

DECISION-MAKING



GOALS

One of DDS's legislatively mandated goals is that adults with developmental disabilities "make increasingly responsible choices" and "exert greater control over their life circumstances" (CRS 27-10.5-102-30-a). The ability to make choices and the choices you make are a major factor that distinguishes you from other people around you; it defines your individuality. The right to determine the direction your own life will take is also referred to as self-determination, empowerment, self-direction, making choices, increasing independence, etc. But, regardless of what terms are used to describe it, the right to make decisions that affect your own life is a key attribute of adulthood. Decisions may range from the more mundane decisions about what to wear, what to eat, etc., to the more significant decisions about what job to pursue or home to select. Everyone wants to have control over their life circumstances, including adults with developmental disabilities. It is DDS' goal that consumers are provided as many choices as possible within services, taking health, safety, and cost concerns into account.

PROGRESS TOWARDS GOAL

This section of the report compares the amount of involvement that adults with developmental disabilities have in making decisions about their own lives. This report will present information relevant to answering the following questions regarding involvement in decision-making:

- ❖ In what types of decisions are persons with developmental disabilities being involved and what level of involvement are they provided?

- ❖ Do opportunities for involvement in decision-making vary by service approach? If so, is this variation related to differences in the support needs of persons receiving those services?
- ❖ Are adults receiving services provided similar opportunities to make decisions as are other adult citizens of Colorado?
- ❖ Are persons with developmental disabilities more involved in making decisions in 2000 than they were in 1993?
- ❖ Does involvement in decision-making for adults vary by age, income, gender, minority status or urban/rural setting?

METHODOLOGY

The Core Indicator survey determined the degree to which each consumer is involved in making decisions by asking if decisions were made independently, with the involvement of others or by others in each of several decision areas such as choosing their roommates, clothes to buy or wear, deciding how to spend spare time or spare money, etc. During the survey, consumers were always provided the opportunity to respond to these questions directly, but when they were unwilling or unable to, then other respondents familiar with the consumer's involvement in decision-making were interviewed. When consumers responded directly, a consistency check was performed to ensure that they understood the questions and were not being affected by a desire to please or a tendency to select the choice offered most recently. (Refer to the methodology section of this report for further details.)

LIMITATIONS OF ANALYSES

This evaluation concentrates on the numbers and types of decisions in which people with developmental disabilities are involved and their level of involvement. The underlying assumption within this section of the report is that having greater involvement and in more decisions is an indicator of having greater control over one's life and is a desirable outcome of services. However, this evaluation has some limitations. No information is available to address issues such as how choices are presented; whether people are provided choices, but they are unable or unwilling to take advantage of these opportunities; or whether the decisions being made are "responsible" ones. There are also many other types of decisions that individuals may be involved in that were not a part of this survey. The decision areas covered by the Core Indicators survey are those identified at the national level as the most critical.

Outcomes of Services and Supports for Persons with Developmental Disabilities

Figure 6: Involvement in Decision-Making Comparing CCB Major Services, CCBs to RCs, and Adults in Services in 2000 to the General Population and to Adults in Services in 1993 (note that this table is continued to the next page)

Questions Related to Involvement in Decision-making	Comparison of CCB Adult Services			Comparison of CCB and RC Services			Comparison to General Population & Time		
	Supp'ed Living Services (SLS)	Compr ehensiv e Service (Comp)	Stat. Signif. Level	CCB Adults (SLS + Comp)	RC Adults	Stat. Signif. Level	Adults in Service in 2000	Adults in General Pop.	Adults in Service in 1993
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7	Col. 8	Col. 9
Can you talk to your case manager when you want to?					N/A*	N/A*	N/A*	N/A*	N/A*
Yes, usually no problem	93.0%	89.5%		91.3%					
In between	5.2%	4.1%		4.7%					
No, hard to reach him/her, calls aren't returned promptly	1.7%	6.4%		4.1%					
At your last planning meeting, did people listen to what you had to say?					N/A*	N/A*	N/A*	N/A*	N/A*
Yes, most times	87.1%	90.5%		88.8%					
Sometimes	10.5%	4.7%		7.6%					
No, rarely	2.3%	4.7%		3.5%					
Did you choose some of the programs, services & supports you are receiving?					N/A*	N/A*	N/A*	N/A*	
Yes	82.1%	82.4%		82.2%					76.9%
In between	11.9%	8.2%		10.1%					17.3%
No	6.0%	9.4%		7.7%					5.8%
Do you make most of the important decisions and choices that affect your life? Do you feel in control of your life?					N/A*	N/A*	N/A*	N/A*	
Yes	73.7%	65.6%		69.6%					76.9%
In between, make some important decisions	22.3%	26.2%		24.3%					17.3%
No	4.0%	8.2%		6.1%					5.8%
Did you help choose the place where you live? (if you do not live with relatives)						.0001			
Yes, unassisted	20.7%	14.5%		15.8%	0.0%		14.4%	42.1%	10.0%
Yes, with assistance	42.4%	39.9%		40.4%	14.3%		38.1%	45.4%	41.8%
No, someone else chooses	37.0%	45.6%		43.8%	85.7%		47.4%	12.6%	48.2%
Did you help choose the people you live with? (if you do not live alone & do not live with relatives)			.0001			.001			
Yes, unassisted	32.7%	6.7%		10.2%	0.0%		9.2%	75.4%	5.1%
Yes, with assistance	10.2%	18.3%		17.2%	2.3%		15.6%	21.5%	28.7%
No, someone else chose	57.1%	75.0%		72.6%	97.7%		75.2%	3.1%	66.2%
Do you decide what time you have dinner or what time you go to bed?			.002			.0001			
Yes, unassisted	58.7%	47.8%		52.5%	0.0%		49.2%	79.4%	31.9%
Yes, with assistance (or choose one but not the other)	18.5%	30.5%		25.3%	67.4%		28.0%	26.2%	35.3%
No, someone else decides	22.8%	21.7%		22.2%	32.6%		22.8%	4.1%	32.8%
Did you help choose the people or agencies that help you in your home?)			.005			.001			
Yes, unassisted	17.3%	7.0%		9.8%	0.0%		9.0%	56.2%	2.5%
Yes, with assistance	15.0%	13.8%		14.1%	0.0%		12.9%	21.9%	18.7%
No, someone else chose	67.7%	79.2%		76.1%	100.0%		78.1%	21.9%	78.8%
Do you help choose the things you do for fun?			.004			.0001			
Yes, unassisted	74.5%	64.5%		68.8%	7.0%		64.8%	73.9%	64.9%
Yes, with assistance	15.1%	25.9%		21.2%	65.1%		23.9%	24.2%	25.6%
No, someone else chooses	10.4%	9.6%		10.0%	27.9%		11.2%	1.8%	9.5%

* N/A = not available. Under the RC Adults Column 6, those results were unavailable as those questions were asked directly of consumers and too few RC consumers were able to respond due to their more significant disabilities. For that same reason, the Total 'Adults in Service in 2000' (Column 7) is not available, and only a CCB total (Column 4) is available. For Columns 8 and 9, these questions were not asked in that manner at those points in time or of that population.

Outcomes of Services and Supports for Persons with Developmental Disabilities

Figure 6: Involvement in Decision-Making Comparing CCB Major Services, CCBs to RCs, and Adults in Services in 2000 to the General Population and to Adults in Services in 1993 (this figure is continued from the previous page)

Questions Related to Involvement in Decision-making	Comparison of CCB Adult Services			Comparison of CCB and RC Services			Comparison to General Population & Time		
	Supp'ed Living Services (SLS)	Compr ehensiv e Service (Comp)	Stat. Signif. Level	CCB Adults (SLS + Comp)	RC Adults	Stat. Signif. Level	Adults in Service in 2000	Adults in General Pop.	Adults in Service in 1993
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6	Col. 7	Col. 8	Col. 9
Can you see your friends when you want to?						.0001			
Yes, unassisted	86.6%	86.1%		86.3%	60.7%		85.1%	66.5%	48.6%
Yes, with assistance	9.4%	11.4%		10.5%	25.0%		11.1%	29.4%	36.0%
No, someone else chooses	4.0%	2.5%		3.2%	14.3%		3.8%	4.1%	15.4%
Can you call or see your family when you want to see them? (leaving out families who don't want contact)						.0001			
Yes, unassisted	95.1%	92.0%		93.0%	61.8%		90.6%	N/A*	N/A*
Yes, with assistance	2.4%	5.5%		4.6%	20.6%		5.8%		
No, someone else chooses	2.4%	2.4%		2.4%	17.6%		3.6%		
Can you have or get to your own money whenever you want?			.0001			.0001			
Yes, unassisted	33.1%	14.3%		22.5%	4.7%		21.3%	N/A*	N/A*
Yes, with assistance	25.5%	34.7%		30.7%	16.3%		29.8%		
No, someone else decides	41.4%	51.0%		46.8%	79.1%		48.9%		
Who chooses what to buy with your own money?			.01			.0001			
I do, unassisted	55.0%	43.4%		48.4%	9.5%		46.0%	65.2%	39.9%
I do, with assistance	30.6%	39.8%		35.8%	38.1%		36.1%	31.7%	39.9%
Someone else chooses	14.4%	16.8%		15.7%	52.4%		18.0%	3.0%	20.2%
Are you currently an active member of a self-advocacy organization?									
Yes	8.5%	6.7%		7.5%	11.9%		7.8%	N/A*	N/A*
No	91.5%	93.3%		92.5%	88.1%		92.2%		

*N/A – not available, these questions were not asked in that manner at those points in time or of that population

RESULTS

Figures 6 through 8 present information relevant to answering several of the questions listed under “Progress Towards Goal”. These figures provide the percentage of adults by involvement level in choice areas surveyed overall and with comparisons by different service approaches, to the general population of Colorado, across time, and by setting size for out-of-home placements (Comprehensive Services).

OVERALL RESULTS: (Refer to Figure 6.)

Looking at the individual choice areas for all adults in service surveyed in 2000, a general impression may be formed regarding how likely adults with developmental disabilities are to be involved in different types of decisions.

- ❖ Looking at Figure 6, Column 4, most adults at CCBs had involvement in choosing their services (82%), felt they were listened to at program planning meetings (89%), felt they made most of the important decisions in their lives (70%) and could talk to their case managers when they wanted to (91%). These same questions were also asked of advocates of these consumers and the agreement level between these responses

was quite good (91-95% agreement in responses).

- ❖ 70% of adults at CCBs said they felt that they made most of the important decisions and felt in control of their life. (Figure 6, Column 4).
- ❖ Looking at Figure 6, Column 7, most adults (at CCBs plus RCs) choose without assistance what they do for fun (65%), can see their friends when they want to (85%), and can see their family when they want to (91%). When choice with and without assistance in considered, then the percentages are even higher.
- ❖ There were some areas where choice was rarely provided. The majority of adults receiving services have had no involvement in choosing: who they live with (75%) or the people and/or agencies who provide them with supports in their home (78%). Almost half of the adults in services had no involvement in choosing the place where they live (47%) and were not given access their money when they wanted (49%). (Figure 6, Column 7)

Outcomes of Services and Supports for Persons with Developmental Disabilities

COMPARISONS OF MAJOR CCB SERVICE SYSTEM APPROACHES (Refer to Figure 6, Columns 1-3)

In the first three Columns of Figure 6, involvement in decision-making for adults receiving services is compared by the two major CCB service approaches: Supported Living Services (Column 1) and Comprehensive Services (Column 2) with the statistical significance level, if any, noted in Column 3 based on the Chi Square test. The findings are summarized below:

- ❖ Adults receiving CCB services under SLS and under Comprehensive Services were involved in making choices to a similar degree for 8 of the 14 choice areas surveyed (i.e., the differences were not statistically significant).
- ❖ Adults in SLS were provided more involvement in making choices for 6 of 14 choice areas (where the differences were statistically significant). These choice areas were: choosing the people you live with; the time to have dinner or to go to bed; choosing the people or agencies who provide supports in the home; choosing things that are done for fun; having access to their money when they want it, and what to buy with their own money.
- ❖ When overall choice was compared in terms of an index that summed the involvement levels across all questions, then the difference between SLS (average choice index of 13) and Comprehensive Services programs (average choice index of 11) was small, but still statistically significant (ANOVA, .01). (Not shown on the above figure.)

COMPARISONS OF CCB and RC SERVICE SYSTEM APPROACHES (Refer to Figure 6, Columns 4-6)

Involvement in decision-making is compared by community service system (CCB, Column 4) and state-operated service system (RC, Column 5) with the statistical significance level noted in Column 6 based on the Chi Square test. These results are summarized below.

- ❖ Adults receiving support through CCBs were provided more involvement in making decisions in 9 of the 14 choice areas surveyed (where the difference was significant). However, since RC consumers have more significant disabilities on the average, this finding is not surprising. (See the methodology section for cautions when making comparisons of outcomes for RC and CCB consumers.)
- ❖ All other differences in choice areas were not statistically significant.
- ❖ The difference in the overall choice involvement (as measured by the average choice index value) was statistically significant (ANOVA, .0001) between CCB (average choice index of 12) and RC programs (average choice index of 7). Again, based on the higher support needs of individuals served at RCs, this finding was expected.

“Speaking for yourself begins in day-to-day life. To learn to act as a responsible adult, other people (parents, relatives, friends, and staff people) have to see you and treat you as a responsible adult every day.”

*Carabello and Bittinger
Consumer Advocacy, 1992*

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IMPACT OF SUPPORT LEVELS

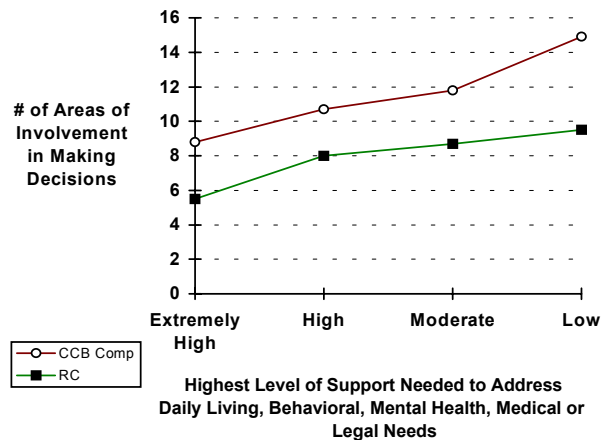
We investigated the potential that the decision-making involvement of adults by the service approaches (i.e. CCB or RC) was more a function of the higher average needs of the adults in RCs as compared to those in CCBs rather than a function of differences in service values or opportunities. A two-way ANOVA (Analysis of Variance) test was used, which is a statistical approach for examining the relative impact and interaction of two variables [i.e. need/support level and service approach (RC or CCB)] on a third variable (i.e., involvement in making decisions). This allowed us to statistically adjust for support level and independently compare involvement in decision making at RCs and CCBs for each support level.

An index was calculated by summing the involvement levels across all decisions in which each individual was involved with an adjustment for missing data. This index was then compared for adults in each need/support category for RCs and CCBs. The support/need category was based on the highest support level provided to address their needs in the areas of daily living, behavioral, mental health, medical, and legal.

The following trends were statistically significant (see Figure 7):

- ❖ Adults provided out-of-home comprehensive services have more involvement in making choices when served by CCBs than when served by RCs, regardless of their support level needs (ANOVA, .0001). Therefore, differences observed in decision making between RCs and CCB are not simply due to differences in the support level needs of the adults who receive those services, but instead adults at any need/support level are more likely to be involved in decisions if they are served by CCBs than by RCs. That difference is small (about 2 areas of decision making), but statistically significant.
- ❖ It is a very positive finding that adults at both RCs and CCBs are provided more involvement in making choices as their need for support decreases (ANOVA, .0001). This indicates that, as persons are more capable of making decisions they are also being provided more opportunities to make decisions. This also explains part of the differences observed between Columns 4 and 5 on Figure 6 (i.e. consumers at CCBs would be expected to have a higher overall average involvement in decision making than RCs on a question by question basis, since CCBs have a higher proportion of persons at lower support levels.)

Figure 7: Decision-making Involvement by Support Level and Residential Setting



GENERAL POPULATION COMPARISON (Refer to Figure 6, Columns 7-8)

It might be argued that it is axiomatic that adults with developmental disabilities would make fewer decisions independently than the general population of adults, due to the very characteristics that make them eligible for services. However, there is little reason that most adults with developmental disabilities should not be involved in making decisions with the assistance of others. Therefore, the comparison to the Colorado general population might best be made comparing the sum of the “Yes, unassisted” and “Yes with assistance” rows (or alternatively by comparing the “No, someone else chose”). Some findings include:

- ❖ While statistical significance tests were not possible, an assumption might be made that a difference of 5% or greater is significant. Given that assumption, a much larger proportion of citizens of Colorado had some involvement in all 7 choice areas where data was available for both groups.
- ❖ While a surprising number of adults in the general population also expressed no involvement in many of these choice areas (anywhere from 2% to 22%), this percentage was always substantially lower than for adults receiving services. Also, when the general population was asked if they would like to have more say in those areas, generally less than a fraction of one percent of them wanted more say. This indicates that they were allowing or asking others in their lives to make such decisions for them. This, then, was their decision.

Outcomes of Services and Supports for Persons with Developmental Disabilities

CHANGES FROM 1993 to 2000 (Compare Columns 7 and 9 on Figure 6.)

- ❖ While statistical significance tests were not possible, an assumption was made that a change of 5% or greater is significant.
- ❖ Given that assumption, there was an increase in involvement in choices (decisions made by self or with the help of others) from 1993 to 2000 for 2 of the 7 areas: choosing when to have dinner or to go to bed and seeing friends when you want to.
- ❖ There was a decrease from 1993 to 2000 in making decisions in one area where the change exceeded 5%, which was in helping to choose the people you live with.

COMPARISON OF SETTING SIZE FOR CCB COMPREHENSIVE SERVICE APPROACHES (Refer to Figure 8, Columns 1-3)

In the first three Columns of Figure 8, involvement in making decisions is compared for adults served in CCB Comprehensive Services by whether they are in a larger setting (group home of 4 or more persons) or in a smaller setting of 3 or fewer persons. If the differences are statistically significant based on the Chi Square test, then the level is noted in Column 3. The findings are below.

- ❖ Adults receiving Comprehensive Services from CCBs had similar levels of involvement in decision making (i.e. any differences noted were not statistically significant) regardless of setting size for 8 of the 10 choices areas that could be compared.
- ❖ Adults receiving support in smaller settings had more involvement in choices (where the difference was statistically significant) in 2 areas (when to have dinner or to go to bed and choosing things to do for fun).

COMPARISONS OF SETTING SIZE FOR RC COMPREHENSIVE SERVICE APPROACHES (Refer to Figure 8, Columns 4-6)

In the last three Columns of Figure 8, involvement in making decision is compared for adults served in RCs by whether they are in a larger setting (campus) or in a smaller settings (groups homes of 8 or less or smaller apartments). If the differences are statistically significant then the level is noted in Column 6 based on the Chi Square test. Findings are summarized below.

- ❖ Involvement in decision-making was similar (i.e. no statistically significant differences) for 8 of the 10 choice areas compared across RC setting sizes.
- ❖ The areas where adults were afforded more choice in RC smaller settings as compared to the campus, was in being able to call or see their friends and family members when they wanted to (these differences were statistically significant). However, it should be noted that persons in the campus settings might have appropriate restrictions related to such social activities due to behavioral or legal issues.



“We learn, when we respect the dignity of people, that they cannot be denied the right to participate fully in the solutions of their own problems...To give people help, while denying them a significant part of the action, contributes nothing to the development of the individual...Denial of the opportunity for participation is denial of human dignity and democracy. It will not work.”

Saul Alinsky, 1992

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Figure 8: Involvement in Decision-Making Comparing Comprehensive Services by CCB Setting Size and RC Setting Size

Questions Related to Involvement in Decision-making	Comparison of Sizes of CCB Comprehensive Services			Comparison of RC Campus to Group Home/Apt Programs		
	Individual Setting (3 or fewer persons)	Group Home (4+ persons)	Statistical Significance Level	RC Group Hm or Apt	RC Campus	Statistical Significance Level
	Col. 1	Col. 2	Col. 3	Col. 4	Col. 5	Col. 6
Did you help choose the place where you live? (if you do not live with relatives)						
Yes, unassisted	17.2%	8.8%		0.0%	0.0%	
Yes, with assistance	40.3%	38.6%		14.8%	13.3%	
No, someone else chose	42.4%	52.6%		85.2%	86.7%	
Did you help choose the people you live with? (if you do not live alone & do not live with relatives)						
Yes, unassisted	9.1%	2.6%		0.0%	0.0%	
Yes, with assistance	18.8%	17.4%		3.6%	0.0%	
No, someone else chose	72.1%	80.0%		96.4%	100.0%	
Do you decide what time you have dinner or what time you go to bed?			.002			
Yes, unassisted	54.3%	35.0%		0.0%	0.0%	
Yes, with assistance (or choose one but not the other)	25.9%	39.2%		64.3%	73.3%	
No, someone else decides	19.8%	25.8%		35.7%	26.7%	
Did you help choose the people or agencies that help you in your home?						
Yes, unassisted	7.7%	5.9%		0.0%	0.0%	
Yes, with assistance	14.4%	12.6%		0.0%	0.0%	
No, someone else chose	77.9%	81.5%		100.0%	100.0%	
Do you help choose the things you do for fun?			.02			
Yes, unassisted	69.1%	55.0%		7.1%	6.3%	
Yes, with assistance	21.4%	35.0%		57.1%	75.0%	
No, someone else chooses	9.5%	10.0%		35.7%	18.8%	
Can you see your friends when you want to?						.054
Yes, unassisted	85.8%	86.8%		72.7%	20.0%	
Yes, with assistance	11.6%	12.1%		13.6%	60.0%	
No, someone else chooses	2.6%	1.1%		13.6%	20.0%	
Can you call or see your family when you want to see them? (leaving out families who don't want contact)						.003
Yes, unassisted	93.5%	90.5%		81.0%	25.0%	
Yes, with assistance	4.9%	6.7%		14.3%	33.3%	
No, someone else chooses	1.6%	2.9%		4.8%	41.7%	
Can you have or get to your own money whenever you want?						
Yes, unassisted	16.4%	9.9%		3.4%	6.7%	
Yes, with assistance	33.6%	37.2%		20.7%	6.7%	
No, someone else chooses	50.0%	52.9%		75.9%	86.7%	
Who chooses what to buy with your own money?						
I do, unassisted	47.7%	34.7%		7.1%	13.3%	
I do, with assistance	36.6%	46.3%		42.9%	33.3%	
Someone else chooses	15.6%	19.0%		50.0%	53.3%	
Are you currently an active member of a self-advocacy organization?						
Yes	7.1%	5.8%		14.8%	6.7%	
No	92.9%	94.2%		85.2%	93.3%	

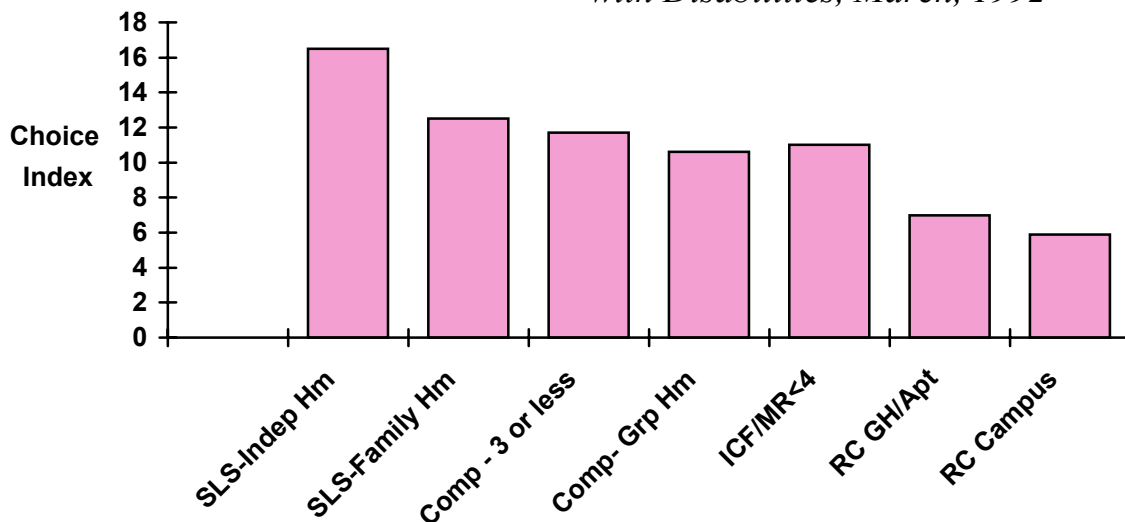
INVOLVEMENT IN DECISION-MAKING BY WHERE YOU LIVE AND SUPPORTS PROVIDED

Figure 9 compares the overall choice index for adults with developmental disabilities by where the adult is living and how he/she is supported. (Refer to the Program Evaluation Methodology section earlier in this report for a definition of the service categories.) The purpose of this comparison is to determine if some settings/support type combinations are more successful in providing choice than others.

The following statements summarize this figure:

- ❖ Of all settings, adults having the most involvement in decision-making are those receiving SLS while living in their own homes or apartments. However, this finding may be more related to the support level of the individuals in that setting than due to a difference in opportunities provided by that program. As earlier ANOVA analyses indicated, the lower the need/support level, the higher the activity level. Adults in SLS who live in their own home/apartment are typically also those with the lowest average need/support level.
- ❖ Adults living in Regional Centers had the least involvement in making decisions, on the average. As discussed previously, ANOVA analyses indicate that much of this difference is attributable to higher average need/support levels of the individuals living in these settings.
- ❖ CCB Comprehensive services provide a similar level of involvement in decision-making regardless of whether the person lives in a Group Home or a smaller setting.

Figure 9: Comparison of Involvement in Choices by Where Someone Lives



IMPACT OF DEMOGRAPHICS ON INVOLVEMENT IN DECISION MAKING

Age

No statistically significant differences were found in the level of involvement in decision making of adults in services based on their age.

Gender

No statistically significant differences were found in the level of involvement in decision making of adults served based on gender.

Minorities

Minority adults did have a slightly lower involvement in decision-making on the average than did other adults (ANOVA, .05). The difference was very small (less than 1 on average.) This result was also present in 1993. This difference did not exist in the Colorado general population data.

Urban versus Rural Setting

Adults living in urban areas were more involved in decisions on the average than were adults living in rural areas (ANOVA, .0001). This difference was small (about 2 on the average).

“Personal life satisfaction increases when people are able to select their own goals, make choices, and exercise control over their life situations.”

Accreditation Council on Services for People with Disabilities, March, 1992