

Family Survey

Phase II Technical Report



A Collaboration of
the National Association of State Directors of Developmental Disabilities Services and
Human Services Research Institute

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Over eight thousand parents, guardians, siblings, spouses, and others responded to the surveys described in this report. The Core Indicators Project would not be possible without their participation and willingness to express their opinions. To families and others across the country who responded to a survey, we extend our appreciation for your important contribution to the project.

Project Background

In December 1996, the NASDDDS Board of Directors launched the Core Indicators Project (CIP). The project's aim is to support state developmental disabilities authorities (SDDAs) in developing and implementing performance/outcome indicators and related data collection strategies that will enable them to measure service delivery system performance. The project strives to provide SDDAs with sound tools in support of their efforts to improve system performance and thereby to better serve people with developmental disabilities and their families. The Association's active sponsorship of CIP facilitates states pooling their knowledge, expertise and resources in this endeavor.

CIP Phase I began in January 1997. In August 1997, the Phase I Steering Committee selected a "candidate" set of 61 performance/outcome indicators in order to test their utility/feasibility. Six states agreed to conduct a field test of these indicators, including administering the project's consumer and family surveys and compiling other data. Field test data were transmitted to project staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

CIP Phase I had mixed results. Several states found that the information compiled during Phase I was immediately useful in its own right. However, Phase I revealed the need to refine project instrumentation and to make other changes. Nonetheless, the Phase I results were sufficiently promising to prompt the NASDDDS Board of Directors to renew its sponsorship of CIP and invite additional NASDDDS member agencies to participate in the project. CIP Phase II was launched in January 1999. Phase II data collection wrapped up in June 2000 and set the stage for continuation and further expansion of the project.

Twelve states (AZ, CT, KY, MA, MN, NE, NC, PA, RI, VA, VT, WA) participated in Phase II. Four additional states have since joined the project (DE, IA, MT, UT). State participation in the project is entirely voluntary. Other NASDDDS member agencies also are participating in the project on a limited basis. During Phase II, the Phase I indicators were revised and project data collection tools and methods were improved. The "Version 2.0" indicator set consists of 60 performance and outcome indicators. Going forward, the project is expanding its scope to include services for children with developmental disabilities and their families, continuing to develop and refine the indicators, and recruiting additional states to participate in the project. Phase II data is considered baseline project data. For the first time, the results are being released publicly. While participating states move forward collecting the next round of data, project staff efforts are concentrated on compiling and presenting the baseline data in formats that are accessible to a variety of audiences. Selected information from this and other technical reports will soon be available online at www.hsri.org/manage/core.html.

Phase II Instruments and 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.

In this report we describe the surveys developed by the project, the indicators that are being measured, how the surveys were administered and how the results were analyzed. The results are displayed state-by-state and in the aggregate.

Family Support Survey

IN PHASE I of the project, the steering committee established the SUPPORTING FAMILIES sub-domain/indicator to provide information about the effectiveness of service systems in supporting families who have an adult family member with a developmental disability living at home with them. With respect to this indicator, a stand-alone family survey instrument was developed. The survey was designed to be administered by mail, and the questions were drawn primarily from similar instruments developed and tested previously by HSRI. Participating states were instructed to mail this survey to 1,000 randomly selected families. All seven field test states conducted the family survey.

Nearly 3,300 survey questionnaires were returned in Phase I. Among the participating states, the return rate (number of questionnaires returned divided by the total number mailed) ranged from 37 to 48 percent. These were relatively good return rates for this type of mail survey. Phase I proved that the survey was relatively straight-forward to administer, yielded high response rates, and provided sound feedback to SDDAs. However, the results also revealed:

- the need for some improvements to the wording and construction of the survey
- the need for a clearer distinction between families with a consumer living in the home vs. families/guardians of a consumer living outside the family home
- regarding the "comments" section, which provides space for open-ended responses, the need for a mechanism that would allow respondents to waive confidentiality if they report a situation that merits follow up by the SDDA

In light of these findings, the Phase I instrument was slightly modified and reissued to states for administration during Phase II.

IN PHASE II, twelve states administered the revised "Family Support Survey" (see Appendix A). As in Phase I, each participating state was asked to mail this questionnaire to 1,000 randomly-selected families who met two criteria: (1) an adult family member with a developmental disability was living in the household and (2) either the individual or the family was receiving at least one service or support besides case management. If fewer than 1,000 families met this criteria, the state was instructed to mail the questionnaire to all qualified families. The requirement that questionnaires be mailed to 1,000 families was based on an expected return rate of 40%, which in turn would yield 400 completed questionnaires in hand for each state. Since all states used the standard questionnaire, the results are comparable state-to-state.

The survey instrument asks families to express their overall level of satisfaction (or dissatisfaction) about services and supports. However, most of the survey questions probe particular aspects of supporting individuals and families that may contribute to satisfaction or are important in their own right with respect to promoting family-centered services. For example, with respect to service coordination, families are asked: "Can you contact this person's service coordinator whenever you want to?" Ready access to a service coordinator may contribute to family satisfaction. It also is

important in its own right since access to a service coordinator is very important in assuring that the service system is responsive to consumers.

The instrument is constructed so that the family member may select from three possible responses to each question ("yes or most of the time", "some of the time", and "no or not at all") or indicate that they don't know the answer or that the question does not apply. The instrument also contains a background information section where the family member is asked to provide certain information about the family and the family member with a disability and to indicate what services and supports are being furnished to the family member and/or the family. Finally, the instrument provides the family member the opportunity to make open-ended comments concerning any topic.

States that administer the Family Support Survey agree to employ the project's base instrument and questions. If it wishes, a state may include additional questions to address topics not dealt with in the base instrument.

Family/Guardian Survey

During Phase II, a new sub-domain -- FAMILY INVOLVEMENT -- was added to the core indicators set. Participating states expressed interest in obtaining feedback from family members of individuals who no longer live with the family concerning how well the family member with a disability is being supported and the extent to which their ongoing involvement with the person was supported. This interest led to the development of the "Family/Guardian Survey" (see Appendix B).

This survey is mailed to families or guardians of adults with developmental disabilities who live outside of the family home. There are some similarities between this instrument and the Family Support Survey. However, there also are many differences. The Family Support Survey concerns services and supports provided to the family member and/or in support of the family. The Family/Guardian Survey concentrates on services the family member is receiving.

Again, each state was required to mail this questionnaire to 1,000 randomly-selected families (or all such families if they number fewer than 1,000). This figure again is based on an expected return rate of 40% in order to yield 400 completed questionnaires in hand. Administration of this survey was optional during Phase II.

The Indicators

As mentioned above, the family surveys are designed to measure two indicators that fall under the CONSUMER OUTCOMES domain of the Phase II Core Indicators. The two sub-domains listed in the original documents are called SUPPORTING FAMILIES and FAMILY INVOLVEMENT.

The concern statement for SUPPORTING FAMILIES reads:

Families who have a family member living at home receive adequate and satisfactory supports.

The indicator itself reads:

The proportion of families with an adult family member living in the home who report satisfaction with the following: supports received by the family and the family member, availability and utility of information, choices, planning, linkages to supports, service coordination, and crisis response.

The concern statement for FAMILY INVOLVEMENT reads:

Families/guardians maintain connections with family members who do not live at home.

The indicator itself reads:

The proportion of families/guardians of individuals not living at home who report (a) satisfaction with the services and supports their family member receives; and (b) the extent to which the system supports continuing family involvement

For the purpose of displaying the results in a clear manner, we propose some slight modifications to these two indicators. The suggested changes are outlined in the gray boxes on the following two pages. The names of the sub-domains have been changed, and the SUPPORTING FAMILIES indicator is split into two parts (reflecting families opinions about supports provided to the family vs. supports provided to the individual with a developmental disability). The indicators are further broken down into sub-indicators, and the related survey questions are listed with bullets under each sub-indicator. [Note: Sub-indicators do NOT correspond exactly to the subheadings on the actual survey form.] A reliability analysis was performed to determine whether the sub-indicators can be presented as "scaled" or grouped scores. An asterisk (*) beside the sub-indicator denotes that this group of items constitutes a reliable scale¹.

¹ If the reliability analysis resulted in an alpha score of .70 or higher, the scale was considered to be reliable.

REORGANIZATION OF INDICATORS, SUB-INDICATORS, AND SURVEY ITEMS

Sub-domain: **IN-HOME FAMILY OUTCOMES (formerly: SUPPORTING FAMILIES)**
Data Source: Family Support Survey
Indicator: Split into Part 1 and Part 2 (see below)

Part 1: The proportion of families with an adult family member living in their home who report satisfaction with family supports, specifically...

1.a. Availability and utility of information about family supports

- Do you receive information about services and supports that are available to your family?
- If yes, is the information easy to understand?

1.b. Planning family supports*

- Do staff help you figure out what you need as a family to support your family member with a disability?
- Do staff talk to you about different options to meet your family's needs?
- Do staff respect your choices and opinions?

1.c. Access to needed family supports*

- Does your family get the supports you need, such as respite care, training, or education?
- Do the supports offered meet your family's needs?
- Are supports available when your family needs them?
- If English is not your first language, are there staff who speak with you in your preferred language?
- Are frequent changes in support staff a problem for your family?

1.d. Links to community and natural supports*

- Do staff help you get family supports in your community, such as services offered through recreation departments, churches, or medical services?
- Do staff help you make arrangements with family, friends, or neighbors who can provide some of the supports your family needs?

1.e. The proportion of families who make choices about their service providers*

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

Part 2: The proportion of families with an adult family member living in their home who report satisfaction with individual supports received by their family member, specifically...

2.a. Participation in planning individual supports*

- Did you get enough information to help you participate in planning services for your family member with a disability?
- Did you help develop this person's service plan?
- Does the service plan include things that are important to you?
- Does the agency providing day/employment services to this person involve you in important decisions (such as where to work, type of work, work setting)?

2.b. Availability and effectiveness of service coordinators*

- Can you contact this person's service coordinator/case manager whenever you want to?
- When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?

2.c. Access to needed individual supports*

- If this person does not speak English or uses a different way to communicate (for example, sign language), do you feel that there are enough staff available who can communicate with him/her?
- Do you feel that this person has access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

2.d. Overall satisfaction with individual supports

- Do you feel that this person's day/employment setting is a healthy and safe environment?
- Overall, do you feel that this person is happy?
- Overall, are you satisfied with the services and supports this person currently receives?

2.e. Satisfaction with grievance process

- Are you satisfied with the way complaints/grievances are handled and resolved by the state agency?

2.f. Satisfaction with crisis response

- If you have ever asked for the state agency's assistance in an emergency or crisis, was help provided to you right away?

Sub-domain: **OUT-OF-HOME FAMILY/GUARDIAN OUTCOMES (formerly: FAMILY INVOLVEMENT)**

Data Source: Family/Guardian Survey

Indicator:

The proportion of families/guardians of individuals not living at home who report satisfaction with...

a. Participation in planning individual supports*

- Did you get enough information to help you participate in planning services for your family member with a disability?
- Did you help develop this person's service plan?
- Does the service plan include things that are important to you?
- Does the agency providing residential services to this person involve you in important decisions (such as where to live, roommates, medical, dental)?
- Does the agency providing day/employment services to this person involve you in important decisions (such as where to work, type of work, work setting)?

b. Availability and effectiveness of service coordinators

- Can you contact this person's service coordinator/case manager whenever you want to?
- When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?

c. Access to needed individual supports

- If this person does not speak English or uses a different way to communicate (for example, sign language), do you feel that there are enough staff available who can communicate with him/her?
- Do you feel that this person has access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

d. Overall satisfaction with individual supports*

- Do you feel that this person's residential setting is a healthy and safe environment?
- Do you feel that this person's day/employment setting is a healthy and safe environment?
- Overall, do you feel that this person is happy?
- Overall, are you satisfied with the services and supports this person currently receives?

e. Satisfaction with grievance process

- Are you satisfied with the way complaints/grievances are handled and resolved by the state agency?

Methodology

Sampling/Administration

States administered the Family Support Survey by selecting a minimum sample of 1,000 randomly selected families who have an adult family member with a developmental disability living in the family home and were receiving at least one service or support over and above service coordination. Adults were defined as age 18 or older. A sample size of 1,000 was selected with the expectation that the survey return rate would be 40%, yielding 400 usable responses per state. So long as 400 usable responses are obtained per state, the results may be compared across states within a confidence level of $\pm 10\%$. In states where there were fewer than 1,000 potential respondent families, surveys were sent to all eligible families.

The sampling strategy was similar for the Family/Guardian Survey. States that elected to administer the Family/Guardian Survey mailed it to a minimum sample of 1,000 (or all potential respondents, if less than 1,000) families or guardians of adults living outside of the family home.

Each state entered survey responses into a standard file format and sent the data file to HSRI for analysis. As necessary, HSRI personnel “cleaned” (i.e., excluded invalid responses) based on three criteria:

- The question "Does your family member live at home with you?" was used to screen out respondents who received the wrong survey (e.g. some families of consumers who live at home received the "Family/Guardian Survey" by mistake and vice versa). Surveys filled out by mistake were dropped.
- Both CIP surveys targeted families of adult consumers. If the respondent indicated that their family member was under the age of 18 (or the age could not be determined), the response was dropped.
- In a few cases, demographic information was entered into the file but no survey questions were answered. These responses also were dropped.

Survey Scope and Response Rates

During Phase II, ten states administered the Family Support Survey. In the case of two states (Minnesota and Virginia) sample sizes were not sufficient to permit analysis of the responses. Seven states administered the Family/Guardian Survey. Table 1a shows the number of surveys that each state mailed out, and the number and percent that were returned:

Table 1a: Number of Surveys Mailed Out and Returned

	Family Support Survey		Family/Guardian Survey	
	Mailed	Returned (%)	Mailed	Returned (%)
Arizona	1,000	397 (39.7%)	N/A	N/A
Connecticut	1,192	575 (48.2%)	1,978	853 (43.1%)
Kentucky	2,121	406 (19.1%)	2,078	458 (22.0%)
Minnesota	N/A	N/A	1,000	383 (38.3%)
North Carolina	858	129 (15.0%)	N/A	N/A
Nebraska	800	371 (46.4%)	2,800	1056 (37.7%)
Pennsylvania	2,950	1733 (58.7%)	2,950	1821 (61.7%)
Virginia	N/A	N/A	796	329 (41.3%)
Vermont	N/A	226 (58%*)	N/A	N/A
Washington	1,955	472 (24.1%)	2,000	461 (23.1%)
Total*	10,876	4309 (39.6%)	13,602	5361 (39.4%)

*Vermont's return rate is based on a total of 957 surveys mailed to families of both children and adults. Of those returned, 226 were from families of adults and 297 from families with children, and 54 were "undeliverable" or did not qualify for inclusion in the sample. In this table, Vermont's surveys are not included in the Total.

Nebraska surveyed all potential respondents for each survey. Pennsylvania constructed its sample so that it could obtain baseline data for each local county mental retardation authority as a first step in its multi-year plan to collect data on a rotating basis to measure performance county-by-county. Since the project's minimum sample does not yield reliable results at a sub-state level, Pennsylvania increased its sample to ensure that it would have sufficient returns to establish performance baselines for each county authority. Washington and Kentucky decided to increase the sample size from required minimum, as did Connecticut in the case of the Family/Guardian Survey. In addition, Washington constructed its sample to include families of individuals who were receiving service coordination and receiving a service through any Department of Social and Health Services program rather than only services managed by the Division of Developmental Disabilities. Two states, Connecticut and Vermont, chose to send their surveys to families with children under 18 in addition to families of adults. Only the "adult" surveys are included in this report. As in any survey, the greater the number of families surveyed the more reliable the results will be. North Carolina, new to the project in Phase II, was able to conduct the family survey only in parts of the state where the local area program could be enlisted to participate. As a result, North Carolina's results are not representative of the state as a whole. It should also be noted that Virginia's figures are not representative of their service population. The majority of respondents in Virginia were families or guardians of individuals living in training centers (residential facilities).

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. For technical reasons, the exact response rate during Phase II cannot be calculated precisely. Table 1a estimates the response rates by state, based on the number of returned surveys entered into the database and submitted for analysis, compared to the total number mailed out.

Unless noted, these figures do not include the number of "undeliverable" surveys (e.g. those returned due to incorrect addresses) or surveys that were returned but were excluded from the database for other reasons (e.g. did not meet the state's inclusion criteria). It appears that across all states, the overall response rate was just under 40%. In the case of the Family Support Survey, Connecticut, Nebraska, Pennsylvania and Vermont had response rates well over 40%. Each of these states participated in Phase I of the Core Indicators Project and, thus, could draw on that experience in administering this round of surveys. States that conducted these surveys for first time tended to have lower response rates. Some states believe that their response rates have been affected by "survey fatigue" – when families are surveyed often, the response rate tends to drop. In the case of some states, low response rates were due to underlying problems concerning the accuracy and availability of the information they have about involved family members. When such information is not accurate, the survey instrument may not reach the family member and, hence, a low response rate is experienced.

Survey Responses Accepted

Table 1b shows the number of valid surveys accepted for inclusion in data analysis, overall and by state for each survey.

	Family Support Survey	Family/Guardian Survey
Arizona	243	N/A
Connecticut	313	805
Kentucky	369	453
Minnesota	N/A	374
North Carolina	122	N/A
Nebraska	342	992
Pennsylvania	1,355	1,519
Virginia	N/A	241
Vermont	226	N/A
Washington	421	446
Total	3391	4830

Of those returned, close to 80% of the Family Support Surveys and 90% of the Family Guardian Surveys were accepted and included in the data analysis. Altogether more than 8,000 surveys were returned by families and accepted for data analysis.

Demographic Profile of Respondents and Family Members with a Disability

Respondents were asked to indicate some basic demographic information about their family and the family member with a disability. Tables 2-5 summarize the characteristics of respondents and their family members, in aggregate and by state. Keep in mind that all figures are compiled from self-reported data, and respondents were assured of anonymity.

Table 2. Family Support Survey - Characteristics of Family Member with a Disability

STATES:		ALL	AZ	CT	KY	NC	NE	PA	VT	WA								
Number of Surveys:		3391	243	313	369	122	342	1355	226	421								
	N	%	N	%	N	%	N	%	N	%	N	%						
Gender:																		
Male	1841	55.0	133	56.1	157	50.2	199	54.1	67	57.8	191	56.0	723	54.3	135	59.7	236	56.7
Female	1507	45.0	104	43.9	156	49.8	169	45.9	49	42.2	150	44.0	608	45.7	91	40.3	180	43.3
Level of MR:																		
No MR label	159	5.8	19	9.5	12	3.8	24	8.0	3	3.2	6	2.1	54	5.1	16	10.2	25	7.4
Mild	658	24.0	39	19.4	111	35.5	61	20.3	20	21.5	54	18.9	271	25.8	35	22.3	67	19.7
Moderate	1196	43.6	77	38.3	139	44.4	130	43.2	33	35.5	144	50.3	468	44.6	64	40.8	141	41.5
Severe	526	19.2	55	27.4	40	12.8	63	20.9	20	21.5	51	17.8	175	16.7	37	23.6	85	25.0
Profound	202	7.4	11	5.5	11	3.5	23	7.6	17	18.3	31	10.8	82	7.8	5	3.2	22	6.5
Other disabilities (duplicated counts):																		
Mental illness	513	15.1	35	14.4	66	21.1	59	16.0	36	29.5	45	13.2	205	15.1	24	10.6	43	10.2
Cerebral palsy	510	15.0	63	25.9	49	15.7	79	21.4	22	18.0	78	22.8	95	7.0	38	16.8	86	20.4
Brain injury/neurological	682	20.1	59	24.3	49	15.7	80	21.7	19	15.6	69	20.2	263	19.4	32	14.2	111	26.4
Autism	215	6.3	14	5.8	21	6.7	31	8.4	9	7.4	20	5.8	66	4.9	22	9.7	32	7.6
Age of consumer:																		
Mean (years)	33.3		34.5		33.4		34.1		33.7		32.5		33.9		32.1		30.9	
Range	18 - 80		19 - 78		18 - 73		18 - 70		18 - 79		19 - 74		18 - 80		18 - 77		20 - 75	

Table 3. Family Support Survey - Characteristics of Respondents

STATES:	ALL		AZ		CT		KY		NC		NE		PA		VT		WA	
Number of Surveys:	3391		243		313		369		122		342		1355		226		421	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Race:																		
American Indian/Eskimo/Aleut	69	2.1	17	7.6	11	3.6	2	0.5	1	0.9	5	1.5	19	1.4	3	1.4	11	2.7
Asian/Pacific Islander	45	1.4	1	0.4	3	1.0	0	0.0	1	0.9	3	0.9	13	1.0			24	5.8
Black	172	5.2	8	3.6	32	10.5	21	5.7	47	40.2	13	3.8	39	2.9			12	2.9
White	2996	89.9	183	81.7	252	82.4	343	93.5	67	57.3	316	93.2	1262	93.6	215	98.2	358	87.1
Other/unknown	50	1.5	15	6.7	8	2.6	1	0.3	1	0.9	2	0.6	16	1.2	1	0.5	6	1.5
Ethnicity:																		
Hispanic	125	4.2	52	24.6	15	5.3	7	2.2	6	5.8	8	2.6	21	1.7	3	1.7	13	3.4
Non-Hispanic	2887	95.8	159	75.4	267	94.7	310	97.8	98	94.2	296	97.4	1210	98.3	175	98.3	372	96.6
Age of primary caregiver:																		
Mean (years)	59.0		59.7		61.2		59.0		58.1		59.7		59.4		58.9		55.7	
Range	19 - 97		25 - 94		32 - 85		28 - 97		38 - 96		38 - 88		26 - 89		32 - 87		19 - 88	
Health of primary caregiver:																		
Excellent	788	23.7	52	22.4	79	25.7	66	18.1	25	21.6	84	25.0	295	22.0	69	31.1	118	29.0
Good	1808	54.4	116	50.0	155	50.5	177	48.5	62	53.4	192	57.1	749	55.9	121	54.5	236	58.0
Fair	620	18.6	52	22.4	68	22.1	97	26.6	19	16.4	43	12.8	264	19.7	30	13.5	47	11.5
Poor	110	3.3	12	5.2	5	1.6	25	6.8	10	8.6	17	5.1	33	2.5	2	0.9	6	1.5
Relationship to consumer:																		
Parent	2761	84.1	183	79.2	256	82.8	304	83.1	50	70.4	297	87.9	1110	83.4	192	85.7	369	89.1
Sibling	312	9.5	22	9.5	31	10.0	40	10.9	12	16.9	26	7.7	138	10.4	22	9.8	21	5.1
Other relative	188	5.7	24	10.4	20	6.5	20	5.5	7	9.9	13	3.8	72	5.4	9	4.0	23	5.6
Spouse	23	0.7	2	0.9	2	0.6	2	0.5	2	2.8	2	0.6	11	0.8	1	0.4	1	0.2
Respondent is legal guardian:																		
Yes	2536	76.6	146	62.7	237	76.7	272	74.3	96	82.1	222	66.5	1102	83.7	178	79.1	283	68.7
MR/DD supports received:																		
Service coordination (family)	2059	70.0	185	88.9	179	65.8	153	47.4	78	72.2	244	78.2	847	72.5	156	76.1	217	63.1
Service coordination (individual)	1961	73.7	183	88.0	188	74.6	173	54.4	89	78.8	272	89.2	839	75.0			217	62.5
Financial support	1287	44.0	72	36.2	99	35.7	130	39.2	49	48.0	106	36.8	594	50.8	77	40.3	160	43.4
Staff support	642	21.8	69	33.5	44	15.8	62	18.9	61	55.0	45	14.8	208	18.1	89	45.6	64	17.4
Respite care	1268	40.8	152	67.9	98	34.8	142	41.4	58	50.4	89	28.8	944	81.9	141	66.2	136	34.3
Day/employment supports	2173	70.1	147	67.4	207	73.7	300	85.2	65	57.0	278	86.1	842	68.6	124	59.9	210	55.7
Transportation	1414	46.4	106	49.5	149	54.4	167	48.7	72	63.2	217	67.6	514	42.8	110	53.4	79	21.2
Other	764	26.8	75	38.3	49	19.1	102	31.6	48	43.2	115	40.1	265	23.7	55	28.5	55	15.1
Family on waiting list for:																		
Residential services	484	17.1	14	7.3	84	33.6	61	19.2	7	6.7	99	34.9	184	16.4	6	3.0	29	8.1
Day/employment supports	291	11.1	20	10.9	29	13.4	36	12.5	9	8.8	29	11.7	128	12.1	12	6.4	28	8.2

Table 4. Family/Guardian Survey - Characteristics of Family Member with a Disability

STATES:	ALL		CT		KY		MN		NE		PA		VA		WA	
Number of Surveys:	4830		805		453		374		992		1519		241		446	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Gender:																
Male	2548	54.4	427	53.0	242	53.7	199	53.6	527	54.2	765	54.5	146	61.1	242	54.5
Female	2138	45.6	378	47.0	209	46.3	172	46.4	446	45.8	638	45.5	93	38.9	202	45.5
Level of mental retardation:																
No MR label	95	2.0	11	1.4	12	2.7	5	1.4	24	2.5	20	1.4	1	0.4	22	5.3
Mild	807	17.3	174	21.6	59	13.2	89	24.3	170	18.0	246	17.1	7	2.9	62	14.8
Moderate	1153	24.7	158	19.6	114	25.6	95	25.9	299	31.7	356	24.7	17	7.1	114	27.2
Severe	1115	23.9	220	27.3	137	30.7	87	23.7	161	17.1	335	23.2	85	35.6	90	21.5
Profound	816	17.5	242	30.1	73	16.4	48	13.1	77	8.2	197	13.7	102	42.7	77	18.4
Don't know	674	14.5			51	11.4	43	11.7	212	22.5	287	19.9	27	11.3	54	12.9
Other disabilities (duplicated counts):																
Mental illness	917	19.0	196	24.3	91	20.1	72	19.3	194	19.6	248	16.3	40	16.6	76	17.0
Cerebral palsy	651	13.5	132	16.4	98	21.6	55	14.7	131	13.2	128	8.4	43	17.8	64	14.3
Brain injury/neurological	908	18.8	159	19.8	106	23.4	60	16.0	171	17.2	238	15.7	57	23.7	117	26.2
Autism	371	7.7	97	12.0	35	7.7	27	7.2	58	5.8	78	5.1	24	10.0	52	11.7
Type of residence:																
Specialized facility	962	20.3	154	19.1	215	48.1	48	13.0	55	5.7	212	14.2	194	81.2	84	19.7
Group home	2338	49.2	513	63.7	127	28.4	216	58.7	456	47.0	867	58.1	32	13.4	127	29.8
Apartment program	247	5.2			26	5.8	16	4.3	118	12.2	56	3.8	3	1.3	28	6.6
Independent home/apt	670	14.1	99	12.3	35	7.8	40	10.9	245	25.2	155	10.4	1	0.4	95	22.3
Foster care/host home	212	4.5	39	4.8	15	3.4	28	7.6	34	3.5	67	4.5			29	6.8
Nursing facility	117	2.5			4	0.9	11	3.0	32	3.3	51	3.4	2	0.8	17	4.0
Other	203	4.3			25	5.6	9	2.4	31	3.2	85	5.7	7	2.9	46	10.8
Age of consumer:																
Mean (years)	42.9		44.7		40.5		43.3		42.0		44.0		40.3		42.9	
Range	18 - 97		19-92		18-82		18-79		18-77		18-97		20-86		18-97	

Table 5. Family/Guardian Survey - Characteristics of Respondents

STATES:	ALL		CT		KY		MN		NE		PA		VA		WA	
Number of Surveys:	4830		805		453		374		992		1519		241		446	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Race:																
American Indian/Eskimo/Aleut	49	1.0	8	1.0	4	0.9	7	1.9	6	0.6	17	1.1			7	1.6
Asian/Pacific Islander	18	0.4	3	0.4					1	0.1	4	0.3	2	0.9	8	1.8
Black	126	2.7	27	3.4	23	5.1	7	1.9	10	1.0	39	2.6	12	5.2	8	1.8
White	4525	95.4	741	94.2	424	94.0	354	96.2	942	97.3	1433	95.7	215	93.5	416	94.5
Other/unknown	23	0.5	8	1.0					9	0.9	4	0.3	1	0.4	1	0.2
Ethnicity:																
Hispanic	76	1.7	24	3.3	4	1.0	3	0.9	17	1.9	15	1.1	8	3.3	5	1.2
Non-Hispanic	4318	98.3	711	96.7	389	99.0	338	99.1	873	98.1	1367	98.9	233	96.7	407	98.8
Relationship to consumer:																
Parent	2760	62.3	459	62.8	280	63.2	192	54.2	517	60.3	849	59.0	153	76.1	310	76.2
Sibling	1183	26.7	190	26.0	112	25.3	120	33.9	228	26.6	416	28.9	44	21.9	73	17.9
Other relative	485	10.9	81	11.1	51	11.5	42	11.9	113	13.2	171	11.9	3	1.5	24	5.9
Spouse	5	0.1	1	0.1							3	0.2	1	0.5		
Respondent is legal guardian:																
Yes	3429	73.2	683	87.1	359	79.4	233	63.7	770	80.0	885	61.0	166	71.2	333	75.9
MR/DD supports received:																
Service coordination (individual)	4160	90.2	728	95.9	375	87.6	345	94.0	937	96.4	1213	83.8	228	96.2	334	83.1
Residential supports	2177	52.6	372	57.9	123	37.4	175	53.2	646	70.3	543	41.0	150	65.5	168	45.8
Day/employment supports	3451	77.3	613	84.7	295	77.2	313	85.8	850	88.0	1020	72.7	129	55.4	231	59.2
Transportation	3860	85.1	679	92.1	358	88.0	320	87.9	879	90.4	1152	80.8	199	84.3	273	69.6
Other	2850	65.6	531	75.5	276	71.9	228	65.5	593	65.0	812	59.1	207	88.5	203	51.9
Family on waiting list for:																
Day/employment supports	111	2.5	11	1.5	16	4.2	2	0.5	23	2.4	37	2.5	4	1.7	18	4.6
Sees family member:																
Once a week	1745	38.5	258	35.7	155	34.8	117	31.9	408	43.1	551	39.8	50	21.5	206	47.4
Once a month	1961	43.3	308	42.7	234	52.5	196	53.4	381	40.3	571	41.3	98	42.1	173	39.8
Once a year	583	12.9	102	14.1	47	10.5	46	12.5	117	12.4	180	13.0	53	22.7	38	8.7
Less than once a year	243	5.4	54	7.5	10	2.2	8	2.2	40	4.2	81	5.9	32	13.7	18	4.1

These demographic data provide a profile of both families and family members with disabilities. In particular:

- Across the states, the average age of the family member with a disability was remarkably similar in each survey group. On average, adults who live with their families are in their early 30s and, hence, have been out of school for roughly a decade. Adults who no longer live with their families tend to be about 10 years older. However, in every state there is a wide range in the ages of individuals in each survey group, ranging from youth with developmental disabilities to octogenarians.
- For both survey samples across all states, the percentage of males was slightly higher than the percentage of females.
- In the case of individuals who live with their families, there also was remarkable similarity in the average age of the person's primary care giver. Primary caregivers are in their late 50s or early 60s – underscoring the fact that many people with developmental disabilities are supported by older caregivers. Indeed, in each state there were caregivers in their 80s and often in their 90s. About 84% of these family caregivers were parents of the individual with a disability. Significantly, about 22% of family caregivers rated their own health as “fair” to “poor” rather than “good” to “excellent.”
- The Family Support Survey sample was a slightly more racially diverse group. States with significant minority populations made efforts to provide translations of both surveys. However, additional strategies may need to be employed in order to increase the response rate of non-English speaking families (e.g. phone interviews or targeted sampling).
- In the case of individuals who no longer live with their families, the involved family member was predominately a parent but 37% are siblings or other relatives (versus 15% in the case of individuals who live with their families). This difference between the two groups probably is related to the fact that individuals who no longer live with their families tend to be older than those that do.
- In the case of individuals who live with their families, some 17% reported that they were actively seeking residential services for their member but had been wait listed for such services. However, there were substantial differences across the states in terms of the percentage of individuals wait listed for residential services, ranging from about 7% to 34%.
- People who lived with their families most commonly received service coordination and day supports. A lower percentage of these families received respite or in-home supports. There is considerable variation across the states in the extent to which these primary family support services were furnished to the family. The percentage of families receiving financial support varied somewhat less across states, ranging from 35% to 50%.
- As a group, individuals who no longer live with their families tended to have been diagnosed as having more severe levels of mental retardation than persons who were living in the family home. Slightly more persons receiving residential services were reported to have a mental illness or autism than those living in the family home.

- The family members of individuals who live away from their families appeared to be regularly involved with the person. Some 82% reported seeing their family member at least once a month and 38% seeing the person each week.
- As would be expected, service rates were generally higher for those individuals living outside of the family home. Transportation services showed a particularly wide gap -- 46% of Family Support Survey respondents vs. 85% of Family/Guardian Survey respondents reported receiving this type of service.
- The percentage of Family/Guardian Survey respondents who reported that their family member receives "residential supports" was 52.6%. This figure is low considering the sampling strategy that was used (we would expect it to be closer to 100%). Looking back at the survey form, we believe that this result is due to the vagueness of the definition provided for "residential supports," which reads, "staff come to the person's home to help with daily activities (such as eating or getting dressed) or with home health care." It is likely that many respondents did not interpret this to include residential programs and facilities.

Survey Results by Question

Tables 6 and 7 list the distribution of responses to each question on the Family Support Survey. Table 8 lists results from the Family/Guardian Survey. Tables 7 and 8 contain many of the same questions and may be used to compare results between the two different survey samples. The number of valid surveys from each state is listed at the top of each table. Please note that the figures listed are "valid percents" - meaning that the percents were calculated based on the actual number of people who responded to a particular question. Since not every person responded to every question, the actual N's (number of responses) vary by question.

When looking through these results, it is useful to keep the following in mind:

- Generally, it is better to focus on the "yes or most of the time" and "no or not at all" responses to a question. The response "some of the time" is more difficult to interpret.
- With respect to satisfaction per se, the final question in each survey ("Overall, are you satisfied with the services and supports this person currently receives?") is the broad measure of performance for each indicator.
- By and large, the remaining questions address various elements of service provision that may contribute to satisfaction but also are important in their own right, especially in furnishing feedback to states concerning the experiences that families are having in their interactions with the public system.
- Broadly, the "all states" aggregate responses to a question constitute a benchmark for comparing states. For example, when a particular state's proportion of "yes or most of the time" responses is appreciably higher than the all states aggregate average, the quality or characteristic is better reflected in the state's system than in others. On the other hand, in states where the proportion

of “no or not all” responses is appreciably higher than the aggregate, then there is a valid basis for stakeholders to probe further.

- In no instance should the aggregate responses be interpreted as necessarily defining “acceptable” levels of performance or satisfaction. Instead, they are a multi-state “norms” that describe present levels of performance or satisfaction across the eight states. Where levels of satisfaction are about the same state-to-state, it means that all states are performing about the same. Where levels of satisfaction are especially high (considerably above the aggregate level) in one or two states, the levels of satisfaction achieved there might define a level of performance that may serve as a guidepost for other states.
- This section displays raw results, that is, the breakdown of responses to each question, for each state and overall. These results are provided so that states can view and compare the detailed responses to each question. In the next section, however, we present broad results by indicator, grouping items together where possible. The results presented by indicator should be used to make general comparisons about performance state to state on broad measures.

Table 6. Family Support Survey Results - Part One

STATES:	ALL	AZ	CT	KY	NC	NE	PA	VT	WA
Number of Surveys:	3391	243	313	369	122	342	1355	226	421
Do you receive information about services and supports that are available to your family?									
% yes, or most of the time	46.0	51.4	36.0	34.5	51.5	48.0	51.5	54.6	32.4
% some of the time	36.1	34.1	42.8	44.4	29.7	34.5	31.4	30.6	47.6
% no, or not at all	18.0	14.5	21.2	21.1	18.8	17.4	17.2	14.8	20.1
If yes, is the information easy to understand?									
% yes, or most of the time	66.5	66.1	63.2	57.3	56.6	66.7	72.3	68.3	58.6
% some of the time	29.2	29.8	31.0	39.0	38.2	30.4	24.6	29.3	32.4
% no, or not at all	4.3	4.1	5.8	3.7	5.3	2.9	3.1	2.4	9.1
Do you choose the agencies or providers that work with your family?									
% yes, or most of the time	45.5	50.8	35.2	50.7	53.8	46.2	45.6	46.7	41.6
% some of the time	16.0	13.1	15.2	18.1	16.3	15.8	14.1	16.4	22.0
% no, or not at all	38.5	36.2	49.5	31.2	29.8	37.9	40.3	36.9	36.4
Do you choose the staff that work with your family?									
% yes, or most of the time	21.3	33.9	15.1	19.3	34.6	11.0	18.3	31.8	25.3
% some of the time	14.8	13.7	9.7	17.4	24.0	17.3	11.9	21.5	15.9
% no, or not at all	63.9	52.5	75.1	63.3	41.3	71.8	69.8	46.7	58.8
Are frequent changes in support staff a problem for your family?									
% yes, or most of the time	17.1	23.5	13.9	20.6	24.0	16.2	12.3	19.8	23.0
% some of the time	25.4	25.3	24.3	28.4	28.1	25.3	23.3	28.3	27.8
% no, or not at all	57.5	51.2	61.8	51.0	47.9	58.5	64.5	51.9	49.2
Do staff help you figure out what you need as a family to support your family member?									
% yes, or most of the time	32.9	33.5	31.5	22.3	47.1	32.3	35.2	37.6	26.7
% some of the time	27.5	31.9	28.0	23.8	29.4	31.5	25.3	33.5	26.1
% no, or not at all	39.6	34.6	40.5	54.0	23.5	36.3	39.6	28.9	47.3
Do staff talk to you about different options to meet your family's needs?									
% yes, or most of the time	37.4	38.5	35.0	27.0	49.5	39.7	40.8	41.7	26.8
% some of the time	30.2	32.8	27.6	30.9	26.2	35.3	27.7	34.4	31.8
% no, or not at all	32.5	28.6	37.4	42.2	24.3	25.0	31.5	24.0	41.4

Table 6. Family Support Survey Results - Part One (continued)

STATES:	ALL	AZ	CT	KY	NC	NE	PA	VT	WA
Number of Surveys:	3,391	243	313	369	122	342	1355	226	421
Do staff respect your choices and opinions?									
% yes, or most of the time	73.9	72.0	69.5	67.6	72.3	72.3	79.4	77.3	65.9
% some of the time	17.1	19.4	18.1	20.7	18.8	20.2	12.5	20.0	20.7
% no, or not at all	9.0	8.6	12.4	11.7	8.9	7.4	8.1	2.7	13.4
Does your family get the supports you need?									
% yes, or most of the time	50.8	62.4	38.4	46.0	61.4	51.4	53.5	65.7	35.8
% some of the time	27.3	21.5	32.8	34.8	21.8	25.1	24.2	22.1	36.9
% no, or not at all	21.9	16.1	28.9	19.2	16.8	23.5	22.3	12.3	27.3
Do the supports offered meet your family's needs?									
% yes, or most of the time	50.4	58.1	32.2	41.6	62.4	50.6	54.8	61.3	39.9
% some of the time	32.8	27.8	43.6	38.3	23.8	34.9	30.9	27.6	35.0
% no, or not at all	16.8	14.1	24.2	20.1	13.9	14.5	14.2	11.1	25.2
Are supports available when your family needs them?									
% yes, or most of the time	48.7	52.9	34.4	35.3	57.3	44.4	55.4	61.5	37.0
% some of the time	34.3	30.9	42.6	43.5	31.1	40.1	30.7	27.7	36.4
% no, or not at all	17.0	16.2	23.1	21.3	11.7	15.5	13.9	10.8	26.6
If you have ever asked for the state agency's help in a crisis, was help provided to you right away?									
% yes, or most of the time	43.3	50.5	30.7	41.2	41.5	41.4	49.4	47.1	31.5
% some of the time	15.0	13.8	14.9	13.4	24.6	17.2	13.5	14.1	16.4
% no, or not at all	41.7	35.8	54.5	45.4	33.8	41.4	37.1	38.8	52.1
If English is not your first language, are there staff who speak with you in your preferred language?									
% yes, or most of the time	52.4	69.2	43.8	55.6	55.6	33.3	50.5	60.0	50.0
% some of the time	10.5	15.4	16.7	3.7	22.2	8.3	9.3		9.4
% no, or not at all	37.1	15.4	39.6	40.7	22.2	58.3	40.2	40.0	40.6
Do staff help you get family supports in your community?									
% yes, or most of the time	31.7	41.5	31.0	28.9	34.3	34.9	32.3	35.1	22.3
% some of the time	24.3	24.0	27.4	17.8	24.2	26.1	24.0	25.3	25.4
% no, or not at all	43.9	34.4	41.6	53.3	41.4	39.0	43.7	39.7	52.3
Do staff help you make arrangements with family, friends, or neighbors to provide some supports your family needs?									
% yes, or most of the time	15.6	18.6	10.9	16.9	23.7	15.0	15.9	22.7	9.7
% some of the time	13.2	12.2	12.6	13.6	18.3	17.1	13.1	15.3	8.7
% no, or not at all	71.2	69.2	76.6	69.5	58.1	67.9	71.0	62.0	81.7

Table 7. Family Support Survey Results - Part Two

STATES:	ALL	AZ	CT	KY	NC	NE	PA	VT	WA
Number of Surveys:	3391	243	313	369	122	342	1355	226	421
Did you get enough information to participate in planning services for your family member with a disability?									
% yes, or most of the time	57.0	68.7	54.4	42.1	59.0	68.4	58.1	63.3	48.2
% some of the time	29.8	18.5	35.3	39.1	24.8	25.0	29.0	27.6	33.8
% no, or not at all	13.1	12.8	10.4	18.9	16.2	6.6	12.9	9.2	18.0
Did you help develop this person's service plan?									
% yes, or most of the time	57.8	73.6	50.2	50.5	56.3	67.8	53.0	75.6	55.5
% some of the time	25.1	16.1	35.6	28.6	21.4	23.3	24.9	15.7	28.9
% no, or not at all	17.1	10.4	14.2	20.9	22.3	9.0	22.1	8.6	15.6
Does the service plan include things that are important to you?									
% yes, or most of the time	66.3	78.7	62.6	54.9	60.8	77.4	65.7	74.7	59.8
% some of the time	25.9	15.7	31.1	36.6	24.5	19.2	26.1	20.5	28.2
% no, or not at all	7.8	5.6	6.3	8.6	14.7	3.4	8.2	4.7	12.1
Can you contact this person's service coordinator whenever you want to?									
% yes, or most of the time	80.4	80.3	81.9	75.5	75.7	87.7	83.9	87.4	62.9
% some of the time	14.8	17.2	14.5	16.1	17.5	10.0	12.7	9.6	25.6
% no, or not at all	4.8	2.5	3.6	8.4	6.8	2.3	3.4	3.0	11.5
When you ask the service coordinator for assistance, does s/he help you get what you need?									
% yes, or most of the time	71.2	76.5	68.8	60.6	71.2	77.1	75.0	75.0	59.5
% some of the time	23.1	19.6	26.2	29.2	20.2	19.9	20.6	21.9	30.2
% no, or not at all	5.7	3.9	5.1	10.2	8.7	2.9	4.5	3.1	10.4
Does the agency providing day/employment services to this person involve you in important decisions?									
% yes, or most of the time	61.2	63.9	67.5	55.9	54.2	66.9	59.4	74.4	55.5
% some of the time	21.0	20.4	19.6	23.4	19.4	20.2	21.2	13.2	24.5
% no, or not at all	17.8	15.6	12.9	20.7	26.4	12.9	19.4	12.4	20.1
If this person does not speak English or uses a different way to communicate, are there enough staff available who can communicate with him/her?									
% yes, or most of the time	53.6	60.0	55.4	42.9	55.0	60.0	56.5	52.3	44.4
% some of the time	28.1	24.0	32.4	41.0	27.5	29.5	24.6	20.5	25.6
% no, or not at all	18.3	16.0	12.2	16.2	17.5	10.5	19.0	27.3	30.0

Table 7. Family Support Survey Results - Part Two (continued)

STATES:	ALL	AZ	CT	KY	NC	NE	PA	VT	WA
Number of Surveys:	3391	243	313	369	122	342	1355	226	421
Does this person have access to the special equipment or accommodations that s/he needs?									
% yes, or most of the time	61.2	67.7	64.5	56.7	58.3	69.4	65.3	64.0	44.2
% some of the time	22.4	21.2	21.1	26.2	19.4	22.4	19.6	16.3	30.9
% no, or not at all	16.7	11.1	14.5	17.1	22.2	8.2	15.1	19.8	24.8
Do you feel that this person's day/employment setting is a healthy and safe environment?									
% yes, or most of the time	81.0	76.5	83.8	79.0	72.7	75.7	82.0	90.4	82.8
% some of the time	16.6	21.6	15.3	19.0	19.5	22.5	15.5	8.2	13.4
% no, or not at all	2.4	2.0	0.9	2.0	7.8	1.8	2.5	1.4	3.7
Overall, do you feel that this person is happy?									
% yes, or most of the time	80.5	83.3	81.9	79.8	74.5	82.1	80.5	84.2	77.0
% some of the time	17.0	14.1	15.1	18.4	18.9	17.3	17.0	13.5	20.1
% no, or not at all	2.5	2.6	3.0	1.8	6.6	0.6	2.5	2.3	2.9
Are you satisfied with the way complaints/grievances are handled and resolved by the state agency?									
% yes, or most of the time	60.8	55.8	64.6	49.8	61.3	63.7	65.2	61.4	54.3
% some of the time	27.1	27.2	25.1	28.9	20.4	29.8	27.8	25.2	25.3
% no, or not at all	12.0	17.0	10.3	21.3	18.3	6.5	7.0	13.4	20.4
Overall, are you satisfied with the services and supports this person currently receives?									
% yes, or most of the time	64.1	67.3	62.5	53.1	67.3	70.1	68.6	70.0	49.9
% some of the time	27.7	23.0	31.2	33.3	20.9	26.4	25.4	23.2	35.8
% no, or not at all	8.2	9.7	6.3	13.6	11.8	3.5	6.0	6.8	14.4

Table 8. Family/Guardian Survey Results

STATES:	ALL	CT	KY	MN	NE	PA	VA	WA
Number of Surveys:	4830	805	453	374	992	1519	241	446
Did you get enough information to participate in planning services for your family member with a disability?								
% yes, or mostly	78.7	86.7	73.4	82.7	82.1	73.3	87.8	70.2
% somewhat	16.2	11.0	21.9	13.4	15.1	18.7	9.5	20.1
% no, or not at all	5.2	2.3	4.7	3.9	2.8	8.0	2.7	9.8
Did you help develop this person's service plan?								
% yes, or mostly	46.9	54.4	50.7	49.6	54.7	36.0	38.8	49.1
% somewhat	30.2	27.9	32.8	24.9	31.4	30.4	34.5	30.3
% no, or not at all	22.9	17.7	16.5	25.5	13.8	33.6	26.7	20.6
Does the service plan include things that are important to you?								
% yes, or mostly	79.9	87.3	75.8	85.1	82.1	75.6	84.2	71.3
% somewhat	16.9	10.9	21.3	11.6	16.0	19.8	13.3	22.6
% no, or not at all	3.3	1.8	2.9	3.3	1.8	4.6	2.5	6.1
Can you contact this person's service coordinator whenever you want to?								
% yes, or mostly	91.9	95.0	89.0	92.6	93.8	91.9	95.8	82.1
% somewhat	6.7	4.0	9.6	6.6	5.2	6.5	4.2	14.2
% no, or not at all	1.4	0.9	1.4	0.8	1.0	1.7		3.7
When you ask the service coordinator for assistance, does s/he help you get what you need?								
% yes, or mostly	83.7	89.6	77.4	85.4	87.2	81.3	93.0	71.7
% somewhat	14.1	9.2	21.0	12.6	11.7	15.7	7.0	22.6
% no, or not at all	2.1	1.2	1.6	2.0	1.0	3.0		5.7
Does the agency providing residential services to this person involve you in important decisions?								
% yes, or mostly	69.1	79.9	67.3	69.2	74.4	58.4	78.9	67.8
% somewhat	20.0	15.1	22.9	19.6	18.4	23.0	17.4	21.2
% no, or not at all	11.0	5.0	9.8	11.2	7.2	18.6	3.8	11.0
Does the agency providing day/employment services to this person involve you in important decisions?								
% yes, or mostly	54.1	63.1	57.0	54.4	62.2	42.4	57.7	45.4
% somewhat	23.5	19.2	25.2	21.5	24.9	24.4	20.3	26.5
% no, or not at all	22.4	17.7	17.8	24.1	12.9	33.2	22.0	28.1

Table 8. Family/Guardian Survey Results (continued)

STATES:	ALL	CT	KY	MN	NE	PA	VA	WA
Number of Surveys:	4830	805	453	374	992	1519	241	446
If this person does not speak English or uses a different way to communicate, are there enough staff available who can communicate with him/her?								
% yes, or mostly	75.4	79.4	69.5	76.5	78.1	74.1	78.6	67.5
% somewhat	20.2	18.0	25.9	18.9	18.4	19.9	19.8	25.8
% no, or not at all	4.4	2.5	4.6	4.5	3.5	6.0	1.6	6.6
Does this person have access to the special equipment or accommodations that s/he needs?								
% yes, or mostly	86.9	89.4	87.7	90.5	85.0	85.1	93.1	83.8
% somewhat	10.4	8.9	11.7	5.2	12.3	11.3	6.4	12.0
% no, or not at all	2.7	1.8	0.6	4.3	2.6	3.6	0.5	4.2
Do you feel that this person's residential setting is a healthy and safe environment?								
% yes, or mostly	86.0	88.4	82.0	88.8	83.3	86.3	94.0	84.0
% somewhat	12.0	9.7	15.4	8.5	14.9	11.5	6.0	13.8
% no, or not at all	2.0	1.9	2.7	2.7	1.8	2.2		2.1
Do you feel that this person's day/employment setting is a healthy and safe environment?								
% yes, or mostly	87.4	90.7	85.4	91.5	85.8	86.4	90.7	85.9
% somewhat	11.1	8.5	12.5	7.9	13.1	11.6	8.6	11.7
% no, or not at all	1.5	0.8	2.2	0.6	1.1	2.0	0.7	2.3
Overall, do you feel that this person is happy?								
% yes, or mostly	79.4	81.3	76.5	81.1	80.7	78.7	82.2	75.5
% somewhat	18.6	17.4	21.0	16.1	17.3	19.3	17.8	20.9
% no, or not at all	2.0	1.3	2.5	2.8	2.1	2.0		3.5
Are you satisfied with the way complaints/grievances are handled and resolved by the state agency?								
% yes, or mostly	71.9	74.8	64.9	76.5	74.3	70.4	84.0	62.0
% somewhat	22.8	21.0	27.8	19.4	21.1	24.5	15.0	26.3
% no, or not at all	5.4	4.2	7.2	4.1	4.6	5.1	1.0	11.7
Overall, are you satisfied with the services and supports this person currently receives?								
% yes, or mostly	83.1	88.5	78.3	86.3	82.7	82.8	89.4	73.7
% somewhat	14.4	10.5	18.5	10.7	15.3	14.6	10.2	20.5
% no, or not at all	2.5	1.0	3.1	3.0	2.0	2.6	0.4	5.8

Performance Indicator Results

How are results "by question" different from results "by indicator"?

Although the CIP involves the complexities of a national research project, the results are intended to be simple in their presentation and thus useful to anyone interested in knowing how a state system is performing relative to other states. In order to produce reliable and valid data, the project follows standard research practices. Tedious as it may be, it is crucial to demonstrate that the methods used to collect and process the CIP data are not only sensible but scientifically sound. In this report, we have made an effort to present the technical aspects of the project in a way that is easy to understand. Throughout the evolution of this project, we have tried to keep an eye on the prize, so to speak, which is ultimately to create a valid, reliable, nationally-recognized set of performance measures that can be reported out on a regular basis. Just as the states have had a learning curve in data collection strategies, the project staff have experienced a learning curve in managing, processing, and presenting the data. For all involved, the CIP encompasses a large set of tasks that must be reduced into a manageable and timely process. We continue to learn, and with this set of baseline data reports, have hopefully reached a turning point and provided roots for the project for future years.

The idea behind CIP is and has always been to report system-level, "performance indicator" data. In Phase I, we struggled to break down the performance indicators into measures, data sources, survey questions, etc. to ensure sound data collection methods. Now, with loads of data in hand, our task is to validate and make sense of the data, and to "rebuild" the information back into the original measures we hoped to report. In most cases (though not all), we have been able to fit the pieces back together. The previous section presented results by question so that every state would be able to see the detailed, raw information that makes up the indicators. However, this section of the report contains the "prize" -- the results packaged back up into performance indicators. We present the results in graphical form, by state and overall, for each family-related indicator.

The following graphs display results based on "sub-indicators." You may refer to "The Indicators" Section of this report (pages 8-11) for a detailed summary of how the indicators, sub-indicators, and survey items are organized.

How to interpret these graphs:

Each graph represents either one survey question or the average across a group of related survey questions. As noted earlier, the sub-indicators are organized according to groups of survey items that fit together, or in scientific terms, have "face validity." Each sub-indicator was subjected to a statistical test to determine whether or not the group of items constituted a "reliable" scale. The sub-indicators that were found to be reliable are presented as an average of "yes" responses to the series of related questions rather than showing the results for each survey question. Each bar represents the average percent of respondents in a particular state (or across all states) who answered "yes, or most of the time" to the related questions.

For the sub-indicators that were not able to be grouped reliably, we present results separately for each item. Each bar represents the percent of respondents in a particular state (or across all states) who answered "yes, or most of the time" to the question.

Each graph shows a range of 0 to 100%. The y-axis scale is marked in increments of 20. Each bar is labeled at the bottom with the state abbreviation, and the exact percentage value is shown at the top

of the bar. In every graph, the first bar represents the aggregate results across all states shown. Although the aggregate "all states" score is not weighted by sample size, for the purposes of this report one can look at the aggregate figure to represent the "national" score and a basis for comparison with individual state scores (i.e. "how did my state do compared to the rest of the states in the project?").

These graphs are intended to display general trends in the baseline data. Consider the following questions when looking at the results for a particular sub-indicator or survey item: Did all states score within the same small range? If yes, is the range high, low, or in the middle? If there is a lot of variation across states, which ones tended to score higher or lower than the aggregate?

IN-HOME FAMILY OUTCOMES

Results by sub-indicator:

Figures 1-14 display results for the following sub-indicators: 1a. availability and utility of information about family supports, 1b. planning family supports, 1c. access to needed family supports, 1d. links to community and natural supports, 1e. make choices about service providers, 2a. participation in planning individual supports, 2b. availability and effectiveness of service coordinators, 2c. access to needed individual supports, 2d. overall satisfaction with individual supports, 2e. satisfaction with grievance process, and 2f. satisfaction with crisis response.

Figure 1: The proportion of families who receive information about services and supports available to their family.

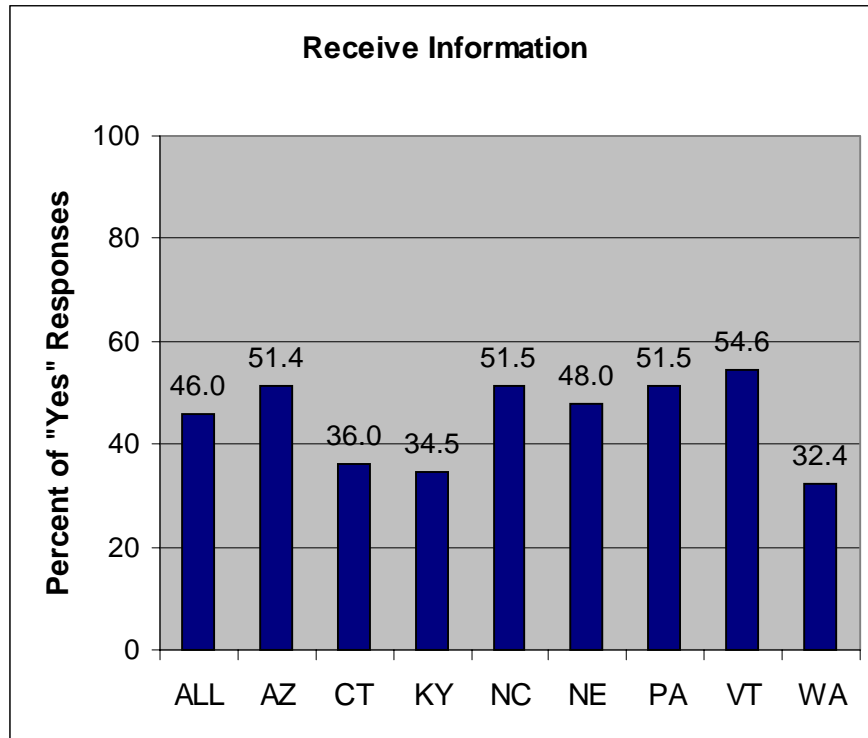


Figure 2: The proportion of families who report that the information they receive is easy to understand.

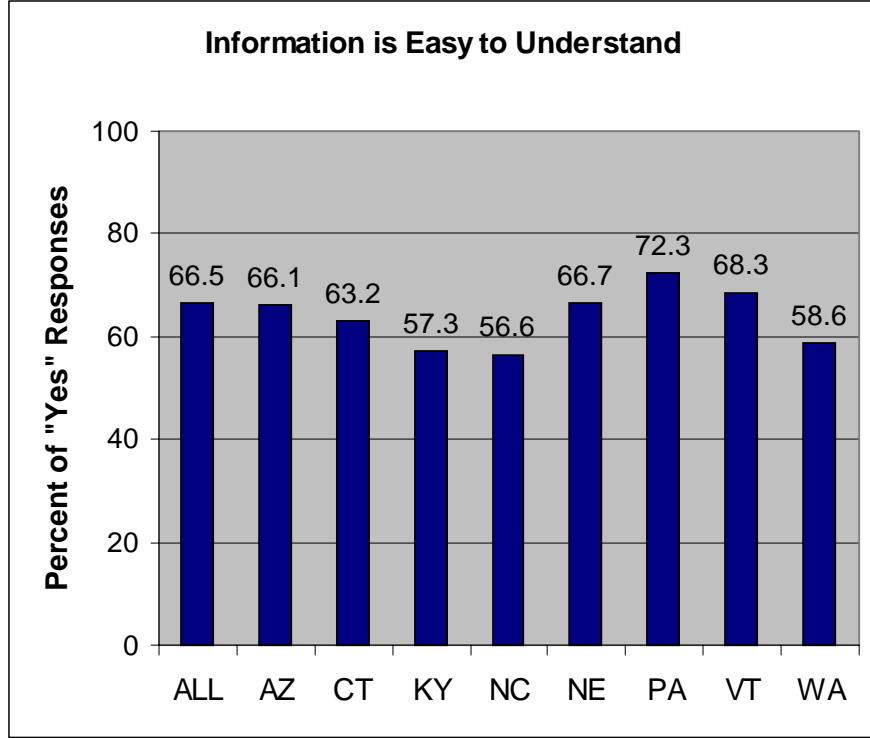


Figure 3: The proportion of families who report that they participate in planning family supports.

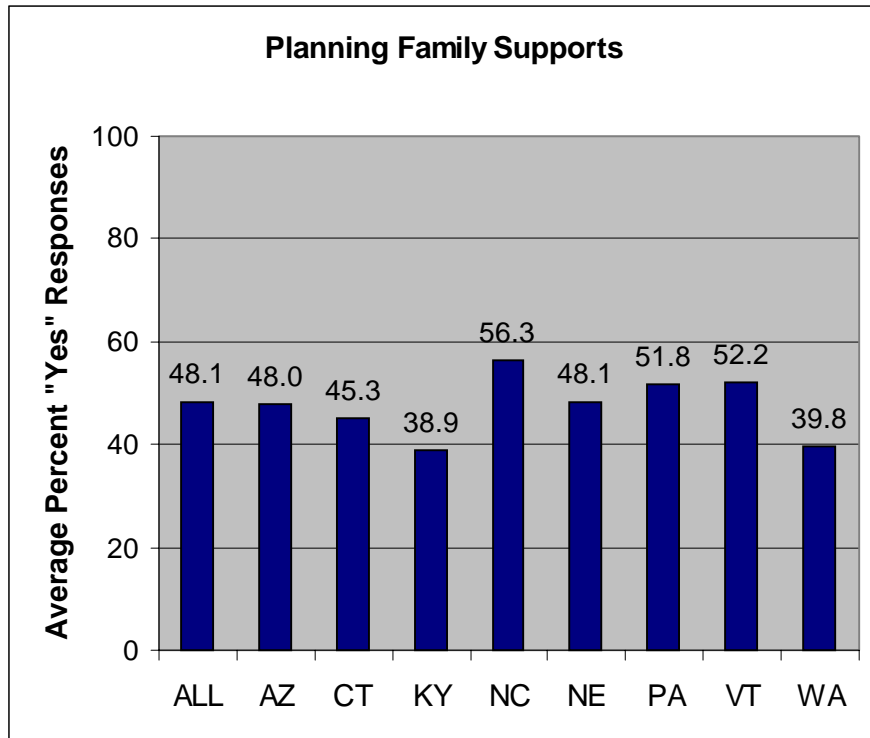


Figure 4: The proportion of families who report that they have access to the family supports they need.

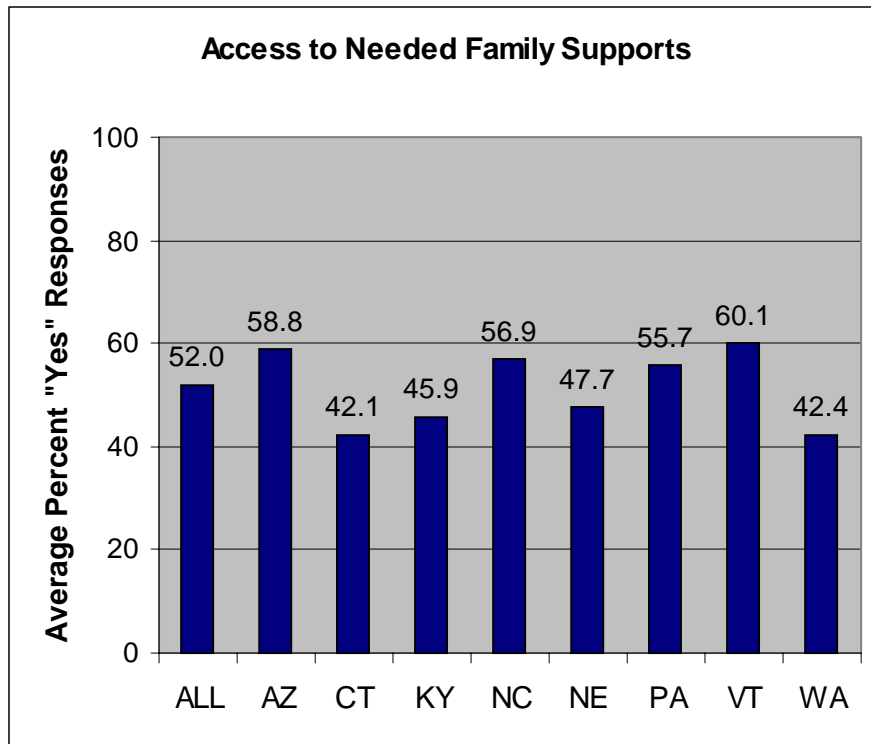


Figure 5: The proportion of families who report that staff help provide links to community and natural supports.

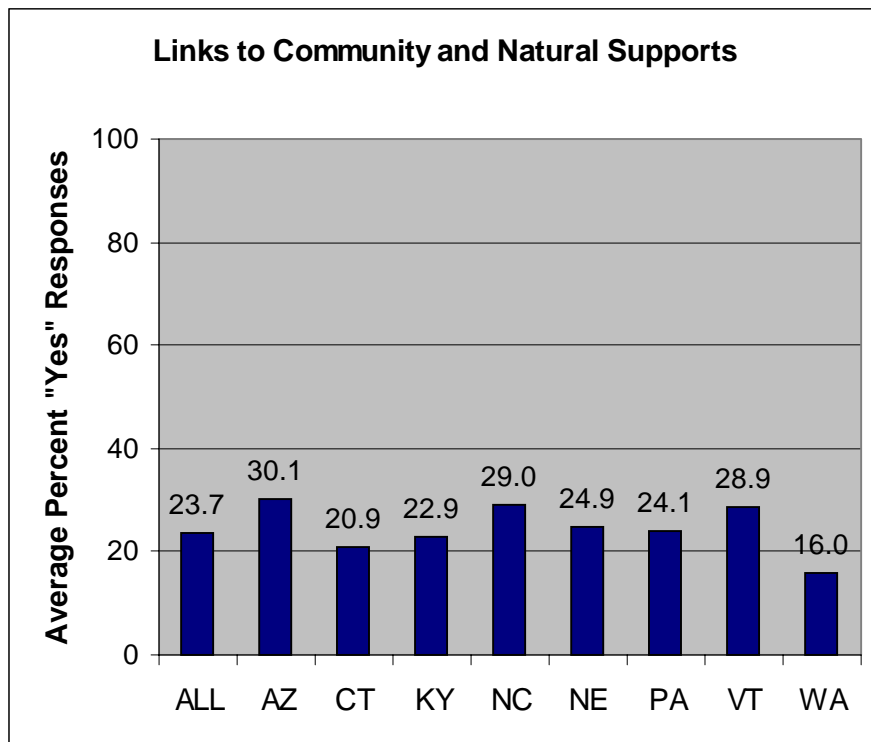


Figure 6: The proportion of families who make choices about their service providers.

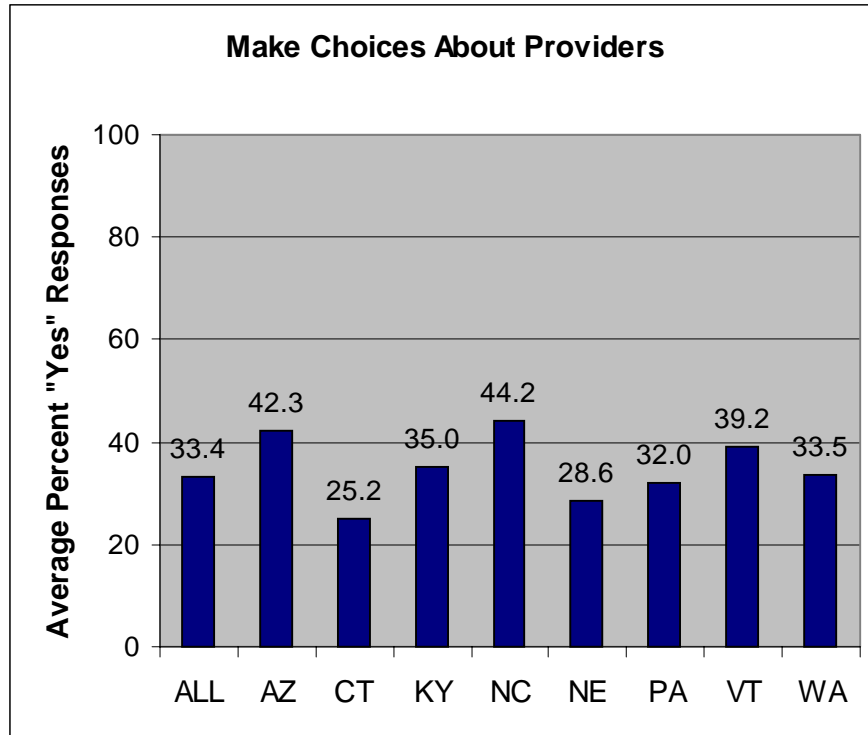


Figure 7: The proportion of families who report that they participate in planning supports for their family member.

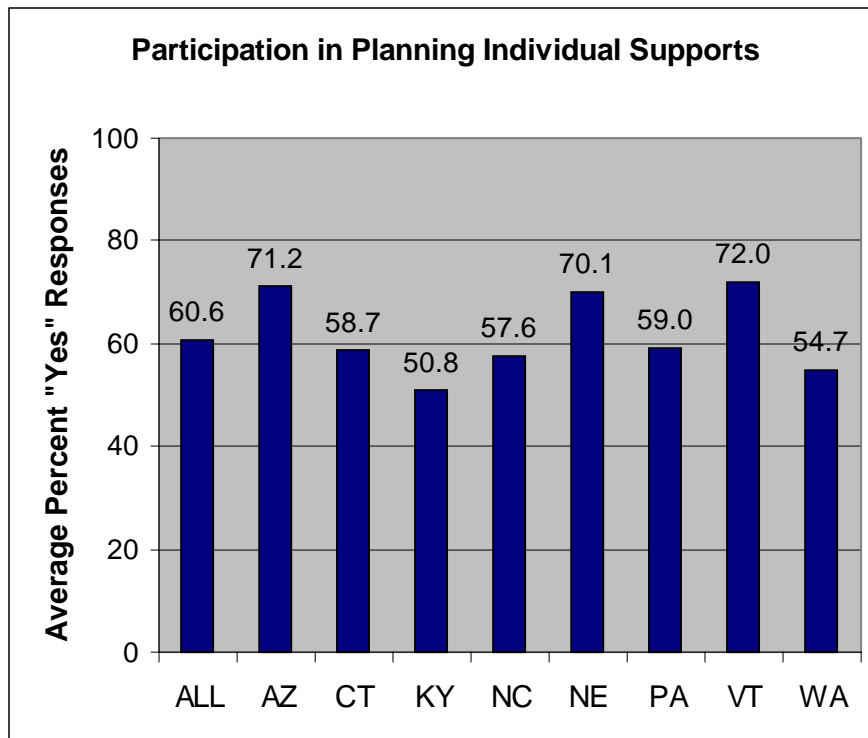


Figure 8: The proportion of families who report that service coordinators are available and effective.

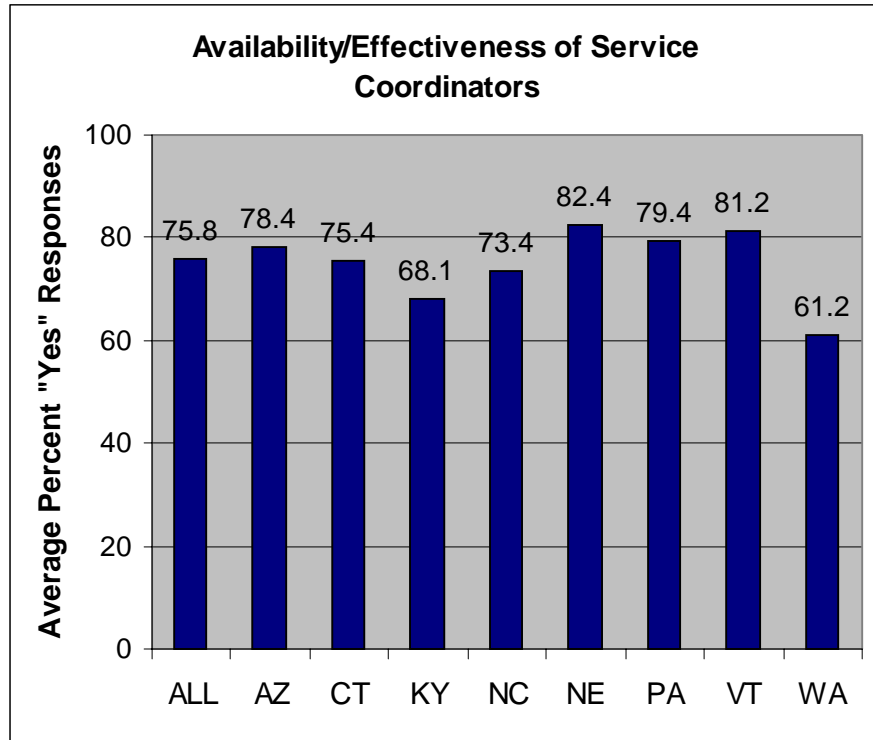


Figure 9: The proportion of families who report that their family member has access to needed supports.

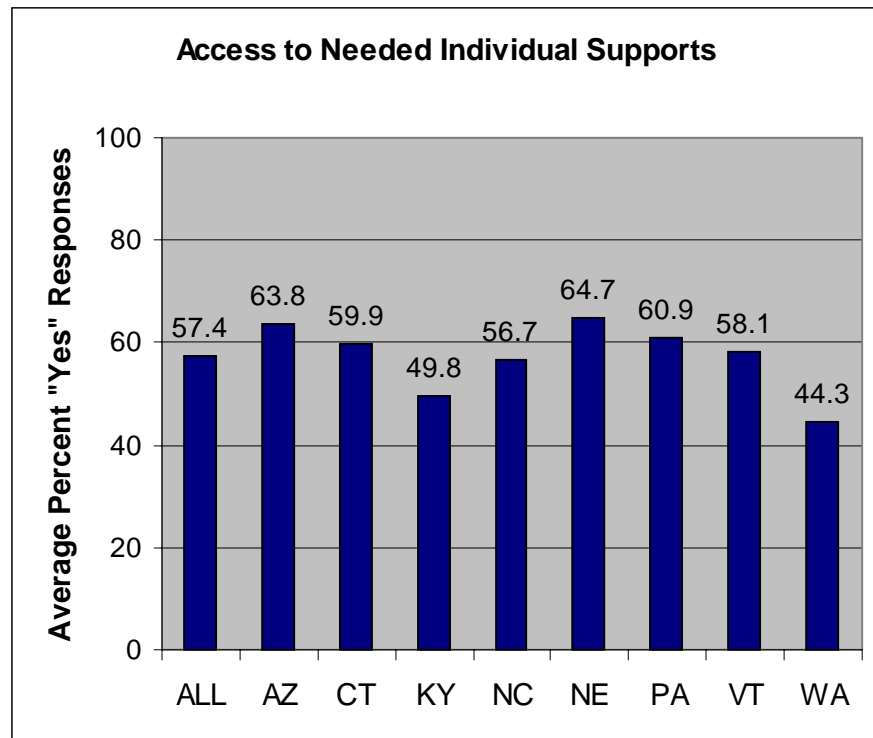


Figure 10: The proportion of families who report that their family member's day/employment setting is healthy and safe.

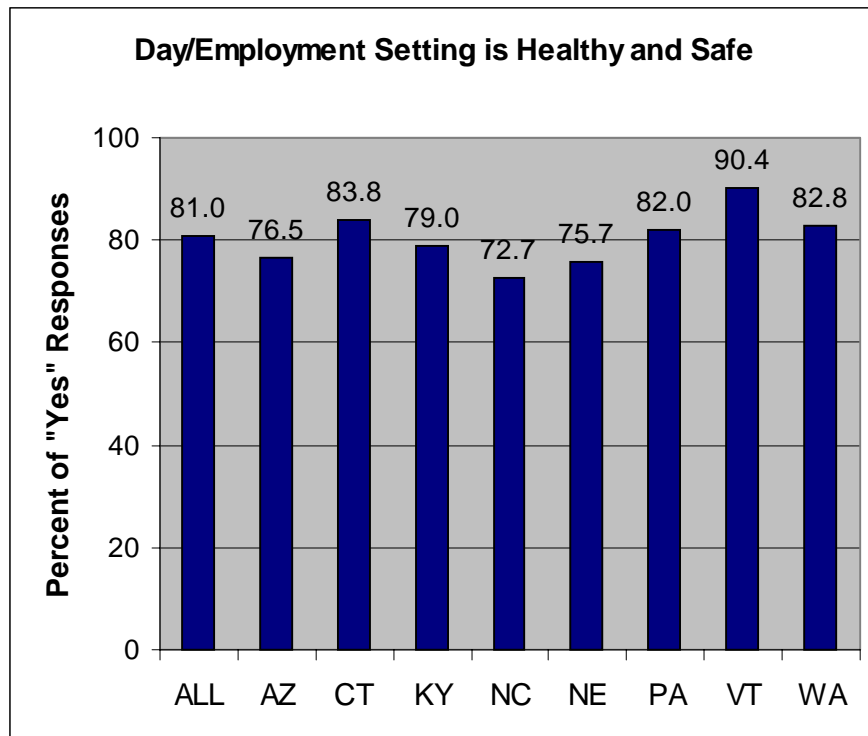


Figure 11: The proportion of families who report that their family member is happy.

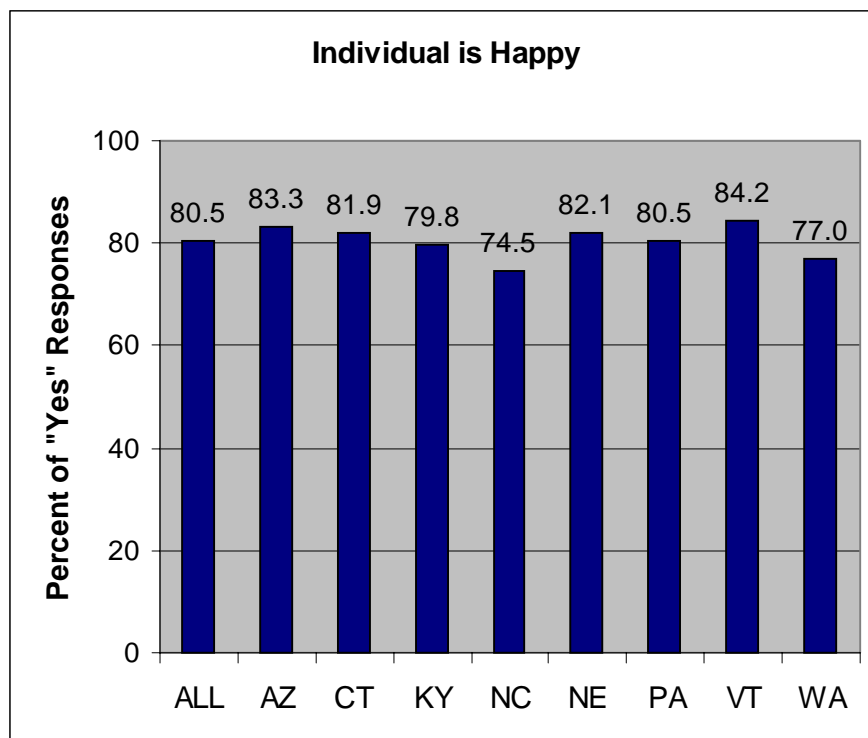


Figure 12: The proportion of family members who report overall satisfaction with their family member's supports.

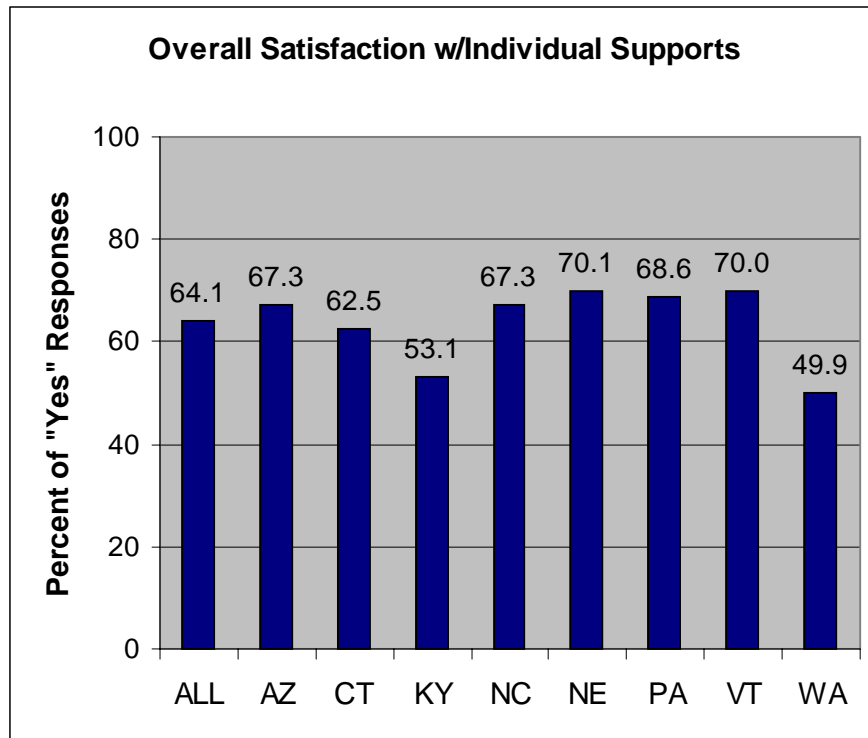


Figure 13: The proportion of families who report satisfaction with the grievance process.

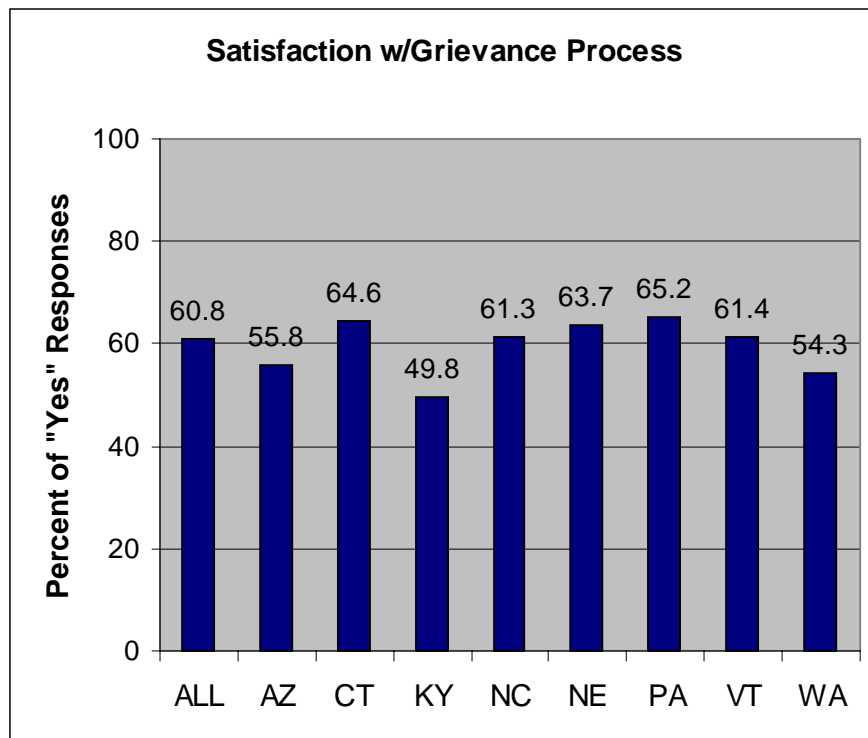
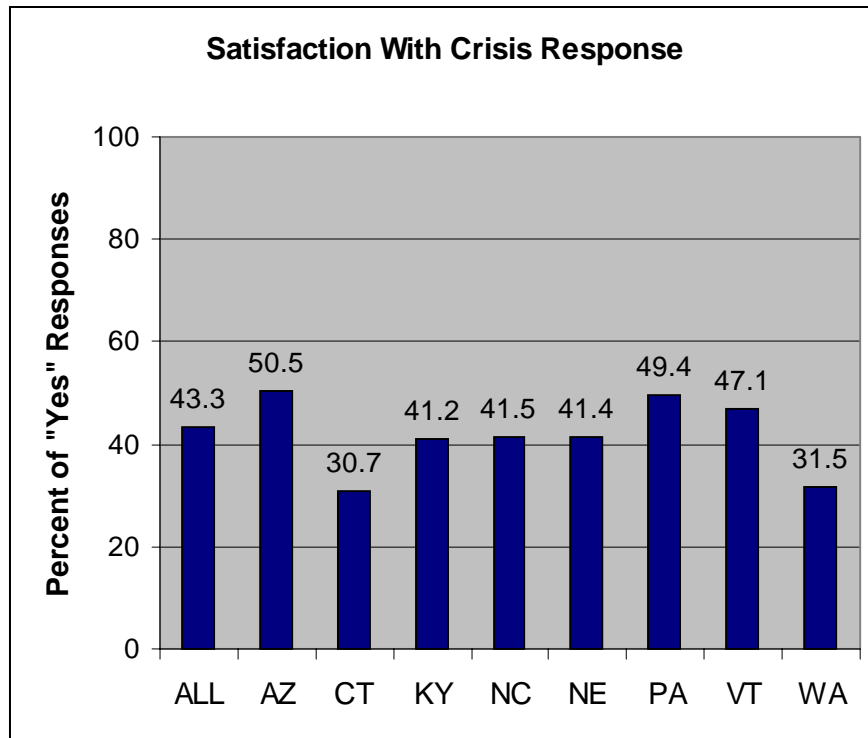


Figure 14: The proportion of families who report satisfaction with crisis response.



OUT-OF-HOME FAMILY/GUARDIAN OUTCOMES

Results by sub-indicator:

Figures 15-21 display results for the following sub-indicators: a. participation in planning individual supports, b. availability and effectiveness of service coordinators, c. access to needed individual supports, d. overall satisfaction with individual supports, and e. satisfaction with grievance process.

Figure 15: The proportion of families/guardians who participate in planning individual supports.

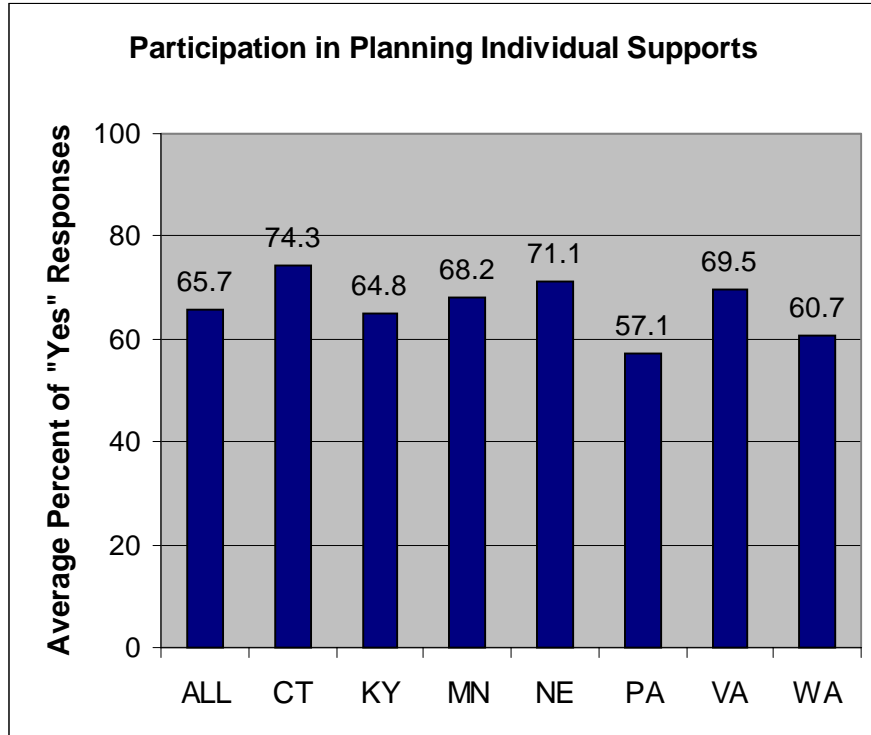


Figure 16: The proportion of families/guardians who report that service coordinators are available.

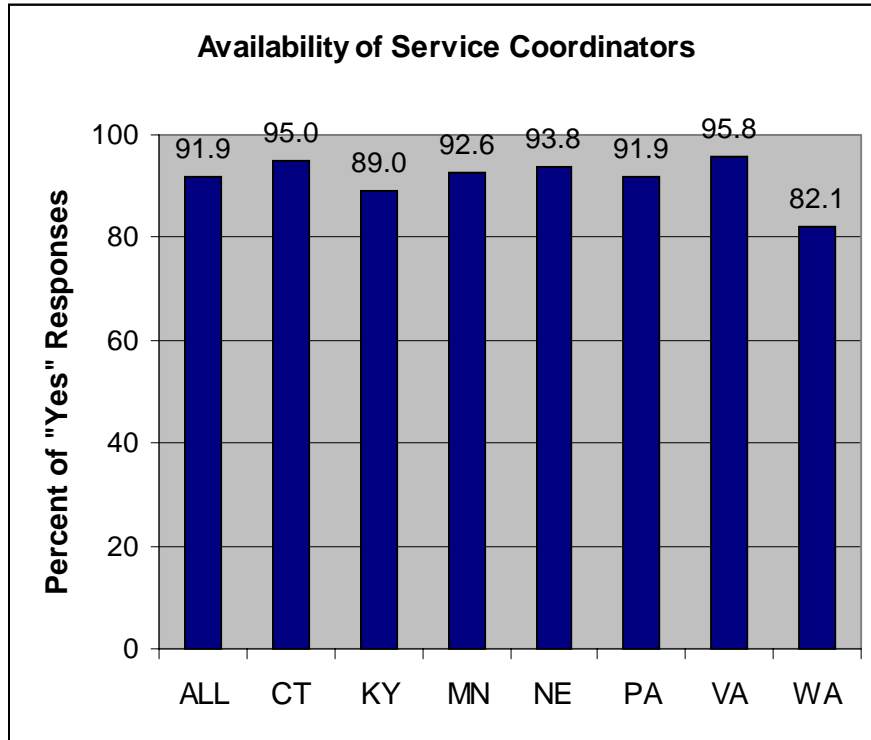


Figure 17: The proportion of families/guardians who report that service coordinators are effective.

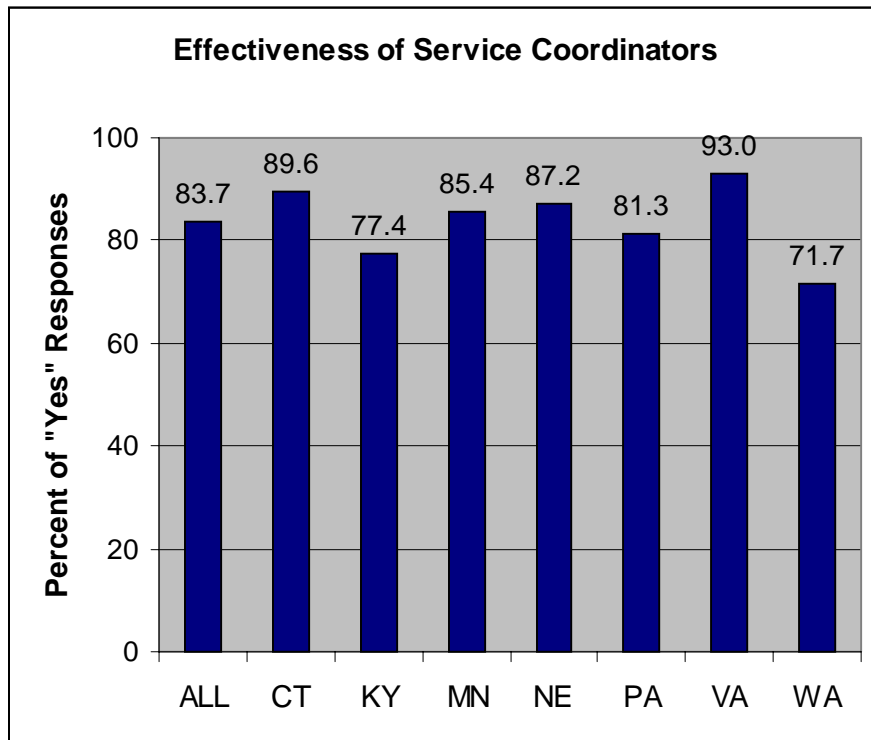


Figure 18: The proportion of families/guardians who report that the individual's communication needs are met.

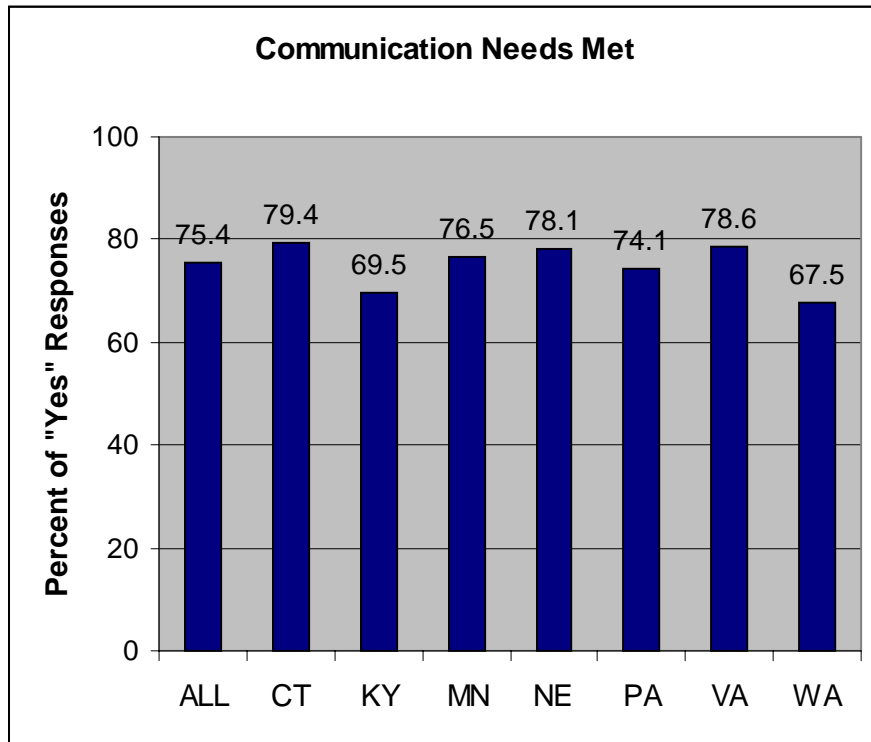


Figure 19: The proportion of families/guardians who report that individuals have access to needed special equipment.

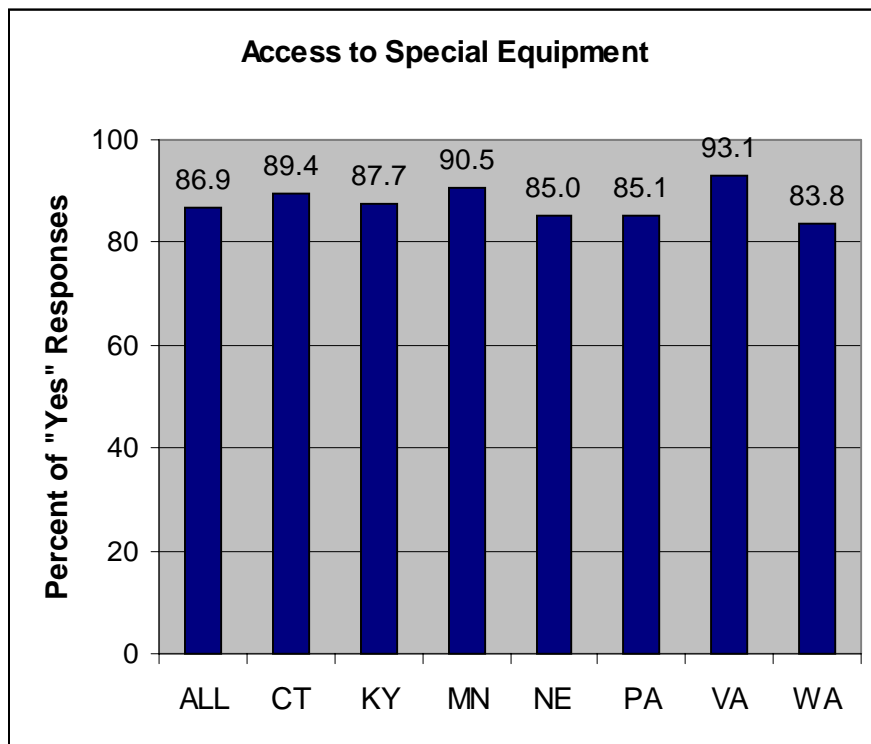


Figure 20: The proportion of families/guardians who are satisfied with the supports received by the individual.

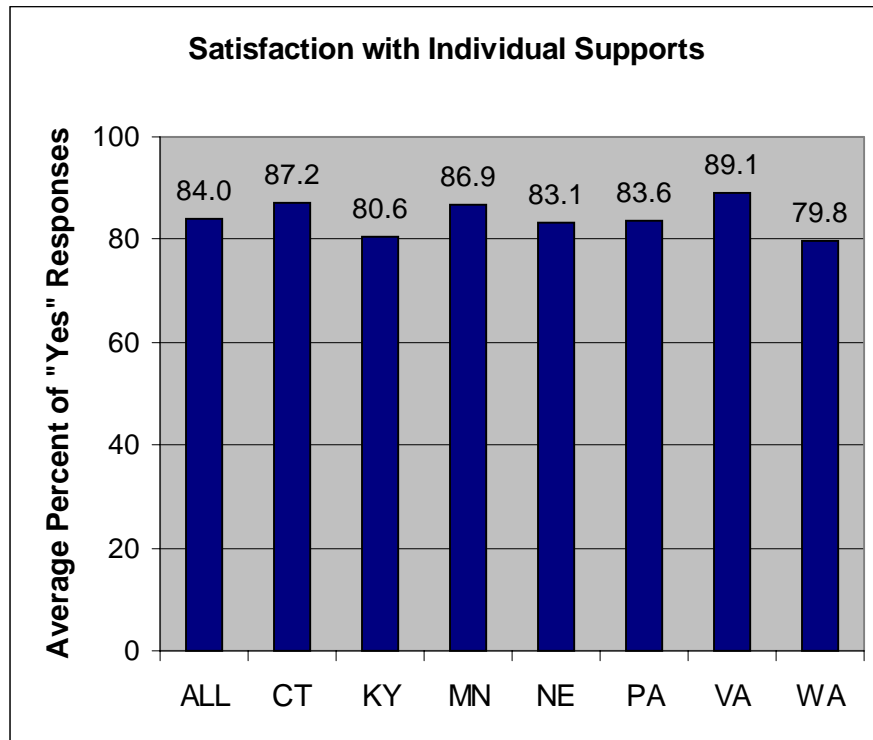
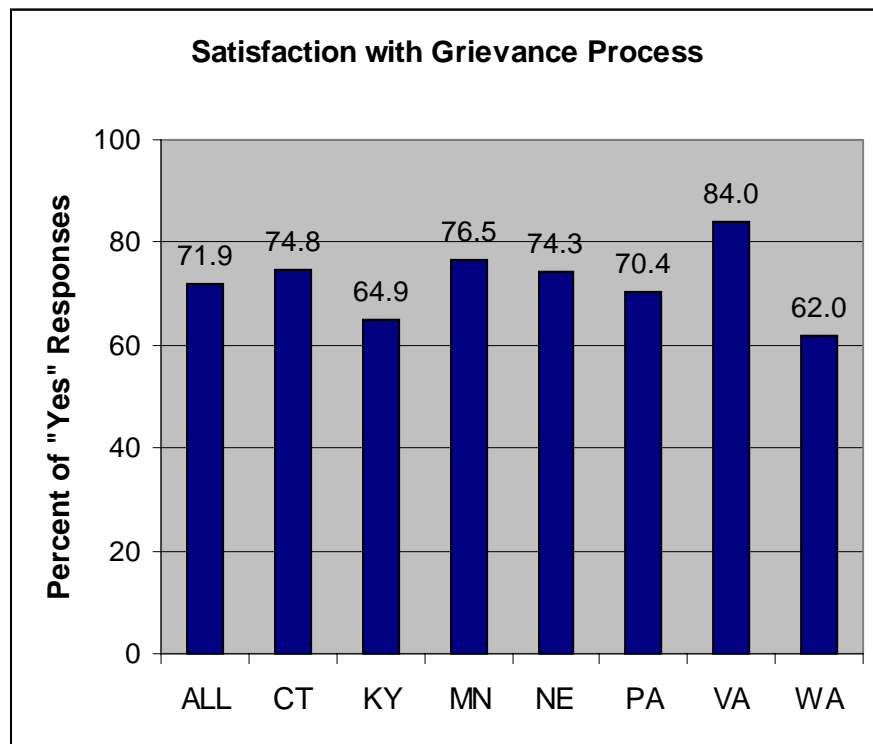


Figure 21: The proportion of families/guardians who are satisfied with the grievance process.



Discussion of Results

In this section, we will summarize and highlight the Phase II results for each survey and provide some comparisons between the two data sets.

FOR IN-HOME FAMILY OUTCOMES, state performance varies the most on the following measures: whether families receive information, whether families participate in planning individual supports, how families rate the availability and effectiveness of service coordinators, whether people have access to individual supports, families' overall satisfaction with individual supports, and families' satisfaction with crisis response. State performance was relatively consistent across these measures. That is, states that tended to be at the high end of the range (AZ, NE, PA, and VT) on one measure also tended to score high on the other measures. This is also true for states that tended to be at the lower end of the range (KY, WA). States fared much the same on measures of: whether families report that the individual is happy, and whether the staff provide links to community and natural supports. More specifically:

- positive ratings of availability and effectiveness of service coordinators ranged between 60% - 80%
- positive ratings of health and safety of the day/employment setting ranged from 70% - 90%
- positive ratings of satisfaction with crisis response ranged from 30% to 50%
- ratings of whether or not the individual was "happy" were high across all states -- the positive response rate ranged from 75% - 85%
- links to community and natural supports were generally low or infrequent across states -- the highest positive response rate was only 30% and the lowest score was 16%

OVERALL, FOR IN-HOME FAMILIES:

- only 46% report receiving information about service and supports; of these, 67% find the information easy to understand
- 52% report that they have access to needed family supports, and 48% report that they participate in planning family supports
- 57% report that their family member has access to needed supports
- 81% report that their family member is happy
- 64% report overall satisfaction with individual supports
- 33% report that they make choices about staff and service providers
- 60% report that they participate in planning supports for their family member
- 81% report that their family member's day/employment setting is healthy and safe

- 61% report satisfaction with the grievance process
- only 43% report satisfaction with crisis response

FOR OUT-OF-HOME FAMILY/GUARDIAN OUTCOMES, there was much less variation in performance levels across states. States varied most on two measures: ratings of effectiveness of service coordinators and ratings of satisfaction with the grievance process. Again, state performance levels were fairly consistent on these measures. Specific results include:

- positive ratings of effectiveness of service coordinators ranged from 71% to 93%
- positive ratings of satisfaction with the grievance process ranged from 62% to 84%
- positive ratings of satisfaction with individual supports were generally very high and fell within a small range, from 79% to 89%

OVERALL, FOR OUT-OF-HOME FAMILIES:

- 84% report satisfaction with individual supports
- 72% report satisfaction with the grievance process
- 92% report that service coordinators are available, and 84% report that they are effective
- 66% report that they participate in planning individual supports
- 75% report that their family member's communication needs are met, and 87% report that they have access to special equipment

IN COMPARISON, positive responses of 80% or higher were more common in the responses to the Family/Guardian Survey than in the Family Support Survey. Specifically, those with family members living outside the home expressed higher levels of satisfaction with individual supports than those with family members living at home (84% vs. 64%). As noted earlier, this out-of-home group tended to be older and their family members were utilizing more services. The expressed level of satisfaction with individual supports was about the same across the states for the out-of-home group (80% to 90%), and the variation was much greater across the in-home group (50% to 70%).

Analysis of Open-Ended Comments

Both family surveys included a page at the end for respondents to record comments. This section summarizes the Family Support Survey comments from AZ, CT, KY, NC, PA and VT.

Many common themes were reported across states. In all states, many respondents expressed that they were pleased with the services and supports they receive. Families generally gave high praise to the case managers and staff who work directly with their families and family members with developmental disabilities.

"[Our service coordinator] really cares for K and our family and would do anything we needed to help us. She is very professional and well versed on the areas we need. She is thoughtful and tuned into K's needs. I also feel she is very 'available' and I could call her with questions or concerns if I needed to." - Nebraska parent

Compliments were more common than complaints; however, there were some respondents in every state who noted concerns and unmet needs. These comments/requests included: the need for more respite care, frustration with unresponsive case managers and/or state agencies, the need for more information about available services and supports, concerns about high turnover and low salaries of direct support staff, and the need for more options for daytime programs/activities.

Other themes emerged that were specific to certain states. Respondents in Arizona, Connecticut, Pennsylvania and Vermont expressed a need for more financial support; and some families suggested that they should receive financial support for caring for their family member at home. Families in these states also wrote about the need for more transition and job-training services.

I think it should be noted that with all the money and emphasis on mainstreaming / inclusionary settings, etc. there should be more opportunities and awareness of the need for more options and services after 21 for people who will always be dependent on others and for parents who face a lifetime of worry about the care and dignity for people with special needs.
- Connecticut parent

Some families touched upon ways states could improve or expand their efforts to serve particular communities and cultures. In Connecticut, there were a number of respondents who commented on the need for multi-lingual staff and information available in other languages. This comment came from a respondent in Arizona:

I would like for DDD to continue there [sic] support and efforts in working with the Tohono O'odham Nation to provide more services here for our people with disabilities. - Arizona respondent

In addition to families in AZ, CT, and VT, respondents in North Carolina and Kentucky expressed concerns about the quality of day programs, specifically about the lack of work/activities for consumers attending day programs. NC and KY families also mentioned concerns about the lack of available residential care, with older caregivers/aging parents in KY expressing specific concerns about future planning and residential options. Many families in KY, AZ, and CT wrote about frustrations with waiting lists, and in AZ, PA and CT many asked for more transportation services. In Arizona, families observed that services have improved over the last few years. However, families in this state also made specific requests for better medical and dental care, more insurance coverage, and home modifications and adaptive equipment.

Overall, these comments reflect general levels of satisfaction with service system performance and also highlight some of the critical areas that could be targeted for improvement and expansion: respite care, financial support, transition services, housing options, transportation, and system responsiveness, among others. Individual states have also used this feedback to respond to specific family requests and to identify and address issues unique to their state systems. Using this information in combination with the question-by-question results could provide cues at a more detailed level for states to use in management of their systems. For example, concerns of staffing issues and system responsiveness were raised in the comments section. Looking back at the survey results, it can be noted that:

- 42.5% of respondents to the Family Support Survey report that staff turnover is a problem some or all of the time
- 41.7% of respondents to the Family Support Survey report that the state agency did not respond in a crisis

The current baseline data points out areas where states are performing well and areas that need attention. It is the hope of the project and its participants that this information will provide a basis for system change and improvement. In the future, CIP results will include an analysis of trend data that will inform states how performance levels change from year to year, as well as state-to-state.

Changes Going Forward

For the next round of data collection, minor changes will be made to the Family Support Survey and Family/Guardian Survey: some graphics will be added to make the survey more visually interesting, easier to follow and more appealing to answer, and some of the demographic questions will be reworded and clarified based on feedback from participating states. Regarding the content of the survey, a few questions will be added to gauge the level of interest in self-management of supports and services. No substantial changes will be made to the existing questions. The Family/Guardian Survey will continue to be optional for states to administer. In addition, another optional survey will be developed for the project - a Children/Family Survey, aimed at families who have a child with a developmental disability living at home.

Appendices

Appendix A: Family Support Survey

Appendix B: Family/Guardian Survey

APPENDIX A

Family Support Survey: **Opinions of Services and Supports in [State]** **For People with Disabilities and their Families**

Thank you for helping us by completing the attached questionnaire. Your opinions will make it possible to improve services and supports to people with developmental disabilities and their families in [State]. The results of this survey will also allow us to compare family satisfaction with similar information collected in other states. We expect that it will only take about 15 minutes to complete this survey.

[Phase I states only:] You may have received a similar survey last year. This survey has some new questions; we ask that you please help us by responding again.

There are two parts to this survey:

- Part 1 asks about support (such as respite care or financial support) provided to families who have a family member with a disability living at home. You only need to answer Part 1 if you receive family support services.
- Part 2 asks about whether you are included in planning any services or supports your family member with a disability receives (such as a day program), and what you think of those services and supports. You only need to answer Part 2 if the person with a disability currently receives services.

INSTRUCTIONS:

Note: If there is more than one person with a disability in your family, please answer the questions considering the person who is named on the address label.

- For most questions, all you need to do is check the box that applies to you. Remember that your answers will be kept confidential. If you come to a question that you feel uncomfortable answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.**
- When you have completed the questionnaire, please return it to us in the enclosed pre-addressed and pre-stamped envelope. Please try and return the survey as soon as possible.**
- ? **If you need help reading or understanding this survey, or if you need an interpreter, please call: [name & phone]**

Again, THANK YOU!

Please provide the following information about your family. All responses will be kept confidential.

a.) Does your family member with a disability live at home with you?

1 Yes

2 No

Note: If you answered "no" to the question above, please stop here and return the survey.

b.) What is the age of the primary caregiver in your household? _____

c.) How would you describe the health of the primary caregiver?

1 Excellent

2 Good

3 Fair

4 Poor

d.) What is your relationship to the person with a disability?

1 Parent (biological or adoptive)

2 Sibling

3 Other relative

4 Spouse

e.) Are you the legal guardian for the person with a disability?

1 Yes

2 No

f.) If no, is there someone else who is the legal guardian?

1 Yes

2 No

g.) How old is the person with a disability?

h.) What is the gender of the person with a disability?

1 Male

2 Female

i.) How has this person's level of mental retardation been labeled?

1 No MR label

2 Mild

3 Moderate

4 Severe

5 Profound

6 Don't know

j.) Has this person been diagnosed with any other disabilities listed below (check all that apply)?

1 Mental illness/psychiatric diagnosis

2 Autism

3 Cerebral Palsy

4 Brain injury/neurological problem

5 Chemical dependency

k.) What is your race? (check one)

1 American Indian/Eskimo/Aleut

2 Asian/Pacific Islander

3 Black

4 White

5 Other/Unknown

l.) What is your ethnicity? (check one)

1 Hispanic

2 Non-Hispanic



PART 1. SUPPORTS PROVIDED TO YOUR FAMILY.

Please check whether your family is currently receiving any of the following services or supports:

Does your <u>family</u> receive:	YES	NO	DON'T KNOW
i. Case management or service coordination -- provides assistance with planning services, meetings, and supports for your family.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
ii. Financial support -- family receives money from the state to purchase items, equipment, or needed services.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
iii. Staff support -- staff are paid to come to your home to provide assistance to your family.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
iv. Respite -- someone takes care of the person with a disability, either in your home or elsewhere, to give the family a break.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

If your family receives any of the services listed above, please answer the rest of the questions in Part 1. If not, please skip to Part 2.

INFORMATION		YES, OR MOST OF THE TIME	SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
1.	Do you receive information about services and supports that are available to your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
2.	If <u>yes</u> , is the information easy to understand?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
CHOICES & PLANNING		YES, OR MOST OF THE TIME	SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
3.	Do you choose the <u>agencies or providers</u> that work with your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4.	Do you choose the <u>staff</u> that work with your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5.	Are frequent changes in support staff a problem for your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6.	Do staff help you figure out what you need as a family to support your family member with a disability?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7.	Do staff talk to you about different options to meet your family's needs?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8.	Do staff respect your choices and opinions?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
ACCESS		YES, OR MOST OF THE TIME	SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
9.	Does your family get the supports you need, such as respite care, training, or education?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	
10.	Do the supports offered meet your <u>family's</u> needs?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11.	Are supports available when your family needs them?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12.	If you have ever asked for the state agency's assistance in an emergency or crisis, was help provided to you right away?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13.	If English is <u>not</u> your first language, are there staff who speak with you in your preferred language?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

LINKS TO COMMUNITY		YES, OR MOST OF THE TIME	SOME OF THE TIME	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
14.	Do staff help you get family supports in your community, such as services offered through recreation departments, churches, or medical services?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15.	Do staff help you make arrangements with family, friends, or neighbors who can provide some of the supports your family needs?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

PART 2. SUPPORTS PROVIDED TO THE PERSON WITH A DISABILITY.

Please check whether your family member with a disability is currently receiving any of the following services or supports:

Does your family member with a disability receive:		YES	NO	DON'T KNOW
v.	Case management or service coordination -- provides assistance with planning services, meetings, and supports for the person with a disability.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
vi.	Day/employment supports -- the individual goes to a day program, workshop, or receives vocational supports such as job training or job coaching at a job in the community.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
vii.	Transportation -- a staff person arranges for transportation for this individual to go to a day program, work, medical appointments, etc.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
viii.	Other services / supports -- such as mental health care, or other therapies (such as physical therapy, occupational therapy, speech, or recreational therapy).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Is your family member with a disability on a formal, state agency Waiting List for:		YES	NO	DON'T KNOW
ix.	Residential services	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
x.	Day/employment supports	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

If your family member with a disability currently receives any of the services listed above, please answer the rest of the questions in Part 2. If not, please turn to the last page of this survey.

FAMILY INVOLVEMENT IN SERVICE PLANNING		YES, OR MOSTLY	SOME-WHAT	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
1.	Did you get enough information to help you participate in planning services for your family member with a disability?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2.	Did you help develop this person's service plan?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3.	Does the service plan include things that are important to you?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4.	Can you contact this person's service coordinator/case manager whenever you want to?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5.	When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6.	Does the agency providing day/employment services to this person involve you in important decisions (such as where to work, type of work, work setting)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
FAMILY SATISFACTION		YES, OR MOSTLY	SOME-WHAT	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
7.	If this person does not speak English or uses a different way to communicate (for example, sign language), do you feel that there are enough staff available who can communicate with him/her?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8.	Do you feel that this person has access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9.	Do you feel that this person's day/employment setting is a healthy and safe environment?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10.	Overall, do you feel that this person is happy?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11.	Are you satisfied with the way complaints/grievances are handled and resolved by the state agency?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12.	Overall, are you satisfied with the services and supports this person currently receives?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Thank you for taking the time to complete these questions. Please use the space below for any other comments you would like to make.

Please note: Your responses to this survey are anonymous and confidential. However, if you need help with a problem or concern, you may choose to waive confidentiality by signing below and letting us know how to contact you.

Signature:

Print Name:

Phone:

APPENDIX B

Family/Guardian Survey: **Opinions of Services and Supports in [State]** **For People with Disabilities**

Thank you for helping us by completing the attached questionnaire. Your opinions will make it possible to improve services and supports to people with developmental disabilities in [State]. The results of this survey will also allow us to compare family satisfaction with similar information collected in other states. We expect that it will only take about 15 minutes to complete this survey.

INSTRUCTIONS:

Note: If there is more than one person with a disability in your family, please answer the questions considering the person who is named on the address label.

- For most questions, all you need to do is check the box that applies to you. Remember that your answers will be kept confidential. If you come to a question that you feel uncomfortable answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.**
- When you have completed the questionnaire, please return it to us in the enclosed pre-addressed and pre-stamped envelope. Please try and return the survey as soon as possible.**
- ? **If you need help reading or understanding this survey, or if you need an interpreter, please call: [name & phone]**

Again, THANK YOU!

Please provide the following information about your family member with a disability.

a.) Does your family member with a disability live at home with you?

1 Yes

2 No

Note: If you answered "yes" to the question above, please stop here and return the survey.

b.) What is your relationship to the person with a disability?

1 Parent (biological or adoptive)

2 Sibling

3 Other relative

4 Spouse

c.) Are you the legal guardian for the person with a disability?

1 Yes

2 No

d.) If no, is there someone else who is the legal guardian?

1 Yes

2 No

e.) About how often do you see your family member with a disability?

1 Once/week

2 Once/month

3 Once/year

4 Less than once/year

f.) How old is the person with a disability?

g.) What is the gender of the person with a disability?

1 Male

2 Female

h.) Where does your family member live?

1 Specialized facility for persons with MR

2 Group home

3 Agency-owned apartment

4 Independent home or apartment

5 Adult foster care/host family home

6 Nursing home

7 Other

i.) How has this person's level of mental retardation been labeled?

1 No MR label

2 Mild

3 Moderate

4 Severe

5 Profound

6 Don't know

j.) Has this person been diagnosed with any other disabilities listed below (check all that apply)?

1 Mental illness/psychiatric diagnosis

2 Autism

3 Cerebral Palsy

4 Brain injury/neurological problem

5 Chemical dependency

k.) What is your race? (check one)

1 American Indian/Eskimo/Aleut

2 Asian/Pacific Islander

3 Black

4 White

5 Other/Unknown

I.) What is your ethnicity? (check one)

1 Hispanic

2 Non-Hispanic

Please check whether your family member with a disability is currently receiving any of the following services or supports:

Does your family member with a disability receive:		YES	NO	DON'T KNOW
i.	Case management or service coordination -- provides assistance with planning services, meetings, and supports for the person with a disability.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
ii.	Residential supports -- staff come to the person's home to help with daily activities (such as eating or getting dressed) or with home health care.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
iii.	Day/employment supports -- the individual goes to a day program, workshop, or receives vocational supports such as job training or job coaching at a job in the community.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
iv.	Transportation -- a staff person arranges for transportation for this individual to go to a day program, work, medical appointments, etc.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
v.	Other services / supports -- such as mental health care, or other therapies (such as physical therapy, occupational therapy, speech, or recreational therapy).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
		YES	NO	DON'T KNOW
vi.	Is your family member with a disability on a formal, state agency Waiting List for Day/employment supports?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

FAMILY INVOLVEMENT IN SERVICE PLANNING		YES, OR MOSTLY	SOME-WHAT	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
1.	Did you get enough information to help you participate in planning services for your family member with a disability?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2.	Did you help develop this person's service plan?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3.	Does the service plan include things that are important to you?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4.	Can you contact this person's service coordinator/case manager whenever you want to?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5.	When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6.	Does the agency providing residential services to this person involve you in important decisions (such as where to live, roommates, medical, dental)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7.	Does the agency providing day/employment services to this person involve you in important decisions (such as where to work, type of work, work setting)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

FAMILY SATISFACTION		YES, OR MOSTLY	SOME-WHAT	NO, OR NOT AT ALL	DON'T KNOW	DOES NOT APPLY
8.	If this person does not speak English or uses a different way to communicate (for example, sign language), do you feel that there are enough staff available who can communicate with him/her?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9.	Do you feel that this person has access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10.	Do you feel that this person's residential setting is a healthy and safe environment?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11.	Do you feel that this person's day/employment setting is a healthy and safe environment?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12.	Overall, do you feel that this person is happy?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13.	Are you satisfied with the way complaints/grievances are handled and resolved by the state agency?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14.	Overall, are you satisfied with the services and supports this person currently receives?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Thank you for taking the time to complete these questions. Please use the space below for any other comments you would like to make.

Please note: Your responses to this survey are anonymous and confidential. However, if you need help with a problem or concern, you may choose to waive confidentiality by signing below and letting us know how to contact you.

Signature:

Print Name:

Phone: