

# **BAY AREA QUALITY MANAGEMENT SYSTEM**

## **ADULT FAMILY SURVEY RESULTS**

**Medicaid Waiver Sample**

**Year One Data (2005)**

### **FINAL REPORT**

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## Executive Summary

### **Background**

The California Department of Developmental Services (DDS) was awarded a *Real Choice Systems Change* grant from the Centers for Medicare and Medicaid Services (CMS) in 2003 to strengthen its current quality assurance and improvement system. One of the primary objectives of the grant is to develop a process for measuring participant satisfaction and outcomes. To achieve this goal, the Department implemented a pilot project in the San Francisco Bay Area across three sites: Golden Gate Regional Center (GGRC), Regional Center of the East Bay (RCEB), and San Andreas Regional Center (SARC).

The three-year pilot project has two overarching goals: (1) to provide data for the *Bay Area Quality Management System (QMS)*, which is involved with the transition of people from the Agnews Developmental Center to community-based settings, and (2) to pilot an assessment tool that may potentially be used across California's 21 regional centers.

This report is one of a series of analyses prepared by the Human Services Research Institute (HSRI) to summarize the results of the grant activities related to the first goal stated above. Each report addresses a different target group and presents results of data collected using survey tools developed for the National Core Indicators (NCI) program. There are several NCI mail surveys designed to gather feedback from families and guardians. The two mail surveys used in this study include the "**Adult Family Survey**," which is administered to families who have an adult consumer living at home with them, and the "**Family Guardian Survey**," which is administered to families or guardians of consumers who receive supports outside of the family home. **This report presents results from the Adult Family Survey, which was administered to a sample of families and guardians of consumers who receive Medicaid Waiver services and supports in the family home.** Results of the Family Guardian Survey are presented in a separate report.

### **Methods**

The pilot project steering committee selected the National Core Indicators (NCI) instruments to be used as the data collection tools for this activity. These surveys are used across the country by 27 state developmental disabilities service systems and by one regional center in California. The tools have been tested for validity and reliability, and they also have the advantage of producing national benchmarks for comparison purposes. The surveys are specifically designed to measure performance and outcome indicators. The committee selected these tools for their benchmarking potential and for their correspondence with the quality measure domains of interest to the California DDS.

The NCI Adult Family Survey (conducted by mail) was administered by a private contractor, XenologiX. The first year of data collection took place in 2005.

## **Sample**

At the time of the survey, there were 7,901 consumers over age 18 on the Medicaid Waiver. Adult Family Surveys were mailed to a sample of 773 families across the three regional centers. A total of 190 useable Adult Family Survey responses were obtained.

## **Positive Findings and Trends**

- A greater percentage of Bay Area families (67%) are having their needs met by services and supports than in the other NCI states (58%).
- Over 90% of Bay Area families have access to necessary medications for their family member (91%).
- Adult family members in the Bay Area report that staff turnover is less of a problem than it is in other NCI states. Only 14% reported that frequent changes in support staff are a problem for the family; this is compared to 23% in other NCI states.
- Only 7% of respondents report that they have seldom or never helped with developing their family member's service plan
- A much greater percentage of respondents (46%) report that they know how much money is spent by the MR/DD agency on behalf of their family member as compared to the other NCI states (27%).
- 80% of respondents state that services and supports have made a positive difference in the life of their family member (other NCI states: 70%).

## **Possible Target Areas for Quality Improvement**

- Of those respondents whose first language was not English, only 56% report that there were support workers or translators available to them who spoke in their preferred language. This was compared to 69% in other NCI states.
- Only a little over half (53%) of respondents receive help when asking for services or supports in an emergency or crisis. These findings are similar to the other NCI states.
- There seems to be a significant gap concerning community activities. Only 38% of respondents state that their family member has access to community activities (other NCI states: 51%), and 18% report that their family member participates in community activities (other NCI states: 32%).
- While 60% of families want themselves or their family member to have control over hiring/management of the support workers, only 41% actually have it.
- Less than half (46%) of Bay Area adult family members report receiving enough information to help participate in the planning of services. This was compared to 52% in the other NCI states.

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## **I. INTRODUCTION**

The California Department of Developmental Services (DDS) was awarded a *Real Choice Systems Change* grant from the Centers for Medicare and Medicaid Services (CMS) in 2003 to strengthen its current quality assurance and improvement system. One of the primary objectives of the grant is to develop a process for measuring participant satisfaction and outcomes. To achieve this goal, the Department implemented a pilot project in the San Francisco Bay Area across three sites: Golden Gate Regional Center (GGRC), Regional Center of the East Bay (RCEB), and San Andreas Regional Center (SARC).

### ***Overall Purpose of the Study***

The three-year pilot project has two overarching goals: (1) to provide data for the *Bay Area Quality Management System (QMS)*, which is involved with the transition of people from the Agnews Developmental Center to community-based settings, and (2) to pilot an assessment tool that will eventually be used consistently across California's 21 regional centers.

The specific goals of the pilot project are to:

- ◆ Support value based outcomes
- ◆ Keep people safe and ensure their well-being
- ◆ Ensure consumer and family satisfaction
- ◆ Identify and close gaps in the community system
- ◆ Develop a system with potential for statewide use
- ◆ Meet the expectations of the Centers for Medicare and Medicaid Services

In 2004, the project Steering Committee selected the National Core Indicators (NCI) as the best assessment tool to gauge participant satisfaction and designated a private company, XenologiX, to carry out evaluation activities.

### ***Focus of this Report***

The results presented herein represent information gathered through a mail survey of a sample of families of adult consumers (18+) who receive Medicaid Waiver services and live in the family home.

Data are presented in this report by outcome area so that the Bay Area QMS can evaluate how well the measures inform the stated Outcome Performance Indicators, many of which correspond to the National Core Indicators domains. The data included here are from the first year of data collection (2005). Both quantitative and qualitative data are presented in an effort to capture the nuances of the experiences of families. The data are organized by the following domains:

- ◆ Information And Planning
- ◆ Access And Delivery Of Services And Supports
- ◆ Choices And Control
- ◆ Community Connections
- ◆ Satisfaction With Services And Outcomes

## II. METHODS

This section describes the survey tools, research methodology, and administrative procedures used to collect the data and to ensure the validity of the information gathered.

The pilot project steering committee selected the National Core Indicators (NCI) instruments to be used as the data collection tools for this activity. These surveys are used across the country by 24 state developmental disabilities service systems and by one regional center in California. The tools have been tested for validity and reliability, and they also have the advantage of producing national benchmarks for comparison purposes. The surveys are specifically designed to measure performance and outcome indicators. The committee selected these tools for their benchmarking potential and for their correspondence with the quality measure domains of interest to the California DDS.

### ***Overview of National Core Indicators***

In 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI) launched the Core Indicators Project (CIP). The project's aim was to support state developmental disabilities authorities (SDDAs) in developing and utilizing performance/outcome indicators and related data collection strategies. These indicators, along with the results from data collection efforts, would enable them to measure their service delivery system's performance, and inform future decision-making around systems change. The indicators, measurement tools, and results offered by this project provide SDDAs with a fundamental resource to improve system performance, and ultimately better serve people with developmental disabilities and their families.

CIP began in 1997 when its Steering Committee selected a "candidate" set of 61 performance/outcome indicators (focusing on the adult service system), in order to test their utility/feasibility. Seven states field tested these indicators by administering the project's consumer and family surveys and compiling other data. The results were compiled, analyzed and reported to participating states.

In the ensuing years, the original indicators, data collection tools, and methods have been periodically revised and improved under the guidance of the project's steering committee. In 2001, the project expanded its scope to include services for children with developmental disabilities and their families. In 2002, The Core Indicators Project (CIP) officially changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. By 2005, NCI had grown to include participation by 23 states and three local developmental disabilities authorities.

NASDDDS' active involvement and sponsorship of NCI efforts continues to facilitate states' efforts to pool their knowledge, expertise and resources in this endeavor.

The following table illustrates current participation in the National Core Indicators:

Table 1 State Participation in NCI	
Alabama	Massachusetts
Arizona	New Mexico
Arkansas	North Carolina
CA - Bay Area Regional Centers	Oklahoma
CA - Regional Center of Orange County	Pennsylvania
Connecticut	Rhode Island
Delaware	South Carolina
District of Columbia	South Dakota
Georgia	Texas
Hawaii	Vermont
Indiana	Washington
Kentucky	West Virginia
Maine	Wyoming

### ***Family Indicators***

Obtaining direct feedback from families is an important means for states to gauge satisfaction with services and supports as well as to pinpoint potential areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to gauge changes in performance over time. In addition, these results permit a state to compare its own performance against other states. The table below details the Family Sub-Domains, Concerns, and Indicators, and identifies the survey instruments in which the indicators are explored.

**Table 2**  
**Family Indicators**

<b>Table 2</b>			
<b>Family Indicators</b>			
<b>DOMAIN</b>	<b>FAMILY INDICATORS</b>		
	The project's family indicators concern how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.		
<b>SUB-DOMAIN</b>	<b>CONCERN</b>	<b>INDICATOR</b>	<b>DATA SOURCE</b>
<b>Information &amp; Planning</b>	Families/family members with disabilities have the information and support necessary to plan for their services and supports.	The proportion of families who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	All Surveys
		The proportion of families who report they have the information needed to skillfully plan for their services and supports.	All Surveys
		The proportion of families reporting that their support plan includes or reflects things that are important to them.	All Surveys
		The proportion of families who report that staff who assist with planning are knowledgeable and respectful.	All Surveys
<b>Choice &amp; Control</b>	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.	The proportion of families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).	Children & Adult Family Surveys
		The proportion of families who report they choose, hire and manage their service/support providers.	All Surveys
		The proportion of families who report that staff are respectful of their choices and decisions.	All Surveys
<b>Access &amp; Support Delivery</b>	Families/family members with disabilities get the services and supports they need.	The proportion of eligible families who report having access to an adequate array of services and supports.	All Surveys
		The proportion of families who report that services/supports are available when needed, even in a crisis.	All Surveys
		The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication .	All Surveys
		The proportion of families who report that service and support staff/providers are available and capable of meeting family needs.	All Surveys
		The proportion of families who report that services/supports are flexible to meet their changing needs.	All Surveys
		The proportion of families who indicate that services/supports provided outside of the home (e.g., day/employment, residential services) are done so in a safe and healthy environment.	Both Adult Surveys
<b>Community Connections</b>	Families/family members use integrated community services and participate in everyday community activities.	The proportion of families/family members who participate in integrated activities in their communities.	All Surveys
		The proportion of families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	All Surveys
<b>Family Involvement</b>	Families maintain connections with family members not living at home.	The proportion of families/guardians of individuals not living at home who report the extent to which the system supports continuing family involvement.	Family/Guardian Survey
<b>Satisfaction</b>	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	All Surveys
<b>Family Outcomes</b>	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Children & Adult Family Surveys

## ***Description of the Adult Family Survey***

The Adult Family Survey is administered to families who have an adult family member living at home with them. The survey asks families to express their overall level of satisfaction with services and supports their family member receives, as well as probes specific aspects of the service system's effectiveness. Along with demographic information, the survey includes questions related to: the planning for services and supports; access to and delivery of services and supports; choice in and control over supports; connections with the community; and satisfaction and outcomes. Combined, this information provides an overall picture of family satisfaction.

- **Demographics** – The survey instrument begins with a series of questions tied to characteristics of the family member with disabilities (e.g., individual's gender, age, race, type and level of disability), followed by questions pertaining to the respondent (e.g., respondent's age, relationship to individual, health and income).
- **Services Received** – This section of the survey asks respondents to identify the services and supports their family member and or family receive.
- **Service Planning, Delivery & Outcomes** – The survey contains several groupings of questions that probe specific areas of quality service provision (information and planning, access to and delivery of services, choice and control, community connections, satisfaction and outcomes). Each question is constructed so that the respondent can select from three possible responses ("always or usually", "sometimes", and "seldom or never"). Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable.
- **Additional Comments** – Finally, the survey provides an opportunity for respondents to make additional open-ended comments concerning their family member's participation in and experiences with the service system.

## ***NCI Recommended Sampling & Administration***

NCI recommends that states administer the Family Guardian Survey by selecting a random sample of 1,000 families who: a) have an adult family member with developmental disabilities living at home, and b) receive service coordination/case management and at least one additional "direct" service or support. Adults are defined as individuals with disabilities age 18 or older. A sample size of 1,000 is selected in anticipation that states obtain at least a 40% return rate, yielding 400 or more usable responses per state. With 400 usable responses per state, the results may be compared across states within a confidence level of +10%. In states where there were fewer than 1,000 potential respondent families, surveys are sent to all eligible families.

## ***Sampling Methodology\****

\* Information in this section is summarized from an earlier XenologiX report.

Xenologix developed a sampling plan to conduct the NCI Consumer Survey, and then targeted the families of these individuals to develop a sampling plan for the two NCI Family

Surveys. Below, brief descriptions of both the consumer and family sampling plans are provided:

The Bay Area Pilot Project is focused on assessing the quality of services and supports provided to consumers who are 18 years of age or older, and served by one of the three local regional centers.

NCI parameters require conducting a minimum of 400 in-person interviews for the Consumer Survey. The XenologiX study parameters dictated that the results be analyzed across the regional centers. Therefore, a larger sample would be needed. For participation in the Consumer Survey, a census to include 100% of the population of consumers who transitioned to the community was targeted. For the population of consumers who receive Medicaid Waiver funding, a random sample was drawn and provided by DDS. The DDS sample contained key contact information, including consumer and parent/guardian names, addresses, type of residence, and primary language. After receiving the sample records, XenologiX “cleaned” the sample, removing all invalid records. For the purpose of this study, invalid was defined as records where the address provided was insufficient for mailing or where the consumer’s status with the regional center was inactive, closed, deceased, or transferred.

The random sample was designed to assure a 95% confidence interval (i.e.,  $\pm 5\%$  margin of error). This included the overage required to compensate for invalid contact information and refusals to participate. For both sample populations, regional center staff obtained consent from the consumer or legal guardian to release consumer contact information to XenologiX. The original sampling plan was later revised to a sampling plan with a 90% confidence interval and  $\pm 10\%$  margin of error due to timeline/workload issues encountered.

The chart below details the populations served by each of the participating regional centers, the sample size pulled for each population segment, the consumer interview/family survey consents received, and the number of interviews required for each confidence interval.

Regional Center	Population Served	Sample	Consents	Interviews (95%)	Interviews (90%)
GGRC • Medicaid Waiver, 18+ • Consumers transitioned	2,039 11	588	277	377	221
RCEB • Medicaid Waiver, 18+ • Consumers transitioned	3,349 11	691	312	414	249
SARC • Medicaid Waiver, 18+ • Consumers transitioned	2,513 42	798	304	397	243
• Medicaid Waiver, 18+ • Consumers transitioned	<b>TOTAL</b> <b>7,901</b> <b>64</b>	<b>2,077</b>	<b>893</b>	<b>1,188</b>	<b>713</b>

The sampling plan developed for the Consumer Survey was also utilized for the two NCI Family Surveys (Adult Family Survey, Family Guardian Survey). The family surveys, however, targeted the family members and guardians of consumers, rather than the consumers themselves as respondents. XenologiX's target number of completions for the family surveys, combined, was 400. (Please note: NCI actually recommends a target number of 400 completed surveys for EACH survey. That is, NCI recommends submission of 400 Adult Family Surveys, and 400 Family Guardian Surveys). The following chart provides, for each of the three regional centers, a summary of the sample records received, and then details the number and type of surveys disseminated per regional center.

<b>Table 4</b>				
	<b>GGRC</b>	<b>RCEB</b>	<b>SARC</b>	<b>Total</b>
DDS Records Received	527	687	798	2,012
Invalid Records	2	4	6	12
= Valid Records	525	683	792	2,000
Adult Family Survey (English)	191	242	259	692
Adult Family Survey (Spanish)	25	25	13	85
Family Guardian Survey (English)	306	420	465	1,191
Family Guardian Survey (Spanish)	3	8	21	32
<b>Total Mailing</b>	<b>525</b>	<b>683</b>	<b>792</b>	<b>2,000</b>

### **Data Collection Methodology\***

\* Information in this section is summarized from an earlier XenologiX report.

Each of the three regional centers was provided a sample introduction (pre-notification) letter for the Adult Family Survey, which they could modify to accompany the survey. The letter described the survey's purpose and encouraged families to respond.

Letters and Adult Family Surveys were mailed to 773 families (in the family's preferred language), along with a postage-paid, return envelope. Survey envelopes were stuffed by The Arc of Ventura County, based on instructions provided by XenologiX. The mailings were sent in several distributions during July 2005, and responses were received until XenologiX's target number was reached in October 2005.

### **Data Analysis**

XenologiX's target number of survey completions (for both the Adult Family and Family Guardian Surveys) was 400. XenologiX received 431 responses. After data cleaning by XenologiX, it was determined that 396 of the responses were usable. Target completes by regional center were not established due to the relatively small number of total responses targeted and the number of surveys that were found invalid.

HSRI received from XenologiX data that included 200 responses to the Adult Family Survey and 196 responses to the Family Guardian Survey, totaling 396 survey responses. Further data cleaning of the Adult Family Survey responses by HSRI staff

determined that 190 of the 200 submitted responses were valid for analysis. HSRI personnel “clean data” (i.e., exclude invalid responses) based on four criteria:

- ◆ The question "Does your family member live at home with you?" was used to screen out respondents who received a survey by mistake. For instance, if a respondent indicated that their family member with disabilities lived outside of the family home, yet received the Adult Family Survey, their responses were dropped. Four (4) Bay Area Regional Center survey responses were dropped for this reason.
- ◆ If the respondent indicated that their family member with disabilities was under the age of 18, their responses were dropped.
- ◆ If the respondent indicates that no services other than case management are received, their responses were dropped. Six (6) Bay Area Regional Center survey responses were dropped for this reason.
- ◆ If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state/local authority, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 14) software for statistical analysis and N6 software for support in analysis of open-ended comments.

### III. RESULTS

The figures below provide the findings from the Adult Family Survey. It is important to note that the tables provide Bay Area Regional Centers results and state average results:

1. **Bay Area Regional Centers (“BARC”) Data** indicate the numbers and percentages across all three bay area regional centers.
2. **State Averages** indicate the numbers and average percentages across the other seven states and one local DD authority that conducted this survey in 2005. These include: California’s Orange County Regional Center, Connecticut, Hawaii, Oklahoma, Pennsylvania, South Carolina, West Virginia and Wyoming.

No statistical comparisons have been made between national and bay area results. The national data provided in the following tables and charts is solely provided for reference.

## Characteristics of Family Members with Disabilities

This section provides information about the individual with disabilities living in the household.

Characteristics of Family Member with a Disability			
	Bay Area Regional Centers		NCI State Avg. (8 Sites)
Number of surveys	190		4,031
	n	%	%
<b>Gender:</b>			
Male	98	53.3	53.2
Female	86	46.7	46.8
	184		
<b>Age:</b>			
Mean	36.7		33.4
Range	18-81		18-94
<b>Race/Ethnicity* (duplicated counts):</b>			
White	88	46.8	70.4
Black	20	10.6	9.2
Asian	41	21.8	9.4
American Indian/ Eskimo/Aleut	3	1.6	3.8
Hawaiian/Pacific Islander	4	2.1	2.8
Hispanic	29	15.4	5.3
Mixed Races	12	6.4	4.5
Other/Unknown	4	2.1	0.8
<b>More than 1 person with DD in household:</b>			
Yes	23	12.3	11.5
No	164	87.7	88.5
	187		
<b>Level of MR:</b>			
No MR label	16	8.8	4.6
Mild	22	12.1	19.5
Moderate	51	28.0	32.5
Severe	44	24.2	17.1
Profound	7	3.8	7.6
Don't know	42	23.1	18.8
	182		
<b>Other disabilities* (duplicated counts):</b>			
Mental illness	23	12.9	14.9
Autism	27	15.2	11.0
Cerebral Palsy	34	19.1	19.5
Brain injury	16	9.0	11.1
Seizure disorder/ neurological	44	24.7	30.8
Chemical dependency	1	0.6	0.9
Vision or hearing impairments	45	25.3	24.6
Physical disability	42	23.6	27.2
Communication disorder	44	24.7	22.8
Alzheimer's disease	0	0.0	0.4
Down Syndrome	39	21.9	18.7
Other disability	31	17.4	17.3

## Characteristics of Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the individual with disabilities living in the household.

Characteristics of Respondents			
	Bay Area Regional Centers		NCI State Avg. (8 Sites)
Number of surveys	190		4,031
<b>Age:</b>			
	n	%	%
Under 35	14	7.4	4.9
35 to 54	43	22.9	36.8
55 to 74	109	58.0	47.8
75 and Over	22	11.7	10.6
	188		
<b>Relationship to consumer:</b>			
Parent	156	82.1	83.0
Sibling	22	11.6	8.7
Spouse	0	0.0	0.8
Other	12	6.3	7.6
	190		
<b>If other relationship, please specify</b>			
Sister	4	36.4	Not Available
Aunt/Uncle/Niece	5	45.5	
Grandparent	1	9.1	
Step-Parent	1	9.1	
	11		
<b>Respondent is primary caregiver:</b>			
Yes	179	94.7	96.1
No	10	5.3	3.9
	189		
<b>Respondent is guardian or conservator:</b>			
Yes	103	56.9	67.2
No	78	43.1	32.8
	181		
<b>Health of respondent:</b>			
Excellent	45	23.8	20.2
Good	101	53.4	52.4
Fair	39	20.6	23.3
Poor	4	2.1	4.2
	189		
<b>Household Income</b>			
Below \$15,000	26	15.9	28.7
\$15,001-\$25,000	49	29.9	22.1
\$25,001-\$50,000	45	27.4	27.8
\$50,001-\$75,000	24	14.6	11.8
Over \$75,000	20	12.2	9.6
	164		

## Services and Supports Received

This section provides information about the services and supports (other than service coordination) that adults with developmental disabilities and their families receive.

Services & Supports Received			
	Bay Area Regional Centers		NCI State Avg. (8 Sites)
Number of surveys	190		4,031
<b>Financial Support</b>			
	n	%	%
Yes	75	43.9	36.9
No	96	56.1	63.1
	171		
<b>In-Home Support</b>			
Yes	82	44.1	34.8
No	104	55.9	65.2
	186		
<b>Out-of-Home Care</b>			
Yes	53	28.8	27.8
No	131	71.2	72.2
	184		
<b>Day/Employment Supports</b>			
Yes	161	86.6	64.0
No	25	13.4	36.0
	186		
<b>Transportation</b>			
Yes	143	76.9	57.9
No	43	23.1	42.1
	186		
<b>Other Services/Supports</b>			
Yes	44	24.4	26.4
No	136	75.6	73.6
	180		

## National Core Indicators

On the next several pages, the questions and results are discussed that tie directly to the National Core Indicator domains for assessing service and support quality. These questions are grouped as they pertain to 1) information and planning; 2) access and delivery of services and supports; 3) choice and control; 4) community connections; and 5) overall satisfaction and outcomes.

For each domain and question, a Table and Chart are provided. The Tables detail results (by domain) for the Bay Area Regional Centers, and the state/local DD authority average (i.e., the average percentage of the state-by-state results) for other sites participating in this survey. The Charts detail the same information, but in a question-by-question format.

## Information and Planning

Information and Planning		
	Bay Area Regional Centers	NCI State Avg. (8 Sites)
<b>Q1 - Do you receive information about the services and supports that are available to your family?</b>		
Number of surveys	176	
% always or usually	45.5	47.3
% sometimes	36.4	37.1
% seldom or never	18.2	15.6
<b>Q2 - If you receive information, is it easy to understand?</b>		
Number of surveys	166	
% always or usually	55.4	55.7
% sometimes	39.2	37.6
% seldom or never	5.4	6.7
<b>Q3 - Do you get enough information to help you participate in planning services for your family?</b>		
Number of surveys	162	
% always or usually	46.3	52.4
% sometimes	34.6	31.2
% seldom or never	19.1	16.4
<b>Q4 - If your family member has a service plan, did you help develop the plan?</b>		
Number of surveys	135	
% always or usually	72.6	75.1
% sometimes	20.0	15.9
% seldom or never	7.4	9.0
<b>Q5 - If your family member has a service plan, does the plan include things that are important to you?</b>		
Number of surveys	142	
% always or usually	71.1	68.8
% sometimes	22.5	24.0
% seldom or never	6.3	7.2
<b>Q6 - Do the staff who assist you with planning help you figure out what you need as a family to support your family member?</b>		
Number of surveys	159	
% always or usually	59.7	61.2
% sometimes	26.4	26.6
% seldom or never	13.8	12.2
<b>Q7 - Do the staff who assist you with planning respect your choices and opinions?</b>		
Number of surveys	160	
% always or usually	78.8	78.0
% sometimes	16.3	17.4
% seldom or never	5.0	4.7
<b>Q8 - Are the staff who help you with planning generally respectful and courteous?</b>		
Number of surveys	163	
% always or usually	90.8	89.0
% sometimes	6.7	9.0
% seldom or never	2.5	2.0
<b>Q9 - Are the staff who assist you with planning generally effective?</b>		
Number of surveys	157	
% always or usually	71.3	68.2
% sometimes	22.9	25.9
% seldom or never	5.7	5.9
<b>Q10 - Can you contact the staff who assist you with planning whenever you want to?</b>		
Number of surveys	168	
% always or usually	80.4	77.6
% sometimes	15.5	18.1
% seldom or never	4.2	4.3

## Access and Delivery of Services and Supports

Access and Delivery of Services and Supports		
	Bay Area Regional Centers	NCI State Avg. (8 Sites)
<b>Q11 - When you ask the service/support coordinator for assistance, does he/she help you get what you need?</b>		
Number of surveys	172	
% always or usually	73.8	68.7
% sometimes	22.7	25.2
% seldom or never	3.5	6.1
<b>Q12 - Does your family get the services and supports you need?</b>		
Number of surveys	173	
% always or usually	68.2	59.3
% sometimes	23.7	32.4
% seldom or never	8.1	8.3
<b>Q13 - Do the services and supports offered meet your family's needs?</b>		
Number of surveys	167	
% always or usually	67.1	58.1
% sometimes	24.6	33.4
% seldom or never	8.4	8.5
<b>Q14 - Are supports available when your family needs them?</b>		
Number of surveys	156	
% always or usually	62.2	54.2
% sometimes	28.8	36.1
% seldom or never	9.0	9.7
<b>Q15 - Do families in your area request that different types of services and supports be made available in your area?</b>		
Number of surveys	104	
% always or usually	38.5	41.8
% sometimes	46.2	38.7
% seldom or never	15.4	19.5
<b>Q16 - If yes, does either the state agency or provider agency respond to their requests?</b>		
Number of surveys	52	
% always or usually	30.8	43.1
% sometimes	48.1	39.0
% seldom or never	21.2	18.0
<b>Q17 - If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?</b>		
Number of surveys	94	
% always or usually	53.2	54.9
% sometimes	19.1	20.5
% seldom or never	27.7	24.6
<b>Q18 - If English is not your first language, are there support workers or translators available to speak with you in your preferred language?</b>		
Number of surveys	50	
% always or usually	56.0	69.4
% sometimes	30.0	13.1
% seldom or never	14.0	17.5
<b>Q19 - If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?</b>		
Number of surveys	57	
% always or usually	59.6	52.9
% sometimes	17.5	25.5
% seldom or never	22.8	21.7

Access and Delivery of Services and Supports (cont'd)		
	Bay Area Regional Centers	NCI State Avg. (8 Sites)
<b>Q20 - Does your family member have access to the special equipment or accommodations that he/she needs?</b>		
Number of surveys	70	
% always or usually	61.4	60.4
% sometimes	21.4	21.6
% seldom or never	17.1	18.0
<b>Q21 - Do you have access to health services for your family member?</b>		
Number of surveys	172	
% always or usually	85.5	87.5
% sometimes	9.9	9.2
% seldom or never	4.7	3.3
<b>Q22 - Do you have access to dental services for your family member?</b>		
Number of surveys	164	
% always or usually	81.7	75.2
% sometimes	12.2	9.4
% seldom or never	6.1	15.4
<b>Q23 - Do you have access to necessary medications for your family member?</b>		
Number of surveys	168	
% always or usually	91.1	91.7
% sometimes	5.4	5.8
% seldom or never	3.6	2.5
<b>Q24 - Are frequent changes in support staff a problem for your family?</b>		
Number of surveys	133	
% always or usually	14.3	22.6
% sometimes	43.6	38.4
% seldom or never	42.1	39.1
<b>Q25 - Do you feel that your family member's day/employment setting is a healthy and safe environment?</b>		
Number of surveys	155	
% always or usually	80.0	82.3
% sometimes	16.1	15.5
% seldom or never	3.9	2.3
<b>Q26 - Are support staff generally respectful and courteous?</b>		
Number of surveys	179	
% always or usually	84.9	88.2
% sometimes	12.8	10.8
% seldom or never	2.2	1.0

## Choices and Control

Choices and Control		
	Bay Area Regional Centers	NCI State Avg. (8 Sites)
<b>Q27 - Do you or your family member choose the agencies or providers that work with your family?</b>		
Number of surveys	147	
% always or usually	58.5	63.7
% sometimes	16.3	17.7
% seldom or never	25.2	18.7
<b>Q28 - Do you or your family member choose the support workers that work with your family?</b>		
Number of surveys	137	
% always or usually	48.2	44.4
% sometimes	16.8	20.8
% seldom or never	35.0	34.8
<b>Q29 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?</b>		
Number of surveys	128	
% always or usually	66.4	67.4
% sometimes	22.7	21.5
% seldom or never	10.9	11.0
<b>Q30 - Do you or your family member have control and/or input over the hiring and management of your support workers?</b>		
Number of surveys	107	
% always or usually	41.1	40.0
% sometimes	15.0	15.8
% seldom or never	43.9	44.2
<b>Q31 - Do you or your family member <u>want</u> to have control and/or input over the hiring and management of your support workers?</b>		
Number of surveys	106	
% always or usually	60.4	58.7
% sometimes	20.8	22.3
% seldom or never	18.9	19.0
<b>Q32 - Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?</b>		
Number of surveys	178	
% always or usually	45.5	26.7
% sometimes	14.6	11.0
% seldom/never/don't know	39.9	62.3
<b>Q33 - Do you or your family member get to decide how this money is spent?</b>		
Number of surveys	117	
% always or usually	49.6	41.5
% sometimes	22.2	18.0
% seldom or never	28.2	40.6

## Community Connections

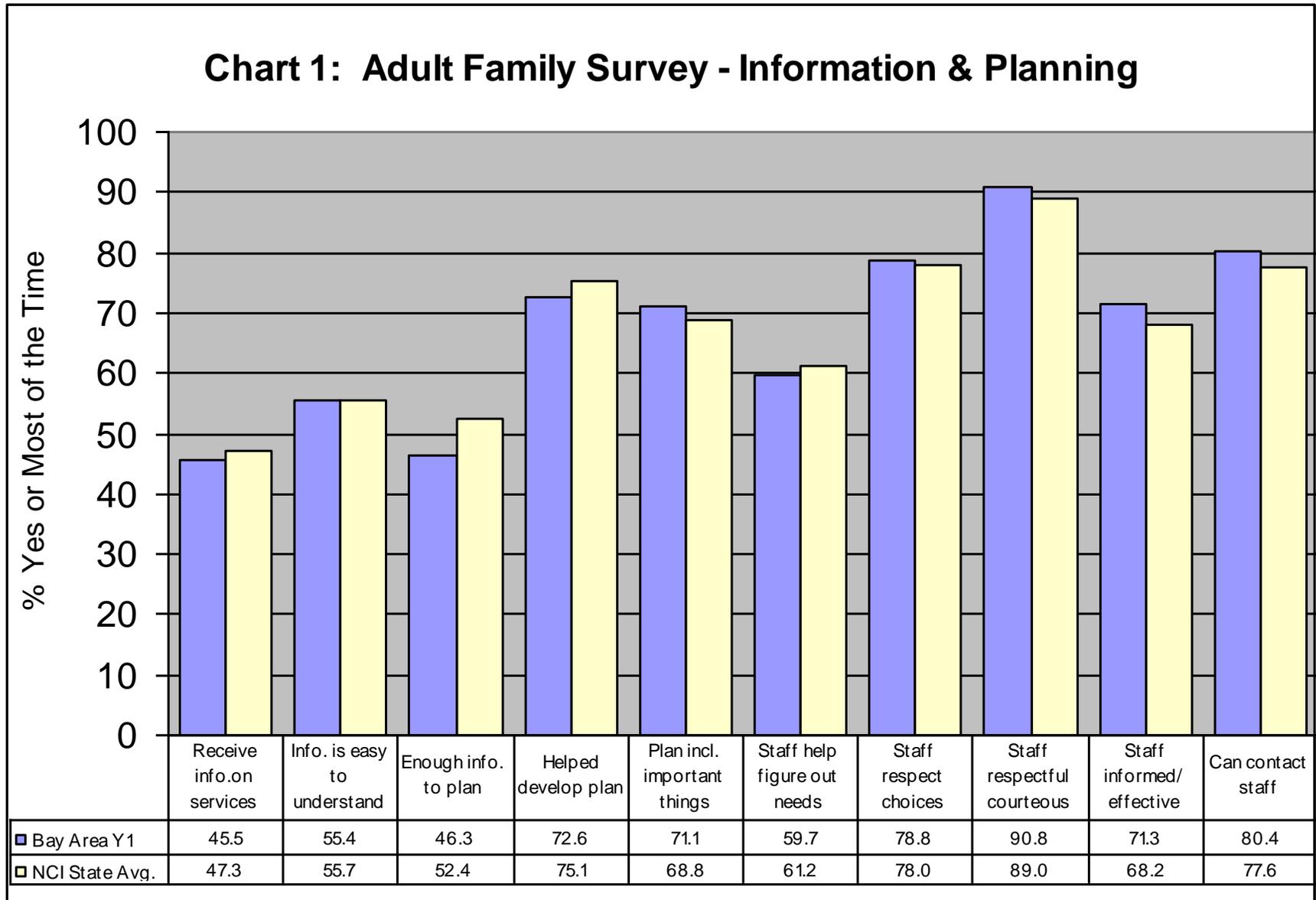
Community Connections		
	Bay Area Regional Centers	NCI State Avg. (8 Sites)
Q34 - If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?		
Number of surveys	99	
% always or usually	25.3	33.6
% sometimes	31.3	27.2
% seldom or never	43.4	39.3
Q35 - If you would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?		
Number of surveys	85	
% always or usually	31.8	38.2
% sometimes	25.9	20.1
% seldom or never	42.4	41.8
Q36 - Do you feel that your family member has access to community activities?		
Number of surveys	154	
% always or usually	37.7	51.0
% sometimes	42.9	31.1
% seldom or never	19.5	17.9
Q37 - Does your family member participate in community activities?		
Number of surveys	160	
% always or usually	18.1	31.9
% sometimes	43.1	35.6
% seldom or never	38.8	32.5

## Satisfaction with Services and Outcomes

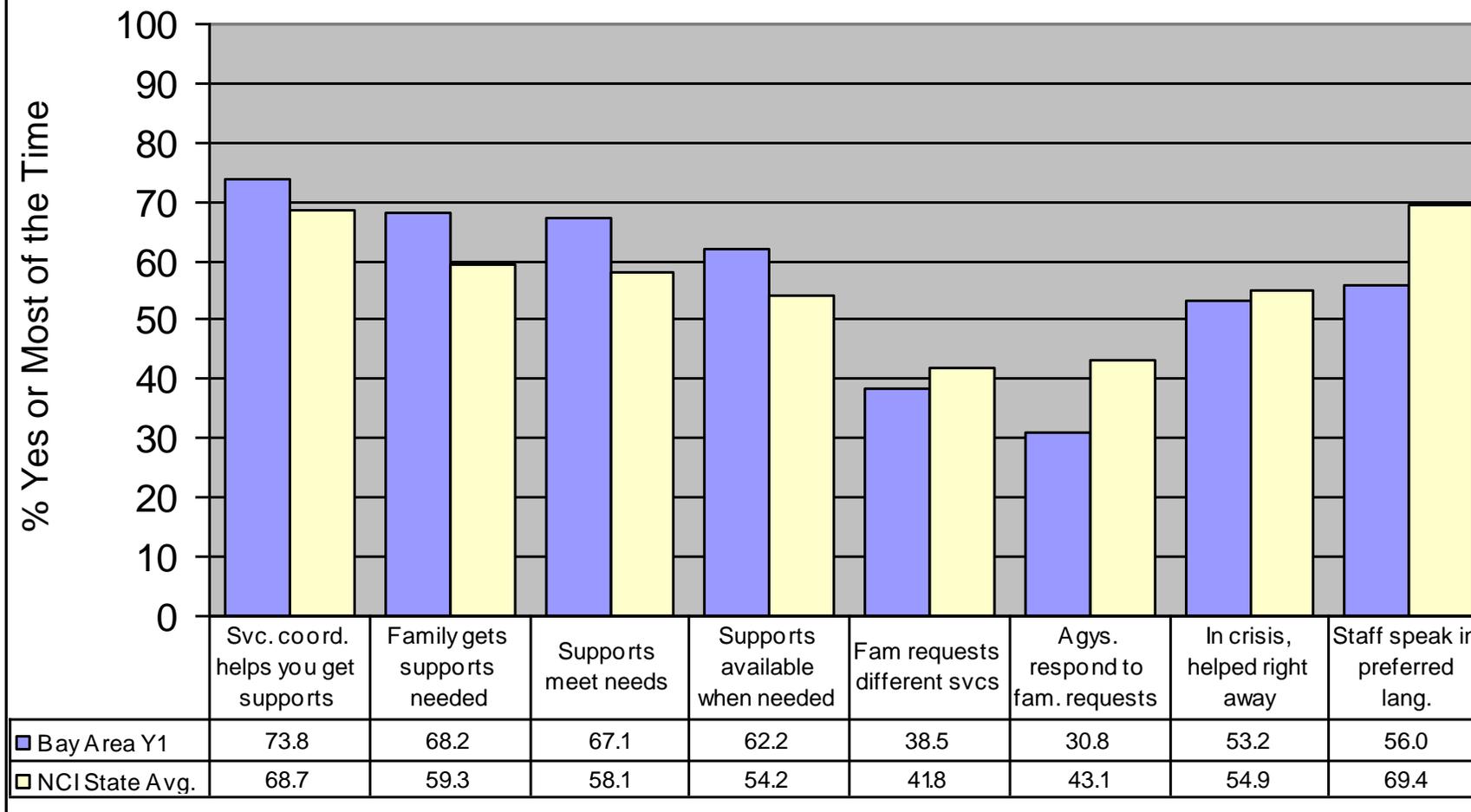
Satisfaction with Services and Outcomes		
	Bay Area Regional Centers	NCI State Avg. (8 Sites)
Q38 - Overall, are you satisfied with the services and supports your family member currently receives?		
Number of surveys	171	
% always or usually	74.9	65.9
% sometimes	21.1	27.9
% seldom or never	4.1	6.2
Q39 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?		
Number of surveys	156	
% always or usually	42.9	47.5
% sometimes	12.2	11.1
% seldom/never/don't know	44.9	41.4
Q40 - Are you satisfied with the way complaints/grievances are handled and resolved?		
Number of surveys	83	
% always or usually	57.8	61.4
% sometimes	31.3	26.2
% seldom or never	10.8	12.4
Q41 - Do you feel that services and supports have made a positive difference in the life of your family?		
Number of surveys	170	
% always or usually	80.0	69.7
% sometimes	15.9	25.6
% seldom or never	4.1	4.7
Q42 - Have services made a difference in helping keep your family member at home?		
Number of surveys	166	
% always or usually	84.3	76.7
% sometimes	9.0	14.0
% seldom or never	6.6	9.3
Q43 - Would your family member still be at home if you did not receive any services?		
Number of surveys	122	
% always or usually	77.0	84.1
% sometimes	5.7	4.6
% seldom or never	17.2	11.3
Q44 - Overall, do you feel that your family member is happy?		
Number of surveys	179	
% always or usually	89.9	85.7
% sometimes	8.4	13.3
% seldom or never	1.7	1.0

**Results by Domain Compared to Aggregate Results**

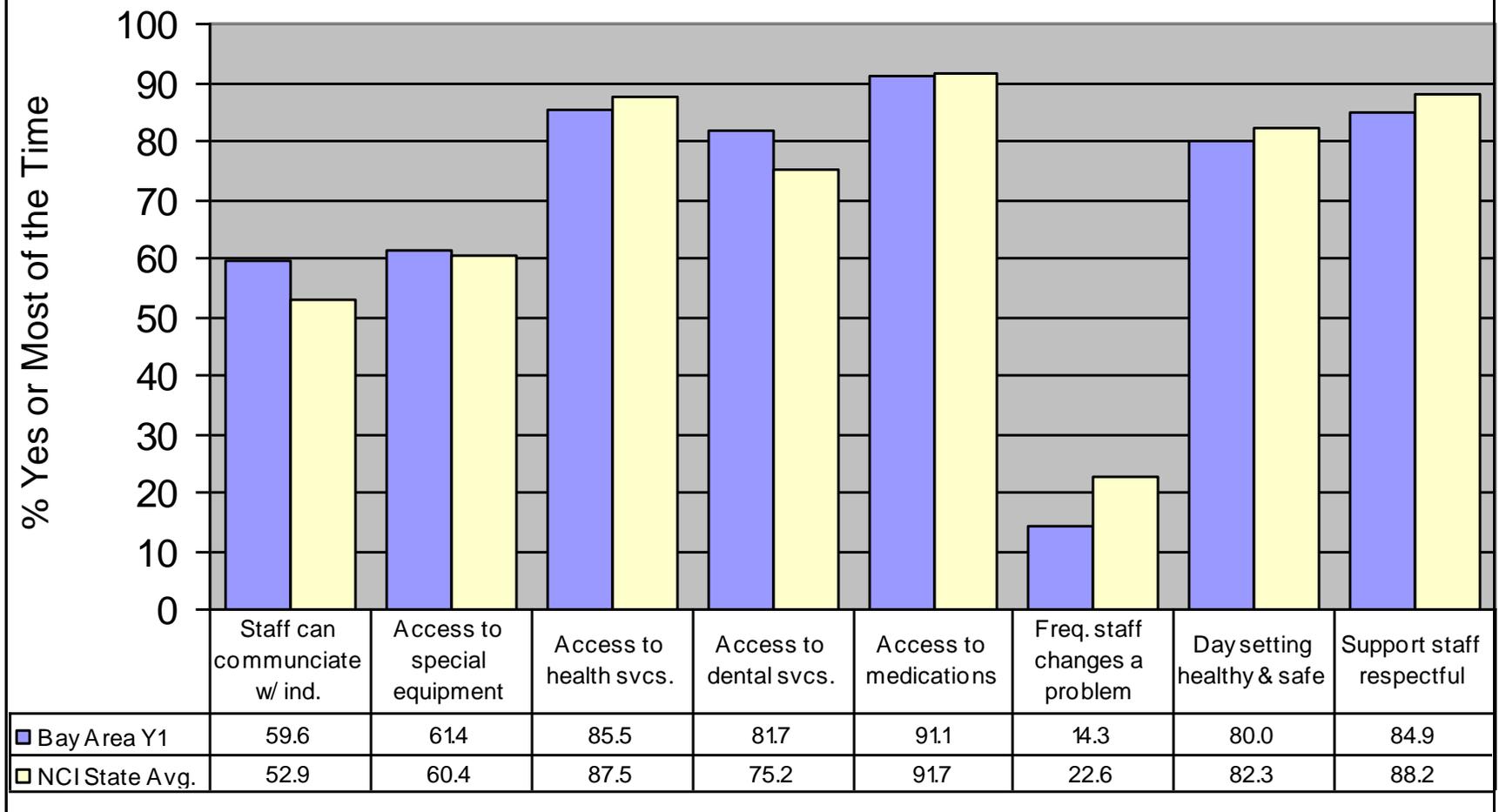
Here, the Bay Area Regional Centers results are presented by topic grouping, and compared against the state averages.



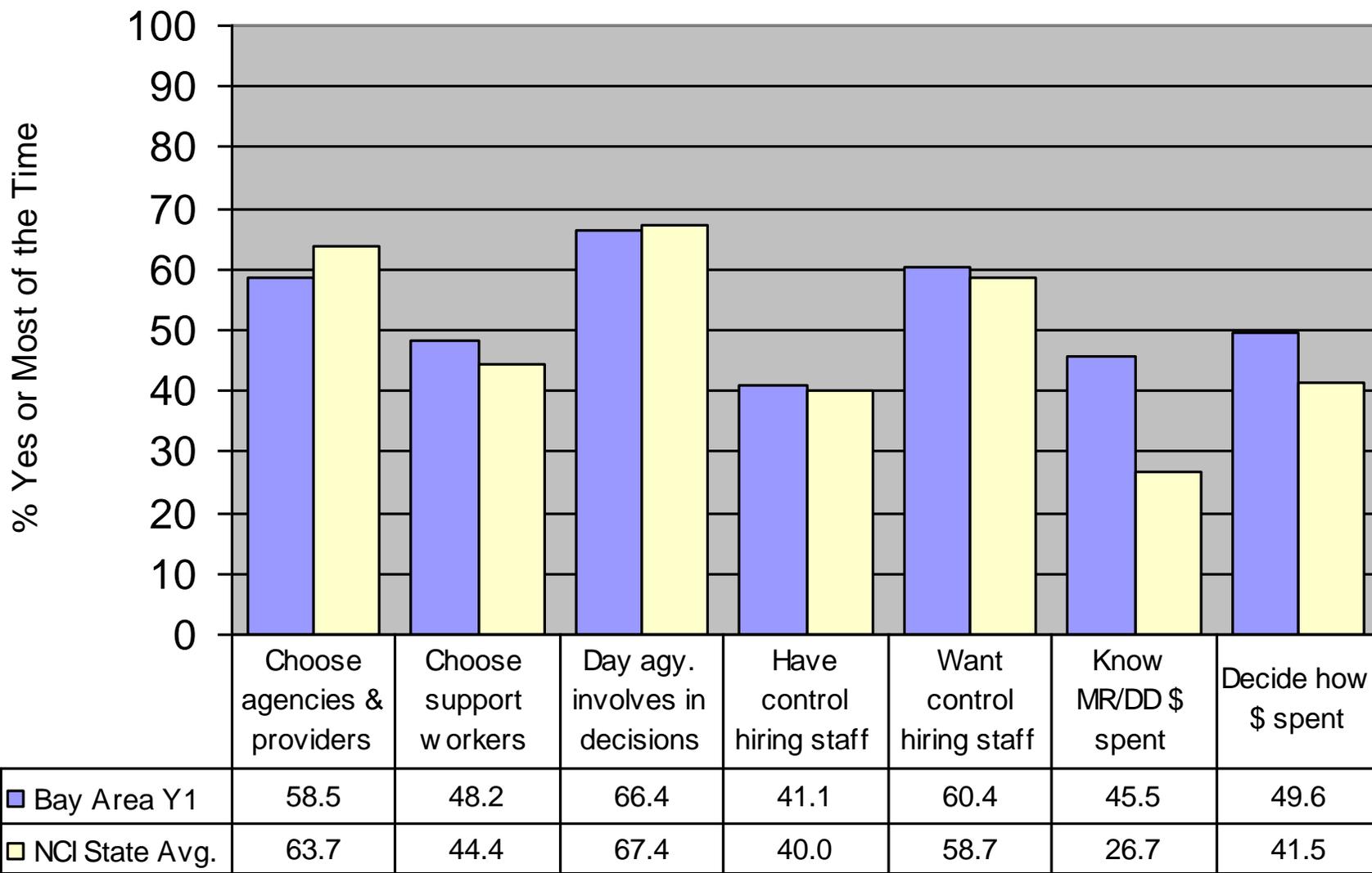
### Chart 2a: Adult Family Survey - Access to Services



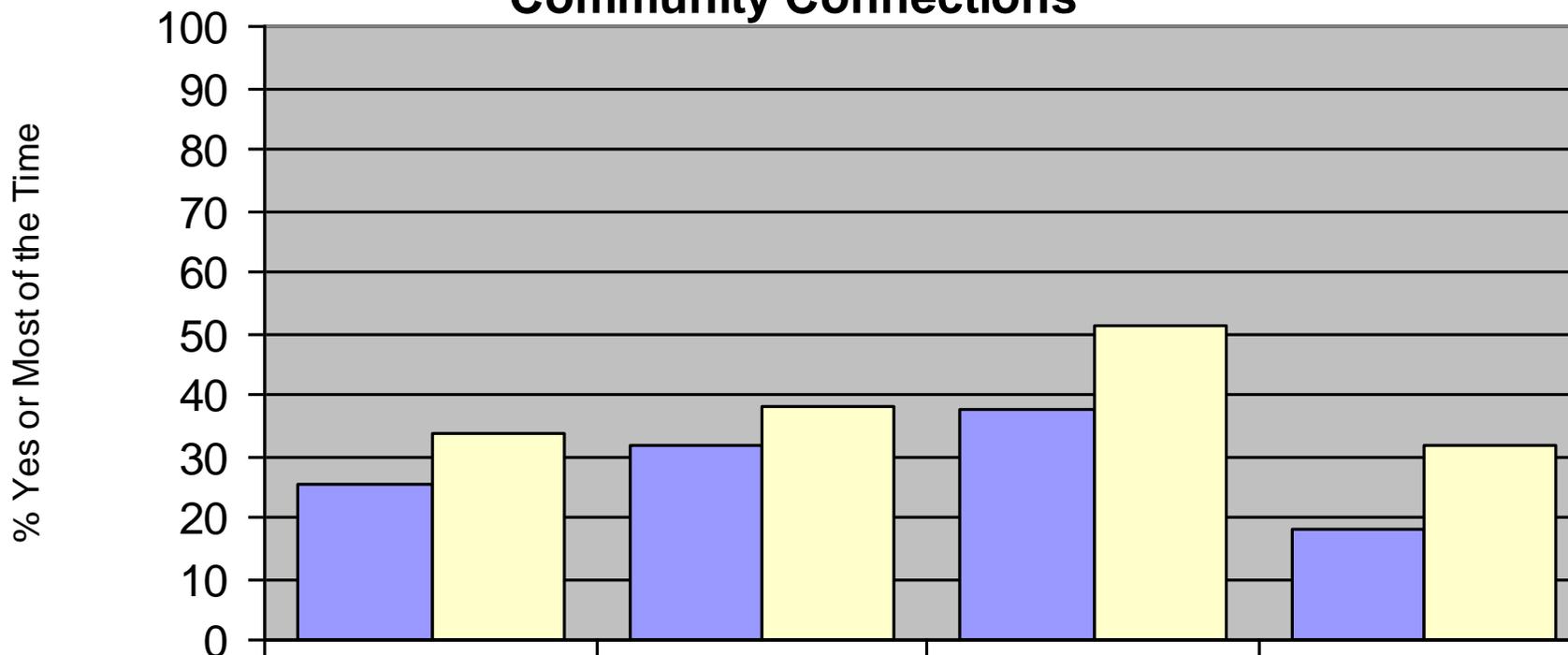
### Chart 2b: Adult Family Survey - Access to Services



### Chart 3: Adult Family Survey - Choice & Control

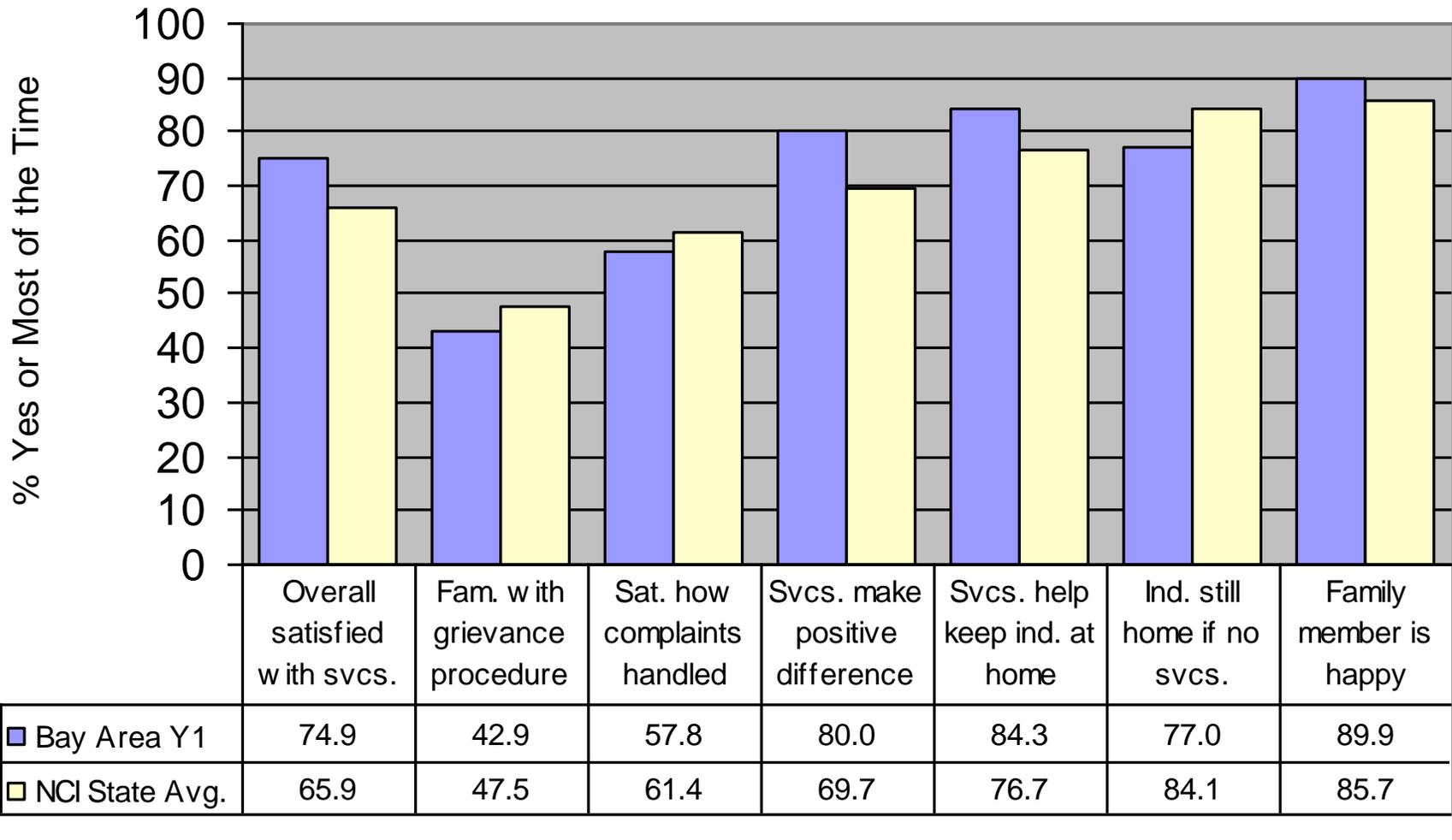


### Chart 4: Adult Family Survey - Community Connections



	Staff connect to comm. supports	Staff connect to family, friends, and neighbors	Fam. member has access to community	Fam. member participates in community
■ Bay Area Y1	25.3	31.8	37.7	18.1
■ NCI State Avg.	33.6	38.2	51.0	31.9

### Chart 5: Adult Family Survey - Satisfaction & Outcomes



## IV. COMMENTS

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. All comments are included below. Where possible, comments are categorized by regional center.

### ***San Andreas Regional Center***

- We as a family and my brother have had the best of care and support from San Andreas. It has made such a significant difference in my brother's quality of life.
- SARC does a great job! Our worker is wonderful!
- I am very happy with the services our case manager has provided. She is very professional, yet warm and caring and responds to our needs efficiently and effectively. We have been associated with San Andreas Regional Center for many years and have better and better experiences, even as my son and I age. Our case manager demonstrates caring and as an RN I fully appreciate her suggestions and support. So, Hurrah for our case worker as a superb case manager for SARC.
- I feel San Andreas and especially the case worker does as much as possible in helping life better for family client. The things that are lacking are social and recreational activities to be with people of the client's age. I realize that this is something the community could provide and they do, but very little.
- To: San Andreas Regional Center  
While answering the question #43 "Would your family member still be at home if you did not receive any services?" I would say "NO" with my family deep gratitude toward your noble organization providing supports and services to persons, including my unfortunate son, with developmental disabilities and their families. As a matter of fact, my family with limited income and resource cannot afford anything to my son survive and still be at home, if we did not receive any supports and services. Through voluntary services, advocacy, the San Andrea Regional centers are making great difference of life for all unfortunate persons with developmental disabilities and their families in California.
- San Andreas Regional Center changes personnel so often that we are without a social worker much of the time.
- At this time we are receiving benefits enabling our loved one to live in our home, attend a day program which she loves, and receives transportation daily to take her there and back. Additionally, we receive a small amount of respite funds so our family can occasionally watch her while we are gone. However, none of these amounts begin to totally care for an individual who is severely disabled. We do it because we love her and wouldn't dream of having it any other way. I worry about her care after we are gone, her parents.

Her whole life, we have had to fight and argue and pester in order to get services she needs. Nothing was ever completely divulged to us about options available. We would find out through some other source (usually another parent of a disabled child) that certain benefits were available - and then would inquire about them - and then eventually could get some type of similar benefit for our daughter. By no means has the regional center ever been forthcoming with availability or information about more benefits. Some workers have been horrible - completely unable to reach them or get them to respond in a caring manner. Some have been wonderful. We continue to care for our daughter daily and at this time mostly satisfied with SARC.

- We are extremely happy with San Andreas services.

### ***Golden Gate Regional Center***

- Unable to locate speech therapy. GGRC said "no one" available!
- [Name] is very knowledgeable, available and helpful. Her support is excellent. Receiving therapy not paid for by GGRC or Mental Health. We need more respite programs that last longer than 6 days, ex. Provide minimum 10 day respite. Also need sessions for 17 year olds to 25-30 years middle gap. Medical services are inadequate. Dental Services are inadequate. Access to necessary medications is inadequate. Services provided meet our need, however are very little. Need more social weekend care. Are needs are larger what is available. Would like to use family and friends to provide supports however, there are no staff available to participate
- Thank you so much for providing services and support for my family member for many years. My sister (with Down Syndrome) is very happy with her day program at [name] in San Francisco. The GGRC is only helping my sister but it also helping my family as well because we can go to work while she is at the program. We deeply appreciate your help. Your services make a big different in my sister's life.
- I feel that GGRC tries, but does not give all the info to client so they can choose what service and choices of service they want. The budget seems to be the overriding factor for many choices. For 2 month no day program has been provided due to firing of last provider. When asked for money to provide transportation I was told there was no emergency fund to handle (e.g. \$20 a week). That seems absurd to me. So as a parent I'm just supposed to absorb the expense along with my time. Not acceptable. There have been other issues also which my case worker argues with me about when I tell her "no" client doesn't want that. We need a new plan closer to home. I would like to have access to my budget and help make choices - not be told this is the only option.
- GGRC's greatest gift to us is that for the last twelve plus years we have had [Name] as our representative. 2) Because our daughter is a GGRC client she has employment at [Name] 3) Because we ask for nothing except bus service home from work each day, N/A serves as the answer to your questions
- I am very satisfied with Golden Gate Regional Center. It had helped me with my daughter's disability and programs. Her current case manager had been helping her with any problems, etc. when needed. I give GGRC 100% of all the hard work that they do for the people (adults and kids) with disabilities. Without GGRC and special day programs and special education, etc., my daughter and all other disables, would not be able to do what they do/are doing now! God Bless all the GGRC staff and special day programs!

### ***Regional Center of the East Bay***

- The Regional Center has changed for the better over the years. When my daughter was younger, the support we needed wasn't there because the money was targeted for people in institutions - we are happy that is no longer true - (although, at the time it was disheartening). My daughter and I are very pleased with the staff we are in touch with at the Regional Center of the East Bay.
- East Bay (Concord) has a very responsive staff.

- The regional center was not initially responsive in establishing programming for my sibling. There was no activity for about 4 months at which time I pushed the issue with RCEB management. All of a sudden the case worker assigned became responsive. Currently, direct communication with case worker is via fax. The case worker has not been present at the scheduled annual review for the past 2 years. Last year it was done via phone. This year there has been no follow-up for the missed annual review by the case worker from RCEB. I understand that the staff have case overloads, so I/we just wait until they get around to us.
- We are very pleased with my daughter's case manager (at RCEB). He always goes out of his way to help us with our problems. Unfortunately it has taken the Occupational Therapist more than a year to get us the much needed walker and transfer chair. One other important thing to mention is that Agencies (not Regional Center) e.g. Housing Authority would not let a disabled person rent from a relative. This makes hard to find a decent place under Section 8 to rent. IHSS In Home Supportive Services will not pay more than 8 hrs/day for the very sick disabled person. In other words, these agencies and the like want to separate families and force the disabled persons to a Nursing Home, which will cost more and not benefit the disabled or old people.

### ***Non-Specified Regional Center***

- Will I be given results of this survey? I do want the results. When my granddaughter start using paratransit to return home Thursday nights from [center] she will be paying the highest fare like general public & traveling like one unless there is a change. Other Developmental Disabilities clients are traveling together on ??? Bus with discounted fare for disable. It's being said I complain too much. When a paratransit bus try to run my granddaughter down....the driver says do not write anything down. You cannot do anything about it nor to me. He was right & the next day nobody saw or heard anything. The street was full of clients, instructors & 2 other paratransit busses. When a staff person hit my granddaughter in chest & stomach with her fist. Because she would not agree to say the other staff person hit her first. When the first and only time all chairs are around the table at city called 2 staffers and my family member is on her knees crawling around under the table on the floor. The other clients see me enter the dining room & push their chairs back. When I am told it's a fire drill or earthquake practice. Who is fooling whom? I am told not to enter the building again and I said "I will go to the President of the College". I live here and both children graduated here.
- Summer respite camp has been cut from 7 nights to 5 days. Pick up on Friday by 1:00 pm is a huge inconvenience for people who work during is a real hardship.
- My son is very happy with services he gets at workshop and especially thank you for the transportation. Everyone I have spoken to who I have met is very special people.
- They do a very good job with my son. Everyone loves him because he is so courteous and has a good personality. He's a very happy boy.
- I like the person in charge - he LISTENS! Wish we could keep this case manager for a while and not change so often
- Vietnamese speaking need the home and board that have staffs speak Vietnamese to help them. My brother was in the board and care home he did not want to stay there since he could not speak English and cannot eat their food. Otherwise, the staff are very helpful for them.

- Our service coordinator is a very effective and understanding person. She is always patient and willing to share her time and knowledge to make our situation more comfortable.
- The only complaint I'd have is to get A to increase the payments to the vendors, i.e. day care program that provide respite care, etc. The payment level has been stuck at the same rates since 2001! As long as my wife is in good health, we'll take care of our daughter at home. Hopefully when we can no longer care for her, the state will have a good and caring setting to send her.
- The Adult programs need to get their clients out into the community. Sure the centers have some programs, but they are lacking in getting our adult children out in the community - having a purpose to outings and constructive things - like handling money to make purchases, communicating, riding city buses and etc. My son (or all the clients) needs to be out experiencing life and socializing not only with the disabled community but the community itself. What I'm trying to say is an hour 2x a day is not realistic they need to get clients out and given them all the opportunities the rest of us have. Thank you.
- We moved in April and our daughter was able to get into a program until July which is 3 days a week because of space. Transportation is a problem, I have to transport her to Vacaville because there is no transportation, that's 70 miles each trip and if I return home that's 140 miles, so I stay there, go places and wait for her. She has been in workshops or school in the East Bay and this county offers the least in every way. They are housed in small facilities in Solono County. The two I looked at were over crowded. 16 cents a mile is not realistic. Gas for my car is \$2.899 per gallon. How long has it been at this rate?
- Sometime I would like to take my daughter to a respite care, but they told me it's none.
- My child has tried group homes and SLS and unfortunately the safest place has turned out to be mom & dad's. That isn't right.
- Our representative has been very helpful in planning for my son's needs. We receive in-home respite care through R.C. and it is very important in that I (mom) am responsible for all my son's needs and care. Thank you!
- We are very happy for all the services my son is receiving. Thank you.
- As a family of a 48 year retarded daughter, the help and support is important. We don't know what our family would do without the support. We need her to have a person on weekends, that she does have a 5 day program. Thanks.
- There need to be more day programs for adults who need assistance in bathrooming but can go into the community. The Center needs to make considerable improvements to the Marin site. There needs to be a lending library for wheelchairs, etc. Group homes need to be made to strictly follow the licensing laws about religion. Too many are forcing clients to go to their churches and not allowing access to the client's religious services and activities. The provider does not have the right to push their religion on the clients. Some homes should be for clients of the same religion with care providers who respect and promote the clients religion and not have other religions celebrations in the home.
- You've been a great service over the years! Great support. Thanks.
- Dear Sir, as a concerned parent I don't feel that my service worker is available to me or explains to me about services. For instance, I did not know about HIS until four or five years ago. Also there is no respite care available to me. And as of today I still don't know who my son's social worker is. One of the suggestions to Reg Center should have a group meeting for parents and caregivers to help us to facilitate our options. Sincerely, a loving parent.

- The only big problem we have is the delay for authorities in charge of paying providers. Sometimes it takes two or three months for providers to wait for the pay check. I would be very thankful if this problem can be addressed or solved.
- The case manager slowly responds to calls pertaining to the person with disability (e.g. three phone calls regarding a serious situation were placed to the case manager and took ten days to respond). Some past social workers/case managers appeared to be unconcerned or aloof.
- Family member is happy because her family helps her be that way. She is loved and cared for by those who love her best. Family!
- Reg Center is a great help with my daughter. I don't know what I would do without their help. Only negative I have been Trans. They (the office) personnel are rude, uncaring, lazy individuals and could care less about welfare of their rides. Bus drivers on the most part are great but there are a few that should be riding the bus not driving.
- Very well pleased with all aspects of the agency. Doing a great job. Thank you.
- Thank you for your support & help!
- [Name] is our worker and she is a great help in all areas. Thanks to your organization :)
- We are very pleased with the services provided.
- Am happy with services and very grateful for them.
- I as a parent and a service provider feel that the people with Disabilities are underserved, and overworked. The transportation component has so many bad apples they beat the clients, steal from them, and talk to them really bad. I have written many complaints about the drivers using profanity at my son, stealing his wallet, and pinching him in the mouth, sending him home with a bloody lip. No one deserves to be treated that way. The drivers should be given sensitivity training, before being hired to work with this population.  
Concerned Parent

### ***Survey-Related Comments***

- Your answer sheet needs a N/A box and some require yes and no answers
- Part 1. [Question] G put ADD/ADHD as a choice. [Question] M Put Non-Taxable choices e.g. SSI/SSD. Many of the questions are so broad that it was harder to answer them. People with developmental disabilities often have fairly unique needs in some areas. It can become a real problem when the state or programs try to make more specific guidelines as the individuals needs then get missed sometimes.
- This questionnaire is way too complicated - in Spanish or English, in the opinion of this consumer's mother and me. Way too long

## **V. DISCUSSION**

The results of the Adult Family Survey provide one lens through which the Bay Area Leadership Group can assess the quality of Regional Center services and supports being provided to adults living in their family home, from the perspective of the families. This section presents a summary and discussion of findings by topic (domain) area, as well as specific process recommendations to be considered for future quality assurance survey activities. Where appropriate, observations regarding policy implications are also presented.

### ***Information and Planning***

The findings in this section are remarkably similar to the NCI state averages. They also display a pattern similar to the NCI results – respondents to the Adult Family Survey are comparatively less satisfied than respondents to the Family Guardian Survey. In terms of information and planning, a little less than half of the sample of respondents with an adult family member living at home report that they receive information about services and supports. Just over 70% of respondents participated in their family member’s plan development, and about the same percentage felt that the plan included things that were important to them. Most respondents reported that service coordinators were respectful of their choices, effective, and available. As with the Family Guardian Survey, it appears that families need additional information provided to them about available services and supports. This concern was echoed in some of the qualitative comments as well.

### ***Access and Delivery of Services and Supports***

The Regional Centers performed better than the NCI state averages on several of the items in this section. Over two-thirds of respondents indicated that their family gets the services and supports they need, and 62% reported that supports are available when they need them. Fewer families in the Bay Area request that different services be made available, and the state and/or provider agency is less likely to respond to such requests, as compared with the NCI states. About 53% of respondents report that crisis services were provided upon request in an emergency situation.

Results on communication were slightly different than on the Family Guardian Survey, and the differences in the questions on the two surveys may provide some insight. On the Adult Family Survey, 23% of respondents report that support workers who are able to communicate with their family members are “seldom or never” available. This result is similar to the NCI state average. However, this survey has an additional question, “If English is not your first language, are there support workers or translators available to speak with you in your preferred language? In the Bay Area, only 56% reported “always or usually” as compared with 69% in the NCI states. Language competency (e.g., Vietnamese) was also mentioned as an issue in one of the written comments. This is

an issue that the Regional Centers are likely aware of given the wide cultural and language diversity of the service population.

Compared to the NCI state averages, the Bay Area respondents report relatively similar access to special equipment, health services, and medications. Access to dental care is somewhat better than average. As with the Family Guardian Survey, fewer Bay Area respondents report that frequent changes in staff are problematic, although some of the write-in comments allude to turnover of service coordinators.

### ***Choices and Control***

In general, respondents' level of choice and control is similar to what has been reported in the NCI states. About two-thirds report being involved in decisions made by the day service provider agency. Interestingly, 60% report wanting to have more control input over the hiring/management of support workers, and 40% of respondents report that they have this control. Compared with other states, the Bay Area respondents have much more knowledge of how much is spent on services for their family member (46% vs. 27%), and nearly half report that they have some input into deciding how this money is spent.

### ***Community Connections***

Bay Area respondents report lower scores on all items in this section as compared to the NCI state averages. Only 38% report that their family member "always or usually" has access to community activities" vs. 51% in the NCI state sample, and 18% report that their family member participates in community activities, vs. 32% in NCI. This issue similarly came up in the Family Guardian Survey results, and it emerges as a theme in some of the write-in comments. The findings suggest that improved ways to facilitate community connections are needed.

### ***Satisfaction with Services and Outcomes***

Overall, respondents seem slightly more satisfied with services than their counterparts in the NCI states. The majority report feeling that the supports provided make a positive difference in their lives, help them keep their family member at home, and that their family member is happy.

Similar to the findings of the Family Guardian Survey, only 43% of respondents were familiar with the grievance process, suggesting that this is an area where more information dissemination is necessary.

### ***Process Recommendations***

If the QMS decides to administer this survey again, some of the same recommendations made regarding the Family Guardian Survey also apply. Specifically, the Regional centers may want to add a "waiver of confidentiality" so that they are able

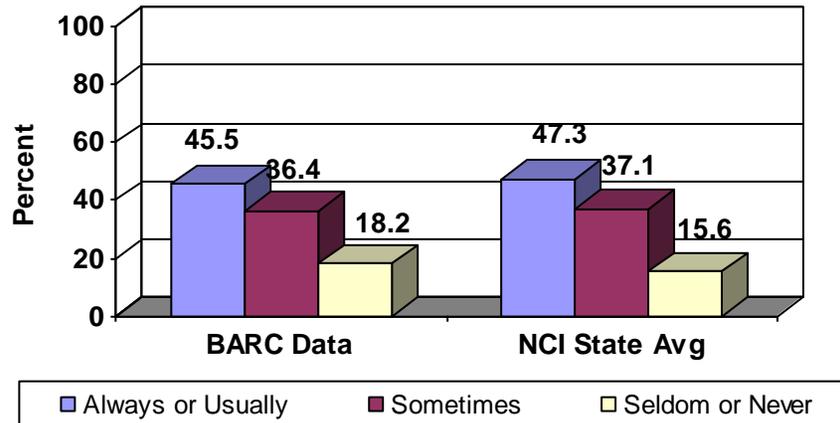
to respond to requests for follow up, and future iterations of this survey should include some way to code which Regional Center the response came from.

In conclusion, this activity was a major undertaking for the Bay Area Regional Centers, and they should be commended for their efforts to gather feedback from service users and their families. Positive results should be seen as confirming for Regional Center staff and management who are working every day to ensure that people and their families have the supports they need. The results also suggest some potential opportunities for improvement. Further discussion among leadership and with a variety of stakeholders will shed additional light on these areas of concern and hopefully generate ideas that will lead to the development and implementation of improvement strategies at a system level.

## **APPENDIX A: Charts of Results by Question**

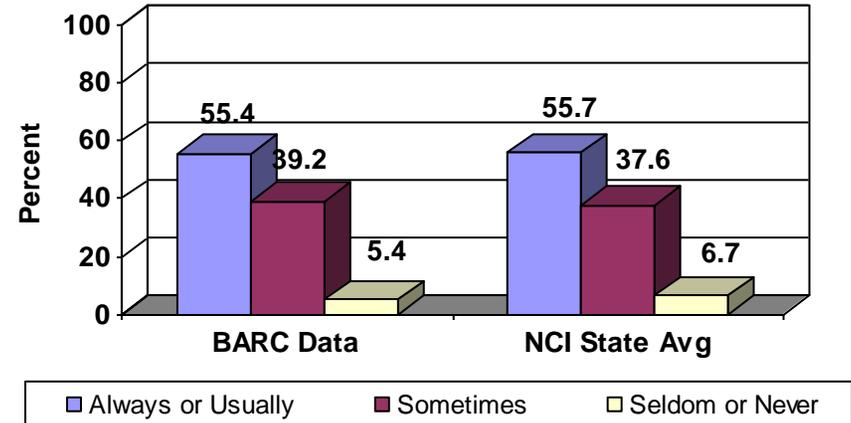
**Chart Q1**

Do you receive information about the services and supports that are available to your family?



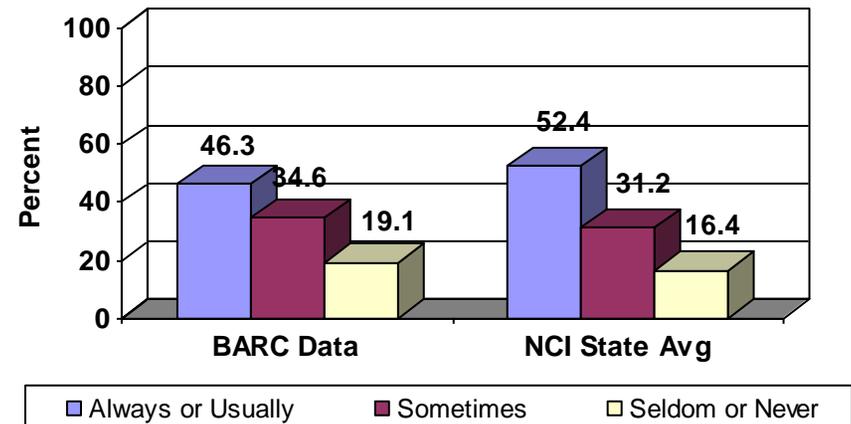
**Chart Q2**

If you receive information, is it easy to understand?



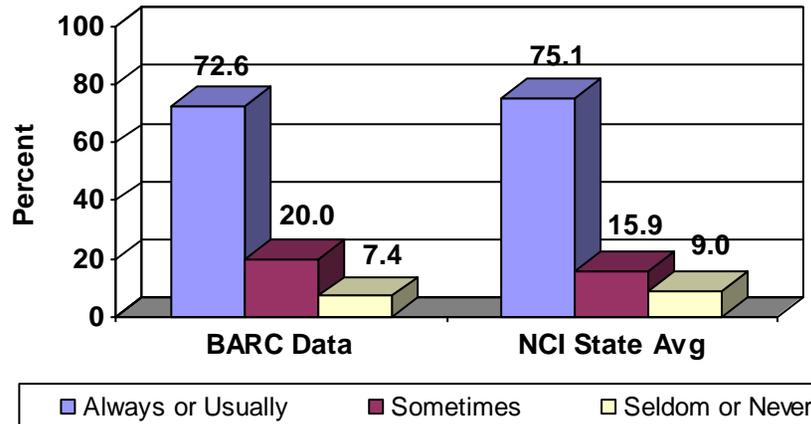
**Chart Q3**

Do you get enough information to help you participate in planning services for your family?



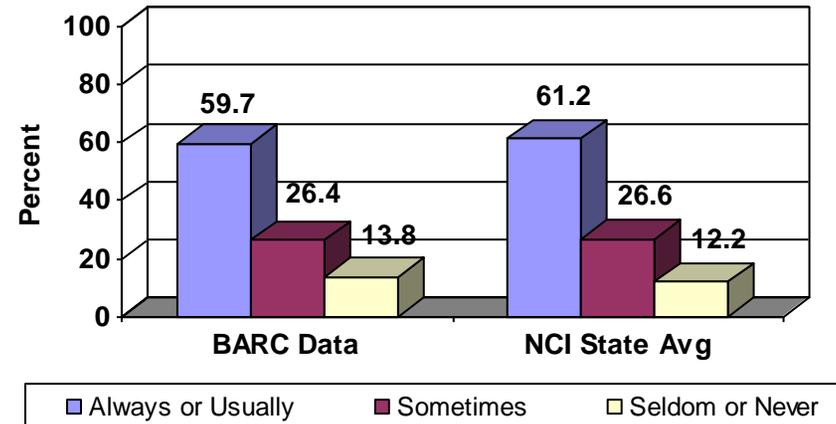
**Chart Q4**

If your family member has a service plan, did you help develop the plan?



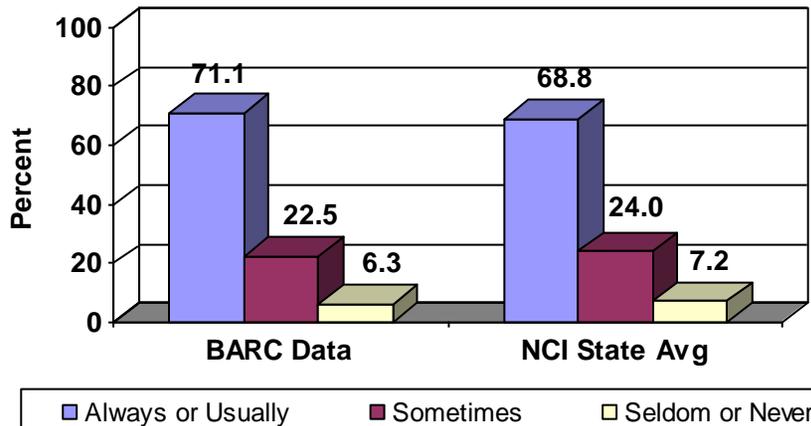
**Chart Q6**

Do the staff who assist you with planning help you figure out what you need as a family to support your family member?



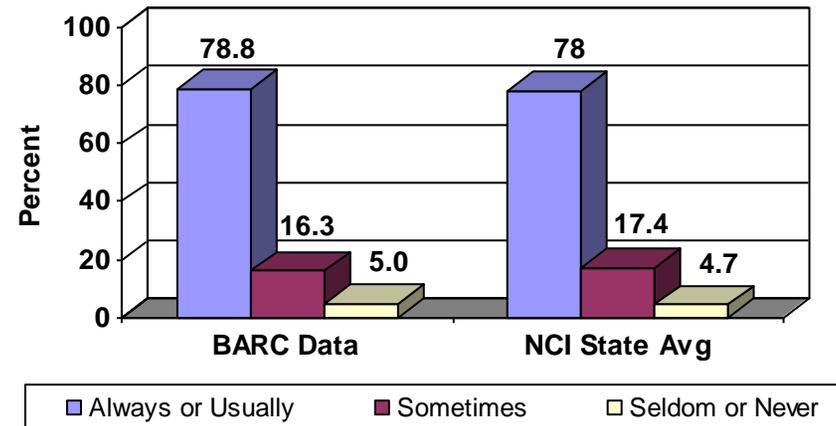
**Chart Q5**

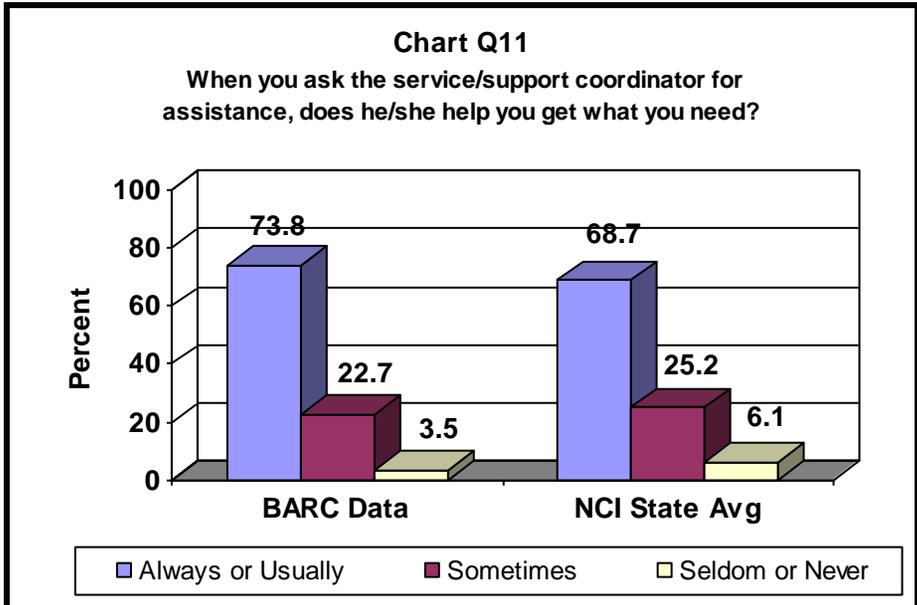
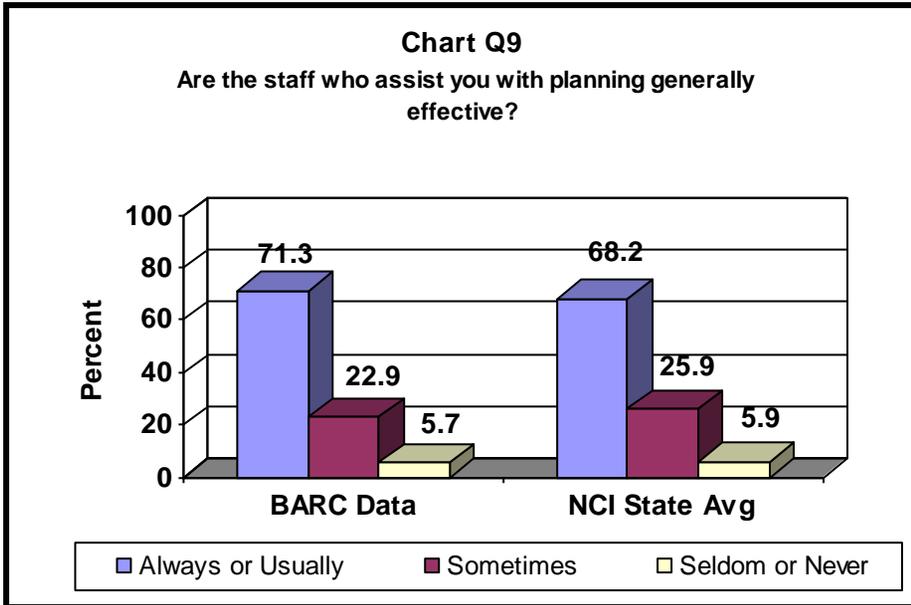
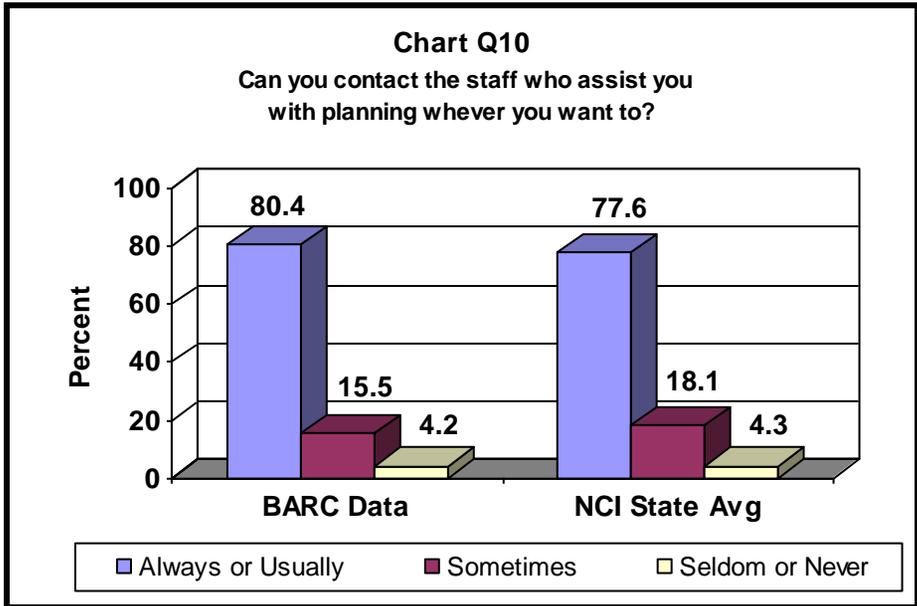
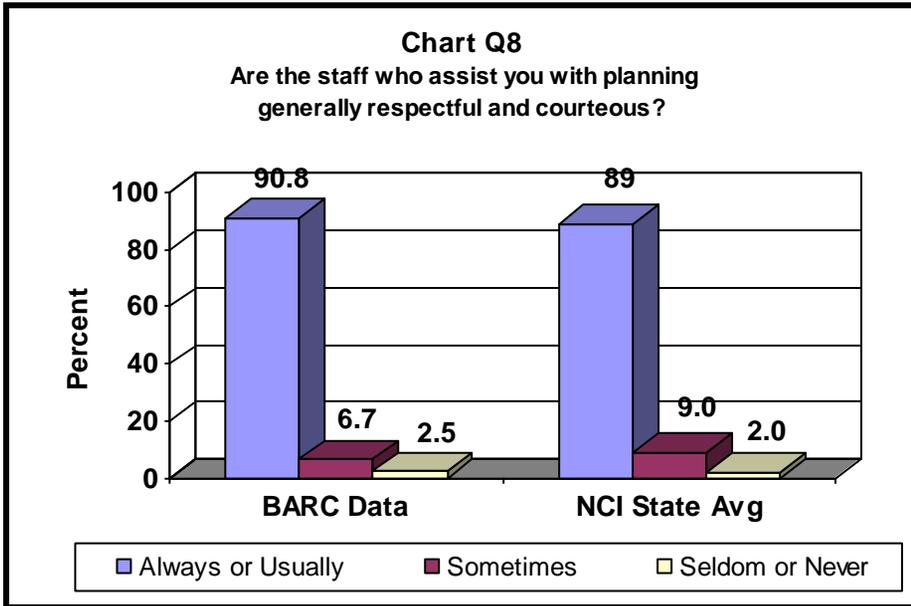
If your family member has a service plan, does the plan include things that are important to you?



**Chart Q7**

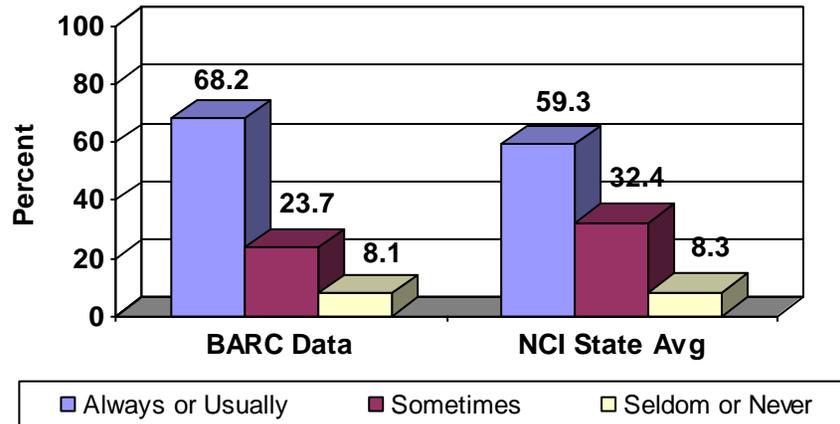
Do the staff who assist you with planning respect your choices and opinions?





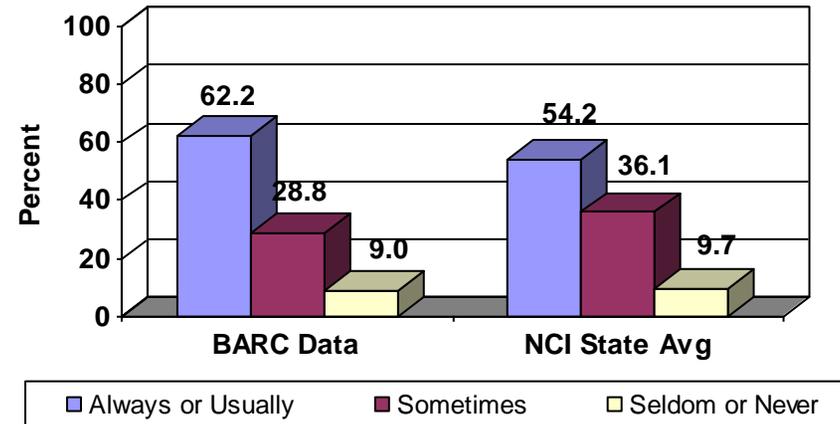
**Chart Q12**

Does your family get the services and supports you need?



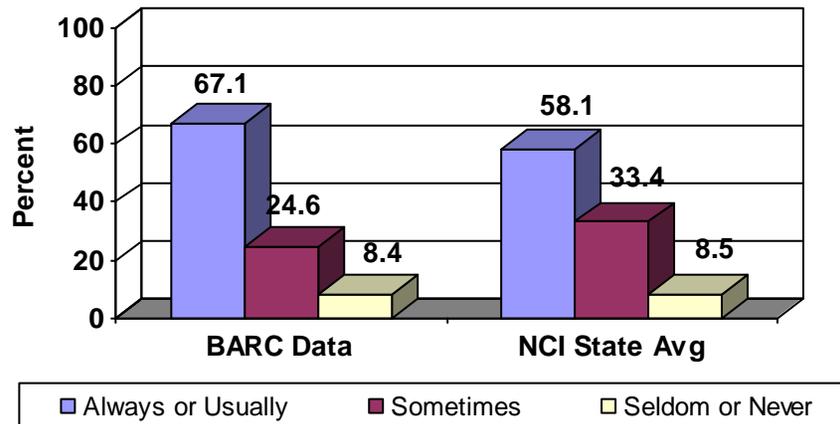
**Chart Q14**

Are supports available when your family needs them?



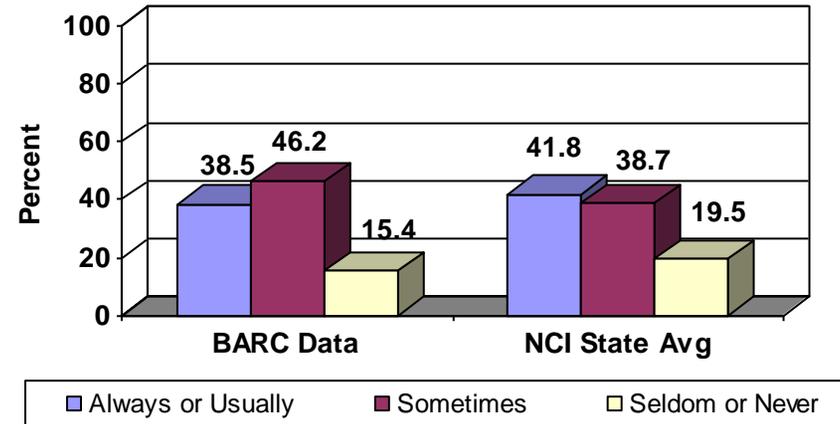
**Chart Q13**

Do the services and supports offered meet your family's needs?



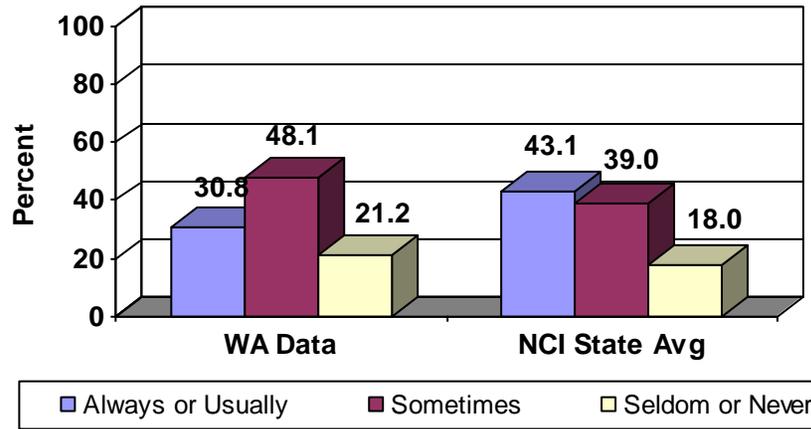
**Chart Q15**

Do families in your area request different types of services and supports be made available in your area?



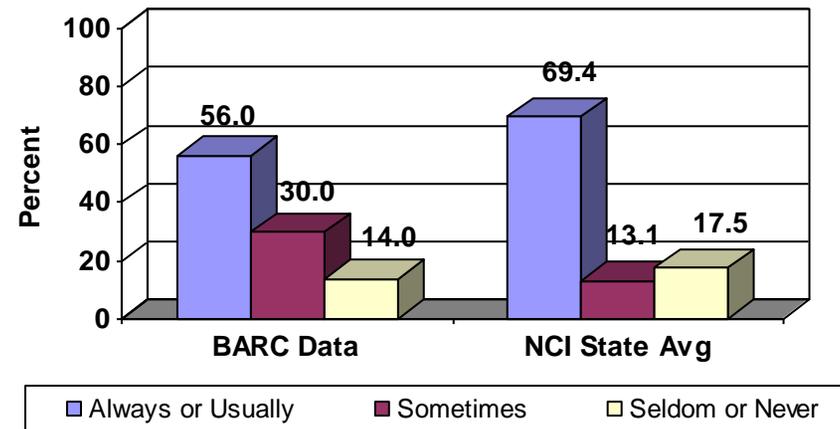
**Chart Q16**

If yes, does either the state agency or provider agency respond to their requests?



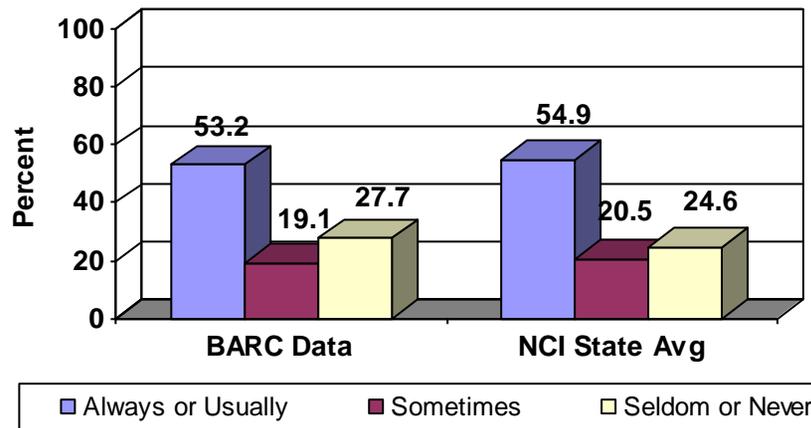
**Chart Q18**

If English is not your first language, are there support workers or translators available to speak with you in your preferred language?



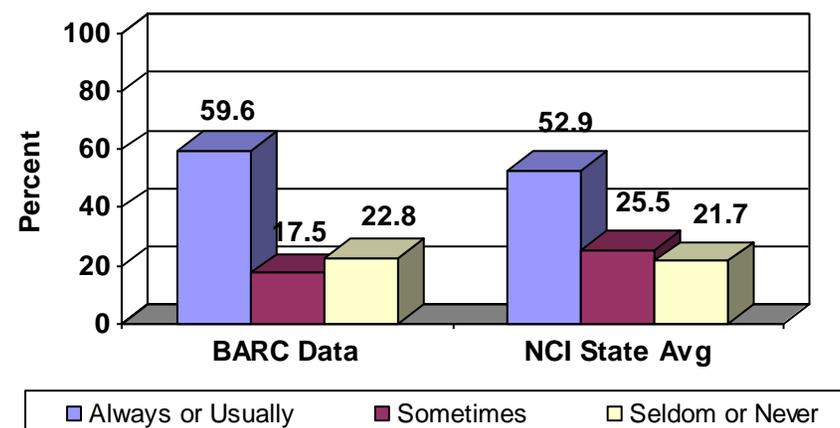
**Chart Q17**

If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?



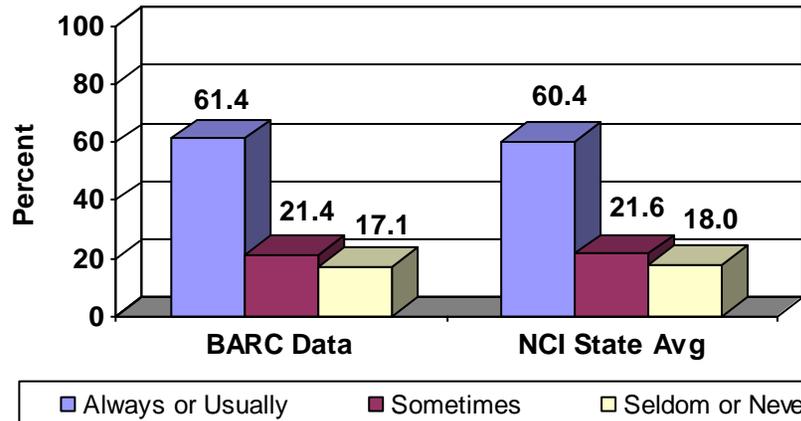
**Chart Q19**

If your family member does not speak English, or uses a different way to communicate, are there enough support workers available who can communicate with him/her?



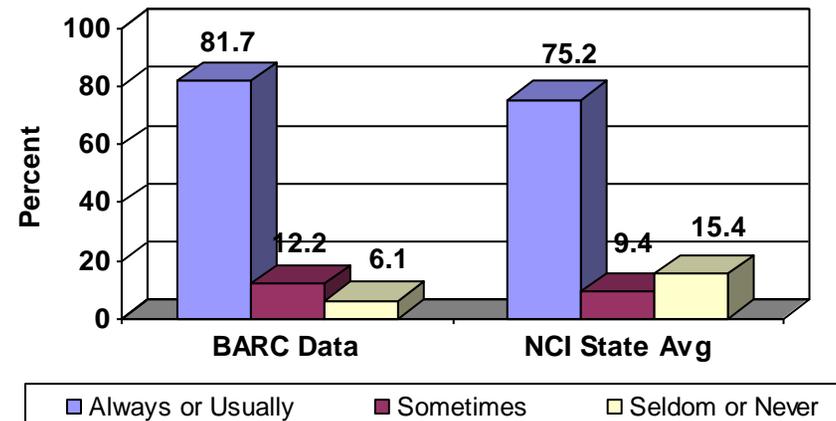
**Chart Q20**

Does your family member have access to the special equipment or accommodations that he/she needs?



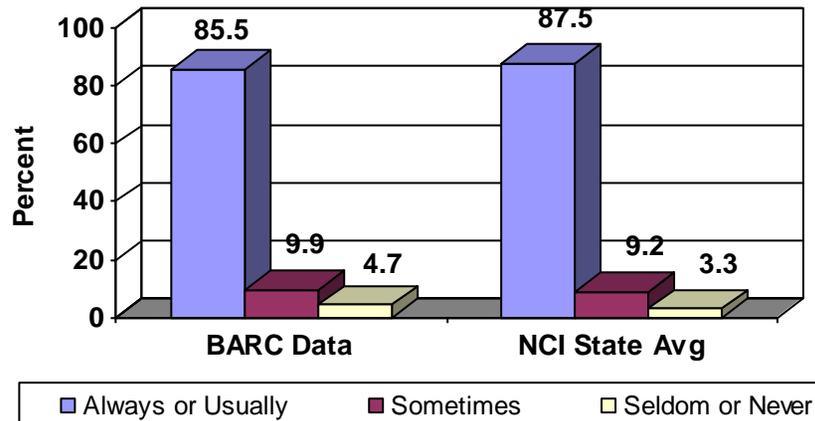
**Chart Q22**

Do you have access to dental services for your family member?



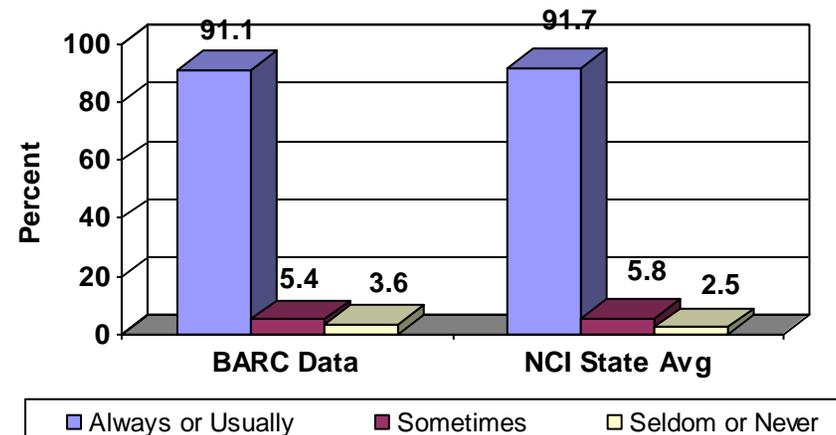
**Chart Q21**

Do you have access to health services for your family member?



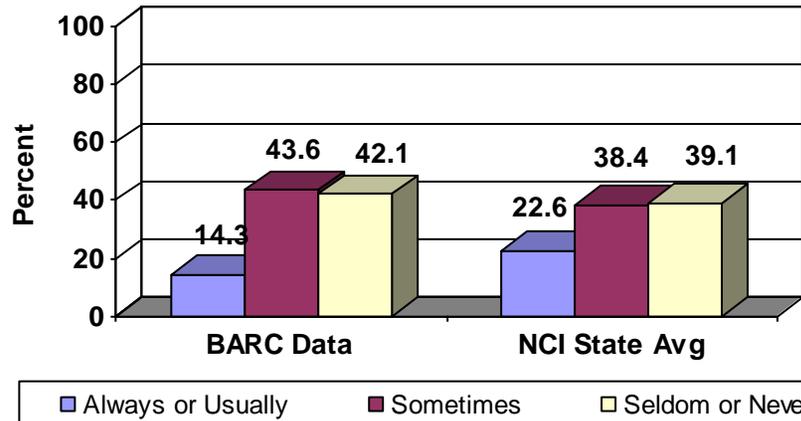
**Chart Q23**

Do you have access to necessary medications for your family member?



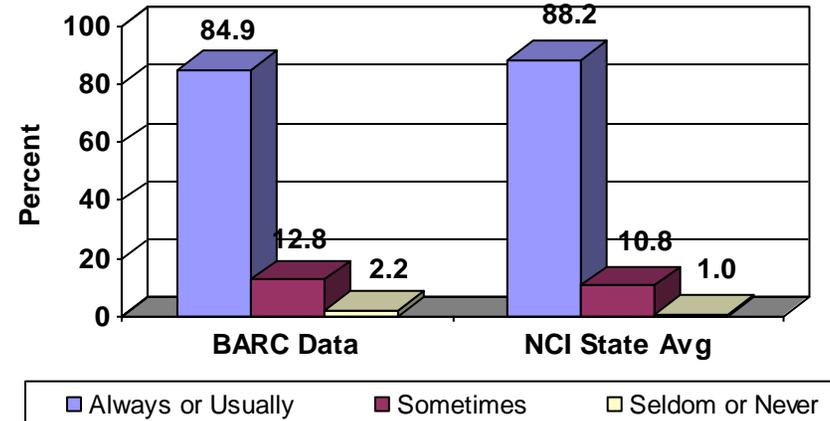
**Chart Q24**

Are frequent changes in support staff a problem for your family?



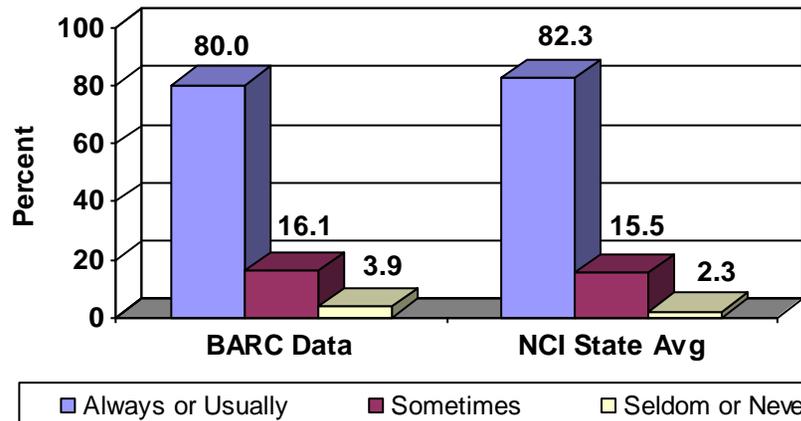
**Chart Q26**

Are support staff generally respectful and courteous?



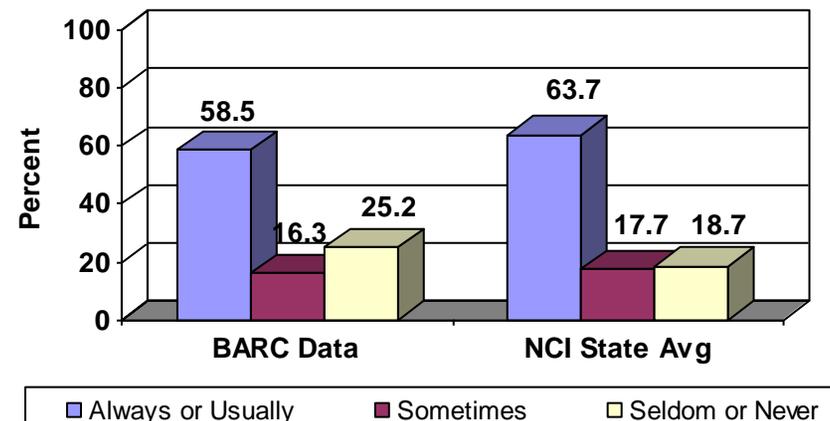
**Chart Q25**

Do you feel that your family member's day/employment setting is a healthy and safe environment?



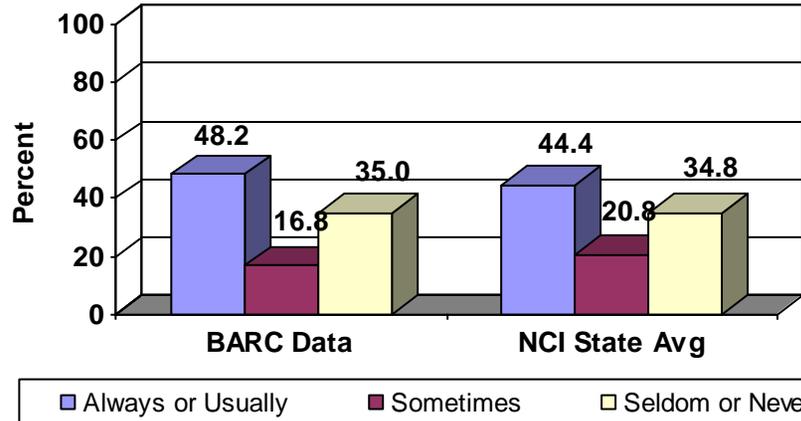
**Chart Q27**

Do you or your family member choose the agencies or providers that work with your family?



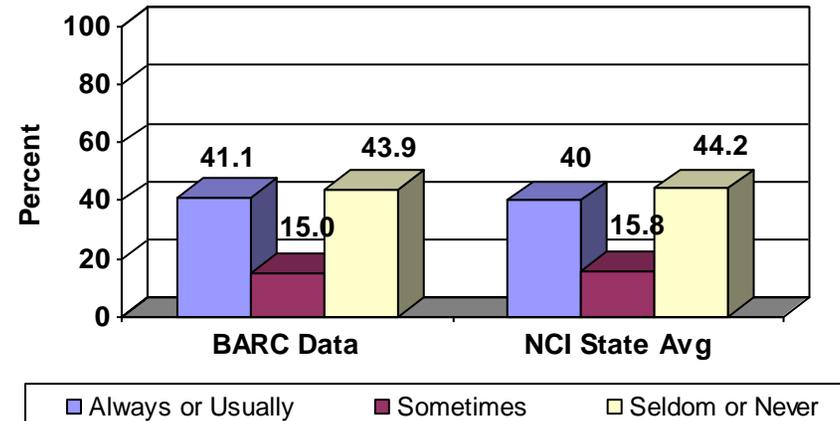
**Chart Q28**

Do you or your family member choose the support workers who work with your family?



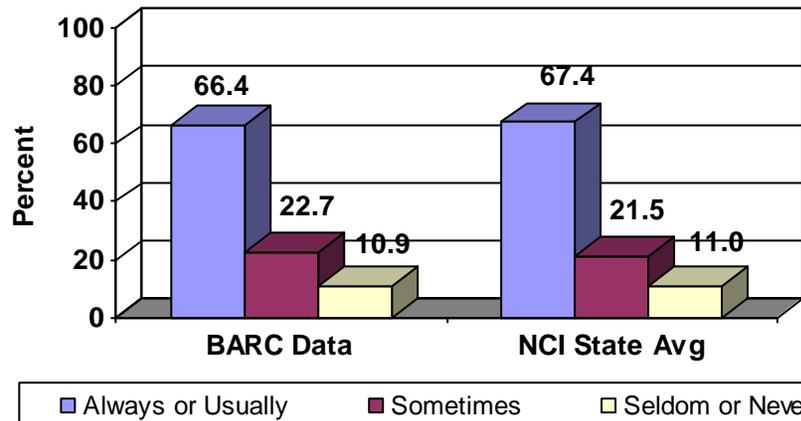
**Chart Q30**

Do you or your family member have control and/or input over the hiring and management of your support workers?



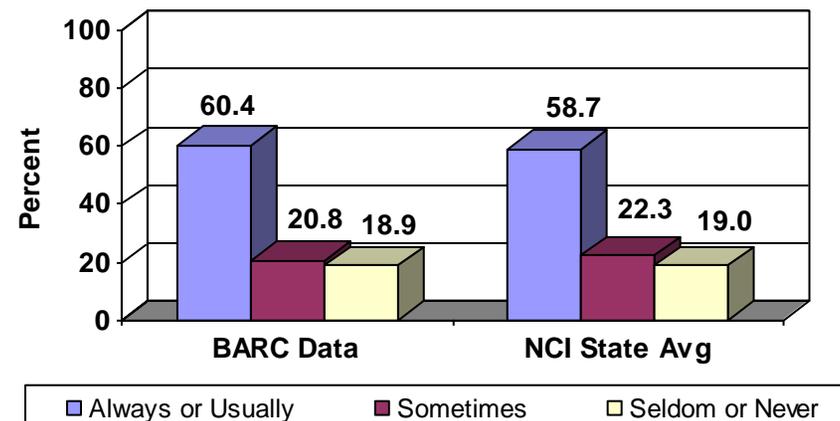
**Chart Q29**

If your family member gets day or employment services, does the agency providing these services involve you in important decisions?



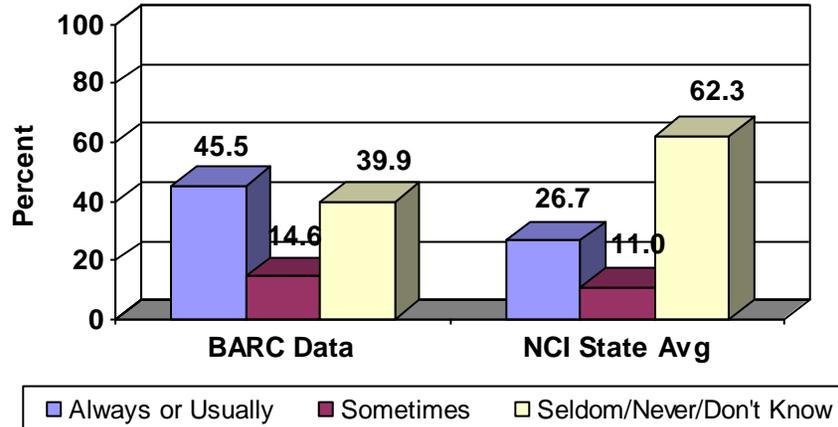
**Chart Q31**

Do you or your family member want to have control and/or input over the hiring and management of your support workers?



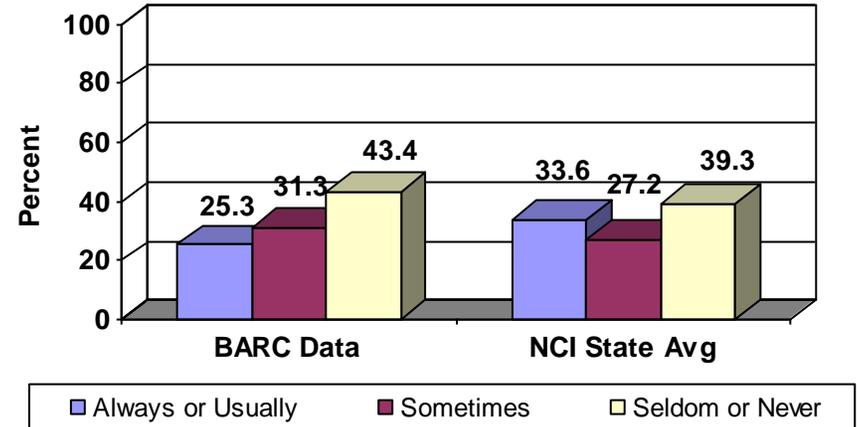
**Chart Q32**

Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?



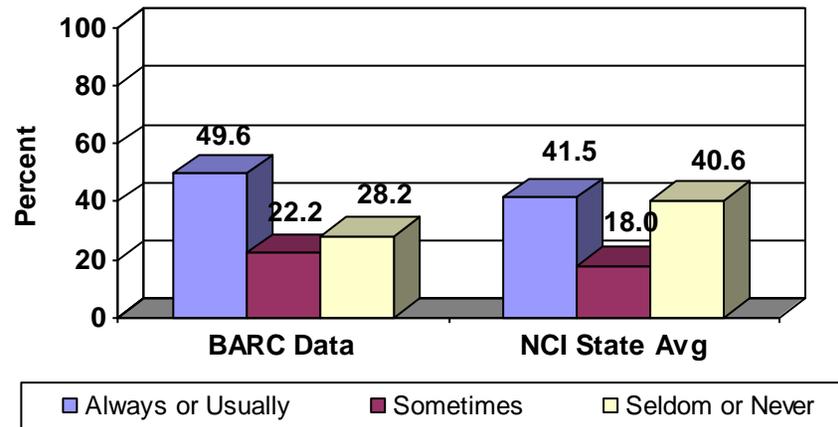
**Chart Q34**

If you want to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?



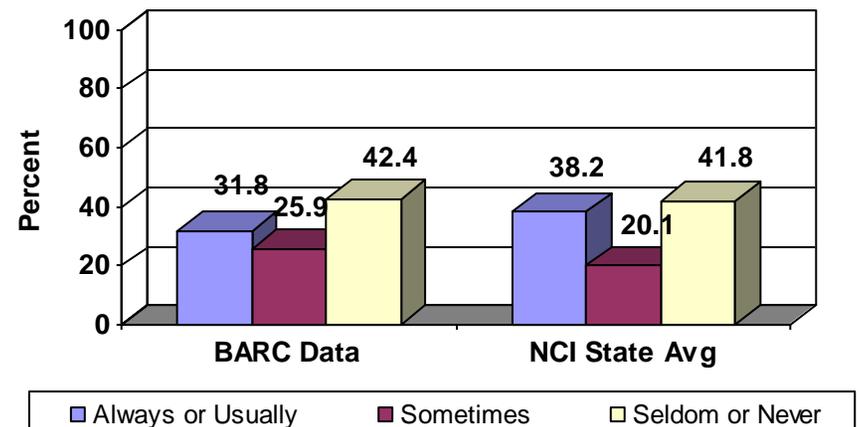
**Chart Q33**

Do you or your family member get to decide how this money is spent?



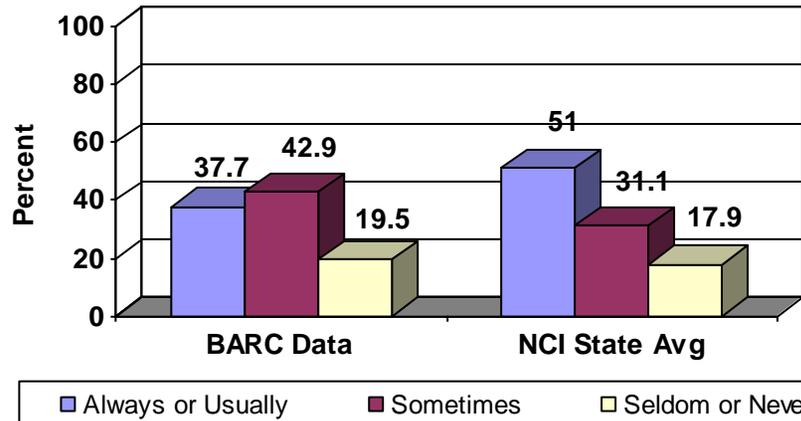
**Chart Q35**

If you would like to use family, friends or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?



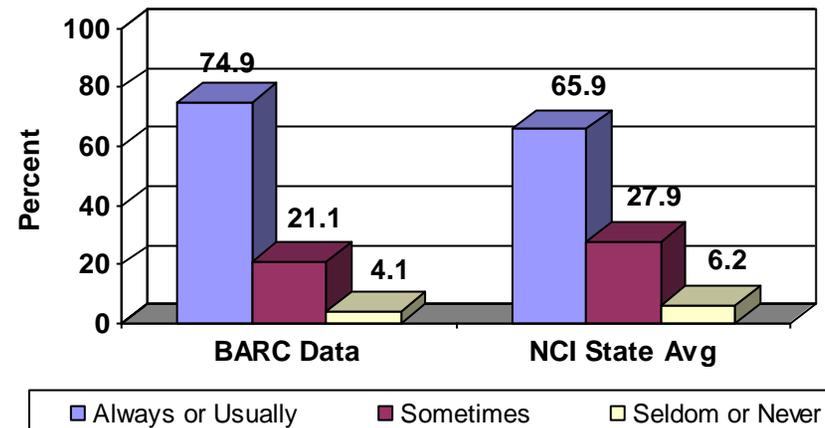
**Chart Q36**

Do you feel that you family member has access to community activities?



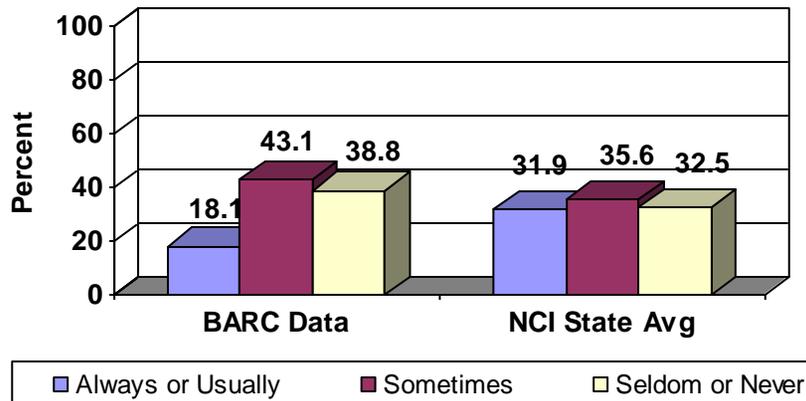
**Chart Q38**

Overall, are you satisfied with the services and supports your family and family member currently receive?



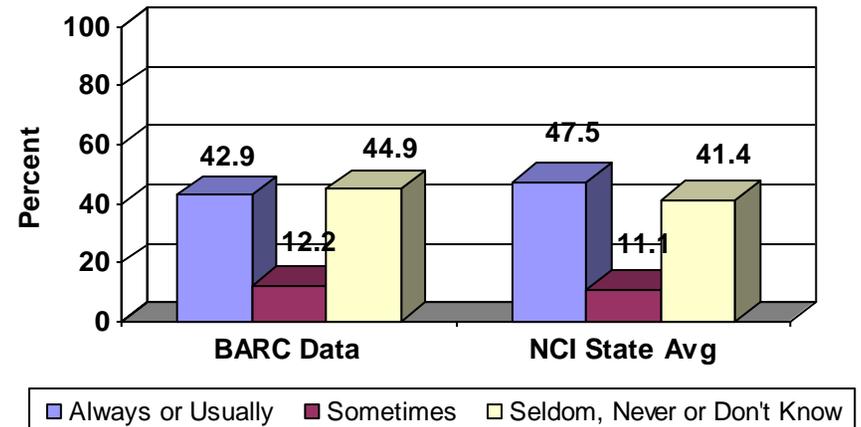
**Chart Q37**

Does your family member participate in community activities?



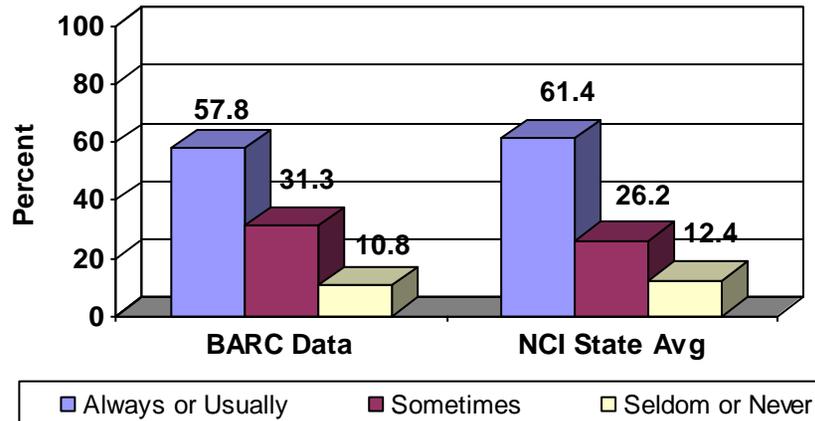
**Chart Q39**

Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?



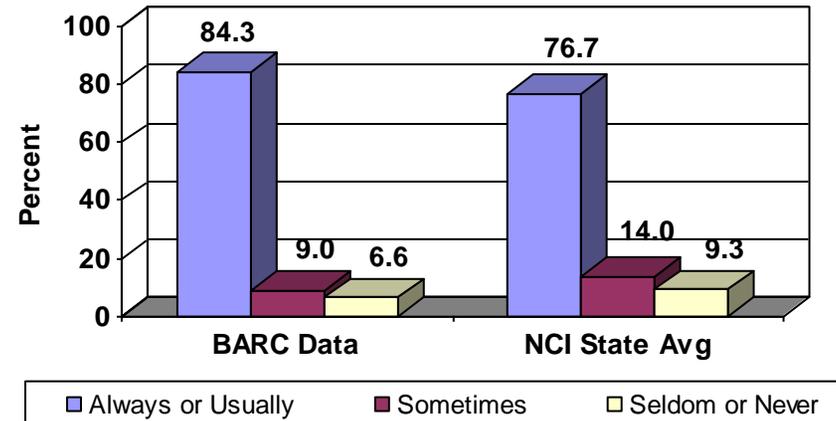
**Chart Q40**

Are you satisfied with the way complaints/grievances are handled and resolved?



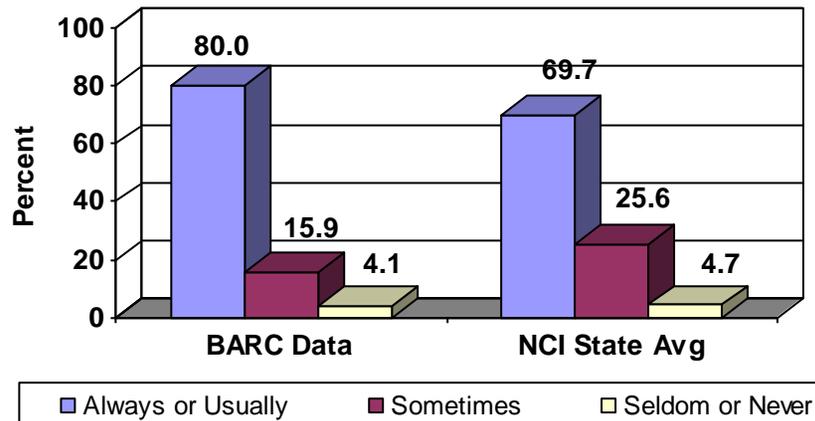
**Chart Q42**

Have services made a difference in helping keep your family member at home?



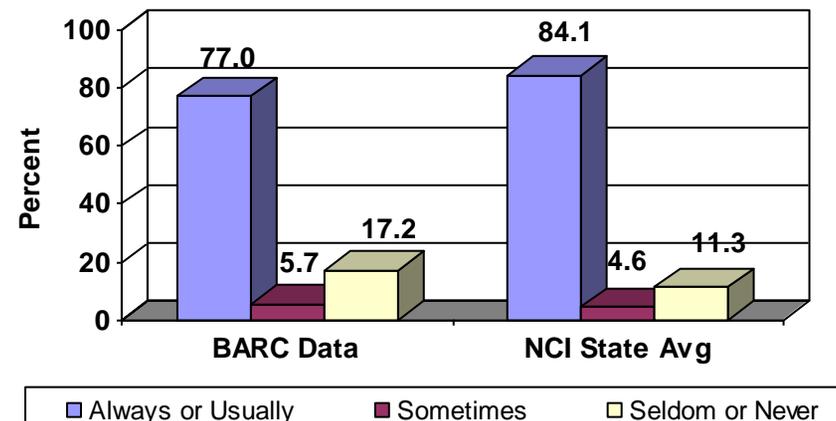
**Chart Q41**

Do you feel that services and supports have made a positive difference in the life of your family?



**Chart Q43**

Would your family member still be at home if you did not receive any supports?



**Chart Q44**

Overall, do you feel that your family member is happy?

