

SECOND INTERIM REPORT

Evaluation of the Consumer Directed Community Supports Service

Submitted to the Minnesota Department of Human Services

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Introduction

The purpose of this report is to summarize the current status of the evaluation of the Consumer Directed Community Supports Service (CDCS). As stated in previous reports, the purpose of the evaluation is (1) to assess the first-year implementation of the CDCS waiver amendment policies and their initial impacts on county staff, Fiscal Support Entities, and consumers, and (2) to provide evaluation results and recommendations to all stakeholder groups to guide decisions regarding CDCS improvement and expansion. The 16-month study (September 15, 2004 – January 30, 2006) includes three main components: an online survey of county staff, a telephone survey of consumers, and interviews with Fiscal Support Entities. The four main evaluation questions are:

1. Have the new CDCS waiver amendment policies been implemented as planned?
2. What can be learned from the early implementation experiences of counties and fiscal support entities that can be used to guide statewide expansion?
3. What is the impact of the new CDCS waiver amendment policies on consumer budgets and enrollments?
4. What is the impact of the new CDCS waiver amendment policies on consumers' experiences?

Completed Work to Date

The evaluation team has completed all of the expected deliverables to date, with some modifications in the timeline (see Appendix). Although there is no change in the final completion date of the study, two changes were made in the task timeline. First, the interviews with Fiscal Support Entities (FSEs), which were originally scheduled for January – March, have been moved to the fall. This change was made because the FSEs had just been selected at the start of 2005, contracts were not yet in place, and it would be several months before the FSEs had sufficient experience with consumers to make the interviews profitable. Second, we had originally expected to begin the Consumer Survey on July 1. Some timeline delays in CDCS implementation and other workload issues caused us to delay the stakeholder meetings by a month. Then, we incurred a one-week delay due to the shutdown in state government. As a result, we finished piloting the Consumer Survey on August 3 and began formal data collection on August 4.

The major focus of this report is on the Consumer Survey – its background development and pilot. To set this work in context, however, we will briefly highlight the results from the two main evaluation reports that have been completed to date: the Interim Report to the Legislature (March 15, 2005) and the Report on the Survey of County Administrators and Case Managers (March 18, 2005). Both of these reports have been posted on the DHS website.

Interim Report to the Legislature

This report focused on the implementation status of the CDCS amendment and related policies. It also examined the initial effects of the new policies on consumer enrollment and budgets. In order to understand the budget methodology and its initial effects, we requested background information and CDCS enrollment data from DHS. To answer the questions of interest, we also drew from our key informant interviews from fall, 2005; reviewed program materials, and analyzed selected items from our Survey of County Administrators and Case Managers.

In our report we concluded that DHS and the 37 counties participating in CDCS had invested considerable time to support the roll-out of the new amendment, but the process had not been smooth and some key operational milestones (such as the completion of the county and consumer handbook, approval of FSEs) had taken longer to accomplish than planned. In response to specific requests by the Legislature, we reported that:

- Enrollment by MR/RC consumers in CDCS declined by 438 in 2004, and by 687 persons since December of 2003. These figures were within DHS projected declines, although the majority of exits are not expected to occur until later in 2005 and into 2006.
- The most frequently listed reasons for MR/RC consumer departures by county staff were loss of eligibility (due to changes in the amendment); the comparative ease of obtaining the same or similar service on the waiver without CDCS; and insufficient funds in an individual's CDCS budget to sustain needed supports. Few individuals were exited from the program in 2004 due to immediate health and safety concerns, maltreatment, or suspected fraud.
- County administrators in greater Minnesota, as well as in the 7-county metro area, expected enrollments in CDCS to grow during 2005. Most of the enrollment growth is expected for waivers serving elderly persons and disabled individuals.
- We were unable to state what the service "replacement costs" would be for MR/RC consumers who leave CDCS. In greater Minnesota, county administrators estimated that about 117 persons left CDCS and returned to traditional waiver services because they understood higher service authorization dollars were available to them if they were not in CDCS. More work with DHS staff will be required over the coming year in order to understand actual costs.

We concluded this report by saying that we believed the CDCS to be a worthy, complex service with the potential to significantly benefit consumers. We noted the history of concerns that had been expressed from consumers, county staff, and the Legislative Auditor's Office. The main issue of concern at the time of our report seemed was the statewide budget methodology for determining individual budgets. We encouraged the Department to improve their methodology to the extent possible prior to the scheduled statewide expansion of CDCS (April 1, 2005).

Survey of County Administrators and Case Managers

This report focused on the implementation status of CDCS amendment policies and related activities at the county level. It examined county readiness to implement the new policies as well as the barriers to implementation. It also provided information about their experiences with implementation – what staff members were learning and what they recommended or needed that could guide DHS in the statewide expansion of CDCS.

The survey was administered online during the last two weeks of January 2005. Just over 400 individuals from 37 counties were identified for the survey; 269 (67%) responded. The respondent group reflected a fairly balanced split between staff who were responsible for MR/RC waiver consumers (60%) and those working with one or more of the other four waiver groups (40%). The respondents were also fairly evenly divided between two major geographic groups: the seven-county metro area (43%) and counties in greater Minnesota (57%). The sample appropriately reflected a large complement of case managers (82%) over administrators (18%).

In terms of staff readiness to implement CDCS, we found that:

- Respondents registered strong support for the basic tenets of consumer direction.
- While 44% had no prior experience with CDCS cases, “consumer direction” was not a new concept to 80% of the respondents.
- County staff members were motivated to implement the CDCS for various reasons. About half said they were motivated because they felt that CDCS would provide a better quality of life or health outcomes for consumers; about half said there was strong consumer demand for CDCS.
- Staff training on the new amendments policies had been started, but with somewhat greater participation by metro area and MR/RC staff than by others.
- Other signs of county readiness, such as having county policies and materials in place, were reported. The greatest time lag was with contracting with FSEs.
- Counties had taken many steps to inform *current* CDCS consumers about the amendment, mostly through in-person visits and telephone calls. Comparatively less communication had occurred for new and potential CDCS consumers.
- Staff confidence in their own ability to explain CDCS was not high overall. They were least comfortable in trying to explain the FSE options to consumers, and how the statewide budget formulas applied to existing and new consumers.

In terms of barriers to implementation, we found that:

- Incomplete readiness on the part of DHS to roll out all the program elements needed was the major barrier cited.
- A legacy of emotions about the process by which the amendments were crafted and introduced also affected the morale of some staff.
- Inadequate” training provided by DHS and problematic communication with DHS had further stressed timely implementation at the county level.

In terms of needed supports at the state and county levels for success, we found that:

- County staff wanted a variety of hands-on and interactive training formats that provided more “real world” applications and more opportunities for getting “the tough questions answered.”
- County staff needed more encouragement and support to see their way through the complexity of CDCS. Beyond getting needed information, staff needed to hear more positive things about the program. They needed to see actual successes. They wanted to hear more from families and individuals for whom CDCS was working well.

Perceived effects of the amendment policies (including the statewide budget methodology) on consumers, on enrollment in CDCS, and their service choices:

- Staff commonly cited two main positive effects of the new CDCS amendment: it allowed parents of minors and spouses to be paid for the care they provide to the consumers; and it expanded CDCS to the four other waiver groups.
- Administrators estimated that nearly 600 consumers had left CDCS in the past year. More of the departures ($n = 361$) were believed to be for “voluntary” reasons (e.g., insufficient budget to remain in CDCS, other services more appropriate, change in consumer status unrelated to CDCS) than for “involuntary reasons” (e.g., loss of eligibility, health and safety concerns).
- Administrators expected enrollments in CDCS to decline in the coming year for MR/RC waiver consumers, and to grow for the four other waiver groups. “CDCS is not for everyone” was a common refrain.
- Many respondents said it was “too early to tell” what the budget impacts would be on consumer. However, concerns about “inadequate budgets” were voiced by all respondent groups. About half felt that CDCS policies compromise consumer health, safety, and welfare. This finding did not vary by region, waiver group, or respondent role (administrator vs. case manager).
- The most frequent type of service being dropped by MR/RC waiver consumers as a result of decreased CDCS budgets was reported to be “staffing.”
- The most frequent type of service being added by MR/RC waiver consumers as a result of increased CDCS budgets was also staffing, followed by respite care.

Perceived effects of the amendment on county resources, staff, and service capacities:

- Respondents listed more disadvantages than advantages of the CDCS amendment for county staff in their role, but they had a lot to say about both. The main advantages were “greater clarity” (or potential for clarity) in service operations, and “greater equity” (or potential for equity) of service delivery across consumers and counties. The main disadvantages had to do with the delays and degree of “confusion” surrounding the program rollout, and the negative impacts of the state-set budgets (both in terms of budget cuts and flawed methodology).
- CDCS was perceived as a time consuming service option to administer – more time consuming than serving waiver recipients who are not in CDCS.

- Many case managers saw problematic gaps and conflicts with the required vs. flexible case management “system.” Many also mourned the loss of a role they had valued, which changed as a result of differentiating between “required” and “flexible case management” and separate billing mechanisms.

Extent to which staff thought CDCS policies met the goals of consumer direction:

- More than 75% of the respondents felt that the CDCS and its new policies met goals such as helping consumers remain in the community in the most integrated setting possible, and supporting person-centered planning and consumer control.
- “Flexibility,” “consumer control,” and “consumer involvement” (e.g., empowerment, satisfaction, quality of life) were the main benefits of CDCS.
- The loss of flexibility with planning as a result of the new policies was the main criticism of CDCS.

Extent to which staff thought CDCS policies addressed issues of accountability, questionable expenses, and inequities:

- Two-thirds of the respondents felt CDCS ensures fiscal accountability for consumer expenses, reduces county guesswork in approving budget expenses, and maintains budget neutrality at the county level.
- Less than half (44%) felt the policies avoid or reduce service inequities among consumers with the same risk levels and needed, due to flaws in the budget methodology, or “grey areas” in the list of allowed and not allowed expenses.
- Concerns about ensuring protections for consumer health and safety were frequently voiced.

County suggestions and advice to DHS to better support statewide expansion:

- “Reduce the confusion” was the number one response. Finish the critical program materials and elements, resolve thorny details, “work out the bugs.”
- Continue to provide training, but improve make it more interactive and responsive to county staff needs.
- Help counties know how to respond to consumers with high needs. The inability of CDCS budgets to adequately address high-needs consumers was expressed across all waiver groups.

We concluded the report by saying that although implementation had not exactly occurred “as planned,” there appeared to be momentum in terms of counties training their staff, providing consumer education, and contracting with FSEs. There was a solid base of support for consumer direction as a philosophy of service delivery, and fairly strong agreement that the CDCS amendment policies preserve key components of consumer direction (e.g., person-centered planning). According to about two-thirds of the respondents, the amendment policies also appeared to successfully address accountability concerns expressed in the Legislative Auditor’s (2004) Report. We offered the Disability Services Division several observations to consider (see next page):

1. MR/RC staff members constitute an important resource for expansion. Staff members serving MR/RC recipients were the strongest critics of CDCS, but they were also its strongest supporters. They were understandably more invested in CDCS, more experienced than others who were new to CDCS, and more insightful about how to make consumer direction work. They constituted the only group that could provide new county staff with “CDCS success stories,” techniques and tactics for ensuring consumer protection, or assurances about how empowered clients can actually consume less county staff time. As such, it seemed to us that experienced MR/RC staff members represented a valuable, and possibly underused resource for DHS as it moved to expand CDCS.
2. County concerns about consumer health, safety, and welfare merited further discussion. Half the respondents (51.7%) felt the CDCS amendment policies compromise consumer health, safety, and welfare. Because this finding did not vary by region, waiver group, or staff role, it seemed important for DHS to talk further with county representations to understand their concerns.
3. County concerns about perceived budget inequities merited further discussion. One of the prime reasons a standardized budget methodology was adopted was to address the problem of county variation and inequities across consumers. Our survey found that less than half of the respondents (44%) felt the CDCS amendment policies “avoid or reduce service inequities among consumers with the same risk levels and needs.” Open-ended comments about the “flawed” methodology were second in frequency to comments describing the effects of limited budgets. Next to reducing the overall “confusion” in CDCS, “fixing the budget” was considered the most important problem to address.
4. Current training strategies could be improved. We encouraged DHS to revisit its training strategies and consider focusing more attention and resources on case managers. They were less positive about CDCS than administrators, and they clearly felt the amendment had some important negative impacts for their jobs. Yet they are the ones who in the end will make CDCS truly available and beneficial for consumers. Based on their reported levels of confidence, the most important training issues for case managers were related to: understanding CDCS budgets; understanding and knowing how to work with the FSEs; explaining the consumer’s options for fiscal control within the FSE structure; and resolving issues related to flexible and required case management.

Lastly, delays and complications with the state’s rollout of CDCS had negatively colored many people’s impressions of it. CDCS was viewed by many as a “complicated,” “daunting,” and even “scary” program. Respondents were looking for ways to simplify the program for staff members and for families. Yet over half of the county staff members thought CDCS would *not* reduce the burden to families and caregivers. Changing the persona of the program may require enlisting the support of people who have seen consumer direction work, and know how to make it work.

Current Status of the Consumer Survey

The purpose of the Consumer Survey is to understand the current and potential impacts of the CDCS amendment policies on consumers. Only adult proxies (parents, legal guardians, or other responsible parties) are being interviewed. Only proxies speaking for MR/RC waiver consumers are eligible for the survey. This is a statewide survey of people who have participated in CDCS for some amount of time in the last year (April 1, 2004 – May 15, 2005). The goal is to survey an equal number of currently enrolled,¹ and formerly enrolled CDCS participants; the sample proportionally represents counties that have been grouped into one of three categories.² This is a structured telephone survey conducted by skilled interviewers. The Current Participant survey contains 53 items; the parallel version for Former Participants contains 40 items. Some of the items include follow-up probes, others are free response; most, however, are “closed ended” items.

In addition to a demographic section that asks questions about the nature of the consumer’s disability and relationship to the proxy, the survey covers five main areas:

1. Current services, compared to previous or future services³
2. Satisfaction with current services
3. Experiences with CDCS (current participants only)
4. Reasons for departure from CDCS (former participants only)
5. Goals of consumer direction / quality of life

The main questions we are expecting to answer with the survey are:

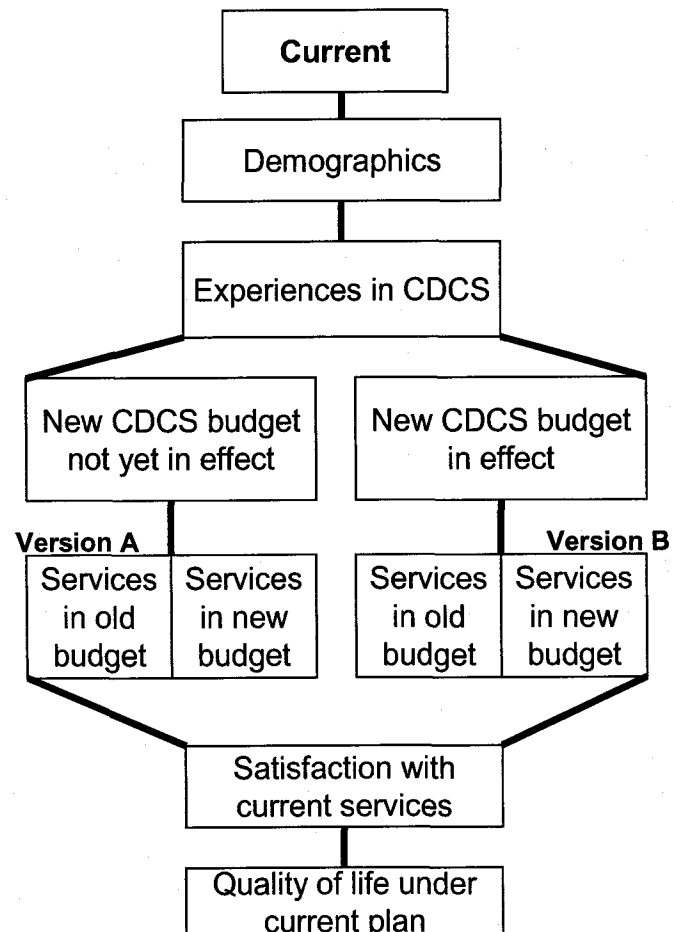
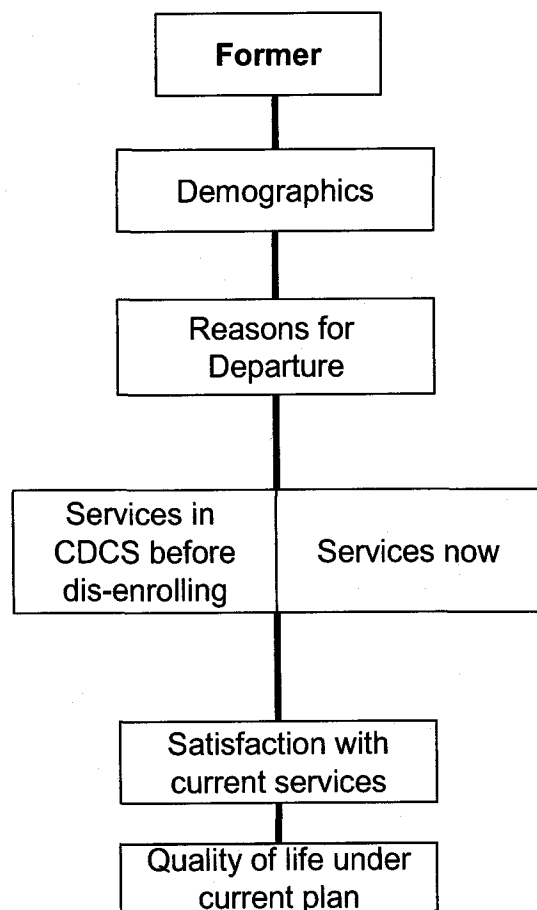
- What are current participants’ experiences with implementing elements of the CDCS (e.g., developing consumer support plans, working with required and flexible case managers and with FSEs)? Do their experiences suggest areas for further consumer education or county staff training?
- To what extent have the new CDCS policies negatively or positively impacted current participants’ services, service satisfaction, and quality of life? For participants whose new CDCS budget is not yet in effect, how do they expect the policies will impact them once their budget goes into effect?
- To what extent does departure from CDCS result in a loss of services, service satisfaction, or perceived quality of life?
- To what extent are service use, satisfaction with current services, and attainment of personal goals and quality of life related to consumer and respondent characteristics? To what extent are these outcomes related to county category?

¹ Enrolled as of May 15, 2005

² 1) Hennepin and Ramsey counties; 2) the five other counties in the metro area; 3) greater Minnesota

³ See chart on the following page for the different points of comparison for different respondents.

**MR/RC Waiver
Enrolled in CDCS (4/01/04 - 5/15/05)**



Key Challenges to Date and their Resolution

After several months of development, meetings with DHS staff and stakeholders, pre-pilot sessions with DHS staff and a formal pilot with 18 consumer representatives, the survey is now ready for administration. The main challenges we have wrestled with in the last several months have been:

- ***Defining the survey population.*** Originally, the evaluation team proposed to compare responses across MR/RC waiver recipients and those from the four other waiver groups. We decided to focus exclusively on consumers on the MR/RC waiver because fewer than 50 consumers from the four other groups had enrolled by late April, and it would have been premature to survey them due to the short amount of time they would have had with the service.
- ***Deciding who should be surveyed*** (consumers vs. proxies). The decision to orient the survey for proxies was made as a result of our own growing questions and concerns and the feedback we received from the stakeholder meetings (see later section of this report).
- ***Determining how to best identify intended respondents*** via use of the MMIS database, and how to address these respondents in pre-notification letters and introductory telephone scripts. The envelopes are addressed to consumers, and the letters are addressed “to whom this may concern.” Many cases in the database do not have an authorized representatives or other “responsible party” listed. When calling the consumer’s telephone number, the interviewers ask for proxies by name if one is listed; otherwise, they ask to speak to “whoever is most responsible for managing [consumer’s] service plan.”
- ***Resolving issues of terminology and jargon,*** and learning how to ask about services has been difficult, given the fact that the CDCS is a highly individualized service option for consumers, and has been administered somewhat differently across counties. Our pilot has resolved most of these issues, but more may arise.
- ***Working with missing and incorrect telephone numbers.*** About 10% of the cases in the database have no listed phone number for the consumer or other representative. These cases have been tabled for now, and will be pursued only if we run out of cases within a subgroup category (see section on sampling). Some minor bias may be introduced into the obtained sample as a result.

In the next section of the report we outline key milestones in the development of the survey. The completed products (e.g., pre-notification letters, scripts, surveys) can be found in the Appendix. Throughout the development of the survey, we have been greatly assisted by Karen Langenfeld at the Disabilities Services Division and by data analysts from the Department who secured the needed background data on the survey population. We wish to recognize and thank them for their support.

Milestones in Consumer Survey Development

1. Submission of the IRB Application. Our application was submitted April 14, 2005, and approved approximately one month later. Pre-notification letters were revised in order to respond to IRB requests to provide a mechanism for consumers to avoid being telephoned in the first letter (sent by DHS), and in the second letter sent by the evaluation team; and to include the IRB-approved privacy notice [DHS HIPPA template] in our letter so it would be “closer in time” to when the consumer would be called. (Telephone scripts also provide a third opportunity for consumers to decline to be interviewed.) The IRB also advised us to request ethnicity data and “languages spoken at home” from DHS. The IRB reviewed legal issues related to surveying consumers who had filed an appeal with the DHS. They approved the inclusion of such respondents in our sample, and also including an item in the survey that asks consumers whether they had filed (or intended to file) an appeal. Lastly, the IRB requests completed copies of the survey and materials.
2. Background Development of Survey Content. A literature review of research on consumer directed programs had been conducted by the evaluation team prior to submitting our original proposal in June of 2004. To this collection of materials we added additional survey instruments and CDCS program materials as potential sources for items and guidance on survey content. While we had hoped to find more easily replicable items, particularly on quality of life, we ended up developing unique items with few exceptions. The most useful sources were the CDCS Lead Agency Operations Manual and the CDCS Consumer Handbook. This is probably because the evaluation is so specific to the CDCS. Other articles and tools that were reviewed and provide some context for our findings are listed in the Appendix.
3. Meetings with Consumer Stakeholders. Originally, we had planned to conduct an information and feedback meeting with stakeholders on May 15 at the St. Paul Center for Independent Living. We had also worked through a process for inviting representatives from all five waiver groups. Because of slow program start-up and low enrollment in CDCS by recipients from the four new waiver groups, we and DHS determined to focus the survey just on consumers in the MR/RC waiver group. After rescheduling the meeting for June 16, we invited members of the relevant advocacy organizations (e.g., ARC, Governor’s Council on Developmental Disability) to attend, and asked them to help disseminate our invitation to consumers and family representatives to attend. Two one and ½ hour sessions were held at the DHS Roseville Office. Ten stakeholders attended the afternoon session and eight attended the evening session.

We presented a power point presentation that reviewed the evaluation, the purpose of the Consumer Survey, our sampling plan, and questions and concerns we had for which we asked for feedback.⁴ We shared draft outlines of two parallel surveys: one for adult consumers, and one for proxies. We also opened the floor up to participants and answered questions they had about the evaluation.

⁴ See our previous deliverables with the invitations, handouts, and power point presentation.

These were very productive sessions from our point of view. We received lots of important feedback during the meeting, and additional written feedback from invited stakeholders who were unable to attend. We also ended up reviewing five actual community support plans that were sent to us by a participant from the stakeholder meeting. As a result of the meetings, several follow-up actions took place:

- ***We decided to interview proxies only.*** Stakeholders were very cautious about our being able to survey adult consumers over the telephone using the outline of questions we presented at the meeting. They raised concerns about being able to identify adult consumers who would be appropriate to interview based on MMIS data (“you’d have to go to the counties for accurate information on that”). They raised concerns about the social pressures on consumers to respond even when they didn’t understand the questions, and to response in socially desirable ways when they did. They suspected we would have low response rates, as consumers are often trained to not answer the phone, or to not speak to people whom they don’t know. Stakeholders also identified many important ways we would have to accommodate individual consumer needs, based on a large range of potential disabilities. Although they would likely have preferred that we survey people face-to-face or with assistive technologies, we ultimately determined that we didn’t have the time, the budget, or the appropriate method for an actual consumer survey.
- ***For the most part, budget impacts haven’t happened yet, so the “point of comparison” had to be reframed.*** Stakeholders’ feedback highlighted the importance of clarifying whether the new budgets have taken effect yet for current CDCS participants, and for comparing current services and service satisfaction with expected future impacts, for those whose new budgets are not yet in effect.
- ***Our definitions and language needed more work.*** We role played the introductory telephone script and asked participants to review the survey outlines. We quickly ran into trouble with communicating what we meant by such things as “community support plan,” “PCA,” “FSE,” “Flexible Case Manager,” and other terms. We also received very helpful advice for the first phrase or two in the telephone script to avoid having the person hang up on us (e.g., “insert the consumer’s name in the first sentence”).
- ***Stakeholder comments highlighted the importance of having a written version of the survey.*** Because of the length of the survey and the complexity of some of the questions, some stakeholders felt we should offer to send a written version to people prior to scheduling the interview. Because we had already committed to offering a written version for people with language or communication disabilities, we proceeded to act on this request as well.

4. Meetings with DHS Staff. Key meetings with DHS staff⁵ took place both before and after the June 16 stakeholder meetings. We requested the meeting with DHS staff after the stakeholder meeting specifically to address some of the language and communication problems we had, and to clarify some content questions of our own. We role played the script and entire first draft of the Current Participant survey with one of the staff members at this meeting. Subsequently, we made revisions to both the Current and Former Participant versions. These versions were also pre-piloted with a DHS staff member and a flexible case manager.
5. Training for Survey Staff. The entire evaluation team (the three principal members, plus the four main interviewers) attended the stakeholder meeting, and the interviewers also attended the follow-up meeting with DHS staff. Additionally, we held several internal meetings to review CDCS program features, key terms and definitions, data security and privacy practices, all of the survey items, and to prepare for the pilot. The team leader for the survey group, Marcy Huggins, was responsible for training five other interviewers and managing the survey administration process. During the pilot, she and the other interviewers met weekly to debrief the pilot results. She and the data manager also consult with the evaluation directors daily to manage the survey process.
6. Defining the Survey Population and Obtaining MMIS Data. Our population of interest is defined as: MR/RC waiver recipients who were enrolled for some amount of time in CDCS between April 1, 2004 (when the amendments were approved by Centers for Medicaid and Medicare), and May 15, 2005. On June 17, the evaluation team requested a download of data from the DHS Medicaid Management Information System (MMIS) in order to identify respondents and their contact information. The resulting population was 3,095 persons. After excluding 81 cases that were missing an identified county of financial responsibility, the population was reduced to 3,014. This population is shown below, sorted by enrollment status (current vs. former) and by our three county groupings (which are based on county of financial responsibility, not consumer address).

Table 1. Population of Interest for the CDCS Consumer Survey

MR/RC Recipients in CDCS (4/1/04 – 5/15/05)	Hennepin and Ramsey County	Anoka, Carver, Dakota, Scott, Washington	Greater MN (remaining CDCS counties)
Current CDCS participants (in CDCS on 5/15/05)	1231	777	145
Former CDCS participants (not in CDCS on 5/15/05)	423	216	222
Total: N = 3,014	1654	993	367

DHS data (MMIS), as of June 17, 2005.

⁵ K. Langenfeld, K. Kelly, P. Erkel, Lisa Rotegaard, and L. Wolford were at the initial meeting, and in a later meeting we discussed the survey with some of them as well as S. York and M. A. Mowry. After the stakeholder meeting, we met with K. Langenfeld, K. Kelly, L. Zoladkiewicz.

Our evaluation budget allows us to interview up to 400 persons. Stratified random sampling is being employed to yield the anticipated number of cases shown below in Table 2 with the goal of getting the highest possible response rate.

Table 2. Expected Number of Completed CDCS Surveys

MR/RC Recipients in CDCS (4/1/04 – 5/15/05)	Hennepin and Ramsey County	Anoka, Carver, Dakota, Scott, Washington	Greater MN (remaining CDCS counties)
Current CDCS participants (in CDCS 5/15/05)	75	75	50
Former CDCS participants (not in CDCS 5/15/05)	75	75	50
Total	150	150	100

The download of data we requested from DHS also contained a number of background data fields.⁶ We requested this information for several reasons. Some of it has been placed on “call sheets,” and is being used by our staff to prepare for the interview and to help them orient the introductory telephone script for the appropriate person. These data will also be used to describe the survey population in terms of key characteristics and to compare respondents with non-respondents. Initially, we had also hoped to be able to avoid asking some demographic items in the survey, if the database could reliably supply such information. Lastly, we conjecture that service utilization, satisfaction with services, and possibly other survey responses (such as reasons for leaving CDCS) might be related to consumers’ backgrounds or needs. Having access to potential covariates for the analysis was therefore desirable.

After reviewing the data fields, we reduced the potential survey population in a number of ways. First, we eliminated consumers with out-of-state addresses ($n = 14$). Second, DHS alerted us to the fact that 17 consumers in our list were deceased; these names were immediately removed. Third, 307 cases were found to have missing phone numbers. After considering several different ways to find these numbers (e.g., work with DHS to contact county administrators), we decided to compare consumers with and without telephone numbers according to their background characteristics. We found some statistically significant differences between the two groups in terms of enrollment status, county of financial responsibility, age, guardianship status, and number of months in CDCS.⁷ There were no differences in their ethnicity, languages spoken at home, or annual CDCS budget. Because our sampling plan overcomes the problem of enrollment status and county grouping, the main bias introduced by eliminating people without phones is with age, guardianship status, and length of time in CDCS. Because these differences were not huge in actual size, and because it is difficult and costly to pursue people without telephones, we decided to set those consumers aside for now, and only pursue them if they are needed to fill our quotas.

⁶ See Appendix

⁷ Consumers without phones were somewhat older ($m = 23$ vs 20 years old), less likely to have a parent as a legal guardian (44% vs. 53%), and had spent a bit less time in CDCS ($m = 39$ months, vs. 48 months).

7. Survey Pilot and Administration. The Disability Services Division sent their letter of notice to consumers on June 30th. The decision was made to send this letter to all MR/RC waiver participants in CDCS for practical reasons (it was easier to do this once, for all persons, rather than on a rolling basis). Additionally, DHS was interested in having all consumers understand that the survey was taking place and alerting them to the fact they might be called. It also adds a further protection to the anonymity of responses. (DHS doesn't even know which names were randomly selected.) DHS has been sending us returned envelopes with new forwarding addresses as they have come in.

The evaluation team is randomly selecting consumers in batches; 24 names are drawn at a time so as to reflect our six subgroups (former vs. current, by three county groupings). Our pre-notification letters are sent in waves to those individuals, unless they have contacted DHS and asked to be removed from our list. (In which case, they are counted as "refusals.") Our letter also instructs people on how to have their name removed from our call list. To date, seven people have either contacted DHS or our offices and asked to be removed from the survey.

Six interviewers have been assigned to the study. Each receives a batch and begins calling approximately 3-5 days after our pre-notification letters have been sent. The interviewers will work their batch until the number of contacts is almost exhausted, and then receive a new batch. The batch system helps us monitor completion rates by subgroup and also yields higher response rates (because fewer calls are attempted). Up to 20 attempts to reach a consumer will be made before the case is counted as a "soft" refusal. Those that are contacted and choose to not take the survey are no longer called, and they are counted as "hard" refusals.

The pilot began on July 20 and was completed on August 3. It was based on a sample of 50 potential names and 18 completed interviews (half former, half current, from various counties). One of the principal changes made as a result of the pilot was to change an item that involved using listed diagnoses from MMIS to a free-response item. We now ask the proxies to tell us the diagnoses and related conditions as they understand or remember them. Other changes have included such things as adding ways to probe further on certain responses. For example, several current participants have insisted they "have no FSE." (All consumers had to have an FSE by July 1.) Along with recording their answers qualitatively, we are learning how to inquire further about their arrangements (e.g., by asking, "To whom do you submit your bills?").

Currently, our response from current CDCS participants has been fairly high and positive, in the sense that they have generally been aware of the pre-notification letters and have agreed to do the survey. It is proving more difficult to reach former participants. Most of the incorrect or discontinued telephone numbers have been for former participants, and the same has been true for "hang ups" and outright refusals. On some of these calls, former participants have expressed basic confusion about

CDCS and the MR/RC waiver. Interviews have varied in terms of length, but most have taken about 25-30 minutes.

8. Data Security and Privacy Practices. The highest data security measures have been in place for the Consumer Survey beginning with the original receipt of the consumer data from DHS. Rather than sending any of this information over the internet, we picked up the CD-ROM in person from DHS. The database with consumer names, contact information, and other information has been set up on two computers in our offices (both of which have an electronic security system and are not reachable after 5:00 pm or on weekends without a key). No identifiable data are being electronically transmitted even *within* our office among internal staff.

Survey ID numbers were assigned to all cases in the database; this number follows cases throughout the survey process and is used in lieu of names⁸ except for the interviewers' call sheets, which require persons' names (for obvious purposes). Additionally, some pertinent information from the database has been merged and printed on these call sheets (e.g., age, severity of MR condition, authorized representative if listed). These call-sheets are created in batches and not printed until the pre-notification letters have been mailed and the case has been assigned to an interviewer. This reduces the amount of paper with identifiable data on it and the amount of time such sheets exist. The interviewers have been instructed to keep the sheets secure should they take them home for evening and weekend calls; during office hours the sheets are kept in a secure location.

Files have been set up in SPSS to collect the survey data. Additionally, excel files have been set up for the items requiring longer open-ended responses (short answers of less than 250 characters are entered in SPSS as a text field). Data entry is done on a daily basis; all responses in both SPSS and Excel are keyed to the survey ID number (not name).

Next Steps

In conclusion, the evaluation team is on course in terms of implementing its contract and its evaluation plan. As for our immediate next steps, we will closely monitor the collection of the Consumer Survey data; some small revisions in item wording are not unexpected as we gain more experience. We will also begin reading the longer open-ended items and develop a coding scheme that the interviewers will ultimately use while they write down verbatim answers. We will develop a more detailed data analysis plan as we get closer to the end of the data collection period. In September, we will begin work on the Fiscal Support Entity interview component.

⁸ Written versions of the survey are available to consumers who request them. No names are printed on the survey, only the consumer ID number.

Appendix

- Evaluation Tasks and Deliverables
- Sources Reviewed for Possible Survey Content and Items
- The Survey Population: List of Data Fields Obtained from DHS
- Pre-notification Letter to Consumers from the Department of Human Services
- Pre-notification Letter to Consumers from Professional Evaluation Services
- Telephone Scripts for Current and Former CDCS Participants
- Survey of Current CDCS Participants
- Survey of Former CDCS Participants
- Instructions for Written Versions of the Consumer Survey
- Telephone Call Sheet

Evaluation Timeline and Deliverables (as of October, 2004)
(Shaded areas denote completion)

Evaluation Task	Month	Deliverable
1. Meet with DHS staff to review evaluation plan. Obtain and review background materials. Meet individually with program and policy staff, key leaders to understand evaluation context, CDCS policy changes and implementation.	Sept-Oct '04	1. Revised evaluation plan, tasks, and timeline.
2. Meet with Legislative Auditor evaluation staff to understand their perspectives.	Sept '04	
3. Meet with DHS staff to identify key administrative data and determine measures of operational success.	Oct '04	
4. Meet with representatives of advocacy organizations to discuss the evaluation.	Oct '04	
5. Convene and facilitate 1 st stakeholder meeting to discuss the evaluation.	Oct '04	2. Meeting agenda and notes.
6. Draft the county administrator survey, secure respondent list and DHS approval.	Dec '04	3. Completed survey instrument, admin. protocol.
7. Collect, analyze, and report county administrator survey data.	Dec '04-Feb '05	4. Oral report of findings with power point presentation.
8. Summarize evaluation progress, preliminary findings, and recommendations to date.	Feb '05	5. <u>Interim Report for Legislature</u>
9. Draft fiscal entity interview guide; secure respondent list and approval from DHS.	Jan-Feb '05	6. Completed interview guide and administration protocol.
10. Collect, analyze, and report fiscal entity interview data.	Mar '05	7. Oral report of findings with power point presentation.
11. Convene 2 nd stakeholder meeting to discuss the consumer survey.	Mar '05	8. Meeting agenda and notes.
12. Develop protocol for identifying and surveying consumers. Obtain human subjects approval. Train interviewers.	April '05	9. Completed administration protocol and staff training.
13. Review background documents, literature; draft parallel forms of the consumer survey for waiver recipients and caregivers; pre-test with a small sample.	Mar-May '05	10. Completed consumer survey instrument.
14. Meet with DHS to review results of county administrator and fiscal entity surveys; consider recommendations; and approve the consumer survey.	June '05	11. <u>Interim Report on Evaluation Progress and Findings</u>
15. Identify / recruit consumers for the survey.	May-July '05	15. Final sample.
16. Collect consumer data, review data.	July-Sept '05	16. Descriptive statistics.
17. Analyze consumer data and summarize results.	Oct-Dec '05	17. Oral report of findings with power point presentation.
18. Meet with DHS to incorporate administrative data, review all findings and discuss implications for CDCS and future summative evaluation.	Jan '06	18. Final Report: Summary of Project Findings and Recommendations for CDCS.

Sources Reviewed for Possible Survey Content and Items

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- Market Response International. (2001). *Quality of Life Assessment Survey*; conducted on contract for the Minnesota Governor's Council on Developmental Disability.
- National Core Indicators: *Adult Family Survey Opinions of Services and Supports for People with Developmental Disabilities and their Families in South Carolina* (NASDDDS and Human Services Research Institute: National Core Indicators Project, CMS).
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- Benjamin, A. E. & Snyder, R. E. (2002). Consumer Choice in Long-term Care. Chapter 5 in: *Robert Wood Johnson Foundation Anthology*.
- Benjamin, A. E., Matthias, R., & Franke, T. M. (2000). Comparing consumer-directed and Agency Models for Providing Supportive Services at Home. *Health Services Research* 35:1, Part II, 351-366
- Beatty, P.W., et al. (1998). Personal Assistance for People with Physical Disabilities: Consumer-Direction and Satisfaction with Services. *Archives of Physical Medicine & Rehabilitation* (79), 674-677.
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- Project for Long-Term Supportive Services for Developmentally Disabled Residents of New Hampshire. (2003). Grant results report. Robert Wood Johnson Foundation.
- Foster, L., Phillips, B., & Schore, J. (2005). *Consumer and Consultant Experiences in the New Jersey Personal Preference Program*: Draft Report submitted to the University of Maryland Center on Aging. Mathematica Policy Research, Inc.

We also referred back to our Survey of County Administrators and Case Managers for any parallel items of interest.

The Survey Population: List of Data Fields Obtained from DHS

Contact Information

- Consumer name
- Consumer street address
- Consumer city / town
- Consumer zip code
- Consumer telephone
- County of financial responsibility
- Name of “authorized representative”
- Authorized representative street address
- Authorized representative city, state, zip code
- Authorized representative telephone number
- Name of “responsible person”

Consumer Background Information

- Consumer birth date (mm/dd/yyyy)
- Guardianship status
- Disability level (MR/RC level)
- Date consumer first enrolled in MR/RC waiver (mm/dd/yyyy)
- Date consumer first enrolled in CDCS (mm/dd/yyyy)
- Total time (months) spent in CDCS (- -)
- Current annual budget
- Ethnicity (however MMIS lists this)
- Languages spoken at home (however MMIS lists this)
- Diagnosis (codes 1-4)

Requested, Not Available

- Parental fee assigned 2004-05
- Enrollment status in PCA Choice (as of 5-15-05)
- Enrollment status in Family Support Grant (as of 5-15-05)
- Living situation (home, licensed foster care, settings licensed by DHS or MDH, assisted living – however MMIS lists this)

(DHS Letter of Introduction -- DHS Letterhead)

Date: June, 2005
To: Former and Current Participants in the **MR/RC Home and Community-Based Waiver Program** and their representatives
From: Shirley York, Director
Minnesota Department of Human Services
Disability Services Division
Re: **Telephone Survey** of Current and Former Participants in the Consumer Directed Community Supports (CDCS) Service Option

The Department of Human Services has hired **Professional Evaluation Services** to do a **telephone survey** of MR/RC Waiver recipients who have participated in the Consumer Directed Community Supports service (CDCS) in the last year. Minnesota is evaluating the CDCS and this survey is part of the evaluation. The purpose of the survey is to collect information that will help us know more about how recent changes in CDCS have affected consumers, how the program is working, and why some people leave CDCS.

About 400 interviews will be conducted. About half of the interviews will be done with people who left CDCS, the other half with people still in CDCS. The interviews will be conducted with persons who are responsible for the consumers' well being (e.g., parent, guardian).

If your name is randomly chosen, someone from Professional Evaluation Services will send you a letter, inviting you to take the survey. This letter will also contain information on consumers' rights to privacy and what to do if you do not want to be called. If you do not respond to their letter, an interviewer may call and ask if you would be willing to take the survey. If your answer is "yes," then the interviewer will ask some questions about the services and supports your family member receives, and your satisfaction with them. The survey may take 20 to 30 minutes to complete. The person you care for will not lose any of his or her current services, whether you decide to take the survey or not.

We want to thank you for your help if you are selected to do this survey.

If you have any questions about the survey, or do not wish to be contacted by Professional Evaluation Services, please contact Karen Langenfeld at (651) 582-1941 or email her at: Karen.langenfeld@state.mn.us.

Sincerely,

Shirley York, Department of Human Services, Disability Services Division Director

Pre notification letter to Consumers From PES

To Whom It May Concern:
2005

September 14,

We are an independent evaluation team, hired by the Department of Human Services (DHS) to conduct a telephone survey on the **Consumer Directed Community Supports** service (CDCS). As you know, CDCS is an option for people on MR/RC Waivers who wish to have more control over their care. The survey applies to both current and former users of CDCS. This household was selected at random to take the survey. In a few days, we will call and ask to speak with the person who is most responsible for managing the plan of care for the MR/RC waiver recipient. *Please know that this person's services will remain the same, whether or not you decide to take the survey.*

The purpose of the survey is to understand how recent changes in CDCS have impacted people who have used CDCS in the past, and how these changes may impact current participants in the upcoming year. We are also hoping to learn why people leave CDCS. The results of this survey will be used to help improve CDCS and make it available to more people.

You do not need to do anything until we call you. However, you can write or telephone us at the number below for one of the following:

- If you do not want to be surveyed, we will immediately take your name off our list.
- If you would like to set up a specific time for the interview.
- If your telephone number has changed in the last year and you want to be interviewed, let us know how to reach you.
- If you would like to see a written copy of the survey before we call.
- If you have trouble hearing or speaking on the telephone, we can send you a written version of the questionnaire and a self-addressed, stamped return envelope.

We hope you will consider taking the survey when our interviewer calls you. All of the information you provide will remain entirely private. If you have any questions or concerns, please contact me.

Connie Schmitz, PhD

Write us at:
Professional Evaluation Services
219 SE Main Street, #303
Minneapolis, MN 55414

Or call (612) 623-9110 or toll-free at (866) 418-5480 if you are outside of the metro calling area and ask for Marcy or Laura.

Telephone Script – Current Participants

Telephone Script: Designated Person / Proxy -- CURRENT

If proxy name is known, start with Q1; if not, start with Q2.

Q1. Hello, may I speak to [proxy]?

→ (If yes, go to Q2.)

→ (If not, "Is there a better time for me to reach him / her?" Hang up and call back later.)

Q2. Hello I am calling about the survey on the MR/RC Waiver program and the services and supports that [consumer] receives. Are you the parent or guardian most responsible for managing [consumer's] service plan?

→ (If respondent is the correct person, go to Q3.)

→ (If not, "Who is that person, and how can he/she be contacted?"

Q3. Some letters about this survey from the Department of Human Services and the independent evaluator were mailed to your address recently. Did you get those letters and did you have any questions about them? (If no need for further explanation, continue at Q4)

If they did not receive the letters or need more time to read them, ask if they would like to be mailed a new set and/or if they want to have a chance to read them before doing the survey.

If they would be willing to go forward anyways, but would like an explanation of what was in the letters, read the following:

"The letters explained that we're independent evaluators. DHS hired us to do a survey of people who have used the Consumer Directed Community Support service option in the last year. We want to know how recent changes in CDCS have affected people choosing that option now and in the next year. We'll be talking with both current and former CDCS participants. This survey is voluntary and confidential, and it's being done to help improve the CDCS. [Consumer's] services are not affected whether or not you are willing to take the survey."

Ask if this answered their questions or if they would prefer to have more time to look at letters or have a new set mailed. If ok to go forward, ask Q4

Q4. Is this a good time to do the survey? It takes about 20-30 minutes. (If appropriate say, "We can start now and if we're interrupted, I can call you again later to finish.") **Confirm: My records show that [consumer] was enrolled in CDCS on May 15* of this year -- is that correct? (If not, go to FORMER survey.**

(If yes)

"Great! Before we begin (respondent name), I'm going to mention again that this survey is voluntary. If I ask any question you'd rather not answer, just tell me to skip it. Your answers are confidential and will be grouped with everyone else taking this survey. Only the evaluators will know whether you took this survey or how you answered any of the questions. Do you have any questions before we begin?"

*** May 15, 2005 is the date on which CURRENT or FORMER is based.**

Telephone Script – Former Participants

Telephone Script: Designated Person / Proxy -- FORMER

If proxy name is known, start with Q1; if not, start with Q2.

Q1. Hello, may I speak to [proxy]?

→ (If yes, go to Q2.)

→ (If not, "Is there a better time for me to reach him / her?" Call back later.)

Q2. Hello. I am calling about the survey on the MR/RC Waiver program and the services and supports that [consumer] receives. I'd like to speak to the parent or guardian most responsible for overseeing [consumer's] county service plan. Are you that person?

→ (If respondent is the correct person, go to Q3.)

→ (If not, "Who is that person, and how can he/she be contacted?"

Q3. Some letters about this survey from the Department of Human Services and the independent evaluator were mailed to your address recently. Did you get those letters and did you have any questions about them? (If no need for further explanation, continue at Q4)

If they did not receive the letters or need more time to read them, ask if they would like to be mailed a new set and/or if they want to have a chance to read them before doing the survey.

If they would be willing to go forward anyways, but would like an explanation of what was in the letters, read the following:

"The letters explained that we're independent evaluators. DHS hired us to do a survey of people who used the Consumer Directed Community Support service option in the last year.. We want to know some of the reasons (consumer) is no longer in that program and how recent changes in CDCS affected people who had chosen that option. We'll also be talking with current CDCS participants. This survey is voluntary and confidential, and it's being done to help improve the CDCS. Your decision on whether to take the survey would not affect [Consumer's] services now or in the future"

If this answered their questions ask Q4

If they would prefer to have more time to look at letters or have a new set mailed (ask for a good mailing address), make arrangements for a call back time

Q4. Is this a good time to do the survey? It takes about 20-30 minutes. **Confirm: My records show that [consumer] was not enrolled in CDCS on May 15 of this year -- is that correct? (If they were enrolled, go to CURRENT survey.** (If appropriate say, "We can start now and if we're interrupted, I can call you again later to finish.")

(If yes)

"Great! Before we begin (respondent name), I'm going to mention again that this survey is voluntary. If I ask any question you'd rather not answer, just tell me to skip it. Your answers are confidential and will be grouped with everyone else taking this survey. Only the evaluators will know whether you took this survey or how you answered any of the questions. Do you have any questions before we begin?"

*** May 15, 2005 is the date on which we base Current or Former**

Survey – Current Participants

SURVEY ID# _____

LAST NAME _____

CDCS Consumer Survey (PROXY): Current Participant

DEMOGRAPHICS

1. I'd like to start by asking how you are related to [consumer]?
- ☐ ^a Parent (biological, adoptive, or foster)
 - ☐ ^b Sibling
 - ☐ ^c Spouse
 - ☐ ^d Non-relative guardian
 - ☐ ^e Case manager
 - ☐ ^f Other: _____
 - ☐ ^g *Refused to answer*
2. Are you the primary caregiver for [consumer]?
- ☐ Yes ☐ No ☐ *Don't know* ☐ *Refused to answer*
- (If yes, ask 2a; if no, skip to Q3)**
- 2a. Do you receive payment for the care you provide?
- ☐ Yes ☐ No ☐ *Don't know* ☐ *Refused to answer*
- (If yes, ask 2b; if no, skip to Q3)**
- 2b. Is this payment part of [consumer's] county service plan, or does it come only from a private resource, such as a family member?
- ☐ County service plan ☐ Private resource ☐ *Don't know* ☐ *Refused to answer*
3. Does [consumer] live at home with you?
- ☐ Yes ☐ No ☐ *Refused to answer*
- (If no, ask 3a; if yes, skip to Q4)**
- 3a. If no, where does (he/she) live?
- ☐ Other private home ☐ Other: _____
- ☐ *Don't know / Can't say*
- ☐ *Refused to answer*
4. Would you please describe [consumer's] racial or ethnic background? I can mark more than one group.
- Do you consider [consumer] (*read list*):
- ☐ ^a White / Caucasian
 - ☐ ^b African American
 - ☐ ^c Asian American
 - ☐ ^d Hispanic / Latino
 - ☐ ^e Native American
 - ☐ ^f Other (*if offered*: _____)
 - ☐ ^g *Don't know*
 - ☐ ^h *Refused to answer*

Survey – Current Participants

In order for me to understand your circumstances, I'd like to ask a few questions about [consumer's] background.

5. Can you tell me what medical diagnoses or conditions [consumer] has? (*prompt if needed: such as mental retardation, autism, cerebral palsy*)

- a _____
b _____
c _____
d _____

- ☐ Don't know / Can't say
☐ Refused to answer

- 5a. How would you rate the severity of [consumer's] developmental or related disability?

(*read choices – check only one*)

- ☐ Not applicable ☐ Mild ☐ Moderate ☐ Severe
☐ Don't know / Can't say
☐ Refused to answer

- 5b. How would you rate the level of [consumer's] need for specialized medical care?

(*read choice – check only ones*)

- ☐ No need for specialized medical care ☐ Low ☐ Medium ☐ High need
☐ Don't know / Can't say
☐ Refused to answer

- 5c. How would you rate the level of (consumer's) need for help with disruptive, harmful, or other challenging behaviors? (*check one*)

- ☐ No need for such help ☐ Low ☐ Medium ☐ High need
☐ Don't know / Can't say
☐ Refused to answer

6. Next, would you tell me about the amount of support [consumer] needs: (*read from most intense to least and stop when they identify as correct*)

- ☐ ^a 24-hour, on-site support or supervision (*people living with, or being available*)
☐ ^b Daily on-site support for a limited number of hours a day (*not around-the-clock*)
☐ ^c Less frequent than daily support
☐ ^d As needed visitation and phone contact
☐ ^e Don't know / can't say
☐ ^f Refused to answer

Survey – Current Participants

7. Is there anything else you'd like me to understand about [consumer's] strengths or special needs?
(open-ended):

[illegible]

Survey – Current Participants

EXPERIENCES WITH CDCS

8. I'd like now to talk a little about [consumer's] current service plan. How much were you involved in developing or revising the current plan?

- ☐ ^a Very involved
- ☐ ^b Somewhat involved
- ☐ ^c Not very involved
- ☐ ^d Not at all involved
- ☐ ^e Don't know / can't say
- ☐ ^f Refused to answer

(If "not at all involved," skip to Q13)

9. On a scale of 1-5, how difficult was it for you to complete [consumer's] plan, with 1 being not at all difficult and 5 being very difficult?

- ☐ 1 Not at all difficult ☐ 2 Fairly easy ☐ 3 Neutral 4 Somewhat difficult ☐ 5 Very difficult
- ☐ Don't know / Can't say
- ☐ Refused to answer

10. Did you refer to any written instructions or guidelines when you were developing or revising your plan (such as a consumer toolkit or DHS website)?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

(If yes, ask 10a; if no, skip to Q11)

- 10a. How did you learn about these instructions or guidelines? (mark all that apply)

- ☐ ^a Had used in past years
- ☐ ^b County social worker
- ☐ ^c Other paid advisor
- ☐ ^d Friend / relative
- ☐ ^e Internet
- ☐ ^f Other: _____
- ☐ ^g Don't know / Can't remember
- ☐ ^h Refused to answer

11. Did [consumer's] county social worker help you develop or revise your current plan?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

(If yes, ask 11a; if no, skip to Q12)

- 11a. How helpful was the county social worker for developing or revising the plan?

- ☐ ^a Not helpful
- ☐ ^b Somewhat helpful
- ☐ ^c Very helpful
- ☐ ^d No opinion
- ☐ ^e Not sure / don't know
- ☐ ^f Refused to answer

Survey – Current Participants

12. Did you pay someone like a case manager to help you develop, revise or implement the plan?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

(If yes, ask 12a; if no, ask 12b)

12a. (If yes) Was that person the county social worker?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

12b. (If no) Why didn't you hire anyone? (Mark all that apply)

- ☐ ^a Didn't know I could
☐ ^b Couldn't afford it
☐ ^c Didn't need assistance
☐ ^d Couldn't find someone to hire in my area
☐ ^e County social worker helped me (at no charge)
☐ ^f Other: _____
☐ ^g Not sure / don't know
☐ ^h Refused to answer

FSE

Now I want to ask you some questions about your arrangements with the Fiscal Support Entity (FSE). Do you know what I mean by FSE? *(if yes, go to Q13; if no, read definition)* The FSE is the provider agency that you hire to bill the state [Medical Assistance] for your CDCS services. This agency might be assisting you in paying for [consumer's] services, supports, and workers and other responsibilities, such as filing employer taxes.

13. Do you know which agency is serving as [consumer's] FSE?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

If unusual situation without "standard FSE" please note details: _____

(If yes, ask 13a; if no, skip to Q14)

13a How did you find out about this agency? (mark all that apply)

- ☐ ^a County helped me
☐ ^b Had used them previously
☐ ^c Found through DHS website or internet search
☐ ^d ARC
☐ ^e Other CDCS participant
☐ ^f Friend / relative
☐ ^g Flexible case manager
☐ ^h Other: _____
☐ Not sure / don't know
☐ Refused to answer

14. Currently, is the agency helping you recruit, hire, supervise, or evaluate paid staff?

- ☐ Yes ☐ No ☐ No paid staff ☐ Don't know / can't remember ☐ Refused to answer

answer

If have NO paid staff, skip to Q15; else ask Q14a

14a. (If have paid staff): Who is responsible for paying workers and paying payroll taxes: you or the agency?

- ☐ Respondent/proxy ☐ Agency ☐ Don't know / can't remember ☐ Refused to answer

Survey – Current Participants

15. Who is responsible for paying for (consumer's) other (non-staff) services and support? You or the agency? *(read as needed: such as managing billing, other paperwork for state)*
☐ Respondent/proxy ☐ Agency ☐ Don't know / can't remember ☐ Refused to answer

16. On a scale of 1-5 with 1 being very unclear and 5 being very clear, how clear are you about the agency's roles and responsibilities?
☐ 1 Very unclear ☐ 2 Somewhat unclear ☐ 3 Neutral ☐ 4 Fairly clear ☐ 5 very clear
☐ Don't know / Can't say
☐ Refused to answer

If answer 3,4 or 5 skip to Q17, if answer 1 or 2 ask Q16a

16a. What are you most unclear about? _____

17. On a scale of 1-5 with 1 being very dissatisfied and 5 being very satisfied, how satisfied are you with the agency overall?
☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Fairly satisfied ☐ 5 Very satisfied
☐ Don't know / Can't say
☐ Refused to answer

If answer 3,4 or 5 skip to Q18, if answer 1 or 2 ask Q17a

17a. What are you most dissatisfied about? _____

CURRENT SERVICES

I am going to ask some questions now about the goods, services, and supports that [consumer] receives from the **current** service plan. Under the **current** plan and budget

18. Are there designated hours in your current service plan to pay someone to provide personal care for [consumer]? *(activities of daily living such as dressing, bathing, eating, laundry and meal preparation)*
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
(If Yes, ask 19; if No, skip to Q22)

19. **Who** is paid to provide personal care? *(prompt with list as needed, check all that apply)*
- ☐ ^a Parent
 - ☐ ^b Spouse
 - ☐ ^c Other relative
 - ☐ ^d Friend
 - ☐ ^e Neighbor
 - ☐ ^f Babysitter
 - ☐ ^g Teacher
 - ☐ ^h Licensed support person (like a Personal Care Assistant)
 - ☐ Other: _____
 - ☐ Don't know / can't remember
 - ☐ Refused to answer

Survey – Current Participants

20. In total, how many people are being paid to provide personal care? (may include proxy)

21. How many hours a week on average does [consumer] get of personal care assistance from paid workers (may include proxy, if applicable) _____
22. Does the current support plan have a budget for any specialized treatments or therapies, such as those provided by a nurse, doctor, therapist, or other professional?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
(If Yes, ask 22a; if No, skip to Q23)
- 22a. (If yes), what type of treatments or therapies does the plan pay for?

23. Does the current support plan have a budget for training or help for (consumer) to learn things related to (his/her) functioning, well-being, or employment?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
(If Yes, ask 23a; if No, skip to Q24)
- 23a. (If yes), what type of training or help does the plan pay for?

(Ask **ONLY IF** consumer is **OVER 18 years old**; if not, skip to Q25)

24. Does (consumer) receive this training or help as part of an adult day program (DT+H)?
☐ Yes, part of adult day ☐ No, separate from DT&H
☐ Don't know / can't remember ☐ Refused to answer
25. Does the current support plan have a budget for any transportation or travel costs?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
26. Does the current support plan have a budget for any home or vehicle modifications?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
27. Does the current support plan have a budget for any other special types of tools, or equipment that help (consumer) care for (himself / herself), work, socialize, or get around?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
28. Does the current support plan have a budget for any prescribed dietary supplements?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
29. Does the current support plan have a budget for respite care?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
30. Does the current support plan have a budget for crisis services?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

Survey – Current Participants

31. Is there anything else the current plan includes that you'd like to mention?

32. Are there goods, services, or supports that you wish (consumer's) current plan could include that it doesn't? If so, what?

Is that because of a Limited Budget, or is Disallowed?

- | | | | |
|---|-------|---------------------------------|-------------------------------------|
| a | <hr/> | <input type="checkbox"/> Budget | <input type="checkbox"/> Disallowed |
| b | <hr/> | <input type="checkbox"/> Budget | <input type="checkbox"/> Disallowed |
| c | <hr/> | <input type="checkbox"/> Budget | <input type="checkbox"/> Disallowed |
| d | <hr/> | <input type="checkbox"/> Budget | <input type="checkbox"/> Disallowed |

SATISFACTION WITH SERVICES

I'm going to ask you now some questions about your satisfaction with various parts of the services [consumer] currently receives. If you would rate these on a scale of 1-5, with 1 being very dissatisfied and 5 being very satisfied.

33. The overall scope of goods, services, and support that [consumer] currently receives?
☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
☐ Not applicable ☐ Don't know / Can't say ☐ Refused to answer
34. [Consumer's] county social worker (case manager)?
☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
☐ Not applicable ☐ Don't know / Can't say ☐ Refused to answer
35. Any other interactions with the county that you may have had?
☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
☐ Not applicable ☐ Don't know / Can't say ☐ Refused to answer
36. The number of hours of paid personal care that (consumer) receives?
☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
☐ Not applicable ☐ Don't know / Can't say ☐ Refused to answer

Survey – Current Participants

37. The quality of personal care that (consumer) receives from other people?
☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
☐ Not applicable ☐ Don't know / Can't say ☐ Refused to answer
- 37a. In the past 12 months, how many new people have you hired to help care for (consumer)? _____
- 37b. Have any of these new helpers have quit since they were hired?
☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer
- 37c. (If yes) How many? _____

Just to let you know, we're more than halfway done.

The Next Section is on GOALS/QUALITY OF LIFE. I'd like to ask your opinions now about how [consumer's] current service plan is meeting his / her overall goals and needs. In [consumer's] case:

38. How true is the statement: "The plan is flexible enough to meet [consumer's] specific needs."
☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ Don't know / Can't say
☐ Refused to answer
39. How true is the statement: "The plan helps (consumer) to get out into the community."
☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ Don't know / Can't say
☐ Refused to answer
40. How about this statement: "The plan puts us (consumer and proxy) in the driver's seat in terms of deciding what works best for (him / her)."
☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ Don't know / Can't say
☐ Refused to answer
41. How true do you find this to be? "(Consumer) is able to work towards (his / her) own personal goals under the current plan."
☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ Don't know / Can't say
☐ Refused to answer
42. The next statement is "(Consumer) is able to be as independent as (he or she) can be under this plan."
☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ Don't know / Can't say
☐ Refused to answer
43. Next, "I worry about (consumer's) health or safety under this plan."
☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ Don't know / Can't say
☐ Refused to answer

Survey – Current Participants

44. Next “The plan helps reduce family stress and burden.”

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ Don't know / Can't say
☐ Refused to answer

45. And last, “The budget is well directed towards the things that (consumer) needs the most.”

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ Don't know / Can't say
☐ Refused to answer

CDCS BUDGET

As you know, a new statewide formula determines individual CDCS consumer budgets. These new budgets started to take effect last October and are being phased in over the coming year.

46. Has the new statewide formula budget gone into effect yet for [consumer]?

(interviewer, please prod if possible for answer)

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

(If Yes, skip to Q51; if No, ask Q47)

47. Once the new budget goes into effect, do you believe [consumer] will continue in CDCS?

(interviewer, please prod if possible for answer)

- ☐ Yes ☐ Probably yes ☐ Probably no ☐ No
☐ Don't know / Can't say
☐ Refused to answer

(If Yes or Probably Yes, skip to Q50; if No or Probably No, ask Q48)

48. If [consumer] were to disenroll from CDCS, would you expect (him/her) to remain on the MR/RC waiver?

- ☐ Yes ☐ No ☐ Don't know / can't say ☐ Refused to answer

49. If [consumer] were to disenroll from CDCS, would [he/she] continue to live where [he/she] is living now?

- ☐ Yes, would remain same **SKIP TO Q50** ☐ No, would have to change **ASK Q49a**
☐ Don't know / can't say **SKIP TO Q50** ☐ Refused to answer **SKIP TO Q50**

49a. If [consumer] living situation were to change, where would [consumer] be likely to be living?

- ☐ ^a Nursing home
☐ ^b Foster care
☐ ^c Group home
☐ ^d Assisted living
☐ ^e ICF-MR
☐ ^f Other relative
☐ ^g Other: _____
☐ ^h Not sure / don't know
☐ ⁱ Refused to answer

Survey – Current Participants

50. How will (consumer's) service plan change with the new budget? What will be different, if anything, about the goods, services, and supports we just talked about?

[illegible]

(skip to Q52)

YES, CDC'S BUDGET IS IN EFFECT

Goods, Services, and Supports

51. If you would think back on your old budget (the one [consumer] had before the new CDCS budget went into effect. What do you think is the main difference between the goods, services, and supports (he/she) had in the old budget, and those (he/she) is getting now?

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Survey – Current Participants

You've been very helpful. We're almost done – just a few last questions.

52. Have you / (the consumer) filed an appeal with the county about CDCS in the past 12 months?

- ☐ Yes ☐ No ☐ Not yet, but will likely in future
☐ Don't know / can't remember ☐ Refused to answer

(If Yes, ask 52a; if No, skip to Q53)

52a. Which of these categories was most related to your appeal? Was it (*read choices, mark one*)

- ☐ ^a Budget related
☐ ^b Allowable expenses
☐ ^c Eligibility
☐ ^d Other: _____
☐ ^e Not sure / don't know
☐ ^f Refused to answer

53. Would you recommend CDCS to other MR/RC Waiver families with situations similar to yours?

- ☐ ^a Definitely yes
☐ ^b Probably yes
☐ ^c Not sure / undecided
☐ ^d Probably no
☐ ^e Definitely no
☐ ^f Don't know / can't say
☐ ^g Refused to answer

That's it – we've come to the end. Thank you for giving us your valuable time for this survey. When the study is complete, that summarizes the results will be posted on the DHS website. As I told you earlier, no one will know if you participated or the specific answers you gave. Do you have any questions before I go?

SURVEY ID# _____

LAST NAME _____

CDCS Consumer Survey (PROXY): Former Participant

DEMOGRAPHICS

1. I'd like to start by asking if [consumer] is still enrolled in the MR/RC Waiver program?
☐ Yes ☐ No ☐ Don't know ☐ Refused to answer
- 1a. Is (consumer) participating in another consumer directed program offered by the state / county, such as **Consumer Support Grant** or the **Family Support Grant**?
☐ ^a Consumer Support Grant
☐ ^b Family Support grant
☐ ^c Other: _____
☐ ^d Don't know / can't remember
☐ ^e Refused to answer
- 1b. Does [consumer] receive any other services provided by the county or the state, such as Medical Assistance?
☐ Yes ☐ No ☐ Don't know ☐ Refused to answer
- 1c. If yes, what? _____
Prompt, anything else? _____
2. How are you related to [consumer]?
☐ ^a Parent (biological, adoptive, or foster)
☐ ^b Sibling
☐ ^c Spouse
☐ ^d Non-relative guardian
☐ ^e Case manager
☐ ^f Other: _____
☐ ^g Refused to answer
3. Are you the primary caregiver for [consumer]?
☐ Yes ☐ No ☐ Don't know ☐ Refused to answer
(If yes, ask 3a; if no, skip to Q4)
- 3a. Do you receive payment for the care you provide?
☐ Yes ☐ No ☐ Don't know ☐ Refused to answer
(If yes, ask 3b; if no, skip to Q4)
- 3b. Is this payment part of [consumer's] county service plan, or does it come only from a private resource, such as a family member?
☐ County service plan ☐ Private resource ☐ Don't know ☐ Refused to answer

Survey - Former Participant

4. Does [consumer] live at home with you?

☐ Yes ☐ No ☐ Refused to answer

(If no, ask 4a; if yes, skip to Q5)

- 4a. If no, where does (he/she) live?

☐ ^a Nursing home

☐ ^b Foster care

☐ ^c Group home

☐ ^d Assisted living

☐ ^e ICF-MR

☐ ^f Other _____

☐ ^g _____ *Don't know / Can't say*

☐ ^h Refused to answer

5. Would you please describe [consumer's] racial or ethnic background? I can mark more than one group.

Do you consider [consumer] *(read list)*:

☐ ^a White / Caucasian

☐ ^b African American

☐ ^c Asian American

☐ ^d Hispanic / Latino

☐ ^e Native American

☐ ^f Other *(if offered: _____)*

☐ ^g Don't know

☐ ^h Refused to answer

In order for me to understand your circumstances, I'd like to ask a few questions about [consumer's] background.

6. Can you tell me what medical diagnoses or conditions [consumer] has? *(prompt if needed: such as mental retardation, autism, cerebral palsy)*

1 _____
2 _____
3 _____
4 _____

☐ Don't know / Can't say

☐ Refused to answer

- 6a. How would you rate the severity of [consumer's] developmental or related disability?

(read choices – check only one)

☐ Not applicable ☐ Mild ☐ Moderate ☐ Severe

☐ Don't know / Can't say

☐ Refused to answer

- 6b. How would you rate the level of [consumer's] need for specialized medical care?

(read choice – check only ones)

☐ No need for specialized medical care ☐ Low ☐ Medium ☐ High need

☐ Don't know / Can't say

☐ Refused to answer

Survey - Former Participant

6c. How would you rate the level of (consumer's) need for help with disruptive, harmful, or other challenging behaviors? (check one)

- ☐ No need for such help ☐ Low ☐ Medium ☐ High need
- ☐ Don't know / Can't say
- ☐ Refused to answer

7. Next, would you tell me about the amount of support [consumer] needs: *(read from most intense to least and stop when they identify as correct)*

- ☐ ^a 24-hour, on-site support or supervision (*people living with, or being available*)
- ☐ ^b Daily on-site support for a limited number of hours a day (*not around-the-clock*)
- ☐ ^c Less frequent than daily support
- ☐ ^d As needed visitation and phone contact
- ☐ ^e *Don't know / can't say*
- ☐ ^f *Refused to answer*

8. Is there anything else you'd like me to understand about [consumer's] strengths or special needs?
(open-ended):

[illegible]

Reasons for Departure

9. Why did [consumer] leave CDCS?

10. Have you / (the consumer) filed an appeal with the county about CDCS in the past 12 months?

- ☐ Yes ☐ No ☐ Not yet, but will likely in the future
☐ Don't know / can't remember ☐ Refused to answer

(If Yes, ask 10a; if No, skip to 11)

10a. Which of these categories was most related to your appeal? Was it *(read choices, mark all that apply)*

- ☐ ^a Budget related
☐ ^b Allowable expenses
☐ ^c Eligibility
☐ ^d Other: _____
☐ ^e Not sure / don't know
☐ ^f Refused to answer

Skip to Q26 if consumer is IN GROUP HOME OR INSTITUTION (Ask q11-26 if consumer lives at home or in foster home).

Skip to Q41 if consumer is NO LONGER ON MR/RC WAIVER .

CURRENT SERVICES

I am going to ask some questions now about the goods, services, and supports that [consumer] receives from the **current** service plan. Under the **current** plan and budget

11. Are you paying someone to provide personal care for [consumer] *(activities of daily living, such as dressing, bathing, eating, laundry and meal preparation)?*

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

(If Yes, ask 12; if No, skip to Q16)

12. How many people are paid to provide personal care? (may include proxy)

13. **Who** is paid to provide personal care? (*prompt with list as needed, check all that apply*)

- ☐ ^a Parent
- ☐ ^b Spouse
- ☐ ^c Other relative
- ☐ ^d Friend
- ☐ ^e Neighbor
- ☐ ^f Babysitter
- ☐ ^g Teacher
- ☐ ^h Licensed support person (like a Personal Care Assistant)
- ☐ ⁱ Other: _____
- ☐ ^j Don't know / can't remember
- ☐ ^k Refused to answer

14. How many hours a week on average does [consumer] get of personal care assistance from paid workers (*may include proxy, if applicable*) _____

15. Does the current support plan have a budget for any specialized treatments or therapies, such as those provided by a nurse, doctor, therapist, or other professional?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

(If Yes, ask 15b; if No, skip to Q16)

15b. (If yes), what type of treatments or therapies does the plan pay for?

16. Does the current support plan have a budget for training or help for (consumer) to learn things related to (his/her) functioning, well-being, or employment?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

(If Yes, ask 16b; if No, skip to Q17)

16b. (If yes), what type of training or help does the plan pay for?

(Ask ONLY IF consumer is OVER 18 years old; if not, skip to Q18)

17. Does [consumer] receive this training or help as part of an adult day program (DT+H)?

- ☐ Yes, part of adult day ☐ No, separate from DT&H
☐ Don't know / can't remember ☐ Refused to answer

18. Does the current support plan have a budget for any transportation or travel costs?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

19. Does the current support plan have a budget for any home or vehicle modifications?

- ☐ Yes ☐ No ☐ Don't know / can't remember ☐ Refused to answer

Survey - Former Participant

20. Does the current support plan have a budget for any other special types of tools, or equipment that help [consumer] care for (himself / herself), work, socialize, or get around?
☐ Yes ☐ No ☐ *Don't know / can't remember* ☐ *Refused to answer*

21. Does the current support plan have a budget for any prescribed dietary supplements?
☐ Yes ☐ No ☐ *Don't know / can't remember* ☐ *Refused to answer*

22. Does the current support plan have a budget for respite care?
☐ Yes ☐ No ☐ *Don't know / can't remember* ☐ *Refused to answer*

23. Does the current support plan have a budget for crisis services?
☐ Yes ☐ No ☐ *Don't know / can't remember* ☐ *Refused to answer*

24. Is there anything else the current plan pays for that you'd like to mention?

25. Are there goods, services, or supports that you wish (consumer's) current plan could pay for that it doesn't? If so, what?

Is that because of Limited Budget
or is Disallowed?

a	<hr/>	<input type="checkbox"/> Budget	<input type="checkbox"/> Disallowed
b	<hr/>	<input type="checkbox"/> Budget	<input type="checkbox"/> Disallowed
c	<hr/>	<input type="checkbox"/> Budget	<input type="checkbox"/> Disallowed
d	<hr/>	<input type="checkbox"/> Budget	<input type="checkbox"/> Disallowed

26. In a few words, what's the main difference between the goods, services and supports that [consumer] receives **today** and those (he/she) was enrolled in CDCS?

SATISFACTION WITH SERVICES

I'm going to ask you now some questions about your satisfaction with the county or state services [consumer] currently receives. If you would rate these on a scale of 1-5, with 5 being very satisfied and 1 being very dissatisfied.

27. The overall scope of goods, services, and support that [consumer] currently receives from the county or state?
- ☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
- ☐ Don't know / Can't say
- ☐ Refused to answer
28. [Consumer's] county social worker (case manager)?
- ☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
- ☐ Don't know / Can't say
- ☐ Refused to answer
29. Any other interactions with the county that you may have had?
- ☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
- ☐ Don't know / Can't say
- ☐ Refused to answer
30. The number of hours of paid personal care assistance and support that (consumer) receives?
- ☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
- ☐ Not Applicable
- ☐ Don't know / Can't say
- ☐ Refused to answer
31. The quality of personal care and assistance that (consumer) receives from other people?
- ☐ 1 Very dissatisfied ☐ 2 Somewhat dissatisfied ☐ 3 Neutral ☐ 4 Somewhat satisfied ☐ 5 Very satisfied
- ☐ Not Applicable
- ☐ Don't know / Can't say
- ☐ Refused to answer

Just to let you know, we are more than half-way done with the survey and really appreciate your time.

GOALS/QUALITY OF LIFE

Next, I'd like to ask your opinions about how [consumer's] current service plan is meeting his / her overall goals and needs.

32. How true do you think this next statement is: "The plan is flexible enough to meet [consumer's] specific needs."
- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
- ☐ Don't know / Can't say
- ☐ Refused to answer
33. How true do you find the next statement: "The plan helps [consumer] to get out into the community."
- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
- ☐ Don't know / Can't say
- ☐ Refused to answer

Survey - Former Participant

34. How about this statement: "The plan puts us [consumer and proxy] in the driver's seat in terms of deciding what works best for (him / her)."

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ *Don't know / Can't say*
☐ *Refused to answer*

35. How true do you find this to be? "[Consumer] is able to work towards (his / her) own personal goals under the current plan."

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ *Don't know / Can't say*
☐ *Refused to answer*

36. The next statement is "[Consumer] is able to be as independent as (he or she) can be under this plan."

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ *Don't know / Can't say*
☐ *Refused to answer*

37. Next, "I worry about [Consumer's] health or safety under this plan."

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ *Don't know / Can't say*
☐ *Refused to answer*

38. Next "The plan helps reduce family stress and burden."

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ *Don't know / Can't say*
☐ *Refused to answer*

39. And last, "The budget is well directed towards the things that (consumer) needs the most."

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ *Don't know / Can't say*
☐ *Refused to answer*

40. And our final question is, although you are not currently in CDCS, would you recommend it to other MR/RC Waiver families?

- ☐ ^a Definitely yes
☐ ^b Probably yes
☐ ^c Not sure / undecided
☐ ^d Probably no
☐ ^e Definitely no
☐ ^f *Don't know / can't say*
☐ ^g *Refused to answer*

That's it – we've come to the end. Thank you for giving us your valuable time for this survey. When the study is complete, the results will be posted on the DHS website. As I told you earlier, only the independent evaluators will ever know if you participated or the specific answers you gave. Do you have any questions before we end?

END OF SURVEY

ASK THESE QUESTIONS ONLY IF [CONSUMER] IS NO LONGER ON MR/RC WAIVER

41. In a few words, what's the main difference between the goods, services and supports that [consumer] receives **today** and those (he/she) received when (he/she) was enrolled in CDCS?

GOALS/QUALITY OF LIFE

The next set of questions applies only to consumers who have an individual support plan as a result of receiving county or state-supported services. Does [consumer] have a support plan?

If YES, ask next question, if NO skip to Q50.

42. How true do you think this next statement is: "The plan is flexible enough to meet [consumer's] specific needs."
- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
- ☐ Don't know / Can't say
- ☐ Refused to answer
43. How true do you find the next statement: "The plan helps [consumer] to get out into the community."
- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
- ☐ Don't know / Can't say
- ☐ Refused to answer
44. How about this statement: "The plan puts us [consumer and proxy] in the driver's seat in terms of deciding what works best for (him / her)."
- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
- ☐ Don't know / Can't say
- ☐ Refused to answer
45. How true do you find this to be? "[Consumer] is able to work towards (his / her) own personal goals under the current plan."
- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
- ☐ Don't know / Can't say
- ☐ Refused to answer
46. The next statement is "[Consumer] is able to be as independent as (he or she) can be under this plan."
- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
- ☐ Don't know / Can't say
- ☐ Refused to answer
47. Next, "I worry about [Consumer's] health or safety under this plan."
- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
- ☐ Don't know / Can't say
- ☐ Refused to answer

Survey - Former Participant

48. Next "The plan helps reduce family stress and burden."

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ *Don't know / Can't say*
☐ *Refused to answer*

49. And last, "The budget is well directed towards the things that (consumer) needs the most."

- ☐ Very untrue ☐ Mostly untrue ☐ Neutral ☐ Mostly true ☐ Very true
☐ *Don't know / Can't say*
☐ *Refused to answer*

50. And the final question is, although you are not currently in CDCS, would you recommend it to other MR/RC Waiver families?

- ☐ ^a Definitely yes
☐ ^b Probably yes
☐ ^c Not sure / undecided
☐ ^d Probably no
☐ ^e Definitely no
☐ ^f *Don't know / can't say*
☐ ^g *Refused to answer*

That's it – we've come to the end. Thank you for giving us your valuable time for this survey. When the study is complete, a report that summarizes the results will be posted on the DHS website. As I told you earlier, only the independent evaluators will ever know if you participated or the specific answers you gave. Do you have any questions before we end?

END OF SURVEY

Consumer Directed Community Support Service 2005 Consumer Survey

Thank you for requesting a written version of the telephone survey of the Consumer Directed Community Supports (CDCS) survey. This survey is being administered by the independent evaluator, Professional Evaluation Services and Professional Data Analysts, Inc., on behalf of the Minnesota Department of Human Services.

There are a few things you will need to know in order to complete the survey as a written questionnaire:

- When you read the word "consumer," that means the MR/RC waiver recipient who is in CDCS.
- Several questions ask for short answers in your own words. Please use the amount of space shown in the survey as a guide for the length of your answer.
- Please write or print as clearly as possible so that we may correctly understand your answers.
- **For all questions, circle just one answer, unless the directions tell you otherwise.**

Finally, we want to remind you that this is a voluntary survey. If there is any question you would prefer not to answer, just leave it blank. Your responses will only be read by the independent evaluator and will be grouped together with everyone else's in our final report. No one besides the evaluator will know whether you took the survey, or what your answers were. **The answers you give will NOT affect the consumer's current services.**

If something in the survey needs to be clarified before you can answer, please call Marcy at 612/623-9110, (email: Marcy@pdastats.com) or write to the address below. A self-addressed, stamped envelope has been provided to return the survey. If you misplace the envelope, you may mail it to us at:

Professional Evaluation Services
219 SE Main Street, Suite 303
Minneapolis, MN 55414

Please try to return the completed survey to us within 14 days in order to have your responses included in this survey.

Consumer Directed Community Support Service 2005 Consumer Survey

Thank you for requesting a written version of the telephone survey of the Consumer Directed Community Supports (CDCS) survey. This survey is being administered by the independent evaluator, Professional Evaluation Services and Professional Data Analysts, Inc., on behalf of the Minnesota Department of Human Services.

There are a few things you will need to know in order to complete the survey as a written questionnaire:

- When you read the word "consumer," that means the MR/RC waiver recipient who is in CDCS.
- Several questions ask for short answers in your own words. Please use the amount of space shown in the survey as a guide for the length of your answer.
- Please write or print as clearly as possible so that we may correctly understand your answers.
- **For all questions, circle just one answer, unless the directions tell you otherwise.**

Finally, we want to remind you that this is a voluntary survey. If there is any question you would prefer not to answer, just leave it blank. Your responses will only be read by the independent evaluator and will be grouped together with everyone else's in our final report. No one besides the evaluator will know whether you took the survey, or what your answers were. **The answers you give will NOT affect the consumer's current services.**

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Professional Evaluation Services
219 SE Main Street, Suite 303
Minneapolis, MN 55414

Please try to return the completed survey to us within 14 days in order to have your responses included in this survey.

CDCS SURVEY CALL SHEET**Circle Survey Version Administered:**

Current

Former

Survey ID # «**SURV_ID**»Batch #: «**C_BATCH2**»Database Status: «**CURRFORM**»Birthday: «**BIRTHDAT**»Guardianship Level: «**GUARSTAT**»Proxy Name: «**RESPNAME**»Consumer Name: «**FULLNAME**»MR Level: «**MRLEVEL**»TELEPHONE #: «**C_PHONE**»Street Address: «**C_ADDR1**» «**C_ADDR2**»City: «**C_CITY**»CDCS Start Date: «**CDCSDATE**»MRRC Enroll Date: «**MRENRRDAT**»Region: «**DHSREG**»

Call #	Day of Week / Date / Time of Day	Outcome	Notes?
1	/ /		
2	/ /		
3	/ /		
4	/ /		
5	/ /		
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20	/ /		

Outcome _____

Date _____ Initials _____

Data Entry

Initials Entry 1

2

Outcome: _____

Data Entered: _____

Open Entered: _____

Notice of Privacy Practices

This information is available in other forms to people with disabilities by contacting us at 651-297-4946 (voice). TDD users can call the Minnesota Relay at 711 or 1-800-627-3529. For the Speech-to-Speech Relay, call 1-877-627-3848.

This notice describes how medical information and other private information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

You have privacy rights under the Minnesota Government Data Practices Act and the federal Health Insurance Portability and Accountability Act (HIPAA). These laws protect your privacy, but also let us give information about you to others if a law requires it. We may tell you before we give the information.

Why do we ask you for this information?

We are conducting a research study to understand how health care is coordinated in Minnesota. Information we collect will be used in a written report. The report will be used for improving health care services delivered to all patients.

Do you have to answer the questions we ask?

Participation in the study is completely voluntary. You can refuse to answer any question we ask. Your eligibility, payment, or treatments will not be affected.

With whom may we share the information about you?

The written report will be shared with the public. Your name and other identifying information will not be part of the report and will remain private. We will not share private information about you with anyone other than the Minnesota Department of Human Services or members of the research team unless required by law.

You have rights regarding your information.

- You may ask if we have any information about you and get copies. You may have to pay for the copies. We will give you a copy of your signed consent form. If you do not understand the information, you may ask to have it explained to you.
- You may give other people permission to see and have copies of private data about you, including protected health information (referred to below, collectively, as "protected information").
- If we have collected protected information about you, we may use it only for the purposes that we have listed in this notice.
- You may question the accuracy of any information we have about you.
- You have the right to ask us to share *your protected health information* with you in a certain way or in a certain place. For example, you may ask us to send health information to your work address instead of your home address. You must make this request in writing. If we find that your request is reasonable, we will grant it.
- You can ask us to restrict uses or disclosures of your *protected health information*. Your request must be in writing. You must explain what information you want to restrict from being disclosed and to whom you want these restrictions to apply. You can request to end these restrictions at any time by calling or by writing to us. We are not required to agree to your restrictions.
- You have the right to receive a record of the people or organizations that we have shared *your protected health information* with. We must keep a record of each time we

share your health information for six years from the date it was shared. If you want a copy of this record, you must send a request in writing to the Privacy Official listed below.

What if you believe the information we have about you is wrong? Send your concerns in writing, telling us why the information is not accurate or complete. You may send your own explanation of the facts you disagree with. Your explanation will be attached any time that information is shared with another agency.

What if you believe your privacy rights have been violated? You may complain if your privacy rights have been violated. You cannot be denied service or treated badly because you have made a complaint. If you believe that your doctor or clinic, a health insurer, a health plan, or a pharmacy violated your medical privacy, you may send a written complaint either:

- Directly to that organization, *or*
- To the federal Office of Civil Rights at:

Office of Civil Rights
U.S. Department of Health and Human Services
233 N. Michigan Ave., Suite 240
Chicago, IL 60601
Voice Phone: 312-886-2359
FAX: 312-886-1807 TDD: 312-353-5693

If you think that the Minnesota Department of Human Services has violated your privacy rights, you may send a written complaint to the U.S. Department of Health and Human Services at the address above, or to:

Privacy Official
Minnesota Department of Human Services
444 Lafayette Rd. N
St. Paul, MN 55155-3813