INTERIM REPORT:

Evaluation of the Consumer Directed Community Supports Service

Submitted to the Minnesota Department of Human Services

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Dr. Constance C. Schmitz
Professional Evaluation Services
219 SE Main Street, #303
Minneapolis, MN 55414

(612)623-8223
connie@PESeval.com

Dr. Michael G. Luxenberg
Professional Data Analysts, Inc.
219 SE Main Street, #302
Minneapolis, MN 55414

Dr. Nancy Eustis
University of Minnesota
Hubert Humphrey Institute of Public Affairs
301 19th Avenue South, #133
Minneapolis, MN 55455

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Minnesota Laws 2004, Chapter 288. Article 3. Sec.32.

Sec.32. [CONSUMER-DIRECTED COMMUNITY SUPPORT EVALUATION.] The commissioner of human services, in consultation with interested stakeholders, including representatives of consumers, families, guardians, advocacy groups, counties, and providers, shall evaluate the new consumer-directed community support service under the home and community-based waiver programs, as required by the federal Center for Medicare and Medicaid Services. The evaluation shall include, but not be limited to, an examination of whether any current consumer-directed participants will have their funding reduced so significantly that their health, safety, and welfare at home will be jeopardized, and whether replacement services will cost more or be of lower quality than their current consumer-directed services. The preliminary findings of the evaluation shall be provided to the house and senate committees with jurisdiction over human services policy and finance by February 15, 2005.

Report Abstract

An independent evaluation of the Consumer Directed Community Supports (CSCS) service was commissioned by the Department of Human Services (DHS) in September of 2004. This evaluation, which completes its work in January of 2006, is designed to assess the first-year implementation of the CDCS waiver amendment policies and their initial impacts on county staff, fiscal support entities, and consumers. The evaluation entails three main projects: an online survey of over 400 county administrators and case managers (January, 2005); interviews with fiscal support entities (spring, 2005); and a telephone survey of 400 consumers (or their legal representatives) (summer, 2005).

Authorized changes in the CDCS went into partial effect on October 15, 2004, in 37 participating counties. This report includes background information on the changes and the status of the evaluation. Because the changes are being phased in over time and the results of the evaluation team's county survey are still being analyzed, only preliminary information is available for this report. In response to the Legislature's specific requests, the DHS reports that enrollment in CDCS has declined by 687 persons since December of 2003, after growing for five straight years. The primary reason for *involuntary departure (*as cited in the county survey) SINCE the amendments' approval was the new eligibility requirements, which restrict CDCS to-persons living in their own homes. Few individuals were exited due to immediate health and safety concerns, maltreatment, or suspected fraud. The primary reasons for *voluntary* departure were the comparative ease of obtaining the same or similar services on the waiver without CDCS, insufficient funds in the CDCS budget to sustain needed supports, and higher service authorizations available from the waiver if not in CDCS. These reasons were more frequently cited by county administrators in greater Minnesota than in the 7-county metro area. County administrators projected further CDCS departures, as well as new enrollments, through this year. By December, 2005, over 3,000 CDCS enrollees (700 from new waiver groups) are expected.

The evaluation team believes the CDCS to be a worthy, complex service which has the potential to significantly benefit consumers. Current issues of concern with implementation focus on the statewide budget methodology for determining individual budgets. The Department is encouraged to refine their methodology prior to statewide expansion of CDCS.

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1. Introduction

The purpose of this report is twofold: to describe the status of the independent evaluation that has been contracted by the Department of Human Services for the Consumer Directed Community Supports service, and to provide very preliminary information relevant to the report requested by the Minnesota state legislature, as stated in Minnesota Laws, Sec. 23.

2. Background on the Consumer Directed Community Supports Service

Consumer directed care represents a growing trend in disability support programs around the country. Briefly defined, consumer directed care means that disabled individuals (and their family members or legal guardians) have greater options to plan, manage, and evaluate the persons, goods, and services they need to maintain independent community living. One of the primary benefits of consumer direction is that it can increase consumers' access to informal supports and services (such as personal care assistants) which may be lacking in consistency, quality, or availability. According to a recent report by the National Council of Disabilities, studies of consumer direction "indicate positive outcomes in terms of consumer satisfaction, quality of life, and perceived empowerment. There is no evidence that consumer direction compromises safety—in fact, the opposite appears to be true."[1] To date, the research on the cost effectiveness of consumer directed programs is sparse, and variations in study designs have led to inconclusive results *(ibid, p.11)*.

In Minnesota consumer direction is available through four mechanisms: the Consumer Support Grant, the Family Suppport Grant, the Personal Care Assistant Option, and the Consumer Directed Community Support (CDCS) service. The CDCS began as a pilot program in three grant demonstration counties in 1998. Over the ensuing five years, 37 counties signed memoranda of understanding with the Department to offer the CDCS; the option was available only to consumers with mental retardation or related conditions (MR/RC) receiving a Medicaid Home and Community-Based Service (HCBS) waiver. In December of 2003, DHS submitted waiver amendments to the federal Centers for Medicare & Medicaid Services to expand CDCS statewide and across all five HCBS waiver groups.[2] These amendments were approved in April of 2004. On October 1, 2004, the new policies were phased in for the 37 currently participating counties. By April 1 of 2005, the CDCS becomes available to approximately 40,000 waiver recipients statewide. As shown in Table 1 (next page), consumer enrollment in all of the waiver programs has climbed over the last five years in Minnesota, reflecting both the state's and the nation's movement to de-institutionalize care for the disabled and elderly by enhancing the community-based delivery support system.

[1] National Council of Disabilities (October, 2004), "Consumer Directed Health Care: How Well Does it Work?" (p. 11).

[2] In addition to the five waiver groups, CDCS is now also available to elderly consumers enrolled in Alternative Care (a State-funded, non Medical Assistance program) and in two health plans: Minnesota Disability Health Options (MnDHO) and Minnesota Senior Health Options (MSHO).

Table 1
Growth in the Number of Minnesotans
Receiving Home and Community Based Waivers (2000-2004)

Waiver Program[3]	FY 2000 Recipients	FY 2001 Recipients	FY 2002 Recipients	FY 2003 Recipients	FY2004 Recipients
MR/RC	8,313	14,031	15,264	15,704	15,090
CAC	128	128	126	165	216
CADI	3,957	4,669	6,022	8,420	9,449
TBI	408	474	603	861	1,202
Elderly	9,772	10,890	11,912	13,405	16,259[4]
Total	**22,578**	**30,192**	**33,927**	**38,555**	**42,216**

Source: MN House Research Department (February 2004), updated with DHS November 2004 forecast.

As enrollment in HCBS waiver programs grew, so did the costs (see Table 2). Between 2000 and 2004, the state's annual payments doubled for each waiver except for the Community Alternative Care (CAC) waiver for chronically ill individuals. As enrollment in the MR/RC waiver and CDCS participation grew, so did the costs (see Table 3).

Table 2
Growth in Annual Payments (State Portion Only)
of HCBC Waiver Programs in Minnesota (2000-2004)

Waiver Program	FY2000 Annual State Payments	FY2004 Annual State Payments
MR/RC	175,156,398	377,559,203
CAC	2,343,599	3,004,654
CADI	9,711,772	47,655,032
TBI	5,864,792	23,951,342
EW (Fee for Service)	17,812,794	52,025,485
EW (Managed Care)	1,800,716	4,692,821

Source: DHS staff, February, 2005 (R. Meyers).

Table 3
Growth in CDCS Enrollments (MR/RC Waiver Only) and Costs (1999-2004)

Fiscal Yr	1999	2000	2001	2002	2003	2004
Enrollment (paid)[5]	100	214	1,435	2,923	3,222	3,112
Average payment[6]	$10,112	$20,837	$58,102	$179,814	$156,113	$136,221
Total year payments	$618,778	$1,271,214	$6,788,401	$52,613,971	$69,668,673	$74,915,866

Source: DHS, Disability Services Division, report generated 11/12/04. Includes consumers in foster care.

[3] CAC= Community Alternative Care for chronically ill individuals; CADI = Community Alternatives for Disabled Individuals; TBI = for persons with traumatic brain injury; EW = elderly persons over 65.
[4] Includes EW fee for service (n = 14,781) and EW managed care (n = 1,478)
[5] Based on the number of individuals for whom payments were paid for the fiscal year
[6] Average cost per unit (person) paid during fiscal year

3. Context for Evaluation

Due to concerns about the rising costs of the MR/RC waiver program and anecdotal reports of unusual costs for CDCS participants, the Legislative Auditor was directed to evaluate the MR/RC waiver program during the fall of 2003. The Auditor's report[7] included a specific assessment of the costs, variation in county spending, and types of expenditures of MR/RC persons participating in the CDCS. Their study included analysis of 267 case files as well as surveys with county administrators. The Auditor's results indicated a lack of "sufficient controls over the [CDCS], leading to questionable purchases, inequitable variation in administration, and unmet prospects for cost efficiencies."[8] Costs for CDCS participants also exceeded those for individuals with comparable functional profiles, as determined by the DHS assessment screening document.

The waiver amendments submitted by DHS in 2003 represented several years of planning and revision of CDCS, undertaken in part to respond to state legislation passed in 2001 that instructed DHS to begin making CDCS available to consumers in all five waiver groups. The proposed policy changes were also crafted to address the same types of concerns as those raised in the Auditor's report, and by other stakeholders as well. The challenge to the Department was to maintain consumer flexibility and control (which is the essence of consumer direction), and at the same time reduce questionable expenditures, obtain greater equity in consumer budgets within and across counties for individuals with the same risk levels and service needs, improve accountability mechanisms, and maintain budget neutrality at the state and county levels.

Significant policy and procedural changes in CDCS were ushered into effect as a result of the amendments. Although lead agencies at the county level are responsible for administering and monitoring the service, state-level oversight has increased. As a result of the amendments:

- Eligibility for CDCS is now limited to people living in their own homes; persons who reside in licensed foster care settings are no longer eligible.
- Each CDCS consumer is required to submit a detailed individual support plan, and all waiver services related to the plan must be paid for out of the consumer's CDCS budget.[9]
- The individual support plan can include conventional and self-designed services, paid and unpaid supports, and personal risk management plans to meet health and safety needs. CDCS services cannot begin until the support plan is approved by the (county) lead agency.

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[7] Office of the Legislative Auditor (February, 2004), Medicaid Home and Community-Based Waiver Services for Persons With Mental Retardation or Related Conditions. St. Paul, MN: Program Evaluation Division.

[8] *Ibid*, p. 42.

[9] Previous MR/RC enrollees in CDCS could also access additional funds for services such as Day Treatment & Habilitation as well as their CDCS funds.

- DHS has set new criteria and guidelines on allowable and non-allowable expenses to guide the development of the individual support plan.
- A spouse or parent can provide personal assistance and be paid for this assistance for up to 40 hours per week, when other criteria are met.
- While counties continue to provide case management for required tasks, consumers (with some exceptions) who need or desire flexible case management for other tasks must pay for it out of their CDCS budget.
- Flexible case managers must pass a training course and receive certification from DHS to provide service under CDCS.
- Every consumer must have an agreement with a Fiscal Support Entity (FSE) that is an approved Medical Assistance provider. The FSEs are responsible for managing state and federal employment taxes and payroll for consumers' support workers; processing and paying vendor and agency invoices for approved goods and services; and billing DHS for CDCS payments.
- Most important, DHS devised and implemented a statewide budget methodology which sets a maximum amount for each individual's budget.[10] This statewide methodology was based on statistical analyses of factors most predictive of costs in 2003, adjusted to 70% of the statewide average cost of non-CDCS recipients with comparable conditions in the traditional waiver program.[11]

Evaluation of how well these policy changes and new controls are working—prior to expanding the program statewide—was one of the Legislative Auditor's specific recommendations to DHS. Additionally, in response to a federal CMS request, the Department agreed to track MR/RC individuals who transition out of the CDCS, and to sponsor an independent evaluation of the CDCS.[12]

Other stakeholder groups invested in the CDCS have also urged an independent evaluation. Consumer families in the MR/RC waiver program and their advocates have lodged ongoing and significant complaints with DHS regarding the statewide budget methodology and the new list of un-allowed expenses; personal testimonies cite serious harm as a result of budget reductions scheduled to take effect in the coming year.[13] Since October 1, 2004, 150 CDCS appeals have been filed; nearly all cite budget reductions or perceived errors in their budget calculations as their main issue. As for county personnel, while supportive of CDCS generally speaking, MR/RC waiver administrators have also voiced concerns with the Department about perceived flaws in the budget methodology and with the process with which the new amendments were crafted and introduced.

Formerly, each county set the individual consumer budgets based on the county's own policies and management of an aggregate waiver budget allocated by DHS.

As with Minnesota's other MA services, waiver programs are jointly and equally funded by the state's general fund and the federal government. Allocated amounts on a per recipient basis cannot be greater than what would have been spent had the individual been institutionalized.^Letter from Centers for Medicare & Medicaid (

The financial transition to new budgets is being phased in for persons whose new budgets are below their former budgets. Such persons have until one year from the date of their next annual review or April 1, 2006 (whichever is earlier) to either revise the support plan within their new budget, or choose to leave / CDCS and resume regular waiver services (DHS Letter to County Directors / Administrators, 8-09-05). /

4. Description of the CDCS Evaluation

In May of 2004 the DHS Disability Services Division released a Request for Proposals to design and conduct an independent, formative program and policy evaluation of the CDCS. A $99,000 contract was awarded in August to Dr. Connie C. Schmitz (Professional Evaluation Services), with subcontracts to Dr. Michael G. Luxenberg (Professional Data Analysts, Inc.), and Dr. Nancy Eustis (University of Minnesota). This contract runs from September 15, 2004, through January 1, 2005.

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 approved evaluation plan entails three main projects: an online survey of over 400 county administrators and case managers (January, 2005); interviews with 12 fiscal support entities (spring, 2005); and a telephone survey of a random, stratified sample (n = 400) of consumers (or their legal representatives) (summer, 2005). The evaluation plan is guided by the following questions:

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?

With all of the data collected, the evaluation team will examine the extent to which results vary by waiver group (i.e., MR/RC vs. other waiver groups) and by county regions (i.e., the seven county metro area vs. greater Minnesota).

This evaluation has some important limitations. First, as previously stated, the evaluation contract period ends January 1, 2006; its focus is on the first year of the expanded CDCS as the amendment changes are phased in across waiver groups and counties. Because the service choices of MR/RC consumers who are "over budget" won't be fully known until April 6, 2004, the full effects of the amendment on MR/RC consumer enrollment, service choices, and costs won't be available until late 2006 (taking data lags into account), well after our contract has ended.

Second, the evaluation team was not hired to statistically reanalyze consumer data used in the DHS budget formula, nor to test the reliability or validity of the methodology used to set the formula. Another contractor hired by DHS is re-examining the entire MR/RC waiver budget structure and method used by DHS to allocate waiver monies to the

counties. This contractor will likely re-evaluate the CDCS budget formula as part of that process. Additionally, a budget methodology work group comprised of DHS personnel and stakeholder representatives is currently meeting to review the variables used in the statewide formula and to explore different analytic approaches to calculating the individual budgets. As part of our formative evaluation, however, this evaluation team will provide information on the assumptions that guided DHS in generating the formula, and the extent to which these assumptions prove accurate within the time frame of our contract. The evaluation will also examine the impacts of this formula, as experienced by counties and consumers, through our surveys. As requested in our contract, we will also provide ongoing recommendations for improvement in CDCS when appropriate.

5. Status of Evaluation Implementation

DHS staff members from the Disability Services Division's Access Employment and Accountability unit serve as the DHS liaisons for the evaluation team. To date, the evaluation is on schedule with all of its activities.

- In the first month of the contract, the evaluation team completed interviews with evaluation staff members from the Legislative Auditor's Office, 13 DHS staff members and key leaders, and three representatives from consumer advocacy organizations.[14] Many meetings with DHS staff have been held since then.

- On October 25, 2004, the evaluation team held two information and feedback sessions on the CDCS with consumer family members (n=l 1) and county staff members (n = 11). Each 1 1/2 hour meeting focused on the CDCS evaluation and sought stakeholders' input to components of the plan. Stakeholder feedback was compiled and distributed in a document which was made available to the public on the DHS website, along with an Evaluation Fact Sheet, Answers to Questions, and other materials related to the evaluation. A second stakeholder meeting will be scheduled this spring, to support the development of the consumer survey.

- On January 11, the evaluation team administered a 34-item online survey to 409 county administrators and case managers. This survey had been developed and revised based on input from county representatives as well as DHS program staff. A 66% response rate was obtained (n = 268 respondents) after three follow-up reminders. While full analysis of the data and reporting will not be completed until March, results of several survey items relevant to the Legislature's request are presented in this report.

- Preparations are now being made to interview approximately 12 Fiscal Support Entities in the spring.

[14] ARC of Minnesota, Minnesota Brain Injury Association, the Multiple Sclerosis Society, and the MN Consortium of Citizens with Disabilities.

6. Preliminary Findings

At this early stage of the evaluation, we can only provide preliminary information for two of the five guiding evaluation questions: the extent to which the CDCS amendment policies are being implemented as planned, and the current known impacts of the changes on consumer budgets and enrollment. The findings reported in this section were drawn from background materials, information interviews with stakeholders, meetings with the DHS Director of Finance Policy and other key DHS leaders, and responses to several key questions from our recent online survey of county administrators and case managers.

Status of CDCS Waiver Amendment Policy Implementation

Because we have yet to fully analyze the county survey, it is premature to say much about the implementation of CDCS at the county level. But we can speak to the operational milestones that DHS needed to reach in order to phase in the expanded service for the participating counties. We think a fair summary is that a lot of work has been done by both DHS and the counties to support the implementation, but the process has not been smooth and some key operational milestones have taken longer to accomplish than planned. For example, DHS was unable to complete and release the manual instructing lead county agencies on how to implement the CDCS until late January, 2005, almost four months after the amendments went into effect. Lack of a completed consumer manual (as well as the county manual) was identified by county representatives as problematic in our stakeholder meetings.

Also critical were the delays in getting Fiscal Support Entities (FSEs) approved. In December of 2004, DHS and its national consultant had completed readiness reviews for 18 FSE applicants. These comprehensive reviews involved detailed site visits, inspection of FSE materials and policies, and several follow-up meetings. The 11 FSEs who were approved by December were instructed by DHS to apply for their MA provider number. Until FSEs have their MA provider number, they are unable to contract with counties and counties are unable to enroll new CDCS consumers. Thus, counties are just now beginning to be able to offer the CDCS to new consumers, and they have had very little actual experience with CDCS consumers from other waiver groups to date.

Although DHS shared with county waiver managers the CDCS budget methodology and their consumers' budgets in the spring of 2004, subsequent feedback and revisions in the formula occurred through the summer. Currently enrolled CDCS consumers did not receive their new budgets from county staff until September of 2004. Additional corrections to the formula and to individual budgets were made by DHS in November. This resulted in considerable stress and anxiety for consumers.

To prepare counties for the transition, DHS sponsored five two-hour video-conference training sessions for county staff from June through September of 2004. Statewide, a total of 753 people attended one or more videoconferences, and a total of 3,344 training hours was logged. A list of operational milestones, shown on the next page, represents our understanding of the status of this first phase of CDCS amendment implementation.

Implementing the CDCS: Operational Milestones

Feb '04 Request For Information for FSEs issued.
Feb '04 Dissemination of amendment appendices describing the CDCS service categories, detailed service descriptions and provider standards, list of allowable and not allowable expenses, and required vs. flexible case management functions.
Apr '04 New individual consumer budgets first shared with county managers.
June, '04 Dissemination of a consumer brochure: "Consumer Directed Community Supports: A Medical Assistance waiver service that lets you take more control of your life."
Aug '04 Letter to County Directors / Administrators and Social Service Managers and Supervisors on preparing them and their MR/RC waiver recipients in CDCS for the transition to the new amendment policies and budgets (August, 2004).
Aug '04 Dissemination of documents: "CDCS Policy Statement for Involuntary Exits [from CDCS]," DHS policy on appeals, paying parents of minors and spouses.
Sept '04 Current MR/RC consumers receive their new authorized CDCS budget level.
Oct '04 Finalized Community (Individual) Support Plan format disseminated.
Nov '04 Release of an updated Consumer-Directed Tool-kit (not explicitly for the CDCS)
Oct '04 Release of a 9-page document, "Consumer-Directed Services Budget Formula MR/RC Waiver," explaining the DHS budget methodology.
Oct '04 Completion and dissemination of an online assessment process for persons wishing to be certified as a flexible case manager.
Oct '04 Training curriculum developed for flexible case managers and offered to interested persons.
Oct-Dec Readiness reviews with 18 FSE applicants.
Nov '04 Corrections made to the budget formula.
Dec '04 Eleven FSEs approved, directed to apply for their DHS provider number.
Jan '05 Lead Agency CDCS Manual disseminated over *Listserve*
Feb '05 Consumer CDCS Manual

Current Impacts of the Waiver Amendment Policies on Consumer Budgets

The Department's methodology for determining an individual CDCS enrollee's budget was briefly described in a nine-page document, "Consumer-Directed Services Budget Formula MR/RC Waiver" (October, 2004).[15] The formula is based on 27 consumer characteristics (e.g., age, diagnosis) as defined by the DHS screening document, coded by assessment teams during annual screenings, and entered into the DHS Medicaid Management Information System (MMIS). Using statistical techniques not described,[16] DHS used these screening variables to develop a prediction model based on 2003 costs (paid claims). About 45% of the variation in costs could be explained or "accounted for" by these screening variables. This is a moderate proportion, one that would be considered notable in social science research. However, it means that 55% of the

[15] Additional, similar statistical models were developed for the four other waiver groups.
[16] No technical report on the CDCS budget methodology exists.

variation in costs was due to unknown factors, systematic errors due to instrumentation or coding, and random errors. When asked about the likely sources of unexplained variance not captured by the formula, the Department responded that they suspected that one-time equipment or home modification costs, as well as consumers' service choices, also influenced costs.

To calculate the total daily rate allowed for an individual user, information logged in the MMIS is entered into the formula and the result multiplied first by 0.9964 (to reflect a 1% reduction imposed in the 2003 legislative session), and then by .70. These multipliers essentially reduce the allowable budget to be 70% of what a non-CDCS consumer in the MR/RC waiver group would receive. As reported in conversation with DHS staff, the .70 adjustment factor was determined, through a series of budget projections, as the highest level possible that would keep the counties solvent within their total waiver budgets, as allocated by DHS. Higher adjustment levels of 90% and 80% were tried, but the Department found that these levels were not "budget neutral." That is, CDCS would cost DHS more money than they had forecasted to spend and / or the counties would not have sufficient funds to serve all of the recipients for which they were responsible. To make these calculations, the Department needed to take into account the likely enrollment and costs of non CDCS waiver recipients. Historically, those who are not able to choose CDCS have tended to be consumers who are dependent on higher cost, residentially-based services.

To determine whether a county's waiver budget would become insolvent by a particular adjustment level, DHS had to also make projections about the size of two other groups: the proportion of current MR/RC consumers who would leave CDCS, and the proportion of consumers from other waiver groups who would enroll in CDCS. To make these projections, DHS created four categories, based on the difference between consumers' previous budgets and the new CDCS budget as determined by the statewide formula:

Group 1: "High budget" consumers were defined as those people whose previous (2004) budgets are **more than 15% over** their new CDCS budget.
Group 2: "Above budget" consumers were defined as those people **within 15% above** their new CDCS budget,
Group 3: "Below budget" consumers were those **within 15% below** their new CDCS budget.
Group 4: "Low budget" consumers were those who were **more than 15% below** their new CDCS budget).

As described in meetings with DHS staff, the budget formula's adjustment level of .70 was set based on the following assumptions:

- About 330 MR/RC consumers in foster care would leave CDCS by October 1, 2004, because of the new eligibility criteria.
- Two-thirds (n = 702) of "high budget" MR/RC recipients in CDCS would leave CDCS by April, 2006.
- About 1,200 of the current MR/RC consumers would remain in CDCS.