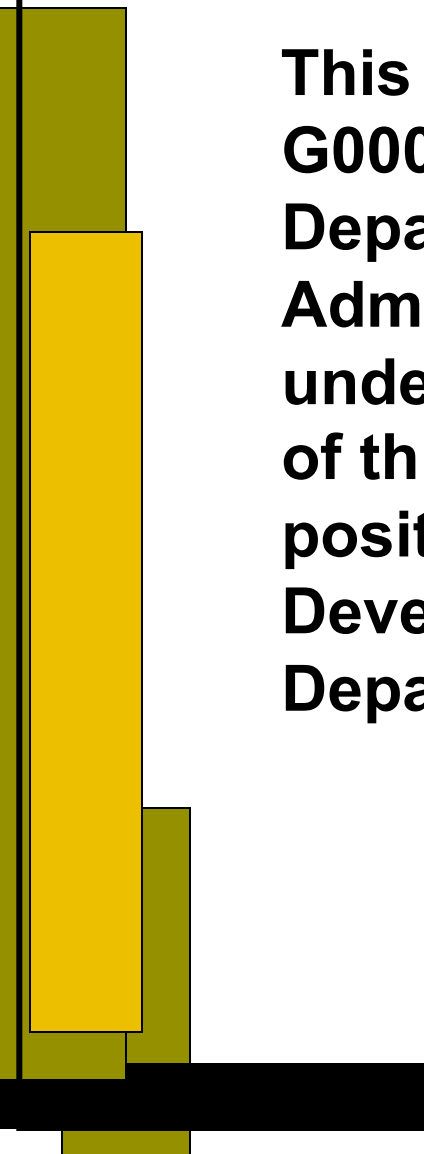


Consumer Directed Community Supports Survey

Minnesota Governor's Council on
Developmental Disabilities

May 2002





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II. Executive Summary

II. Executive Summary

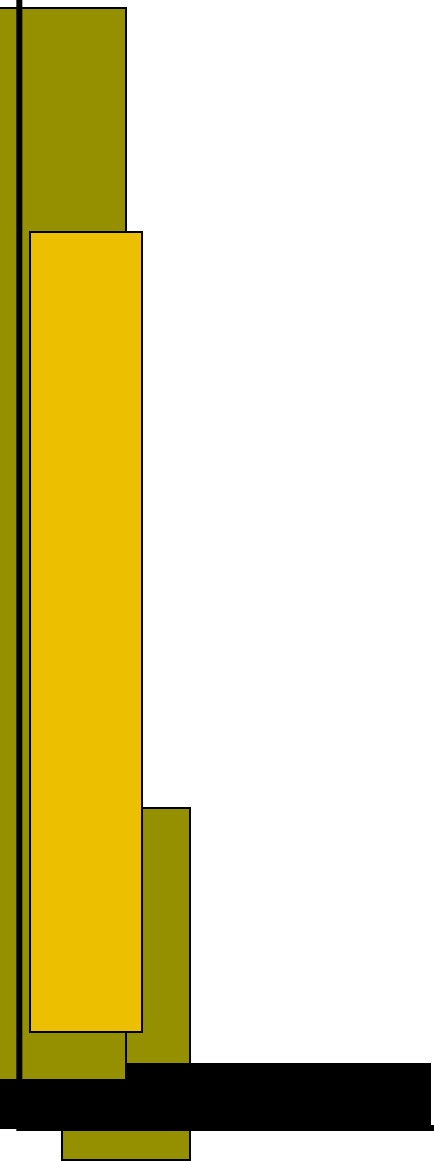
The Consumer Directed Community Supports (CDCS) program has been very successful and highly appreciated by its participants -- 83% are more than somewhat satisfied with the overall program. Participants' satisfaction is driven mostly by their relationship with their county social services department, as well as their belief that the program is flexible, allocates money better within the system, and decreases their overall stress level.

CDCS is clearly the best option that has come along for individuals with developmental disabilities who have access to a support network of family and friends needed to successfully participate. The program should continue to expand to the rest of the counties in the state, as well as to groups not currently participating in the program.

This does not mean, however, that the program cannot be improved. There are dramatic differences in participant satisfaction and in the ways that the program has been implemented across the counties. Counties have identified inconsistencies in their approaches, but have responded to this issue mainly by increasing the guidelines and limiting the flexibility of the program. The counties need to establish a model that provides consistency but maintains the individual's self direction opportunities.

Keys to maintaining CDCS as a successful program are adopting the Dakota County program model and philosophy as much as possible, eliminating the use of terms such as "defensible to the taxpayer" and "normal parental responsibility" as decision making criteria, and keeping the program simple and understandable for participants of all abilities, cultures, and languages.

III. Project Overview



III. Project Overview

- Survey Process -

In April, 2002, 2,444 survey questionnaires were mailed to individuals participating in the Consumer Directed Community Supports (CDCS) program offered by the Minnesota Department of Human Services (DHS). Addresses were provided by the DHS, and questionnaires were addressed to the individual participants -- at the addresses to which DHS-related, CDCS financial documents are sent for them.

Program participants were informed that the survey was confidential. There was no method employed to track an individual response to a particular individual.

650 surveys were returned for an overall response rate of 27%. 53 surveys were returned for an incorrect address or addressee not known.

The survey was developed based on interviews with stakeholders in the CDCS program: county social services managers, county case managers / social workers, fiscal intermediaries, and individuals with a developmental disability and their families. Additionally, comments and quotes in this reports are supplemented by information gathered in these personal interviews.

IV. Respondent Profile

IV. Respondent Profile

- Summary -

- **Ethnically diverse sample**: the survey has a high, and ethnically diverse response -- making it valid to project the results to the entire population of CDCS program participants.
- **Changing set of needs**: the demographics show that the newest people on CDCS are more likely to have autism and more likely to have higher household incomes than people who have been on the program for more than two years, which may indicate a changing set of participant needs. CDCS must be capable of adapting as the base of consumers it serves changes -- especially as CDCS rolls out to more rural communities with different needs than the metro area communities.
- **Ethnic differences between counties**: there are significant differences in ethnic populations between the counties. Hennepin and Ramsey counties' high ethnic populations and numbers of individuals with English as a second language, increases the importance for flexibility in budgetary decision-making, as well as the need for simple, clear guidelines that can be easily explained and/or translated.
- **Inconsistent budgets / fee structures**: According to respondents, budget and fee structures vary dramatically from one county to the next. As much as possible, confusion and/or differences in these structures should be minimized to support consistency of services from one county to another.

IV. Respondent Profile

- Age -

Overall

What is the age of the person with a developmental disability? *n* = 640 _____
%

Under 10 yrs.	29
10-14 yrs.	19
15-18 yrs	11
19-24 yrs	17
25-34 yrs	13
35-44 yrs.	6
45+ yrs.	5
Mean age	18
Median age	15

60.1% of respondents are families with children 18 or under

The Consumer Directed Support Program has strong participation from families with children. This is slightly higher than the 52% of 2000 IPII survey participants who were 18 or under.

Age of Person with Developmental Disability

	Overall	Minor Less than 19 years	Adult 19 years or older
	<i>n</i> = 643	<i>n</i> = 383	<i>n</i> = 256
Who is responding to this survey? _____%	%	%	%
Parent or family member	90	96	82
Other primary care giver	10	6	16
Person with developmental disability	14	5	27

Note: Respondents could select more than one option on this question, so totals will add to more than 100%. Also, some respondents may not have provided information regarding age of person with developmental disability and could not be categorized.

IV. Respondent Profile - Degree and Nature of Disability -

Degree of Disability

	<u>Overall</u>	Mild	Moderate	Severe
<i>n</i> = 604				
<i>What is the nature of your disability? ___%</i>		%	%	%
Total	100	18	44	38
Autism	29	8	16	6
Cerebral Palsy	22	5	7	11
Epilepsy	15	6	5	5
Head Injury	5	1	1	3
Mental Retardation	59	17	27	16
Other	32	5	16	14

Years of Participation in CDCS Program

	<u>Overall</u>	<1 Year	1-2 Years	>2 Years
<i>What is the nature of your disability? ___%</i>		%	%	%
Total	100	52	35	13
Autism	29	35	25	19
Cerebral Palsy	22	23	22	18
Epilepsy	15	12	20	14
Head Injury	5	5	5	5
Mental Retardation	59	54	62	73
Other	32	32	32	33

There has been a large increase in the number of program participants with autism in the past year. This may imply a **changing set of needs** compared to what the program faced prior to open enrollment in 2001.

IV. Respondent Profile

- County of Residence and Support -

<i>County</i>	<u>County of Residence</u>	<u>County of Support</u>
	n= 629 %	n = 618 %
Hennepin	44.8	48.1
Dakota	20.0	20.0
Ramsey	16.1	17.0
Olmsted	4.6	4.4
Washington	4.6	3.6
Anoka	2.2	0.3
Scott	1.1	1.0
Crow Wing	1.0	0.6
Houston	1.0	1.1
Morrison	1.0	1.0
Mower	0.8	0.8
Todd	0.5	0.5
Blue Earth	0.3	0.5
Carver	0.3	0.2
Rice	0.3	0.2
Steele	0.3	0.3
Wright	0.3	0.0
Chisago	0.2	0.0
Isanti	0.2	0.2
Pine	0.2	0.0
Sibley	0.2	0.0

Respondents living in 21 counties, and receiving supports from 17 counties participated in this survey.

84.9% of respondents live in Hennepin, Dakota, and Ramsey counties, while 85.1% of respondents receive their support from these counties.

IV. Respondent Profile - Ethnicity -

Ethnicity	2000 Minnesota	Total	County of Support			
	Census	Survey	Hennepin	Dakota	Ramsey	Other
	%	%	%	%	%	%
White only	89.4	80.5	77.9 ↓	89.3 ↑	72.5 ↓	93.4 ↑
<u>Any Ethnic Minority</u>	10.6	19.5	22.1 ↑	10.7 ↓	27.5 ↑	6.6 ↓
Any Black or African American	4.1	8.2	11.0 ↑	3.3	8.8 ↑	2.2
Any American Indian or Alaska Native	1.6	2.5	3.1	1.6	2.9	0.0 ↓
Any Asian	3.3	7.6	6.2	4.9	14.7 ↑	3.3
Any Hispanic	2.9	2.2	2.8	0.8	3.9	1.1

There are obvious ethnic differences between the counties included in this sample. Ramsey and Hennepin counties have significantly higher ethnic minority participation in this program relative to Dakota and the other counties, which may imply a *different set of individual needs* driven by cultural issues.

Additionally, 7.6% of respondents say that English is not their native language (11.5% in Ramsey County and 9.1% in Hennepin County) -- which creates *language issues* for county case managers and program documentation.

Overall, the survey sample has a much higher ethnic minority representation than the 2000 Minnesota Census; but this may be due to the high percentage of respondents coming from Hennepin and Ramsey counties (60.9%), which are known to be more ethnically diverse than the rest of the state.

IV. Respondent Profile

- Years of Participation / Budget -

<u>Years of participation in CDCS program</u>	<u>Total Survey</u>	<u>County of Support</u>			
		<u>Hennepin</u>	<u>Dakota</u>	<u>Ramsey</u>	<u>Other</u>
	%	%	%	%	%
Less than 1 year	52.2	55.6 ↑	25.8 ↓	76.0 ↑	56.7 ↑
Between 1 year and 2 years	34.7	35.5 ↓	50.0 ↑	23.1 ↓	21.1 ↓
More than 2 years	13.1	8.9 ↓	24.2 ↑	1.0 ↓	22.2 ↑

Hennepin, Dakota, and Olmsted are the only counties with a significant number of individuals that have been participating in the program for more than two years. There was a large wave of new participants in this program in the past year, which peaked in the summer of 2001.

<u>Current annual CDCS budget per individual</u>	<u>Total Survey</u>	<u>County of Support</u>			
		<u>Hennepin</u>	<u>Dakota</u>	<u>Ramsey</u>	<u>Other</u>
	%	%	%	%	%
Less than \$25,000	19.7	11.2 ↓	34.0 ↑	14.6 ↓	45.5 ↑
\$25,000 - \$31,999	19.7	20.5	17.5	15.7	21.8
\$32,000 - \$37,999	19.1	29.8 ↑	8.2 ↓	10.1 ↓	5.5 ↓
\$38,000 - \$45,999	18.7	15.9	15.5	39.3 ↑	3.6 ↓
\$46,000 or more	22.0	22.5	23.7	20.2	21.8
Mean	\$36,121	\$37,161 ↑	\$34,567 ↓	\$40,686 ↑	\$29,229 ↓

According to survey respondents, Ramsey County has the largest individual budgets set for participants in the CDCS program. Level of disability is a key budgeting factor*, but the only significant differences in self-reported levels of disability by county are that Hennepin County has relatively more individuals that identify themselves as having “Moderate” levels, and the “Other” counties have relatively more “Mild” levels. Otherwise, levels of disability are comparable across counties.

*Please note: There are significant differences in the average budget at the total level for the varying degrees of reported disability: “Mild” = \$27,935 / “Moderate” = \$33,825 / “Severe” = \$42,725.

IV. Respondent Profile

- Household Income / Parental Fees -

Years of Participation in CDCS Program

	<u>Overall</u>	<1 Year	1-2 Years	>2 Years
What is your total household income? __%	%	%	%	%
Total	100	52	35	13
Under \$35,000	46	40 ↓	51	55
\$36,000 - \$50,000	20	21	20	17
\$51,000 - \$75,000	18	21 ↑	12	15
\$76,000 - \$100,000	12	12	12	10
Over \$100,000	5	6	5	3

There has been a large increase of households with higher incomes participating in this program in the past year. This may also indicate a *changing set of needs*.

	<u>Total Survey</u>	<u>County of Support</u>			
		Hennepin	Dakota	Ramsey	Other
_____	n = 618	n = 277	n = 121	n = 101	n = 88
	%	%	%	%	%
Do you pay an annual fee?	37.5	32.9	39.7	51.5 ↑	38.6
If so, how much?	n = 232	n = 91	n = 48	n = 52	n = 34
\$300 or less	37.6	36.5	24.4	39.5	54.9
\$301 - \$2099	21.1	17.6	24.4	25.6	19.4
\$2100 - \$4199	20.1	23.0	29.3	18.6	3.2
\$4200 or more	21.1	23.0	22.0	16.3	22.6
Mean	\$2697	\$2795	\$2617	\$3154	\$2087
Std. Dev	3727	3559	2523	5155	3195

The TEFRA fee is not a requirement for CDCS, but is a requirement for MA and applies only to children. That said, parents often are under the impression that this fee is for participating in the CDCS program. Respondents report a wide range of how this fee is structured.

V. Overall Satisfaction

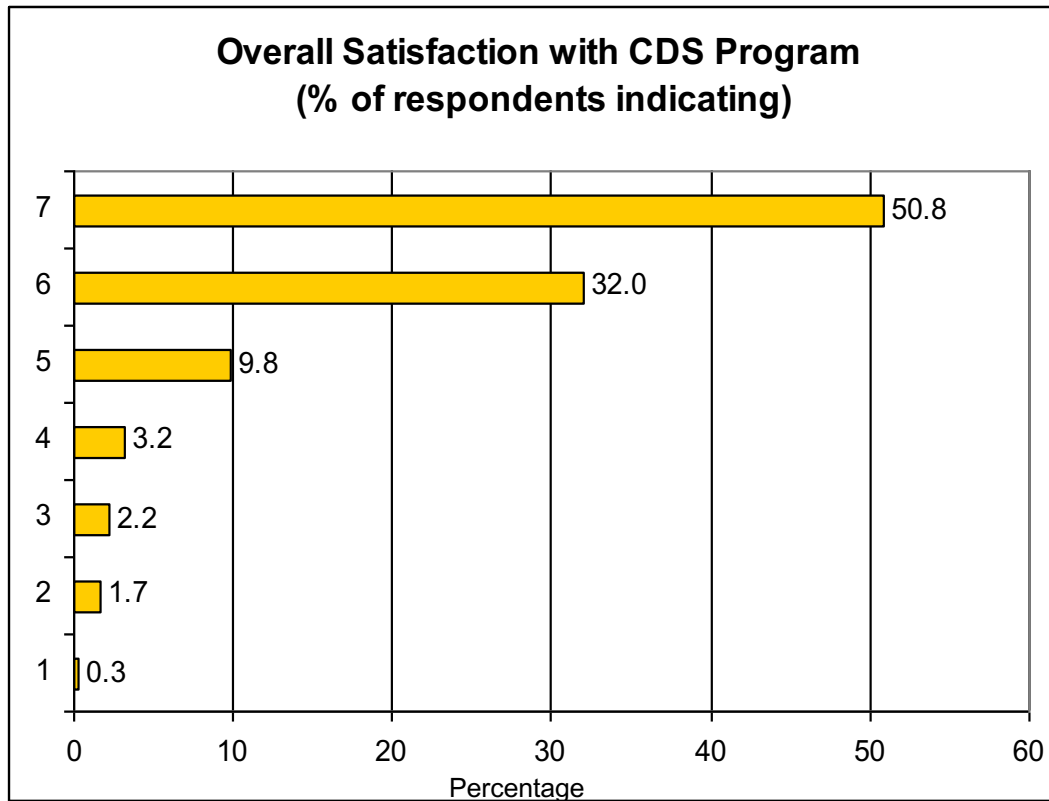
V. Overall Satisfaction with CDCS Program

- Summary -

- **CDCS has changed people's lives:** It is clear that CDCS is a very powerful program that has dramatically changed the lives of many of its participants and should be continued and expanded.
- **Satisfaction and Likelihood to Recommend rated highly:** 83% of CDCS participants are more than somewhat satisfied with the program, and 88% are more than somewhat likely to recommend this program to a friend who finds him/herself in a similar situation. This means that knowing what they know about this program, these people believe that it is the best option out there for individuals and families with developmental disabilities.
- **Most participants' expectations have been met:** 73% of CDCS participants say that the program has more than met their expectations. This is a slightly lower number than for the other questions, but it is still strong. The distribution of answers on this question was much broader, however -- with 27% of participants saying that the program has merely met or has failed their expectations.
- **CDCS has significant opportunities for improvement:** From both the quantitative and qualitative analysis, it is clear there are dramatic differences in the ways this program has been implemented by the various counties and fiscal intermediaries. This has created inconsistencies in decision making and put pressure on the individual and family to find ways to successfully work within the system to make this program meet their needs.
- **The flexibility of the program is in jeopardy:** A quality program should strive to eliminate inconsistencies in delivery. The counties have identified this need and recognize inconsistency in their decision making. The typical response from the counties, however, has been to clamp down on individuals and families "taking advantage of the program" and limit the ability of all participants to make product and service decisions that best serve their needs. Taking away this flexibility will eliminate the most important benefit of this program -- and some participants have already begun to experience frustration with this. (See driving factors of overall satisfaction).

V. Overall Satisfaction with CDCS Program

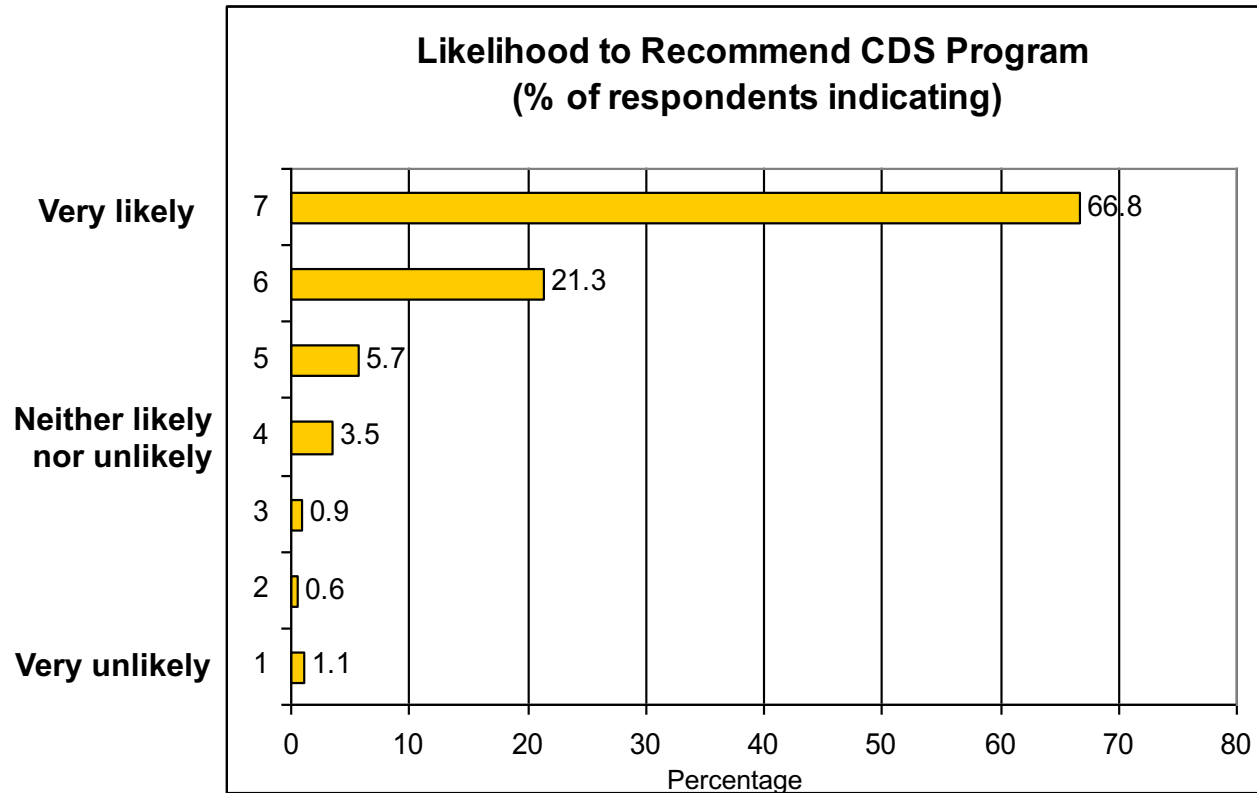
- Total Survey Population -



Overall, respondents are satisfied with the Consumer Directed Support Program, with 82.8% giving it a rating of “6” or “7” on a 7-point scale. While these numbers seem high, it still means that almost 1-in-5 program participants are less than fully satisfied with the program. The CDCS program is a very emotional topic for some of those involved, and there is a great deal of concern expressed by some families about the direction and future of the program; as well as a fear that it might be taken away by public officials.

V. Overall Satisfaction with CDCS Program

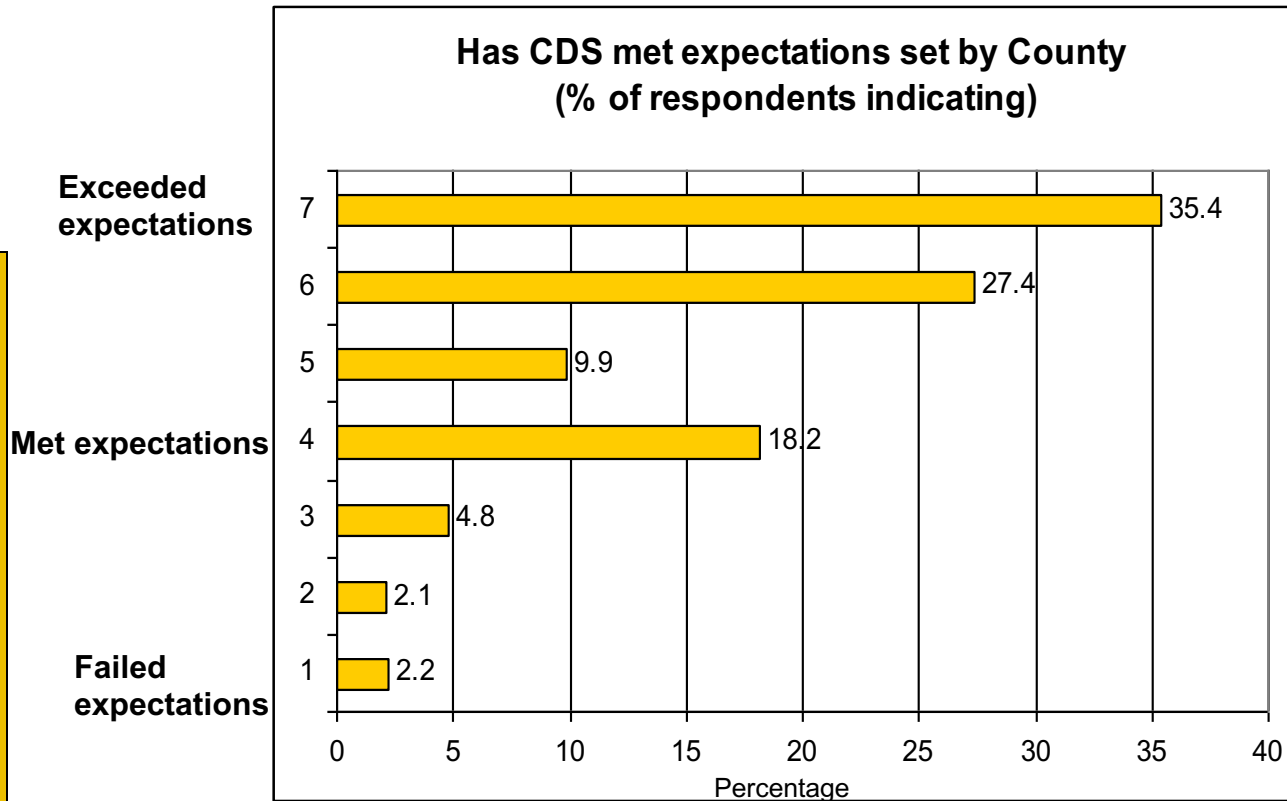
- Likelihood to Recommend - Total Survey Population -



Likelihood to recommend a program to a friend in a similar situation is another good indicator of overall satisfaction. Respondents seem very willing to recommend other people sign up for the CDCS program, with 88.1% giving it a rating of “6” or “7” on a 7-point scale.

V. Overall Satisfaction with CDCS Program

- Expectations - Total Survey Population -



Meeting participants' expectations depends heavily on the county's ability to set the individuals' expectations for participation appropriately. While these numbers are not as high as the overall satisfaction or likelihood to recommend ratings, it appears that, in general, counties are doing a good job meeting participants' expectations. 73% of respondents indicated that the CDCS program has more than met expectations set for them by their case manager or county social services department.

V. Overall Satisfaction with CDCS Program

- Problem Definition Tree Representation -

The Problem Definition Tree Representation (see appendix) is an analysis that groups respondents into clusters that represent the best explanation of their responses to the overall satisfaction question based upon their responses to other questions in the survey.

This analysis gives us an indication of which questions are most closely related to a respondent's overall satisfaction.

Questions taken into consideration for this analysis were:

- Consumer Directed Supports questions related to quality of life, environment, flexibility, staffing, individual development, and the system
- Overall satisfaction questions for the county social services, county case manager, and fiscal intermediary
- Overall satisfaction questions for independence, productivity, integration, inclusion, and self-determination

V. Overall Satisfaction with CDCS Program

- Driving Factors -

From this analysis, it is clear that the most important factor in determining the overall satisfaction with the program, is the participant's overall **satisfaction with his/her county social services department.**

Other contributing factors include the participant's agreement that

- the program provides more **flexibility,**
- **money is being better allocated,**
- and the program has **reduced the participant's/family's stress levels.**

These factors combine to explain 50% of the variance in overall satisfaction responses (which is good for this type of analysis). If a person agrees with these statements, he/she is likely to have higher overall satisfaction.

V. Overall Satisfaction with CDCS Program

- Driving Factors -

These three factors (*flexibility*, *better allocation of money*, and *stress reduction*) had relatively highly rated responses -- with participants agreeing that these are benefits that have been realized through the CDCS program. However, if a person tends to disagree with these statements, he/she is likely to have much lower overall satisfaction.

For example, if a participant rated his/her overall satisfaction with county social services as a "7" out of 7, and rated his/her level of agreement with the program providing flexibility as a "5" out of 5 -- the average rating for overall satisfaction for respondents who answered similarly (Group 7) was an extremely high 6.9 out of 7.0. On the other hand, if a participant rated his/her overall satisfaction with county social services anywhere from "1" to "5" out of 7, and rated his/her level of agreement with the program providing flexibility as anywhere from "1" to "3" out of 5 -- the average rating for overall satisfaction for respondents who answered similarly (Group 1) was a relatively low 4.0 out of 7.0.

V. Overall Satisfaction with CDCS Program

- Driving Factors - Flexibility -

The program has given me more flexibility to meet my specific needs

The term “Consumer Directed” implies that the individual will have some control over how money will be spent, rather than some sort of government agency, social worker, or institution making all the decisions regarding therapies, living arrangements, activities, education, etc. for the individual or family. One of the greatest benefits that we heard from program participants was CDCS’s ability to give people the power to make decisions according to their specific needs.

The [old] system was trying to fit a square peg in a round hole. It was designed for people with obvious physical disabilities. CDCS has helped us design something to fit the specific needs of our child -- you don't have to deal with a bunch of stuff that isn't quite right.

People who are not as satisfied with the flexibility given them by the program, are likely upset by a perception that the implementation of the program has moved away from the original idea of self-determination, which was intended by the program.

In spirit, the CDCS program is on the forefront of what social care should be. The administration of it is not following the spirit, however. The county doesn't want the parent to make choices. They give “guidelines” and caps and we are back to the original waiver situation where you are spending money on things you don't need.

The county is saying “we know what's right for you - you come begging to us.” The program was designed to promote self-direction and individual planning. It doesn't resemble its intent. You can file an appeal, but it's complicated. We've had three different sets of guidelines in the past year and the fourth is on the table. They keep excluding things. It's becoming more regimented and less self-directed.

V. Overall Satisfaction with CDCS Program

- Driving Factors - Better Allocation of Money -

Money is being better allocated within the system

The allocation of money is closely related to flexibility, but implies that the funding is going for products and services that more directly benefit the individual with a developmental disability. This has had a huge impact on many people's ability to obtain the things they need.

Prior to CDCS, we were only able to receive 6 hours/week of direct care staff and \$3000 - \$5000 in adaptive equipment (depending on whether we were fully staffed). The staff was paid \$8/hr. We had one staff person for a year, the rest of the time we had a variety of staff. We had gone for weeks without staff and we had to pay for all their training. Now, we are able to get 12 hours / week of staffing, 48 days respite, and \$10,500 worth of equipment and environmental modifications and we've known our staff for three years.

However, some people are extremely frustrated and feel betrayed by the counties that promised them hope. They feel there is still a large bureaucracy and that the counties might be benefiting more than they are.

The county got the money by making these promises to the federal government. Now they are playing god. They got all of us on the waiver because it was a huge savings to the county since they don't have to use county money to pay for PCA services.

There are also issues with purchases being "defensible to the taxpayer", parental fees, caps on certain allocations such as activities or equipment purchases, and the reimbursement process which may have negatively affected people's responses to this statement.

V. Overall Satisfaction with CDCS Program

- Driving Factors - Stress Reduction -

This program had reduced my (or my family's) overall stress level -- life is easier

Another important promise that this program had was an increased quality of life for the individuals and their families. Dealing with all the government agencies involved when you have a developmental disability can be overwhelming. Having a child with a developmental disability can add a lot of pressure onto a family. This program has helped many individuals and families achieve a quality of life they thought impossible.

It has alleviated a ton of stress from our family. We are not just watching our son foundering. This had created a domino effect of stress through the family structure. The divorce rate is very high among families with children with developmental disabilities. I would expect to see a significant difference under this program.

It gives you time to be a parent and not just a staff person.

For some folks, however, the CDCS program has added a new layer of stress to an already difficult situation.

They made promises. This is an emotional roller coaster. We work very hard to develop the plans and then half the stuff is refused. It's very draining. People get hope and then they take it away.

This program is a huge time commitment. You have to prove things to the county. The onus is on the parents to document everything. I've spent one hundred hours documenting my need for a service animal. It shouldn't be for me to prove that it's not a pet. It should be for them to prove it's not a service animal.

V. Overall Satisfaction with CDCS Program

- Key Demographic Factors -

	<u>Very satisfied</u>		<u>Somewhat</u>	<u>Neither/Not</u>
	7	6	5	4-1
<i>Years of participation</i>				
< 1 year	46.8 ↓	34.9	10.7	7.6
1-2 years	52.8	29.8	9.6	7.9
> 2 years	59.3 ↑	27.2	7.4	6.1
<i>Age of affected individual</i>				
18 or under	50.3	31.2	10.1	8.5
over 18	52.2	33.2	8.9	5.6
<i>Degree of disability</i>				
Mild	50.0	33.0	10.4	6.5
Moderate	50.2	31.4	10.7	7.7
Severe	53.8	30.9	9.4	5.8
<i>Ethnicity</i>				
White only	49.8 ↓	32.6	10.2	7.4
Any Ethnic Minority	54.2	31.7	5.8	8.3
Any Black or African American	64.7 ↑	23.5	3.9	7.9
Any Asian	37.0 ↓	45.7	10.9	6.5
Any Other	69.0 ↑	20.7	0.0	10.3
<i>County</i>				
Hennepin	49.5 ↓	33.2	10.0	7.2
Dakota	64.5 ↑	24.0	5.8	5.8
Ramsey	42.7 ↓	35.0	13.6	8.7
Other	51.7	31.5	7.9	9.0

Individuals and families that have participated in the CDCS program for less than one year are less enthusiastic about the program than those that have been participating in the program for two or more years.

Some of the largest variances in responses are driven by ethnicity and county of support. Results show that Whites and Asians are less enthusiastic than Black or African Americans, or other ethnic minorities (Native American and Hispanics). There is a relationship between ethnicity and county of support which may explain some of these differences.

Dakota County has significantly higher ratings than the rest of the counties even though it has a higher percentage of "White only" respondents, who rated lower on satisfaction in this survey. Ramsey County has the lowest ratings of the larger counties.

Note: Arrows (↑ ↓) indicate significant differences between means or percentages, at the 95% confidence level or more.

V. Overall Satisfaction with CDCS Program

- Impact of individual budget/fee on Overall Satisfaction -

	<u>Satisfied</u>	<u>Somewhat</u>	<u>Neither/Not</u>	
	7-6	5	4-1	
<i>Current annual budget</i>	%	%	%	At a total-sample level, there does not appear to be a correlation between the individual's annual budget, whether they pay a parental fee, and the amount of that fee, with the individual's overall satisfaction.
Less than \$25,000	83	8	9	
\$25,000 - \$31,999	83	10	7	
\$32,000 - \$37,999	89	5	6	
\$38,000 - \$45,999	85	10	5	
\$46,000 or more	77	13	10	
<i>Pay parental fee</i>				This does not mean that the budget and fees are not important, only that there are other factors that carry more weight on overall satisfaction.
Yes	82	11	7	
No	83	9	8	
<i>Amount of parental fee</i>				
\$300 or less	77	9	12	
\$301 - \$2099	85	5	7	
\$2100 - \$4199	84	5	7	
\$4200 or more	80	15	5	

VI. Program Benefits

VI. PROGRAM BENEFITS

- All Counties -

<u>Program Benefits</u>	<u>Mean</u>	<u>Std. dev</u>	<u>Correlation with Overall Satisfaction</u>
Reduced stress level	4.4	.87	.447
Flexibility to meet specific needs	4.4	.82	.465
Select who works with me	4.4	.96	.271
Get out in the community more	4.4	.81	.344
My life routine has become more typical	4.3	.83	.344
Staff more personal care hours	4.3	.99	.283
Retain staff longer	4.3	.99	.309
Obtain higher quality staff	4.3	.96	.345
Money better allocated	4.2	.96	.486
I feel more empowered	4.1	.89	.329
Obtain more respite care	4.1	1.05	.246
Improved relationships with family members	4.1	.94	.307
Develop skills more quickly	4.0	.91	.314
Live where I choose	3.9	1.05	.137
Make necessary adaptations to home	3.8	1.04	.285
Overall cost has decreased	3.8	1.10	.247
Spend time with people w/o dev. dis.	3.7	1.10	.305
Obtain equipment	3.7	1.01	.264

Mean of 5 point scale
5 = Strongly agree
1 = Strongly disagree

All of the factors listed here were perceived as benefits of the program to a varying degree. The higher the mean, the stronger the agreement that this was a benefit of the CDCS program.

The correlation with overall satisfaction, indicates how strongly related each benefit is to the overall satisfaction . The three benefits with the highest correlation, are the same three benefits that factor into the Problem Definition Tree -- the program reduces stress level, provides flexibility, and better allocates money within the system.

A higher standard deviation indicates that there is a larger difference of opinion regarding the benefit. Various sub-groups within the sample may perceive certain benefits differently -- which fits nicely into the self-determination philosophy of the program. The benefits with higher means are less likely to have high standard deviations because there is less room for variance (you can't select anything higher than a "5") -- so the benefits with higher means and higher standard deviations are the most interesting.

VI. PROGRAM BENEFITS

- Top Benefits by County -

Top 4 Program Benefits - Hennepin County

	<u>Mean</u>
Get out in the community more	4.5
Flexibility to meet specific needs	4.4
Select who works with me	4.4
Obtain higher quality staff	4.4

Top 4 Program Benefits - Dakota County

	<u>Mean</u>
Flexibility to meet specific needs	4.7
Money better allocated	4.6
Get out in the community more	4.5
My life routine has become more typical	4.4

Top 4 Program Benefits - Ramsey County

	<u>Mean</u>
Select who works with me	4.7
Staff more personal care hours	4.6
Retain staff longer	4.6
Obtain higher quality staff	4.6

Top 4 Program Benefits - All Other Counties

	<u>Mean</u>
Flexibility to meet specific needs	4.4
My life routine has become more typical	4.3
Reduced stress level	4.3
Get out in the community more	4.3

Mean of 5 point scale / 5 = Strongly agree / 1 = Strongly disagree

Dakota and Ramsey counties had higher ratings for their top benefits than the other counties.

Dakota has the strongest appreciation that money has been better allocated within the system, and was the only county to rate it in the top 4, which explains the high standard deviation for that factor at the total sample level.

Staffing issues appear to be of particular benefit in Ramsey County, where they had much higher ratings than in the other counties, again explaining much of the variance at the total sample level.

Although it doesn't appear in the top 4 for all other counties, there appears to be a greater appreciation for the ability-to-live-where-I-choose in counties outside of the metro area. Additionally, staffing is perceived as a lesser benefit of the program here.

Additional analysis shows that individuals/families with children under 18 and those with higher degrees of disability have greater appreciation for adaptations and equipment, but those benefits are still rated relatively low by these groups.

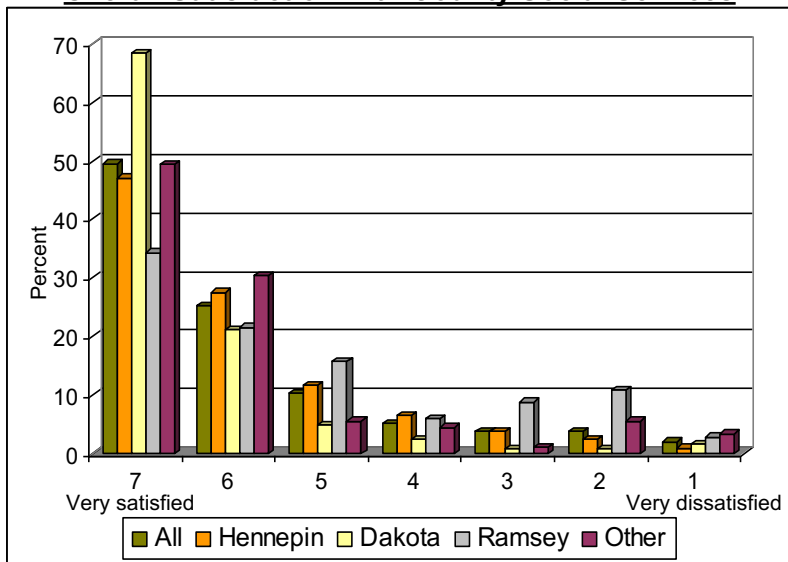


VII. Evaluation of County Social Services

VII. Evaluation of County Social Services

- All Counties -

Overall Satisfaction with County Social Services



Satisfaction with the county social service department was identified as the **biggest factor in overall satisfaction with the program**. Dakota County received the highest ratings with 89.4% in the top two boxes for overall satisfaction and high averages on all evaluation factors.

Ramsey County received the lowest ratings with 56.3% in the top two boxes for overall satisfaction and significantly lower ratings on every single evaluation factor.

Statistical analysis showed an extremely high correlation between the set of factors below and the overall satisfaction for the county (R-sq. = .85). Overall satisfaction was most strongly related to "Make things simpler," "Show flexibility," and "Understands our needs." "Not intimidating or overwhelming" is the only factor not considered to be a statistical driver of satisfaction.

Evaluation Factors

- Information available in format I can understand
- I know whom to contact with questions
- Not intimidating or overwhelming
- Responsive to needs
- Treat me with respect
- Understands needs of people with dev. disability
- Tries to make things simpler for me
- Show flexibility
- Genuinely try to do the right thing
- Sets clear expectations for participation

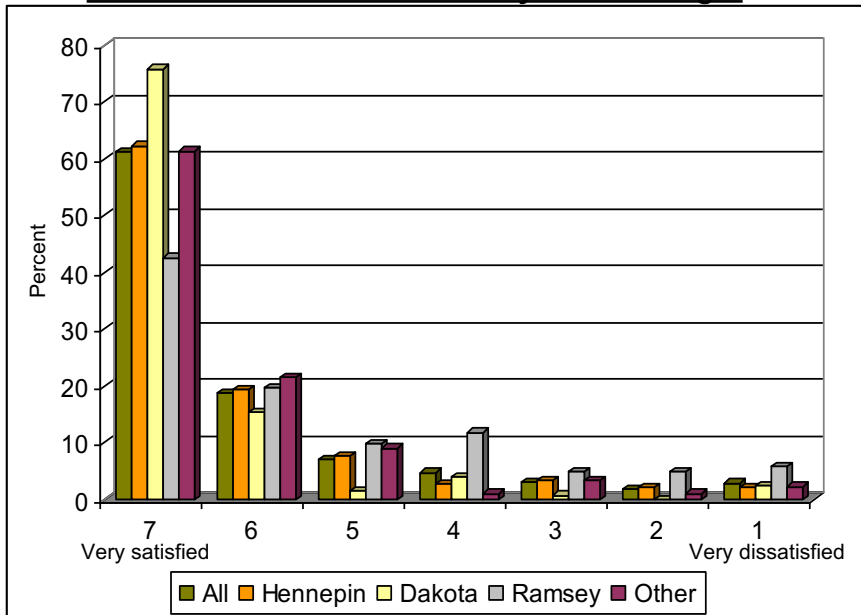
Evaluation Factor	Total Survey	County of Support			
		Hennepin	Dakota	Ramsey	Other
Information available in format I can understand	4.0	3.9 ↓	4.3 ↑	3.8 ↓	3.8 ↓
I know whom to contact with questions	4.5	4.5	4.7 ↑	4.2 ↓	4.6
Not intimidating or overwhelming	3.9	3.9	4.3 ↑	3.5 ↓	4.0
Responsive to needs	4.2	4.3	4.5	3.7 ↓	4.4
Treat me with respect	4.6	4.7	4.7	4.3 ↓	4.6
Understands needs of people with dev. disability	4.3	4.4	4.6 ↑	3.7 ↓	4.3
Tries to make things simpler for me	4.1	4.1	4.5	3.5 ↓	4.1
Show flexibility	4.2	4.2	4.6 ↑	3.6 ↓	4.3
Genuinely try to do the right thing	4.5	4.5	4.7 ↑	4.1 ↓	4.4
Sets clear expectations for participation	4.2	4.2	4.5 ↑	3.6 ↓	4.1

Mean of 5 point scale / 5 = Strongly agree / 1 = Strongly disagree

VII. Evaluation of County Social Services

- Case Managers All Counties -

Overall Satisfaction with County Case Manager



On average, county case managers received higher ratings than the counties on the evaluation factors. Dakota County case managers received the highest ratings with 91.1% rating within the top two boxes for overall satisfaction and high scores on every evaluation factor.

Ramsey County case managers obtained the lowest ratings with 63.4% receiving marks in the top two boxes for overall satisfaction and significantly lower averages on every evaluation factor.

Statistical analysis again showed very strong correlation between the evaluation factors and overall satisfaction with the case manager ($R_{sq} = .87$). The attributes most strongly correlated with overall satisfaction were "Responsive," "Advocates," and "Makes things simpler." The only factor not considered to be a driver of overall satisfaction is "Treats me with respect."

Evaluation Factors

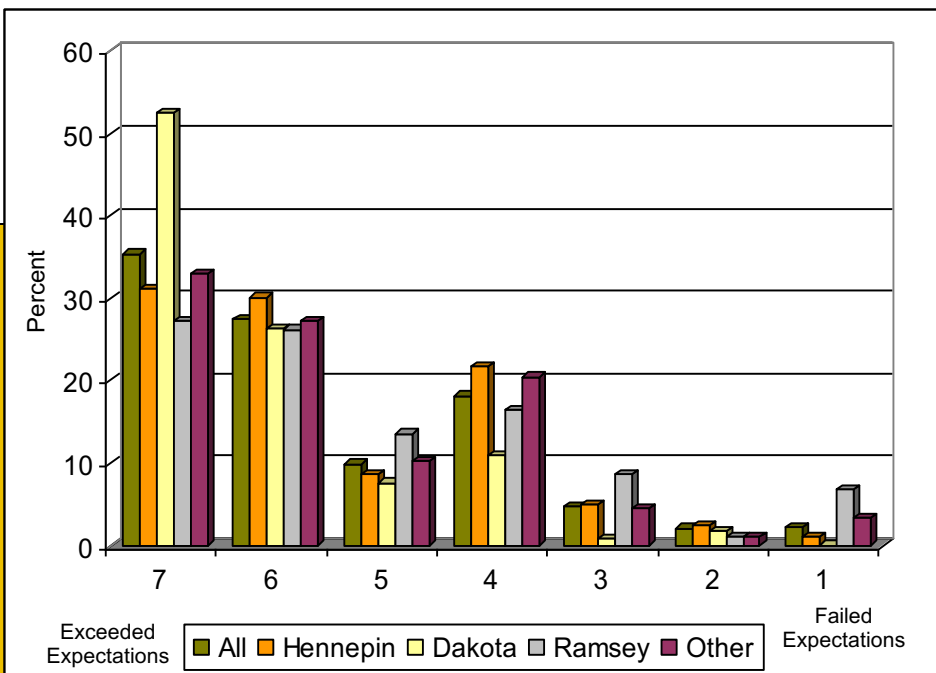
Evaluation Factors	Total Survey	County of Support			
		Hennepin	Dakota	Ramsey	Other
C.M. is well-trained on CDCS	4.3	4.3	4.6 ↑	3.8 ↓	4.3
C.M. is responsive to needs	4.4	4.5	4.7 ↑	4.0 ↓	4.5
C.M. treats me with respect	4.7	4.8	4.8 ↑	4.4 ↓	4.7
C.M. understands needs of people with dev. disability	4.5	4.6	4.8 ↑	4.1 ↓	4.4
C.M. tries to make things simpler for me	4.4	4.5	4.6 ↑	3.9 ↓	4.5
C.M. shows flexibility	4.4	4.5	4.7 ↑	3.9 ↓	4.6
C.M. is an advocate within the system	4.3	4.4	4.6 ↑	3.7 ↓	4.4
C.M. is genuinely try to do the right thing	4.6	4.6	4.8 ↑	4.3 ↓	4.6

Mean of 5 point scale / 5 = Strongly agree / 1 = Strongly disagree

VII. Evaluation of County Social Services

- Participant Expectations - All Counties -

Has CDCS met expectations set by County



Has CDCS met expectations set by County

	All	Hennepin	Dakota	Ramsey	Other
Rating	%	%	%	%	%
7	35.4	31.1	52.5 ↑	27.2	33.0
6	27.4	30.1	26.3	26.2	27.3
5	9.9	8.7	7.6	13.6	10.2
4	18.2	21.7 ↑	11.0	16.5 ↑	20.5
3	4.8	4.9 ↑	0.8	8.7 ↑	4.5
2	2.1	2.4	1.7	1.0	1.1
1	2.2	1.0	0.0	6.8 ↑	3.4
Mean	5.6	5.5	6.1 ↑	5.2	5.5
Std. Dev.	1.52	1.45	1.17	1.74	1.55

When we look at how well the various counties and case managers were able to set individuals' and families' expectations for participation in the CDCS program, some obvious differences are apparent. Dakota County clearly did a superior job in setting expectations with 52.5% of respondents claiming the program exceeded their expectations and 97.5% saying the program met or exceeded expectations.

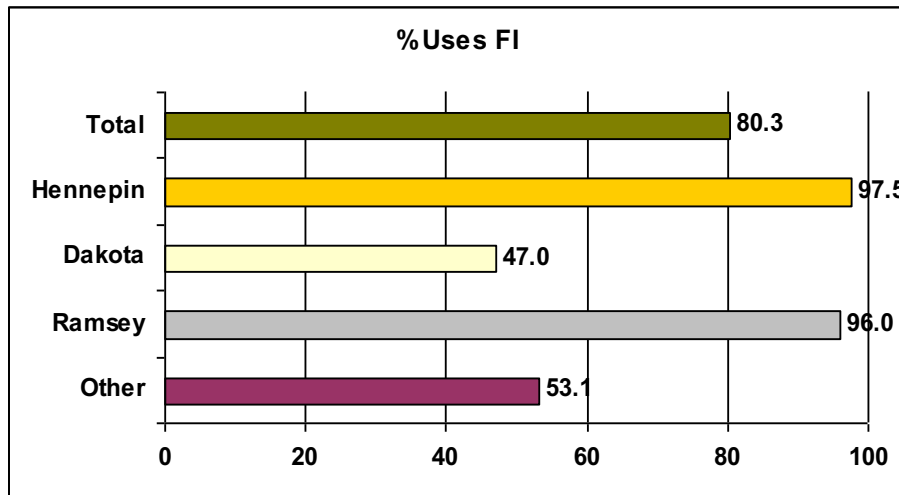
Ramsey County did not fare as well, with 16.5% of respondents stating that the program did not meet their expectations. Ramsey County also had the most inconsistency in its responses, as seen by its high standard deviation, and evidenced by the 6.8% of respondents claiming the program failed their expectations.



VIII. Evaluation of Fiscal Intermediaries

VIII. Evaluation of Fiscal Intermediaries

- All Counties -

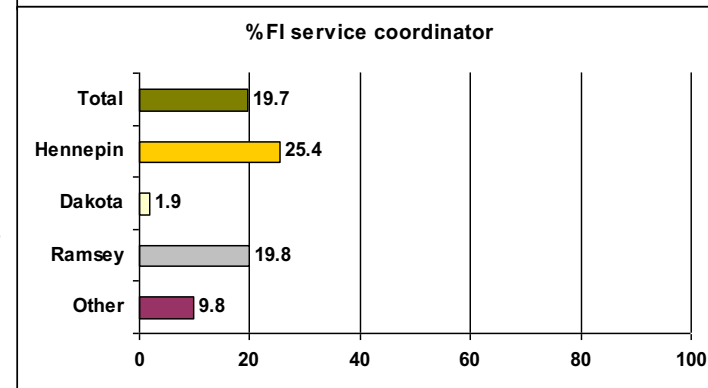
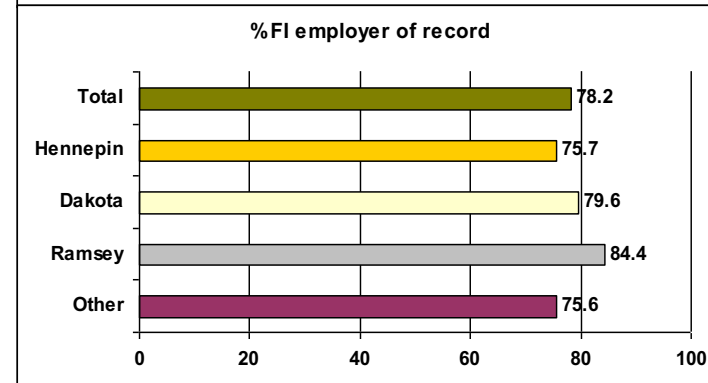
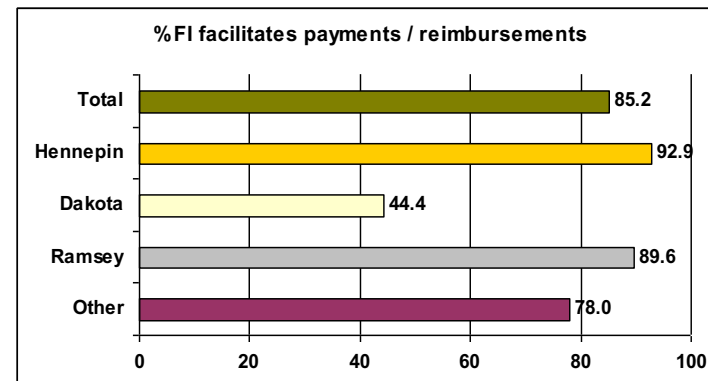


The Fiscal Intermediary serves various purposes for participants in the CDCS program. In Hennepin and Ramsey counties FIs are used most often to facilitate the payments and reimbursements to the program participants.

Dakota and some other counties offer a “Checkbook” option, where the participants write their own checks; therefore some participants from those counties may not use an FI at all.

The other main reason for using an FI is as an employer of record, in order to be the legal entity for staffing and payroll issues for the participants. This is a very common function provided for participants from all counties.

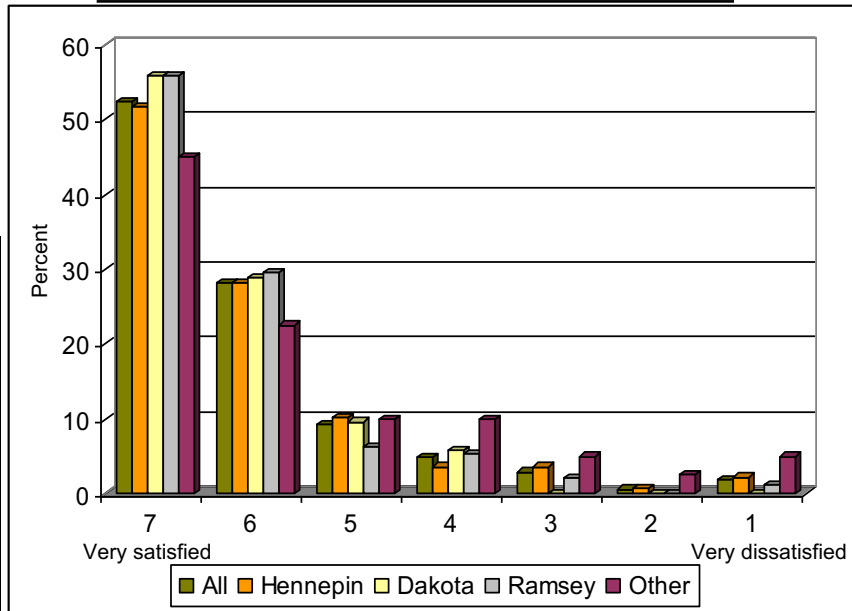
FIs may also function as a service coordinator for individuals and families that want to take advantage of the CDCS program, but may need some extra assistance. This function is not as widely used in any county.



VIII. Evaluation of Fiscal Intermediaries

- All Counties -

Overall Satisfaction with Fiscal Intermediaries



While Fiscal Intermediaries rated a bit lower on overall satisfaction than the counties or the case managers, they still received 80.5% of their marks in the top two boxes. Ramsey County FIs received the highest ratings with 85.3% rating within the top two boxes for overall satisfaction and high scores on every evaluation factor.

FIs outside of Hennepin, Dakota, and Ramsey counties obtained the lowest ratings with only 67.5% receiving marks in the top two boxes for overall satisfaction and significantly lower averages on several factors.

Statistical analysis again showed very strong correlation between the evaluation factors and overall satisfaction with the FI (Rsq. = .78). The attributes most strongly correlated with overall satisfaction were "Responsive," "Makes things simpler", and "Shows flexibility." Factors not considered drivers are "Understands needs", "Respect," and "Try to do the right thing."

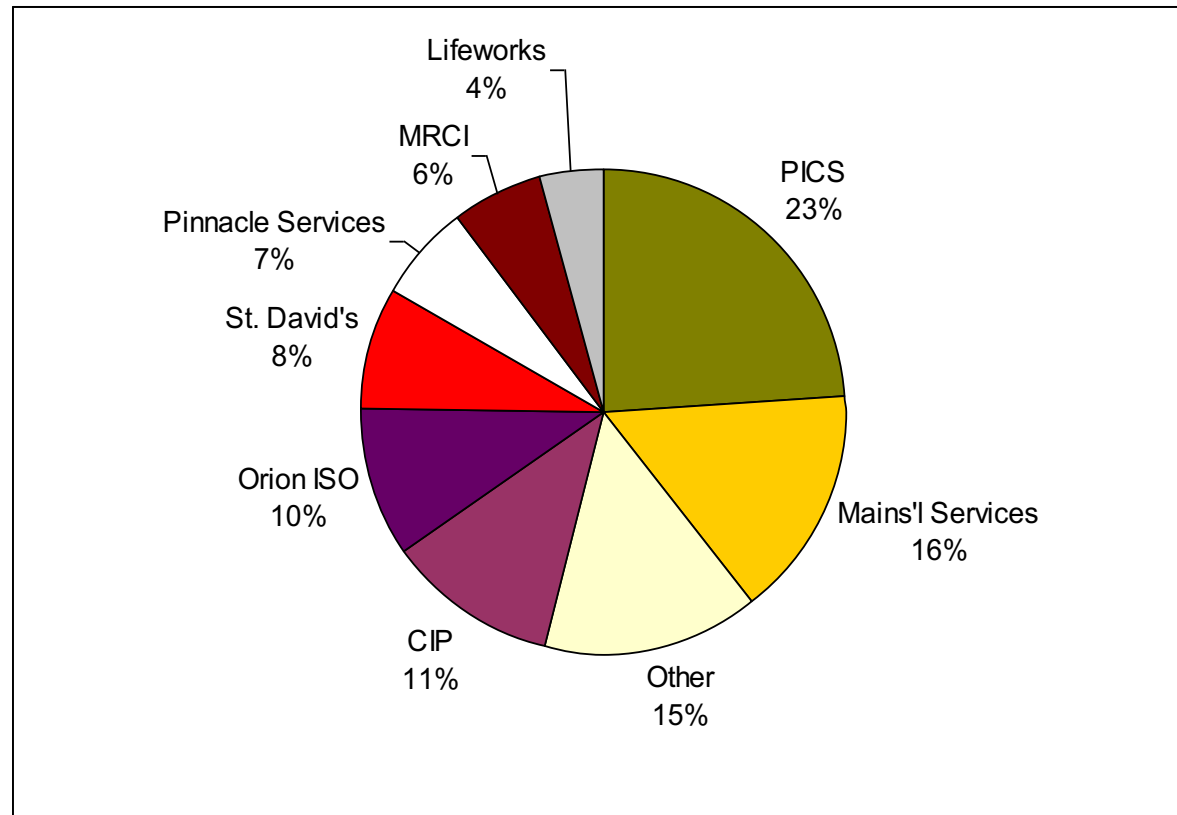
Evaluation Factors	Total Survey	County of Support			
		Hennepin	Dakota	Ramsey	Other
F.I. is well-trained on CDCS	4.4	4.5	4.4	4.5	4.1 ↓
F.I. is responsive to needs	4.4	4.4	4.4	4.5	4.1 ↓
F.I. treats me with respect	4.6	4.6	4.6	4.7	4.6
F.I. understands needs of people with dev. disability	4.5	4.5	4.3	4.5	4.0 ↓
F.I. tries to make things simpler for me	4.4	4.4	4.3	4.6 ↑	3.9 ↓
F.I. shows flexibility	4.4	4.4	4.3	4.5	4.2 ↓
F.I. is an advocate within the system	4.1	4.1	4.0	4.2	3.7 ↓
F.I. is genuinely try to do the right thing	4.5	4.5	4.4	4.6	4.2
F.I. keeps accurate records	4.5	4.5	4.5	4.5	4.3

Mean of 5 point scale / 5 = Strongly agree / 1 = Strongly disagree

VIII. Evaluation of Fiscal Intermediaries

- Largest FIs in Hennepin County -

Share of Fiscal Intermediary services in county

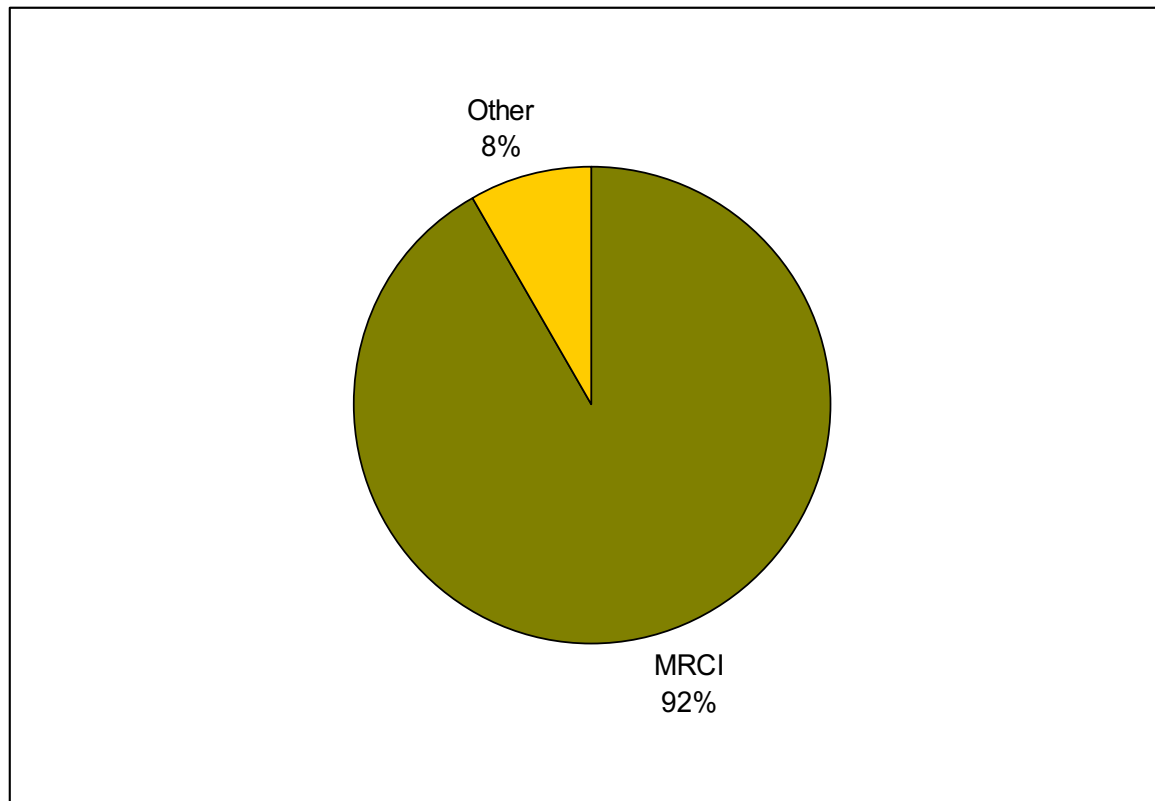


98% of Hennepin County participants use a Fiscal Intermediary. Hennepin County has the largest number of licensed Fiscal Intermediaries. The four largest providers of these services are PICS, Mains'l Services, CIP, and Orion ISO.

VIII. Evaluation of Fiscal Intermediaries

- Largest FIs in Dakota County -

Share of Fiscal Intermediary services in county

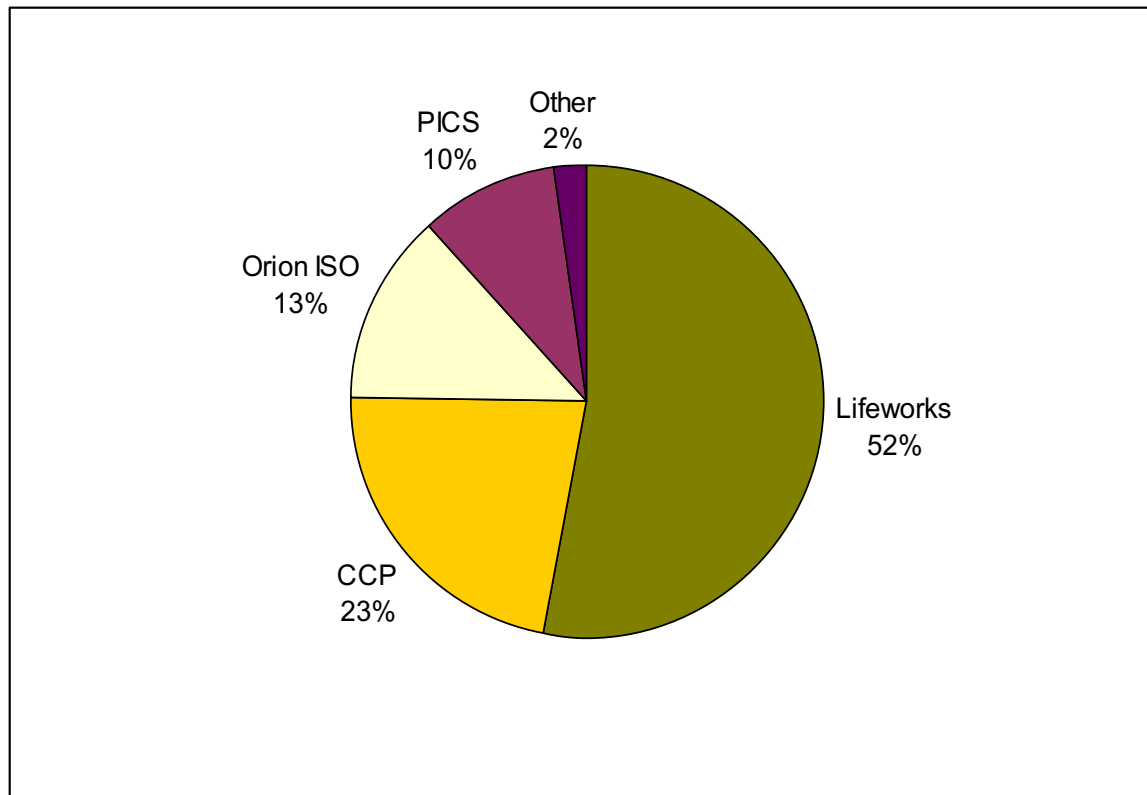


Only 47% of Dakota County participants use a Fiscal Intermediary. MRCI is the dominant provider -- functioning mostly as an Employer of Record for program participants.

VIII. Evaluation of Fiscal Intermediaries

- Largest FIs in Ramsey County -

Share of Fiscal Intermediary services in county

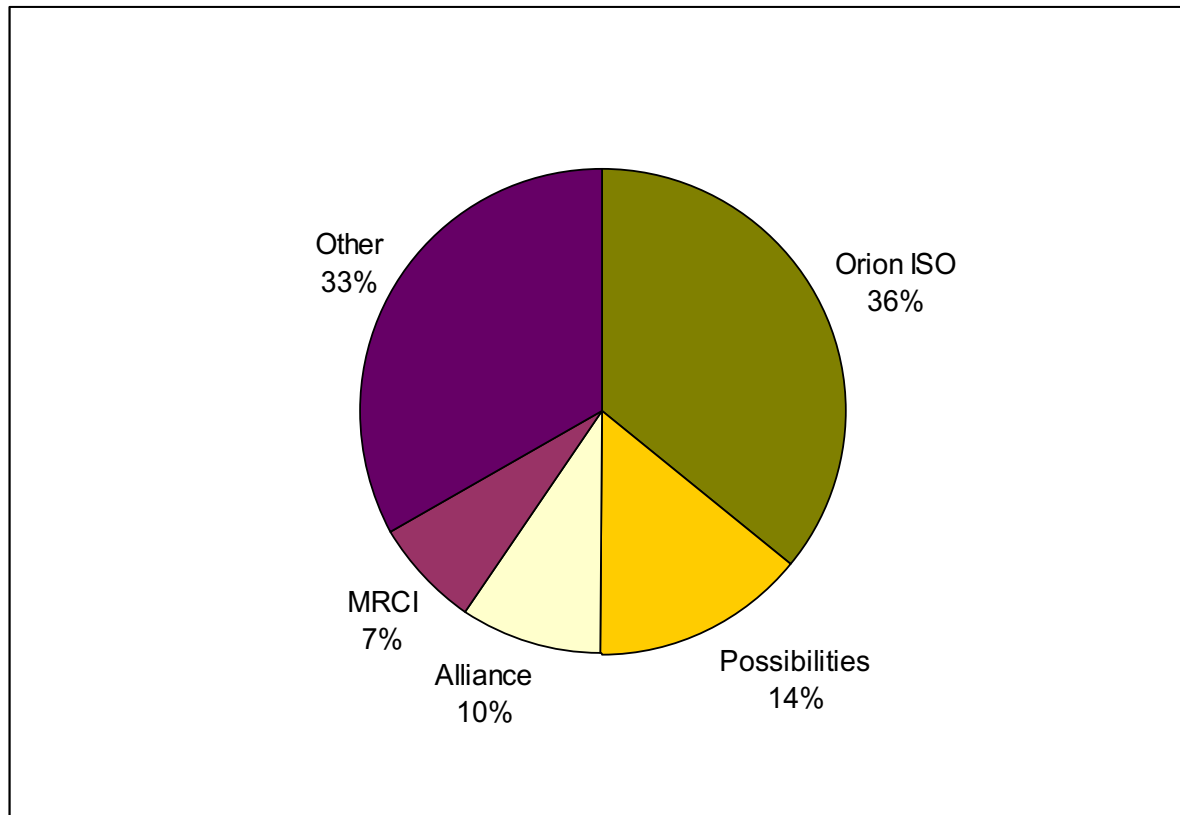


96% of Ramsey County participants use a Fiscal Intermediary and Lifeworks has the majority share. Other organizations providing these services in Ramsey County are CCP, Orion ISO, and PICS.

VIII. Evaluation of Fiscal Intermediaries

- Largest FIs in Other Counties -

Share of Fiscal Intermediary services in county



53% of program participants outside of Hennepin, Dakota, and Ramsey counties. The four largest out-state FI service providers are Orion ISO, Possibilities, Alliance, and MRCI.

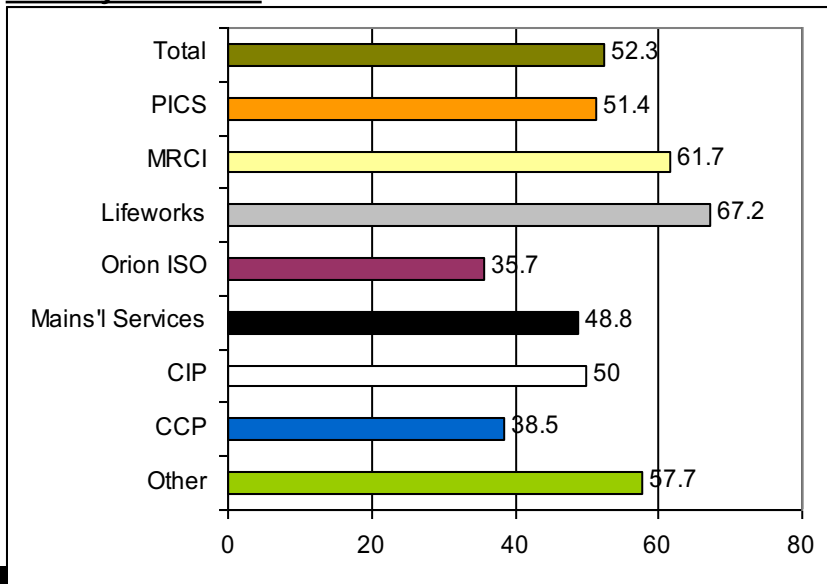
VIII. Evaluation of Fiscal Intermediaries

- Largest FIs - All Counties-

Overall Satisfaction with Fiscal Intermediaries

	Total	PICS	MRCI	Lifeworks	Orion ISO	Mains'l Services	CIP	CCP	Other
Count	488	75	63	62	56	43	30	26	100
	%	%	%	%	%	%	%	%	%
7 - Very Satisfied	52.3	51.4	61.7 ↑	67.2 ↑	35.7 ↓	48.8	50.0	38.5 ↓	57.7
6	28.2	29.7	25.0	26.2	33.9	34.9	23.3	46.2 ↑	20.6
5	9.2	9.5	8.3	1.6	16.1	4.7	16.7	3.8	11.3
4 - Neither	4.8	5.4	5.0	4.9	5.4	0.0	3.3	3.8	3.1
3	2.9	4.1	0.0	0.0	5.4	4.7	0.0	3.8	3.1
2	0.6	0.0	0.0	0.0	1.8	2.3	0.0	0.0	1.0
1 - Very Dissatisfied	1.9	0.0	0.0	0.0	1.8	4.7	6.7	3.8	3.1
Mean	6.1	6.2	6.4 ↑	6.6 ↑	5.8	6.0	5.9	6.0	6.1
Std. Dev	1.28	1.07	0.84	0.76	1.38	1.58	1.57	1.37	1.42

% "Very Satisfied"



Overall, the Fiscal Intermediaries received high ratings, but when we look at how the larger FIs were rated, some differences in performance become apparent.

Lifeworks (mostly in Ramsey County) and MRCI (mostly in Dakota County) were the most highly rated Fiscal Intermediaries. Both organizations received statistically-significant, higher averages and the lowest variance (standard deviation) in their ratings.

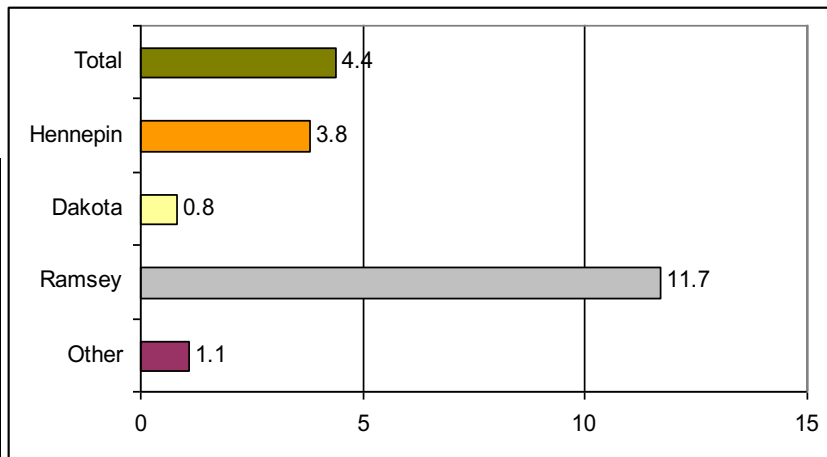
Orion ISO (mostly in Hennepin County) was the lowest rated of the larger Fiscal Intermediaries. Mains'l Services and CIP were also rated lower and had the highest variance in their responses. A higher variance implies more inconsistency in responses, which can be seen in the relatively high number of "Very Dissatisfied" responses for both of these organizations.

IX. Evaluation of Appeal Process

IX. Evaluation of Appeal Process

- All Counties -

% of Respondents filing an appeal



Only 4.4% of total participants have filed an appeal. While these numbers are too small for much meaningful statistical analysis, there were significantly more appeals filed by participants from Hennepin and Ramsey counties than the others.

Ramsey had by far the most appeals with more than 1 in 10 program participants filing an appeal. Appeal participants gave the appeal process below average ratings on three of the four evaluation factors, with "Respect" being the only positively perceived attribute.

On the whole, only 23.1% of appeal participants were satisfied with the overall appeal process.

This did not, however have an overwhelming impact on appeal participants overall evaluation of the program. 67.9% of appeal participants still rated the overall program with high satisfaction -- as compared with 80.7% for the total sample.

Evaluation Factors

- Not intimidating or overwhelming
- Individ.s involved well trained on CDCS
- Treated me with respect
- Understand needs of people with dev. disability
- Overall Satisfaction with appeal process
- Top 2 boxes

Total Survey	<u>County of Support</u>	
	Hennepin	Ramsey
2.8	2.7	2.7
2.8	2.7	2.9
3.5	3.5	3.7
2.7	2.2	3.0
3.6	3.6	3.5
23.1%	20.0%	27.3%

Mean of 5 point scale
5 = Strongly agree
1 = Strongly disagree

Mean of 7 point scale
7 = Very satisfied
1 = Very dissatisfied



X. Potential Training Options

X. POTENTIAL TRAINING OPTIONS

- All Counties -

<u>Potential Training Options</u>	<u>Total Survey</u>	<u>Ethnicity</u>		<u>Age of Individual</u>	
		<u>White only</u>	<u>Any ethnic minority</u>	<u>18 & under</u>	<u>Over 18</u>
Parent mentor program	3.9	3.9	4.0	4.1 ↑	3.8 ↓
Support groups of similar age /dd	3.9	3.8 ↓	4.2 ↑	4.0 ↑	3.6 ↓
Parent to parent training	3.8	3.8 ↓	4.2 ↑	4.0 ↑	3.6 ↓
Finding and hiring staff	3.8	3.8 ↓	4.1 ↑	3.9 ↑	3.7 ↓
Finding diagnosis specific catalogs	3.7	3.6 ↓	4.1 ↑	3.8	3.4
Diagnosis, treatments, and methods	3.7	3.6 ↓	4.1 ↑	3.9 ↑	3.4 ↓
Staff management training	3.6	3.5 ↓	4.0 ↑	3.6	3.6
Math/Financial/Accounting training	3.3	3.2 ↓	3.8 ↑	3.2 ↓	3.4 ↑
Cultural / language support	3.3	3.1 ↓	4.0 ↑	3.3	3.2

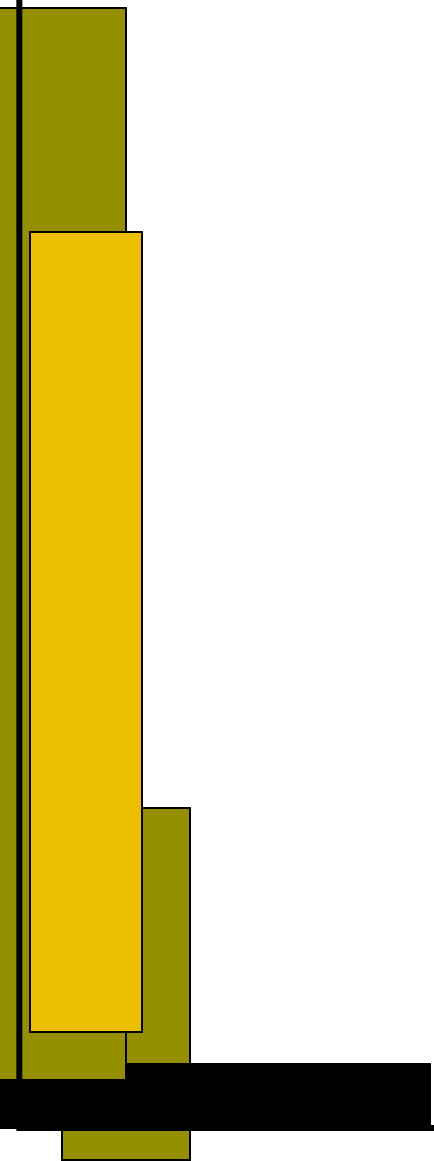
Mean of 5 point scale / 5 = Very important / 1 = Very unimportant

Program participants were asked to evaluate the importance of several training options that came up as possibilities during interviews with individuals and families. Opportunities for parents & families to interact, be trained by, and obtain support from other parents & families came across as the most important potential options.

Significant differences were seen in this evaluation between ethnic groups and families with children v. adults. Ethnic minorities tended to view all the training as more important -- with the biggest difference coming in support for people of different languages and cultures.

Since a lot of the training options were specifically addressing the parents, it is not surprising that there are significant differences between families with children v. adults. Additionally, families with younger children are still adjusting to their new responsibilities, whereas families of adults may be more settled in their roles.

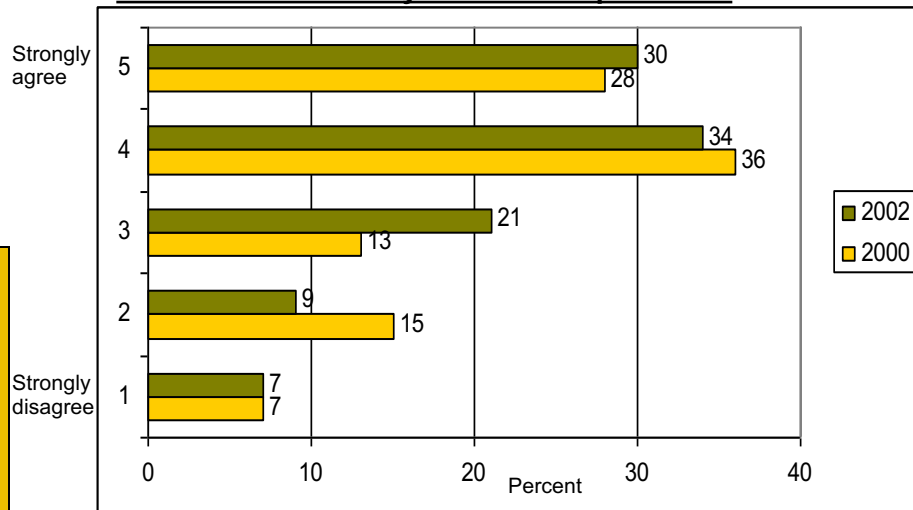
XI. Evaluation of IPSII



XI. IPSII Evaluation

- Independence - All Counties -

I am satisfied with my level of independence



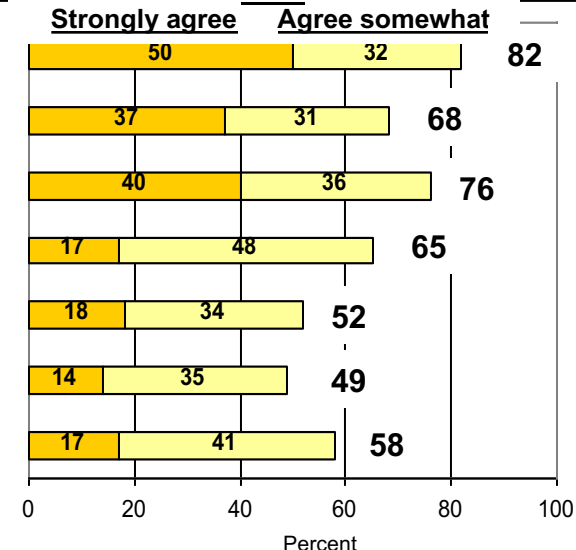
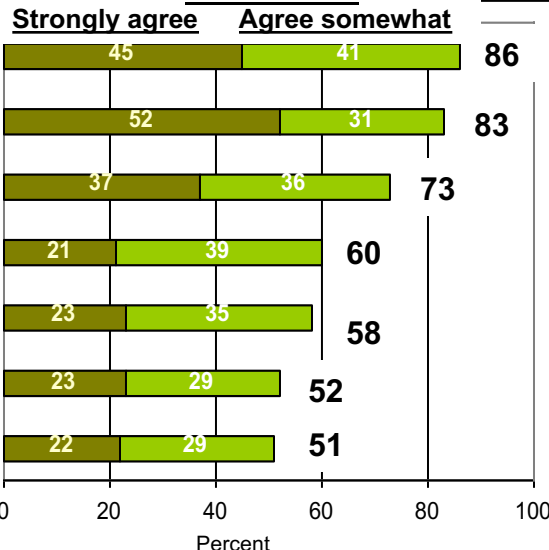
CDCS participants were asked to evaluate their overall level of independence and several factors which impact independence. These same questions were also asked in a survey conducted in 2000 of individuals with developmental disabilities (not exclusively CDCS participants). Overall satisfaction with independence is up slightly in 2002 over the results in 2000.

The biggest difference between the two surveys is a higher level of agreement from CDCS participants that only people who are supposed to know their personal information have access to it. It is somewhat surprising that program participants didn't have a higher feeling of control around decision making and money, given the goals of the program.

2002 / CDCS

2000

- I can get to where I want to go
- Only people who are supposed to know my personal info. have access
- I have privacy to be alone or with people I choose*
- I have control over my daily schedule
- I can set desired outcomes for myself
- I can make decisions that will affect my future
- I can decide how to spend my money

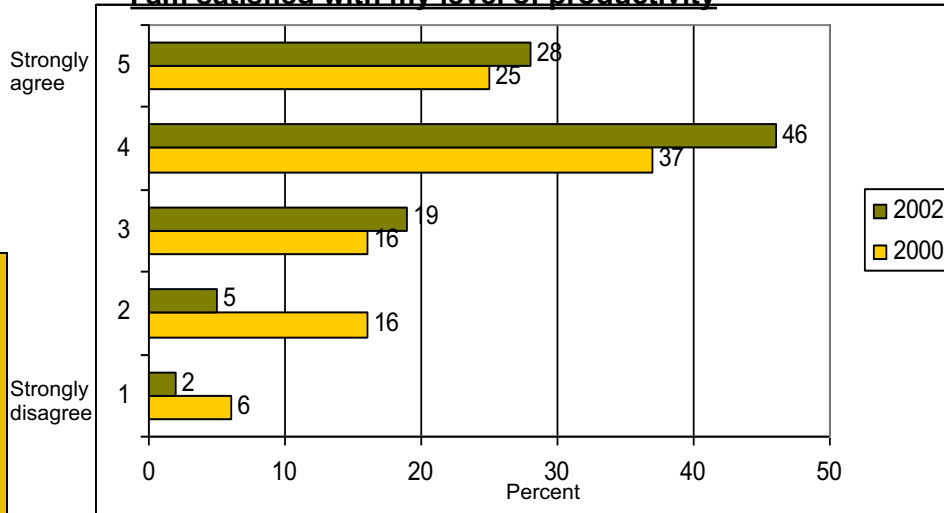


* combines two questions from 2000 survey

XI. IPSII Evaluation

- Productivity - All Counties -

I am satisfied with my level of productivity

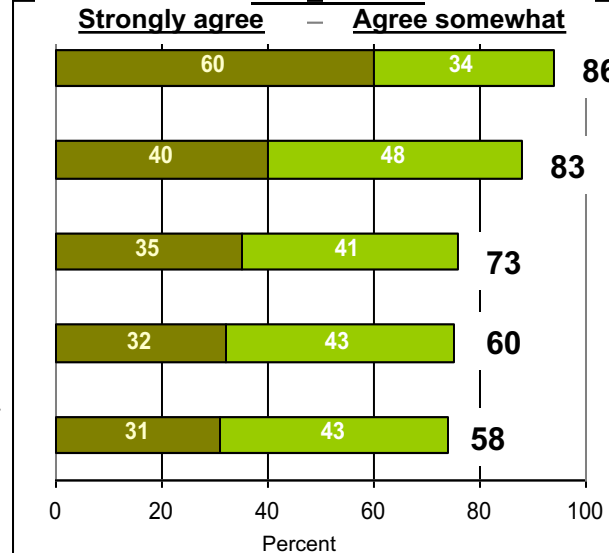


CDCS participants were also asked to evaluate their overall level of productivity and several factors which impact productivity. A couple of questions were added to this survey to improve the effectiveness of this section over the survey in 2000. Overall satisfaction with productivity is higher in 2002 compared to 2000.

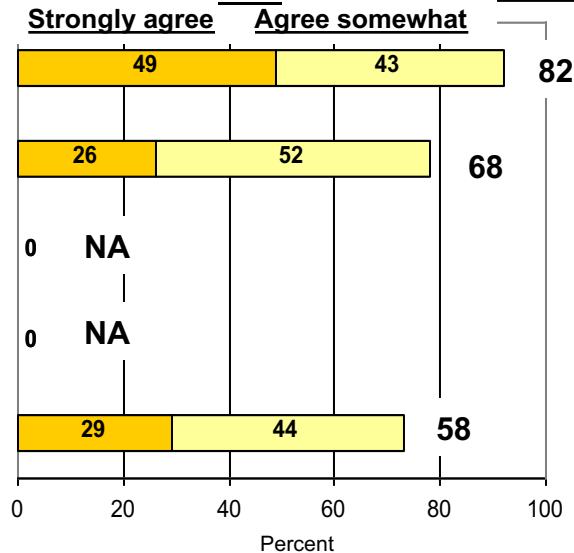
CDCS participants (2002 survey) agree more strongly that they have been improving their skills, than survey respondents in 2000. Adding "The system supports my productivity" dramatically improved the correlation of the factors with the overall question, and was seen as a driver of overall satisfaction with productivity, along with having the appropriate amount of responsibility and improving skills.

2002 / CDCS

- I receive recognition for the things I do
- I have been improving my skills
- The system supports my productivity*
- I have access to assistive products and technology*
- I have an appropriate amount of responsibility



2000

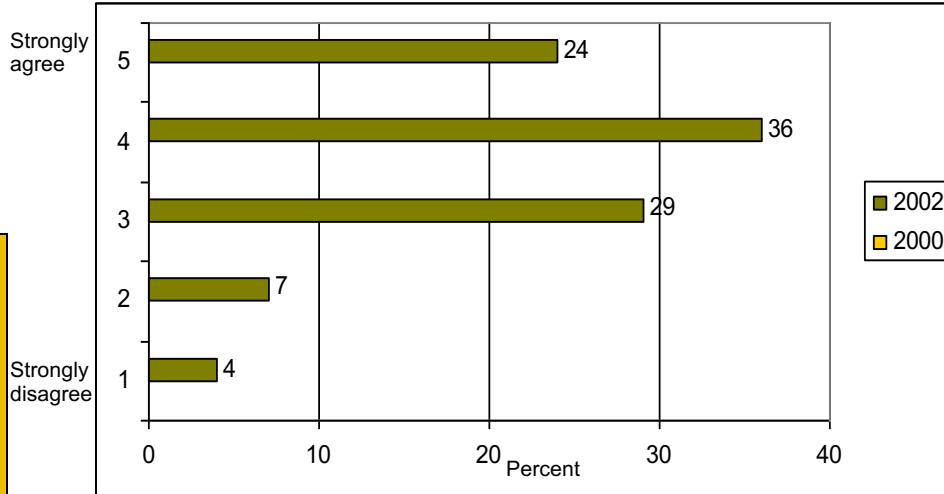


* these questions were added since the 2000 survey

XI. IPSII Evaluation

- Self-Determination - All Counties -

I am satisfied with my level of self determination

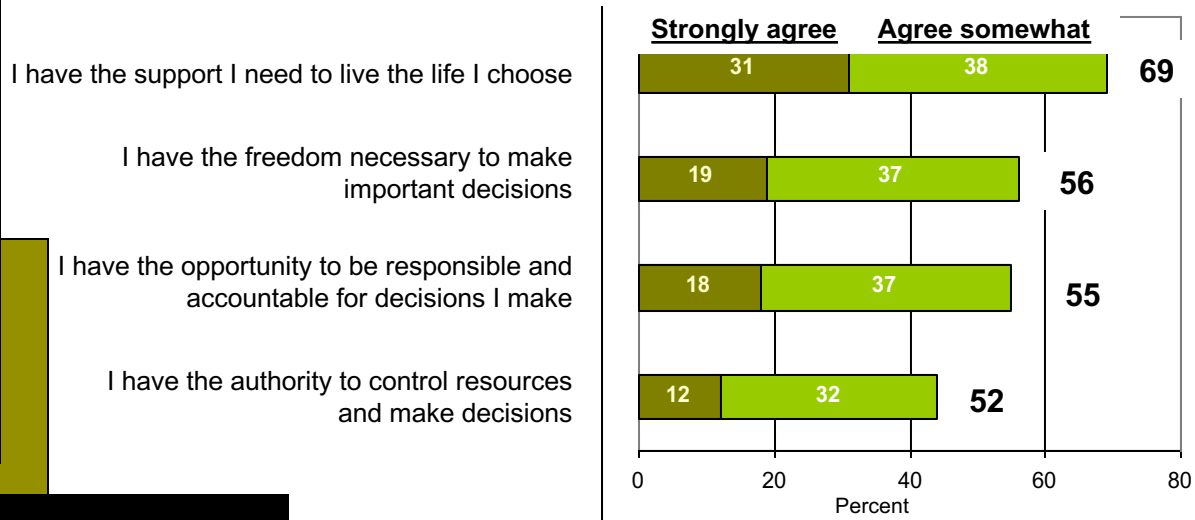


As part of the 2000 DD Act reauthorization, the term self-determination was added as an outcome of government programs. A self-determination section was not included in the 2000 survey but was added to this survey. The factors were derived from the governmental definition of the term.

This section received some of the lowest ratings in the entire survey. Only 60% of respondents are satisfied with their overall level of self-determination, and the only factor to score better than the overall rating was "I have the support I need" -- with 69% agreement.

Statistical analysis shows that these factors have a strong correlation with the overall evaluation of self-determination and that all four factors are considered drivers of the overall evaluation.

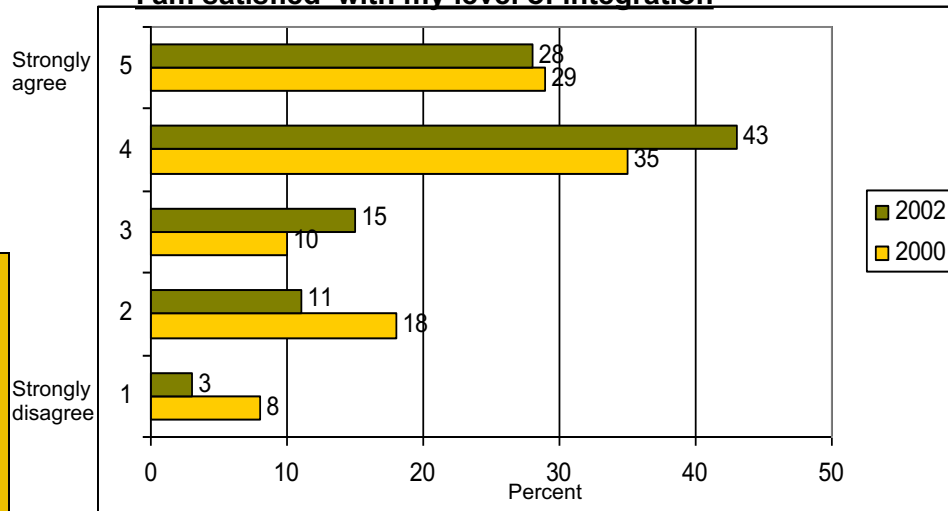
2002 / CDCS



XI. IPSII Evaluation

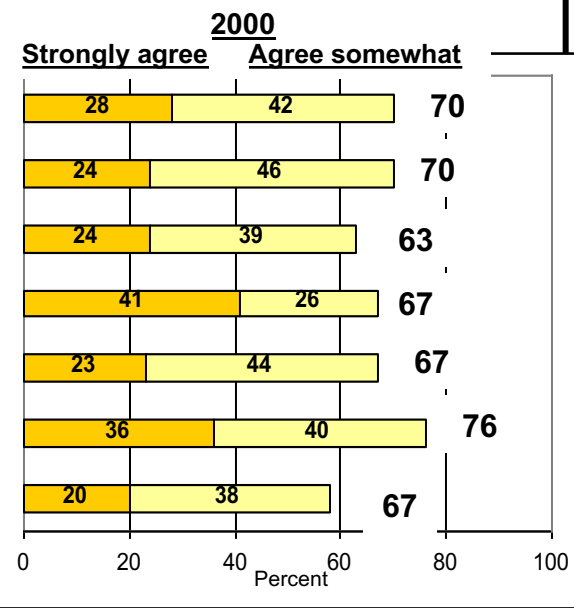
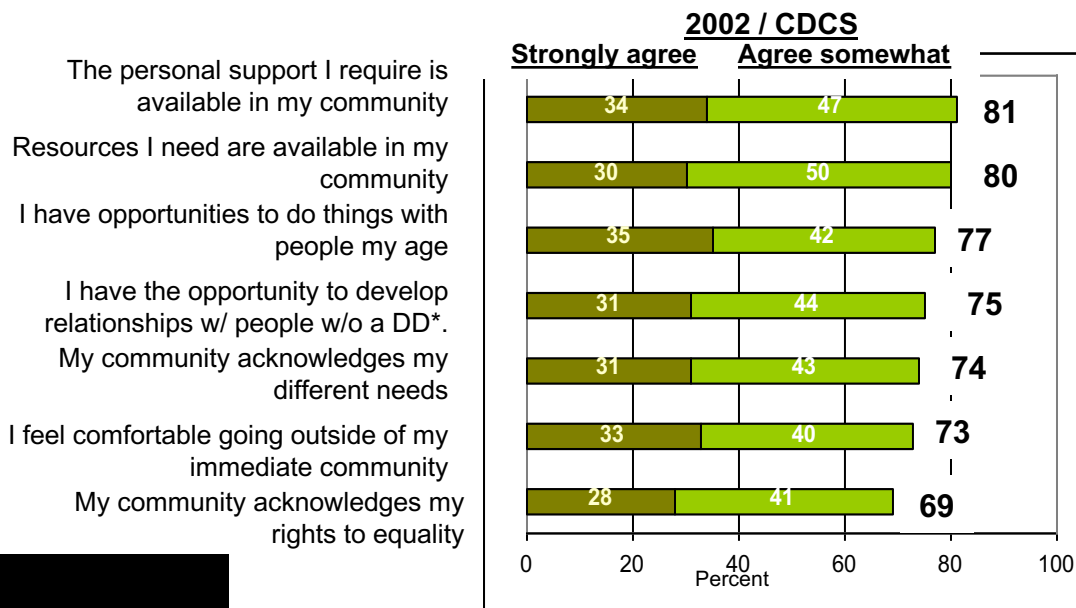
- Integration - All Counties -

I am satisfied with my level of integration



CDCS Participants were slightly more satisfied with their levels of integration than respondents in the 2000 survey.

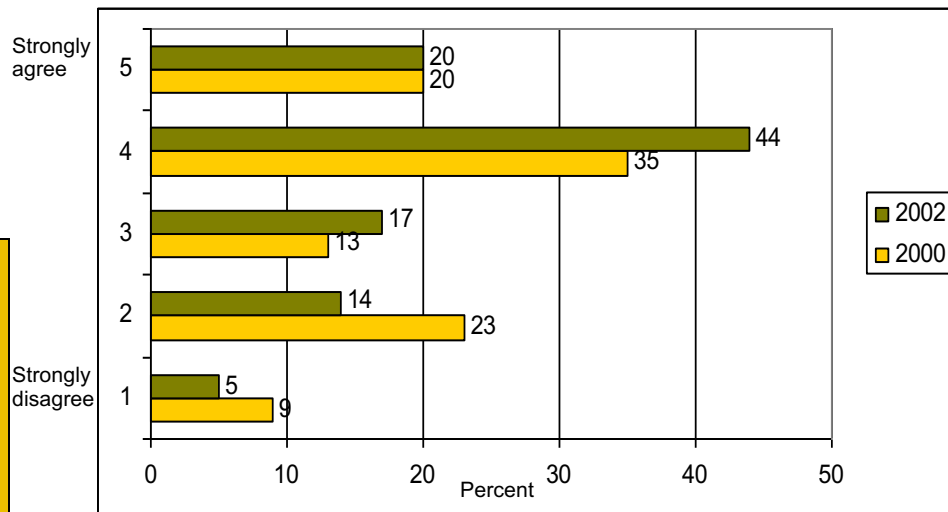
Several of the individual factors, however, were rated much higher by the CDCS participants than the 2000 survey participants. Such as: having support available in the community, having resources available in the community, and having opportunities to interact with people of the same age.



XI. IPSII Evaluation

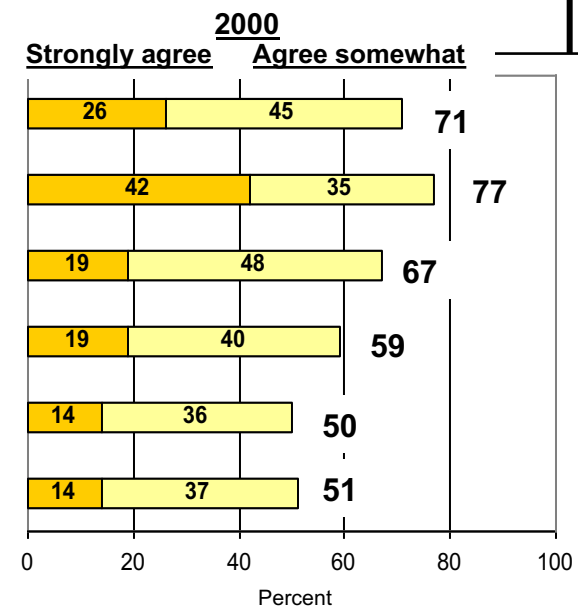
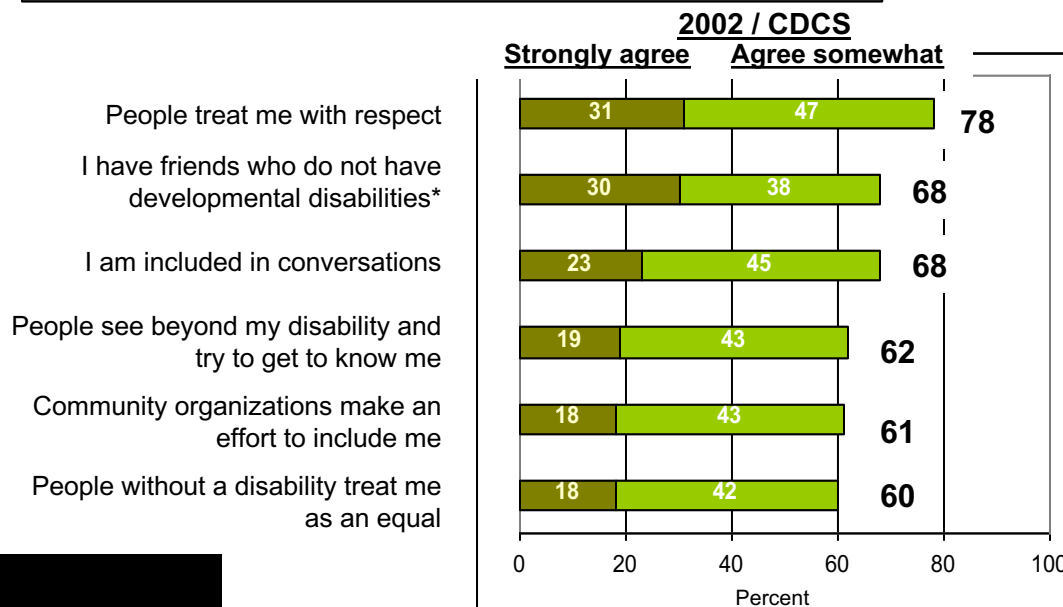
- Inclusion - All Counties -

I am satisfied with my level of inclusion



CDCS Participants again gave slightly higher satisfaction ratings with their levels of inclusion than respondents in the 2000 survey.

A couple of individual factors were rated higher by CDCS participants. Such as: "People treat me with respect", "Community organizations make an effort to include me", and "People without a disability treat me as an equal."



XII. Recommendations

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Continue to expand the program

- By all accounts, this program has saved money, provided participants with better services, and everyone involved believes that it is the way of the future for social services programs. The key to the success of the program, however, is finding the right model for the counties so that inconsistencies in delivery can be eliminated, while maximum possible flexibility for the individual participant is maintained.

Move towards Dakota County philosophy as much as possible

- Dakota County has the highest satisfaction rates, with the lowest budgets, low parental fees and only one reported appeal. Additionally, in interviews with county case managers and supervisors, Dakota County claimed to have only 1% “difficult” participants -- those who were identified as trying to take unfair advantage of the system. Hennepin and Ramsey counties said this figure was closer to 10% for them.
- Dakota County has a different philosophy about people’s participation in the program. They advocate for the participants and don’t just follow the rules. They try to listen to the individuals and families and get them what they need -- as opposed to only approving what they know will be approved by higher authorities. Also, Dakota County has faith in the participant’s ability to make decisions. Dakota County knows that some people will try to get away with things, but they will deal with them when it happens.
- Dakota County also does a lot of work setting participants expectations up front -- how the process works, what will be approved, what won’t be. This leads to a better understanding of the program by the consumer, which translates to less conflict, less stress, less work, and higher satisfaction.

XII. Recommendations

Discontinue use of “defensible to the tax payer” and “normal parental responsibility” as decision making criteria for budget requests.

- The counties need to develop guidelines that provide clear, consistent structure regarding what is allowable under this program, but still allow for the individualization of the program, which is its greatest strength.
- The counties shouldn’t just develop restrictive guidelines that limit consumer direction. This just makes things easier for the counties to administer the program, but betrays the reason for the program’s existence -- consumer direction.
- “Defensible to the taxpayer” and “normal parental responsibility” are too subjective and open to individual interpretation by individual decision makers. These concepts play on an individual’s personal value system and beliefs -- which leads to inconsistent decisions as well as conflict within the counties and with participants.

Develop ways to expand program to individuals who do not have a large personal support system.

- In addition to the geographical expansion of the program, means should be identified to help individuals who do not have the wherewithal to participate in the CDCS program as it exists now.
- The current system requires a huge support network of family, relatives, and friends who are willing to assist the individual with the CDCS budget, staffing issues, etc.

XII. Recommendations

Keep the program simple.

- There is an extraordinary amount of paperwork and an increasing number of rules and guidelines for participation and expenditure decisions in the CDCS program.
- Participating individuals and families are struggling to deal with difficulties presented to them because of their disabilities and don't have the time or emotional energy to deal with an overly complicated process.
- Additionally, there are a significant number of participants and families who are not native English speakers. Participation and guideline information needs to be kept simple so that it can be easily understood and translated if necessary

XII. Appendix

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- Problem Definition Tree Representation -

