Consumer 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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Table of Contents

TABLE OF CONTENTS	3
ACKNOWLEDGEMENTS	4
I. ORGANIZATION OF REPORT	5
II. INTRODUCTION	6
Overview of ProjectPhase II Indicators	
III. PHASE II CONSUMER SURVEY	9
Organization of the Survey Reliability Validity Consistency Analysis	9 10
IV. METHODS	12
Sampling Administration. Training Surveyor Feedback. Changes to the Instrument.	12 13
V. DATA ANALYSIS	14
Computing the Core Indicators Outcome Adjustment	
VI. RESULTS: DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS	17
Demographic Profile of Sample	20 27 33
VII. RESULTS: CORE INDICATOR OUTCOMES AND COMPARISONS ACROSS STATES	
Summary of Aggregate Results	44 53 55 57
Respect/Rights	64
APPENDIX A: RULES FOR RECODING AND COMBINING VARIABLES TO COMPUTE CORE INDICATORS	
Table A1: Outcome Adjustment Variables and Rules for Collapsing Response Codes	73 74 75
APPENDIX B: DETAILED HEALTH QUESTION RESULTS	76
Table B1: Frequency of Physical Examination	77 78
ADDENDIS C. ITEM BY ITEM SUDVEY DESULTS	70 7 0

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I. Organization of Report

This document serves as the final technical report for the consumer survey portion of Phase II of the Core Indicators Project (CIP). The data described in this report was collected in twelve participating states during the fiscal year of 1999-2000. The report is organized as follows:

INTRODUCTION -- Gives a brief overview of the project to date, and presents the core indicators measured with the consumer survey.

PHASE II CONSUMER SURVEY -- Describes in detail the development and structure of the survey instrument. Summarizes the psychometric properties of the survey, including results of reliability and validity tests and features designed to test for consistency of responses.

METHODS -- Describes the protocol for administering CIP consumer surveys. Includes sampling criteria, administration guidelines, interviewer training procedures, summary of interviewer feedback from Phase II, and changes to be made in the next iteration of the survey instrument.

DATA ANALYSIS -- Explains the statistical methods used to analyze the consumer survey data. Includes an explanation of how indicators are computed, and how certain outcomes are "adjusted" for the purposes of making comparisons across states.

RESULTS: DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS -- Presents aggregate and state-by-state results of demographic information collected on survey respondents. Includes variables used for outcome adjustment, other demographic data, and information about services/supports received by respondents.

RESULTS: CORE INDICATOR COMPARISONS ACROSS STATES -- Presents aggregate and state-by-state results for each core indicator.

APPENDICES -- Include detailed crosswalks of how survey items relate to core indicators and detailed item-by-item results.

II. Introduction

Overview of Project

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 joined the project in 2000 (DE, IA, MT, UT), and six new states have recently signed on for 2001 (HI, IL, IN, OK, WV, WY). 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 are available online at www.hsri.org/cip/core.html.

Phase II Indicators

The survey instrument is designed specifically to measure certain core indicators. Most indicators correspond to single survey items. A few indicators are measured by clusters of related items. Table 1 presents a crosswalk between core indicators collected using the Consumer Survey and their corresponding survey item(s).

Ta	Table 1. Crosswalk Between Core Indicators and Consumer Survey Questions					
	Key to codes: CI = core indicator					
CI #	CORE INDICATOR:	REFERS TO QUESTIONS:				
CI-6.	The proportion of people who participate in integrated activities in their communities, including: shopping, using public services, attending religious events, playing sports, attending arts/entertainment events, and dining out.	CS-39 through CS-44				
CI-7.	The proportion of people who make choices about important life decisions, including: housing, roommates, daily routines, jobs, support staff or providers, and social activities.	CS-46 through CS-54				
CI-8.	The proportion of people reporting that their service plan includes or is about things that are important to them.	CS-35				
CI-11.	The proportion of people reporting that they control their own spending money (i.e. have access to it and choose what to buy with it).	CS-55, CS-56				
CI-12.	The proportion of people who report having friends and caring relationships with people other than support staff and family members.	CS-11				
CI-13.	The proportion of people who report having a close friend, someone they can talk to about private matters.	CS-12				
CI-14.	The proportion of people who are able to see their families and friends when they want to.	CS-13, CS-17				
CI-15.	The proportion of people reporting feeling lonely.	CS-15				
CI-16.	The proportion of people who report satisfaction with where they live.	CS-19				
CI-17.	The proportion of people reporting satisfaction with their job or day program.	CS-2, CS-6				
CI-18.	The proportion of people reporting that they work as many hours as they want to.	CS-9				
CI-19.	The proportion of people reporting that they received support to learn or do something new in the past year.	CS-36				

CI-20.	The proportion of people who report having adequate transportation when they want to go somewhere.	CS-63
CI-21.	The proportion of people who are able to contact their service coordinators when they want to.	CS-27
CI-22.	The proportion of people who report that they participated in the development of their service plan.	CS-33, CS34
CI-28.	The proportion of people reporting that service coordinators help them get what they need.	CS-29
CI-30.	The rate at which people report that "needed" services were not available.	CS-62
CI-36.	The proportion of people reporting that they have an "advocate" or someone who speaks on their behalf.	CS-31
CI-40.	The proportion of people who report that they feel safe in their home and neighborhood.	CS-22, CS-23
CI-41.	The number of days in the past month people report that their normal routines were interrupted due to illness.	BI-18
CI-42.	The proportion of people who have had a physical exam in the past year.	BI-22
CI-43.	The proportion of women who have had an OB/GYN exam in the past year.	BI-23
CI-45.	The proportion of people who have had a routine dental exam in the past six months.	BI-24
CI-46.	The proportion of people receiving psychotropic medications.	BI-19
CI-47.	The proportion of people who report that their basic rights are respected by others.	CS-57 through CS-61
CI-48.	The proportion of people who have attended activities of self-advocacy groups or other groups that address rights.	CS-45
CI-49.	The proportion of people reporting satisfaction with the amount of privacy they have.	CS-21
CI-53.	The proportion of people indicating that most support staff treat them with respect.	CS-4, CS-8, CS- 25
CI-57.	The proportion of people who have changed residences more than once in the past year.	BI-25

III. Phase II Consumer Survey

The Core Indicators Project Consumer Survey was initially developed by the project's technical advisory subcommittee with the purpose of collecting information directly from individuals with developmental disabilities and their families or advocates. The survey is designed to measure 29 of the 60 core indicators. Each year, project staff have tested and refined the instrument. In Phase I, six participating states field-tested the survey with approximately 400 recipients of services in each state. The results of Phase I enabled the project to solidify the interview protocol and the procedures for administration. Phase II results contained in this report represent baseline data for the 12 states that participated in this round of data collection. Results are presented by state and in aggregate.

The original survey tool was designed in consultation with a group of technical experts from around the country. Many questions were drawn from survey instruments already in use in the field; other questions were developed specifically for this project. Project staff held a focus group with eight individuals with developmental disabilities to pre-test the face validity of the questions. The focus group participants highlighted problematic questions, identified words that needed further definition, and suggested alternative ways of phrasing questions. These results were incorporated into the draft survey.

Organization of the Survey

The Phase II Consumer Survey was composed of a pre-survey form and three sections. The direct interview consists of 64 questions.

- THE PRE-SURVEY FORM was developed to collect information necessary to schedule face-to-face interviews, including contact information for consumers, and the names of guardians, advocates, or other individuals who might be asked to provide responses. The form also was used by surveyors to identify special communication needs that individuals might have prior to conducting the interview, define terms the individual would be most familiar with (such as "ISP" or other acronyms), and document that informed consent was obtained. In most instances, information for the pre-survey form was obtained from the individual's case manager. [Note: Individual identifying information was excluded from data submitted to HSRI.]
- THE BACKGROUND INFORMATION SECTION requested data that would most likely be found in agency records or information systems. In some states, case managers completed this section at the same time the pre-survey form was completed. In other states, surveyors completed the section during the direct interview. Some questions in this section were included on the consumer survey to potentially serve as a verification of data collected from system-wide sources. This section consists of 36 items.
- SECTION I of the survey, which concerned questions aimed at obtaining expressions of satisfaction and opinions from each individual, could be completed only through a direct interview with the individual; proxy responses were not acceptable.
- SECTION II questions were to be answered by the individual if possible. If the person
 was unable to respond, an advocate was asked to answer. Service providers were not

permitted to respond to this section since the questions addressed issues concerning service provision and coordination.

The last page of the survey was the SURVEYOR FEEDBACK SHEET. Surveyors were asked to record the length of the interview with the individual and describe any problematic questions.

Reliability

To date, the interview tool has undergone three separate reliability tests:

OCTOBER 1997: Pilot test conducted with thirty individuals in Connecticut. A sample of 30 individuals was selected to include 15 consumers who were expected to be able to respond and 15 consumers who were not expected to be able to respond to the questions. Inter-rater reliability resulted in 93% agreement between the two raters.

NOVEMBER 1998: Inter-rater and test-retest reliability data collected in Nebraska as part of CIP Field Test (Phase I). The inter-rater reliability test (N=25) resulted in 93% agreement between the raters, and an average kappa score (indicating the percent agreement over chance) of 0.794. Test-retest reliability (N=27) resulted in 80% agreement between the two administration times, and an average kappa score of 0.502. ¹

APRIL 1999: Inter-rater reliability test with twenty-seven individuals in Minnesota, prior to Phase II of CIP. An analysis of inter-rater reliability found 92% agreement between raters. Feedback from the interviews enabled project staff to fine-tune the wording of questions and response codes. The study also flagged some survey construction and training issues, such as spelling out "not applicable" choices and "skips" more clearly, changing/adding some consistency check questions, and establishing rules for coding difficult questions.

Validity

The consumer interview consistently yields high response rates. In Phase II, the average percentage of individuals who were able to respond to Section I of the survey was 71.7% across states. This finding is similar to Phase I, which resulted in an average response rate of 65.1%. The CIP response rates are high, but not unreasonably so. Our method of excluding incomplete and/or inconsistent responses is conservative and is described in more detail below. By comparison, Vermont's Consumer Satisfaction Study (which surveyed all consumers over a four-year period) found that 69% of all adults served could respond to a satisfaction survey that includes many parallel questions to the CIP survey.² The Ask Me!? Survey conducted by the Arc of Maryland found that 80% of consumers surveyed were able to respond for themselves.³

¹ Given that (a) most of the survey questions do <u>not</u> specify a point in time (e.g., "in the last month...") and (b) many of the questions measure preferences or opinions that are likely to vary, we would expect the test-retest scores to be lower, since there may have been legitimate changes in responses within a short period of time.

² Source: Vermont Consumer Satisfaction Survey Statewide Report 1999, Division of Developmental Services, Department of Developmental and Mental Health Services, Waterbury, VT.

³ Source: Bonham, Gordon Scott. Ask Me! Year 2, The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA Funded Supports. Bonham Research: November 1999.

The project uses a number of strategies to ensure that the data collected are valid.

INTERVIEWER TRAINING. Project staff conduct a "train the trainer" session and provide a set of training materials to all states so that all interviewers receive consistent training. The training includes instruction on basic skills for interviewing persons with developmental disabilities and question-by-question review of the survey tool.

VALIDITY CHECK QUESTIONS. Throughout Section I of the survey, there are several questions designed to pick up inconsistent response patterns, such as "acquiescence" (answering "yes" to every question in order to please the interviewer, rather than responding to the content of the question). During data analysis, we are able to exclude those sections where an individual did not respond in a consistent manner.

INTERVIEWER FEEDBACK. Interviewers are asked to give formal input on every interview conducted. At the end of Section I, there are two questions that ask the interviewer to make a judgment about the individual's comprehension of the questions and consistency of responses. We use this information in conjunction with the check questions to determine the validity of an individual's responses. In addition, interviewers complete a Feedback Sheet at the end of every interview. This information helps project staff improve the survey questions and instructions each year.

Consistency Analysis

For Section I, only consumers who responded to at least half of the questions in that section are included. In addition, we exclude those respondents whose interviewers recorded that they did not understand the questions being asked.

The final exclusion decision is based on the validity check questions. Two sets of questions were used:

- "Can you be by yourself as much as you want to?" and "Do you wish you had more time by yourself?"
- "When you want to talk to your service coordinator, is it easy to get in touch with him/her?" and "When you want to talk to your service coordinator, is it hard to get in touch with him/her?"

Both sets of questions test for acquiescence bias, or the tendency to answer "yes" regardless of what question is asked. If the person "failed" both of these checks (e.g. answered "yes" to all four questions), his/her responses were excluded from the analysis of Section I questions.

For the respondents who were excluded from Section I but had also answered Section II, their responses to Section II were thrown out as well.

The total number of surveys completed was 5096. After excluding incomplete and inconsistent responses, the number of valid respondents to Section I=3655. The number of valid respondents to Section II=5096. The breakdown of number of valid surveys completed by state is shown in Table 2.

IV. Methods

Sampling

The goal of each state was to conduct a minimum of 400 interviews. Each state drew a random sample of individuals over age 18 who were receiving at least one service, besides case management. Most states also drew an over-sample to account for refusals. Some states did not complete 400 interviews, for a variety of reasons (from natural disasters to difficulty obtaining contact information from local administrative entities), and others exceeded this goal. Those that did not complete 400 are included in this report; however readers are cautioned to take sample sizes into consideration when comparing results across states. Table 2 presents the breakdown of the sample by state.

Table 2: Sample Size by State

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<u>State</u>	<u>N</u>	Percent of total
AZ	531	10.4
CT	345	6.8
KY	178	3.5
MA	617	12.1
MN	332	6.5
NC	136	2.7
NE	379	7.4
PA	1599	31.4
RI	272	5.3
VA	299	5.9
VT	200	3.9
WA	208	4.1
Total	5096	100.0

The small sample from North Carolina represents a random sample of those area programs that chose to participate and does not include representation from several major urban areas.

Administration

All participating states, with the exception of Vermont, used the basic survey tool developed by the project. Vermont used a previously developed survey as part of a four-year study already in progress and modified certain questions so that the data would be comparable to the CIP data. Footnotes to the data tables indicate questions where wording was significantly different. [It is also important to note that Vermont only interviews consumers who are able to self-report. Vermont does not interview "proxy" respondents. In the results of responses to Section II, it should be noted that the Vermont sample includes consumers only, whereas the other states include a mix of consumers and proxy respondents.]

States used a variety of types of surveyors, including: consumers and families, university students, marketing firms, and state case managers. Some independent interviewers were paid; others were unpaid volunteers. All of the above methods were acceptable and no major differences were noted in terms of using different types of interviewers. The only stipulation was that if case managers are used, they do not interview consumers on their own caseload.

Training

Two "train-the-trainer" sessions were provided to the lead agencies from each state. Both were conducted by conference call, and transcriptions and recordings were made available to all states following the calls. The first session reviewed the survey tool in detail, question by question. The second session reviewed general interviewing techniques. The participants, or "trainers" from each state, then conducted training with the actual interviewers. The project provided a packet of standardized materials (including scripts for contacting respondents, frequently asked questions, general interviewing tips and skill exercises) to be used at these in-state training sessions.

Surveyor Feedback

The average time to complete the direct interview (Sections I and II) was 38.4 minutes (standard deviation 19.3). The average time to complete the entire form (including setting up interviews, gathering background information, travel time, follow-up calls, etc.) was 2.6 hours (standard deviation 7.3).

Changes to the Instrument

The subsequent version of the consumer survey will reflect the following recommendations, based on feedback and analysis of Phase II data:

- Remove repetitive and "annoying" consistency questions. Keep and/or modify those
 questions that worked best. Reduce the number of checks in order to avoid insulting or
 confusing the respondent..
- Combine questions about day programs and jobs. Surveyors indicated that it was difficult
 to distinguish between the two, and that the separate sets of questions were tedious to
 administer. As a check, the Background Information Section provides data on what types
 of vocational services the person receives.
- Remove questions about service plan meetings. These questions were found to be confusing, and response rates were poor. Keep basic questions about access to service coordinators.
- Add two general questions to the Community Inclusion sub-section to measure whether respondents choose the activities they do in the community and whether they participate as much as they would like to.
- Emphasize instructions and references to pre-survey information (e.g. names and terms
 that are familiar to the respondent) using graphical symbols. Analysis of feedback
 revealed some training gaps some surveyors were not using the pre-survey information
 to prompt the respondent, and some were not reading all instructions embedded in the
 tool.

V. Data Analysis

CIP data management and analysis is coordinated by Human Services Research Institute (HSRI). The majority of tasks are performed by HSRI project staff. Higher level data analyses, such as outcome adjustment procedures, are conducted in collaboration with a statistical consultant. The data management and analysis process involves these ten major steps:

- 1. Examine data files submitted by participating states for completeness and compliance with standard CIP formats.
- 2. Merge all data into an aggregate file.
- 3. Eliminate incomplete, inconsistent, and invalid responses (according to criteria described in Section III of this report).
- 4. Compute frequencies of demographic variables (descriptive information about respondents, primarily from Background Information section of survey) and distribution of responses to direct interview questions (Sections I and II of survey).
- 5. Distribute preliminary, unadjusted results to states for review and correction as necessary.
- 6. Collapse response categories to create 0/1 variables for indicator analysis (see Appendix A for specific protocol).
- 7. Recode and combine survey items as necessary for indicator analysis (see Appendix A for specific protocol).
- 8. Run outcome adjustment procedure on selected outcomes.4
- 9. Display demographic data in table format (Section VI of this report).
- 10. Display outcome results in table format (Section VII of this report).

Computing the Core Indicators

COLLAPSING RESPONSE CODES. The consumer survey is designed to measure 29 core indicators. Most indicators are expressed as a proportion of respondents who achieved a particular outcome. On the survey form, some questions have two possible responses ("yes/no"). Other questions have more than two response options ("yes/sometimes/no"). For those questions that have more than two options, it is necessary to collapse responses in order to report them as indicators. In other words, the "middling" response must be assigned to either the "yes" or the "no" category, based on how the actual indicator is phrased. Similarly, the variables used in the adjustment analysis must be converted to 0/1 variables. The logic used for collapsing response codes is presented in detail in Appendix A.

⁴ Where adjusted figures are used, a footnote appears in the data table. The outcomes that were subject to adjustment include: community inclusion, choice and decision-making, control of money, some access items, and some restriction of rights items.

COMBINING MULTIPLE ITEMS. Several of the core indicators are measured by one survey item, while others are designed to be assessed through multiple questions. Initially, nine indicators were designed to be measured using a "scaled" score (See Appendix A, Table A3). After conducting analyses of scale reliability, it was decided that several of the composite indicators need further refining. Alpha scores are displayed in Appendix A, Table A3. A cutoff point of 0.60 or higher is used to determine the reliability of a scale. For the purposes of this report, all items will be reported separately rather than combined into scaled indicators.

Outcome Adjustment

In Phase I of CIP, a statistical method was developed to adjust certain consumer outcome results by taking into account differences in the characteristics of individuals in the sample, thereby permitting more accurate comparisons of results from state to state. The premise is that if we can account or control for the effect of individual differences, then any remaining differences can be attributed to differences in system performance rather than differences in the individuals themselves. The method tested in Phase I was shown to be a feasible way of adjusting results. Phase II employed this method to establish baseline adjusted consumer outcomes across states and in aggregate. For more details about the adjustment procedure, please see the CIP Technical Report: *Outcome Adjustment Phase I Results*.

The mean scores of the various core indicators are reported in one of two ways:

- For outcomes that are <u>not</u> expected to be influenced by consumer characteristics (for example, the proportion of people who are able to see friends and family) the "raw" or "unadjusted" mean scores are presented for the whole sample and by state. These indicators are calculated simply by computing the average (mean) proportion, without controlling for any individual factors.
- Some indicators may be influenced by individual characteristics that can vary across state populations. For example, whether an individual goes shopping in the community can be a function of, among other things, the person's age and gender. Thus, if the age and gender mix is different across state populations, the mean scores need to be weighted accordingly so as to provide scores that can be meaningfully compared. The second way in which we report the mean scores by states, therefore, is to present an "adjusted" score based on a variety of individual factors. Specifically, we adjust the mean scores by using the following characteristics:
 - age
 - gender
 - legal status (independent or has a guardian)
 - level of mental retardation (mild, moderate, severe)
 - diagnosis of mental illness
 - diagnosis of autism
 - diagnosis of cerebral palsy
 - presence of brain injury

- diagnosis of chemical dependence
- presence of any other diagnosis
- primary means of expression (verbal/nonverbal)
- level of mobility
- vision (sees well/has little or no vision)
- frequency of seizures (frequent or infrequent)
- requirement of medical care (frequent or infrequent)
- problem behavior (indicating the presence of at least one of the four behaviors: self injury, property destruction, disruptive behavior, and uncooperative behavior)⁵

Since the core indicators are qualitative in nature (e.g., whether an individual goes shopping or not), they are coded as zero-one variables, with a score of 1 indicating a positive response (i.e., the individual does go shopping) and a score of 0 indicating a non-positive response (i.e., the individual does not go shopping). The appropriate adjustment technique, therefore, is to conduct a non-linear regression and compute the predicted values of the core indicator, controlling for all the factors listed above. For purposes of the present analysis, we assume that the error term is distributed according to the cumulative normal distribution and use standard multinomial probit regression to compute the adjusted outcomes.

For purposes of comparison, we used standard Tukey HSD test techniques to obtain the cluster ordering for each indicator such that states within a cluster do not differ significantly from each other, but differ significantly as compared to states in other clusters. In this report, we simply indicate at the bottom of the indicator table if differences among states were significant at the 0.05 level.

Based on the analytical methods reported above, indicator results were computed and are displayed in tabular format in Section VII.

16

⁵ The behavioral data for Massachusetts was not included in the adjustment procedure due to data compatibility issues. The exclusion of this variable from the analysis does not significantly affect the results.

VI. Results: Demographic Characteristics of Respondents

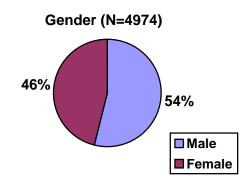
First, we present descriptive information about the sample of respondents. Twelve states participated in Phase II of the CIP and conducted a total of 5096 interviews. The participating states are: AZ, CT, KY, MA, MN, NC, NE, PA, RI, VA, VT, and WA. A summary of respondent characteristics is found in **Table 3**.

Table 3. Characteristics of Respondents

Total $N = 5096$	<u>Number</u>	<u>Percent</u>
Gender of consumer		
Male	2688	54.0
Female	2286	46.0
Race of consumer		
American Indian/Eskimo/Aleut	93	2.0
Asian/Pacific Islander	37	0.8
Black	298	6.4
White	4177	89.6
Other/unknown	57	1.2
Ethnicity of consumer		
Hispanic	191	5.1
Non-Hispanic	3556	94.9
Level of MR		
No MR label	78	1.6
Mild	1763	36.1
Moderate	1399	28.6
Severe	846	17.3
Profound	636	13.0
Unspecified or unknown	171	3.4
Other disabilities (duplicated counts)		
Mental illness	1111	21.8
Cerebral palsy	676	13.3
Brain injury	363	7.1
Autism	226	4.4
Chemical dependency	187	3.8
Type of residence		
Specialized facility	421	8.4
Group home	1179	23.5
Apartment program	416	8.3
Independent home/apartment	737	14.7
Parent/relative's home	1631	32.5
Foster care/host home	345	6.9
Nursing facility	82	1.7
Other	210	4.2
Average age		
Mean in years (range)	41.2 (18 - 95)	

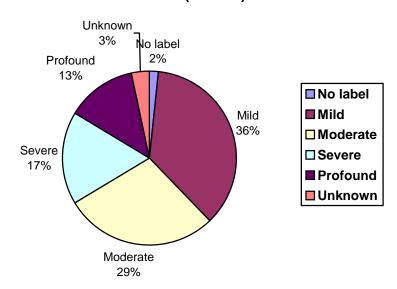
This section summarizes selected demographic characteristics of the overall sample.

✓ All states, with the exception of RI, had a slightly higher percentage of males in their samples. Overall, the total sample was 54% male and 46% female.



- ✓ The average age of respondents was 41 years old, with a range of ages from 18 to 95.
- ✓ The reported levels of mental retardation among respondents varied by state. Overall, about 65% of the sample had a diagnosis of "mild" or "moderate" MR, and 30% had a diagnosis of "severe" or "profound" MR.

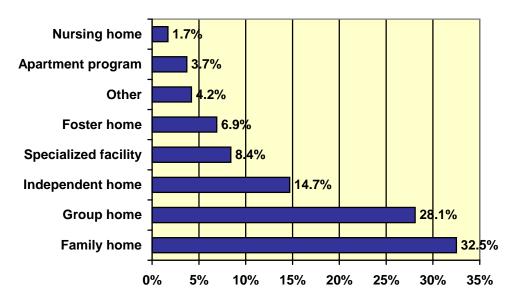
Level of MR (N=4890)



- ✓ 14% of respondents in the total sample used a nonverbal form of communication as their primary means of expression (e.g. gestures, sign language, communication device).
- ✓ The overall sample of respondents was not particularly diverse in terms of race and ethnicity (90% white; 95% non-Hispanic). However, results by state do reflect higher (and clearly more representative) numbers of minority respondents -- most notably in AZ, CT, KY, MA, NC, RI, and VA.

✓ About a third of the total respondents live with their families. The percent of respondents living in other types of homes is shown in the table below.





- ✓ The types of day/employment services and supports received by respondents varied by state. Overall, about 22% receive supported employment services, 12% receive group employment services, 39% receive facility-based vocational services, and 33% receive non-vocational day services.
- ✓ 42.3% of respondents in the overall sample receive Home and Community Based Waiver Services.

Tables 4 - **37** present more detailed descriptive information about the state samples and the aggregate total.

Outcome Adjustment Variables

As explained in the previous section, several variables related to individual characteristics were used to "adjust" certain consumer outcome results. **Tables 4** through **17** present the data for these adjustment variables, by state and for the sample as a whole. Note that the percentages listed are "valid" percents; that is, they are based on the total number of valid responses to that question ("Valid N"). Thus, both the state-by-state and total N's vary by table. For the adjustment variables, "Don't Know" responses were counted as missing, and missing cases were excluded from Valid N counts.

Table 4: Mean Consumer Age

<u>State</u>	Valid N	Mean	Std Deviation	Minimum	Maximum
AZ	525	39.5	11.5	19	75
CT	335	42.1	13.9	19	89
KY	178	40.7	11.7	18	71
MA	617	41.7	14.6	19	86
MN	321	44.0	15.1	19	87
NC	133	38.9	13.1	19	83
NE	357	45.4	10.1	29	69
PA	1590	40.6	14.3	18	95
RI	266	42.1	14.3	21	78
VA	298	39.6	11.4	18	79
VT	199	40.6	16.4	18	82
WA	195	38.7	11.3	20	68
Total	5014	41.2	13.6	18	95

Table 5: Gender

<u>State</u>	<u>Valid N</u>	<u>Male</u>	<u>Female</u>
AZ	526	57.8%	42.2%
CT	339	50.4%	49.6%
KY	178	56.7%	43.3%
MA	617	53.8%	46.2%
MN	323	50.8%	49.2%
NC	134	64.2%	35.8%
NE	357	56.0%	44.0%
PA	1530	51.6%	48.4%
RI	268	49.6%	50.4%
VA	296	65.2%	34.8%
VT	200	51.5%	48.5%
WA	206	54.4%	45.6%
Total	4974	54.0 %	46.0%

Table 6: Consumer Legal Status

	ici negai status			
		Independent/		
		<u>Legally</u>		State/County
<u>State</u>	<u>Valid N</u>	<u>Competent</u>	Private Guardian	<u>Guardian</u>
AZ	524	32.6%	53.6%	13.7%
CT	337	32.0%	65.9%	2.1%
KY	178	30.3%	51.1%	18.5%
MA	540	58.5%	41.5%	
MN	322	8.1%	31.7%	60.2%
NC	133	51.9%	42.9%	5.3%
NE	357	46.2%	52.4%	1.4%
PA	1531	77.5%	20.3%	2.2%
RI	265	80.4%	18.9%	0.8%
VA	288	56.9%	41.7%	1.4%
VT	200	35.5%	37.0%	27.5%
WA	196	34.7%	63.8%	1.5%
Total	4871	53.6 %	37.9 %	8.5%

Table 7: Diagnostic Level of Mental Retardation

		No MR					Unspecified
<u>State</u>	Valid N	<u>Label</u>	<u>Mild</u>	Moderate	<u>Severe</u>	Profound	or Unknown
AZ	514	1.4%	39.1%	30.4%	16.1%	12.1%	1.0%
CT	332	0.6%	31.9%	31.0%	21.4%	14.8%	0.3%
KY	176	1.1%	25.6%	30.7%	18.8%	18.2%	5.7%
MA	611	4.7%	37.6%	28.8%	15.7%	6.9%	6.2%
MN	317	0.3%	34.4%	14.2%	16.4%	23.3%	11.4%
NC	134	6.7%	35.1%	25.4%	21.6%	9.0%	2.2%
NE	354	1.7%	46.6%	27.4%	15.0%	7.3%	2.0%
PA	1497	0.4%	35.8%	32.5%	17.9%	10.5%	2.7%
RI	266	2.6%	35.7%	28.2%	16.2%	12.4%	4.9%
VA	294	•••	10.2%	23.5%	25.5%	39.8%	1.0%
VT	196	•••	70.9%	20.9%	7.7%	0.5%	
WA	199	4.0%	31.7%	29.6%	15.1%	15.1%	4.5%
Total	4890	1.6%	36.1 %	28.6 %	17.3%	13.0%	3.4%

Table 8: Primary Means of Expression

			<u>Speaks</u>				
			<u>Other</u>			<u>Uses</u>	
		Speaks	Primary	<u>Uses</u>	<u>Uses Sign</u>	Communication	<u>1</u>
State*	Valid N	English	<u>Language</u>	<u>Gestures</u>	<u>Language</u>	<u>Device</u>	<u>Other</u>
AZ	530	70.6%	1.5%	15.7%	2.5%	1.3%	8.5%
CT	339	77.3%	0.6%	10.6%	0.9%	1.8%	8.8%
KY	178	74.2%	•••	13.5%	0.6%	1.1%	10.7%
MN	319	66.5%	•••	11.9%	1.6%	3.4%	16.6%
NC	133	79.1%	0.7%	12.7%	0.7%	1.5%	5.2%
NE	357	77.9%	•••	8.4%	4.5%	2.8%	6.4%
PA	1528	86.8%	0.1%	7.9%	0.7%	0.9%	3.7%
RI	265	83.4%	0.8%	10.9%	0.4%	1.1%	3.4%
VA	298	57.0%	0.3%	29.2%	1.7%	1.7%	10.1%
VT	197	92.4%	•••	1.0%	0.5%	3.0%	3.0%
WA	182	81.3%	•••	10.4%	0.5%	0.5%	7.1%
Total	4327	78.8 %	0.4%	11.2 %	1.3%	1.5%	6.7 %

^{*}No data was available for MA

Table 9: Level of Mobility

Tuble of Level of Mid	, 		
		Walks with or	
State*	<u>Valid N</u>	without aids	Non-ambulatory
AZ	531	85.9 %	14.1%
CT	342	88.6%	11.4%
KY	177	85.9 %	14.1%
MN	321	83.2%	16.8%
NC	134	89.6%	10.4%
NE	359	93.3%	6.7%
PA	1552	89.8%	10.2%
RI	268	91.0%	9.0%
VA	297	83.2%	16.8%
VT	199	93.0%	7.0%
WA	206	85.4%	14.6%
Total	4386	88.4 %	11.6 %

^{*}No data was available for MA

Table 10: Visual Impairments

	•		Vision problems	Limited or no
<u>State</u>	Valid N	Sees well	limit activities	vision/legally blind
AZ	523	82.6%	12.0%	5.4%
CT	335	85.1%	7.8%	7.2%
KY	175	85.1%	9.7%	5.1%
MA	594	88.7%	6.7%	4.5%
MN	314	72.9%	14.6%	12.4%
NC	134	91.0%	6.0%	3.0%
NE	357	91.3%	5.3%	3.4%
PA	1542	90.5%	5.7%	3.8%
RI	268	89.2%	4.9%	6.0%
VA	293	82.6%	10.2%	7.2%
VT	197	94.4%	3.6%	2.0%
WA	204	84.8%	6.9%	8.3%
Total	4936	87.2 %	7.5%	5.2 %

Table 11: Frequency of Seizures

I apic II	. i icqueii	cy of Seizures				
		Less than			More than	<u>Not</u>
State*	Valid N	once/month	Once/month	Once/week	once/week	<u>applicable</u>
AZ	480	6.9%	3.5%	1.7%	3.1%	84.8%
CT	323	8.7%	3.1%	1.5%	2.5%	84.2%
KY	175	8.6%	1.7%	2.3%	3.4%	84.0%
MA	465	7.3%	1.5%	1.3%	4.9%	75.4%
MN	287	10.8%	5.9%	5.2%	2.4%	75.6%
NC	133	5.3%	2.3%	0.8%	2.3%	89.5%
NE	353	9.3%	2.5%	1.1%	3.4%	83.6%
PA	1514	9.4%	2.7%	1.2%	2.0%	84.6%
RI	265	6.8%	1.9%	1.1%	2.6%	87.5%
VA	297	11.8%	6.1%	2.0%	2.7%	77.4%
WA	181	8.8%	2.2%	2.8%	3.3%	82.9%
Total	4473	8.8%	3.0%	1.7%	2.8 %	82.7 %

^{*}No data was available for VT

Table 12: Frequency of Medical Care Required

						<u>Requires</u>
		Less than				<u>24-hours</u>
State*	Valid N	once/month	Once/month	Once/week	Once/day	<u>access</u>
AZ	497	79.7%	14.9%	1.8%	•••	3.6%
CT	332	72.0%	16.9%	5.1%	2.4%	3.6%
KY	176	59.1 %	13.6%	0.6%	2.3%	24.4%
MA	551	75.3%	13.1%	4.0%	3.4%	4.2%
MN	320	26.9%	55.3%	9.7%	5.3%	2.8%
NC	133	67.7%	21.8%	4.5%	3.8%	2.3%
NE	350	84.6%	12.9%	0.9%	0.3%	1.4%
PA	1523	83.1%	12.0%	1.2%	1.3%	2.4%
RI	265	60.8%	18.5%	13.2%	2.3%	5.3%
VA	295	59.0%	16.3%	13.9%	1.4%	9.5%
WA	187	73.8%	11.8%	3.7%	2.7%	8.0%
Total	4629	72.7 %	16.8 %	4.2 %	1.9%	4.4%

^{*}No data available for VT

Table 13: Who Provided Behavior Information

		Advocate,				
		<u>parent,</u>	Staff at		<u>Case</u>	
State*	Valid N	<u>guardian</u>	<u>home</u>	Day staff	<u>manager</u>	<u>Other</u>
AZ	521	2.9%	1.2%	0.6%	92.7%	2.7%
CT	330	12.4%	29.1%	1.8%	54.8%	1.8%
KY	172	23.8%	5.8%	12.8%	47.1%	10.5%
NC	134	6.7%	7.5%	5.2%	76.1%	4.5%
NE	348	0.6%	2.0%	1.4%	94.8%	1.1%
PA	1276	12.1%	6.0%	0.8%	78.6%	2.4%
RI	263	3.4%	13.3%	8.4%	57.4%	17.5%
VA	263	3.4%	5.7%	•••	42.2%	48.7%
WA	156	5.8%	14.7%	0.6%	70.5%	8.3%
Total	4348	14.2%	10.1%	2.2%	66.9%	6.7 %

^{*}Data not available for MA or MN

Table 14: Presence of Self-Injurious Behavior

C	37 1: 1 NT	N.T.	X 7
<u>State</u>	<u>Valid N</u>	<u>No</u>	<u>Yes</u>
AZ	521	78.1%	21.9%
CT	333	80.8%	19.2%
KY	171	82.5%	17.5%
MA	560	76.6%	23.4%
MN	319	61.4%	38.6%
NC	134	83.6%	16.4%
NE	358	76.0%	24.0%
PA	1494	86.5%	13.5%
RI	267	80.1%	19.9%
VA	260	69.6%	30.4%
VT	198	91.4%	8.6%
WA	183	79.8%	20.2%
Total	4798	80.1 %	19.9%

Table 15: Presence of Property Destruction Behavior

<u>State</u>	<u>Valid N</u>	<u>No</u>	Yes
AZ	522	81.6%	18.4%
CT	334	81.1%	18.9%
KY	172	81.4%	18.6%
MA	561	81.8%	18.2%
MN	319	50.2%	49.8%
NC	134	76.1%	23.9%
NE	356	75.0%	25.0%
PA	1495	87.2%	12.8%
RI	267	76.8%	23.2%
VA	259	69.9%	30.1%
VT	199	88.9%	11.1%
WA	182	82.4%	17.6%
Total	4800	80.1 %	19.9%

Table 16: Presence of Disruptive Behavior

Tubic 10. I reserve o	n Distupuve Denavior		
<u>State</u>	<u>Valid N</u>	<u>No</u>	<u>Yes</u>
AZ	522	67.0%	33.0%
CT	332	64.5%	35.5%
KY	172	64.0%	36.0%
MA	560	70.7%	29.3%
MN	319	47.3%	52.7%
NC	134	69.4%	30.6%
NE	356	53.4%	46.6%
PA	1478	70.2%	29.8%
RI	267	56.2%	43.8%
VA	260	45.8%	54.2%
VT	199	78.4%	21.6%
WA	184	68.5%	31.5%
Total	4783	64.6 %	35.4 %

Table 17: Presence of Uncooperative Behavior

<u>State</u>	<u>Valid N</u>	<u>No</u>	<u>Yes</u>
AZ	521	67.8%	32.2%
CT	331	68.3%	31.7%
KY	172	69.2%	30.8%
MA	559	69.8%	30.2%
MN	319	50.8%	49.2%
NC	134	64.2%	35.8%
NE	356	43.8%	56.2%
PA	1471	74.5%	25.5%
RI	267	68.5%	31.5%
VA	258	48.1%	51.9%
VT	199	78.9%	21.1%
WA	183	71.0%	29.0%
Total	4770	67.6 %	33.3%

Other Demographic Variables

Additional demographic variables were collected as background information but not used in the outcome adjustment analysis. These items are presented in **Tables 18** through **26**, by state and for the total sample. Note that the percentages listed are based on the total number of valid responses to that question ("Valid N"), therefore the N's vary by table.

Table 18: Race

		<u>American</u>				
		<u>Indian/</u>	<u>Asian/</u>			
		Eskimo/	Pacific			Other/
<u>State</u>	Valid N	<u>Aleut</u>	<u>Islander</u>	<u>Black</u>	<u>White</u>	<u>Unknown</u>
AZ	503	8.7%	1.0%	4.8%	79.1%	6.4%
CT	326	0.9%	1.5%	13.8%	81.3%	2.5%
KY	177	•••	•••	10.7%	89.3%	•••
MA	588	•••	0.9%	6.3%	92.9%	•••
MN	141	1.4%	0.7%	1.4%	95.7%	0.7%
NC	120	1.7%	0.8%	30.0%	66.7%	0.8%
NE	349	2.6%	0.9%	5.2%	90.8%	0.6%
PA	1514	1.2%	0.4%	3.8%	94.4%	0.3%
RI	256	2.3%	0.8%	5.5%	89.5%	2.0%
VA	290	0.7%	1.0%	15.5%	82.1%	0.7%
VT	197	1.5%	•••	0.5%	98.0%	
WA	201	2.0%	2.0%	•••	94.5%	1.5%
Total	4662	2.0%	0.8%	6.4%	89.6 %	1.2%

Table 19: Ethnicity

State*	<u>Valid N</u>	<u>Hispanic</u>	Non-Hispanic
AZ	472	26.3%	73.7%
CT	272	7.7%	92.3%
KY	143	•••	100.0%
MN	141	0.7%	99.3%
NC	128	1.6%	98.4%
NE	316	1.6%	98.4%
PA	1430	1.3%	98.8%
RI	196	4.6%	95.4%
VA	285	2.5%	97.5%
VT	181	0.6%	99.4%
WA	183	1.1%	98.9%
Total	3747	5.1%	94.9%

^{*}No data was available for MA

Table 20: Type of Residence

	JI	<u>Specialized</u>	Group	<u>Apartment</u>	<u>Independent</u>	Parent/	Foster care/	Nursing	
<u>State</u>	Valid N	<u>facility</u>	<u>home</u>	<u>program</u>	home/apt	Relative's home	Host home	<u>facility</u>	<u>Other</u>
AZ	531	8.1%	31.5%	3.6%	15.6%	31.1%	4.1%	0.6%	5.5%
CT	343	8.5%	36.4%	5.2%	15.2%	24.2%	6.7%	0.9%	2.9%
KY	178	24.2%	6.7%	6.2%	5.6%	31.5%	11.8%	1.1%	12.9%
MA	615	3.6%	37.6%*	•••	2.3%	52.4%	•••	4.2%	• • •
MN	306	•••	64.1%	•••	8.8%	5.6%	19.3%	2.3%	• • •
NC	134	12.7%	28.4%	3.7%	16.4%	32.1%	0.7%	3.0%	3.0%
NE	358	1.7%	32.4%	10.6%	27.1%	16.8%	5.3%	2.0%	4.2%
PA	1589	6.0%	21.3%	3.8%	13.5%	40.2%	6.7%	1.8%	6.7%
RI	268	1.9%	38.1%	6.7%	19.8%	29.5%	2.6%	•••	1.5%
VA	298	45.3%	20.1%	2.7%	8.1%	21.1%	1.7%	•••	1.0%
VT	200	1.0%	4.0%	2.0%	31.0%	24.5%	36.5%	•••	1.0%
WA	201	11.9%	8.0%	2.0%	38.3%	27.4%	4.0%	1.5%	7.0%
Total	5021	8.4%	28.1 %	3.7 %	14.7 %	32.5 %	6.9%	1.7%	4.2 %

^{*}This figure includes both group homes and apartment programs (MA only)

Table 21: Who Owns/Leases Consumer Home

		<u>Family,</u>			Person	Person		
	<u>Valid</u>	<u>guardian,</u>	Private	State/county	<u>rents</u>	<u>owns</u>	Don't	
State*	<u>N</u>	<u>friend</u>	<u>agency</u>	<u>agency</u>	<u>home</u>	<u>home</u>	<u>know</u>	<u>Other</u>
AZ	531	34.3%	31.5%	11.9%	10.9%	4.9%	1.3%	5.3%
CT	343	24.2%	34.1%	14.6%	16.9%	1.7%	0.9%	7.6%
KY	175	36.6%	28.0%	18.9%	5.7%	1.7%	1.1%	8.0%
MN	320	10.3%	70.6%	6.6%	6.9%	0.3%	1.3%	4.1%
NC	134	31.3%	32.1%	16.4%	15.7%	1.5%	•••	3.0%
NE	355	20.0%	34.9%	8.7%	25.4%	1.7%	2.8%	6.5%
PA	1578	43.2%	27.8%	8.2%	9.8%	1.8%	1.7%	7.5%
RI	266	27.8%	19.5%	21.1%	21.8%	1.5%	4.1%	4.1%
VA	298	23.8%	16.4%	51.0%	7.7%	0.3%		0.7%
VT	195	26.7%	4.1%	3.6%	21.0%	5.1%	•••	39.5%
WA	203	28.6%	15.3%	12.8%	27.6%	4.4%	4.4%	6.9%
Total	4398	32.1 %	29.6 %	13.4%	13.4 %	2.2%	1.7%	7.5 %

^{*}No data available for Massachusetts.

Table 22: Live-in Paid Caregivers

State*	Valid		<u> </u>		Nu	mber of	live-in	paid car	egivers				
	<u>N</u>	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	<u>9</u>	<u>10</u>	<u>12</u>	<u>50</u>
AZ	200	72.0%	17.5%	9.5%	1.0%			•••	•••	•••			
CT	140	78.6%	17.9%	2.1%								0.7%	0.7%
KY	165	77.0%	13.9%	6.7%	1.8%		0.6%						
MA	542	89.9%	8.1%	1.7%	•••	•••		0.2%	•••	0.2%			•••
MN	99	76.8%	21.2%	2.0%	•••	•••		•••	•••	•••			•••
NC	128	85.2%	7.0%	3.9%	1.6%	0.8%		•••	0.8%	0.8%		•••	
NE	241	77.2%	17.0%	4.6%	0.4%	•••		0.8%	•••	•••			•••
PA	52	71.2%	19.2%	5.8 %	1.9%	1.9%		•••	•••	•••	•••	•••	
RI	261	97.7%	1.5%	•••	•••	0.4%		•••	•••	0.4%			•••
VA	294	97.3%	.7%	1.4%	0.7%			•••	•••	•••			•••
WA	94	59.6%	24.5%	13.8%	1.1%	•••	•••	•••	•••	•••	1.1%	•••	•••
Total	2216	84.5 %	10.7 %	3.6 %	.5%	.1%	.0%	.1%	.0%	.1%	.0%	.0%	.0%

^{*}No data available for Vermont.

Table 23: Intensity of Staff Support

Tubic 20. Inc	<u> </u>	Бирроп		Less frequent	
		24-hour on	Daily on-site	than daily	None of the
<u>State</u>	Valid N	site support	support	support	above
AZ	519	48.4%	16.8%	11.8%	23.1%
CT	343	58.9 %	13.7%	10.8%	16.6%
KY	177	57.6%	7.3%	11.3%	23.7%
MA	561	45.1%	9.8%	6.1%	39.0%
MN	322	79.5%	7.5%	11.5%	1.6%
NC	133	44.4%	22.6%	14.3%	18.8%
NE	358	54.5%	19.0%	13.1%	13.4%
PA	1567	40.5%	10.1%	11.1%	38.3%
RI	266	54.1%	12.8%	9.8%	23.3%
VA	297	68.7%	4.7%	8.4%	18.2%
VT	200	64.5%	8.5%	7.5%	19.5%
WA	197	59.4%	18.3%	10.7%	11.7%
Total	4940	51.5 %	11.8 %	10.5%	26.2 %

Table 24: Location Of Residence

		<u>Physically</u>	Within walking	Centrally located
<u>State</u>	<u>Valid N</u>	<u>remote</u>	distance to town	within town
AZ	526	29.1%	21.1%	49.8%
CT	340	34.4%	31.8%	33.8%
KY	178	43.8%	15.2%	41.0%
MA	561	29.1%	35.7%	35.3%
MN	319	14.4%	28.2%	57.4%
NC	132	40.2%	29.5%	30.3%
NE	357	6.4%	24.6%	68.9%
PA	1564	35.7%	32.7%	31.6%
RI	263	24.3%	28.5%	47.1%
VA	298	40.3%	37.2%	22.5%
VT	200	37.0%	25.5%	37.5%
WA	199	28.1%	28.6%	43.2%
Total	4907	30.0 %	30.0%	40.0%

Table 25: Number of People with Disabilities Living with Consumer

	•		Std.		
State*	<u>N</u>	<u>Mean</u>	<u>Deviation</u>	<u>Minimum</u>	Maximum
AZ	504	3.31	3.96	0	22
CT	332	3.83	5.47	0	80
MA	560	2.75	2.44	0	9
MN	312	6.50	11.71	0	121
NC	127	4.13	7.37	0	71
NE	346	2.66	2.01	0	18
PA	1499	3.31	9.21	0	184
RI	263	3.05	2.71	0	18
VA	290	7.71	6.29	0	19
VT	190	1.38	1.21	1	12
WA	192	4.85	7.73	0	80
Total	4792	4.72	14.12	0	188

^{*}No data available for KY

Table 26: Number of People without Disabilities Living with Consumer

			Std.		
State*	<u>N</u>	<u>Mean</u>	Deviation	Minimum	Maximum
AZ	336	1.40	1.42	0	6
CT	181	2.22	6.46	0	75
MA	551	1.49	1.97	0	9
MN	205	3.01	18.56	0	176
NC	127	1.54	5.51	0	60
NE	248	0.87	2.10	0	24
PA	1249	2.94	30.50	0	790
RI	262	0.66	1.21	0	9
VA	294	0.52	1.13	0	8
VT	188	1.90	1.56	0	7
WA	102	5.15	27.82	0	200
Total	3913	2.02	18.59	0	790

^{*}No data available for KY

Services and Supports Currently Received

The Background Section of the Consumer Survey requests information about the types of services and supports received by respondents. These results are displayed in **Tables 27** through **37**, for each state and for the aggregate sample. The percentages listed are based on the total number of valid responses to each item (Valid N), therefore the N's vary by table. For this set of items, we include "Don't Know" as a valid response.

Table 27: Receives Service Coordination/Case Management

<u>State</u>	<u>Valid N</u>	<u>Yes</u>	<u>No</u>	Don't Know
AZ	529	99.8%	0.2%	•••
CT	341	99.4%	0.6%	•••
KY	176	96.0%	4.0%	•••
MA	562	89.3%	7.8%	2.8%
MN	318	98.4%	1.6%	•••
NC	134	91.8%	7.5%	0.7%
NE	359	100.0%	•••	•••
PA	1552	99.5%	.4%	0.1%
RI	267	98.9%	0.4%	0.7%
VA	296	98.3%	1.7%	
VT	198	97.0%	3.0%	
WA	201	98.5%	1.5%	
Total	4933	97.7%	1.8%	0.4%

Table 28: Receives Supported Employment Services

	corres a mpporte m			
<u>State</u>	<u>Valid N</u>	Yes	<u>No</u>	Don't know
AZ	476	23.1%	75.4%	1.5%
CT	307	29.0%	69.1%	2.0%
KY	173	17.9%	82.1%	•••
MA	560	25.2%	73.8%	1.1%
MN	143	32.2%	59.4 %	8.4%
NC	134	23.1%	74.6%	2.2%
NE	332	13.6%	86.4%	•••
PA	1437	16.0%	82.5%	1.5%
RI	260	34.2%	63.5%	2.3%
VA	291	9.6%	90.4%	•••
VT	191	32.5%	67.5%	•••
WA	176	36.9%	60.8%	2.3%
Total	4480	21.6 %	77.0 %	1.5%

Table 29: Receives Group Employment Services

<u>State</u>	<u>Valid N</u>	Yes	<u>No</u>	Don't know
AZ	473	15.2%	82.5%	2.3%
CT	305	36.1%	62.6%	1.3%
KY	172	1.7%	97.1%	1.2%
MA	558	10.6%	87.3%	2.2%
MN	142	29.6%	61.3%	9.2%
NC	134	5.2%	91.8%	3.0%
NE	332	16.0%	84.0%	•••
PA	1427	5.6%	92.6%	1.8%
RI	256	18.4%	80.1%	1.6%
VA	291	10.3%	88.0%	1.7%
VT	192	3.1%	96.9%	•••
WA	168	17.3%	79.2%	3.6%
Total	4450	12.1 %	86.0 %	1.9%

Table 30: Receives Facility Based Vocational Services

	1. 1			
<u>State</u>	<u>Valid N</u>	<u>Yes</u>	<u>No</u>	<u>Don't know</u>
AZ	473	27.9%	70.2%	1.9%
CT	300	27.0%	72.3%	0.7%
KY	175	56.0%	44.0%	•••
MA	560	44.1%	54.6%	1.3%
MN	142	54.9%	40.1%	4.9%
NC	134	44.0%	54.5%	1.5%
NE	350	69.7%	30.0%	0.3%
PA	1467	39.9%	58.8%	1.3%
RI	259	51.4%	47.1%	1.5%
VA	291	21.6%	77.3%	1.0%
VT	190	1.6%	98.4%	•••
WA	173	24.3%	72.8%	2.9%
Total	4514	39.1 %	59.6 %	1.3%

Table 31: Receives Non-Vocational Day Services

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<u>State</u>	<u>Valid N</u>	<u>Yes</u>	<u>No</u>	Don't know
AZ	485	45.6%	53.4%	1.0%
CT	300	33.3%	65.3%	1.3%
KY	175	49.1%	50.3%	0.6%
MA	558	35.3%	63.1%	1.6%
MN	142	17.6%	72.5%	9.9%
NC	134	22.4%	75.4%	2.2%
NE	334	25.1%	74.6%	0.3%
PA	1454	30.5%	68.0%	1.6%
RI	259	28.2%	69.1%	2.7%
VA	297	57.9%	41.4%	0.7%
VT	188	20.7%	79.3%	•••
WA	164	16.5%	81.7%	1.8%
Total	4490	33.3%	65.1 %	1.6%

Table 32: Receives Community Participation Supports

<u>State</u>	Valid N	<u>Yes</u>	<u>No</u>	Don't know
AZ	484	54.5%	41.9%	3.5%
CT	321	70.4%	27.1%	2.5%
KY	176	64.2%	33.0%	2.8%
MA	557	50.3%	47.0%	2.7%
MN	142	78.9 %	14.1%	7.0%
NC	134	64.9%	33.6%	1.5%
NE	340	67.9%	30.6%	1.5%
PA	1472	54.4%	41.8%	3.7%
RI	261	70.9%	24.1%	5.0%
VA	297	75.4%	23.2%	1.3%
VT	188	67.0%	33.0%	•••
WA	177	47.5%	45.8%	6.8%
Total	4549	60.1 %	36.7 %	3.2 %

Table 33: Receives Assistive Technology Services

	** 1. 1 * *	eemiology service	• •	-
<u>State</u>	<u>Valid N</u>	<u>Yes</u>	<u>No</u>	<u>Don't know</u>
AZ	472	14.4%	82.4%	3.2%
CT	308	16.9%	81.5%	1.6%
KY	173	16.2%	80.9%	2.9%
MA	555	18.6%	79.5%	2.0%
MN	320	9.7%	88.4%	1.9%
NC	134	9.0%	86.6%	4.5%
NE	332	13.0%	86.4%	0.6%
PA	1429	8.6%	88.0%	3.4%
RI	257	11.7%	84.8%	3.5%
VA	290	33.4%	66.6%	
VT	188	9.6%	90.4%	•••
WA	170	14.7%	77.6%	7.6%
Total	4628	13.6 %	83.8%	2.6%

Table 34: Receives Clinical Services

		11000		
<u>State</u>	<u>Valid N</u>	<u>Yes</u>	<u>No</u>	Don't know
AZ	489	38.7%	59.1%	2.2%
CT	321	64.8%	34.3%	0.9%
KY	175	51.4%	47.4%	1.1%
MA	559	49.0%	49.0%	2.0%
MN	320	25.6%	73.1%	1.3%
NC	134	59.7 %	37.3%	3.0%
NE	343	47.8%	52.2%	•••
PA	1467	37.2%	60.6%	2.1%
RI	262	58.4%	37.8%	3.8%
VA	297	63.0%	36.7%	0.3%
VT	189	42.9%	57.1%	•••
WA	172	44.8%	46.5%	8.7%
Total	4728	45.1 %	53.0 %	1.9%

Table 35: Receives Transportation Services

<u>State</u>	Valid N	Yes	<u>No</u>	Don't know
AZ	498	66.5%	32.3%	1.2%
CT	338	92.3%	7.4%	0.3%
KY	176	85.8%	14.2%	•••
MA	560	79.5%	19.8%	0.7%
MN	320	90.6%	9.1%	0.3%
NC	134	83.6%	15.7%	0.7%
NE	349	89.4%	10.6%	•••
PA	1486	62.2%	35.9%	2.0%
RI	265	89.4%	9.4%	1.1%
VA	297	85.2%	14.8%	•••
VT	192	60.9%	39.1%	•••
WA	183	71.0%	23.0%	6.0%
Total	4798	75.3 %	23.5 %	1.2%

Table 36: Receives Respite Services

<u>State</u>	<u>Valid N</u>	<u>Yes</u>	<u>No</u>	<u>Don't know</u>			
AZ	479	29.4%	68.9%	1.7%			
CT	317	21.1%	77.0%	1.9%			
KY	172	23.3%	75.6%	1.2%			
MA	560	26.4%	71.1%	2.5%			
MN	320	7.5%	90.3%	2.2%			
NC	133	16.5%	78.9%	4.5%			
NE	336	9.8%	89.9%	0.3%			
PA	1450	19.5%	78.0 %	2.5%			
RI	251	6.4%	88.4%	5.2%			
VA	285	4.6%	95.1%	0.4%			
VT	194	47.9%	52.1%	•••			
WA	162	9.9%	86.4%	3.7%			
Total	4659	19.2 %	78.6 %	2.1%			

Table 37: Receives Home and Community-Based Waiver Services

	01.00 1101110 4114	Community Dasc		
<u>State</u>	<u>Valid N</u>	<u>Yes</u>	<u>No</u>	Don't know
AZ	520	22.7%	63.3%	14.0%
CT	334	62.9%	29.9%	7.2%
KY	176	23.9%	64.2%	11.9%
MN	318	61.9%	38.1%	•••
NC	134	34.3%	53.0%	12.7%
NE	358	73.2%	26.3%	0.6%
PA	1543	29.6%	69.0%	1.5%
RI	267	52.4%	36.7%	10.9%
VA	296	41.9%	57.8%	0.3%
VT	196	82.7%	17.3%	•••
WA	193	39.9%	42.5%	17.6%
Total	4335	42.3%	52.5 %	5.2 %

VII. Results: Core Indicator Outcomes and Comparisons across States

The data from the Consumer Survey were analyzed to assess 29 core indicator outcomes for the sample as a whole and separately by state. The results for the states are indicated by the two letter abbreviations and for the sample as a whole by the term "Total." The results are presented for each of the core indicators. The tables indicate the valid N, the proportion of consumers who indicate the presence of the outcome, as well as an indication of whether there are significant differences among states.

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

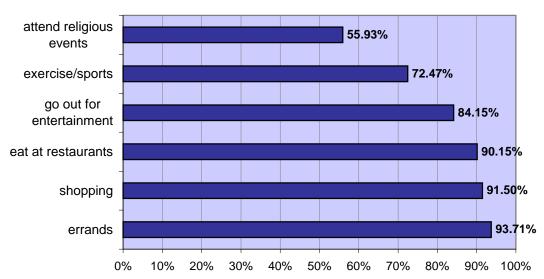
- Results are presented for each core indicator measured by the consumer survey.
- Tables that display "adjusted" results are so noted. For these indicators, the sample sizes
 are slightly smaller because cases that are missing data for the adjustment variables drop
 out of the analysis.
- Question-by-question, "raw" results are included in Appendix C of this report. States may
 find the raw results useful for probing further into the breakdown of responses to specific
 questions.
- For all indicators, we tested for significant differences among states at the .05 level. This means that where noted, we can say with 95% confidence that the results state-to-state are significantly different. It does not mean that every state is different from every other state. It does indicate that there is a statistically significant difference between the highest and lowest scores, and that at least two states are different from one another.
- Broadly, the "total" aggregate responses to a question constitute a benchmark against which states can compare their results. For example, when a particular state's mean score is <u>appreciably</u> higher than the proportion for the aggregate sample, the quality or characteristic is better reflected in the state's system than in others. On the other hand, in states where the score is <u>appreciably</u> lower 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 multi-state "norms" that describe present levels of performance or satisfaction across the twelve states. Where no significant differences were found state-to-state, it means that all states are performing about the same. Where significant differences were found and scores are especially high (considerably above the aggregate level) in one or two states, the levels achieved there might define a level of performance that may serve as a guidepost for other states.

In this section we highlight findings from the baseline CIP data for the total sample.

Community Inclusion

For the different types of community activities asked about in the survey, participation was high, ranging from 55.9% to 93.7% for various activities.

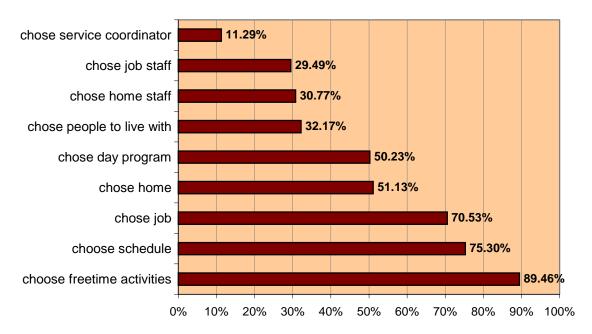
Community Inclusion - Adjusted Results for Total Sample



Choice and Decision-making

- Results for choice and decision-making questions were mixed. For day-to-day decisions (e.g. choosing schedule and free time activities), the majority of respondents have input or make these choices independently.
- For most "major" life decisions (e.g. where to live, whom to live with, who provides your support, which day program to attend), 49% or more of respondents reportedly had <u>no</u> input in making these choices. The exception was choosing jobs, where 70% of respondents had input or made this decision independently.

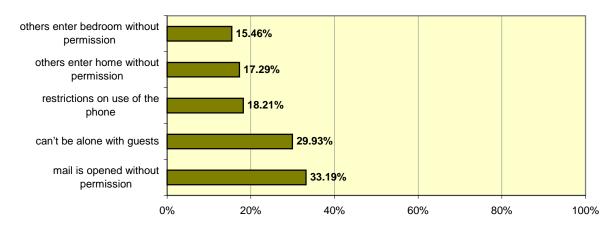




Respect and Rights

- ⇒ 88% of all respondents report that they have enough privacy.
- Only 25.5% of all respondents have attended a self-advocacy group meeting or event.
- ⇒ 29% of all respondents report that they do not have an advocate or guardian.

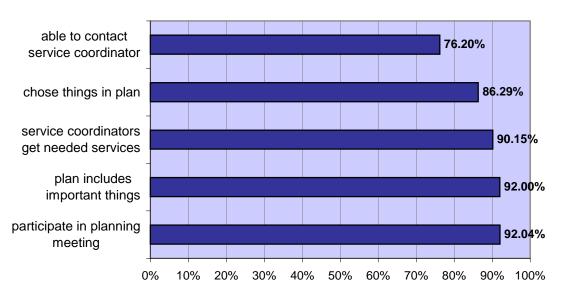
Respect and Rights - Adjusted Results for Total Sample



Service Coordination

The majority of respondents report that they have access to their service coordinators and participate in planning their services and supports.





Access

⇒ 81.3% of respondents reported that they almost always have a way to get where they want to go.

Safety

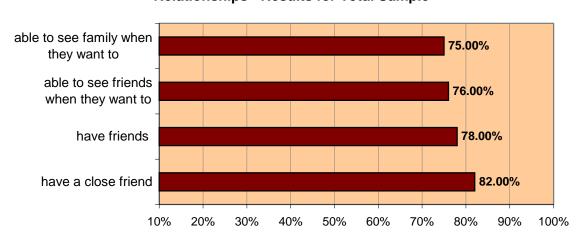
⇒ 93% of respondents report feeling safe in their neighborhoods. 96% report feeling safe at home.

Satisfaction

- ⇒ Satisfaction with home (93%) and work (96%) is high across all respondents.
- A little over one-third of respondents (35%) report that they would like to work more hours.

Relationships

The majority of respondents report having friends (other than family and staff), best friends, and being able to see their friends and family when they want to. However, a little more than half the respondents report "sometimes" or "always" feeling lonely.



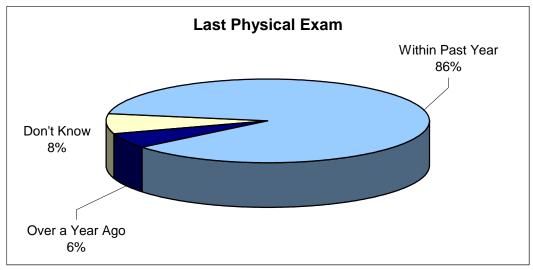
Relationships - Results for Total Sample

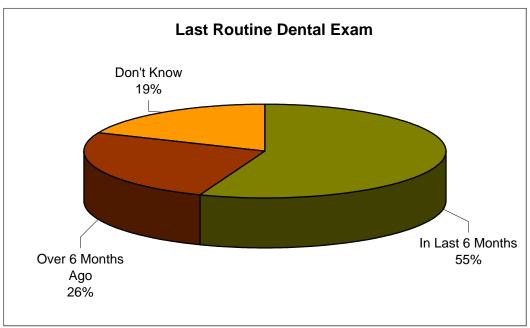
Acceptability

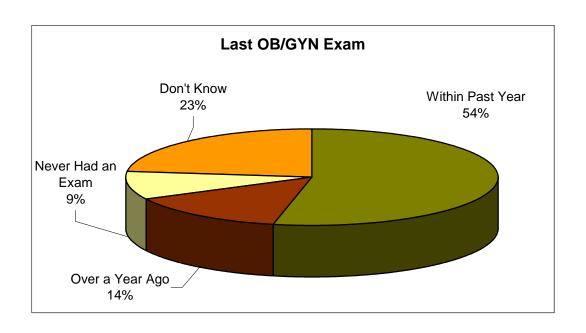
- Across the board, approximately 92% of respondents report that support staff (at home, day program, and jobs) treat them with respect.
- ⇒ Place of residence is fairly stable across the sample only 13% of respondents changed residences in the past year.

Health

- Across the board, women's access to yearly OB/GYN exams is low (only 53.5% had an exam in the past year and 9.4% have never had one).
- The percentage of respondents who take psychotropic medications is 40.2% across all states.







The following tables display outcomes by indicator, for each state and for the total sample. Outcomes are grouped by subdomain.

Community Inclusion

Concern: People use integrated community services and participate in everyday community activities.

Core Indicator #6a: Proportion of people in the sample who go shopping.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	145	95.23%
PA	1273	93.55%
NC	124	91.87%
RI	234	91.66%
NE	325	91.59%
WA	137	91.22%
CT	297	90.78%
MA	437	90.67%
AZ	455	90.33%
KY	158	89.97%
MN	263	89.54%
VA	259	86.18%
Total	4107	91.50%

^aAdjusted scores are shown.

^bScores differ significantly state-to-state.

Core Indicator #6b: Proportion of people who go out on errands.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	146	95.32%
PA	1277	94.40%
NE	326	94.02%
MA	436	93.96%
CT	297	93.79%
RI	239	93.75%
NC	128	93.70%
WA	138	93.67%
KY	159	93.13%
AZ	458	92.98%
MN	266	92.72%
VA	262	91.11%
Total	4132	93.71%

^aAdjusted scores are shown.

^bScores differ significantly state-to-state.

Core Indicator #6c: Proportion of people in the sample who exercise/play sports.		
<u>State</u>	<u>Valid N</u>	Mean Proportion a,b,c
NC	125	74.63%
PA	1278	73.83%
WA	136	72.64%
CT	295	72.58%
NE	325	72.44%
RI	238	72.44%
KY	157	72.10%
AZ	457	72.02%
MA	438	70.93%
VA	260	70.52%
MN	263	70.21%
Total	3972	72.47%

Core Indicator #6d:	Core Indicator #6d: Proportion of people who go out for entertainment.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}	
MN	266	86.32%	
KY	159	86.10%	
WA	139	85.70%	
CT	297	85.44%	
NC	126	85.13%	
AZ	455	85.12%	
VA	261	84.31%	
VT	145	83.88%	
PA	1274	83.39%	
RI	237	83.14%	
NE	323	83.14%	
MA	438	82.97%	
Total	4120	84.15%	

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state. ^cData not available for VT.

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #6e: Proportion of people in the sample who go to restaurants.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	147	93.14%
NC	128	90.96%
CT	296	90.89%
NE	330	90.73%
PA	1278	90.56%
WA	138	90.30%
MN	266	90.20%
KY	158	89.97%
RI	238	89.92%
AZ	457	89.76%
MA	436	89.52%
VA	262	86.42%
Total	4134	90.15%

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #6f: Proportion of people who attend religious events.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	146	57.97%
WA	139	57.59%
PA	1280	57.50%
RI	230	56.72%
CT	296	56.23%
KY	154	55.71%
NC	125	55.28%
AZ	433	55.24%
NE	317	55.18%
MA	434	54.52%
MN	263	53.66%
VA	251	52.10%
Total	4068	55.93 %

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Choice and Decision-Making

Concern: People make life choices and participate actively in planning their services and supports.

Core Indicator #7a: Proportion of people who make choices about housing.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	138	66.12%
PA	788	58.31%
NE	265	56.30%
RI	164	54.59%
NC	92	53.38%
WA	109	49.74%
CT	223	49.34%
AZ	329	49.08%
MA	270	48.45%
KY	115	40.82%
MN	241	39.56%
VA	206	32.04%
Total	2940	51.13%

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #7b: Proportion of people who make choices about roommates.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	72	44.46%
PA	612	37.46%
NE	192	35.40%
MA	236	34.27%
RI	125	32.72%
NC	67	32.23%
AZ	267	30.96%
CT	184	30.44%
WA	76	29.76%
MN	222	25.75%
KY	104	25.56%
VA	194	19.89%
Total	2351	32.17%

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #7c: Proportion of people who make choices about daily routine.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	94	84.75%
PA	1272	79.05%
NE	326	77.34%
RI	231	77.11%
MA	434	76.42%
NC	124	75.47%
WA	139	74.38%
CT	290	73.67%
AZ	460	73.13%
KY	159	70.92%
MN	257	67.11%
VA	262	64.41%
Total	4048	75.30 %

^aAdjusted scores are shown.

Core Indicator #7d: Proportion of people who make choices about social activities. Mean Proportion^{a,b} Valid N **State** VT 94.95% 142 PA 1268 91.80%RI 235 90.67% NC 122 90.63%NE 324 90.09% MA 434 89.83% WA 139 88.80% CT293 $\pmb{88.59\%}$ AZ456 87.37% KY 87.16%158 MN 262 $\pmb{84.33\%}$ VA 261 83.59% **Total** 4094 89.46%

bScores differ significantly state-to-state.

^aAdjusted scores are shown.

^bScores differ significantly state-to-state.

Core Indicator #7e: Proportion of people who make choices about day program.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	27	67.50%
PA	716	57.46%
RI	168	55.50%
NE	269	53.18%
NC	62	52.23%
WA	34	50.12%
KY	106	50.08%
CT	211	47.26%
MA	309	46.51%
AZ	276	45.25%
MN	178	38.87%
VA	184	37.98%
Total	2540	50.23%

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #7f: Proportion of people who make choices about place of work.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	67	76.79%
MA	142	75.06%
PA	550	73.58%
RI	128	72.33%
AZ	181	71.49%
WA	60	70.60%
NE	142	69.23%
NC	51	69.21%
VA	67	67.77%
CT	186	65.37%
KY	75	65.17%
MN	134	60.46%
Total	1783	70.53%

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #7g: Proportion of people who make choices about residential support staff.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	17	37.08%
MA	256	34.53%
PA	725	33.17%
NE	267	32.44%
RI	164	31.95%
WA	105	30.83%
NC	93	30.81%
CT	218	30.49%
AZ	316	29.66%
KY	99	28.53%
MN	247	25.65%
VA	201	22.97%
Total	2708	30.77%

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #7h: Proportion of people who make choices about work support staff.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	38	35.30%
AZ	179	32.08%
WA	64	31.87%
KY	84	30.92%
NC	56	29.97%
CT	231	29.56%
NE	241	29.55%
PA	562	29.00%
MA	139	28.66%
RI	159	28.60%
MN	213	28.40%
VA	83	26.40%
Total	2049	29.49%

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #7i: Proportion of people who make choices about service coordinator.		
<u>State</u>	<u>Valid N</u>	Mean Proportion a,b,c
RI	205	12.80%
NE	316	12.75%
PA	1199	12.73%
NC	108	11.81%
WA	134	11.27%
CT	281	10.67%
AZ	438	10.64%
KY	145	10.20%
MA	397	9.76%
VA	248	8.96%
MN	247	8.27%
Total	3718	11.29%

Core Indicator #8: Proportion of people reporting that their service plan includes things or is about things that are important to them.

<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
NC	76	99.00%
VT	101	99.00%
KY	49	98.00%
RI	159	96.00%
WA	71	93.00%
AZ	274	93.00%
CT	168	92.00%
NE	264	92.00%
PA	814	91.00%
MA	271	91.00%
MN	82	87.00%
VA	96	85.00%
Total	2425	92.00 %

^aScores differ significantly state-to-state.

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state. ^cData not available for VT.

Core Indicator #11a: Proportion of people reporting that they have access to their own spending money.

<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	146	85.77%
PA	1270	83.46%
RI	231	82.89%
NC	119	81.08%
NE	321	80.96%
WA	138	78.62%
MA	433	77.34%
CT	288	76.88%
AZ	454	76.43%
KY	159	75.42%
MN	262	73.30%
VA	259	68.73%
Total	4080	79.28%

Core Indicator #11b: Proportion of people reporting that they choose how to spend their money.

	then money.	
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	146	93.76%
PA	1276	89.81%
RI	236	88.54%
NE	320	87.07%
NC	125	$\pmb{86.95\%}$
MA	433	85.30%
WA	138	85.22%
CT	291	84.18%
AZ	456	83.08%
KY	157	82.44%
MN	260	79.26%
VA	258	75.70%
Total	4096	85.95%

^aAdjusted scores are shown.

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

bScores differ significantly state-to-state.

Relationships Concern: People gain and maintain friendships and relationships.

Core Indicator #12: Proportion of people who report having friends and caring relationships with people other than support staff and family members.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
VT	134	94.00%
RI	198	86.00%
WA	143	82.00%
VA	130	82.00%
MA	429	80.00%
NC	102	79.00%
KY	78	79.00%
PA	1270	77.00%
MN	190	77.00%
CT	224	75.00%

339

287

3524

AZ

NE

Total

Core Indicator #13: Pr	Core Indicator #13: Proportion of people who report having a close friend.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a	
KY	74	91.00%	
NC	97	88.00%	
NE	261	87.00%	
RI	175	83.00%	
CT	192	82.00%	
WA	133	82.00%	
AZ	302	82.00%	
PA	1174	82.00%	
MA	396	80.00%	
VA	117	79.00%	
MN	174	75.00%	
VT	158	72.00%	
Total	3253	82.00%	

^aScores differ significantly state-to-state.

72.00%

69.00%

78.00%

^aScores differ significantly state-to-state.

Core Indicator #14a: Proportion of people who are able to see their families when they want to. **Mean Proportion State** Valid N 74 81.00% KY VT 146 78.00% PA 1184 77.00% RI 181 77.00% NE 269 77.00% 76.00% MN180 VA 76.00% 119 WA 132 75.00%CT199 74.00% MA 386 73.00% NC 97 70.00% AZ311 69.00% 3278 **Total 75.00**%

Core Indicator #14b: Proportion of people who are able to see their friends when they want to.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
VA	93	86.00%
KY	52	81.00%
PA	854	81.00%
MN	160	81.00%
RI	139	79.00%
WA	95	75.00%
MA	386	73.00%
NE	237	73.00%
CT	171	73.00%
NC	80	71.00%
AZ	219	68.00%
VT	141	65.00%
Total	2627	76.00 %

^aScores differ significantly state-to-state.

Core Indicator #15: Proportion of people reporting that they sometimes or always feel lonely.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
MA	275	52.08%
VT	148	52.39%
PA	1024	53.55%
WA	98	53.89%
VA	106	54.46%
CT	180	54.66%
AZ	280	54.83%
KY	72	55.06%
NE	241	55.34%
RI	165	55.39%
NC	91	56.28%
MN	147	60.15%
Total	2827	54.32 %

Satisfaction

Concern: People are satisfied with the services and supports they receive.

Core Indicator #16: Proportion of people who report satisfaction with where they live.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
KY	80	98.00%
AZ	343	96.00%
MN	198	96.00%
WA	146	95.00%
NE	290	95.00%
MA	431	94.00%
PA	1282	94.00%
NC	105	93.00%
CT	226	92.00%
VA	132	89.00%
RI	203	87.00%
VT	195	84.00%
Total	3631	93.00%

^aScores differ significantly state-to-state.

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #17a: Proportion of people reporting satisfaction with their job.		
<u>State</u>	<u>Valid N</u>	Mean Proportion
VT	120	99.00%
VA	87	97.00%
PA	761	97.00%
AZ	177	97.00%
NC	64	97.00%
RI	134	97.00%
NE	242	95.00%
WA	43	95.00%
MA	286	94.00%
MN	137	94.00%
CT	150	93.00%
KY	62	92.00%
Total	2263	96.00%

Core Indicator #17b: Proportion of people reporting satisfaction with their day program.		
<u>State</u>	<u>Valid N</u>	Mean Proportion
NC	47	100.00%
WA	74	99.00%
AZ	170	98.00%
PA	493	98.00%
VT	87	97.00%
RI	97	97.00%
MN	112	96.00%
CT	136	96.00%
KY	24	96.00%
VA	50	96.00%
NE	108	95.00%
MA	182	94.00%
Total	1580	97.00%

Core Indicator #18: Proportion of people reporting satisfaction with the number of hours worked.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
AZ	171	77.00%
NE	104	74.00%
KY	23	70.00%
WA	73	70.00%
VT	75	68.00%
MN	103	67.00%
RI	89	65.00%
PA	493	64.00%
NC	47	62.00%
CT	133	60.00%
MA	180	57.00%
VA	50	36.00%
Total	1541	65.00%

^aScores differ significantly state-to-state.

Access

Concern: People are informed about available resources and those eligible have access to an adequate complement of services and supports.

Core Indicator #19: Proportion of people reporting that they received support to learn or do something new in the past year.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VA	100	74.87%
CT	156	73.42%
MN	134	72.74%
NC	90	72.14%
AZ	276	72.02%
WA	87	71.61%
NE	219	71.16%
VT	132	71.03%
KY	60	71.02%
PA	960	70.82%
MA	277	69.86%
RI	143	68.39%
Total	2634	71.23%

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #20: Proportion of people who report having adequate transportation when they want to go somewhere.

<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VA	260	83.49%
PA	1267	82.05%
KY	159	81.58%
NC	123	81.44%
CT	289	81.40%
RI	232	81.19%
MN	265	80.93%
WA	138	80.72%
MA	433	80.54%
AZ	456	80.06%
NE	321	80.04%
VT	146	79.96%
Total	4089	81.28%

Core Indicator #30: Proportion of people who report that needed services were not

	avanabie.	
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
NE	331	15.00%
AZ	510	17.00%
PA	1480	18.00%
RI	242	20.00%
KY	170	21.00%
MN	278	22.00%
NC	105	23.00%
СТ	306	25.00%
VA	276	29.00%
WA	201	36.00%
MA	589	37.00%
Total	4488	23.00%
1		

^aScores differ significantly state-to-state.

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Service Coordination

Concern: Service coordinators are accessible, responsive, and support consumer participation in service planning

Core Indicator #21: Proportion of people who are able to contact their service coordinators when they want to.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
RI	185	85.90%
KY	68	82.40%
VA	120	81.70%
NC	98	80.60%
VT	160	80.00%
PA	1234	77.60%
AZ	328	77.40%
NE	277	75.50%

381

174

215

140

3380

74.30%

71.30%

69.80%

55.00%

76.20%

MA

MN

CT

WA

Total

Core Indicator #22a: Proportion of people who report getting a chance to say what they wanted at the plan meeting.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
MN	136	94.78%
NE	246	93.21%
MA	206	92.96%
VT	101	92.91%
AZ	240	92.53%
CT	159	92.28%
KY	51	92.19%
RI	149	91.89%
WA	59	91.84%
NC	72	91.49%
VA	95	91.30%
PA	742	90.74%
Total	2256	92.04%

^aAdjusted scores are shown.

^aScores differ significantly state-to-state.

bScores differ significantly state-to-state.

Core Indicator #22b: Proportion of people who report choosing the things that are in
their plan.

<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
MN	123	87.37%
VT	92	87.01%
MA	202	86.94%
PA	723	86.76%
RI	139	86.49%
NE	228	86.42%
KY	46	85.86%
VA	89	85.65%
CT	143	85.47%
NC	73	84.95%
AZ	251	84.89%
WA	52	84.69%
Total	2161	86.29%

Core Indicator #28: Proportion of people who report that their service coordinators help them get what they need.

mosp and a got when and a com-		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
NC	92	97.00%
VT	157	96.00%
KY	67	94.00%
NE	276	94.00%
AZ	327	92.00%
RI	182	92.00%
VA	120	91.00%
PA	1185	87.00%
MA	365	85.00%
CT	205	80.00%
MN	173	80.00%
WA	131	62.00%
Total	3280	87.00 %

^aScores differ significantly state-to-state.

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Safety
Concern: The system ensures that people are safe from abuse, neglect, and injury.

Core Indicator #40a: Proportion of people who report that they feel safe in their home.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
KY	77	100.00%
WA	143	97.00%
MN	198	97.00%
NE	285	97.00%
PA	1278	97.00%
AZ	341	97.00%
VT	171	96.00%
MA	426	96.00%
RI	198	95.00%
CT	221	95.00%
NC	104	91.00%
VA	133	88.00%
Total	3575	96.00%

^aScores differ significantly state-to-state.

Core Indicator #40b: Proportion of people who report that they feel safe in their neighborhood.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
KY	78	96.00%
NC	105	96.00%
RI	190	95.00%
MN	187	94.00%
WA	145	94.00%
PA	1252	94.00%
NE	281	93.00%
CT	215	93.00%
VT	164	92.00%
AZ	332	92.00%
MA	412	91.00%
VA	129	84.00%
Total	3490	93.00%

^aScores differ significantly state-to-state.

Core Indicator #41: Proportion of people who report that their normal routine was interrupted due to illness in the last month.

<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
KY	178	15.00%
NE	379	17.00%
VA	299	18.00%
MN	332	21.00%
RI	272	22.00%
NC	136	22.00%
PA	1599	23.00%
MA	565	26.50%
CT	345	30.00%
AZ	531	36.00%
WA	208	45.00%
Total	4844	25.00 %

 $^{{}^{}a}Scores\ differ\ significantly\ state-to-state.$ ${}^{b}Data\ not\ available\ for\ VT.$

Core Indicator #42: Proportion of people who had a physical exam in the past year.

<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
MN	317	95.60%
NE	357	93.30%
MA	563	92.00%
CT	336	91.70%
VA	298	91.30%
RI	262	87.00%
KY	177	85.30%
PA	1547	83.60%
NC	133	83.50%
AZ	519	77.10%
WA	194	71.10%
Total	4703	86.20%

^aScores differ significantly state-to-state. ^bSee Appendix B for more detailed results.

Core Indicator #43: Proportion of women who had an OB/GYN exam in the past year.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
CT	163	66.90%
MN	155	65.80%
RI	131	62.60%
NC	47	61.70%
MA	262	54.20%
KY	75	53.30%
PA	732	51.00%
AZ	209	49.80%
NE	151	45.70%
WA	87	43.70%
VA	102	41.20%
Total	2114	53.50 %

Core Indicator #45: Proportion of people had a routine dental exam in the past six months.

<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
MN	319	77.10%
CT	330	71.80%
MA	557	70.60%
RI	259	65.60%
NE	351	62.70%
KY	178	61.20%
VA	296	59.50%
WA	189	46.00%
NC	133	45.90%
PA	1524	44.40%
AZ	485	42.70%
Total	4621	55.90%

^aScores differ significantly state-to-state. ^bSee Appendix B for more detailed results.

^aScores differ significantly state-to-state. ^bSee Appendix B for more detailed results.

Core Indicator #46: Proportion of people receiving psychotropic medications.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
AZ VA	473 290	28.12% 37.59%
CT PA KY	311 1444	38.59% 38.85%
MN MA	175 304 561	40.57% 42.11% 42.78%
NE WA	323 157	44.58% 44.59%
RI NC	253 126	51.78% 54.76%
Total	4417	40.21%

Respect/Rights

Concern: People receive the same respect and protections as others in the community.

Core Indicator #36: Proportion of people reporting that they have an advocate or someone who speaks on their behalf.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
WA	142	87.00%
NC	100	77.00%
KY	74	76.00%
AZ	324	76.00%
MN	177	73.00%
PA	1201	73.00%
MA	415	68.00%
CT	206	67.00%
RI	178	67.00%
NE	273	65.00%
VA	112	48.00%
Total	3202	71.00%

^aScores differ significantly state-to-state.

^aScores differ significantly state-to-state. ^bSee Appendix B for more detailed results.

Core Indicator #47a: Proportion of people who report that their mail is opened without permission. Mean Proportion^{a,b} **State** Valid N VT22.98% 129 RI 29.69% 218 PA 1236 29.70% NE 304 31.09% NC 31.56% 118 WA 136 34.31% CT272 35.26% 35.43% 428 MA AZ439 35.75% KY 153 37.07% MN 253 39.52% VA244 42.30% **Total 3930 33.19**%

bScores differ significantly state-to-state.

Core Indicator #47b: Proportion of people who report that they have some
restrictions on being alone with guests.

<u>Valid N</u>	Mean Proportion ^{a,b}
194	19.89%
126	23.21%
419	24.31%
104	25.56%
222	25.75%
76	29.76%
184	30.44%
267	30.96%
67	32.23%
125	32.72%
192	35.40%
612	37.46%
2588	29.93%
	194 126 419 104 222 76 184 267 67 125 192 612

^aAdjusted scores are shown.

^aAdjusted scores are shown.

bScores differ significantly state-to-state.

Core Indicator #47c: Proportion of people who report that other people enter their home without permission. Mean Proportion^{a,b} **State** Valid N VT 134 11.40% MA 422 13.59% 1234 14.00% PA NC 123 16.81% RI 221 17.14% NE 313 17.48% WA 18.02% 137 AZ450 19.04% 287 19.42% CTKY 154 21.22%

257

257

3989

24.40%

27.03%

17.29%

VA

MN

Total

Core Indicator #47d: Proportion of people who report that others enter their bedroom without permission. Mean Proportion^{a,b} Valid N State VT 10.56% 132 PA 1235 12.88% RI 223 14.20% NE 314 14.26% MA 424 14.32% NC 120 15.25% WA 138 16.29% CT288 17.00% AZ450 17.08% KY 157 18.79% MN 255 21.05% VA 256 22.32% **Total** 3992 **15.46**%

^aAdjusted scores are shown.

bScores differ significantly state-to-state.

^aAdjusted scores are shown.

^bScores differ significantly state-to-state.

Core Indicator #47e: Proportion of people who report that there are restrictions on their use of the phone. Mean Proportion^{a,b} **State** Valid N MA 311 15.35% RI 187 17.44% VT 127 17.67% PA 1077 17.90% NE 258 18.48% 18.71% MN 181 AZ291 18.84% KY 114 19.18% WA 19.32% 111

103

222

160

3142

Core Indicator #48: Proportion of people who have attended activities of self-

19.40%

19.43%

21.08%

18.21%

25.22% 24.99%

24.64%

23.67%

23.22%

20.35%

25.53%

NC

CT

VA

Total

advocacy groups.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^{a,b}
VT	137	29.78%
MA	416	27.85%
NE	305	27.44%
RI	215	25.90%
PA	1132	25.85%
WA	134	25.39%

121

441

267

142

242

234

3786

NC

AZ

CT

KY

MN

VA

Total

^a**Adjusted** scores are shown.

^bScores differ significantly state-to-state.

^aAdjusted scores are shown.

bScores differ significantly state-to-state.

Core Indicator #49: Proportion of people reporting that they can be alone as much as they want to.		
<u>State</u>	<u>Valid N</u>	Mean Proportion a,b
MA	269	89.49%
PA	986	89.04%
KY	71	88.52%
RI	164	88.47%
NC	84	87.59%
VT	136	87.58%
VA	103	87.53%
WA	81	87.41%
CT	177	87.24%
MN	151	86.94%
AZ	252	86.76%
NE	227	86.01%
Total	2701	88.11 %

Acceptability

Concern: The system is sensitive to consumer preferences and demands.

Core Indicator #53a: Proportion of people reporting that most day support staff treat them with respect.		
<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
RI	134	95.00%
KY	64	95.00%
NC	65	94.00%
VA	86	93.00%
WA	43	93.00%
PA	755	93.00%
MA	281	91.00%
MN	138	91.00%
CT	146	90.00%
AZ	172	90.00%
NE	238	89.00%
Total	2122	92.00%

^aData not available for VT.

^a**Adjusted** scores are shown. ^bScores differ significantly state-to-state.

Core Indicator #53b: Proportion of people reporting that most job support staff treat them with respect. **State** Valid N Mean Proportion^a VA 46 96.00% 96.00% 105 MN 20 95.00% KY 95.00%WA 64 NC 95.00% 44 82 RI 94.00%MA 154 92.00% PA 428 92.00% NE 90 91.00% 90.00% CT130 89.00% AZ151 **Total** 1314 93.18%

^aData not available for VT.

Core Indicator #53c: Proportion of people reporting that most residential support staff treat them with respect.		
<u>State</u>	<u>Valid N</u>	Mean Proportion
RI	143	95.00%
VT	22	95.00%
WA	99	93.00%
PA	660	93.00%
KY	44	93.00%
AZ	191	92.00%
MA	234	91.00%
MN	186	91.00%
NE	237	91.00%
CT	164	90.00%
NC	81	90.00%
VA	83	89.00%
Total	2144	92.00%

Core Indicator #57: Proportion of people who have changed residences more than once in the past year.

<u>State</u>	<u>Valid N</u>	Mean Proportion ^a
VA	299	5.35%
MA	563	7.50%
CT	345	8.41%
AZ	531	11.00%
RI	272	12.00%
PA	1599	14.00%
NC	136	16.00%
KY	178	17.00%
MN	332	17.00%
NE	379	18.00%
WA	208	19.00%
VT	200	23.00%
Total	5042	13.00%

^aScores differ significantly state-to-state.

Appendix A: Rules for Recoding and Combining Variables to Compute Core Indicators

Table A1: Outcome Adjustment Variables and Rules for Collapsing Response Codes

BI Item #	Variable Name	Recode/Collapse ^a
4	AGE	continuous variable
5	GENDER	0-1 variable
8	LGLSTAT	Combine 2&3 = not independent
11	LEVELMR	Combine into 3 categories: no MR+mild,
		moderate, severe + profound
12	MENTILL, AUTISM,	These have been recoded. Use each disability as
	CERPALS, BRAININJ,	separate adjustment variable. (1=has disability, 0=
	CHEMDEP,	does not have disability)
	OTHERDX	·
13	EXPRESS	Combine into verbal $= 1+2$, and non-verbal $=$
		3+4+5+6
14	MOBILITY	As is
17	VISION	Combine 2&3 = has vision problems
20	SEIZURES	Combine $2+3+4 =$ frequent seizures
21	MEDCARE	Combine $2+3+4+5 =$ requires frequent medical
		care
33-36	SELFINJ, SIFREQ,	New variable (BEHAVIOR) created to indicate the
	PROPDES, PDFREQ,	presence of any one of the four behaviors.
	DISBEH, DBFREQ,	
	UNCPBEH, UBFREQ,	
	BEHAVIOR	

^aUnless specified, all "don't know" responses are treated as missing values.

Table A2: Survey Items Recoded/Collapsed for Indicator Analysis

Table Az. Survey	/ items recoded/collapsed for indicator Analysis
Survey Item #	Recode/Collapse ^a
Q2	Collapse in-between (1) with yes (2), and no (0) is separate
Q4	Combine in-between (1) with no (0), yes (2) is separate
-	·
Q6	Same as Q2
Q8	Same as Q4
Q9	As is
Q11	Same as Q4
Q12	As is
Q13	Same as Q4
Q15	Same as Q4
Q17	Same as Q4
Q19	Same as Q2
Q21	As is
Q22	Same as Q2
Q23	Same as Q2
Q25	Same as Q4
Q27	Same as Q4
Q29	Same as Q27
Q31	Combine no (0) with sometimes (1), yes (2) remains separate
Q33	Same as Q27
Q34	Same as Q27
Q35	Same as Q27
Q36	As is
Q39-Q44	As is
Q45	As is
Q46-Q56	Combine yes unassisted (2) with yes with assistance (1), no (0) remains
-	separate
Q57-Q61	Combine 1 and 0 (Q57-Q58 only), 2 remains separate
Q62	As is
Q63	Combine 1 and 0, 2 is separate
2T T 1 .O 1	

^aUnless specified, all "not applicable" (8) and "no response" (9) codes are treated as missing values.

Table A3: Crosswalk for Core Indicators Corresponding to Multiple Survey Items

Core Indicator #	Refers to Questions ^a	Scale Reliability (Alpha) ^b
CI 6	CS 39-CS 44	0.54
CI 7	CS 46 – CS 54	0.80
CI 11	CS55, CS 56	0.63
CI 14 (a&b)	CS 13, CS 17	0.41
CI 17 (a&b)	CS 2, CS 6	0.65
CI 22	CS 33, CS 34	0.58
CI 40 (a&b)	CS 22, CS 23	0.36
CI 47 (a-e)	CS 57 - CS 61	0.47
CI 53 (a&b&c)	CS 4, CS 8, CS 25	0.35

Table A4: Background Information Items Corresponding to Core Indicators

Core Indicator #	Background Info Item	Recode/Collapse
CI 41	BI 18	Recode <=1 as 0 and >1 as 1. Report proportion of those sick more than one day.
CI 42	BI 22	Report all categories, including "don't know."
CI 43	BI 23	Report all categories, including "don't know."
CI 45	BI 24	Report all categories, including "don't know."
CI 46	BI 19	Use proportion who take psychotropic meds.
CI 57	BI 25	Recode as <=1 as 0 and >1 as 1. Report proportion who moved more than once in the past year.

^aAll other core indicators correspond to single survey items. ^bItems are considered reliable if alpha score is 0.60 or higher.

Appendix B: Detailed Health Question Results

Table B1: Frequency of Physical Examination

<u>State</u> ^a	<u>Valid N</u>		Last physical exam	
		Within past year	Over a year ago	Don't know
AZ	519	77.1%	7.7%	15.2%
CT	336	91.7%	4.8%	3.6%
KY	177	85.3%	11.3%	3.4%
MA	563	92.0%	5.9%	2.1%
MN	317	95.6%	2.8%	1.6%
NC	133	83.5%	3.8%	12.8%
NE	357	93.3%	5.6%	1.1%
PA	1547	83.6%	5.8%	10.5%
RI	262	87.0%	8.0%	5.0%
VA	298	91.3%	4.7%	4.0%
WA	194	71.1%	5.7%	23.2%
Total	4703	86.2%	5.9 %	7.8 %

^aNo data available for Vermont

Table B2: Frequency of OB/GYN Examination

State ^a	Valid N	IN Examination	Last ob/	gyn exam	
		Within past	Over a year	Never had an	Don't
		<u>year</u>	<u>ago</u>	<u>exam</u>	<u>know</u>
AZ	209	49.8%	13.4%	5.3%	31.6%
CT	163	66.9%	13.5%	7.4%	12.3%
KY	75	53.3%	14.7%	9.3%	22.7%
MA	262	54.2%	13.4%	18.7%	13.7%
MN	155	65.8%	18.1%	7.1%	9.0%
NC	47	61.7%	10.6%	2.1%	25.5%
NE	151	45.7%	23.2%	7.9%	23.2%
PA	732	51.0%	11.3%	10.1%	27.6%
RI	131	62.6%	9.9%	6.9%	20.6%
VA	102	41.2%	25.5%	8.8%	24.5%
WA	87	43.7%	10.3%	3.4%	42.5%
Total	2114	53.5 %	14.0 %	9.4%	23.2 %

^aNo data available for Vermont

Table B3: Frequency of Dental Examination

State ^a	Valid N	Ī	ast dentist visit	
		Within last 6	Over 6 months	Don't know
		<u>months</u>	<u>ago</u>	
AZ	485	42.7%	29.3%	28.0%
CT	330	71.8%	15.8%	12.4%
KY	178	61.2%	24.2%	14.6%
MA	557	70.6%	25.5%	4.5%
MN	319	77.1%	16.3%	6.6%
NC	133	45.9%	27.1%	27.1%
NE	351	62.7%	35.3%	2.0%
PA	1524	44.4%	28.7%	26.8%
RI	259	65.6%	17.0%	17.4%
VA	296	59.5%	23.0%	17.6%
WA	189	46.0%	21.7%	32.3%
Total	4621	55.9 %	25.5 %	18.6%

^aNo data available for Vermont

Table B4: Proportion of Sample Taking Medication for Mood, Anxiety or Behavior

Table D4. I Toportion	1	edication for wood, Anxiety	OI Deliavioi
<u>State</u> ^a	<u>Valid N</u>	Medications for mood	<u>l anxiety or behavior</u>
		<u>Yes</u>	<u>No</u>
AZ	473	28.1%	71.9%
CT	311	38.6%	61.4%
KY	175	40.6%	59.4%
MA	561	42.8%	57.2%
MN	304	42.1%	57.9%
NC	126	54.8%	45.2%
NE	323	44.6%	55.4%
PA	1444	38.9%	61.1%
RI	253	51.8%	48.2%
VA	290	37.6%	62.4%
WA	157	44.6%	55.4%
Total	4417	40.2%	59.8 %

^aNo data available for Vermont

Appendix C: Item-by-Item Survey Results

Table C1. Community Inclusion

		-											
STATE	S: ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section II Total	N: 5096	531	345	178	617	332	136	379	1599	272	299	200	208
*Note: Actual N's vary b	y question.	Figures sh	own are va	alid percen	its.								
Do you go shopping?													
% no	8.3	13.7	6.1	8.0	10.1	4.3	6.7	7.5	7.6	5.2	15.8	6.0	8.7
% yes	91.7	86.3	93.9	92.0	89.9	95.7	93.3	92.5	92.4	94.8	84.2	94.0	91.3
Do you go out on errands o	or appointm	nents?											
% no	6.4	7.8	3.2	6.8	5.9	3.7	5.9	6.4	7.4	1.9	11.0	6.7	3.4
% yes	93.6	92.2	96.8	93.2	94.1	96.3	94.1	93.6	92.6	98.1	89.0	93.3	96.6
Do you go out to exercise o	or play spor	ts?											
% no	27.0	24.5	32.9	41.4	32.1	24.9	30.8	30.5	25.7	23.1	28.8	N/A	18.5
% yes	73.0	75.5	67.1	58.6	67.9	75.1	69.2	69.5	74.3	76.9	71.2		81.5
Do you go out for entertair	nment?												
% no	16.6	15.1	11.5	17.5	19.1	10.8	20.1	16.0	19.5	12.7	10.7	33.3	14.5
% yes	83.4	84.9	88.5	82.5	80.9	89.2	79.9	84.0	80.5	87.3	89.3	66.7	85.5
Do you always eat at home	e, or do you	sometim	es go out	t to eat?									
% always at home	9.7	12.0	8.6	11.9	10.4	4.3	14.7	11.4	10.2	5.6	13.8	4.2	5.8
% sometimes go out	90.3	88.0	91.4	88.1	89.6	95.7	85.3	88.6	89.8	94.4	86.2	95.8	94.2
Do you go to religious serv	vices or eve	nts?											
% no	44.5	51.9	51.2	35.7	48.0	43.9	28.0	42.8	40.7	46.3	50.9	53.7	49.0
% yes	55.5	48.1	48.8	64.3	52.0	56.1	72.0	57.2	59.3	53.7	49.1	46.3	51.0

Table C2. Choice and Decision-making

STATES:	ALL	AZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section II Total N:	5096	531	345	178	617	332	136	379	1599	272	299	200	208
*Note: Actual N's vary by question	n. Figures	shown are	valid percer	nts.									
Did you choose or pick the plac	e where y	ou live?											
% no, someone else chose	49.6	49.9	55.0	64.0	52.4	55.9	48.4	37.7	43.1	42.8	77.2	46.6	52.3
% yes, with assistance	35.4	37.1	36.2	25.6	33.8	36.5	36.8	48.4	39.0	41.7	18.4	2.5	38.9
% yes, unassisted	15.0	13.1	8.8	10.4	13.8	7.6	14.7	14.0	17.9	15.5	4.4	50.9	8.7
Did you choose or pick the peop	ole you live	e with?											
% no, someone else chose	68.1	64.2	75.1	59.6	66.0	74.1	80.0	59.2	65.2	65.0	84.2	56.3	70.6
% yes, with assistance	19.3	24.9	14.7	27.2	18.3	22.1	11.4	25.9	17.7	23.8	10.7	6.3	22.0
% yes, unassisted	12.6	10.9	10.1	13.2	15.7	3.8	8.6	14.9	17.0	11.2	5.1	37.5	7.3
Do you choose your daily sched	ule?												
% no, someone else chose	24.3	31.4	25.3	22.6	24.7	29.3	35.6	24.4	22.3	20.8	26.0	1.8	20.2
% yes, with assistance	32.1	32.4	34.6	20.9	36.1	39.2	26.5	30.8	31.0	27.3	45.7	22.5	33.7
% yes, unassisted	43.6	36.2	40.1	56.5	39.2	31.5	37.9	44.8	46.8	51.9	28.4	75.7	46.2
Do you choose or pick the thing	s you do f	or fun?											
% no, someone else chose	10.5	22.5	10.4	7.4	9.0	13.0	11.5	4.9	9.2	6.5	11.4	3.7	8.2
% yes, with assistance	37.6	39.7	46.0	36.4	28.7	48.4	34.6	41.5	31.9	36.5	59.3	9.2	34.6
% yes, unassisted	51.8	37.8	43.6	56.3	62.2	38.5	53.8	53.6	58.8	57.0	29.3	87.1	57.2
Did you choose your day progra	ım?												
% no, someone else chose	49.0	64.2	56.1	52.9	66.4	57.7	43.3	46.6	39.8	47.3	58.5	10.7	49.2
% yes, with assistance	32.3	26.2	31.3	25.2	23.0	30.9	34.3	32.9	35.5	32.6	30.0	28.6	42.9
% yes, unassisted	18.7	9.6	12.6	21.8	10.6	11.4	22.4	20.5	24.7	20.1	11.5	60.7	7.9
Did you choose your job?													
% no, someone else chose	30.4	32.9	44.4	40.7	30.0	40.1	22.2	32.9	24.5	28.0	22.2	19.2	28.9
% yes, with assistance	43.1	49.8	38.3	38.3	44.2	45.2	51.9	40.9	41.2	46.2	55.6	28.2	50.6
% yes, unassisted	26.5	17.4	17.3	21.0	25.8	14.6	25.9	26.2	34.3	25.9	22.2	52.6	20.5

Table C2. Choice and Decision-making (continued)

STATES:	ALL	AZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section II Total N:	5096	531	345	178	617	332	136	379	1599	272	299	200	208
*Note: Actual N's vary by question	n. Figures	shown are	valid percer	its.									
Did you choose or pick who help	s you at h	nome?											
% no, someone else chose	69.2	66.2	78.9	66.4	59.2	72.8	57.7	75.3	65.1	51.6	83.4	73.9	74.0
% yes, with assistance	20.9	26.5	16.7	27.3	34.3	22.6	26.8	15.3	20.2	33.5	12.6	13.0	16.0
% yes, unassisted	9.9	7.3	4.4	6.4	6.5	4.7	15.5	9.4	14.7	14.9	4.0	13.0	10.0
Did you choose or pick who help	s you at y	our job?											
% no, someone else chose	70.1	61.6	84.8	60.0	75.1	62.7	68.3	78.6	68.7	69.3	68.0	38.1	83.9
% yes, with assistance	19.7	31.8	9.1	28.4	14.5	35.3	16.7	11.6	18.2	21.0	15.0	19.0	9.7
% yes, unassisted	10.2	6.6	6.1	11.6	10.4	2.0	15.0	9.8	13.1	9.7	17.0	42.9	6.5
Did you choose or pick your case	manage	r?											
% no, someone else chose	88.7	86.3	94.1	89.6	91.8	91.8	86.8	83.3	89.3	75.0	93.5	55.9	96.5
% yes, with assistance	5.7	9.5	2.5	6.7	2.6	4.9	7.0	7.2	5.1	9.9	2.2	9.7	1.5
% yes, unassisted	5.6	4.2	3.4	3.7	5.6	3.3	6.1	9.4	5.5	15.1	4.4	34.4	2.0
Can you get your money whenev	er you w	ant it?											
% no, needs permission	22.6	33.9	23.1	26.6	22.6	21.9	19.5	22.7	18.2	12.6	24.9	42.9	17.9
% yes, with some restrictions	35.5	47.4	31.8	47.9	31.0	36.0	31.0	37.7	35.0	28.9	31.9	0.6	45.8
% yes	41.9	18.7	45.1	25.4	46.4	42.1	49.6	39.6	46.8	58.5	43.2	56.5	36.3
Do you choose the things you bu	y with yo	ur spendii	ng money?	•									
% no, someone else decides	14.1	24.7	13.4	14.9	14.6	14.9	9.0	12.8	10.8	8.3	23.1	11.9	13.1
% yes, with assistance	49.0	48.9	59.1	52.0	40.5	61.3	37.6	61.2	45.5	47.3	53.1	9.5	52.9
% yes, most unassisted	36.9	26.4	27.5	33.1	44.9	23.8	53.4	26.0	43.7	44.3	23.8	78.6	34.0
STATES:	ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section I Total N:	3655	343	226	80	433	199	105	293	1292	203	134	200	147
*Note: Actual N's vary by question	n. Figures	shown are	valid percer	its.									
Do you think what's in your serv	ice plan i	s importar	nt?										
% not important	7.8	6.6	8.3	2.0	8.9	13.4	1.3	8.0	9.2	4.4	14.6	1.0	7.0
% in-between	11.6	13.5	12.5	10.2	5.2	12.2	10.5	14.8	12.7	6.9	7.3	3.0	8.5
% important	80.6	79.9	79.2	87.8	86.0	74.4	88.2	77.3	78.1	88.7	78.1	96.0	84.5

Table C3. Respect and Rights

abie C3. Respect and Rig	gnts												
STATES:	ALL	ΑZ	CT	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section II Total N:	5096	531	345	178	617	332	136	379	1599	272	299	200	208
*Note: Actual N's vary by qu	uestion. Fi	gures show	n are valid	percents.									
ave you ever participated in	a self-adv	ocacy gro	up meetin	ıg, confere	ence, or ev	ent?							
% no	75.0	77.0	76.9	79.2	73.3	74.7	60.6	64.4	78.3	62.4	83.8	65.6	79.1
% yes	25.0	23.0	23.1	20.8	26.7	25.3	39.4	35.6	21.7	37.6	16.2	34.4	20.
oes anyone ever open your n	nail witho	out your pe	ermission?	•									
% yes, always opened	14.6	21.2	18.1	13.5	19.8	17.4	14.4	13.8	13.7	6.1	15.3	12.8	8.4
% some mail opened	18.0	22.6	19.7	8.8	16.3	22.8	12.0	17.0	17.2	21.9	25.0	1.3	13.
% no, not opened	67.4	56.2	62.3	77.6	64.0	59.8	73.6	69.3	69.1	72.1	59.7	85.9	78.
oes anyone come into your h	ome with	nout asking	g?										
% yes	17.5	22.4	21.3	10.5	11.4	29.5	4.7	22.2	12.6	14.9	29.2	7.1	17.
% no	82.5	77.6	78.7	89.5	88.6	70.5	95.3	77.8	87.4	85.1	70.8	92.9	82.
oes anyone come into your b	edroom v	without as	king?										
% yes	15.3	19.2	18.4	17.2	12.7	17.9	13.4	17.3	12.1	13.1	21.2	12.5	12.
% no	84.7	80.8	81.6	82.8	87.3	82.1	86.6	82.7	87.9	86.9	78.8	87.5	87
re you allowed to use the pho	one wher	you want	to?										
% no, some restrictions	18.9	21.8	18.3	16.8	15.4	18.0	26.4	16.3	20.5	9.5	32.0	16.2	4.8
% yes	81.1	78.2	81.7	83.2	84.6	82.0	73.6	83.7	79.5	90.5	68.0	83.8	95.
hen you have guests over, c	an you be	alone wit	h them or	does som	eone have	to be with	ı you?						
% no, can't be alone	11.4	20.3	9.2	12.7	13.0	7.2	10.6	17.1	9.8	8.9	8.9	14.6	4.4
% not always	14.6	28.4	14.3	5.4	10.3	17.0	18.7	11.0	13.3	9.3	12.5	4.9	12.
% yes, can be alone	74.0	51.3	76.4	81.9	76.7	75.7	70.7	72.0	76.9	81.9	78.6	80.6	82.
able C3. Respect and Rig	ghts (co	ntinued)											
STATES:	ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	W
*Section I Total N:	3655	343	226	80	433	199	105	293	1292	203	134	200	14
*Note: Actual N's vary by qu	uestion. Fi	gures show	n are valid	percents.									
an you be by yourself as muc													
% no	11.5	15.4	10.1	9.2	14.7	8.8	26.1	15.9	10.3	7.7	14.8	8.4	8.3
% yes	88.5	84.6	89.9	90.8	85.3	91.2	73.9	84.1	89.7	92.3	85.2	91.6	91.
o you have an advocate or gu	uardian -	someone v	who helps	you make	decisions	?							
% no	22.4	19.1	24.3	23.0	27.0	22.6	22.0	27.1	22.1	25.3	30.4	N/A	9.0
% maybe, not sure	5.7	4.6	8.7	1.4	4.6	4.5	1.0	7.7	4.4	7.3	21.4		2.8
% yes	71.9	76.2	67.0	75.7	68.4	72.9	77.0	65.2	73.4	67.4	48.2		87.

Table C4. Service Coordination

STATES:	ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section I Total N:	3655	343	226	80	433	199	105	293	1292	203	134	200	147
*Note: Actual N's vary by	question.	Figures show	wn are valid	percents.									
Can you talk to your service	coordina	tor whenev	er you wa	nt to?									
% no	13.2	9.1	22.3	8.8	16.3	16.1	7.1	10.1	12.2	9.7	9.2	10.6	37.1
% sometimes	10.4	13.4	7.9	8.8	9.4	12.6	12.2	14.4	10.1	4.3	9.2	9.4	7.9
% yes	76.4	77.4	69.8	82.4	74.3	71.3	80.6	75.5	77.6	85.9	81.7	80.0	55.0
When you ask your service c	oordinat	or for help,	does h/sh	ne get you	what you	need?							
% no	12.5	8.3	20.0	6.0	14.5	19.7	3.3	5.8	13.4	7.7	9.2	3.8	38.2
% sometimes	10.2	15.6	12.7	4.5	8.2	7.5	6.5	11.2	9.3	8.2	9.2	9.6	11.5
% yes	77.3	76.1	67.3	89.6	77.3	72.8	90.2	83.0	77.3	84.1	81.7	86.6	50.4
Did you have a planning mee	eting this	year?											
% no, not sure	25.3	25.5	21.7	27.4	21.6	14.1	23.0	7.3	31.8	15.3	18.7	24.0	47.2
% yes	74.7	74.5	78.3	72.6	78.4	85.9	77.0	92.7	68.2	84.7	81.3	76.0	52.8
At the meeting, did people li	sten to w	vhat you ha	d to say?										
% no	8.1	6.6	7.4	7.3	3.1	3.0	6.3	4.3	11.8	5.8	8.3	5.1	9.8
% sometimes	4.1	8.4	6.3	1.8	2.2	7.1	2.5	5.4	2.8		2.8	2.6	2.4
% yes	87.8	85.0	86.3	90.9	94.7	89.9	91.1	90.4	85.3	94.2	89.0	92.3	87.8
Did you choose the things th	at are in	your service	e plan?										
% no	13.1	11.5	12.6	2.0	9.8	11.4	7.5	12.3	17.4	7.5	13.9	2.8	15.5
% some	17.1	20.2	17.8	6.0	16.1	30.2	16.3	16.1	18.4	8.7	11.9	4.7	18.3
% yes	69.8	68.3	69.5	92.0	74.1	58.4	76.3	71.6	64.2	83.9	74.3	92.5	66.2

Table C5. Access

STATES:	ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section II Total N:	5096	531	345	178	617	332	136	379	1599	272	299	200	208
*Note: Actual N's vary I	by question	n. Figures s	shown are v	alid percen	ts.								
Can you think of anything	you aske	d for help	with but o	lidn't get?									
yes	20.5	16.7	24.5	21.2	37.0	21.6	22.9	15.4	18.1	20.2	28.6		35.8
no	79.5	83.3	75.5	78.8	63.0	78.4	77.1	84.6	81.9	79.8	71.4		64.2
When you want to go som	ewhere,	do you hav	e a way to	get there	≘?								
almost never	2.1	3.3	3.0	1.1	4.1	0.9	1.5	1.1	2.1	1.9	2.1	2.4	1.9
sometimes	15.8	26.2	13.0	7.9	17.6	14.3	18.3	19.8	15.3	11.5	15.0	5.4	12.6
almost always	82.2	70.6	83.9	91.0	78.3	84.8	80.2	79.1	82.6	86.6	82.9	92.2	85.5
STATES:	ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section I Total N:	3655	343	226	80	433	199	105	293	1292	203	134	200	147
*Note: Actual N's vary I	by question	n. Figures s	shown are v	alid percen	ts.								
Did anyone help you learn	to do so	mething n	ew this ye	ar?									
did not have help	27.9	26.2	30.0	33.3	29.8	25.0	16.0	25.8	30.1	30.5	24.3	24.5	27.3
had help	72.1	73.8	70.0	66.7	70.2	75.0	84.0	74.2	69.9	69.5	75.7	75.5	72.7

Table C6. Safety

STATES	: ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section I Total N	: 3655	343	226	80	433	199	105	293	1292	203	134	200	147
*Note: Actual N's vary b	y question.	Figures sho	wn are valid	percents.									
Do you feel safe where you	live?												
% no	3.6	2.6	4.5		3.5	3.0	8.7	2.8	2.7	4.5	12.0	4.1	3.5
% in-between	5.5	11.1	4.1	1.3	4.5	6.1	8.7	8.1	3.7	5.1	6.0	5.3	5.6
% yes	90.9	86.2	91.4	98.7	92.0	90.9	82.7	89.1	93.7	90.4	82.0	90.6	90.9
When you go outside your	home, do y	you ever fe	el scared o	r do you a	lways feel	safe?							
% feels scared	6.8	7.8	6.5	3.8	9.5	6.4	3.8	7.5	6.2	4.7	16.3	7.9	6.2
% in-between	11.8	16.6	13.0	12.8	15.8	16.0	8.6	8.5	11.7	10.0	10.9	5.5	12.4
% feels safe	81.4	75.6	80.5	83.3	74.8	77.5	87.6	84.0	82.2	85.3	72.9	86.6	81.4

Table C7. Satisfaction

STATES	: ALL	AZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section I Total N	: 3655	343	226	80	433	199	105	293	1292	203	134	200	147
*Note: Actual N's v	ary by ques	tion. Figure	s shown are	e valid perc	ents.								
Do you like your day p	rogram?												
% no	4.0	3.4	6.7	8.1	5.9	5.8	3.1	5.0	3.4	3.0	3.4	0.8	4.7
% in-between	7.7	7.9	10.0	6.5	6.6	10.9	10.9	11.6	5.1	8.2	8.0	9.2	2.3
% yes	88.3	88.7	83.3	85.5	87.4	83.2	85.9	83.5	91.5	88.8	88.5	90.0	93.0
Do you like your job?													
% no	2.8	2.4	4.4	4.2	6.0	4.5		4.6	1.8	3.1	4.0	3.4	1.4
% in-between	6.1	7.6	3.7	12.5	6.6	7.1	10.6	2.8	6.3	3.1	2.0	10.3	5.4
% yes	91.9	90.0	91.9	83.3	87.4	88.4	89.4	92.6	91.9	93.8	94.0	86.2	93.2
Do you work enough h	nours?												
% no	34.0	22.8	39.8	30.4	43.3	33.0	38.3	26.0	35.7	34.8	64.0	32.0	30.1
% yes	66.0	77.2	60.2	69.6	56.7	67.0	61.7	74.0	64.3	65.2	36.0	68.0	69.9
Do you like where you	ı live?												
% no	6.8	4.1	7.5	2.5	6.5	4.0	6.7	5.2	5.9	12.8	11.4	**15.9	5.5
% in-between	6.9	13.7	10.2	3.8	7.0	8.1	8.6	5.9	5.8	3.4	6.1	2.1	8.9
% yes	86.3	82.2	82.3	93.8	86.5	87.9	84.8	89.0	88.3	83.7	82.6	82.1	85.6

^{**}Note: Vermont's questions was worded differently: "Are you happy living there or would you like to live somewhere else?"

Table C8. Relationships

STATES:	ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section I Total N:	3655	343	226	80	433	199	105	293	1292	203	134	200	147
*Note: Actual N's vary by o	question. F	igures shov	vn are valid	percents.									
Do you have friends you like	to talk to	or do thin	gs with?										
% no	6.2	6.8	9.8	3.8	8.2	7.9	5.9	6.6	6.1	4.0	6.9	1.5	4.9
% yes, staff or family	16.2	20.9	15.6	16.7	11.9	14.7	14.7	24.7	16.6	9.6	10.8	4.5	13.3
% yes, not staff/family	77.6	72.3	74.6	79.5	80.0	77.4	79.4	68.6	77.3	86.4	82.3	94.0	81.8
Do you have a best friend?													
% no	18.1	17.9	18.2	9.5	19.9	24.7	12.4	13.4	17.7	16.6	21.4	28.5	18.0
% yes	81.9	82.1	81.8	90.5	80.1	75.3	87.6	86.6	82.3	83.4	78.6	71.5	82.0
Can you see your friends who	en you wa	nt to see t	hem?										
% no	4.6	1.3	4.5	2.7	7.0	3.9	5.2	4.1	4.2	5.0	3.4	18.5	3.0
% sometimes	19.8	29.3	21.1	16.2	19.9	20.6	24.7	18.6	19.1	18.2	21.0	3.4	22.0
% yes	75.6	69.5	74.4	81.1	73.1	75.6	70.1	77.3	76.7	76.8	75.6	78.1	75.0
Do you ever feel lonely?													
% always or often	6.9	6.5	4.2	3.9	6.9	9.0	9.4	8.1	5.6	5.9	6.8	17.4	7.9
% sometimes	46.1	56.8	47.4	58.4	48.1	47.2	49.0	47.6	45.7	45.2	45.3	19.8	42.9
% never	47.0	36.7	48.4	37.7	44.9	43.8	41.7	44.3	48.7	48.9	47.9	62.9	49.3
Can you see your family when	n you war	nt to see th	nem?										
% no	7.8	9.6	7.6	5.8	11.6	1.3	6.3	9.7	5.0	7.2	5.4	**28.4	9.5
% sometimes	15.6	22.8	19.3	13.5	15.6	17.5	22.5	17.3	14.2	13.7	8.6	6.4	15.8
% yes	76.7	67.6	73.1	80.8	72.9	81.3	71.3	73.0	80.8	79.1	86.0	65.2	74.7

^{**}Note: Vermont's survey question was worded differently: "Do you get to see your family as much as you want to?"

Table C9. Acceptability

STATES:	ALL	ΑZ	СТ	KY	MA	MN	NC	NE	PA	RI	VA	VT	WA
*Section I Total N:	3655	343	226	80	433	199	105	293	1292	203	134	200	147
*Note: Actual N's vary by	question.	Figures sho	wn are valid	d percents.									
he staff who help you at yo	ur day pro	ogram - ar	e most of	them nice	and polite	to you?							
% no	1.2		2.1		1.8	0.7		2.1	1.3		3.5	N/A	2.3
% some staff	6.6	9.9	8.2	4.7	7.1	8.0	6.2	8.8	5.4	5.2	3.5		4.7
% yes	92.2	90.1	89.7	95.3	91.1	91.3	93.8	89.1	93.2	94.8	93.0		93.0
he staff who help you at wo	ork - are r	nost of the	em nice an	d polite to	you?								
% no	1.1	0.7	1.5		0.6			2.2	1.4	2.4		N/A	
% some staff	6.4	9.9	8.5	5.0	7.8	3.8	4.5	6.7	6.3	3.7	4.3		4.7
% yes	92.5	89.4	90.0	95.0	91.6	96.2	95.5	91.1	92.3	93.9	95.7		95.3
he staff how help you in yo	ur home -	are most	of them ni	ice and pol	lite to you	?							
% no	2.1	1.0	2.4	2.3	4.3	1.6	1.2	1.3	2.6	1.4	3.6		4.0
% some	5.8	6.8	7.9	4.5	5.1	7.5	8.6	7.6	4.4	3.5	7.2	4.5	3.0
% yes	92.1	92.1	89.6	93.2	90.6	90.9	90.1	91.1	93.0	95.1	89.2	95.5	92.9
ow many different places h	as this pe	erson lived	in the pas	st year?									
mean number	1.11	1.10	1.02	1.18	1.09	1.12	1.20	1.09	1.11	1.13	1.04	1.34	1.10
standard deviation	(.56)	(.45)	(.48)	(.45)	(.38)	(.42)	(1.11)	(.51)	(.52)	(.78)	(.30)	(.85)	(.64)