allowed for a cross-fertilization of ideas, the development of training materials and protocols, and the sharing of documents.

Because SDS was new to most of the CMOs and the state alike, the workgroup was a "work in progress" for both state consultants and CMO participants. A manager who believes that the work group has been "tremendously useful," explained that in the workgroup "We were all learning together, and we wanted to create the best options for our members with no experience [self-directing their services]."   This manager went on to explain what happened in the workgroup meetings, and how it impacted implementation:

> "Everyone got together and sat around the table and tried to hash through guidelines and protocols. One of the CMOs described what they are doing in terms of setting up annual individualized budgets, and what happens if there is money left over or not enough at the end of the year. . . . We could take it back and decide, 'Do we think this is something that would work within our program?'"

Staff at one CMO especially found the workgroup useful because of its delayed timeline for SDS implementation.   The CMO was able to capitalize on the work of the other CMOs that had preceded it: "The state workgroup was very helpful. We're a year younger than the other CMOs [in] age and [in] implementing SDS…we've borrowed a lot of ideas from other places and that was extremely helpful." For example, this CMO adapted a worksheet from another CMO to help

the interdisciplinary teams determine wage ranges for SDS members.

Since the workgroup did not "pick up steam" until 2002, one complaint that surfaced among those interviewed was that the workgroup could have been stronger earlier on in the implementation process. In addition, some interviewees complained that the state did not seem to place a priority on SDS or the SDS workgroup.

Member involvement in early implementation
Most, but not all, CMOs reported that members had been involved during initial SDS policy development. Usually member input was sought via CMO workgroups. For those CMOs that had member involvement in an SDS workgroup, interviewees found to be useful. Managers at one CMO reported that members on the workgroup helped the CMO staff to "get our heads around the philosophy of self-determination," while managers at another CMO found that members "looked at [SDS] through advocates' eyes more than we would have." In a few counties, members actively helped develop policies for SDS. For example, a care manager explained that, "members must be offered an advocate prior to a denial of SDS. . . . Before they are denied they must be informed that they can have an advocate present . . . There was member input into that policy." Some of the CMOs continue to consult with members of their original workgroups as new policies are developed.

In another CMO, members had an indirect impact on implementation despite their absence on committees or workgroups. A care manager explained that there were a number of determined members, especially with physical disabilities, who had a special interest in the SDS concept and pushed to implement SDS as quickly as possible: "They kept pushing—'When can we start this?'" In a multiplicity of ways, members influenced implementation efforts.

ONGOING ISSUES

Even after initial implementation of SDS, issues related to the ongoing administration of SDS have continued to surface in the CMOs. These challenges call for careful consideration since they occur regularly across CMOs.

Staff training
With notable consistency, the need for additional training arose as an issue. In nearly every interview, interdisciplinary teams and managers alike noted that additional SDS training would be useful to staff. Training is essential for the initial implementation of SDS, and staff tends to appreciate trainings. One care manager put it this way: "Training about what SDS is has been useful . . . so we can know what the vision is, what we should be doing, what we can be working toward and striving for." Another care manager attended a training session and said: "I went to the [SDS training] that we just had. It was much better than what we've ever had. It would have been great if we'd had that back [at the beginning]. It gives you an overview of SDS, why it came about, [and] how to explain it to other people."

However, ongoing staff training may be at least as important as the initial training. SDS requires a major shift in philosophy, and working with SDS is a practical, hands-on skill. As care

managers develop more experience with SDS, new questions arise. Therefore, initial trainings, though essential, are of only limited benefit, because trainees are unable to absorb all of the information about SDS until they have used the system in practice. One care manager noted, "I think (the SDS process) is overwhelming until you've actually gone through it a few times. Then it's like, 'Oh, I get it.' I had to ask [my supervisor] a lot of questions when I first got here." Another manager echoed the sentiment that SDS can be overwhelming at first, even with an initial training: "We've learned that there's so much information that goes with [SDS] that if [care managers] don't start using it right away and keep using it, they seem to stay away from it because they don't remember what they were trained on."

The need for special training on setting budgets on an ongoing basis was expressed by many interviewees. Specifically, a care manager suggested the following: "Structured training . . . would be beneficial for us. Even just to brainstorm. To give everyone the same case and to see what they would come up with for hours." In another CMO, where SDS has been implemented more recently, a care manager expressed, "we know the basic things about getting [SDS members] through [the fiscal intermediary], but talking about a budget . . . I have no concept of what that is."

From the interviews themselves, there was evidence that more training would indeed be useful, because care managers sometimes expressed conflicting ideas or misinformation about SDS. In some counties, care managers were using very different methods from one another for setting budgets. In other counties, care managers disagreed with each other about the number of hours that people are eligible for, given various types of needs. In some counties, care managers had little idea about the use or benefit of co-employment agencies, and in others, they had little information about fiscal intermediary services. There was also evidence that in some cases, care managers did not understand the underlying philosophical reasons for existing SDS policies. In at least one county, care managers were familiar with neither the term "self-directed supports" nor "member-directed supports" prior to the interview.

Member training and SDS provider training
Member training was also identified as a key ongoing issue for implementing SDS at the CMOs. Except for one CMO, all counties felt that their current member training was inadequate, and wanted additional member training. This concern is reasonable, since without member training, members may make mistakes as employers. In one CMO, a care manager reported that a member had suspended an SDS worker inappropriately. This care manager also expressed concern that a member could be held liable for such mistakes. Managers at another CMO reported that member training was a barrier for those using a fiscal intermediary, since responsibility for the bulk of member training on hiring, firing, training, and supervising employees was falling on the IDTs. Interviewees at other CMOs echoed the concern that member training was a drain on IDT time. In the one county where member training did not arise as a concern, nearly everyone uses a co-employment agency, rather than a fiscal intermediary.[8] This suggests that member training may be especially important when fiscal intermediaries are used, and the extra services that co-employment agencies offer are unavailable to members except through CMO staff.

Interviewees had a number of ideas for improving member training. Managers at one CMO reported that they would like to make a video for member training, but would need state support for such a project. They also would like to develop training materials for members who are hearing impaired, blind, or non-English speakers (i.e. materials in Hmong, Spanish, etc.), with more sensitivity to ethnic differences. Again, state support would be needed for this.

Closely related to member training is the issue of who trains SDS providers as employees. In some counties, there is a concern that members are not training SDS providers properly, especially when fiscal intermediaries, rather than co-employment agencies, are utilized. A manager remarked, "We've talked about training the staff that are hired [by members]. Many times members would like to have training available for them, so we've talked about our role as far as making available training for caregivers." The special case of training SDS providers in performing highly skilled cares merits mention. In one county, interviewees acknowledged that it is the CMO nurses who make SDS a possibility for some members. Without nurses training the SDS providers in certain skilled cares, some members would not be able to self-direct their supports. However, nurses expressed concern about their liability. They worried that since they assist in training providers, the nurses themselves or the CMOs could be held liable as the employer in a law suit.

Setting budgets
Figuring out how to set individual member budgets also came up frequently in interviews. With the exception of one CMO, where according to staff interviewed, members do not give input into the rates paid to SDS workers; interviewees in each county expressed that they struggle over the gray area of setting budgets. One manager summed up the dilemma succinctly: "The whole budgeting thing is very confusing to case managers and managers."

Deciding upon the number of hours of service and rates of pay to SDS providers in individualized budgets is tricky for CMO staff. Interviewees also discussed inconsistency across care managers in setting budgets, as well as balancing care manager and member input. A care manager stated:

> "We're in the process of developing guidelines and we're really not sure about consistency over teams. . . When you're looking at the same needs, one budget may be higher than another person . . . We have bands of identified pay rates based on the services they're providing . . . But it's really at our discretion, what people are being paid. I find it very challenging to try to establish those rates for people."

Another care manager added that deciding whether or not to leave room in the budget for raises for SDS workers complicates matters further.

Care managers in a number of counties also mentioned that families and providers have networks outside of the CMO in which they discuss SDS budgets, services, and rates of pay to workers. As a result, members and their families sometimes challenge care managers regarding why other members' workers are paid a higher rate, or why other members receive more hours of care.

CMOs also face dilemmas when altering existing budgets. It can be a challenge for care managers to determine if a member's needs have changed sufficiently to warrant altering his or her individual budget, or if the member should be held accountable to stick to the individualized budget previously agreed upon. Closely related to this question is the issue of what to do with unused portions of individual budgets at the end of the month or year. A manager posed these dilemmas: "If the budget is $3000 a month and you've got a hundred left over, what happens in terms of rolling that [amount] over? It all goes back to the CMO coffers anyway, so how [is] that truly an individualized budget? How do you adjust [the budget] based on changing care needs?"

Staff time required
In nearly all of the counties, interviewees expressed that those members who self-direct require more care management time than members who do not. One CMO was the exception, again possibly because nearly all SDS members in that CMO use a co-employment agency. In the other counties, interviewees expressed that caseloads were often too large to give SDS members as much time as they would like. One care manager stated, "I once told the director, if everyone would be SDS, our max [case]load would be twenty. I couldn't do more than twenty." Similarly, another care manager reported that she does not have the time to adequately research and answer many of her members' many questions regarding SDS. She explained that care managers may be caught between wanting to present SDS as an option to members, and maintaining a manageable workload: "Workers have to decide if they're going to promote the concept [to members]."

The SDS time requirement was reported to be especially tricky in particular scenarios. Case management of SDS becomes more time-intensive when: SDS is set up initially, when SDS members have complicated care needs, when members experience frequent turnover of their staff, and when members' care needs change. A manager mentioned that in cases in which a member's informal support people cannot adequately assist the member in self-directing, Interdisciplinary teams must expend additional time "to help them understand their budget and to manage it."

Paperwork
One reason that SDS requires additional staff time is because it often demands more paperwork than non-SDS services. Paperwork is an issue for members using a fiscal intermediary, especially because co-employment agencies handle the majority of the paperwork themselves for the members who chose to use their services. SDS paperwork for members who choose fiscal intermediaries includes not only regular care plans and service authorizations, but also background check forms, W-4 forms, and other related paperwork. Each time a member hires a new worker, paperwork must again be completed.

Two CMOs have attempted to adapt their infrastructure to assist care managers in handling the SDS paperwork for the fiscal intermediary. One of the CMOs seems to have successfully overcome some of the paperwork issues by removing most SDS paperwork from care managers. Said one care manger, "Support staff do the paperwork. It's minimal work for the case managers." In the other CMO, the management has recently instituted a similar system change for the fiscal intermediary paperwork, so that claims staff will be taking over much of the

paperwork. While it is too soon to tell how effective this change will be, it is a change heartily welcomed by care managers.

In only one CMO were both a co-employment agency *and* a fiscal intermediary functioning in practice. In this county, however, interviewees expressed a concern that care managers may be steering members away from the fiscal intermediary option, since the paperwork for co-employment is much more manageable. One manager in this CMO stated, "Sometimes I worry that the growth in [the number of members choosing co-employment] is also because there is lots of paperwork" for the fiscal intermediary. This concern may not be unfounded, because according to one care manager, for members choosing a fiscal intermediary, "[t]here is so much paperwork, at least initially, that it is prohibitive. I try avoiding using [the fiscal intermediary] if I can. . . it takes away too much time, and I've spent a whole day sometimes trying to get things set up." On the flip side, another care manager remarked that with their co-employment agency, paperwork is practically a non-issue: "They fill out the paper work. I mean *literally*, we have to sign something, and that's *it*."

Issues unique to target populations
Finding ways to creatively address the needs of different target groups within CMOs presents an ongoing challenge. Some CMOs have care managers that specialize in one or two target groups, and in other CMOs, each care manager works with all three target groups (frail older adults, adults with developmental disabilities, and adults with physical disabilities).

While people with developmental disabilities have benefited from SDS, there remain some real barriers. Problems arise, according to those interviewed, when members do not have informal supports or guardians who can help them self-direct their care. Interviewees reported that the primary challenges for people with developmental disabilities are finding and keeping enough appropriate SDS staff, and arranging for backup. One care manager said about a member with a developmental disability: "He's lonely, so sometimes he grabs for some of these not-so-good-ones out of loneliness or desperation. He has nobody there [to assist him with managing his care], and he doesn't want to go to an agency." Another care manager added that "monitoring provider liability, performance, and general behavior" are important extra care management responsibilities for clients with developmental disabilities using fiscal intermediaries, because these members "are vulnerable and can be easily manipulated." An additional care manager also points out that the people who really advocate for SDS for members with developmental disabilities "tend to be . . . a family member or friend who is sick of the existing system not meeting their [loved one's] needs."

SDS issues for people with physical disabilities are similar to yet different from SDS issues for people with developmental disabilities. First, some of the people who tend to direct their own services most extensively and with as little outside assistance as possible are often people with physically disabilities.   People with physical disabilities are also more likely to advocate for themselves. One manager reports that people with physical disabilities often "know who they want [to work for them] and what they want that person to do." However, as with people with developmental disabilities, finding sufficient backup staff can be a serious challenge. (See below: **"**Meeting needs for backup" for additional discussion.)

In Wisconsin's Family Care program, frail elders make up the majority of people using SDS, yet there may be qualitative differences between frail elderly members and younger people with disabilities that self-direct. There is a perception among some care managers interviewed, for example, that elders' orientation to SDS may reflect more limited interest in self-directing their care *comprehensively*. A manager reported that while elders do want control over their services (e.g. choosing their own workers and services), "Based on years of experience hearing what older people want, they don't want to sit down with a budget and a calculator or whatever." Another manager added that the elders she works with have fewer demands of SDS. They tend to be appreciative of the fact that a family member can be paid to take care of them, and that is enough to make them feel satisfied with their services.

Consistency across IDTs within a CMO
In most CMOs, at least some interviewees suggested that care managers within the same CMO do not always make decisions about SDS care plans that are consistent with one another. Perhaps not surprisingly, in a CMO serving a large, diverse population, care managers reported some inconsistency across CMUs (care management units--contract agencies that administer Family Care). When asked if there is a wide variety between CMUs with respect to what they offer SDS clients, care managers responded unanimously:

> "Oh yes."

> "Absolutely"

> "This depends on the make up of the case managers, who they have for leaders, and who they have for clients."

> "In talking to these staff at [a CMU serving a similar population] you find out
> that people [there] are interpreting procedures differently, interpreting guidelines
> differently."

Even in at least one small county, similar problems surfaced. With respect to setting the number of hours in a self-directed care plan, one care manager said, "I think one of the problems we have is the tool we use to justify the hours. There's no inter-rater reliability in the tool." Another added, "I'm getting a lot of cases that are new to me, and there is a wide range in the number of hours that have been determined [by other care managers] for supportive home care."

One source of frustration identified by care managers is that members who have networked with one another sometimes confront their care managers about other people who they perceive to have similar needs, but who have been authorized to receive a different number of hours. While needs will often legitimately differ between members, if care managers are not confident that their peers are all using similar methods to set hours and budgets, they feel uncomfortable justifying their decisions to members and their advocates: "I don't think there is good . . . consistency between the teams [for arriving at a] number of hours and a salary. . . . I often get challenged: 'why can't my worker get as much as the lady down the hall's worker?'"

One CMO seems to have avoided some of the problems of consistency, because the program is

older and more established, and because there is a worksheet in place for helping care managers devise budgets with members. Another important mechanism for ensuring consistency is regular staff meetings. Most CMOs reported an absence of regular staff meetings to discuss SDS, though staff members were welcome to bring up SDS issues at general IDT meetings. At another CMO, a care manager lamented the absence of mechanisms to ensure consistency: "At first we had all these team meetings and we didn't make any decisions alone, and [now], some of these decisions we're completely doing on our own, and everyone's making them differently." Without regular venues for discussing SDS within CMOs, problems with consistency across care managers may continue to strain care mangers' relationships with members.

Paying family
Another serious issue that CMOs face is the question of under what circumstances CMOs should authorize family members to be compensated to care for a member who is self-directing services. The state and CMOs collaborated, through the Care Management Workgroup, on a document to help care managers determine when it is appropriate to pay family caregivers. While this effort has helped some to navigate such decisions, other care managers interviewed continue to struggle with this issue. One care manager explained the dilemma: "Some of us hesitate to pay family members. . . .Do we pay them? Do we not pay them? What do we expect of them when they're living with the member? That's a hard area for all of us."   This "extreme ethical dilemma," as another manager termed it, elicited a range of opinions from IDTs and managers. At the root is a complex interplay between cultural norms regarding the expectations of family members to care for one another, questions about what should constitute monetarily remunerated work, the economic needs of low-income families, and state and county fiscal constraints. The issue comes up mostly with respect to supportive home care, since for personal care, few people questioned the importance of paying family members to provide cares.

Some interviewees recognized the important benefits of paying family members to provide care to members. A care manager recalled the first time he was introduced to the idea that paying family makes sense, because family members are positioned to provide the best care: "I remember a specific conference . . . this guy at the conference said, 'who is going to provide the best care other than a loving family member?' And that really was what sent the message home. And he was right. . . . I started to look at things differently."

At the same time, payments of families under SDS challenge deeply held norms about expectations that family members care for their relatives, simply because they are family. A care manager expressed this norm, and her concern about maintaining the integrity of family as an informal support: "I think it's everyone's responsibility to provide care to family members living at home. But if they think they can get paid to do that, then you are destroying informal supports."   Furthermore, care managers understand that the CMO saves money when family provides care free of cost, and this probably also results in less willingness to pay family.

The conditions under which paying a family member felt ethically sound to care managers varied considerably. In some cases, the less attached a family member is to the idea of getting paid, the better care managers felt about actually authorizing that person to be paid. This attitude seemed especially prominent in the rural counties. A care manager explained, "Sometimes, the sons or daughters will say, 'I don't want to be paid. I just don't want to get paid.' That's so wonderful,

but then you've got the other ones who say, 'Let's jump on this money thing.'" Some care managers felt conflicted when family members expected that they would be paid to take care of their relatives, or when they viewed it as an employment opportunity. Another care manager remarked, "A few folks . . . are utilizing family members [to provide cares] just so the family member can get paid." Indeed, navigating this terrain can be difficult for care managers as they try to sort out member needs from the desires of family members, and the best strategies for ensuring good care of the member.

Meeting needs for backup
In some CMOs, finding adequate backup in the event that a member's SDS workers cannot work as scheduled is an ongoing challenge for members self-directing their services. The issue is much more serious for personal care than for supportive home care, because personal care is usually a more urgent need that cannot be postponed until a more convenient time. The problem of ensuring backup is especially acute when members are using a fiscal intermediary rather than a co-employment agency, because co-employment agencies generally arrange for adequate backup support. By contrast, members must arrange for their own backup if they use the fiscal intermediary option.

Backup is can be especially problematic for people without extended family or available social networks. One care manager noted that sometimes the responsibility for arranging back-up comes as a surprise to some members who choose a fiscal intermediary option when they begin self-directing. She explained that members have to weigh the risks and benefits when considering whether or not they would like to use SDS, because they may risk being left without care in the event that a worker does not show up.

Sometimes members or IDTs find creative solutions to the problems of backup. One member has chosen to use an agency as backup. One CMO has been considering creating a network of SDS members so that they can share names of SDS workers, in part to make it easier for members to address backup problems.

Vulnerability of members
Interviewees frequently expressed concern about keeping members who are using SDS safe, since care managers do not have the same tight level of oversight and control when members direct their own care. This issue highlights the tension between a member's right to exert control over his or her services, and staff's responsibility to ensure members' health, safety, and quality of care.

Ensuring that members choose appropriate people as caregivers is one concern expressed by interviewees. As one manager explained, "Sometimes people choose individuals to care for them who might not always be the best individuals to have in their lives." While in general, care managers seemed to support the right of members to choose their own caregivers, they worried about the situations in which people employed by members might not serve the members' (or CMO's) best interest. In one instance interviewees were particularly concerned about a unique situation in which a CMO decided not to renew a contract with a provider due to questions about safety and quality of care with that provider. However, after termination of the contract, this provider contacted members individually about hiring her as a SDS worker, presumably so that

she could maintain her own employment. Staff felt very uncomfortable with this provider as an SDS caregiver, and questioned whether or not the provider coerced members into choosing her as an SDS worker. At the same time, staff felt they could not prevent this provider from providing care if members had legitimately selected her as a SDS worker.

Interviewees in multiple CMOs also raised questions about member control over who actually signs the workers' timesheets. Care managers did not always trust that the member was the actual signer of timesheets. Sometimes they suspected that SDS workers were signing time sheets instead. These suspicions led care managers to question whether or not paid care work was being performed as expected, when expected, by the workers. This concern was especially relevant for members with cognitive impairments. One care manager questioned, "Especially with people who have dementia, with people with memory loss, who is signing that time sheet?"

Care managers recounted some instances in which SDS workers seemed to mold work schedules and activities to their own interests, rather than to the best interests of their employer, the member. One care manager said that sometimes providers engage in "self-fulfilling activities" and "have the client tag along" rather than keeping the client "as the center of the activity or trip." Care managers also expressed concerns that workers might work when convenient for their schedule, rather than when the member really wanted the person to work.

Care managers added that sometimes members care deeply about directing their own care, as well as about the individuals (friends or family) that they have chosen to hire as their SDS workers. As a result, members sometimes go to lengths to protect their staff from losing their jobs, even when the individuals are not performing well as employees. A care manager recounted:

> I had a member who didn't feel comfortable complaining or asking the worker to do things a different way, because it was a friend. The friend wasn't always coming at the same time [each day], or maybe not at the same day every week. [The member] felt she was working the time in, depending on her schedule. . . . If she wasn't doing a good job, [the member] didn't feel comfortable telling her. [The member] didn't want to jeopardize the friendship.

With family, the situation can be equally, if not more challenging, because members are unlikely to jeopardize their relationships with their children, siblings, or others. Interviewees reported that these kinds of tricky situations, with both friends and family as SDS employees, made member supervision of SDS staff a challenge.

Members who cannot independently self-direct
In some situations, interviewees worried about the use of SDS by members with questionable capability to direct their care competently with their current level of support. This issue arose much more with respect to people self-directing through a fiscal intermediary rather than a co-employment agency, simply because co-employment agencies are able to provide backup and other forms of support to members. One care manager expressed her own fear, especially for people who need high levels of care:

You've got people who are so dependent on their cares, like if they're in their own apartment and can't bathe or transfer or eat or toilet. . . . SDS then is a little frightening because you don't have the agency as backup. You don't have anyone to staff this other than the member, and sometimes they don't make contingency plans."

When members are not able to maintain sufficient support networks to help them direct their cares, managing SDS can be a special challenge. One manager explained that "In order to be truly self-directed, the member has to have someone in their life" who can give them attention, outside of the care manager. Finding sufficient staff to cover all needs is an important barrier when a support network is small. Members with challenging personalities also face difficulty in maintaining sufficient staff. One care manager remarked, "Especially people with head injuries or maybe chronic mental illnesses that have had difficulty establishing relationships . . . [have] much more difficult[y] because their support network is usually much more limited. They don't have a pool of people who are thrilled to be hanging with them."

Members who struggle to self-direct given current levels of support can create extra demands on a care manager's time. One care manager explained that in one case, "the guardian . . . is so disorganized that [s/he is] not going to be responsible for getting people paid, so I am forced into doing it." Said another CMO staff person,

Self-directed can be a hassle when the member does not pay attention to [how much money he/she is] utilizing. It technically shouldn't be our job to watch that. I think they don't understand what the responsibility [of SDS] is. . . . The case managers are the ones that end up managing and guiding and helping them through it. . . . What I question is, should some of the people who are on SDS really be on SDS?

One manager jokingly referred to care managers as "care mangers/employment consultants" to illustrate that the burden for overseeing SDS for some members can fall heavily on IDT staff.

Member choice on a continuum
Sometimes interviewees felt that SDS should be more philosophically consistent, or a "truer" form of SDS than the SDS being practiced at their CMO. One manager remarked, "We have very few people, maybe one or two, who are truly directing their entire care plan. SDS is bits and pieces, a service here, a service there. So when you think of the theory of SDS as a general concept, I don't know that we're fully doing that." Similarly, another care manager expressed discomfort with the power that remains with care managers, when SDS is supposed to be member-directed. She questioned whether or not the CMO might be giving mere lip service to self-direction: "You are the member, and we're funding [SDS]. So it's just like any agency. We're setting up a service . . . It's still [the CMO] having this final 'yes' or 'no' stamp, when we're telling the member, 'No, you're in charge, you're the employer.'"

Other interviewees recognized that different members will have different desires and capabilities to self-direct their services, and felt comfortable with a variety of SDS practices, as long as the approaches capture the spirit of member self-determination in practice. One care manager

explained that she would like to see self-directed supports on a continuum, with the fiscal intermediary at one end, with co-employment in the middle, and with greater member input into agency-directed services at the other end. She explained that with greater input from members even in agency-directed services: "SDS could mean that the client has more say in who comes to their house, and what they do . . . They could say, 'I don't like that'. Or they could say, 'I met this person, this person and this person. I like the first two, but don't send the third.'"

One CMO is taking an approach unique among CMOs in that it offers the potential for choice to members throughout the continuum. This CMO has built up an impressively large network of providers for the services that members utilize. Members are able to choose amongst these various agencies, and they enjoy the freedom to change providers within the network at their discretion. This arrangement also enables members to exercise more control over staffing and scheduling at the existing agencies, since the agencies are competing with one another for business and by extension, for member satisfaction. One care manager noted, "With the new system [members] have more independence . . . With the old system they felt, 'That's who's coming in and I have no say.'" Part of the reason that this CMO has such a large network is that, unlike other CMOs, the CMO allowed all eligible providers to join the provider network: "if [a provider] met the contract requirements, and could do the job within the rate structure that we had been accustomed to from our other providers, we contracted with [that provider]."

Another result of an expanded provider network in this county is the opportunity for members to take a "back-ended" approach to SDS. In this approach, an agency hires a worker specifically selected by the member to provide his or her cares, but the agency directs the care. As one care manager explained, the relative of a member "could go to one of our contracted agencies . . . and she would get hired on as that agency's staff. . . . So it really depends on how much control the member wants." While this approach does not meet the technical definition of SDS in Family Care from a record-keeping standpoint, it clearly expands member options in ways that are consistent with the goals of SDS.

Member involvement
None of the CMOs reported having an institutionalized mechanism for ensuring regular member feedback regarding SDS. Although some, but not all, of the CMOs previously had workgroups that included members for creating SDS policy, at this time, none of these workgroups is fully operational.

Interviewees reported that currently, most member feedback regarding SDS takes place through informal feedback mechanisms. Care managers are often the people who receive initial complaints or requests for creative innovations from members. The care managers pass information on to CMO managers. One CMO manager, for example, reported that "People who are currently using self-directed supports, or want to, provide a lot of good feedback [in the form of] comments that they've made to care managers." This manager added these kinds of comments often are discussed in the state SDS workgroup.

The importance of member involvement cannot be overstated. Explained one care manager, "members continue pushing us to expand our awareness. It's not people at the state or experts from other areas of the country. It's members expanding what SDS is based on their needs."

This expanded awareness also can drive development of SDS services at the CMOs. A manager explained: "We have respite, personal care, supportive home care, daily living skills training, and transportation. These are the areas that members have been using, that they have asked for." Lack of explicit member support for innovations likewise impedes development. As a manager from another CMO stated, "We know [SDS] could be available for other services, but to put the attention and time into developing other services is difficult, because [members] are not requesting those services…There have been ideas about developing SDS for transportation or meals. But it's hard to put the effort into developing something that somebody is not actively asking for."

Financial impact

When researchers inquired about the ways in which financial issues impacted SDS, most interviewees expressed that SDS was neither clearly expensive nor clearly a cost-saving mechanism. In most cases, management and care managers reported that cost played little or no role in the frequency with which SDS is used.

Issues Unique to CMOs

While most of the empirical evidence regarding SDS reported in the previous sections applies across all of the Family Care counties, they did not have the same experiences in all respects. In some ways, rural counties differed markedly from the one urban county studied. Counties that were lacking a co-employment agency differed in important ways from those with a co-employment agency, and likewise, those lacking a fiscal intermediary were different from those with a functional fiscal intermediary. In this section, these kinds of divergent experiences are discussed.

Challenges of rural counties

Rural counties, due to smaller populations, have fewer agencies available to serve as providers. The limited availability of providers has a direct impact on SDS services for members, and presents special challenges to rural CMOs. One county CMO manager lamented that it is difficult to provide a choice of fiscal intermediary and co-employment agencies to members, given the rural nature of the county. In fact, this CMO has not yet found a provider to serve as a co-employment agency for the SDS program, and has a single fiscal intermediary agency. A manager explained that in their small county, the limited potential for profit deterred possible providers: "We've had some providers that have been interested in possibly being a co-employment agency or fiscal agent. But when they looked at the numbers, they didn't want to do that."

Interviewees at one rural CMO were especially concerned about how current agency providers would react to the planned implementation and expansion of SDS. Interviewees were concerned that offering SDS workers higher wages than those offered by existing providers was not fair to existing providers. The rationale was that providers have to maintain infrastructure, such as supervision and advertising, which cost the agency money. Interviewees worried that SDS would result in the CMO undercutting the agency providers, and that because of competition, agencies might risk going out of business. A similar concern about agency provider reactions

surfaced again in a discussion among managers about the possibility of developing vouchers to enable members to self-direct meals:

> "I think about the meal vouchers. We're paying $6.50 for a meal or $4.50 or whatever. Why don't we just give [members] the money? What if we gave people that? They could get meals from a restaurant."

> "Providers would go {gasp}!"

> "But I think it's a great idea because it gives people choice."

Unlike large, urban centers, where provider agencies are plentiful, rural CMOs may face some obligation to protect existing providers, lest they be left without an agency to provide a particular service at all. At the same time, it is worth noting that in another rural county the CMO initially expressed the same concern that SDS would undermine the existence of some providers. However, the reality was that SDS did not hurt providers' business as feared. One manager explained,

> Initially there was suspicion among providers that [SDS] would reduce utilization of their services, where everyone would leave the supportive home care agencies . . . They have gotten comfortable over the years now where they don't see a great deal of that. But in their own grumblings, they will say to you, 'Well [SDS] workers] don't have to have health insurance and they don't have to have this and that, so that's why they can do [SDS] for less.'

Challenges when barriers to using co-employment agencies exist
The ONGOING ISSUES section above discussed some of the common problems with SDS reported by interviewees, such as excessive demands on case management time, difficulty finding backup, and member vulnerability. These problems are often exacerbated when members are "in over their heads" in trying to direct their own services. When members want to use SDS, but do not have the skills and support needed to do so effectively and safely using a fiscal intermediary, a co-employment agency can be a good solution. A co-employment agency can give members more control over their services, by providing additional support to members for hiring, firing, training, and supervising their workers. In counties without a co-employment agency, or with a poorly functioning co-employment agency, care managers felt the weight of SDS responsibilities to a greater extent.

One CMO care manager described the co-employment agency at her CMO as problematic and poorly coordinated, with "off the wall" requirements. Another care manager noted, for example, that "with one client, the agency won't let workers do range of motion exercises with him without first calling the nurse and clearing it with him, even though it is simple and shouldn't require a phone call to the nurse each time." In this county, care managers were not well educated about the ideal role of a co-employment agency. During an interview with care managers, this lack of knowledge became apparent to the interviewers. Thus, they explained the concept to the care managers in the course of the focus group. At the conclusion of the interview, the care managers strongly suggested that "a better co-employment agency, or even a

couple," would be a useful improvement. In another CMO, too, the number of members using the co-employment agency is quite low in comparison to the number using a fiscal intermediary. Furthermore, the researchers noticed considerable variation in care managers' knowledge about the existing co-employment agency. For example, in one interview, one care manager explained to another some of the basic benefits of the co-employment agency, and the requirements for using it.

There is also evidence that wider use of the co-employment agency could benefit members in at least one CMO. For example, some care managers reported that they sign time sheets for members when members are unable to sign their own name, when a conflict of interest exists between the guardian and the SDS worker, or when a guardian is too irresponsible for managing time sheets. In these cases, the delineation between employer and care manager becomes blurred, and there is a notable risk that the county or individual care manager could be held liable as the employer. A co-employment agency could help avoid such situations. Nor did managers in this CMO always grasp the benefits of co-employment. For example, one manager explained, "We've talked about training the staff that are hired [by members]. Many times members would like to have training available for them, so we've talked about what is our role as far as making available training for caregivers so that they can do an adequate job." While there may be some role for the CMO in doing this kind of training, a co-employment agency could perhaps circumvent the need for care managers to address this kind of supervisory activity altogether.

Challenges when barriers to using fiscal intermediaries exist
In general, counties have fewer concerns about SDS when a contracted co-employment agency assists members in self-directing their services. The additional level of oversight for members choosing SDS often enables counties to worry less about fraud, misappropriation, and the health and safety of members. However, the fiscal intermediary option offers members far greater latitude and control over their services than the co-employment option. It can empower members in important ways as they assume greater control over functions once performed by county agencies. Assessing the challenges when the fiscal intermediary option is lacking, or when barriers to the use of the fiscal intermediary exist, is difficult without seeking a member perspective. Because this study included only CMO staff interviews, research findings raise more questions than answers regarding the consequences of a CMO lacking a strong fiscal intermediary for SDS.

In one CMO, the fiscal intermediary option is limited to the handful of cases in which employees, selected by members to provide their cares, reject formal training; and to intermittent use for snow removal and lawn care. Interviewees in this CMO reported that the elders they serve do not have an interest in using a fiscal intermediary option to employ workers themselves. Because this research did not involve member input, the researchers cannot assess the veracity of these claims. It is possible that some members would indeed like to exert more control over their services via a fiscal intermediary. The researchers recommend additional research involving members to investigate this question.

As mentioned previously, in one CMO, both managers and care managers hinted that at times care managers avoid using the fiscal intermediary option due to excessive paperwork. In this case again, the researchers recommend further study to determine whether or not the barriers to

using a fiscal intermediary prevent members from asserting as much control as they would like over their own services.

Benefits

Despite the challenges reported by the CMOs with respect to SDS, staff interviewed reported that SDS offers many benefits for members. Interviewers frequently heard from IDT staff, for example that SDS allowed for more privacy: "With one fairly independent member, having a family member allows for more privacy than having a complete stranger coming in." This contributes to supporting the dignity of members in the face of dependence on receiving very personal cares like bathing, and help with toileting or feeding. As one social worker explained, "when they are choosing the person helping them with their personal care, it helps them feel more comfortable than having a rotating staff of people they don't always know well and didn't get to choose themselves." Another agreed that members "can maintain an element of dignity if they have choices."

SDS also offers members, as employers, the opportunity to *call the shots* against a backdrop where they often have limited control. For those members who are able to take on this responsibility, it can make the difference between feeling dependent on larger systems for their day to day needs and feeling autonomous. Consider this example shared by an IDT member: "I had one member who told me that when he went to sign the time sheets for the fiscal agent he felt like a man. It was really powerful. Instead of being needy, he was an employer!"

Those interviewed also reported that SDS allows members increased flexibility in scheduling. For example, SDS can enable scheduling for early mornings or late evenings, times that are typically very difficult for an agency to accommodate. When members wish to alter the care schedule, SDS permits easy changes. "The member can call the person in the morning and say, 'Can you come later?' Or vice versa," explained one social worker. A manager agreed: "[With SDS] you can be more flexible sometimes. There are infrastructures with agencies, and with infrastructure comes protocol. A lot of those are set up for safety, or uniformity and consistency. But with that comes a box, and SDS opens the door to get out of that." An interviewee identified reliability of care as yet another benefit of SDS, because caregivers have pre-established relationships with members: "They're not as apt to call in sick, leaving them in the lurch."

Some of those interviewed identified cost savings as a possible benefit of SDS. One staff person stated, "I think we get a lot of bang for the buck, since people get paid for eight hours, but [care] doesn't stop when the clock does." Additionally, staffing members with complex needs through agencies has traditionally been expensive. A social worker noted that SDS has offered cost savings for these members in some instances: "With another involved case with high levels of physical need, it became much more cost effective, and allowed aging parents to keep their son at home." Another CMO's staff concurred: "With one client who had 20-21 hours a day of care, there was a phenomenal savings when he switched to SDS—thousands of dollars a month—and the support didn't change."

Managers and IDT members alike concurred that SDS expands the workforce of people willing to work as caregivers. Staff interviewed suggested that many people who otherwise might not have become paid caregivers, are willing to provide paid care when it is for a family member or neighbor. The potential expansion of the workforce is especially important given shortages of personal care and supportive home care providers. "We all know about the shortage of direct care providers," explained one CMO staff member, "and I think this has had a major impact on bringing more opportunities to individuals to get those direct care services that they need [while] drawing more people into providing this kind of service…they are interested, because this is already someone they know." A manager concurred, "There's always a shortage of direct service workers. There will always be, especially as our demographics change. . . . If we didn't have SDS as an option, I don't know if our providers could fill the capacity of needs that we have."

While staff interviewed identified many diverse benefits, perhaps the most important benefit identified was an increase in overall member satisfaction with care. "Members," explained one staff member are "much happier knowing that they know who's coming in, when, and what they are going to do. They're satisfied." Despite the challenges in administering SDS, interviewees suggested that self-directed supports can offer a wealth of advantages over agency-directed care for particular members.

Lessons Learned and Recommendations

The following section summarizes the primary lessons learned and provides recommendations based upon these lessons. The recommendations do not represent consensus or majority opinion, but rather reflect themes that emerged from the interviews conducted.[9] It is hoped that this information will be helpful in informing further expansion and increased quality of SDS in the five Family Care counties, as well as informing future expansion of SDS throughout the state of Wisconsin.

PROVIDER CHOICE
- Large provider networks that offer members as much choice as possible for all services are crucial. The larger the network, the more likely it will be that members will be able to exert control over self-directed and agency-directed services alike. When there is competition among providers, providers are more apt to cater to member requests for scheduling, personnel, etc. in order to maintain business. (i.e.: Having *at least* one strong fiscal intermediary and *at least* one strong co-employment agency within the county was noted by staff as being very important. When one of these options is lacking, members have less choice in providers. When a co-employment agency is lacking, members who need additional support to self-direct services also may place an undue burden on care managers, or may be unable to self-direct their services.)

STAFF TRAINING AND MONITORING
- Staff across CMO's reported that it is crucial that CMO training of IDTs extend beyond the initial training. Staff reported that initial training is certainly essential, but ongoing training for IDTs is also important because 1) SDS is used infrequently by some staff, and staff get

rusty in managing SDS cases 2) As IDTs become more competent in working with SDS, they tend to have increasingly sophisticated questions about the SDS system and 3) SDS policies and the programmatic environment shift regularly as CMOs and the state work to streamline SDS.

- Training should cover the idea that SDS is by nature a "messy" concept. Member control over services cannot be expected to mean the same thing for each member. Unique member preference, situations, and skills will drive how SDS is implemented with different individuals. Some members will desire and exercise a great deal of control over services, and others will desire and exercise control over only one or a few aspects of service provision.
- Training should ground SDS in the wider Consumer Directed Care movement, to enable CMO staff to better understand national trends and ideas about SDS.
- CMOs should involve members in training opportunities as much as possible.
- SDS should be discussed in regular staff meetings at CMOs. Drawing on CMO experiences and presenting scenarios for discussion was indicated by staff as a very useful activity for learning.

CMO INFRASTRUCTURE
- Having one or more management staff and care managers (if possible) at each CMO designated as lead contacts for SDS was consistently reported by staff as crucial. It is essential that the person chosen to be a lead for SDS be passionate about member self-determination and have time to dedicate to SDS.
- Paperwork for IDTs should be streamlined, especially for SDS services utilizing a fiscal intermediary. Centralizing some paperwork to remove it from care managers was reported by one CMO as a very effective strategy.
- Nurses' roles in SDS should be clarified. Staff at one CMO reported that nurses are unclear about the extent of training on skilled cares that they can perform for SDS employees. Nurses are concerned that the informal training that they give to SDS workers may be a liability issue both for CMOs and for themselves as individuals.

POLICY DEVELOPMENT
- Staff across CMO's expressed the importance of having policies regarding payment of family members (and guardians) that are clear, consistent, and well conceived. These policies should be developed with input from all stakeholders, including members and advocates, the state, care managers, CMO managers, and community groups. It was also noted by staff that any policies that will, in effect, restrict current services or payments to current SDS workers should seriously consider "grandfather" clauses to protect existing members and their families from potentially unpopular reduction in compensation.
- Policy development should include members to the greatest extent possible.
- Policies or guidelines regarding raises for SDS workers should be developed to ensure that members can offer their employees raises, as appropriate.

SDS INNOVATION
- Staff interviewed expressed the importance of having SDS expand to additional services, such as transportation and respite care.

- CMOs should continue developing innovative forms of SDS that have not yet existed in CMOs in Wisconsin. Staff interviewed had many excellent ideas such as SDS for cooperative housing, debit cards for meals, alternatives to adult day care, and daily living skills for people with disabilities.
- It was also suggested by many staff that it would be extremely helpful to develop strategies for SDS members to network with one another.

MEMBER TRAINING
- Staff reported that it is crucial to have extensive SDS training and educational resources for members. Ideally, resources should include a video for members, materials for members who learn differently, materials for blind and deaf members, and culturally appropriate materials for members of ethnic or cultural minority groups in Wisconsin.
- SDS training for members should take advantage of community resources and co-employment agencies available locally to CMOs.
- Member training needs to include extensive, easily understandable information about legal issues such as wage and hour law, and appropriate grounds for reprimanding or firing workers.

ROLE OF THE STATE
- CMO's reported that it is crucial for the state to allow maximum flexibility to implement innovative strategies for SDS. One CMO suggested that having a waiver that provides more flexibility and innovation would be very helpful.
- CMO's noted the importance of state assistance developing educational materials for members due to the extensive expertise and funds needed to create materials such as videos, Braille materials, and materials in languages besides English that can be adapted or shared by CMOs.
- Staff reported that it is crucial that the state play a key role in working with the CMO's in developing data systems. A number of CMOs reported that adapting their IT systems to meet state specifications for data collection is exceedingly difficult. A manager reasoned that if the state can "make [data collection] work well in the complex urban counties, [it] will have a lesser job . . . to make other smaller modifications in the less complex counties."

EARLY IMPLEMENTATION
- Staff stressed that in early implementation the state needs to provide extra technical assistance to CMOs without previous SDS experience in their county. CMOs with little experience using SDS systems or philosophies need additional time and attention to develop an effective infrastructure and program.
- In early implementation, CMOs need to designate one or two dedicated staff people who feel passionate about SDS to spearhead the implementation process, and ensure the staff have time in their schedules to devote to SDS.
- Staff interviewed recommended strongly that the state maintain a workgroup for SDS across multiple counties so that counties newly developing an SDS program can benefit from input and exchange of ideas from other CMOs. The workgroup should include CMO representatives both from counties with a history of experience with SDS as well as from those that are newer to SDS.

Appendix A: Interview Questions

- Please give an overview of the history of implementation of SDS in your county.
- What factors facilitated implementation of SDS at the beginning? Over time?
- What have been the major barriers to implementation of SDS when implementation first began? Over time?
- How has leadership at the state and/or CMO level played a role in implementation of SDS?
- Given that your CMO has a number of important priorities, how important of a priority has SDS been in comparison to other concerns?
- How has system infrastructure affected implementation of SDS?
- Please explain the agency-related elements that make it easier or more difficult for SDS to be used in your CMO. Possible elements might include bureaucracy, training, finances, resources, caseload, etc.
- How have financial resources/constraints affected implementation of SDS?
- What kind of role have members played in implementation of SDS?
- What are the benefits of SDS?
- What are the drawbacks of SDS?
- What suggestions do you have for improving SDS?
- What should we have asked that we did not ask?

1 Please note that Milwaukee County's CMO provides services to frail older adults only, unlike the remaining four counties which serve both frail older adults as well as adults with physical and/or cognitive disabilities.

2 For a look at trends in consumer-directed care in other countries please see Tilly, J., Wiener, J., Cuellar, A. (2000). Consumer-directed home and community service programs in five countries: Policy issues for older people and government. Washington, DC: Urban Institute. And for a summary of states' activities see both 1) Tilly, J., & Wiener, J. (2001). Consumer-directed home and community service in eight states: Policy Issues for older people and government. *Journal of Aging Social Policy, 12*(4), 1-26, and 2) Velgouse, L., and V. Dize. 2000. A review of state initiatives in consumer-directed long-term care. *Generations 24* (3): 28–33.

3 The third author has had both prior and ongoing experience with the CMOs as a provider of technical assistance in the area of self-directed supports and with the formation of statewide workgroups for the implementation of SDS. In order to avoid role confusion and the possible impact of such confusion on the research process, the third author did not participate in the collection of data at the sites. Additionally, to avoid bias in the interpretation of results phase, she provided assistance in the writing and editing process of this report only once the initial draft of data analysis was completed.

4 CMO managers were asked to identify care managers with extensive experience at the CMO as well as some who were newer to the role. CMO managers were otherwise not given selection criteria and, per their report, the determination regarding who participated was due in part to who was available on the day of our visit. CMO managers reported specifically recruiting individuals who had "a lot to say about SDS—both good and bad" in order to provide us with the range of perspectives we had told them we were looking for. Although encouraging, this doesn't entirely dismiss issues of possible selection bias. Questions therefore remain about with whom we didn't speak and how those perspectives might have altered our findings.

5 Examples of additional clarifying questions include requests for additional information on decision making processes within CMOs concerning such things like co-employment providers or how teams handled challenging situations.

6 In fact, each CMO was given very specific rule language developed by advocates. This rule language included an outline of what each CMO needed to do to implement SDS.

7 Resource Centers are the site for initial program outreach, referral, and assessment. Once a person is approved for Family Care, the Resource Center transfers the member to the CMO.

8 Within Family Care a *Fiscal Intermediary* refers to an organization wherein the member is considered the "employer of record." Fiscal intermediary organizations provide only payroll functions. They do not typically fulfill other employer responsibilities such as writing a job description, keeping necessary employee records, or conducting criminal background checks. A *Co-Employment* agency within Family Care refers to an agency or organization that serves as the "employer of record". Employer/employee responsibilities are shared between the member and the agency and it is up to the member to decide how much he/she wants to share in the responsibility. A co-employment agency offers fiscal support, as well as other services--e.g., back-up services, worker training, recruitment assistance.

9 Please note that the recommendations should not be understood as consensus or majority opinion but rather reflect the themes that emerged, numerous notable examples of successful problem solving at the CMOs, and the authors' benefit of being "a few steps removed." This report therefore reflects the multiplicity of perspectives, experiences, and the varying stages within the continuum of implementation that the CMOs occupy. Recommendations within this report should not therefore be understood as empirically tested Best Practices, but rather as a possible necessary first step toward that end.