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Minnesota Department of **Human Services**

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July 22, 2002

Colleen Wick  
Governor's Council on Developmental Disabilities  
300 Centennial Office Building  
658 Cedar St.  
St. Paul, MN 55155

Re: CDCS Focus Groups - Summary of Findings

Dear Colleen:

During the months of February through April of 2002, a number of statewide focus groups were conducted in counties offering the Consumer Directed Service option, of the MR/RC waiver, to determine the level of consumer satisfaction. The project was designed to give service recipients, and/or their legal representatives a voice, to help facilitate the evolution of a service delivery system, and to ensure the service delivery system meets the original service objectives of providing increased consumer choice and control.

A copy of the Summary of Findings has been enclosed for your review. A copy of the report should also be available on-line at the DHS web site at: <http://www.dhs.state.mn.us> in the next few weeks.

Should you have any questions regarding this project or the Summary of Findings, please feel free to contact me at:  
[Peg.Booth@state.mn.us](mailto:Peg.Booth@state.mn.us) or via phone at: (651) 634-5484

Sincerely,

Peg Booth  
Consumer Directed Specialist

# **Consumer Directed Community Supports Focus Groups Summary of Findings**

**June 2002**



**Minnesota Department of Human Services  
Disability Services Division**

**444 Lafayette Road  
St. Paul, MN 55155-3857**

# **Consumer Directed Community Supports Focus Group**

## **Executive Summary**

### **Introduction:**

The Consumer Directed Community Supports (CDCS) service was approved by the federal government, in December of 1997, as a service through the Mental Retardation/Related Condition (MR/RC) Waiver. Currently in Minnesota, to offer CDCS through the MR/RC Waiver, counties are required to enter into a Memorandum of Understanding (MOU) with the Department of Human Services. At the time of this report, 21 counties have entered into a MOU providing Consumer Directed Community Support services through the MR/RC Waiver to 2,569 consumers.

Historically, Minnesota Department of Human Services has extended a great deal of latitude to each of the state's 87 counties, to develop locally administered approaches to meeting the needs of their consumers. One of the identified challenges with the administration of CDCS has been that policies regarding CDCS frequently differ from county to county.

The goal of this project was to conduct statewide focus groups in counties currently offering the Consumer Directed Service option of the MR/RC Waiver, to determine the level of consumer satisfaction. An additional goal of the project was to improve services and satisfaction levels. This project was designed to give service recipients, or their legal representatives, a voice to help facilitate the evolution of a service delivery system, to ensure that the service delivery system meets the original service objectives of providing increased consumer choice and control.

### **Methodology**

With the exception of the initial focus group, focus group participants were randomly selected from a Medicaid Management Information

System (MMIS) generated roster of all consumers currently receiving CDCS. In the initial focus group, participants were randomly solicited from a roster of CDCS service recipients under 18 years of age. In counties where the number of consumers utilizing CDCS was less than five people, all consumers were contacted.

One of two facilitators, who were not employees of the DHS were used in all of the focus groups. One facilitator was a parent of an adult consumer currently using CDCS. The other facilitator was an independent consultant with a company specializing in quality improvement, and who is also a conservator for an adult consumer.

Focus group participants asked by the facilitator to provide responses to the following questions:

- *What is the value of the Consumer Directed Supports to you?*
- *What do you like most about this service?*
- *What do you like least?*
- *How can Consumer Directed Community Support Services be improved?*

After the responses of the group participants were recorded for each of the four focus group questions, participants were then asked to prioritize their responses.

### **Key Findings/Critical Issues**

A total of 51 individuals representing 42 consumers took part in the seven focus groups that were conducted. Of the 42 consumers represented, 74% were less than 18 years of age. Three consumers were present at and actively participated in the focus groups.

Based on the responses received from the Focus Group participants the ability to choose providers and the flexibility with services was what was most valued about CDCS. In addition, the ability of CDCS to support the entire family unit and their quality of life was also a high priority.

Focus group participants were most clearly frustrated about the lack of accurate information and training available to families regarding CDCS, and the amount and level of difficulty in completing the required paperwork and documentation. These areas are closely associated with Case Management services, and perceived inconsistencies and/or frequent changes regarding services which were also ranked as high priority areas for many of the groups.

Increasing the flexibility of CDCS was the highest scored response category of "How can Consumer Directed Support Services be improved." Other recommendations on how CDCS could be improved included: improving training, communication and access to information, and simplifying the process including statewide user-friendly forms.

## **Summary**

Based on the responses received during the focus groups, the need for better communication and training is evident. In many cases, what has been perceived by families as more restrictions were in fact the counties correctly applying the original intent of the service. As counties have developed a better understanding of the parameters of the service, changes are being made to previously approved services. The evolution of Consumer Directed Services is a fluid process. As DHS goes forward with its submission of the amendment language to the Center for Medicaid and Medicare Services, expanding this service option to CADI, CAC, TBI and EW waiver recipients, what has been learned from these focus groups has already initiated system changes to facilitate use CDCS.

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## **Introduction and Historical Perspective**



# **Consumer Directed Community Supports Focus Groups**

## **I. Introduction and historical perspective:**

Medicaid Home and Community-Based service (HCBS) Waivers allow states the flexibility to develop and implement creative alternatives for Medicaid-eligible individuals currently living in or who need the level of care provided in intermediate care facilities for persons with mental retardation (ICF/MR). In Minnesota, the federal government in 1984 approved the Mental Retardation/Related Condition (MR/RC) Waiver agreement. Today, a large majority of Minnesotans with mental retardation and related conditions requesting services receive Medicaid-financed long-term care through the HCBS program. But this was not always the case. From June of 1987 to June 1999, the number of HCBS recipients had increased from 1,423 to 7,102<sup>1</sup>. As of February 2002, 15,057 consumers were enrolled in the MR/RC waiver.

The **Consumer Directed Community Supports (CDCS)** service was approved by the federal government, in December of 1997, as a service through the MR/RC Waiver. Minnesota pursued an amendment to its waiver plan for the service, in part, because it had been selected to receive a Robert Wood Foundation grant for a self-determination project. The Consumer Directed Community Support service was integral to the objectives of the project, which included promoting the development of individualized supports and consumer control of resources. Three pilot counties participated in Minnesota's Self-Determination Project: Blue Earth, Dakota and Olmstead.

Currently in Minnesota, to offer CDCS through the MR/RC Waiver, counties are required to enter into a Memorandum of Understanding (MOU) with the Department of Human Services. At the time of this report, 21 counties have entered into a MOU. These counties include: Anoka, Blue Earth, Carver, Cass, Crow Wing, Dakota, Fillmore, Hennepin, Houston, Morrison, Mower, Olmstead, Ramsey, Rice, Scott, St. Louis, Steele, Todd, Wadena, Washington and

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<sup>1</sup> Research and Training Center on Community Living, Institute on Community Integration (UPA), University of Minnesota, Report #55, November 2000

Wright. Counties with approved MOU's may authorize the use of CDCS by waiver recipients, for whom they serve as county of financial responsibility, regardless of whether the person is living in that county or in another county.

During the last quarter of fiscal year 2001 (3/23/01 to 6/30/02) open enrollment provided an opportunity for 5,537 additional consumers to enroll in the MR/RC waiver.

The influx of such numbers of individuals into the system put a strain on counties and Case Management resources. Counties were responsible to ensure that all individuals were appropriately screened, and at least case management and one other service were available for use by the recipient no later than June 30, 2001.

For the purpose of comparison, from the period of June 1999 to June 2000 the statewide enrollment of individuals onto the MR/RC waiver increased from 7,102 to 8,213, an average enrollment of 93 consumers/month.

In contrast, during the open enrollment period of 3/23/01 to 6/30/01, the statewide enrollment of individuals onto the MR/RC waiver increased to a statewide average of 2487 consumers/month.

At the time of this report there were 2,569 consumers utilizing the Consumer Directed Support option (with almost \$60 million worth of supports authorized in individualized service agreements). Of these consumers, 1,749 (68.1%) service recipients were 18 years of age or younger.

Historically, Minnesota Department of Human Services has extended a great deal of latitude to each of the state's 87 counties to develop locally administered approaches to meeting the needs of their consumers. One of the identified challenges thus far with the administration of CDCS has been that policies regarding CDCS frequently differ from county to county.

## **Project Goals and Objectives**

## **II. Project Goals and Objectives:**

The goal of this project was to conduct statewide focus groups in counties currently offering the Consumer Directed Service option of the MR/RC Waiver to determine the level of consumer satisfaction, with an additional goal of improving services and satisfaction levels. This project was designed to give service recipients, or their legal representatives, a voice to help facilitate the evolution of a service delivery system, to ensure the service delivery system meets the original service objectives of providing increased consumer choice and control. As DHS looks ahead to providing the Consumer Directed Community Support service, through the CADI, CAC and TBI and EW waivers, it is increasingly important to acknowledge what is working, and at the same time attack the barriers.

## **Methodology**

### **III. Methodology:**

#### **A. Sample Selection:**

With the exception of the initial focus group, focus group participants were randomly selected from a Medicaid Management Information System (MMIS) generated roster of all consumers currently receiving Consumer Directed Community Supports<sup>2</sup>, authorized by their county of financial responsibility and grouped according to their county of residence. In the initial focus group, participants were randomly solicited from a roster of CDCS service recipients under 18 years of age. It should be noted that for many consumers currently receiving CDCS, the county of financial responsibility (CFR), and the county of residence are different. In counties where the number of consumers utilizing CDCS was less than five people, all consumers were contacted.

For each individual focus group, counties were grouped according to geographical proximity and number of consumers receiving CDCS.

#### **B. Solicitation of participants:**

Two to three weeks prior to the focus group date, potential participants were contacted via telephone. When possible, the service recipient was spoken with directly. When this was not possible, the authorized or legal representative was then contacted. The purpose, time, and location of the focus group were discussed and a verbal confirmation of attendance requested.

If no one was at home, a message was left, when possible. An additional phone contact was attempted if no return phone call was received within two days or if no message could be left.

Solicitation of participants continued until a confirmation of 12 to 18 people was received. In addition to the service recipient, no more than two additional participants from each recipient's family unit were invited to attend so that the size of the group was kept small enough

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<sup>2</sup> based on CDCS HCPCS (HCFA Common Procedure Coding System) codes

to ensure that all participants had an opportunity to voice their opinions.

Following receipt of a verbal confirmation of attendance, a written confirmation letter (Attachment 1) was mailed to the focus group participant, five to seven days in advance of the focus group. This letter included the time, location, and directions and the specific focus group questions to be discussed.

### **C. County Notification:**

Prior to the onset of the focus groups, counties were provided verbal and/or written notification of DHS' intent in conducting focus groups in various counties (Attachment 2). Counties were informed that the focus groups came about as a result of DHS' continuing need to evaluate existing service systems, and the department's interest in gathering direct feedback from CDCS system users. Counties were also informed in order to ensure confidentiality, specific information (i.e. individual names) regarding focus group participants would not be shared.

### **D. Focus Groups:**

**Focus Group Facilitators:** In all focus groups one of two facilitators who were not employees of DHS were utilized. One facilitator was a parent of an adult consumer currently using CDCS. The other facilitator was an independent consultant with a company specializing in quality improvement and who also is a conservator for an adult consumer.

In addition to the Focus Group Facilitator, no more than two DHS employees were present at the focus groups. DHS staff was deliberately limited to remove possible barriers that may prevent focus group participants from speaking freely and candidly. The function of the DHS employees was primarily as a "scribe", to record on flip charts focus group participant's comments.

All focus group participants were provided with an Information Folder containing the following items:

- ✓ Focus Group Agenda (Attachment 3)
- ✓ Note Paper
- ✓ Pen
- ✓ Evaluation Form (Attachment 4)
- ✓ Telephone Directory for CSMD<sup>3</sup>
- ✓ List of DHS web sites (Attachment 5)
- ✓ List of Useful Disability Related Web Sites (See Attachment 6)

### **Focus Group Format:**

A similar agenda and format was followed at all focus groups:

- **Welcome and Opening: Department of Human Services**
- **Administrative Items: Facilitator**
- **Introduction of all members of the group**
- **Focus Group Questions:**
  - What is the value of the Consumer Directed Supports to you?*
  - What do you like most about this service?*
  - What do you like least?*
  - How can Consumer Directed Community Support Services be improved?*
- **Summary of the Day: Facilitator**
- **Closing remarks: Department of Human Services**

The duration of the focus groups was limited to less than three hours.

For each Focus Group question posed by the facilitator, all comments were recorded on flip charts. When responses were unclear, the facilitator requested that the participant confirm that the information recorded on the flip chart accurately represented their comments.

To ensure that all participants were provided an equal opportunity to express their thoughts and opinions, the facilitator used a structured

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<sup>3</sup> As the CSMD Division (now known as the Disability Services Division) Directory is updated on a regular basis, it was intentionally not included as an attachment to this report, to minimize any confusion regarding current Disability Services Division employee assignments



approach. This technique prompts participants to respond as they are called upon, typically going in order around the table. Participants also were able to “pass” if they had no additional comments at that time.

After the facilitator had finished gathering responses, each participant was asked to prioritize their top three (to five) comments that he or she felt were the most important from those that had been recorded under each of the four questions on the flip charts.

All participants were also asked to complete a focus group evaluation at the conclusion of the focus group.

Within one week following the focus group participants were sent a letter of appreciation from DHS (Attachment 7)

## **Focus Group Location and County Participation**

**IV. Table No. 1: Focus Group Locations and County Participation**

<b>Group #</b>	<b>Date of Focus Group</b>	<b>Location of Focus Group</b>	<b>Counties of Financial Responsibility solicited for participants</b>
<b>Group #1</b>	2/23/02	Edina	Hennepin
<b>Group #2</b>	3/23/02	Lakeville	Dakota, Carver, Scott, Rice, and Sibley
<b>Group #3</b>	3/26/02	Woodbury	Anoka, Washington, Isanti, Pine and Chisago
<b>Group #4</b>	4/06/02	White Bear Lake	Ramsey
<b>Group #5</b>	4/13/02	Rochester	Olmstead, Winona, Mower and Houston
<b>Group #6</b>	4/20/02	Maple Grove	Hennepin
<b>Group #7</b>	4/27/02	Brainerd	Todd, Morrison and Stearns

## **Focus Group Demographics**

V. Table No. 2: Focus Group Demographics:

Date	Location	Attendees	Age of consumers represented	Date of Waiver Enrollment	No Shows	Age of "No Show" Consumers
2/23/02	Edina	Consumers Represented: 4 Total number of participants: 5	4/4 recipients were under 18 years	4/4 recipients had their DWE after 3/01	Total No Shows: 11  % No Show: 73%	11/11 were under 11 years
3/23/02	Lakeville	Consumers Represented: 10 Total number of Participants: 13 One consumer present	5/10 recipients were under 18	4/10 recipients had their DWE after 3/01	Total No Show: 7  % No Show: 41%	6/7 were under 18 years
3/26/02	Woodbury	Consumers Represented: 6 Total number of participants: 7	5/6 recipients were under 18	5/6 recipients had their DWE after 3/01	Total No Show: 5  % No Show: 45%	4/6 were under 18 years
4/06/02	White Bear Lake	Consumers Represented: 9 Total number of participants: 10	8/9 recipients were under 18	6/9 recipients had DWE after 3/01	Total No Show: 6  % No Show: 40%	6/6 recipients were under 18 years
4/13/02	Rochester	Consumers Represented: 2 Total number of participants: 3 One consumer present	½ recipients was under 18 years	2/2 recipients had their WDE after 3/01	Total No show: 8  % No Show: 80%	2/8 recipients were under 18 years
4/20/02	Maple Grove	Consumers Represented: 5 Total number of participants: 5	4/5 recipients were under 18	4/5 recipients had their WDE after 3/01	Total No Show: 9  % No Show: 64%	4/9 recipients were under 18 years
4/27/02	Brainerd	Consumers Represented: 6 Total number of participants: 8 One consumer present	4/6 recipients were under 18 years	3/6 recipients had WDE after 3/01	Total No Show: 10  % No Show: 62%	10/10 recipients were under 18 years

## **Summary of Findings**

## **VI. Summary of Findings:**

With the exception of Group #1<sup>4</sup>, after the participant's responses were recorded, for each of the four focus group questions, participants were asked to prioritize their top three to five responses by indicating a number from 1 to 5 (with 1 being their highest priority) next to their response. For consistency across all focus groups<sup>5</sup>, the top three prioritized responses were utilized in this report.

These numbers had the following prioritized response point values:

- 1 = 3 points
- 2 = 2 points
- 3 = 1 point

A cumulative total of points, for each response recorded, was then determined.

A total, of the prioritized response points, was then calculated for each of the response categories. Response Categories were developed from a review of the total responses provided to each focus group question.

In the case of Group #1, as responses to each of the focus group questions were prioritized as a group, the total points accumulated for each response provided will not exceed 3.

The following tables (Table 3, 4, 5, and 6) provide a summary of points accumulated for each of the top Response Categories.

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<sup>4</sup> In Group #1, responses were prioritized as a group rather than by the individual participants.

<sup>5</sup> A selected number of focus groups prioritized their top five responses

**Table No. 3: Top 6 Response Categories to Question: What do you value most about Consumer Directed Support Services?**

<b>Response Categories</b>	<b>Group #1*</b> 5 Part.	<b>Group #2</b> 13 Part.	<b>Group #3</b> 7 Part.	<b>Group #4</b> 10 Part.	<b>Group #5</b> 3 Part.	<b>Group #6</b> 5 Part.	<b>Group #7</b> 8 Part.	<b>TOTALS</b> 51 Part.
<b>a. Allows choice of providers and flexibility with services</b>		6	12	11	3	10	30	72 (38.3%)
<b>b. Empowering. Increases consumer/family control</b>		26	15	12	1			54 (28.7%)
<b>c. Individualized – Consumer focused</b>	2	17	4	2				25 (13.3%)
<b>d. Increases community integration and Opportunities and improves consumer self-esteem and independence</b>		4		4		9		17 (9.09%)
<b>e. Better use of resources providing the ability to set wages and retain staff</b>	3			7		1	1	12 (6.3%)
<b>f. Supports family unit and quality of life</b>	1	1	2	4				8 (4.2%)

**Total = 188**

\* Prioritized as a group



**Table No. 4: Top 6 Response Categories to Question: What do you like most about Consumer Directed Support Services?**

<b>Response Categories</b>	<b>Group #1*</b>	<b>Group #2</b>	<b>Group #3</b>	<b>Group #4</b>	<b>Group #5</b>	<b>Group #6</b>	<b>Group #7</b>	<b>TOTALS</b>
	<b>5 Part.</b>	<b>13 Part.</b>	<b>7 Part.</b>	<b>10 Part.</b>	<b>3 Part.</b>	<b>5 Part.</b>	<b>8 Part.</b>	<b>51 Part.</b>
<b>a. Allows choice of providers and flexibility with services</b>	4	28	19	6	5	5	7	74 (33.9%)
<b>b. Supports family unit and quality of life</b>		7	3	13		22	4	49 (22.5%)
<b>c. Individualized – Consumer Focused</b>		8		14			10	32 (14.7%)
<b>d. Empowering. Increases consumer/family control</b>	2	8	1	19				30 (13.8%)
<b>e. Better use of resources providing the ability to set wages and retain staff</b>		1	11	3		4		19 (8.7%)
<b>f. Increases Community integration and opportunities and improves consumer self-esteem and independence</b>		2	4		8			14 (6.4%)

**Total = 218**

\* Prioritized as a group

**Table No. 5:** Top 6 Response Categories to question: **What do you like least about Consumer Directed Community Supports?**

<b>Response Categories</b>	<b>Group #1*</b> 5 Part.	<b>Group #2</b> 13 Part.	<b>Group #3</b> 7 Part.	<b>Group #4</b> 10 Part.	<b>Group #5</b> 3 Part.	<b>Group #6</b> 5 Part.	<b>Group #7</b> 8 Part.	<b>Totals</b> 51 Part.
a. Too Restrictive (e.g. , caps, uncovered services or fees, need for approvals, inability to pay parents of minors, inability to be paid for Employer of Record functions)		11		30		6	4	51 (26.4%)
b. Insufficient or poor Information (including FI reports) and/or training regarding CDCS available	3	12	5	15	2	6	5	48 (24.9%)
c. Perceived inconsistencies and/or frequent changes regarding service	2	28	5				1	36 (18.5%)
d. Case Manager related Issues (e.g. lack sufficient training, non-supportive or trusting, not available)	1		22	2		2	2	29 (15.0%)
e. Amount and difficulty of required paperwork and documentation		3	5	3	5	7		23 (11.9%)
f. Limited choice of quality providers and/or staff turnover			2		3		1	6 (3.1%)

**Total = 193**

\* Prioritized as a group

**Table No. 6: Top 5 Response Categories to question: How can Consumer Directed Support Services be improved?**

<b>Response Categories</b>	<b>Group #1*</b> 5 Part.	<b>Group #2</b> 13 Part.	<b>Group #3</b> 7 Part.	<b>Group #4</b> 10 Part.	<b>Group #5</b> 3 Part.	<b>Group #6</b> 5 Part.	<b>Group #7</b> 8 Part.	<b>TOTALS</b> 51 Part.
a. Increase flexibility of CDCS. (incl., Ability to pay for more services and fees, removal of caps, paying parents of minors, providing a discretionary fund etc.)		25	11			15	9	60 (33.9%)
b. Improve training, communication and access to information (incl. Fiscal Intermediary reports) and resources (incl. Disability specific "specialists")	2	13	7		4		18	44 (24.9%)
c. Simplify Process (e.g. state wide consistency with form and rules, eliminate diff. between children and adults, ease to modify budget, on-line forms, consumer friendly forms)	3	10	17			4	5	39 (22.0%)
d. Trust parents including foster parents to know what is best for their child and family.			3			14	10	27 (15.2%)
e. Make available to families staff related resources including insurance benefits and training materials.		5			2			7 (3.9%)

\* Prioritized as a group

**Total = 177**

**Key Findings/Critical Issues**

**and**

**Follow-up Actions**

## **VII. Key Findings/Critical Issues:**

A total of 51 individuals representing 42 consumers took part in the seven focus groups that were conducted. Of the 42 consumers represented, 74% were less than 18 years of age. Three consumers were present at and actively participated in the focus groups. 28 out of the 42 consumers represented, or 67% had a waiver date of enrollment after 3/23/01 (i.e. date of onset of the open enrollment period).

### **What do you value most about Consumer Directed Support Services?**

Based on the responses received from the Focus Group participants, the ability to choose providers, and the flexibility with services, were what was most valued about CDCS. Not only did this response category receive the highest score, it was also a priority for six of the seven focus groups.

Participant response to this question included:

*"You (the family) have control and responsibility"*

*"Enables the family to deal with the situation"*

*"Increases mental health of family as secure (knowing) that the child is safe"*

In addition to the ability to choose providers and the flexibility of services, four out of seven focus groups also highly valued that CDCS had empowered them, and provided them with more control and that the service option was individualized based upon consumer needs.

### **What do you like most about Consumer Directed Support Services?**

Although this question was very similar to the question above, Table No. 4 indicates that how participants rated responses was slightly different when compared with Table No. 3.

Participant response to this question included:

*"Ability to pay for quality care – rather have less and have higher quality"*

*"CDCS has kept family together"*

*"Services adapt to changing needs"*

The ability to choose providers and the flexibility of services remained the highest priority appearing as a priority issue in all seven focus groups. However, the ability of CDCS to support the entire family unit and their quality of life received the next highest number of points and was a priority for four out of seven focus groups.

### **What do you like least about Consumer Directed Support Services?**

Focus group participants were most clearly frustrated by the following two response categories identified as: the lack of accurate information and training available to families regarding CDCS, and the amount and level of difficulty in completing the required paperwork and documentation. These areas are closely associated with Case Management services and perceived inconsistencies, and/or frequent changes regarding services, which were also ranked as high priority areas for many of the groups.

Participant response to this question included:

*"Inability of foster parents to have a say in the budget"*

*"Utter confusion when getting started"*

*"Don't have guidelines for planning the budget"*

*"Arbitrary decisions: varies from social worker to social worker"*

### **How can Consumer Directed Support Services be improved?**

As indicated earlier, the flexibility that CDCS affords was highly valued by the focus group participants. Increasing the flexibility of CDCS was also the highest scored response category of "How can Consumer Directed Support Services be improved."

Other recommendations on how CDCS could be improved included: improving training, communication and access to information and simplifying the process including statewide user-friendly forms.

Participant response to this question included:

*"Parents should be treated as professionals and respected as being the best person to decide what is best for the child"*

*"Be provided with federal and state rules of what we can and can't do"*

*"Parent's access to decision making team: part of the group rather than outside"*

#### **VIII: Follow up Actions:**

It is acknowledged that the feedback provided the Focus Group Participants regarding CDCS was valid and well thought out. From the input obtained in response to each of the Focus Group Questions, a number of unmet needs were identified. These needs and strategies to address them are outlined in Table No. 7.

**Table No. 7: Focus Group Follow-up Actions**

<i>Identified Needs</i>	<i>Key Strategies</i>	<i>Other Considerations</i>
<b>1. Clear, accurate and current Information provided to consumers and/or their legal representatives</b>	Input from constituents has lead to revision in the CDCS amendment language whose intent will increase flexibility and decision making on the part of the service recipients and their legal representatives.	Federal approval from Centers for Medicaid and Medicare Services (CMS) for amendment language pending
<b>2. Consistent access to Information</b>	Provide consumers and counties with tools and resources in a variety of formats for support and assistance including written materials, web-based resources, etc.	
<b>3. Consistency on the part of the County and Case Manager (inconsistencies due to varied level of expertise, county philosophy, turnover etc.)</b>	<p>Provide consumers and/or their legal representatives and counties with parameters for decision making regarding budget planning.</p> <p>Collaborate and develop partnerships with other entities to assist and provide education and additional resources to families and counties including: person centered planning; community support plan and budget development</p> <p>Develop Statewide Advisory Council to strengthen partnership with stakeholders and ensure on-going – involvement and input with policy development and quality assurance activities regarding CDCS.</p>	Amendment language is a significant system change from historical approach shifting locus of control from government to family
<b>4. Participation of consumers and/or their legal representatives in policy development on the county or state level.</b>		Ability of DHS to effectively communicate CDCS policy to counties and service recipients



## **Focus Group Evaluation and participant feedback**

## **IX. Focus Group Evaluations and participant feedback:**

At the conclusion of the focus groups, a total of 46 evaluations were completed by the participants.

**When asked: My overall reaction to today in one word is: \_\_\_\_.**

44/45 participants provided positive responses including:

- Great (5)
- Good (12)
- Helpful/informative (10)
- Positive/worthwhile (4)

Other words provided included: appreciated; empowering; successful; awesome, necessary, good opportunity and enlightening,

Only one participant indicated a negative comment of "frustrated".

When asked to rate how well the focus group addressed the three established outcomes, using a rating scale of 1 to 3 (1 = not at all, 2 = somewhat, and 3 = very much), an overall average score of 2.87 was received out of a total possible score of 3.

99 total responses received with a score of 3

13 total responses received with a score of 2

Zero responses received with a score of 1

Each of the individual established outcomes received the following ratings:

Question #1: The Value of CDCS (2.94)

Question #2: What do you like most/least about CDCS (2.91)

Question #3: How can this service be improved (2.85)

## **Summary and Closing Remarks**

## **X. Summary and Closing Remarks**

Although the participants who were in attendance at the seven focus groups had varied opinions and concerns regarding the Consumer Directed Support Service of the MR/RC waiver, what was shared by all groups were the strong emotions evoked during the discussions.

Participants willingly shared their concerns that counties were imposing more and more restrictions, regarding CDCS, many times without prior notification. This has led to a great deal of frustration and confusion with many families, who stated that the original philosophy behind CDCS has been lost. Families wanted to be trusted to make the decisions to ensure that the needs of their child were met.

Based on the responses received during the focus groups, the need for better communication and training is evident. In many cases, what has been perceived by families as more restrictions were in fact the counties correctly applying the original intent of the service. As with all services through the waivers, CDCS must be provided in accordance with the assurances outlined in the State's approved waiver plan. As counties have developed a better understanding of the parameters of the service, changes are being made to previously approved services.

It is hypothesized that the inability of many counties to sufficiently communicate and work with families new to the waiver and CDCS was in part a result of the large influx of individuals into the system during open enrollment.

One of the goals of Minnesota Department of Human Services continues to be the strong commitment to listen to and to use information provided from consumers, families, counties and other stakeholders for the process of service improvement. The evolution of Consumer Directed Services is a fluid process. Because Consumer Directed Services is a highly individualized program based on the specific needs of an individual consumer, providing a set of concrete "Can" and "Can't Do" directions conflicts with the original intent of the service. As the number of individuals using CDCS

expands, inevitable changes are necessary to meet the needs of all service recipients.

Based on the feedback received from the Focus Group Participants, Consumer Directed Community Supports has effected positive changes in the lives of almost all service recipients and their families. As DHS goes forward with its submission of the amendment language to the Center for Medicaid and Medicare Services, expanding this service option to CADI, CAC, TBI and EW waiver recipients, what has been learned from these focus groups has already initiated system changes to facilitate use of CDCS.

## **Appendix**

**Appendix i.**  
**CDCS Focus Group #1**  
**2/23/02, Edina**

**What is the Value of CDCS to you?**

- Pay Staff a higher rate of Pay
- Retain Staff
- Purchase of Equipment
- Consumer Control
- Tailor Programs and Supports
- Respite/PCA/Parent Relief
- Customizing Needs
- Flexible
- Specific Equipment for specific needs
- Community Activities (swim lessons)
- Art Center Classes
- Staff/support to do community activities
- More community options
- Design specific supports around one's needs
- Social component
- Flexibility of service
- Hire family members in home rather than use out of home respite

**When the group prioritized the top 5:**

- 1Pay staff a higher rate of Pay (3)
- 2Consumer Control (2)
- 3Respite/PCA/Parent Relief (1)
- 4Hire Family members
- 4a Design specific supports around one's needs
- 4b concept of purchase of equipment

**What do you like Most?**

- Flexibility
- Control
- Available Options
- Creativity
- Diverse Choices
- Financial Support
- Hiring family members

### **Group #1 (con't)**

- Customizing the services
- Fluidity-follow throughout life
- Flexible use through developmental stages

### **When the group prioritized the top 5:**

- Flexibility (3)**
- Control (2)**
- Available Options (1)**
- Fluidity-follow throughout life
- Hiring family members
- Flexible use through developmental stages

### **What do you like Least?**

- Difficulty obtaining (approved) therapist, equipment
- Lack of accountability (MA vs. MR/RC waiver battle)
- Inconsistency between approvals for different people
- Too vague on county forms
- Hardcopy paperwork (on-line preferred)
- Amount of paperwork
- Changes in case managers
- Too complicated forms from counties
- Lack of training for consumers/families
- No coaching or support or training filling out forms
- Need more general public friendly documents from counties
- Counties understanding of issues/terminology
- County expectations from families re: terminology (may be too high)
- Passing the buck- school-MA-MR/RC waiver-county-private insurance
- Word games "they" use
- Give examples, boxes to check off on forms from the county
- Minimum needs control to have service
- Qualifications Process (in order to approve this service at the county level)-  
Dependent on subjective process
- Children who have autism



## **Group #1 (con't)**

### **Top ones (In order of priority)**

- Need more general public friendly documents from counties (3)
- County expectations from families re: terminology (2)
- Counties understanding of issues/terminology (1)
- Word games "they" use
- Too vague on forms from counties

### **How can CDCS be improved?**

- On line with e-mail capability
- 1 form for the State of Minnesota
- Supportive communication
- Information ahead of time
- Shift costs from MA to waiver so waiver could pick up the costs
- Understandable
- Clear outline of what is covered
- Simplify process
- Specific dollar amounts Outlined-Ramsey County
- Trained person other than the Fiscal Intermediary
- Needing a QMRP process for review of plans
- Clear-cut guidelines
- Minimize Differences between counties
- Parent's access to decision-making team: part of the group rather than outside
- Parent's access to federal and state guidelines
- Parent support
- Balance therapeutic vs. financial
- Empower Consumers/families
  - Understand approval criteria from family's perspective
- Who's making the decisions?
- Involve families in decision-making process
- Review Board made up of county, parent, professional like OT (Flexible board that would change due to the needs of the person)
- Review entire needs of the person
- Planning Process
- Information access
- Consistency across case managers
- Accessibility of the person
- Team be supported and represented by all
- Consumer-focused

### **Group #1 ( con't.)**

- Case manager being available 24/7
- County Communication
- Change in Case Manager (transition between old vs. new)
- Information hotline helpdesk-resource
- Web site
- Notification of any changes, email, letter, web site, newsletter, changes on web site
- County Training/Family Training

#### **Top ones:**

- Clear outline what is covered-simplify process make available on-line (3)**
- County Training/Family Training (2)**
- Instill a QMRP process that would assist with the review (1)**
- Understand approval and criteria process-from family's perspective-who is making decisions
- Information Hotline-Helpdesk Resource
- On line with email capacity

**Appendix ii.**  
**CDCS Focus Group #2**  
**3/23/02, Lakeville**

Numbers in front of a comment represent participants prioritizing each section 1 thru 3. The point value is three points for 1, two points for 2, and one point for 3.

**Value of CDCS to You:**

- Improves health/safety
- **17 Individualized**
- **12 Empowering**
- **1 Self-esteem**
- Supports client goals
- Independent
- Recognizes dignity of person
- **3 Opens opportunity**
- Self-education
- Ease of access to services
- Trust & respect
- Cost effective to "traditional service"
- **10 You have control & responsibility**
- Improves quality of life
- **1 Freedom-picking/choosing services**
- Encourages out-of-the-box thinking
- **1 Alleviate family caregiver stress**
- **2 Choice of alternatives**
- Value to family unit
- Make choice for each person
- **4 Enables family to deal with the situation**
- Not "locked in" can make changes
- Be creative i.e. OT & karate lessons
- Child can stay with family
- Peace of mind
- Solidifies relationship with case manager
- Opportunity for growth of consumer
- **3 Flexibility**
- Eliminates financial responsibility of family (i.e. reinforces out-of-pocket expensed related to disability)
- Can try new things

## Group #2 (con't)

### What Do You Like Most:

- **24 Flexibility**
- Responsibility
- **2 Empowering**
- **1 Pay more per hour/keep staff**
- **3 Budget supports keeping family together at home**
- Opportunity to provide for family
- **4 Freedom of choice**
- **6 Control**
- **4 Good quality of life for all**
- **8 Client focused**
- Build support system (opportunity)

### What Do You Like Least:

- **6 Monthly report lacks county detail**
- **6 Parental fees**
- Accounting for money
- Paper trail
- **5 Recent changes**
- Social worker attitude: Some positive, some vocative, inconsistent
- **3 More restrictive**
- Being "employer" and issues around that - legal issues
- Lack of information about services
- Lack of privacy
- Scrutiny
- **2 No benefit packages for employees**
- Give personal/ family information
- **1 Education about options**
- Lack of skill/understanding by social worker
- **3 How to do this**
- **2 Information flow** (i.e. retreat - didn't know)
- Impact of careers
- **3 Time needed to manage supports**
- Regimented scheduling
- **13 New perimeters**
- Budget Approval
- **3 Less consumer directed than original supports (self determination)**
- Beg for supports

## Group #2 (con't)

- 7 "Tightening up" (2<sup>nd</sup> line OK'd one year & "0" the next)
- "Justify to taxpayer"
- Restrictions higher for parents than "providers"

## How Can CDCS Be Improved?:

- % of budget for "whatever"
- **2 Discretionary \$\$\$'s**
- \$600.00 (Dakota) new rules
- **8 Improve "network opportunity" for parents - information/education, finding providers**
- **2 More detailed information in budget report**
- **5 Keep paperwork simple**
- Don't manipulate funds
- Facilitate "checks" for providers i.e. background checks, driver's license
- Training on funding
- **2 Develop "Association" for insurance rates &/or benefits**
- Educate "Employer of Record" for families
- CPR could be mandatory
- **1 Videos for training i.e. blood born pathogens**
- Videos for families also - waiver, etc.
- **2 Ability to pay benefits & bonuses (to staff)**
- Creativity re. budgeting (i.e. benefit when family is EOR's)
- **5 Provide service as early as possible (new families)**
- Consistent between counties as appropriate (i.e. Dakota 20% for EOR, others 25% for EOR)
- Improve transition between counties
- **2 Education**
- Statewide guidelines
- **19 Keep flexibility**
- Simplify budget process
- **1 Improve social worker contact and assistance with plan & budget**
- Improve social worker attitude
- Be supportive/empathic to families
- Stop processes that "squeeze out" providers 2X & 3X dipping (charging hourly rate for three kids)
- ID fraud & process for reporting
- **1 Fairness in parental fee**
- "Report card" for providers available for families
- **1 Make administrative resources available to families**
- **3 Reduce parental fees**
- **1 Tax breaks for families (like Montana) -one more exemption**
- Understanding cost-effectiveness re. home vs. institution

### **Group #2 (con't)**

- Better "Community" understanding
- Public information: share the successes
- Support " Life Planning"
- Improve access to "CDCS" for folks under State guardianship

**Appendix iii.**  
**CDCS Focus Group # 3**  
**3/26/02, Woodbury**

Numbers in front of a comment represent participants prioritizing each section 1 thru 3. The point value is three points for 1, two points for 2 and one point for 3. Number in ( ) represents total points received.

**VALUE OF CDCS to You**

- **1,1,1,1,1 (15) Control**
- **2,2,2,2 (8) Flexibility**
- Support of service
- Flexibility dependent on Social Worker
- Diet control-cost
- Interview and hire PCA
- Ability to determine PCA rate
- **2 (2) Choice of PCA**
- **3 (1) More things covered (diet)**
- Choose a specialist provider (ABA provider)
- **3 (1) More options**
- **3,3,3,3 (4) Individualized**
- Delayed out of home placement
- **2 (2) Allowed parent to care for own child and not have another 3<sup>rd</sup> party in home**

**What do you like MOST about CDCS?**

- Allowed to take child to out of state specialist-coordinate with other medical providers
- **1,3 (4) Ability to provide special diet**
- **2,3,1,2 (8) Flexibility**
- Choice of PCA
- Equipment (Home modifications)
- **3 (1) Purchase of computer**
- PICS (software for computer)
- Improved communication/decreased frustration
- **3 (1) Education for parents and staff (conferences and books)**
- Training for care person (staff)
- Picking specialists (music therapists)
- Able to get OT services in home (specialists)

### **Group #3 (con't)**

- **2,1,1,1 (11) Ability to pay for quality care—rather have less and have higher quality**
- **2,1 (5) Ability to have trade-off's**
- **2 (2) Allowed family to get membership to the Y for child/family-improve social development with other peers; education/classes for teen groups**
- **Swimming lessons**
- **Massage Therapy for both consumer and parents**
- **2,3 (3) Housekeeping Services allows time with child**
- **3 (1) Alternative therapies (chiropractor, naturopathic)**

### **What do you like LEAST?**

- **1 (3) Inability of foster parents to have a say in the budget**
- **2 (2) Foster Parents treated differently**
- **2 (2) Limited Choice of Providers in the county (FI and EOR)**
- **1 (3) No information provided by county regarding waiver services or No information provided by county regarding Medicaid Services**
- **Confused as to the funding source**
- **Rumors about things changing**
- **3,2,2 (5) Dependency on case manager and county can be variable**
- **Implementation of program-insufficient training and understanding of budget**
- **3,3 (2) Education and training was not enough**
- **Inconsistency**
- **Social Workers don't know the answers; they are learning the program**
- **3,3,1 (5) Rules have changed since July; more restrictions**
- **Required Background checks on limited use staff**
- **1099 misc. (Orion –Washington County)**
- **Requirement to provide curriculum prior to including in budget**
- **1 (3) To purchase materials/toys need to provide excessive documentation**
- **1, 2, 1, 1 (11) Communication difficulties between FI and SW and family**
- **Reports from the FI/EOR are not detailed enough. Only lists lump sum amount. Need breakdown.**
- **2, 2 (4) Communication regarding case manager; poor communication with social worker; lack of availability of social worker**
- **2 (2) Switching of Social Workers with little (late) notice**



### Group #3 (con't)

#### How can CDCS be Improved?

- Continue focus groups at county and state level
- Facilitate networking
- **2,1,1, 1 (11) Remove caps that were applied mid-stream (regarding salaries and expenses)**
- **2 (2) Reinstate 1099 misc. for short term/limited \$\$ staff**
- **3 (1) Increase flexibility of hiring and salary**
- Increase Trust and expertise of parents
- **3,3 (2) Provide procedure manual (provide e-manual)**
- Provide classes on services (mandatory for families and SW's)
- **3,3,2,3 (5) Specialist on Autism available at county**
- Specialty training provided to SW
- **1 (3) Foster parents should be treated equally to biological parents.**
- **2 (2) Remove tax on foster parent income (payroll taxes)**
- **2,3 (3) Permit reallocation of funds in budget with minimal paperwork**
- Rules need to stay in place (from term of budget) from budget to budget
- Remove need for employment packages
- Educate FI
- **2 (2) Consistency of percentage (of budget) charged by FI. Need for Scale (Truth and lending process)**
- Consider contracted SW's. Better advocates
- Less Micro Management by FI
- Ability to budget at a summary level and spend at a detail level
- Eliminate county approval at summary level
- Ability to act as own FI
- **1,1,1, 2 (10) Ability/Flexibility of checkbook**
- More choice of FI
- Reduce Paperwork
- More consistency from county to county

**Appendix iv.**  
**Group #4**  
**4/6/02, White Bear Lake**

Numbers in front of a comment represent participants prioritizing each section 1 thru 3. The point value is three points for 1, two points for 2 and one point for 3. Number in ( ) represents total points received.

**Value of Consumer Directed Community Supports (or CDCS):**

- Eased pain
- Decrease waste.... ability to monitor funds
- **3 (1) Ability to keep child at home**
- **Quality time with child**
- **3,3 (2) Increase mental health of family as secure that the child is safe**
- Increase community integration
- Increase social contacts/opportunities
- Ability to plan for future quality of life
- Ability to pay relatives
- **2,3,1,2 (8) Flexibility**
- **1,1 (3) Ability to direct (care)**
- **2 (2) Meets unique needs of person**
- Ability to adapt (to changes)
- **3,2 (3) Parents make choices**
- **2 (2) Parent training/parent support**
- Resources for parents/respite
- Family support - allows time with other children
- Allow PCA to travel with family
- **1 (3) Logical (parents in charge)**
- One-to-one support for child, freeing up parents
- **2 (2) Opened up resources**
- **3 (1) community integration**
- **3 (1) Increase participation**
- Adaptive equipment
- Adaptive activities (i.e. horseback riding)
- Increase time to spend with individual
- **3,2,1 (6) Better use of resources (money & time)**
- More basics for the dollar
- **1 (3) Ability to bring clinical services into home**
- **3 (1) Ability to set wages - reward staff**
- Increase ability to keep staff & increase bonding with staff
- Provides opportunity to learn skills in natural setting
- Expands horizons for family & child
- Ability to bring clinical services into home
- Ability to set wages - reward staff

#### **Group #4 (con't)**

- Increase ability to keep staff & increase bonding with staff
- Provides opportunity to learn skills in natural setting
- Expands horizons for family & child

#### **What do you Like Most about CDCS?**

- That you are there
- Ability to pay daughter
- More positive feelings towards child due to spending more time and removed stress
- **1,3,2,1 (11) Individualized to meet needs of son & family**
- Not having to follow rules of PCA's
- **2,3 (3) Provides family supports (i.e. family membership)**
- **2,1,2,3,1,1,1 (17) Ability to control use of \$\$\$.**
- **1 (3) Realistic amount of money (generous)**
- Well rounded son - enriched
- **3,2,3,3,2,2 (9) Being able to give son what is best for his family members as caregivers/security**
- **3,2 (3) waiver (amount) set on individual needs 3,2**
- PCA is there to help with the family as a whole
- CDCS will encourage others to support kids (through adoption)
- **2 (2) Have control over it**
- Brought son out of his shell - "can do"
- **1,1 (6) Choose our own PCA**
- Our home is the best place for our son (20 years old) 1
- **3,3,2 (4) Better community integration**
- Continuity in staff (due to higher wages)

#### **Like Least?**

- **2 (2) Sometimes social worker needs to "create a miracle" (was not in plan)**
- Unexpected expense (difficult to adjust plan)
- Bureaucrat deciding on definition of parent responsibility
- **2 (2) Parents not involved in task forces**
- Inconsistency in ordering chair with restraints
- Paying for bowling - cannot pay for son's bowling
- Formal providers can pay for things that CDCS cannot
- **3 (1) Paperwork - reconciling expenses**
- **3,1,1 (7) Have to be "in the know" (yourself or case manager)**

#### Group #4 con't

- (Service) Not as accessible to Hispanics
- **2,1 (4) The money (needs have changed but the (waiver) \$\$\$ have not)**
- Accountability - has to have accountability
- **2,2 (4) Need to find out about more options (sharing information)**
- Recreation funds- defining parental responsibility
- Lowered amount
- **2,1,3,1,1 (12) Limits on recreation funds**
- Lack of flexibility
- **1,3 (4) Utter confusion when getting started (dealing with bureaucracy)**
- Get comfortable with before changing
- **2,1 (4) "Caps" (\$ limits) approved swing sets would not work**
- **2 (2) Incorrect information**
- **1,3,2,3 (7) Suppose to be consumer directed but instead have limits (county directed)**
- **3 (1) Not as flexible (recreation)**
- Unavailability of information
- **3,2 (3) Arbitrary decisions: varies from social worker to social worker**
- Lack of flexibility

#### How Can CDCS be improved?

- Allow parents (trusting parents) to make determinations on how monies should be used and to know what is best for their child
- County should trust own assessment
- Allow parents to make choices with budget
- Ability to include costs of advertisements for staff in plan (for costs that are over and above normal costs)
- "Line item" for discretionary funds
- Ability to carry over unused funds to next year
- More flexibility for low income families to obtain items/services that are considered parental responsibilities
- More SW (social work) available to assist in writing plan
- SW should share resources of individuals able to assist in writing plan
- Ability to reimburse parents to assist other parents with writing plan
- Ability for families to utilize "list serve" for current information
- Networking with other families
- Getting more information (difficult to get information) knowing where to find information
- Need to look at CDCS service more outcome based or at least community directed

#### **Group #4 (con't)**

- More family input
- Review federal guidelines
- More checks and balances to minimize abuse
- Inform parents that there is assistance in writing service plan. County SW should inform all "first timers"
- Provide families with information on how to write plan and/or who can be hired to assist in writing plan
- Eliminate arbitrary decision making by social worker
- Ensure that program remains individualized
- Ability to amend plan during year (have funds in place for emergency)

**Appendix v.  
CDCS Focus Group #5  
4/13/02, Rochester**

Numbers in front of a comment represent participants prioritizing each section 1 thru 3. The point value is three points for 1, two points for 2 and one point for 3. Number in ( ) represents total points received.

**What is the Value of CDCS?**

- Runs smoothly when in place
- Fits lifestyle throughout year- School & Non-school
- **1 (3) Potential of excellent programs (social opportunities)**
- **3 (1) Parents can influence services**
- Transportation
- Live in own home versus institution
- Allows to be an advocate
- Flexibility of services
- Creativity of staff training
- **2 (2) ARC Information Newsletter**

**What do you Like Most about CDCS?**

- **1 (3) Cost for "daycare" covered**
- Access to services, long-term and in different setting: Waiver follows (consumer) throughout life
- **2 (3) Services adapt to changing needs**

**What do you Like Least about CDCS?**

- **2 (2) Difficult Paperwork etc., overwhelming**
- Difficult getting started
- Initial access to information difficult
- Work program- transportation
- How to access CDCS is difficult
- Not consistent in staffing (don't show/late)
- **1 (3) Implementation of program (obtaining actual services)**
- **1,2 (4) Staff turnover (salary related)**
- **3,3 (2) Volume of Material too much**

## Group #5 (con't)

### How can CDCS be improved?

- **1 (3) Breakdown information provided to families (too overwhelming)**
- Contact after initial intro
- Outreach regarding CDCS
- Educating Daycare providers about CDCS
- **2 (2) Training of New Staff-Communication**
- More follow-through from county social services to meet needs
- Good program that gives more opportunity (need person-centered planning)
- **More Contact with Case Manager: e-mail or phone call – Quarterly**
- Structured training
- **3 (1) Bullet statement training**
- On-line training

**Appendix vi.**  
**CDCS Focus Group #6**  
**4/20/02, Maple Grove**

Numbers in front of a comment represent participants prioritizing each section 1 thru 3. The point value is three points for 1, two points for 2 and one point for 3. Number in ( ) represents total points received.

**WHAT IS OF VALUE of CDCS TO YOU?**

- Funding for therapy (for autism)
- **2 (2) Ability to choose**
- Ability to choose (beyond what insurance company will fund). Similar to above
- **1 (3) Ability to fund otherwise non-fundable treatments**
- **1,2 (5) Community Integration/activities – i.e., ball games. Funding for activities**
- **1,2 (5) Flexibility**
- **2,2 (4) Have family choose and direct, community integration with persons other than family**
- Therapy options – fund non-fundable treatments that they (family) could not afford
- **3 (1) Staff**

**What do you like LEAST about CDCS?**

- **1,2,3 (6) Paperwork – lots of it**
- Little support to help with paperwork– first time lots of support (and used short form), this year no supports and asked to do long form. Could hire help but then it comes out of child's services. County does offer classes but feels they are not individualized to help their plan/child.
- Paperwork too detailed – needing to predict the outcome of goals before they even get into it. This person is a teacher and finds goal setting overwhelming. How can non-experienced accomplish this?
- **1 (3) Need approvals for amounts over \$100 and then waiting for the approval**
- County using limits or categories to fit in a box... "look for cover" to fit into existing boxes. Using old pigeonholes. Example - trying to buy Rainbow play set.
- Arbitrary Limits
- Eligibility criteria has changed from allowing independence and inclusion to doing what other counties do and assure its defensible. "Customary" treatment – what does "customary" mean for autism?



## Group #6 (con't)

- Seems they are applying MR/RC waiver rules to CDCS
- Seems to be lack of administrative structure – looking for standard turn around time...when can they expect to hear back from county?
- **1,1 (6) Feel as though they have limited understanding of services/CDCS available**
- **3 (1) Difficulty projecting (costs/needs) for the year, especially for the 1<sup>st</sup> year.**
- Difficulty in finding staff issue with turnover).
- CCM slow in responding back
- Paperwork!
- Fear that things covered now won't be covered next year (i.e. dietary supplements, vitamins, Kelation). How should the wording be in the plan? If food cost more than \$7/day can then be covered?
- Difference between County Case Managers. Some responsive others not so. Hold all CCM approvals to same standard. Different levels of support
- **1 (3) Not everything can fit into categories. Would like to develop program specific to child's needs. i.e. Dr says she needs certain amino acids and then allow through CDCS**
- Feels like a medical model.
- Fence not (costing) more than \$9,000
- Feels like micro-managing be county...caps
- **2 (2) Feels that County CM's are not straightforward... feels like they have to jump through hoops to justify and county does not TRUST them (families) to spend appropriately.**
- Need to maintain and repair equipment due to destruction by child vs acquisition. No mechanism to repair/maintain.
- How do they set waiver \$ amounts – seems arbitrary
- No ability to pay family members
- Why do we need fiscal intermediary? Why can't we pay directly?
- Feels like use it or lose it with budgets. If not spend then won't get for next year.
- Feels like you go around and around to secure an item

## WHAT do you like most about CDCS?

- My Social worker
- My provider – FI is helpful
- **2,3 (3) Informality of hiring staff**
- **2,2 (4) Ability to establish wages – good use of money because no administrative overhead costs**

## **Group #6 (con't)**

- Stability of keeping staff... feels is due to ability to pay more
- Ability to choose – found someone that personally knew her consumer 2
- **1 (3) Grateful CDCS is available. Has help entire family. Help for after school, hard to be with both kids at one time (able and disabled).**
- Reduced stress
- **3,2,3 (5) Respite. Provides emotional security. Saved marriage**
- Non-medical model. Allows for non-medical item to satisfy a need.
- **2,3 (3) Chore services... son not toilet trained have carpets cleaned e/o month... health safety need.**
- **1,1,2 (8) Has kept family together. Blamed husband for not helping enough and now has paid support and takes stress off family. Saved marriage**
- Keeps child out of institutional setting. Would have to consider if not for support provided
- **1,1,2 (8) Improves son's quality of life. Son can do more things**
- **2 (2) Allows for grandparent's/parent's free time... respite**

## **How can CDCS be improved?**

- If aligning with other counties – align with the top limit
- Would like more flexibility to make adjustments throughout the year
- Would like to pay family members
- **2,3 (3) Greater ability on how \$\$\$ are spent within (waiver) allotment**  
**Ability to fit services/spending under one umbrella. Not line by line**
- Pay the difference of the usual and customary and the special need  
(difference between a K-mart swing set and a Rainbow swing set)
- **3 (1) Better education to community by County /State (regarding CDCS**  
**i.e. - Support person has to also pay if accompanying a consumer to a**  
**community center)**
- **1,1,2 (7) Trust that family/consumer has best interest of person.**  
**Concept that parents do no harm**
- **2,2 (4) Trust**
- Flexibility throughout year
- **3,3 (2) Structure/change plan for amending the year**
- Pay family members
- Set up networking system/information system
- Make things clear (i.e. expected timelines)
- **1,1 (6) Have things covered that are not medically proven. Come up**  
**with mechanism that defines that x is warranted to benefit the**  
**consumer. Accept recommendation by OT, etc. Experimental**  
**therapies.**

### **Group #6 (con't)**

- Wants CDCS to be safety net when 3<sup>rd</sup> party insurance and MA will not pay
- MA to be more accessible and consumer friendly – is on a “team” and they will get back to her within 48 hours. Can not talk directly to worker
- **2 (2) Improve (simplify) paperwork. Go back to short form**
- Put forms on – line
- Be able to bill directly as employer of record without FI. As employer of record, no one has asked for documentation (audit) – has boxes of stuff
- **2 (2) Feels public school would not meet needs and would like tuition for private school be covered.**
- **3 (1) Pay for some educational services not covered through school**
- **2 (2) Start with probation (3 years) and then if all is spent appropriately then back off on necessary approvals/requirements... have trust (in families)**

**Appendix vii.**  
**CDCS Focus Group**  
**4/27/02, Brainerd**

Numbers in front of a comment represent participants prioritizing each section 1 thru 3. The point value is three points for 1, two points for 2 and one point for 3. Number in ( ) represents total points

**What is the Value of CDCS to you?**

- **1 (3) Allowed us to hire therapists**
- Helps us to be in control of the day's schedule and what the kids do
- Knowing ahead what is funded (Don't have to wonder if something can be funded or if the kids can do it– it's spelled out ahead of time)
- I like knowing how much money is available and that I can use it for other options
- **1,1,1,2,2 (13) Able to be flexible with staff schedule (When I can find someone to work with my son, I can be more flexible. If I see something in the Sunday paper, I can schedule it. I don't have to plan the schedule a month ahead of time)**
- **1,1,2,3 (9) I like being able to hire who I want.**
- **3 (1) Check book allows flexibility to work with staff (Like being able to advance money to workers when they need it. Helps me to retain workers)**
- **2 (2) Expect that I will like the expanded choices**
- **3,3, (2) Flexibility**
- Availability of respite care (Started foster care 44 years ago and did respite care for others. Didn't know what it would mean to them until recently. Now have respite care one weekend a month. Get to spend time with each other).
- **3 (1) Budget flexibility – able to move money to a different area of the budget**
- Has made me a better consumer and better able to use the dollars available to her son. By doing the checkbook system, I'm taking on some of the work, but it makes the money go farther – more bang for the buck
- Provides money to do things (Before when we did things with the kids, it came out of our pocket. Now with it coming out of government funds, we can use money for other things)
- Many options available to do things (Expanded ability of kids to do things. Look at newspaper, listen to radio, decide we can take them to that)
- Provides income for therapists (Staff make more money because they are helping our kids)

## **Group #7 (con't)**

### **What do you like most about CDCS?**

- **3,2 (3) I like the fact that it exists**
- **I like that the government is willing to spend money on keeping people out of institutions**
- **2,2 (4) There are a variety of things (services/supports) available that make for a balanced lifestyle**
- **1,1,1,3 (10) Recognizes the importance of individual decisions**
- **3,2 (3) Flexibility of activity scheduling (our oldest might change his mind the day he's supposed to go swimming – we can do it another day)**
- **3,1 (4) Frees family funds to enhance our family lifestyle**

### **What do you like the least?**

- **That the program is needed (I utilize the program because I have to. If the government wasn't fleecing me all the time (taxation, government interference, regulations), I wouldn't have to use it because I'd have more disposable income. Other than that I don't have any dislikes. The program is fantastic.**
- **The ability of the Fiscal Intermediary to bill for services that a parent can't.**
- **"Rules" are not published (Got a 5-page set of guidelines, but wants information on what will be approved and what won't be).**
- **Differences between counties (We have dealt with two different counties and they are as different as day and night. Counties have different requirements. One requires a fiscal intermediary, the other doesn't. We get a lot of services from one county and almost nothing from another. The difference is vast.) 3**
- **1,3,3 (5) Don't have any guidelines for planning the budget.**
- **3 (1) Hard to find providers for respite care. (Case manager wasn't able to help.)**
- **3 (1) Changes in rules (When we entered the program, we were told the rules weren't set in stone. When I put in the budget for the first two months, everything was approved. When I put in the budget for the next fiscal year, some of the same items that were approved before were not approved this time. Rules seem to have changed or weren't communicated initially. Was told that some expenses, like long distance calls to aides and postage, couldn't be covered.)**
- **Lack of understanding of federal/state/county requirements (People who are implementing the program at the county level don't seem to know what is allowed and what is not allowed.)**
- **2,2 (4) That parents can't benefit directly (parental responsibilities)**

## Group #7 (con't)

- **That waiver funds can't be used for non-traditional/experimental treatments.** (Every disabled person has a right to medical treatment. The waiver or medical assistance should pay for treatments that are being developed and have a scientific basis and aren't harmful even if they aren't in medical journals (e.g., experimental treatments). Medical community discourages non-traditional treatments.
- **Inability to get nutritional supplements paid through CDCS**
- **Want CDCS to pay for what MA will not (If not harmful to consumer)** (doesn't like it that CDCS can't be used to pay for lab work that MA won't pay for)
- **That CDCS can't be used to pay for special diets.**
- **2 (2) People who are administering program aren't properly trained** in the do's and don'ts. (Specifically asked "can I do this?" and was told yes, but when he planned to do it, was told he couldn't do it)
- Requirement to use certain people, who take a % of the budget, whose function is unclear and/or unnecessary (Told at the beginning they'd need a fiscal intermediary (takes a chunk out of the budget). Just a few weeks ago, were told they needed someone else involved besides the FI. Why do we need him? (Didn't know what his title was, what his function was, or why he is needed.) We could do the checkbook ourselves and follow the rules and be honorable. Why punish those who don't abuse the system?)
- Doesn't like it that there are differences between the rules for minors and adults.
- The rules are not the same from one family to another even within the same county for people of similar age and diagnosis
- **2 (2) Lack of family privacy.** (Because I have children with disabilities, my family's privacy seems to be the government's interest. The county wants to be able to interview my staff and I don't want them to talk to them.)
- Social Workers asks questions for the purpose of entrapment. (Social workers should not be allowed to ask pointed questions of an investigative nature.)
- The right of the family to know of any reports that are made against them are being denied (We should have access to any reports that are made against us by a neighbor or anyone else. We should have the right to respond to any reports within a week. They should bring charges against the family within a week.)
- Inability to pay staff out of own pocket to pay for babysitting for ALL children in the family (We should be able to pay our staff additionally out of our pockets to baby-sit our normal children at the same time they are taking care of our children with autism. Wants to safeguard privacy in our home by minimizing number of staff.)
- Program has taken away our freedom to get out of the house.
- Rules are more important than the spirit of the program.

## Group #7 (con't)

- Social workers are not supportive of families to get the services they need. How staff works with the child and what they do with the child should be up to the parents.
- Inability to use CDCS funds to pay for home schooling.
- Language you use when you request something can determine if it is approved or denied.
- That CDCS can't be used to pay for services for parent of child. (Has been told she can't spend money on some things because it would benefit the parent e.g. housekeeping services)
- Inability to pay parents of minor for services, at least when staff aren't available. Still experiences a lack of staff on certain days (Mother's Day, Christmas, etc.)
- Inability to pay for housekeeping services
- Lack of appreciation of how much work parents actually do.
- Inability to pay for support for parents to decreases stress in life.

## How can CDCS be Improved?

- Ensure a good match between family and social worker
- Ability to select SW (ability to fire a social worker and find a new one)
- Make Social Worker's accountable
- Families should be informed of their ability to choose a new social worker and who their social worker's supervisor is
- **1 (3) Ability to have a petty cash fund for activity expenses (for minor child)**
- **1,1,2 (7) Detailed list of what can be paid for, provided to families**
- Be provided with a regular update from FI of all expenditures (with a regular accounting statement of what has been spent and what remains in the budget)
- **3,3, (2) Be provided with federal and state rules of what we can and can't do**
- **2 (2) Discard the differences between what CDCS can be used for with adults versus children**
- Ensure county administrators are trained
- **1 (3) Doesn't want to have to present a conference brochure to the county for approval before getting authorization to go when there's already an approved line item on the budget.**
- **1,1,2 (8) Parents should be treated as professionals and respected as being the best person to decide what is best for the child**
- Have "up-front" funds available (Doesn't want to have to pay for things and then be reimbursed; wants to have a petty cash fund to use)

# **Consumer Directed Community Supports Focus Groups Summary of Findings**

**June 2002**



**Minnesota Department of Human Services  
Disability Services Division**

**444 Lafayette Road  
St. Paul, MN 55155-3857**



## Group #7 (con't)

- **2 (2) Use of checkbook or FI should be parent's choice, not the county's choice.**
- More checks and balances – explanation of what the waiver paid to the county for child's services. Wants to make sure counties aren't committing fraud by transferring money they got from the state for her child's services to the county budget. Wants protection for parents who report fraud by a county agency. Wants to be able to go to another county of her choice for service administration if she doesn't like what her county is doing.
- Uniform rules from one county to another
- **1,2,3 (6) More communication regarding rule changes (example was federal reimbursement rate for mileage) and ability to correct retroactively**
- County needs to have equitable mileage reimbursement rates across programs
- **3,3,3,1 (6) Parents of minors should be paid for providing services (emergency situations, when there are no other staff available)**
- Ability to pay parents when parents do the work of professionals (e.g., case management services, FI/EOR services) they should be paid.)
- Parents should show appreciation to those who are serving them. Parents should write a note of encouragement to those who are trying to service them even if things are not perfect we are head and shoulders above where we used to be.
- Require counties to hold open meetings for parents so that parents can find out what is happening with other families
- CDCS is a RIGHT of individuals with disabilities

## **Attachments**

## **Attachment 1**

### **Sample: Letter of Confirmation**

**Re: Focus Group**

Dear

Thank you for your interest in evaluating the Consumer Directed Community Supports (CDCS) service for persons who are on the Mental Retardation/Related Conditions (MR/RC) waiver. Your thoughts and concerns in examining and assessing this program for people with disabilities will let administrators know if the CDCS service is meeting the needs of participants. Your input will also tell us if changes and improvements are needed. As was mentioned on the phone, we will be sending you information that is learned from the focus groups after they have been completed this summer.

Here is the key information you need for the focus group:

**WHEN:**

**WHERE:**

(Map enclosed)

**TIME:**

Prior to our meeting, please take a moment to think of the entire process as you, or the person you support, receive the Consumer Directed Community Support Option.

1. How do you value about CDCS?
2. What do you like most? What do you value least?
3. What would you recommend for improvements?

Light refreshments will be served. If you have any concerns or need any special accommodations, please call me at 651-634-5484. We look forward to seeing you at the focus group.

Thank You,

Peg Booth  
Community Supports for Minnesotans with Disabilities Consumer Directed Specialist

## Attachment 2

### Letter to Counties

February 25, 2002

Dear County Supervisors:

The Consumer Directed Community Supports (CDCS) unit of DHS wants to inform you and, at the same time, ask for your support for an upcoming series of meetings sponsored by the Department. To be exact, we are in the final stages of coordinating *Consumer Focus Groups*. While DHS is independently coordinating the focus groups we may look to you in the future to obtain recommendations for meeting places and information specific to your community. We are excited about the task at hand and are looking forward to connecting with consumers and their legal representatives.

The focus groups came about as a result of the Department's continuing need to evaluate existing service options. We are also interested in gathering feedback and input from CDCS system users so that issues can be addressed and improvements made. As a Department it is important for us to acknowledge what is working and at the same time, continue to attack the barriers.

To date, we have made contact with a sampling of individuals currently designing their own services through CDCS. There will be a number of meetings throughout the state with a target number of 12 to 15 participants per session. An outside facilitator will lead each session. We anticipate completing all sessions by June 2002. Our primary objective is as indicated above, to find out what is working and identify barriers that need continued attention.

In order to assure confidentiality, specific information regarding participants will not be shared. However, upon the completion of all focus groups, summaries will be sent to participants and counties. We understand that you may or may not have folks participating in the focus groups. However, we felt it important to assure that you were informed in case you hear of the meetings or receive feedback from folks within your county.

Again, we ask for your support in making these focus groups successful. And, in our on-going efforts to address services and quality, we continue to welcome your input and opinions. Look for summary information by summer.

Sincerely,

Merri Miller  
CDCS Staff  
651-582-1974

**Attachment 3**  
**SAMPLE: Focus Group Agenda**



**Agenda**

9:30 am **Welcome and Opening** - MN Department of Human Services,  
Community Supports for Minnesotans with Disabilities Division

**Administrative Items** - Facilitator

**Introductions of all members of the group**

**What is the value of the Consumer Directed Community Supports to you?**

**BREAK**

**What do you like most about this service? What do you like least?**

**BREAK**

**How can Consumer Directed Community Support Services be improved?**

12:15 pm **Summary of the Day**, Facilitator

12:30 pm **Closing Remarks**, MN Department of Human Services

**Attachment 4**  
**CDCS Focus Group Evaluation**

Date: \_\_\_\_\_ Name (optional): \_\_\_\_\_

Using a rating scale of 1 to 3, please rate how well the focus group addressed the established outcomes Including:	Very Much 3	Somewhat 2	Not at All 1
The value of CDCS			
What you like most/least about this service			
How this service can be improved			

In regards to what happens with the information gathered today  
 I am:

\_\_\_ Clear \_\_\_ Unclear \_\_\_ So, So

What I felt worked best today was: \_\_\_\_\_

\_\_\_\_\_

Here's an idea of how to improve the day: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

My overall reaction to today, in one word is: \_\_\_\_\_

Other comments regarding: facilitator, facility, time of day, size of group, etc.:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Attachment 5

### Helpful DHS web links:



- a. DHS Bulletins:  
<http://www.dhs.state.mn.us/infocenter/docs.htm>
- b. County and Regions:  
<http://www.dhs.state.mn.us/infocenter/regional.htm>
- c. Forms and applications: <http://www.eforms.state.mn.us>
- d. MHCP Provider Manual:  
<http://www.dhs.mn.us/infocenter/docs.htm>
- e. Statutes and rules: <http://www.revisor.leg.state.mn.us>
- f. Link to MA services:  
<http://dhs.state.mn.us/hlthcare/asstprog/mmmap.htm>
- g. State Phone Book:  
<http://www.mail.state.mn.us/phonebook.html>

## Attachment 6 - Useful disability related web links:

ORGANIZATION/ TOPICS	WEBSITE ADDRESS	DESCRIPTION
ARC	<a href="http://www.thearc.org">http://www.thearc.org</a>	
Assistive Technology	(1) <a href="http://www.admin.state.mn.us/assistivetec hnology">Http://www.admin.state.mn.us/assistivetec hnology</a> (2) <a href="http://www.able.com">http://www.able.com</a>	(1) The Start Program (2) Assistive technology data base
Association of CILs	<a href="http://www.Macil.org">http://www.Macil.org</a>	Minnesota association for independent living
Association of Residential Resources in Mn (ARRM)	<a href="http://arrm.org">http://arrm.org</a>	
Department of Children and Family Learning Link	<a href="http://www.educ.state.mn.us">http://www.educ.state.mn.us</a>	
Disability Rights	<a href="http://www.ncd.gov/newsroom/publications/disabilityrights.html">http://www.ncd.gov/newsroom/publications/disabilityrights.html</a>	Disability Rights Laws including summaries and contact information
Government (federal) disability website	<a href="http://www.disability.gov">http://www.disability.gov</a>	Has links to many topics
HCBS Resource Network	<a href="http://hcbs.org">http://hcbs.org</a>	
Health Care Financing Administration (federal)	<a href="http://www.hcfa.gov">http://www.hcfa.gov</a>	Links to topics such as waiver services
Job Accommodation Network	<a href="http://www.jan.wvu.edu/">http://www.jan.wvu.edu/</a>	Information about job accommodations for people with disabilities
Minnesota Department of Health Link	<a href="http://www.health.state.mn.us">http://www.health.state.mn.us</a>	
Minnesota Department of Natural Resources	<a href="http://www.dnr.state.mn.us">http://www.dnr.state.mn.us</a>	Link on blue wheelchair emblem for accessibility info in parks, etc.
Minnesota System of Interagency Coordination	<a href="http://www.mnsic.org">http://www.mnsic.org</a>	Information on MnSIC
Institute on Community Integration	<a href="http://www.qualitymall.org">http://www.qualitymall.org</a>	Show casing promising practices and innovations
Office of the Ombudsman for Mental Health and Mental Retardation	<a href="http://www.ombudmhmr.state.mn.us">http://www.ombudmhmr.state.mn.us</a>	
Olmstead Supreme Court Decision	(1) <a href="http://hcfa.gov/medicaid/olmstead/olmshome.htm">Http://hcfa.gov/medicaid/olmstead/olmshome.htm</a> (2) <a href="http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm">http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm</a>	Information on the Olmstead decision
Person Centered Planning	(1) <a href="http://www.ici2umn.edu/pcplanning/info/whatis.htm">http://www.ici2umn.edu/pcplanning/info/whatis.htm</a> (2) <a href="http://soeweb.syr.edu/thechp/everyday.pdf">http://soeweb.syr.edu/thechp/everyday.pdf</a>	(1) Person centered planning information (2) The contributions of person centered planning by: John O'Brien and Herb Lovett
Self-determination	(1) <a href="http://www.self-determination.org">Http://www.self-determination.org</a> (2) <a href="http://www.state.nh.us/sdp">http://www.state.nh.us/sdp</a> (3) <a href="http://www.sabeusa.org">http://www.sabeusa.org</a> (4) <a href="http://www.libertynet.org/speaking">http://www.libertynet.org/speaking</a> (speaking for ourselves)	(1) The National Office on Self-determination (2) New Hampshire Self-determination Project (3) Self advocated becoming empowered



## **Attachment 7**

### **Sample: Thank-you letter**

Dear \_\_\_\_\_,

On behalf of the Department of Human Services, Community Supports for Minnesotans with Disabilities Division, I would like to thank you for coming on \_\_\_\_\_ We appreciated hearing what you had to say. The information that was shared was very valuable.

As was mentioned at the meeting, you will be receiving a summary of all of the statewide focus groups this summer. If you have any questions, please feel free to call me at 651-634-5484 or my email address is [Peg.Booth@state.mn.us](mailto:Peg.Booth@state.mn.us).

Sincerely,

Peg Booth

Community Supports for Minnesotans with Disabilities, Consumer Directed Specialist