Consumer Directed Community Supports (CDCS) for Older Adults in Minnesota

Final Report

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Deborah Paone, MHSA

Paone & Associates, LLC
10413 Rhode Island Circle, S.
Bloomington, MN 55438
952-943-9664
dpaone01@aol.com

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Executive Summary

The implementation of a cash and counseling option for older adults in Minnesota, called Consumer Directed Community Supports (CDCS), was spearheaded through a grant from the Robert Wood Johnson Foundation (October 2004-2007). The grant focused on infrastructure development, training and technical assistance, and outreach and marketing, especially for older persons eligible for or receiving Elderly Waiver (EW) or Alternative Care (AC) services.

A modest evaluation of the experience in Minnesota was included as part of the grant. This is the final report describing that qualitative evaluation. This report explores consumer and family member response to CDCS, presenting the results from key informant interviews held in 2007. An earlier interim report from this evaluation (Paone, 2006) described the background and context for understanding the environment in which CDCS was offered in the marketplace and presented the results from key informant interviews with healthcare, managed care, and social service professionals.

The outcomes of state implementation efforts around infrastructure development, outreach, marketing, and technical assistance were presumed by the evaluator to be: prepared professionals, sufficient enrollment among the target groups (particularly older adults on EW and AC), and high satisfaction among those enrolled.

There is evidence of progress toward these outcomes arising from the implementation activities. However, the low cumulative number of older adults electing CDCS, and the apparent difficulty they had getting into the program (based on consumer and family interviews with a sample of those who did enroll and a small sample of those who could have enrolled but chose not to) indicate that outreach and marketing efforts have not been sufficient in overcoming the environmental factors or other barriers.

Resistance or unfamiliarity with CDCS among professionals who are in the role of describing the program to this target population persists. Key informant interviews of healthcare/social service professionals in 2006 and of consumers/family members in 2007 suggest that the preparation activities by the state have not been echoed in other settings, that many people are still unaware

of the CDCS option, many are unfamiliar with the steps for using the option, and that most organizations have no immediate plans to increase their efforts around marketing or preparing for the option.

At the same time, there is evidence that current service options are satisfactory to many older consumers on EW or AC and that they prefer not to make a change. The small sample of consumers and family members interviewed who elected not to enroll in CDCS indicated that they were satisfied with current home and community-based service options in Minnesota and would not choose another option for their care. Most of these consumers also indicated they were satisfied with the case manager support they received, and would not want to lose that support.

Environmental factors, such as the introduction of Medicare Part D pharmaceutical care options and the Minnesota Senior Health Options passive enrollment in 2006, certainly impacted both organizations and older adults in Minnesota and likely affected participation in CDCS.

Despite these environmental factors and other issues, a small handful of older consumers and their family members found their way into the CDCS program early on and are enthusiastic about the program. These “early adopters” who were interviewed as part of this evaluation are clearly a hardy group who are not easily daunted by administrative or organizational barriers. Some described hurdles, such as program complexity and staff resistance, but these hurdles have not dissuaded them from getting or continuing on CDCS. They were seeking a different way to manage care for themselves or their older relatives at home—and strongly voiced a desire to keep CDCS a viable and growing option in Minnesota. Many also asked for a bigger budget.

At the present time, approximately 120 older adults on EW or AC (about 1% of those eligible) have chosen CDCS—suggesting that additional program acceptance among professionals will be needed and/or new or expanded method(s) for directly reaching these older consumers and their family members.

Evaluation Approach

The State of Minnesota Department of Human Services, Aging and Adult Services, received a 3-year Robert Wood Johnson Foundation (RWJF) Cash and Counseling Grant (October 1, 2004 - October 2007). Grant funding was to bolster Minnesota's efforts to create permanent, multi-point, statewide access to a consumer-directed option for older and physically disabled adults and their family caregivers. This grant-supported effort was directed primarily at expanding access to older adults who receive home and community-based support through the Elderly Waiver and Alternative Care programs. The effort would:

(1) Respond to barriers and address major infrastructure weaknesses
(2) Create statewide access to essential service components including quality fiscal support and counseling services and funding for consumer budgets
(3) Broaden the market demand by building consumer awareness and advocacy
(4) Develop customized web-based consumer planning tools
(5) Evaluate consumer response to the established model

The project proposal incorporated a modest state-specific evaluation to focus on the process of implementation and to gather qualitative information on how the option was being received by constituent groups in Minnesota. This process evaluation would focus on implementation of the cash and counseling option to older adults in Minnesota, particularly those enrolled in the Elderly Waiver (EW) or Alternative Care (AC) programs. This is the final report of that evaluation.

The Interim Report of the evaluation was presented in 2006[1]. The Interim Report provides context and background information about Minnesota's existing service options for older adults and presents the results of key informant interviews conducted with representatives from health plans, counties, provider agencies, and advocacy groups.

Assumptions

In considering the implementation of this cash and counseling option for older adults in Minnesota, the following assumptions were made by the evaluator about probable issues and success factors:

[1] Paone, D. (2006) *CDCS for Older Adults in Minnesota: Interim Report*. Submitted to the MN Department of Human Services. Contract # A80780. December 21.

(1) Implementation of a program statewide is complex, whether it is new or an expansion of an existing program.

(2) Buy-in of key personnel/professionals is key—particularly case managers at the county and health plan level, and AAA staff.

(3) A great variety of organizations and individuals serving older adults must become aware of the Consumer Directed Community Supports option for older adults and how the process works in Minnesota—they will need to either describe it, or be a part of making it work in the state.

(4) Consumers and/or family members need to acquire new skills and knowledge. Consumers and/or family members must have some confidence in their own abilities to manage more of the care processes and decision-making, and confidence in those assisting them.

(5) Timely information, in a way that is comprehensible, is very important, as is accuracy and follow through.

(6) Safeguards and monitoring must be built into this program—previous experiences with other choice options have left some professionals and consumers concerned about abuse.

Key Questions

Key questions for the evaluation were organized around three themes, reflecting the proposed implementation activities: (1) infrastructure development needed to offer this "cash and counseling" option to older adults, (2) acceptance/value of the CDCS option, and (3) readiness for continuation following the grant project completion. Seven questions were developed:

1.) Has the implementation (by the State and other organizations) around infrastructure development, marketing, and technical assistance pertaining to implementation of CDCS to older adults in the State of Minnesota been effective, in the opinions of key informants? How has it worked for the early adopters of the program?

2.) What more is needed to support this as an ongoing, viable option for older adults and organizations serving consumers?

3.) What were the barriers or environmental factors/events that impeded or advanced CDCS—particularly those that may continue to affect acceptance of the CDCS option for eligible older adults and those in the target programs?

4.) In the opinion of the early adopter key informants, what are the biggest advantages or areas of success in the CDCS option for the older consumer?

5.) What are the biggest disadvantages or concerns that key informants have related to the CDCS option for the older consumer?

6.) What more could be done to positively impact market acceptance and program satisfaction?

7.) Is the State positioned for ongoing support of this service option after the pilot is over? Is there a readiness within counties and health plans to continue the option?

Data Sources & Methods

Primary and secondary data sources included:

- telephone interviews with representatives from counties, health plans, advocacy organizations, providers, FSE organizations
- telephone interviews with consumers and family members
- conversations with and reports from DHS Program and other DHS staff
- attendance at Stakeholder group, managed care, case manager and other meetings
- review of survey responses to DHS registration or other surveys
- review of marketing and public relations materials, DHS web site, and agency manuals and consumer handbook
- information provided by DHS on current enrollment and other issues
- previous evaluation reports on CDCS for other populations in Minnesota, and
- information from the Cash and Counseling web site

Findings from Non-Consumer Key Informant Survey

The evaluator conducted a key informant survey of professionals/advocates in the late summer/early fall of 2006. Twenty-four individuals were interviewed. This included individuals from counties, health plans and county-based purchasing plans, fiscal support entities, advocacy organizations, Area Agencies on Aging, and providers (e.g., clinic or care system). Disciplines or roles represented in the sample included case managers, program managers, program directors, and administrators. Questions focused on infrastructure development, training and technical assistance, marketing and outreach, perceived value of the CDCS option, barriers and catalysts for CDCS, external and environmental factors, and readiness for future program development. A brief summary of the results from this survey is provided in Table 1 (next page). For more detailed information, the reader is directed to the Interim Report.

Table 1. CDCS Key Informant Survey 2006 - Summary Responses, by Area of Inquiry (N=24)

Constituent Groups (Key Informants)	**Effectiveness of State Activities** Infrastructure Development Marketing/Outreach Training/Technical Asstnce	**Activities of Surveyed Organizations re:** Infrastructure, Marketing, Training/Tech Asstnce	**Current Perceived Program Value & Acceptance** and **Perceived Barriers**	**Future Readiness** for Program growth into new markets & **Need** for more support – type, nature
Counties – 3 ***Health Plans or CBP*** – 5 organizations ***Fiscal Support Entities*** – 3 organizations ***Case Managers*** -5 people (from a variety of different types of organizations) ***Advocates & Providers*** – 8 organizations	Introduction to CDCS happened some years back (1-3 years ago); During 2005-6 most attended some additional State videoconferences Not a lot of use of DHS web site—one-on-one calls to DHS most helpful, plus some of the State's materials (some were familiar with handbooks and manuals, some were not) Most had seen some of State marketing info, not really using it extensively in their discussions (Case managers said it was not in a useable form for their discussions with their current clients; language and literacy levels are an issue) Direct help from Program Office (Pat Yahnke and Jane Vujovich) most helpful.	Organizations surveyed are not doing a lot of training, or infrastructure development on their own (rely on the State's activities). Some had put in place CDCS for other populations, as needed—others just beginning to explore need for infrastructure development Most have no plans for marketing directly; exception is one advocacy organization Provide help to consumers, families as needed/asked—do not see their role as "advertising" this to the older population. Most describe the CDCS program to potential clients when asked or when reassessment occurs	Program Value: Many believe this will be a good option for some, but current generation of older adults they serve may not be the target market—next generation of more active older adults or those with higher education levels and more familiarity with purchasing services directly may respond positively. Caregivers are also a potential target group Barriers: Bad timing - MSHO expansion & Medicare Part D have been overwhelming during 2006; seniors are confused already by so many options Hard to understand the CDCS option; complex (especially for older adults currently being served in EW, AC); level of difficulty is high. Need an involved family member to make this work Providers, FCMs or FSEs in some areas (rural) are scarce Budget not working for some clients	This option needs extensive one-on-one support for each senior/family—respondents believe seniors/families will need lots of personal attention to get this going. Don't have enough staff if this really grows Slow growth is not surprising (see barriers) Caregivers important, but need to reach in different ways; some older adults don't have family members or family is unreliable Need to really simplify the whole option and materials, and build in more support to persons that does not come out of their budget (e.g., FCM and FSE time)

Program Update

Since September 2006 the Department has concentrated on improving outreach to eligible older consumers already enrolled on EW or AC or who are newly eligible for these services, in order to make these consumers aware of the CDCS option.

Direct marketing efforts included airing the video "You Decide. Your Help." (describing Consumer Directed Community Supports and how it can work for older adults or people with a disability) on forty-four public access television stations. Viewers interested in more information about Consumer Directed Community Supports were directed to contact Senior LinkAge Line® and/or Disability Linkage Line™. These two informational lines did not experience an increase in the number of callers following the video airing. Previous direct mail efforts to EW, AC, and CADI recipients (14,769 households) likewise did not generate new callers into the informational telephone lines.

In December of 2006, DHS contracted with three Centers for Independent Living (CILs) to provide enrollment assistance services (EAS). These three CILs cover 29 of Minnesota's 87 counties. These independent organizations were contracted to:

- Help EW and AC recipients better understand what CDCS is and provide information and technical assistance to consumers, family caregivers, lead agencies, fiscal support entities, flexible case managers, and others about CDCS
- Conduct a minimum of 890 individual (one-on-one) educational sessions from an eligible population of approximately 5,400 EW and AC recipients in the 29-county area
- Refer consumers to lead agencies, FSEs, FCMs to further assist them in the enrollment process
- Minimally enroll 86 EW or AC recipients into CDCS or PCA Choice by September 30, 2007

These CILs mailed to 4,554 persons and made 1,021 "market calls" to eligible consumers during the 6-month period from February-June 2007. From this, 532 consumers requested

more information, and 141 in-person education visits were made, plus another 554 telephone visits. The CILs enrolled 36 persons as a result of this process in both PCA Choice and in CDCS, with 28 persons selecting the CDCS option.

Reports from the CILs described major issues or barriers they have confronted and strategies they have used in their work around educating consumers and professionals about the CDCS service option. Initially, the CILs experienced heavy resistance to their efforts. Recent reports seem to indicate more acceptance and interest in the CDCS option among county representatives and case managers or MSHO care coordinators. Table 2 provides an abbreviated look at the experiences of the three CILs.

Table 2. Experiences from the Centers for Independent Living Under Contract with DHS for CDCS Education & Enrollment of Older Adults, 2007	
Major Issues or Barriers	Consumers already on EW or AC say they have services that "are working" (therefore not interested in a new option). Relationships with current service providers are good and they do not want to change.
	Heavy dependence (by consumers) on the opinion of their case manager regarding whether CDCS option should be considered
	Consumers with no phone numbers or inaccurate numbers
	Case managers change and hard to get in touch with these individuals
	Counties report lack of training/preparedness.
	CILs can't communicate with consumers who do not speak English.
	Consumers with high medical needs and nursing service needs find the budgets are just not adequate.
Catalysts & Strategies	Collaborate with other organizations that have support groups or educational activities; use these as opportunities to educate consumers
	Direct phone calls to the consumers and families; home visits
	More success when family members maintain communication and pursue hiring a FCM
	Some rural counties that have been typically underserved are more receptive and express interest in CDCS.
	Some MSHO care coordinators providing referrals and seeing the value of the option for some of their clients/members.
	Presence at local medical provider staff trainings.
	Provide case manager to case manager training (peer to peer) with examples of what has worked with actual clients.
	Idea to give counties some incentives or rewards for participation.

In terms of infrastructure and training, DHS continued to work with 17 Fiscal Support Entities, including 1 new organization since April 2007 certified to provide fiscal management services for persons electing CDCS. Most of these FSEs have been working toward providing services statewide to all waiver groups/eligible populations.

Three-hundred and forty-seven Flexible Case Managers (FCMs) have been identified and certified through DHS to provide this service under CDCS. The requirements for being a Flexible Case Manager in Minnesota are:

- Be at least 18 years of age
- Successfully pass the assessment with a minimum score of 80% correct
- Receive a CDCS Flexible Case Management certificate via e-mail
- Provide a copy of the CDCS Flexible Case Management certificate to the waiver recipient
- Be able to prepare a community support plan according to the requirements for a plan that have been established by DHS
- Be able to coordinate services with the county or health plan case manager

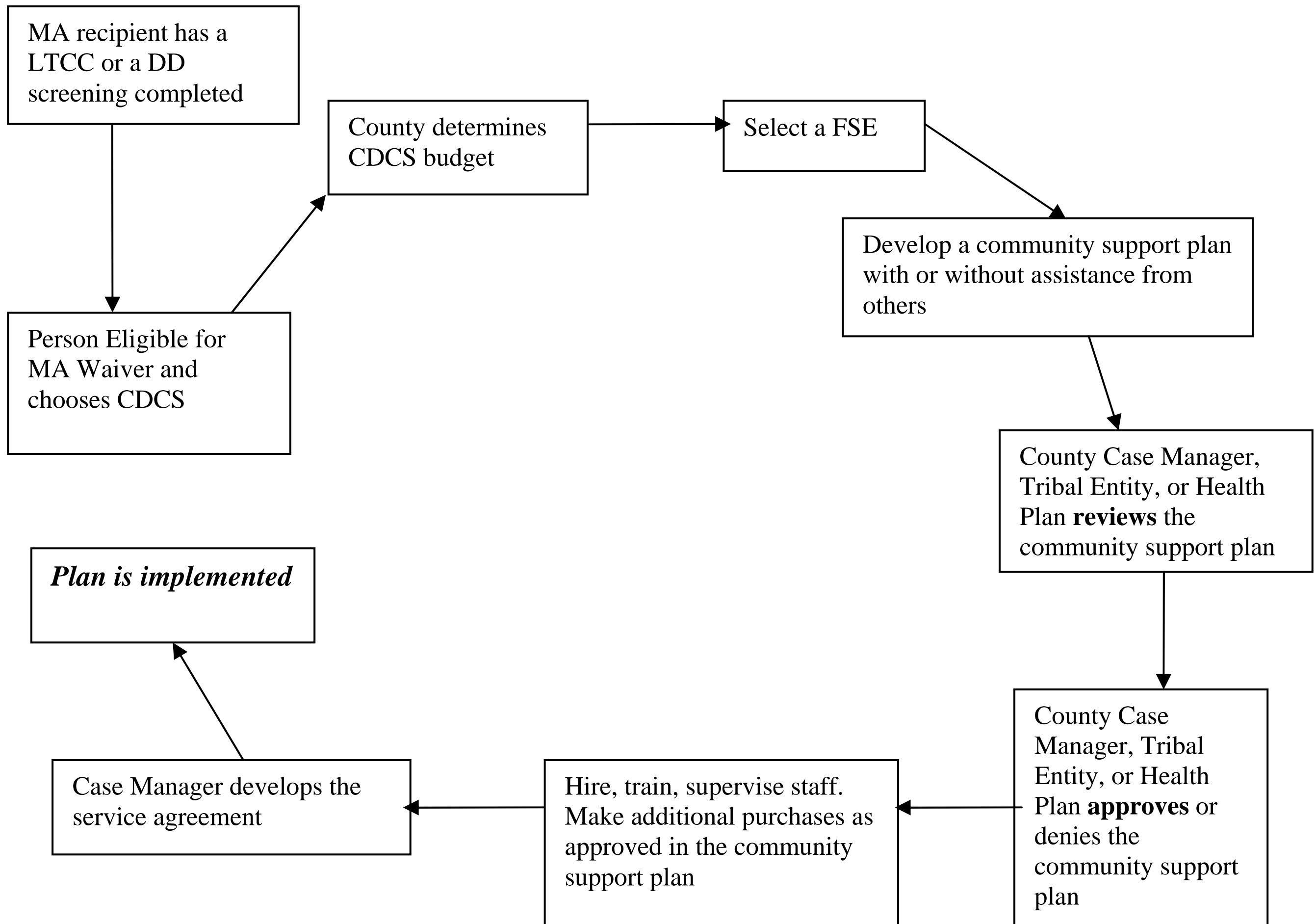
DHS has spent considerable effort developing new service standards for flexible case managers, which were adopted in fall of 2007. The state also has been working on expanding the curriculum for FCM training, creating three one-day sessions and dividing the curriculum into three modules. Thirty-three FCMs have been added to the list of certified case managers since January 2007.

CDCS Process in Minnesota

Choosing and using the CDCS option involves a number of steps for the consumer and county assisting the consumer—from assessment (for eligibility and to understand level of care needs) to initial awareness and education about CDCS, to the determination of the person's budget and preparation of a community support plan, to the selection of a fiscal support entity, to the hiring of staff or purchase of services designed to address the needs identified. Once services have started, the consumer works with the FSE to pay for the services out of the monthly budget. Changes in health or functional status may result in

changes in the level of need determination requiring a reassessment and new community support plan.

The process of using CDCS in Minnesota is illustrated in the *Consumer Handbook* (page 23) as follows.



Methodology for Consumer and Family Member Surveys

The second phase of this evaluation of Minnesota's implementation of a cash and counseling option for older adults focused on obtaining the perspective of older consumers who receive home and community-based services through the Elderly Waiver or Alternative Care programs (both those consumers who elected the CDCS option and those who did not). The evaluator designed a two-part process and created two related telephone survey instruments to obtain this perspective. **Part 1** focused on older

consumers on either the Elderly Waiver (EW) program or Alternative Care (AC) program who did not choose the CDCS option during their last reauthorization. **Part 2** elicited perspectives from older consumers on EW or AC who chose the CDCS option by January 2007.

Part 1. Survey of Consumers who did not choose Consumer Directed Community Supports option – "Non-Responders"

The evaluator worked with the DHS Program Director and Coordinator for the CDCS grant project and with the Office of the Ombudsman of the Minnesota Board on Aging to recruit and train volunteers to conduct telephone interviews with up to 97 "non-responder" older consumers who were enrolled in either the Elderly Waiver (EW) or Alternative Care (AC) programs but did not choose to enroll in the Consumer-Directed Community Supports option.

These interviews would provide information to:

- Determine if older consumers on EW or AC had heard of the CDCS option, and, if so, when/how
- Understand how the program was introduced to older consumers and their reaction to marketing materials
- Determine their reaction to CDCS program features
- Identify the reasons they chose not to enroll
- Identify characteristics of consumers or program features that might lead to selection of the CDCS option

Participant Selection (all criteria had to be met):

- Adults over age 65 (and family representatives who assist in decision-making)
- Persons enrolled in AC or EW (in one of these programs as of January 1, 2006)
- Persons who were reassessed/reauthorized between May 2006 and August 2006
- Persons who lived in the high priority target counties for EW/AC enrollment
- Persons who DID NOT select the CDCS option
- Persons who had some services authorized and in use under their current program

- Persons who were cognitively able to participate in a voluntary telephone survey of approximately 25 minutes in length OR their family member as proxy
- Persons NOT living in a nursing home or assisted living setting

The sample would include a mix of:

- MSHO enrollees and non-MSHO enrollees
- Those on FFS Medicare and managed care Medicare
- Case mix levels, with a skewed sample toward the "community frail"
- Persons living in both metro and rural areas—representative of county regions that are of high priority for EW or AC enrollment

Universe. The high priority target counties for EW and AC enrollment were as follows:

Anoka	Hennepin	Sherburne
Beltrami	Itasca	Sibley
Big Stone	Kanabec	St. Louis
Brown	McLeod	Stearns
Carver	Meeker	Steele
Dakota	Mille Lacs	Traverse
Dodge	Olmsted	Wabasha
Douglas	Pope	Waseca
Freeborn	Ramsey	Washington
Goodhue	Renville	Wright
Grant	Scott	

Within these 32 counties, 1,942 persons were reauthorized/reassessed for Elderly Waiver services and 486 persons were reassessed for Alternative Care during the months May, June, July, or August, 2006, for a total of 2,428 individuals. Of this group, approximately 25 of these individuals selected the CDCS option (therefore these individuals were excluded from the universe). The evaluator estimated that 20% of the remaining persons would have died or moved to a nursing home by the time the sample was selected (January 2007). The final 1,947 remaining persons represented the target universe from which to select the sample.

Sample. A random sample was drawn from this universe, with a target of 5% of the universe to participate in this study (97 persons). The population was over-sampled in order to generate 97

completed interviews. In a previous survey of the EW population in 2004 refusal rates were fairly low; however in order to be sure of an adequate sample size, we randomly selected 308 persons (represents a 18% sample) from the universe and categorized this sample by county. This would allow for a 68% refusal rate.

Health Plan & County Involvement. Counties and health plans were notified of this survey, and were given a sample letter and response card. After an individual indicated his/her willingness to participate, DHS staff notified the case manager/care coordinator of record of the individual's willingness to participate. Then DHS staff provided the name to a trained volunteer interviewer to follow-up via telephone with the individual and set up the interview.

Interviewers. Interviewers were volunteers recruited through the Office of the Ombudsman. Interviewers were trained on the interview guide by the evaluator, DHS project staff, and the manager from the Office of the Ombudsman. The volunteer training agenda is appended (Appendix A).

Invitations. Letters of invitation were sent from DHS to the randomly selected individuals meeting the criteria (in three waves of mailing), with a follow-up response card and informed consent form for the individual to respond within 2-3 weeks. In addition, a simple brochure ("You Decide Your Help") about CDCS was mailed in the same envelope. This brochure was designed as an introductory piece for older persons to understand basic information about CDCS.

Response Rate. There was a low participation rate from the 308 individuals invited. Only 6% agreed to the survey and actually completed the interview resulting in 18 completed interviews. The interviews offer a picture of consumers and their awareness of or interest in CDCS features, however we cannot generalize to the whole population of older persons receiving home and community-based services through Elderly Waiver or Alternative Care who did not elect CDCS when offered it as an option.

Non-Responder Suggested Areas of Inquiry/Questions (see survey instrument, Appendix B)

- Does the consumer have a case manager?

- During the consumer's last reassessment/reauthorization, were there changes to the consumer's needs?
- Had the consumer heard about the CDCS option? When/how was it presented to them?
- What are the consumer and representative reactions to the CDCS program features?
- If the consumer did hear about this option, why did consumer and/or family representative not select this option? What were the main reasons?
- What features make this an attractive option to the consumer?
- What aspects of the program are not desirable to the consumer?

Part 2. Survey of Sample of Older Consumers Who Elected Consumer-Directed Care - "Early Adopters"

Older persons on Elderly Waiver or Alternative Care who had elected the Consumer Directed Community Supports program by January 2007 were considered "Early Adopters" of the program. As of January 2007, the total number of older persons on CDCS enrolled in EW or AC was 58 persons.

The purpose of these interviews was to:

- Identify how/when consumers heard of CDCS option
- Understand how the program was introduced to them and their reaction to marketing materials
- Understand what CDCS program features attracted the older person to this option and the reasons they chose to enroll
- Determine experiences under CDCS so far
- Elicit response regarding activities under CDCS, e.g., experience with community supports plan development, choosing a FSE, setting up services, paying workers, reporting
- Determine how the older person's family is/is not involved in supporting the older person on this option
- Identify how these older people are working with their case managers
- Obtain information on how consumers are using the CDCS option—e.g., what services are being purchased
- Identify barriers and successes so far

- Determine satisfaction with the program thus far
- Identify any areas for improvement

Participant Selection

All individuals on AC or EW by January 2007 who had elected the CDCS option were invited to participate. Family members for these persons were also invited to participate and could serve as proxies for those consumers who were unable to tolerate a 30-40 minute telephone interview.

This group represented:

- adults over age 65 (and family representatives who assist in decision-making)
- persons enrolled in AC or EW, who were on the program as of December 31, 2006
- persons who elected the CDCS option
- persons NOT living in a nursing home or assisted living setting

The evaluator was especially interested in hearing the experience from those persons on CDCS who have already selected a Fiscal Support Entity (FSE) and finished their Community Support Plan, and had received some services under CDCS.

Health Plan & County Involvement. Counties and health plans were notified of this survey, and given a sample letter and response card.

Invitations. Letters of invitation (with joint signature of Jane Vujovich, Program Manager, and Deborah Paone, Evaluator) were sent from DHS to identified individuals, with a follow-up response card and informed consent form to return. When an individual indicated his/her willingness to participate, DHS staff notified the case manager/care coordinator of record of the individual's willingness to participate. Then DHS staff provided the evaluator with the individual's name and a copy of the response card. The evaluator set up the interview with the consumer, based on the consumer's preferences/availability.

Sample. The universe of older persons on AC or EW who had enrolled in CDCS (and had not disenrolled) by January 2007 was 58. All were invited to participate. Nineteen persons sent back a positive response card and signed informed consent. Of these 19 persons, 5 later declined or

could not be reached by telephone, despite multiple attempts. Therefore 14 persons (24% of the eligible population) completed the interview. Family members served as proxies for seven (half) of these older consumers.

The interview protocol is appended (Appendix C). The areas of inquiry are summarized in Table 3 below.

Table 3. ***Older Consumers on EW/AC and enrolled in CDCS & Family Members-*** **Areas of Inquiry**

Marketing & Enrollment	Initial Activities & Plan Development	Current Program Value & Service Experience	Barriers & Concerns	Need For Additional Support
How heard? Why interested? Who helped with enrollment process? What materials seen?	Community Support Plan prep? Decision/use of FSE or FCM? Lead Agency support? State or county support? Technical assistance materials used	How is it working? Services different/better? How FSE supporting? Budget issues? Paperwork? Services/workers?	What is easy/hard? Any suggestions? Recommend to friend?	More help? Type/nature How to make this better?

Table 4 provides more detailed information about the sample of consumers and family members invited to participate in these surveys.

Table 4. **Summary of Consumer Responses to Survey Request** (through July 2007)

	Non-Responder	***Early Adopter***
Invitations Mailed	316	60
Undeliverable	8	2
Apparently Delivered	**308**	**58**
Responses Received	**64** (20%)	**31** (53%)
No, Do not want to participate	42	12
Yes, Want to Participate	24	19
Eligible to Participate	21	19
Refused When Called or ineligible*	3	5
Surveys Completed	**18** (6%)	**14** (24%)

*consumer was ineligible if no longer on EW or AC or if living in an assisted living facility, or if there was no returned signed informed consent card.

Results from the "Non-Responder" Survey

Eighteen persons were interviewed for the "Non-Responder" survey. Counties represented included: Beltrami, Big Stone, Brown, Dakota, Hennepin, McLeod, Ramsey, Sherburne, St. Louis, Washington, and Wright. Because of the low response rate, we cannot be sure that these responses are representative of the whole population of older persons on EW or AC who are receiving home and community-based services and who refused CDCS. Their responses, however, provide a glimpse into issues and their current situations in managing their needs in a home environment.

Receiving Help. All of these individuals said they were receiving some type of help at home. This included cleaning assistance, laundry, and transportation (these three items were most frequently mentioned) as well as some assistance with personal care and other types of support (e.g., meals).

Half (9 persons) said that they had a family member or friend who helped them manage at home. All of the respondents said they had a case manager or care coordinator who helped them by arranging for services to come into their home. Most of these (14/18) said their case manager had been working with them for more than one year. Most (15/18) said that if they needed to in the past, they had been able to reach the case manager.

Decision-Making. When asked about how they would rate their ability to choose the type of help they receive, in order to live at home, one-third of the persons said that all of the decisions are made by them and another third said that their preferences are taken into account. Three persons said that they have no or little choice. In these cases the consumers offered the following comments.:

> *I have no input in what I receive.*
> *I don't feel like I have a choice.*
> *She (nurse or case manager) tells me what to do.*

When asked how important it is for them to choose their own services or workers, 8 people said it is very important for them to make these decisions on their own, 7 people said it is important

for them to have some input, but others can guide them, and 2 people said they would prefer that someone else do this for them (1 did not respond).

Recall on CDCS Option. When referred to information (written and verbal) about CDCS, half of the respondents said that they remembered hearing about this option. The interviewers then asked those who remembered hearing about the option why they decided not to select this option. A set of responses were offered and respondents could list all that applied to them. The most frequent response was "I am happy with what I have now." Other reasons included: "I didn't really understand it," "This wouldn't really be any different with what I have now," or "this has too much paperwork/seems too complicated."

Interest in CDCS. When the material describing CDCS was reviewed, respondents were asked what they thought about the option, as it had just been explained to them. Three individuals were very interested in the option, seven were somewhat interested, and six were not all interested (two people did not respond). Characteristics of the option that were interesting to the respondents included:

- the budget set aside for their own needs
- more choice and control
- the ability to hire family members or friends
- the ability to choose when and what they receive
- the new types of services that they might be able to get to help them live successfully at home

Comments included:

> *Client thinks it would be good to explore this option. Likes the idea of a budget.*
>
> *Client states he is so unhappy with what he has now, that he is desperate for this option.*
>
> *Client would like to have her daughter get paid for her service.*
>
> *Likes the idea of a personal budget, but worried the county might have strings attached.*
>
> *This could help a relative pay for gas.*

Unattractive Factors in CDCS. Asked what the respondents would not like about the CDCS option, they stated the following concerns or issues:

- this might require more of their time in managing services they have coming into their homes
- sounds complicated
- might not want to be the employer for a family member or friend
- paperwork burden
- too many rules

Desired Additional Support. When asked if there was any other type of help or support they wished they had to assist in managing, five respondents said yes. Additional support desired included transportation, foot care, additional help with housekeeping and home repair, and mobility aids (scooter).

Satisfaction. Half of these respondents said that the current service option they had for receiving their home and community-based services was meeting all of their needs. Another five respondents said it was meeting most of their needs. These individuals were happy with what they had now and would not want to make a change. Only two people said the "program" they are currently on (traditional service option) was not meeting their needs at all.

More information. Half of the respondents (9/18) said they would like to hear more about CDCS and receive more information. State staff were notified about the consumers requesting this additional information and followed up by phone and/or mail.

Interviewer comments. Several interviewers noted that CDCS was hard to explain over the phone.

Results from the "Early Adopter" Survey

The evaluator conducted the fourteen Early Adopter interviews. Seven of these interviews were conducted with the primary caregiver (family member) as a proxy, rather than the older consumer. Most often, this was with an adult daughter.

Health Status. Ten of the fourteen individuals (older consumers on CDCS) were rated as having "fair" or "poor" health status, either by themselves or by the primary family caregiver responding to the survey.

Receiving Help. Almost all (13/14) said that they or the older family member were receiving some help at home with things such as personal care assistance, grocery shopping, laundry, rides, etc. Frequently this was for personal care and housekeeping support, but also included other services. Sample comments are provided:

> *Right now we don't have an aide. We had a gal at the time Mom got on the program. We had her for three years and she helped both another family member on CDCS and Mom. We had to cut back when it was just Mom on the program. Now, I do everything.*
>
> *I have someone who helps fill out forms and a computer system that enlarges type font for me. Someone comes by to help me shop.*
>
> *I do almost everything…my family member had a stroke. I have to get her up and dressed, provide meds, do the personal cares, and then do the shopping. I do get some housekeeping and outside help.*
>
> *I have several workers we got through word of mouth. My Mom needs 24/7 care. She is a 2-person transfer and has swallowing difficulties. I also help with my father. We need three personal care assistants throughout the week.*
>
> *I get help two different days of the week. College students seem to work best or an older person who has experience in this kind of work.*

Paid Support. Twelve of the fourteen respondents said they have hours in their current Community Support Plan to pay someone to help out during the day or night. Half said that they did not have this help prior to going on CDCS. In addition another two people said there are other services (besides personal care assistance) provided within their plans that they could not get before they were on CDCS.

The level of paid personal care assistance support varied widely, reflecting the different case mix levels of the respondents in this sample. The high was thirty-four hours a week, the low was two hours a week.

Continuation of Unpaid Family Support. In addition to paid support, these respondents said they continue to receive or provide unpaid family support around the care needs of the older person. The level of unpaid support (estimated) varied widely, with a high of seventy hours a week to a low of two hours a week.

How heard about CDCS. When asked how they heard about the CDCS option, most replied that they heard about this through family, friends, or through their own previous work experience, such as from working with or in a county program. Some also had attended a presentation, read written material, or heard about CDCS through Senior LinkAge Line® or another senior organization. A few people said they had called their county about the program, but that the person they spoke with either did not know about the option or had said it did not apply for their older relative. Some spoke about the resistance they encountered in trying to get on or stay on the program.

> *A year prior I had asked about CDCS and the county said my Mom did not qualify. I contacted county social services again and asked again about getting help under a program like CDCS. They looked into our situation and said that Mom/Dad would more than qualify. I don't know what had changed, but she was eligible. Then we got into the CDCS program. Now we can get paid to help my Mom and can pay the girls who come in.*
>
> *Most elderly don't know about this. Last year I was in a health plan under PMAP and they kept trying to take me off the program, but I would keep calling them and saying I wanted to stay in CDCS. Finally I said I would go to the Attorney General if I didn't get a letter saying I could stay on this program. I talked to my girlfriend and found out she had a hard time getting through to her plan too.*
>
> *I had called the county case worker and said I read about this in AARP. The county didn't know anything about it. I said I wanted to bring my Mom home from the nursing home and she said it wasn't possible. Then I told her about CDCS.*
> *Another family member of mine (younger) was on CDCS and I went to a senior day care and learned this was starting for older people in my county. It had worked for my other family member.*

We got the program going, got the packet, did the [Community Support] *Plan, got the Agency. The workers at the county had changed from when I had first contacted them. I think we were the first in the county on CDCS-- I think it* [CDCS] *was a learning experience for them.*

Initial Interest. Most said that the ability to hire a family member was what initially interested them in CDCS. Another major interest area was the promise of having more control of the services and help that was provided. Additional reasons included: finding/using new types of services, having more choice, and keeping a loved one out of the nursing home.

Case Manager Support. All respondents had a case manager they worked with. Nine respondents said they had been working with the case manager for more than one year. Most (12/14) said they had been able to get in touch with the case manager in the past, when needed. The other two individuals said they had not had to contact their case manager, but that the case manager regularly met with them.

Community Support Plan Development. Early adopter respondents were asked how easy or difficult it was for them to prepare their Community Support Plan. Half said it was "very easy," two said it was "somewhat easy," two said it was "somewhat difficult," and two said it was "very difficult." One person could not recall how easy or difficult this was. Most (11/14) got help writing the plan, either from a sibling/family member, from the county case manager, or from a flexible case manager that they hired. Comments included the following:

I was the first kid on the block with this. No one knew what was going on.

The reason why I say that it is "Somewhat Difficult" is because how you have to write your own Plan out and the rules about what can be covered and what can be changed and how to change things. It (CDCS) works because you write your own Plan, but the rules need to be more flexible.

I wrote it myself. I have that expertise. The public health nurse said go for it. The supervisor from the county reviewed the plan. There was one point that was difficult. Otherwise I thought it was easy because I do this for my other job. The difficult part was that there are pages where you have to write information twice. It doesn't clearly define what the total budget is. Other families have worked 1-3 weeks to get this written (from what I've heard), but it was fairly easy for me to do.

My sister and I worked together with the FSE. I can imagine it would be hard for my Dad to do it by himself. But with a good fiscal agency and because my sister and I are used to planning, we could do it.

My daughter knew about this (she has social work background). My daughter helped me when we wrote the plan out. My daughter and I thought this would be giving us all the help we can get. The therapy part of it, and the respite time for me—they are very important to us managing.

I started researching it and read the Consumer Handbook and I called a fiscal entity to help me through the packet. She recommended a consultant who is an independent FCM. She helped me with the plan and budget and services. We were looking for respite care and not finding any (she helped us); she was great.

Fiscal Support Entities. Most (12/14) said that they were working with a fiscal support agency that helped them with their CDCS budget and paid bills for them. Most could name that agency and their contact person without prompting. When asked to rate the helpfulness or value of the agency's support to the consumer or family member, half (7/14) said the agency they had was "very helpful/very valuable," three said the agency was "somewhat helpful," and two said the agency was "not helpful" or "made things worse (harmful)." Several persons said they had switched agencies since they began on the CDCS program. In a few cases they were dissatisfied with the previous agency, especially around communication and timeliness with paying bills. As mentioned, the respondents with good FSE experiences provided positive comments about those agencies and continued to view the agencies as important resources.

Several family members and older adults stated that their background or work experiences had been helpful in designing the Community Support Plan, budgeting, and hiring/paying workers. One gentleman explained that he had been a businessman with employees and that hiring people and paying taxes was no big deal for him.

The case manager works with me to set up the program. With this program I'm able to live independently and it costs the State less because you don't have to go through a lot of agencies. We've eliminated the middle man. I'm getting all the care I need for about $20/hour where it would cost the State $40/hour. I've developed a system of receipts that tracks everything. I take responsibility for the taxes and everything.

Additional Needs or Wants. When asked if there were additional services that they wished the plan would pay for, but doesn't, respondents offered a variety of needs/wants, with the biggest request to have a bigger pool of dollars to pay for personal care support or respite support. In addition, they requested help with: laundry, housekeeping, supplies, transportation/mileage, and home repairs. Twelve persons said that the limiting factor was the budget. Comments included:

> *Need more hours of personal care time for family.*
>
> *It's a little bit less (budget) than what we need, because we all work and she needs more than the budget. When the budget runs out we still work (for free) until the new month, but it can be a hardship.*
>
> *The budget is inadequate. We need to make this a permanent change to have the budget bigger. I'm saving the government a lot of money by not having Mom in a nursing home. I also save on hospitalizations that might happen. I notice things that are subtle changes in condition and I can act on them right away before things get worse.*

Choice. The seven older adults who responded to the survey were asked how important it is for them to choose their own services or workers. Of these seven, six said it was "very important, and the other senior said "it is important that I have some input, but others can guide me."

Decision-Making. The seven older adults were asked about how they would rate their ability to choose the type of help they receive, in order to live at home. Four of the seven older adults said that all decisions are made by them, two said that their preferences are taken into account, and one person said they get some of what they want, but not everything. No one said they had little or no choice. The one person who provided additional comment said:

> *I'm able to tailor make the program to suit my needs. I'm able to determine how many hours per week I budget for everything. I have great flexibility in every week. I can "borrow" within parameters.*

Overall Satisfaction and Program Improvements. When asked about their overall satisfaction with how the CDCS option was working for them, almost everyone (13/14) said that they were very satisfied (the highest ranking), and the other person said he/she was somewhat satisfied. The slight dissatisfaction had to do with the desire to have a slightly bigger budget and receive more in-home personal care help. Additional comments about the program and how it could be better included:

Need a budget increase. Better education. More resources.

More public awareness of this program.

Need more paid in-home help (bigger budget).

Direct deposit my check. I had to do some implementation to make it work.

Need greater flexibility within the budget amounts.

Strongly advise seniors to hire Flexible Case Manager—it's the only way to go. Don't try to do this on your own. Go through 3 or 4 of the FSEs to choose what is best. Do a complete analysis of which ones charge what fees. The FCM and I went in person to meet the FSE in person.

Gas payments/mileage reimbursement needed.

Just get the word out more and have the county workers promote this and know how to do this. The FSE was so helpful, they are good resource people.

The arrangement relieves so much pressure. Dad had nothing so this is a gift. A little higher rate would be good. Perhaps some kind of equipment & supplies budget. It would be nice to give a raise to the personal care assistants once a year.

The only thing that is bad is the money is a little too limited. They put an amount of money in there, but if you don't get a bill in a timely way, and then that month goes by… later you might not have the money to pay the bills that might come all at a time. Divide up the budget into quarters instead of monthly.

Recommend to a friend. All of these respondents said they would "definitely" recommend CDCS to a friend. Comments included:

YES!! This has been a godsend and we couldn't go on without it.

Why in those couple of years was it kept in secret? If I wouldn't been constantly looking and kept asking, I still wouldn't know about it. We should have been contacted when it became it available. A year would have made such a difference—there must be some others like us right now who could use this and don't know about it. I think that is a terrible shame.

If we didn't have this I don't know where I'd be. I'm on my second year on the program. It's annually renewed. Before we were on CDCS I had a volunteer who would come occasionally but that person had no experience.

Discussion

Participation in CDCS by older persons in Minnesota has been lower than expected (see Table 5 below).

Table 5. **Eligible Recipients, Revised Participation Projections 2006 and Actual Participation 2007 in CDCS**

Program	*Eligible Recipients (by program, 2006)*	*Revised Participation Projections, 7/2006*	*Actual Participation, 7/31/2007*
Elderly Waiver	17,533*	228	78
Alternative Care	5,152	132	41
CADI Waiver	9,403	300	110
Caregiver system	463	83	70
Total:	**32,551**	**743**	**299**

*10,949 of these Elderly Waiver recipients are ineligible for CDCS since they are living in adult foster care or in an assisted living facility.

The observer should not conclude from this that almost all eligible older Minnesotans are not interested in a consumer-directed care option. Enrollment reflects awareness as well as receptivity to program features.

Actual enrollment growth in a consumer-directed option has been slower and lower than expected in other states as well. Experience from the three original cash and counseling demonstration states showed that approximately 8-10% of elderly individuals selected this option when offered, compared to a pre-implementation estimate of one-third of eligible elderly people. The original estimate of 33% was based on initial response and interest expressed by the target group (Phillips, et. al., 2003).

Using the ballpark estimate of ten percent penetration in the EW and AC populations would mean that in Minnesota we could expect approximately 1,174 older adults to elect to use the

CDCS option[2]. Current enrollment hovers around 120 from these two groups (about 1% of eligible persons). This suggests that there are other reasons, besides program features, that have kept enrollment in CDCS low.

In their grant proposal to the Robert Wood Johnson Foundation, State of Minnesota representatives indicated several anticipated barriers to implementation of the Consumer Directed Community Supports program. These included: (1) resistance to consumer-directed services by traditional service providers and counties not offering these services in the past, (2) lack of education or awareness of older consumers and their family members about consumer directed services, and (3) lack of infrastructure.

While the infrastructure largely has been developed and is in place, it is clear that the efforts to reach consumers and family caregivers and to explain the CDCS option have not been sufficient to break through the environmental factors, potential resistance, and unfamiliarity about CDCS among staff within counties, health plans, other organizations, and among consumers. In our small sample of "non-respondents," only half of the older consumers who were eligible or already receiving EW or AC services recalled being offered the option. This is consistent with a finding in Colorado of Medicaid case management services, where only 46% of the elderly individuals surveyed recalled being offered the consumer direction option by their case manager (Colorado Department of Health Care Policy and Financing, 2006).

The "early adopter" consumers we spoke with described the difficulty they had finding out about and initially getting into the CDCS program. Several of these individuals persisted in their search for more options for their family member, despite being turned away or discouraged by "the system." Most of these individuals heard about the program through family members or friends and a few through community presentations. Their enrollment into the program occurred prior to the use of the independent enrollment counselors, therefore we cannot comment on the effectiveness of this method to reach consumers. Experience from the initial three cash and counseling demonstration states suggests that outreach and marketing involves a significant and

[2] As of the end of 2006 there were 17,533 on EW and 5,152 on AC or 22,685 older adults, less the 10,949 who are living in adult foster care or assisted living and therefore are ineligible. The result of "eligible" individuals is 11,736. Ten percent of this is 1,174.

sustained effort. Excerpts from the Mathematica Policy Research evaluation of those states' experiences are offered:

> *To produce enrollment to meet the evaluation sample-size targets (as well as to build caseloads sufficient for viable programs), all three programs eventually relied on workers whose time was dedicated to outreach and enrollment. Arkansas's dedicated state staff successfully conducted outreach and enrollment until the evaluation sample-size target was reached, after which the state shifted responsibility for outreach and enrollment to counselors and phased out the positions for state employees. After months of trying to work through traditional case management and support coordination agencies, Florida hired temporary state employees as dedicated enrollment staff; one group of employees enrolled elderly beneficiaries, another group those with developmental disabilities . . .enrollment surged with their employment and direct mailings to Medicaid supportive services recipients* (Phillips, et. al., 2003).

Environmental or marketplace factors are another consideration for understanding low enrollment. In 2006 seniors, health plans, providers, advocacy agencies, and counties were "overwhelmed" with choices and issues around health insurance, pharmaceutical coverage, and expansion of existing programs (i.e., Minnesota Senior Health Options) and, according to the professional key informants surveyed, this affected their ability to attend to CDCS as another option for older consumers. Compared to 2005 when CDCS was first available to older people, more older adults receiving Elderly Waiver services in Minnesota are now enrolled in MSHO. The effect of this environmental factor seems to be subsiding—another study involving interviews with health plan and county representatives working with older adults throughout the state indicates these organizations have moved beyond the "chaos" of 2006 from Medicare Part D and MSHO expansion (Johnson, Malone, Morishita, Nwoke, Paone, and Ripley, 2007 forthcoming). Therefore, internal capacity and marketing issues should not be as much a factor in 2007 as they were in 2006.

Consumer-directed service options require a change in methods for receiving home support, and change is not for everyone. In our small sample of non-responder older adults who were on

Medicaid or Alternative Care and already receiving home and community-based services, most were comfortable with their current arrangements and with their case manager. Minnesota has a comprehensive service package of home and community-based support for older adults, compared to many other states. The current programs in Minnesota may be meeting most people's needs for home support.

Another factor may be the relationship between an older person already receiving home and community-based services and his/her case manager. This relationship naturally grows over time and in many cases the case managers feel they are advocates for the consumers. Likewise, consumers may be hesitant to get involved in anything that they perceive would come between themselves and their care managers, even if CDCS does not require a change in this relationship. For example, each senior enrolled in MSHO has a designated care coordinator/care manager. The care coordinator is a central figure within the MSHO integrated delivery service model, and other studies have shown that older consumers have responded positively to having this coordinator (Malone, Morishita, Paone, and Schraeder, 2004). A significant number of older consumers are now in MSHO and may have experienced receiving new types of support from their care coordinators or care managers that they do not wish to jeopardize.

One observation supporting this hypothesis (that an established consumer/care manager relationship indicates less willingness to select a CDCS service option) is the fact that more older consumers new to the Elderly Waiver program are selecting CDCS than are the consumers who have already been in the EW program. Those new to EW would be unlikely to have care managers and therefore would not have an existing relationship.

Program complexity is another likely factor in low enrollment. Several of the non-responder Minnesotans interviewed who did recall some presentation of the consumer-directed option, did not really understand CDCS as it was presented. Even the trained telephone interviewers found it difficult to describe the option to the older consumers, echoing the statements of several of the professional key informants interviewed last fall.

The low enrollment has been discouraging to state DHS staff members who see CDCS as a valuable option for older persons and family caregivers whose personal characteristics, preferences, or living situations match the features of CDCS. CDCS seems especially promising for people living in areas without sufficient services, resources, or an existing labor force of personal care providers to provide home-based support. Experience from other states showed that cash and counseling programs tapped into the "hidden labor force" of older adults' family members who were positioned to provide support, building off of their existing relationships with these older people. The experience from the initial three cash and counseling demonstration states also suggests that those from minority cultural or ethnic groups may be attracted to consumer direction because they have preferences for a type of care or service that is "specialized" beyond which the marketplace can provide or they see this option as more in keeping with their cultural norms (Phillips, et. al., 2003).

If our sample of early adopters is representative of the other 70+older persons and their family members currently on CDCS, then this group is clearly committed to the program and wants CDCS to continue. Finding a way to tap into this enthusiasm and share it with other family caregivers or older persons eligible for EW or AC services would seem to be a promising strategy. In fact, during the interviews described, several of the early adopter respondents offered to help spread the word "however I can," in order to ensure that the program continues.

There are efforts underway to encourage greater participation by older adults and family members in shaping the CDCS option. Since completing the interviews described, the Minnesota Department of Human Services has begun seeking members for a statewide consumer-directed advisory task force. The 2007 Minnesota Legislature approved expansion of consumer-directed options under Medicaid using the federal 1915(j) self-directed option. Included in this legislation is development of a task force to advise the commissioner on policy, implementation and other aspects of consumer and self-directed services for older people and people with disabilities.

At the time of this report writing, a consumer (family member) is spearheading an effort to develop a "Self-Directed Services Advocacy Group." The Self-Directed Services Advocacy Group is an offshoot of the National Participant Network of National Program Office for Cash

and Counseling of The Robert Wood Johnson Foundation. This National Participant Network has two Minnesota representatives. The Self-Directed Services Advocacy Group will use what they learn from the National Participant Network and apply it in Minnesota. The goals of the National Participant Network are to:

- identify ways to increase participant involvement,
- identify ways to strengthen advocacy efforts for sustainability of the Cash and Counseling model, and
- facilitate communication between states.

The goals of the Self-Directed Services Advocacy Group are to: educate people about self-directed services, collaborate with other human service agencies receptive to the model, provide support and testimony to public officials, and provide feedback on materials, curriculum, etc. in Minnesota.

Key Questions Revisited

In revisiting the key evaluation questions, I offer the following:

1.) Has the implementation (by the State and other organizations) around infrastructure development, marketing, and technical assistance pertaining to implementation of CDCS to older adults in the State of Minnesota been effective, in the opinions of key informants? How has it worked for the early adopters of the program?

Yes and No. The implementation of the infrastructure around policies and procedures has occurred. The infrastructure development related to certification and approval processes for flexible case managers and fiscal support entities has been expanded from the previous structures (that focused only on other population groups) to allow for older adults to access the CDCS option in Minnesota. The state has offered numerous educational and training sessions, accessible via videoconference and attended by many county, health plan, advocacy organizations, providers, and others. State staff members have provided technical assistance to counties, health plans, advocacy organizations, flexible case managers, fiscal support entities and other organizations involved in serving older adults who are on Elderly Waiver, Alternative Care, or those accessing Title III-E caregiver respite services. Marketing and outreach efforts have included making informational pieces available through organizations working with older consumers, mailing informational materials directly to older consumers,

and utilizing contracted “enrollment counselors” to contact consumers by phone. This has included programs on public and cable-access television.

In terms of effectiveness, the results are not clear. While training materials and manuals are available (written and online), the professional and consumer key informant interviews seem to indicate that not everyone who needs to is using these materials and that there is room for additional information in different formats. Certainly the awareness of CDCS as an optional way to receive home support and knowledge about how to use this option has not permeated consumers in the state.

In terms of technical assistance to consumers and family members, the infrastructure is in place and being used—however program complexity seems to serve as a barrier to acceptance. The early adopters described using the Consumer Handbook and other written material to understand CDCS and follow the steps in using the option. Family members in our sample were very involved and, in fact, often leading this effort. Many had skills or knowledge that was relevant to CDCS from previous work experience or from similar programs involving other family members or friends. A few hired a flexible case manager and found this resource invaluable to them. Four out the fourteen surveyed still found the community support plan “somewhat” or “very” difficult to complete. The non-responders in our sample also mentioned program complexity as a reason they would not choose CDCS.

In terms of how it is being used, the early adopters we spoke with are clearly happy with the program and want it to continue. All of the fourteen early adopter consumers or family members we spoke with would strongly recommend the CDCS service option to a friend.

2.) What more is needed to support this as an ongoing, viable option for older adults and organizations serving consumers?

The early adopters would say: bigger budgets for older consumers, more awareness among older adults and healthcare/social service professionals about CDCS and how to use it, and ongoing technical support from flexible case managers (wrapping this FCM service into the program as a standard feature). They also asked (indirectly) for peer support—the

opportunity to talk to other consumers or family members and share strategies or resource ideas.

Professional key informants would say: changes in the budget methodology, better oversight or monitoring of services provided in the home (particularly personal care services), better and more informational materials which are tailored to a variety of consumer groups (e.g., urban/rural, family caregivers, minority groups) and additional technical assistance that would assist them and consumers--such as worksheets, illustrative examples on how this could work (using case studies) and sample community support plans tied to budget categories.

3.) What were the barriers or environmental factors/events that impeded or advanced CDCS—particularly those that may continue to affect acceptance of the CDCS option for eligible older adults and those in the target programs?

Impediments included: tremendous marketplace activity around Medicare Part D and MSHO expansion affecting both older adults and organizations serving older adults, satisfaction with existing service options, program complexity, and concerns by professionals about fraud, abuse, or neglect—arising from perceptions that fraud in the PCA program in Minnesota has been increasing and that CDCS would experience a similar trend.

Table 6 gives additional information about the characteristics of the 119 older adults on Elderly Waiver or Alternative Care who elected the CDCS service option (cumulative, since the option was offered to this population).

Table 6. Characteristics of Older Adults on EW or AC Receiving Services through the CDCS Option

Category	Characteristic	EW	AC	Total
Total # Older Consumers		78	41	119
Gender	Female	57	30	87
	Male	21	11	32

Table 6. Characteristics of Older Adults on EW or AC Receiving Services through the CDCS Option ---continued				
Category	Characteristic	EW	AC	Total
Age	65-69	16	4	20
	70-79	22	12	34
	80-89	32	15	47
	90+	8	10	18
Race	White or Unknown	68	40	108
	Non-White	10	1	11
Case Mix	A (least H&CB needs)	30	14	44
	B-K	48	27	75
Months on Program	6 months or less	32	23	55
	Over 6 months	48	27	75
Managed Care Enrollees		60	N/A	60

The proportion of managed care enrollees on EW who have elected the CDCS service option is high. Health plans in Minnesota are still in the process of responding to market changes such as MSHO expansion and the evolution of Special Needs Plans requirements. However, DHS staff reports that a greater number of older consumers on managed care are selecting the CDCS option and care coordinators are becoming more familiar with how it works. As a consequence, the health plans have been more receptive to CDCS as a viable way to provide home and community-based support in 2007.

Catalysts for CDCS have included: videotape, other media materials, trainings, and one-to-one assistance by state staff, positive experience of early adopters who have enrolled in CDCS, and philosophical acceptance among professionals of the basic premise that consumers have the right to choose their care.

4.) In the opinion of the early adopter key informants, what are the biggest advantages or areas of success in the CDCS option for the older consumer?

Consumers indicated that the ability to hire family members and the sense of greater control over one's life were two advantages of CDCS. Case managers and other professionals with some experience with CDCS also indicated that the ability to hire a spouse as a personal care aide, and the flexibility for finding new workers (who are not in the existing labor force) or new types of services (e.g., specialty ethnic meals) have been two attractive features of CDCS.

5.) What are the biggest disadvantages or concerns that key informants have related to the CDCS option for the older consumer?

Among professionals it appears that concern about fraud/abuse and safety issues and the belief that consumers have fewer dollars to spend on their own care (as compared to using the traditional home and community-based options) are the two biggest disadvantages to CDCS.

Most of the "non-responder" consumers we interviewed who were receiving EW or AC services through traditional methods stated that they were happy with what they had now. They mentioned the administrative issues and program complexity, and the concerns they had about being an employer for family members as reasons they were not attracted to the CDCS option. However, there was a vocal minority from the non-responder group who felt they did not have any decision-making authority with their current service arrangements and indicated they were very interested to hear about another option that gave them more control. It is also interesting to note that half of the "non-responder" consumers wanted more information about CDCS simply as a result of participating in the telephone survey.

6.) What more could be done to positively impact market acceptance and program satisfaction?

There is a need to build on strategies that are working. Judging from this examination, older consumers on EW and AC and their family members are not hearing about the CDCS option, though the independent CILs contracted by the state to increase awareness have had some effect—increasing awareness of both consumers and of care coordinators/case managers. Language barriers continue to be a problem in trying to reach minority groups.

The lack of experience in working with CDCS on behalf of their members/clients is still a primary deterring factor among some professionals. In 2006, when the professional key informant interviews were conducted, few MCOs or counties had much experience with CDCS or with explaining it to older consumers. In 2007, the CILs indicated that what worked best in educating consumers and families was the one-to-one contact and illustrating successful approaches. Simple examples were provided. There may be lack of confidence or comfort among some case managers about how to effectively talk about CDCS with potential users. According to DHS program staff, there has been some progress in this area. They report that in 2007, a number of case managers have experienced positive feedback and success in working with older clients and these case managers have "come around" where they feel more comfortable discussing and using the service option with other older consumers in their caseload.

Quality oversight and safety were concerns voiced particularly by the MCOs in 2006. Much of this stemmed from their experience with the rapid growth in personal care assistant (PCA) agencies and some agencies' tactics in marketing their services. Some health plan representatives described the tactics as almost predatory. The issue with PCA services is linked to CDCS because some of the health plans think that consumer-direction offers less oversight than the traditional way that home and community-based services are provided. If there were demonstrated safeguards related to PCA, such as an oversight function that could be extended to monitor service provision by family members, the health plans said they would be more reassured about CDCS as an option. As changes have occurred in the PCA Choice program and in state policy, this concern may have diminished.

We know from other states' experiences that concerns about safety and fraud are common reasons given for resisting consumer-direction. The quality of consumer-directed services has been a hotly debated issue ever since the cash and counseling model was developed. In an extensive review of the literature and of eight states' consumer-directed programs, researchers from The Urban Institute found that traditional home and community services programs for older adults attempted to assure quality by relying on governmental regulation

around worker training, certification, agency supervision and paraprofessional standards. These elements are not often present when the personal care attendant is a family member. The quantitative research and qualitative interviews they reviewed, however, found that the quality of care and satisfaction with care under consumer-directed care was at least comparable to agency-directed care, if not better, despite the fact that "almost all of these [regulatory] mechanisms do not exist in consumer-directed care" (Tilly and Weiner, 2002).

7.) Is the State positioned for ongoing support of this service option after the pilot is over? Is there a readiness within counties and health plans to continue the option?

The Consumer Directed Community Supports service option is now in policy and practice through programs administered by the Department of Human Services, Aging and Adult Services and Disability Services Divisions and has been extended to older adult populations. The evaluator expects that this option will continue to be available. At this time, it is unlikely that there will be other available funding for the RJWF Cash & Counseling Project Director and Coordinator to continue their current project duties to spearhead efforts targeting older adults for enrollment into CDCS after the grant project, though they may be asked to advise others or support some of these efforts within the division. The marketing, oversight, technical assistance and educational activities they have performed will likely be subsumed by other areas within the department. It is reasonable to expect that these activities will extend across population target groups. To the extent that the older consumer is different from other population groups eligible for CDCS and is harder to reach (a notion supported by this evaluation), a general effort around marketing and technical assistance across CDCS population groups may not be sufficient to increase penetration among older consumers on EW or AC.

One primary target should be those newly eligible for Elderly Waiver or Alternative Care home and community-based services. There are proportionately more older consumers new to EW and AC who are opting for CDCS. Those who have been on EW and AC for a long time have been less likely to opt for CDCS—either because they are comfortable with what they have or they do not wish to change the relationship with their case manager (or both). For these individuals, case managers are clearly a key to successful introduction of CDCS.

According to DHS staff, the level of effort within counties and health plans around promoting CDCS seems to be changing slowly. Enrollment is still low (1% of eligible older recipients), however education and outreach efforts of the state and the independent enrollment counselors (CILs) effort seem to be opening doors. There are still some professionals who are doubtful about the service option. Another small group of individuals are champions, given their direct positive experience in assisting older clients and having the option work.

Recommendations

Responding especially to the voice of those on CDCS—who are strong proponents of this option for having their care needs met—I offer the following recommendations (not ranked):

1) **Marketing to and Supporting Older Consumers & Families**- Increase direct marketing efforts, though not necessarily through traditional means. Enhance efforts to work through Senior LinkAge Line®, ethnically-oriented advocacy organizations, and other direct service organizations under contract with counties and municipalities to market the option. Target both adult family caregivers and older adults directly in ways and places that match their characteristics and habits.

   The Mathematica evaluation in the initial three Cash and Counseling demonstration states found that "direct, targeted outreach through mailings to Medicaid personal care or waiver recipients was more effective than community education in generating enrollment" (Phillips, et. al., 2003). While other states successfully employed strategies such as a letter from the governor to older individuals and Public Service Announcements on the radio, the direct mailing experience and PSA route in Minnesota did not result in much response.

   Ideas for non-traditional marketing efforts include direct follow-up calls to people calling in to Senior LinkAge Line®, automatic follow-up for any older person receiving a Long-Term Care Consultation, outreach to family caregivers, development of consumer peer support networks, outreach to rural agencies, programs, or municipal service areas, continued use of enrollment counselors, and development of telephone hotlines or other response systems.

   Find ways to reach the family caregivers and work toward involving family members in marketing and outreach methods. Family caregivers often have difficult work/home schedules and therefore outreach may have to occur during the evening or weekends.

   Explore use of the consumers already enrolled as effective messengers to others about CDCS and for supporting each other. Develop peer-to-peer workshops or networks for exchange of

information where families can describe their strategies for making the service option work effectively for them/their older relative.

Explore new strategies to reach ethnically diverse and rural older adults. Consider targeting older adults directly and adult family caregivers as a primary audience in areas or in situations where they are naturally congregating—particularly in ethnic minority neighborhoods. Local resource centers or municipal service agencies that are in frequent contact with low-income, rural, or ethnically diverse older adults and family caregivers may be helpful. Organizations and other programs that serve low-income families, such as energy assistance programs, municipal or volunteer transportation organizations, or home repair assistance programs, may be familiar with people who could meet the eligibility criteria for EW and also be interested in CDCS.

Rural areas, where there is a dearth of PCA and home care services, may be particularly ripe for CDCS. Extensive travel distances and few providers create a situation where family and friends may be the only source of care. Key informants discussed the difficulty case managers and older adults have in finding someone to come into the home. The CILs mentioned that rural counties have been more receptive to CDCS. Solicit input from rural providers and non-metro AAAs on the best ways to reach these rural older adults and family caregivers.

Materials need to fit the audience. The three original cash and counseling states used written, oral, and videotaped descriptions of program features, with written materials tailored to the reading level of the average Medicaid beneficiary. Question and answer formats were particularly well received. Florida and New Jersey secured enrollment specialists who were fluent in other languages or used language-line services to translate information.

Review the response to the independent enrollment counselors under contract with the state. They have found success through home visits or personal telephone calls. This strategy, while effective, is also expensive. They may have additional suggestions for outreach and for modifying the message or the materials provided.

Whatever method is used to inform consumers and family members, be sure that reliable, consistent follow-up is provided. Develop a response mechanism and supportive structures, e.g., a telephone hotline, that will provide consistent, timely response to callers.

2) **Technical Support & Training -** Case managers and care coordinators from provider systems, counties, and health plans will continue to be an important key resource and marketing channel, especially for EW clients. However, describing the option is a labor-intensive, one-on-one process. There may need to be more support to care managers until the program is more widely used. Expanded training opportunities including peer-to-peer learning opportunities may be fruitful. Managed care organizations or counties may be particularly responsive to on-site training of their care coordinators/care managers that demonstrates how CDCS can work within a managed care environment and uses real-life case studies, sample community support plans, and other tools that support and dovetail with existing care coordination methods.

   Tap into the expertise of experienced independent Flexible Case Managers and Fiscal Support Entities as contracted speakers and technical assistance providers. Peer-to-peer learning opportunities where professionals share success stories, strategies, or tips on making the CDCS option work could be held regularly. Topics could include how to: assist in preparing the community support plan, finding services that match the special needs of ethnically diverse older adults, what to do when the level of care needs change, administrative and paperwork tips, etc. Work with FSEs and counties experienced with CDCS through their work with the DD (developmentally disabled) population, and solicit their input more directly in training and technical assistance efforts.

   Ensure that all presentation documents and tools are posted on the two areas of the DHS website. Update these documents in a timely way. Create electronic key contact directories, list-serves or e-alerts to inform all interested parties of policy or program changes, and to give updates on success stories, new resources, or other issues.

3) **Quality & Peer Review** – Support the Self-Directed Services Advocacy Group and other efforts that encourage consumers to share experiences with the CDCS option. Ensure at least an annual survey of older adults and family members using the option (within the EW and AC quality review process).

   The state could consider building contract requirements into existing contracts with managed care organizations or counties that address at least one or two issues that are unique to consumers on CDCS. For example, that annual satisfaction surveys of members on EW must include a random sample of at least X% of older consumers who have elected CDCS (or at least X number of individuals, whichever is greater) where the data provided on results is separated to allow for comparisons between the two groups.

   There may also be additional elements to monitor that are specific or particularly important for CDCS clients, such as the actual service use/claims experience of these individuals, reported paperwork or administrative burden, satisfaction with technical support received, or rate of hospital, rehab, or nursing home admission. These data elements would need to be collected identically across plans or counties in order to compare across organizations. This would help identify potential best practices or highlight trouble spots.

   Quality assurance mechanisms should include older consumers and families themselves. Both the items to review/examine, and the way these things are monitored should be, at least in part, designed or approved by a panel of consumers and families. In addition, the ability of consumers to use this option effectively depends on their knowledge of what services are available and how to put a "package" of support together. A report from Scripps Gerontology Center specifically notes that peer support is a proven component for effective quality improvement (as well as word-of-mouth marketing)—and that consumers (and families) themselves are the best source of information about good providers, effective methods, and other program features or issues (Applebaum, 2004). There should be an ongoing group, forum, or office that maintains this consumer-driven service and quality oversight mechanism.

4) **Budget Methods & Service Experience** – Both consumers and professionals raised the issue of inadequate budgets for older persons electing this service option in Minnesota. While this evaluation did not focus on the merits or flaws of the current budget methodology, the responses received over two years of examination suggest that a re-examination is warranted.

   Such a review might begin with an examination of the actual service and financial experience of older adults on CDCS compared to experience of a matched sample of older adults (same demographic, medical, and social characteristics, perhaps even the same care manager) on EW in terms of services received, non-paid caregiver support provided, and rate of hospitalization, rehab or nursing home admission. In our small sample of "early adopters" there were several family members who said their older relative was using the maximum dollar resources available to them and it "was not enough." This seemed to be particularly the case for the older consumers in the highest or lowest case mix categories.

   In addition to changes to budget methods, there may be other ways to extend additional support to assist older consumers and families electing the CDCS option. For example, one suggestion offered by two current CDCS older consumers was to offer Flexible Case Manager services "free" to CDCS clients—that is, not require these clients to pay for FCM services out of their own budgets. This would free up a few dollars from their budgets, and also provide additional technical support in managing the program effectively. This might also provide some level of oversight that does not currently exist with consumers relying solely on themselves or their family members to find and monitor services or workers. These consumers said that the FCMs had been invaluable sources of information and had helped avoid pitfalls in service and in administrative details that would have cost both the state and themselves "time and money."

Conclusion

The three years of work in extending a cash and counseling option to older adults and other populations in Minnesota has been very valuable.

At the beginning of this evaluation, presumed results from state implementation efforts around infrastructure development, outreach, marketing, and technical assistance for consumer directed care for older adults were anticipated to be: prepared professionals, sufficient enrollment among the target groups, and high satisfaction among those enrolled.

There is evidence of progress toward these outcomes. Enrollment started out slowly but there are encouraging signs of acceptance among a subset of older consumers and their family members, as well as by some care coordinators, case managers, and others working with older adults at health plans, counties, and advocacy organizations. However, the low cumulative number of older adults electing CDCS and the apparent difficulty they had getting into the program indicate that continued efforts will be needed to overcome environmental factors, lack of awareness, or other barriers that exist.

Key informant interviews of healthcare/social service professionals in 2006 and of consumers/family members in 2007 suggest that the preparation activities by the state have not been echoed in other settings, that many people are still unaware of the CDCS option, many are unfamiliar with the steps for using the option, and that most organizations have no immediate plans to increase their efforts around marketing or preparing for the option. These organizations continue to look to the state to take the lead in promoting this option and in providing technical support and information about it.

For some, current service options are satisfactory to older consumers. The small sample of consumers and family members who elected not to enroll in CDCS indicated satisfaction with current home and community-based service options in Minnesota when interviewed. Many said they would not choose another option for their care and that they were satisfied with having their

care manager assist them. They may have perceived (inaccurately) that the CDCS option means they would need to give up their case manager.

Environmental factors, such as the introduction of Medicare Part D and the Minnesota Senior Health Options passive enrollment in 2006, impacted both organizations and seniors in the state. Resistance to additional change—both among consumers and healthcare/social service professionals may be part of the reason that enrollment growth has been slow. Recent reports from DHS staff indicate that there is increasing awareness and acceptance among managed care organizations, however, as more care managers work with clients selecting this service option and have a positive experience.

Despite these environmental factors and other issues, a small handful of older consumers and their family members found their way into the CDCS program and are enthusiastic about the program. These early adopters voiced a strong desire to keep CDCS a viable and growing option in Minnesota. One change requested by many of these early adopters was an increase in their budget allotments. Many also asked that additional marketing or educational efforts be pursued to reach others like them—those facing struggles in trying to stay living safely at home.

Even if CDCS turns out to be a "good match" for only 10% of older consumers on EW or AC (an estimate based on previous cash and counseling experience in other states), this still would mean that approximately 1,174 older adults and family members would be using the CDCS option[3]. At the present time, fewer than 120 older adults on EW or AC have elected the CDCS service option—suggesting that additional program acceptance among professionals will be needed to reach the target group.

Suggested activities to increase program acceptance by healthcare and social service professionals and consumers include:

(1) Expand successful outreach strategies and explore innovative ways to reach consumers and family members,

[3] This figure was derived from the approximately 6584 older adults on EW who were not living in adult foster care or assisted living and the approximately 5,152 older adults on AC, for a total of 11,736 eligible older people who could have elected the CDCS service option in 2006.

(2) Continue to offer regional and statewide technical assistance on CDCS using a variety of methods and developing peer-to-peer professional learning opportunities,
(3) Enhance quality monitoring mechanisms and encourage or support a consumer/family member peer network,
(4) Consider changes to the budget methodology. In particular, examine the characteristics and expenditure history of older adults on CDCS who are using the maximum dollar resources they have available to them.

References and Resources

Applebaum, R. Schneider, B., Kunkel, S., Davis, S. (2004). *A Guide to Quality in Consumer Directed Services*. Scripps Gerontology Center, Miami University. August.

Colorado Department of Health Care Policy and Financing. (2006). *Case Management Client Satisfaction Survey Project: Final Report and Recommendations.* Real Choice Systems Change Grant #915328. August.

Consumer Directed Community Supports Consumer Handbook. (2005). Minnesota Department of Human Services. DHS-4317.

Johnson, A., Malone, J., Morishita, L., Nwoke, S., Paone, D., and Ripley, J. (2007). *A Study of Care Coordination and Case Management in Minnesota's Publicly-Funded Managed Health Care Programs for Seniors: Final Report.* CFMS Contract # A96859. (forthcoming in September).

Malone, J., Morishita, L., Paone, D., Schraeder, C. (2004). *Minnesota Senior Health Options (MSHO) Care Coordination Study: Final Report.* Minnesota Department of Human Services. June.

Paone, D. (2006). *CDCS for Older Adults in Minnesota: Interim Report*. Submitted to the Minnesota Department of Human Services. Contract # A80780. December 21.

Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., Doty, P. (2003). *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report.* Mathematic Policy Research, Inc. June.

Tilly, J. and Weiner, J. (2001). *Consumer Directed Home and Community Services: Policy Issues.* The Urban Institute. Occasional Paper Number 44. January.

Web site: www.dhs.state.mn.us/cdcs

Appendix A - Consumer Directed Community Supports Volunteer Training Agenda

"Conducting the CDCS Consumer Interview Survey"
March 29, 2007

I. Welcome & Introductions (9:30- 9:35)

II. Purpose of Survey (9:35-9:40)

III. What is "CDCS?" (9:40-9:50)

a. Description
b. Video
c. Case stories, other communication pieces

IV. Consumers (9:50-10:00)

a. Who are these consumers?
b. What letter/materials did they receive?

V. Survey (10:00-10:40)

a. Process (steps from scheduling to conducting to finishing)
b. Instrument (walk through)
c. Follow-up and timeframe

Break (10:40-10:45)

VI. Practice the Interview (10:45-11:15)

VII. Confidentiality and Data Handling (11:15-11:25)

VIII. Other Issues (11:25-11:45)

a. Consumers who may not be able to participate – hearing, confusion, changes in status, cannot be reached
b. How to handle family proxies
c. How to handle consumers' questions on CDCS, etc.
d. Importance of Interviewer Notes

IX. Questions/Discussion (11:45-12:00)

Appendix B - State of Minnesota Selected Older Consumer Survey (CDCS-NR) (Non-Responder)

[NOTE TO INTERVIEWER: This survey has been designed to obtain responses from older consumers enrolled in either the "Elderly Waiver" or "Alternative Care grant" Programs, (or from family members) offered through the State of Minnesota. Enrollment into these programs happens within the county where the older person resides. The survey asks if they have heard of a new service option, called "Consumer Directed Community Supports." All persons should have received a pamphlet/card in the mail, describing the option. At times, a family member will respond on behalf of the older person.

Introduction
Hello. I am a trained volunteer from the Office of the Ombudsman for Older Minnesotans. My name is _____________________. I will be asking you a few questions about your care at home. Your answers will help the State of Minnesota plan for older people and their care needs and service preferences. You recently received a letter and materials from the State and sent back your signed consent form agreeing to participate in a telephone survey. Would you like to do this telephone survey now? It will take about 20 minutes. If not, we can schedule a time that works for you.

IF YES. *We appreciate your time today. There are no right or wrong answers—this is your opinion. This does not affect your services in any way and your answers are kept private.*

If you need me to repeat a question, I'll be happy to do so.

Interviewer Name: ____________________________________ Date: _________________

Consumer Name: ____

Phone #: ____________________________________

Name of Person Interviewed: (if not Consumer, list name and describe family relationship, e.g., "son")

____
Name Relationship

Case Manager's Name (on record):____

Starting Point question:

a. What county do you live in?: ____
(e.g., Hennepin, Ramsey, Olmsted, Stearns, etc.)

State of Minnesota Selected Older Consumer Survey (CDCS-NR)

Background

Many of the people we are talking with receive help with things at home, such as: grocery shopping, cleaning, getting meals, laundry, getting dressed, or errands/chores. Some people also get items like ramps or grab bars to help get around safely at home. Others get rides to places they need to go, like the doctor. Some have a personal attendant or home care worker several hours a day at home.

1. **Are you** (is the older family member/client) **currently receiving some help at home?**

   Yes **No** Don't Know

Comments:

____

2. **Can you briefly describe what kind of help you** (OR your older family member/client) **receive?**

Comments:

____

3. **Do you have a family member or friend who helps you manage at home?**

   Yes No [IF NOT, SKIP TO QUESTION #5]

   Relationship to senior: (e.g., daughter, son, etc.)

   ____

4. **Is this family member or friend paid by the State to serve as your Personal Care Attendant (PCA)?** *(that means they help you with your personal needs in your home)*

   Yes No Don't Know/Remember

5. **How would you rate your ability to choose the type of help you receive, in order to live at home?** *I will read you some possible answers. Tell me the one that best matches what you would say.*

1	**2**	**3**	**4**	**5**
All decisions are made by me	My preferences are taken into account	I get some of what I want, but not all	I have little choice in what I get	I have no choice at all

Comments:

____

6. **How <u>important</u> is it to you to choose your own services or workers, or would you rather have someone else do that for you?**
I will read you some possible answers, and you tell me which one is closest to how you would answer:

It is <u>Very Important</u> that I select services and workers on my own	It is <u>Important</u> that I have some input, but others can guide me	I would <u>Prefer</u> that someone else do this for me

Comments: ____

____

7. **Do you have a Case Manager or Care Coordinator who helps you by arranging for services to come into your home or getting you home help?**
First Response: Yes No Don't Know/Remember

Name of Case Manager/Coordinator: ______________________________
(Interviewer: May prompt the person with the name of the case manager listed on front of the survey form)

[IF NO CASE MANAGER, SKIP TO QUESTION #10]

8. **Has your case manager been working with you** (OR your family member) **for <u>more than one year</u>?**
Yes **No** Don't Know

Comments:

____

9. **If you needed to in the past, have you been able to reach your case manager—for example, if you had a change in needs or a question about services you're getting?**
Yes **No** Have not had to contact her/him (N/A)

Comments:

____

CONSUMER DIRECTED CARE OPTION

*The last time the case manager came to see you, she may have talked about a new option called "Consumer Directed Community Supports." We mailed you a card recently about this program. It says: "**You Decide. Your Help**."*

Do you have it there? [*If the senior does not have it there, just continue*.]
I'm going to describe it now for a minute.

This is an optional way for you to get the help you need to live at home. You manage your own care and the delivery of services or support coming into your home. The State sets aside a budget for you. You work with an agency to plan how to meet your care needs. You pick your workers and the agency helps you pay them out of your budget.

For example, an older person can hire a daughter or son, or a neighbor to help get meals together at home, provide rides to the doctor, or other assistance. An agency helps fill out the paperwork and pays the workers. Through this option you can also buy things that are needed to live independently, like snow shoveling or help with yard work, a ramp to get up to your home, or a special lift chair. With this option, you decide when and how you want your help.

10. Do you recall hearing about this new option?

Yes — [IF YES, Question 11 & 12]

No — [IF NO, SKIP to Question#13]

11. [IF YES] **If so, what did you think about this, as it was presented to you?**

Very Interested Somewhat Interested Not at all interested

Comments: ____________________

[YES, REMEMBERS HEARING ABOUT THE OPTION]

12. Why did you decide <u>NOT</u> to select this option? (*Let the person talk without prompting options, then check all that apply below)*

I really didn't understand it
Seemed too complicated/too many decisions to make
Wouldn't be any different than what I have now
Too much paperwork
I was advised against this
Budget might not be adequate for me
Happy with what I have now
Don't remember why/don't know

Other: ____________________

13. [NO, DOES NOT REMEMBER HEARING ABOUT THE OPTION]
What do you think about this option now, as I've explained it to you?

Very Interested   Somewhat Interested   Not at all interested

Comments: ____

____

14. Can you tell me what you <u>might like</u> about this kind of option?

Comments: ____

____

[WAIT FOR ANSWER, THEN PROMPT WITH FOLLOWING OPTIONS]

Are these some of the things that are interesting to you? (check all that apply)
more choice
more control
new types of services or items I can get to help me live successfully at home
can hire a relative or friend
can choose when and what I receive
can have a budget of money that is set aside for my needs
other______________________________

Comments: ____

15. Can you tell me what you <u>might not like</u> about this kind of option?

Comments: ____

____

[WAIT FOR ANSWER, check all that apply from the list below, or add others the person gives you]

sounds complicated
paperwork
might require more of my time in managing the services I have coming into my home
might not want to be the employer for a family member or friend
other______________________________

Comments: ____

16. Is there any other type of help or support that you wish you had, to assist you in managing?

Yes **No** Don't Know

Describe:

___

___

17. [If yes to Q#16] **Would you like me to pass on this information to someone, such as your case manager?**

Yes **No** Don't Know

Comments:

___

18. Thinking about all of your needs and all of the support you receive, how is this support meeting your needs?
(*I will read you some possible answers*)

Meeting All of my needs, Very well
Meeting Most, but not all of my needs
Meeting Some of my needs well, but I would like some changes
Not meeting my needs at all
No opinion/Don't know

Comments:

___

This is the end of our survey. Thank you for your time and your answers!

Do you have any questions for me?

___

Do you want to hear more about Consumer Directed Community Supports? I can have someone call you or send information in the mail. [Check box below if the consumer or family member wanted to receive more information]

Yes, this Consumer wants to hear more/receive more information about Consumer Directed Community Supports. Please contact:

- ___ (name of person to contact)
- contact by (indicate the person's preference): ***phone*** or ***mail*** or ***both*** (circle option)
- phone # or address to contact the person:

END

Approximate length of time that this Interview took: ______________________________

INTERVIEWER NOTES: (*Interviewers are invited to write any notes that are pertinent to our understanding of the responses from this interview. In particular we would like to know if the respondent seemed confused by the questions or did not seem to be able to fully understand what was being asked. We are also interested in any observations with regard to family members or other persons assisting the senior with the interview.)*

Comments of Interviewer: ____

____

____

____

Appendix C - State of Minnesota Selected Older Consumer Survey (CDCS-EA) (Early Adopter)

Version #1: Older Person is the Respondent

This survey has been designed to obtain responses from older consumers enrolled in either the "Elderly Waiver" or "Alternative Care grant" Programs, who have also elected the Consumer-Directed Community Supports option. The survey inquires about how the older person or their family members learned about the Consumer Directed Community Supports program. It obtains information about the older person's current experience in getting the support and care at home that they need. Everyone participating in the survey should have received a pamphlet in the mail, describing Consumer Directed care.

INTRODUCTION

Hello. I am________________, an independent researcher assisting the Department of Human Services. I will be asking you a few questions today about your experience with receiving services through the State's program called "Consumer Directed Community Supports." As a reminder, we mailed you a card about this service option—on the cover it says "You Decide, Your Help."

We received your signed response card indicating you agreed to participate in a telephone survey. Would you like to do this interview now? It will take about 25 minutes. If not, I can schedule a time that works for you.

Your answers will help the State of Minnesota plan for older people and their care needs and service preferences. We appreciate your time today.

There are no right or wrong answers—this is your opinion. This does not affect your services in any way and your answers are kept private. Your answers will be grouped together with other answers to be presented in our final report.

If you need me to repeat a question or ask to explain something, I'll be happy to do so.

Interviewer: ______________________________ Date: ________________

Consumer Name: ____

Phone #: ______________________________

Name of any other Persons helping in the Interview:

____

Name Relationship

Case Manager's Name (on record):____________________________________

We're ready to begin.

State of Minnesota Selected Older Consumer Survey (CDCS-EA)

BACKGROUND

1. **Would you say your current health status** (the health status of the older consumer) **is:**

   Excellent **Good** **Fair** **Poor**

Many of the people we are talking with receive help with things at home, such as: grocery shopping, cleaning, getting meals, laundry, getting dressed, or errands/chores. Some people also get items like ramps or grab bars to help get around safely at home. Others get rides to places they need to go, like the doctor. Some have a personal attendant or home care worker several hours a day at home.

2. **Are you** (the older consumer) **currently receiving some help at home?**

   Yes **No** Don't Know

3. **Can you briefly describe what kind of help you** (older consumer) **receive?**

Comments: ____

According to our records, you are in the Consumer Directed Community Support Program through the State of Minnesota's

"Elderly Waiver" **/** **"Alternative Care"** *program.*

(circle correct program)

As you know, this is an optional way for you to get the help you need to live at home. You manage your own care and the delivery of services or support coming into your home.
The State sets aside a budget for you. You work with an agency to plan how to meet your care needs. You pick your workers and the agency helps you pay them out of your budget.
For example, a person can hire his sons or daughter or a neighbors to help get meals together at home, provide rides to the doctor, or other assistance. An agency helps fill out the paperwork and pays the workers. With this option, you decide when and how you want your help.

CDCS INITIAL

Now I'd like you to think back to when you first heard about the Consumer Directed Community Supports option, and about the steps you took to get into the program.

4. **Do you remember how you heard about this Consumer Directed Community Supports Program service option? Was it from . . .** (check all that apply)

   your case manager a friend or family member county or health plan staff
   presentation you attended written material mailed to you poster you saw

Senior Linkage Line or other senior organization
other: ____

5. **Do you remember what interested you about this option?** (check all that apply)
   more choice   hire family member   Don't Know
   more control   new types of services I can get
   other: ____

Comments: ____

CARE/CASE MANAGER

Some people have a case manager or care coordinator from the health plan or county who helps the senior to set up a care plan and arrange for services to come into the home.

6. **Do you have a Case Manager or Care Coordinator who helps with these things?** [IF NO case manager, SKIP TO QUESTION #10]
   Yes   **No**   Don't Know

7. **Is your case manager? __________________?** *(name of Case Manager/Coordinator see below)*
   Yes   **No**   Don't Know

(Case manager/Coordinator name is: ____)

8. **Has your case manager been working with you for <u>more than one year</u>?**
   Yes   **No**   Don't Know

9. **If you needed to in the past, have you been able to reach your case manager—for example, if you had a change in needs or a question about services you're getting?**
   Yes   **No**   Have not had to contact her/him (N/A)

Comments: ____

COMMUNITY SUPPORT PLAN

The Consumer Directed Community Supports option that you are on requires each senior to have a written <u>Community Support Plan</u>. This is a Plan that <u>describes your needs and explains what services would help you</u>. There is a budget that is prepared that goes along with the Plan. Then the Plan needs to be approved by the county or your health insurance provider.

10. **How easy or difficult was it for you to get this Community Support Plan developed?** *I will read you some answer choices:*

    Very Easy   Somewhat Easy   Somewhat Difficult   Very Difficult
    Don't Know/Remember

Comments:

---

11. **Did you get any help to write the Plan?**

Yes **No** Don't Know/Remember

Comments:

---

12. **Did someone help you figure out the services you could get, within the budget amount allowed?**

Yes **No** Don't Know/Remember

If yes, Who? ____________________

Comments: ____________________

13. **How <u>important</u> is it <u>to you</u> to choose your own services or workers, or would you rather have someone else do that for you?**

I will read you some possible answers:

It is Very Important that I select services and workers on my own	It is Important that I have some input, but others can guide me	I would prefer that someone else do this for me

Comments: ____________________

FISCAL SUPPORT ENTITIES

The next set of questions asks about your arrangements with the Fiscal Support Entity (FSE) Agency. The FSE is the provider agency hired to bill the state Medical Assistance program for your CDCS services. This Agency might be assisting in paying for the services, supports, and workers and other responsibilities, such as filing employer taxes.

14. **Are you working with a Fiscal Support Agency that helps you with your Consumer Directed budget and pays bills for you?**

Yes **No*** Don't Know*****

[*If "No" or "Don't Know", go to #16.]

15. **Overall, how would you rate the helpfulness or value of the Agency's support to you in this Consumer Directed Care service option you have?**

(*I will read you some possible answers*)

Very Helpful/Valuable	Not Very Helpful/Not Valued
Somewhat Helpful/Valuable	Confusing, Makes things worse (Harmful)
	No opinion/Don't know

Comments: ______________________________

CURRENT SERVICES

The next set of questions concerns the goods, services, and support that you receive from the current support plan.

16. **Are there designated hours in your current plan to pay someone to provide personal care to you (for example to help with activities such as dressing, eating, or being with you during the day or nighttime)?**

Yes **No*** Don't Know/Remember*

* If NO, skip to Question #20

17. [If Yes to #16] – **Did you have this help prior to going on the Consumer Directed option?**

Yes **No** Don't Know/Remember

____

____

18. [If Yes to #16] **How many hours a week on average do you get of personal care assistance from paid workers?**

Write the average number of hours a week (Total) here: ______________

FAMILY MEMBER SUPPORT

19. **Do you get regular care or help at home from a family member or friend who is paid through this State service?**

Yes **No** Don't Know/Remember

____

20. **Do you get unpaid help from family members or friends on a regular basis?**

Yes **No**

OVERALL

21. **Are there services provided within your Plan that you could not get before you were on the Consumer Directed option?**

Yes **No** Don't Know/Remember

____

22. **Are there things that you wish your Plan would pay for, but it doesn't?** If so, what?

Item1: ____
❑ Is that because of budget limitations OR ❑because it is not allowed/not covered?

Item 2: ____
❑ Is that because of budget limitations OR ❑because it is not allowed/not covered?

23. **Thinking about all of your needs and all of the support you receive, how is this support meeting your needs?**

(I will read you some possible answers)

Meeting All of my needs, Very well
Meeting Most, but not all of my needs
Meeting Some of my needs well, but I would like some changes
Not meeting my needs at all
No opinion/Don't know

Comments: ____

24. **Is there any other type of help or support that you wish you had, to assist you in managing?**

Yes **No** Don't Know

Describe: ____

____

25. **Would you like me to pass on this information to someone, such as your case manager?**

Yes **No** Don't Know

Comments:

____

26. **Right now, How would you rate your <u>ability to choose</u> the type of help you receive, in order to live at home?** *I will read you some possible answers. Tell me the one that best matches what you would say.*

1	**2**	**3**	**4**	**5**
All decisions are made by me	My preferences are taken into account	I get some of what I want, but not all	I have little choice in what I get	I have no choice

Comments: ____

____

27. **Is your ability to choose the type of help you get <u>Better</u> or <u>Worse</u> than what you had before?** (before you went on the program you are on now)

Better **Worse** Don't Know

Comments:

____

28. **Overall, how is the Consumer Directed Community Supports option working for you** (for the older person)**?**

Very well, I am <u>very satisfied</u>
Okay, I am <u>somewhat</u> satisfied
Not great, I am <u>somewhat dissatisfied</u>
Poorly, I am <u>very dissatisfied</u>
No opinion/Don't know

Comments: ____

29. **Could it be better? How?**

Comments: ____

____

30. **Would you recommend the Consumer Directed Community Supports option to a friend?**

- ❑ Definitely yes
- ❑ Probably yes
- ❑ Probably no
- ❑ Definitely no
- ❑ Don't know / can't say

Comments:

____

This is the end of our survey. Thank you for your time and your answers! Do you have any questions for me?

Approximate length of time that this Interview took: ______________________________

Comments of Interviewer: ____

____

____

____

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____

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____

____

END