

THE CORE REPORT

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Data Brief: Family Support

This data brief compares findings across the three family surveys conducted as part of National Core Indicators (NCI) (www.hsri.org/nci): 1) the Child Family Survey (for families of children with disabilities living at home); 2) the Adult Family Survey (for families of adults with disabilities living at home); and 3) the Family Guardian Survey (for families of adults with disabilities living outside the family's home).

The results reveal surprising and statistically significant differences in families' experiences and satisfaction with information and planning, levels of choice and control, service and support delivery, and connections to the community. These differences exist between families with a family member at home vs. out-of-home, and between families with children vs. families with adults living at home.

Most interesting, perhaps, are comparisons with the Family Guardian Survey (out-of-home adults). In contrast to the other survey results, FGS respondents are clearly more satisfied with the planning and delivery of services, while having less involvement and control in the process. In nearly all instances, comparisons between FGS respondents (out-of-home) and AFS or CFS respondents (in-home) demonstrate significant differences at a level of $p < .001$. For a detailed illustration of statistically significant differences among results, please refer to the table on page 13.

On the following pages, we showcase several interesting and/or unexpected findings. At the end of the report, we provide several questions to stimulate discussion about these findings. We leave, however, the conclusions regarding what these data suggest to policy makers and stakeholders.

INDICATORS:

Within this report, we explore and compare findings related to a) the information and planning process; b) the amount of choice and control families experience with their services, c) delivery of services and supports, and d) connections families/individuals feel to their community; and e) the overall satisfaction of respondents. The indicators covered here include:

- a) Information & Planning: Families/family members with disabilities have the information and support necessary to plan for their services and supports.
 - The proportion of families who have the information needed to skillfully plan for their services and supports
 - The proportion of families who feel that planning staff are knowledgeable and respectful
- b) Choice & Control: Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.
 - The proportion of families who choose, hire and manage their service/support providers
 - The proportion of families who control their own budgets/supports
- c) Service Delivery: Families/family members with disabilities get the services and supports they need.
 - The proportion of families/individuals with services available when needed.

- The proportion of families/individuals with staff available to communicate and provide support in the family/family member’s primary language/method of communication.
- d) **Community Connections:** Families/family members use integrated community services and participate in everyday community activities.
- The proportion of families/family members who participate in integrated community activities
 - The proportion of families who are supported in utilizing natural supports in their communities
- e) **Satisfaction & Outcomes:** Families/family members with disabilities receive adequate and satisfactory supports. Supports make a positive difference in the lives of families.
- The proportion of families who are satisfied with the supports received
 - The proportion of families who feel that services and supports make a positive difference in their lives.

These following data are presented in order to provoke states to ask questions regarding the differences in results. It is important to remember that National Core Indicators Family Surveys results demonstrate that differences exist, but do not suggest why the results line up as they do. It is up to policy makers and stakeholders in each state to probe for the antecedent causes. All figures reported here are derived from the NCI Family Surveys administered during the 2002-2003 and 2003-2004 data collection periods. The chart below illustrates the number of states and number of respondents per survey:

SURVEY PARTICIPATION	2002-2003		2003-2004	
	# of states	# of respondents	# of states	# of respondents
Children/Family Survey (CFS)	7	2,578	6	2,202
Adult Family Survey (AFS)	15	5,190	12	4,846
Family Guardian Survey (FGS)	10	4,638	10	4,826

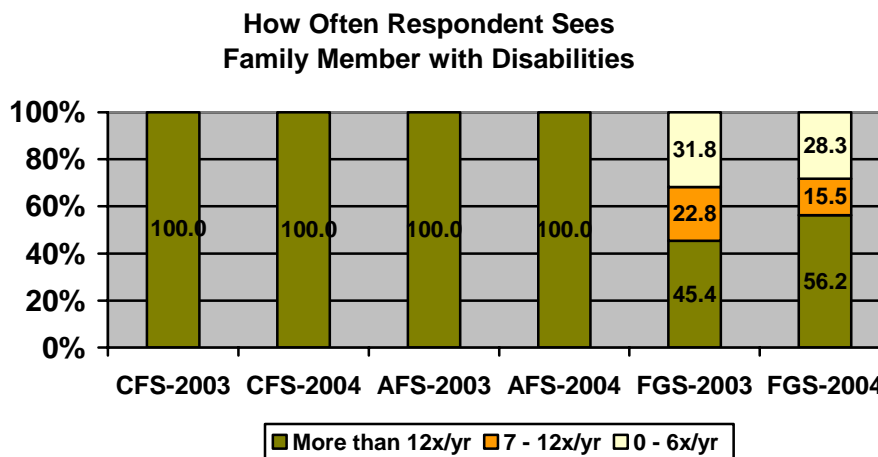
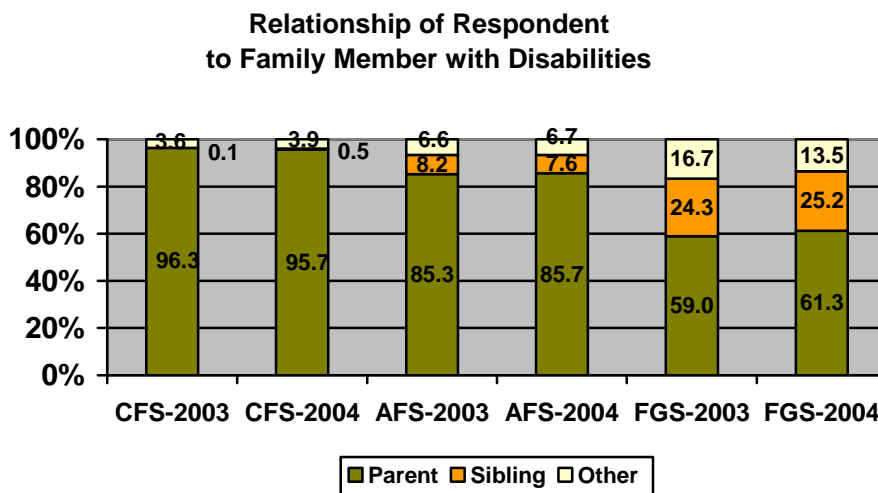
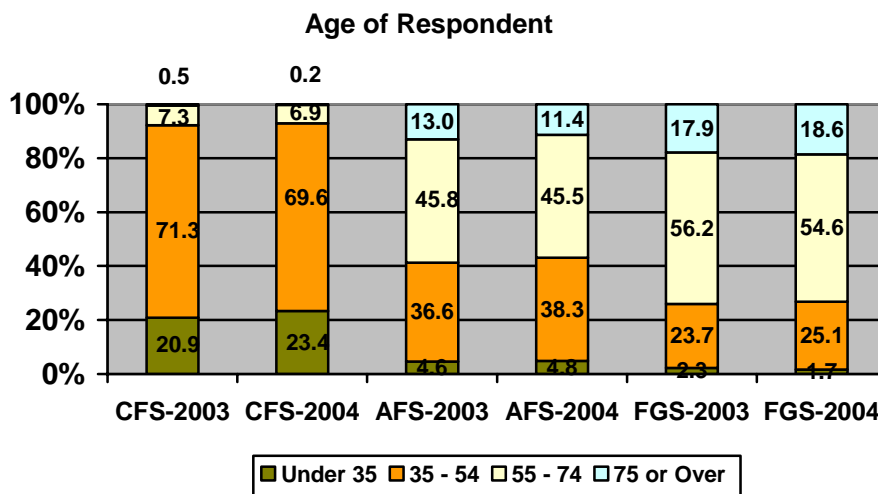
DEMOGRAPHIC INFORMATION

As you review and discuss the findings in this report, it may be helpful to keep in mind some of the similarities and differences among the people who completed the surveys.

Age of Respondents: As one might expect, respondents who completed the two adult surveys (having adult family members with disabilities) were noticeably older than the respondents who completed the child survey (having a child with disabilities at home). Also, though, there are notable age differences between the two adult surveys. A much higher percentage of respondents with out-of-home family members were 55 or older.

Relationship of Respondents to Family Member: In instances where the family member with disabilities lives at home (children and adults), the respondent is more often a parent. Among families where the adult with disabilities lives out-of-home, the majority of respondents are parents, yet there are much larger percentages of sibling and other (e.g., guardians, cousins) respondents.

Frequency in Seeing Family Member: It is assumed that respondents who live with their child or adult family member with disabilities see them regularly/daily. In the Family Guardian Survey, where family members lives outside the family's home, approximately 70% see their family members seven (7) or more times per year.



* Note: An assumption is made respondents living with their children/adults see them regularly.

INFORMATION & PLANNING

Do families have the information needed to skillfully plan for their services and supports?

Families of adults with disabilities living out-of-home are more often informed, less often involved, and more often satisfied with the planning process than either families of children or adults with disabilities living at home.

CHART 1: Do you get enough information to help you participate in planning services for your family?

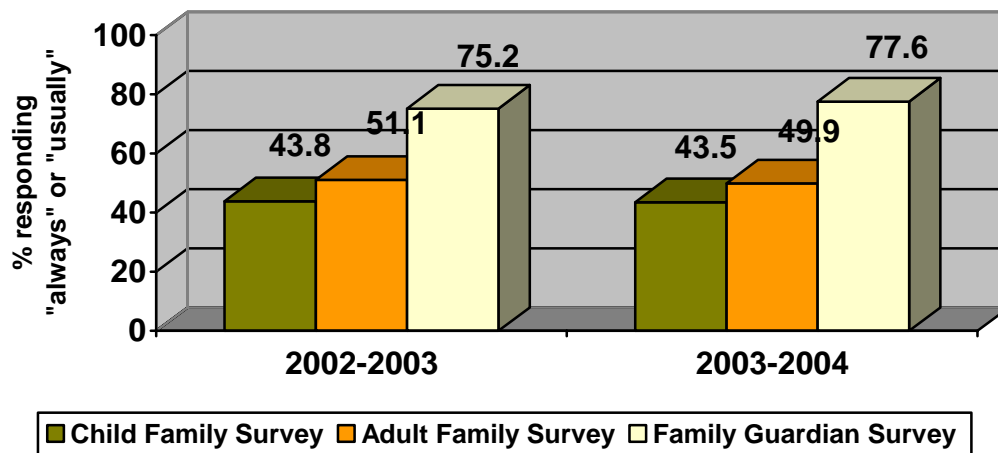


CHART 2: If your family (member) has a service plan, did you help develop the plan?

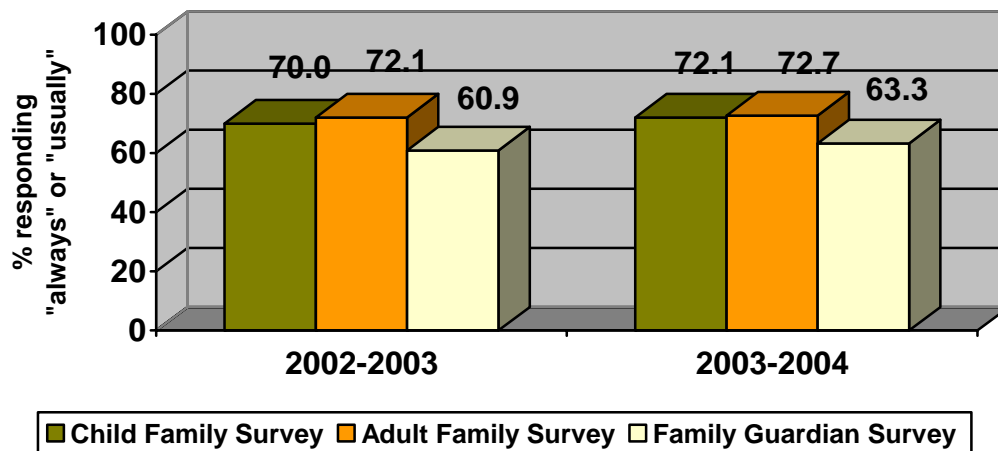
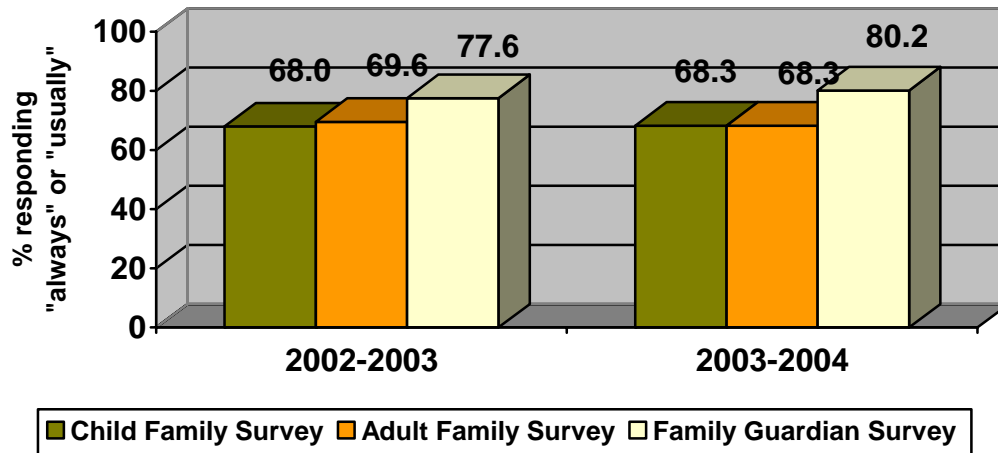


CHART 3: If your family (member) has a service plan, does the plan include things that are important to you?

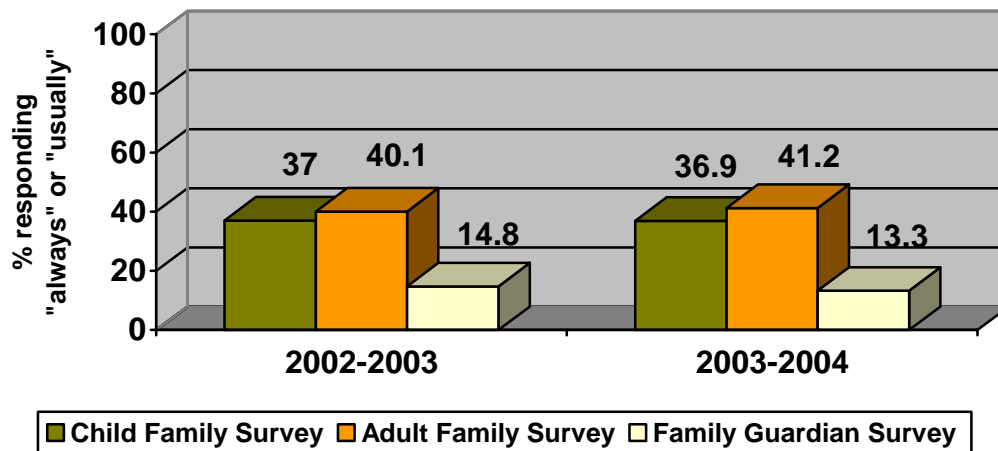


CHOICE & CONTROL

Do individuals with disabilities and their families choose, hire and manage their service/support providers?

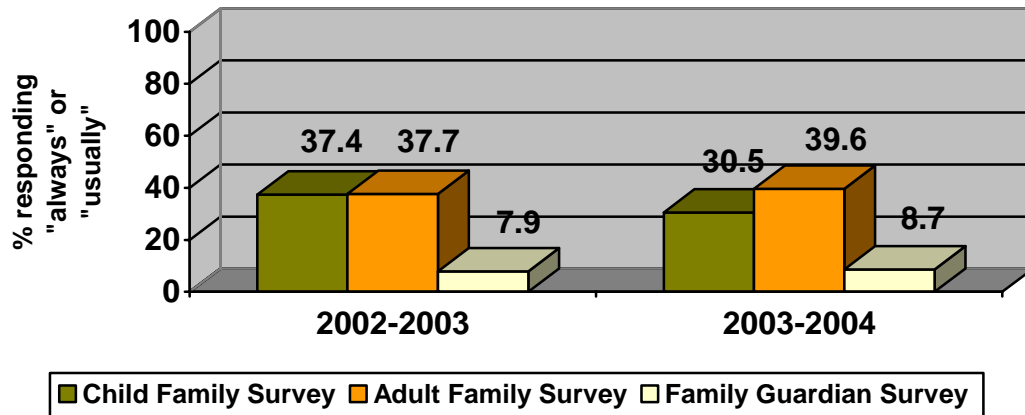
As illustrated in the following charts, families who have a child or adult living at home clearly experience more choice and control in the selection of support workers, and also in their hiring and management, than do individuals with disabilities (and their families) who live outside the family's home.

CHART 4: Do you or your family member choose the support workers who work with your family?



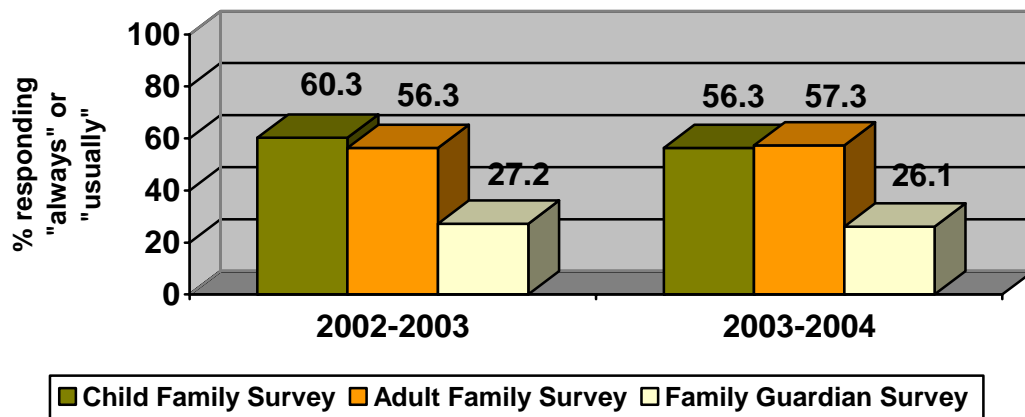
The families of children and adults living at home are three times more likely to have control over hiring and management decisions, and twice as likely to want this type of control, when compared with families of adults living in out-of-home placements.

CHART 5: Do you or your family member have control and/or input over the hiring/management of your support workers?



In all cases, no matter where the individual with disabilities live, more families want control over hiring and management decisions.

CHART 6: Do you or your family member want control and/or input over the hiring/management of your support workers?



Do individuals/families control their own budgets and supports?

Families of adults living in out-of-home placements are as or more likely to know how much money is spent on their family's behalf, yet considerably less likely to decide how that money is spent, when compared to families of individuals living at home.

CHART 7: 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?

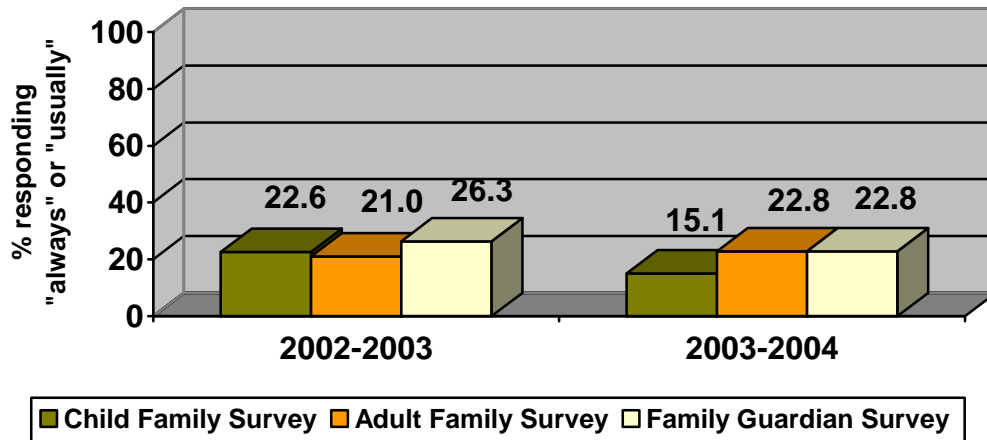
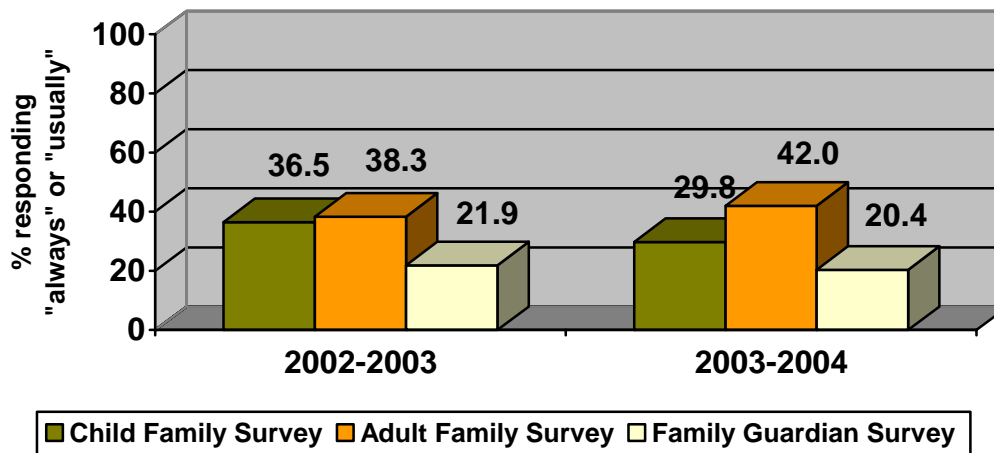


CHART 8: Do you (or your family member) get to decide how this money is spent?



SERVICE DELIVERY

Are services and supports available when needed?

Families of adults living in out-of-home placements clearly feel their needs are better met than those who have family members living at home. When they ask for assistance, they more often get it. They have more access to special equipment and accommodations, as well as staff who can effectively communicate with their family member. Overall, families of individuals living outside the home more frequently get the supports they need.

Results also show that among families having a child vs. an adult living at home, families with adult family members more often receive the services and supports needed.

CHART 9: When you ask your service coordinator for assistance, does s/he help you get what you need?

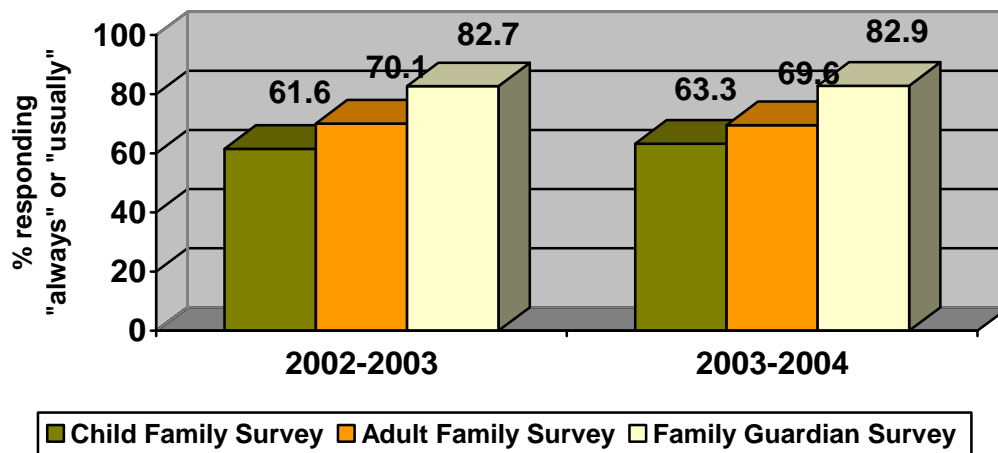


CHART 10: Can you contact the staff who assist you with planning whenever you want to?

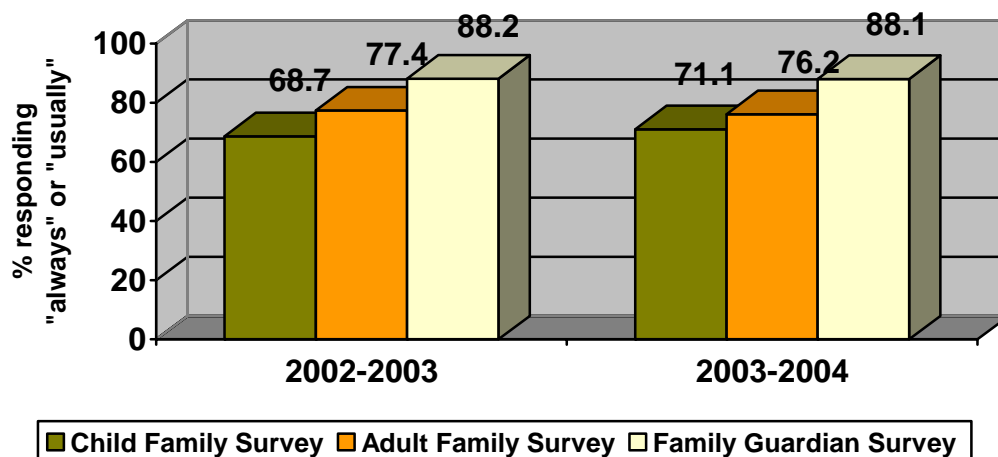


CHART 11: Does your family member have access to the special equipment or accommodations that s/he needs?

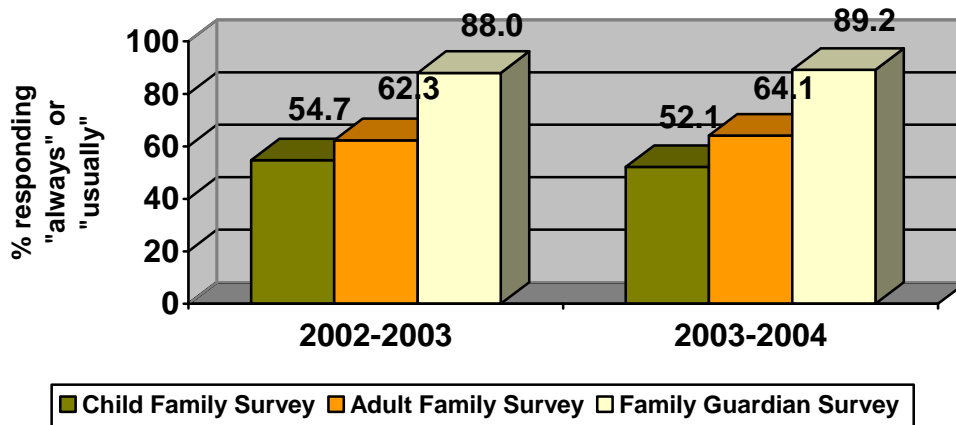


CHART 12: If your family member does not speak English or uses a different way to communicate, are enough support workers available to communicate with him?

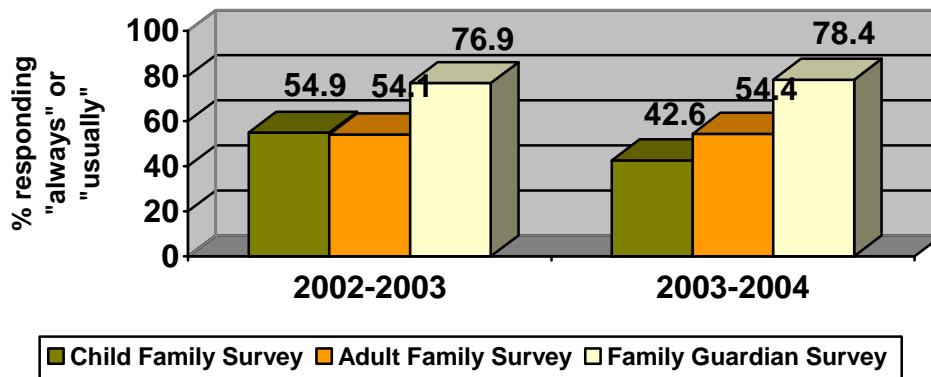
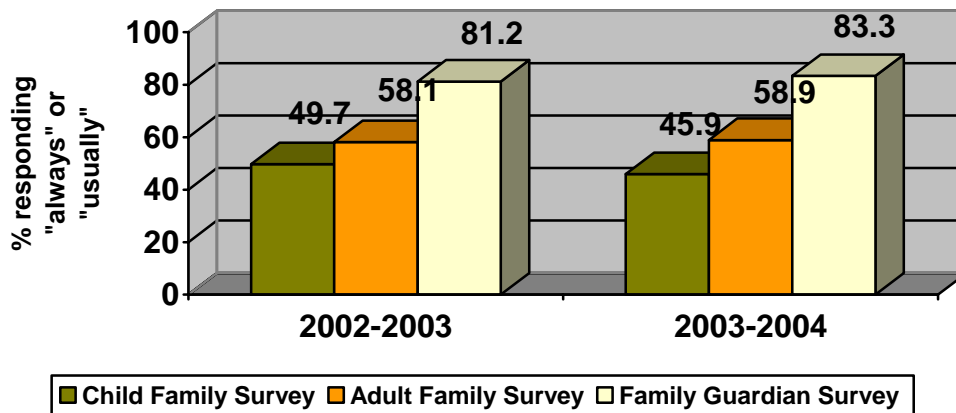


CHART 13: Does your family/family member get the services and supports you need?



COMMUNITY CONNECTIONS

Do family members participate in integrated activities in their communities?

Perhaps surprisingly, children with disabilities living at home with their families have the least access and participation in community activities. Adults with disabilities who live outside the family home, on the other hand, have the most access and participation in their communities.

CHART 14: Do you feel your family member has access to community activities?

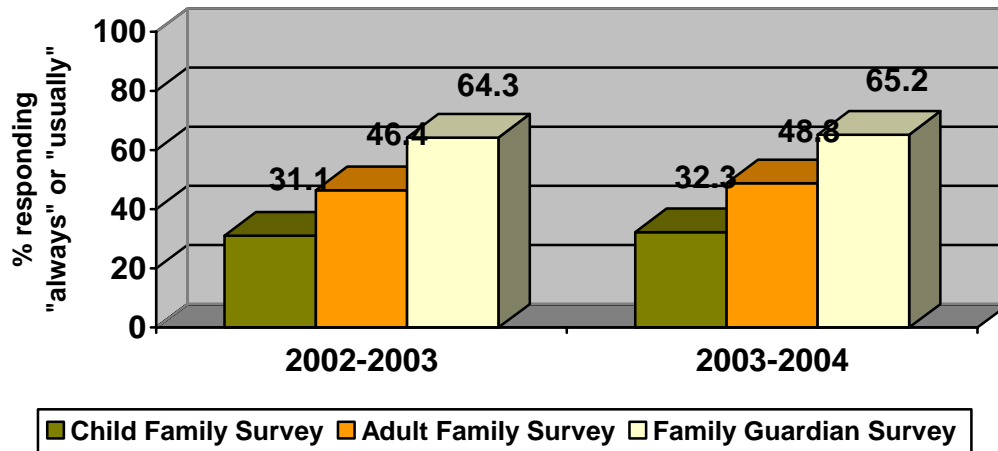
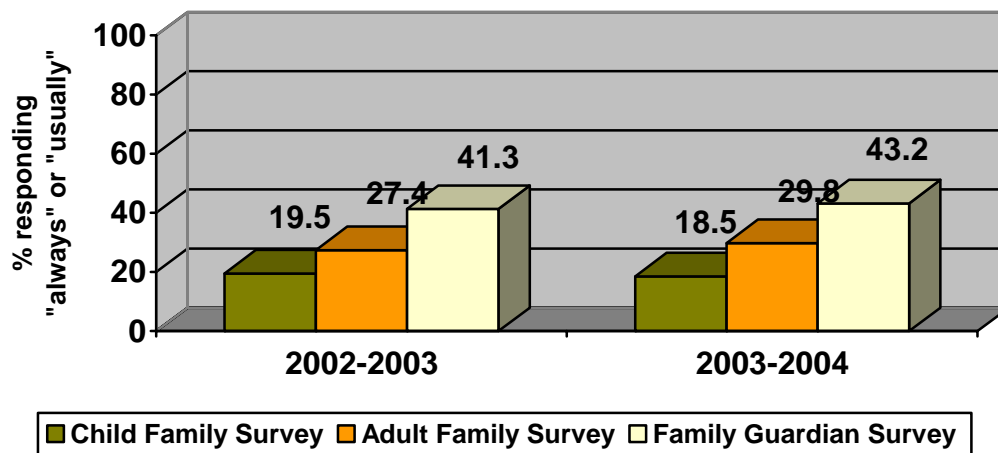


CHART 15: Does your family member participate in community activities?



Are families supported in utilizing natural supports in their communities?

In addition to children having the smallest level of community access and participation, their families feel least supported in making these connections. They are least likely to get assistance from planning or support staff to get connected with community resources, as well as least likely to gain assistance in connecting with family and friends for support. Families of adults living out-of-home are twice as likely to feel supported in these ways.

CHART 16: 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?

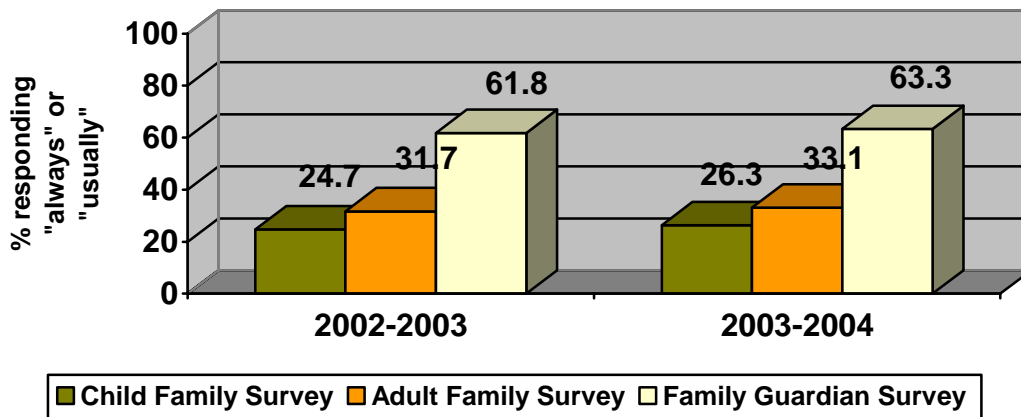
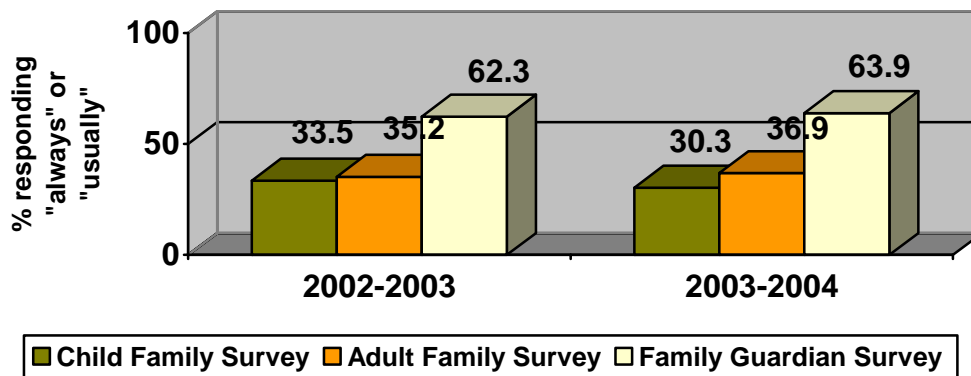


CHART 17: If you would like to use family, friends or neighbors to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you do this?

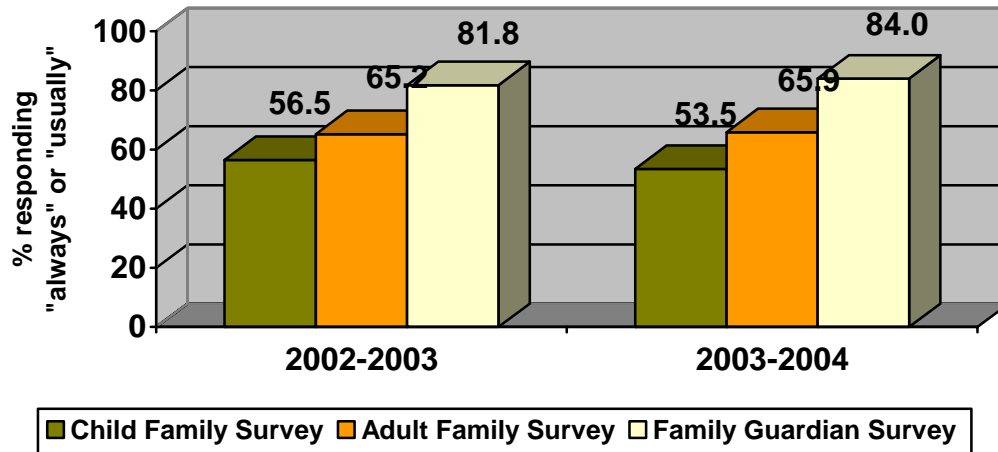


SATISFACTION & OUTCOMES

Are families satisfied with the supports received?

Families of individuals living outside the family home clearly are more satisfied with the services and supports received, when compared with families having children or adults living at home.

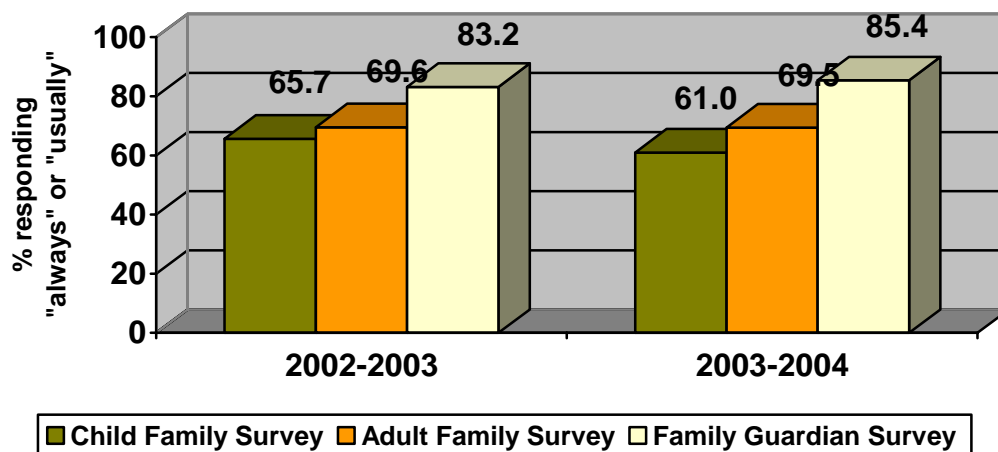
CHART 18: Overall, are you satisfied with the services and supports your family member and family receive?



Do families feel that services/supports make a positive difference in their lives?

While the majority of families, within every survey, feel that supports have affected their lives in positive ways, once again the respondents to the Family Guardian Survey feel this to a greater extent.

CHART 19: Do you feel that family supports have made a positive difference in the life of your family?



DATA ANALYSIS

Using Pearson Chi-Square analysis, statistical significance was tested for each question/variable in four ways:

1. Across all three surveys (Child Family Survey, Adult Family Survey and Family Guardian Survey);
2. Between the Child Family Survey and Family Guardian Survey;
3. Between the Adult Family Survey and Family Guardian Survey; and
4. Between the Child Family Survey and Adult Family Survey.

Illustrated in the table below, strong levels of statistically significant differences (e.g., $p < .001$) were found in each set of survey comparisons. Where differences were not found, the table shows “Not sig.”, indicating that no significant differences were found in the responses for that particular question/variable.

STATISTICAL SIGNIFICANCE OF RESULTS	All 3 Surveys		CFS vs FGS		AFS vs FGS		CFS vs AFS	
	2002-2003	2003-2004	2002-2003	2003-2004	2002-2003	2003-2004	2002-2003	2003-2004
Demographics								
Age of Respondent	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Relationship	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Information & Planning								
Chart 1	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Chart 2	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	Not sig.	Not sig.
Chart 3	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .01$	Not sig.
Choice & Control								
Chart 4	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	Not sig.	$p < .05$
Chart 5	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	Not sig.	$p < .001$
Chart 6	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .05$	Not sig.
Chart 7	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	Not Sig.	Not sig.	$p < .001$
Chart 8	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	Not sig.	$p < .001$
Service Delivery								
Chart 9	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Chart 10	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Chart 11	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Chart 12	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	Not sig.	$p < .001$
Chart 13	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Community Connections								
Chart 14	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Chart 15	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Chart 16	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Chart 17	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	Not sig.	$p < .001$
Satisfaction & Outcomes								
Chart 18	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$
Chart 19	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$	$p < .001$

OBSERVATIONS

These findings raise many questions. For instance:

- Overall, why do families of adults in out-of-home placements (who have less choice and control), feel more informed and satisfied with the planning process, more connected to their communities, and more satisfied with their services and supports?
- Why do “out-of-home” families more often know how much money is spent for their family member’s supports, yet less often decide how it is spent?
- Conversely, why do “at-home” families, who more often contribute to the decision-making process, less frequently know how much money is spent?
- Why do families with out-of-home family members more often get assistance, special equipment and needed supports?
- Why are respondents with adult family members generally more satisfied and supported than families with children? Are they more informed? Are they better at navigating the system? Does funding for adult services overshadow funding for family supports?
- Why do families, with their family member living at home feel more isolated from their communities (less access and less participation)?
- Does the amount of money that states contribute to out-of-home services vs. in-home supports contribute, in some way, to these results?
- Are out-of-home services better? Or better funded?
- Are adult services better? Or better funded?
- Do family expectations differ from one survey group to another? For instance, do families with children have different expectations than families with adults? Do families with a family member living at home have different expectation than those with a family member living out-of-home?
- Does a respondent’s age, relationship or frequency of visits with their family member factor into these results?

These are just a few questions that the data findings raise. You will likely have more. We hope you will use these findings to spur discussion in your state to improve services for all individuals with disabilities, young or old, at-home or out-of-home.

For more information, visit the NCI website at www.hsri.org/nci or contact:

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