

Consumer Outcomes

Phase V Final Report
Fiscal Year 2002-2003 Data



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

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January 2004

Table of Contents

TABLE OF CONTENTS.....	3
LIST OF TABLES	4
LIST OF FIGURES	5
I. ORGANIZATION OF REPORT	6
II. INTRODUCTION.....	7
<i>Overview of NCI.....</i>	<i>7</i>
<i>The Indicators</i>	<i>8</i>
III. CONSUMER SURVEY	10
<i>Organization of the Survey</i>	<i>10</i>
IV. METHODS.....	11
<i>Criteria for Exclusion of Responses</i>	<i>11</i>
<i>Sampling.....</i>	<i>11</i>
<i>Administration.....</i>	<i>12</i>
<i>Training.....</i>	<i>13</i>
V. DATA ANALYSIS	13
<i>Outcome Adjustment</i>	<i>13</i>
<i>Scale Development.....</i>	<i>14</i>
<i>Significance Testing.....</i>	<i>14</i>
VI. RESULTS: DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS	14
<i>Demographic Profile of Sample</i>	<i>21</i>
<i>Additional Outcome Adjustment Variables</i>	<i>23</i>
VII. RESULTS: CORE INDICATOR OUTCOMES AND COMPARISONS ACROSS STATES	26
<i>Summary of Aggregate Results</i>	<i>26</i>
<i>Presentation of Detailed Results by State.....</i>	<i>31</i>
<i>Consumer Outcomes: Work.....</i>	<i>33</i>
<i>Consumer Outcomes: Community Inclusion.....</i>	<i>46</i>
<i>Consumer Outcomes: Choice and Decision-Making</i>	<i>53</i>
<i>Consumer Outcomes: Relationships.....</i>	<i>64</i>
<i>Consumer Outcomes: Satisfaction.....</i>	<i>68</i>
<i>System Performance: Service Coordination.....</i>	<i>70</i>
<i>System Performance: Access</i>	<i>76</i>
<i>Health, Welfare, and Rights: Safety.....</i>	<i>78</i>
<i>Health, Welfare & Rights: Health</i>	<i>80</i>
<i>Health, Welfare & Rights: Medications</i>	<i>82</i>
<i>Health, Welfare & Rights: Respect/Rights</i>	<i>83</i>
APPENDIX A: RULES FOR RECODING AND COMBINING VARIABLES TO COMPUTE CORE INDICATORS.....	90
<i>Table A1. Background Information Variables Used to Adjust Outcomes.....</i>	<i>91</i>
<i>Table A2. Outcome Variables -- Rules for Analysis.....</i>	<i>92</i>
APPENDIX B: SERVICES AND SUPPORTS RECEIVED.....	94
APPENDIX C: ITEM-BY-ITEM SURVEY RESULTS.....	98
APPENDIX D: COMPARABILITY OF QUESTIONS ACROSS PAST VERSIONS.....	130

List of Tables

Table 1. Crosswalk of Core Indicators and Survey Questions: Consumer Survey Version 2002-2003.....	8
Table 2. Valid Number of Surveys and Response Rates, By State	12
Table 3. Gender.....	15
Table 4. Race	16
Table 5. Ethnicity.....	17
Table 6. Level of MR.....	17
Table 7. Other Disabilities (Duplicated Counts).....	18
Table 8. Type of Residence.....	19
Table 9. Age.....	20
Table 10. Consumer Legal Status.....	23
Table 11. Primary Means of Expression.....	24
Table 12. Vision.....	25
Table 13. Earnings and Hours Worked Per Month, By State (Source: Consumer Survey Supplement FY2003)	34
Table 14. Earnings and Hours Worked Per Month, By State – Continued (Source: Consumer Survey Supplement FY2003)	35
Table 15. Earnings and Hours Worked Per Month, By State – Continued (Source: Consumer Survey Supplement FY2003)	36
Table 16. Summary of Monthly Earnings, All States (Source: Consumer Survey Supplement FY2003)	37
Table 17. Summary of Monthly Hours Worked, All States (Source: Consumer Survey Supplement FY2003)	37
Table 18. Total Monthly Wages, All Work Activities Combined, by State (Source: Consumer Survey Supplement FY2003).....	38
Table 19. Competitive Employment Wages, by State (Source: Consumer Survey Supplement FY2003).....	39
Table 20. Individual Supported Employment Wages, by State (Source: Consumer Survey Supplement FY2003).....	40
Table 21. Facility-Based Work Program Wages, by State (Source: Consumer Survey Supplement FY2003)	41
Table 22. Total Hours Worked, All Work Activities Combined, by State (Source: Consumer Survey Supplement FY2003).....	42
Table 23. Total Hours Spent in Non-Work Activities, by State (Source: Consumer Survey Supplement FY2003)	43
Table 24. Community Employment Indicators, by State (Source: Consumer Survey Supplement FY2003).....	44
Table 25. Percent of Respondents Enrolled in Public School, by State (Source: Consumer Survey Supplement FY2003).....	44
Table 26. Funding Sources of Day/Vocational Services Received, by State (Source: Consumer Survey Supplement FY2003).....	44
Table 27. Average Monthly Earnings and Average Hours Worked per Month, by State (Source: State Data Systems FY2002) ...	45
Table 28. Community Inclusion Scale Scores by State, Compared to National Average.....	46
Table 29. Community Inclusion Scale Scores, by Subsets of States	48
Table 30. Proportion of people who go shopping.....	49
Table 31. Proportion of people who go out on errands or appointments	50
Table 32. Proportion of people who go out for entertainment.....	50
Table 33. Proportion of people who go out to eat.....	51
Table 34. Proportion of people who go to religious services.....	51
Table 35. Proportion of people who go to clubs or community meetings	52
Table 36. Proportion of people who exercise or play sports	52
Table 37. Supports-Related Choices Scale Scores by State, Compared to National Average.....	54
Table 38. Personal Choices Scale Scores by State, Compared to National Average.....	54
Table 39. Support-Related Choices Scale Scores, by Subsets of States.....	57
Table 40. Personal Choices Scale Scores, by Subsets of States.....	57
Table 41. Proportion of people who chose place where they live.....	58
Table 42. Proportion of people who choose staff who help them at home	59
Table 43. Proportion of people who chose place of work or day activity.....	59
Table 44. Proportion of people who choose staff who help them at work or day activity	60
Table 45. Proportion of people who chose case manager/service coordinator.....	60
Table 46. Proportion of people who choose people they live with.....	61
Table 47. Proportion of people who choose daily schedule.....	61
Table 48. Proportion of people who choose how to spend free time	62
Table 49. Proportion of people who choose what to buy with spending money.....	62
Table 50. Proportion of people who looked at more than one home	63
Table 51. Proportion of people who looked at more than one job.....	63
Table 52. Proportion of people who report having friends and caring relationships with people other than support staff and family members.....	64
Table 53. Proportion of people who report having a close friend	65
Table 54. Proportion of people who are able to see their families when they want to	66
Table 55. Proportion of people who are able to see their friends when they want to	67
Table 56. Proportion of people who feel lonely.....	67
Table 57. Proportion of people who report satisfaction with where they live	68
Table 58. Proportion of people who report satisfaction with their work/day program	69
Table 59. Service Coordination Scale Scores by State, Compared to National Average.....	70
Table 60. Service Coordination Scale Scores, by Subsets of States.....	72
Table 61. Proportion of people who report that their service coordinators help them get what they need	74
Table 62. Proportion of people who report that they know their case manager.....	74
Table 63. Proportion of people who report that their case manager asks them what’s important.....	75
Table 64. Proportion of people reporting that they received help to reach goals	76
Table 65. Proportion of people who report having adequate transportation when they want to go somewhere.....	77
Table 66. Proportion of people who report that needed services were not available.....	77

Table 67. Proportion of people who report that they feel safe in their home	78
Table 68. Proportion of people who report that they feel safe in their neighborhood.....	79
Table 69. Proportion of people who had a physical exam in the past year.....	80
Table 70. Proportion of people who had a gynecological exam in the past year	81
Table 71. Proportion of people who had a routine dental exam in the past six months.....	81
Table 72. Proportion of people receiving psychotropic medications.....	82
Table 73. Proportion of people reporting that they have an advocate or someone who speaks on their behalf.....	83
Table 74. Proportion of people reporting that their mail is opened without permission	84
Table 75. Proportion of people who report that they have some restrictions on being alone with guests.....	84
Table 76. Proportion of people reporting that there are restrictions on their use of the phone	85
Table 77. Proportion of people reporting that other people enter their home without permission	85
Table 78. Proportion of people reporting that other people enter their bedroom without permission	86
Table 79. Proportion of people who have attended activities of self-advocacy groups.....	87
Table 80. Proportion of people reporting they can be alone (have privacy).....	87
Table 81. Proportion of people reporting that most day support staff treat them with respect.....	88
Table 82. Proportion of people reporting that most residential support staff treat them with respect.....	88

List of Figures

Figure 1. Gender.....	21
Figure 2. Level of MR	21
Figure 3. Type of Residence	22
Figure 4. Community Inclusion – Adjusted Results for Total Sample.....	26
Figure 5. Relationships – Results for Total Sample	28
Figure 6. Time of Last Physical Exam.....	29
Figure 7. Time of Last Dental Exam	29
Figure 8. Time of Last GYN Visit.....	30
Figure 9. Community Inclusion: State Scale Scores Compared with National Average	47
Figure 10. Support-Related Choices: State Scale Scores Compared with National Average.....	55
Figure 11. Personal Choices: State Scale Scores Compared with National Average	56
Figure 12. Service Coordination: State Scale Scores Compared with National Average.....	71

I. Organization of Report

This document serves as the **final** report for the consumer outcomes portion of **Phase V (2002-2003)** National Core Indicators (NCI) data collection. All consumer survey data submitted between **July 2002** and **June 2003** are included in this report. In addition, **Phase V** consumer employment data is included.¹ The report is organized as follows:

INTRODUCTION -- Gives a brief overview of NCI activities to date, and presents the core indicators measured with the Consumer Survey and with the optional Day/Vocational/Educational Support supplement.

CONSUMER SURVEY -- Briefly describes the development and structure of the survey instrument.²

METHODS -- Describes the protocol for administering NCI consumer surveys, including sampling criteria, administration guidelines, and interviewer training procedures.

DATA ANALYSIS -- Explains the statistical methods used to analyze the consumer survey data. Includes an explanation of how certain outcomes are “adjusted” for the purposes of making comparisons across states. Also discusses scale construction and significance testing of results.

RESULTS: DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS -- Presents aggregate and state-by-state results of demographic information used for outcome adjustment.

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

APPENDICES -- Include additional analysis information, services and supports received, and detailed item-by-item results.

¹ Most states collected consumer employment data by using the “Day/Vocational/Educational Support” Supplement to the Consumer Survey. In some states, however, these data are collected from providers on a regular basis and maintained in state data systems.

² For a detailed review of psychometric properties of the survey, including results of reliability and validity tests and features designed to test for consistency of responses, please see the NCI Phase II Technical Report.

II. Introduction

Overview of NCI

In December 1996, the NASDDDS Board of Directors launched the Core Indicators Project (CIP). The aim of CIP was to support state developmental disabilities authorities (SDDAs) in developing and implementing performance/outcome indicators and related data collection strategies that would enable them to measure service delivery system performance. This effort, now called National Core Indicators or NCI, 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 NCI facilitates states pooling their knowledge, expertise and resources in this endeavor.

NCI 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 NCI consumer and family surveys and compiling other data. Field test data were transmitted to NCI staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

NCI 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 NCI. During Phase II, the Phase I indicators were revised, and data collection tools and methods were improved. The Version 2.0 indicator set consisted of 60 performance and outcome indicators. Going forward, NCI expanded its scope to include services for children with developmental disabilities and their families, continued to develop and refine the indicators, and recruited additional states to participate in the collaboration. Phase II data are considered baseline NCI data. Phase II technical reports and other selected documents are available online at www.hsri.org/nci.

Twelve states (AZ, CT, KY, MA, MN, NE, NC, PA, RI, VA, VT, WA) participated in Phase II. Four additional states joined during the following year (DE, IA, MT, UT), and seven states joined in 2001 (AL, HI, IL, IN, OK, WV, WY). Virginia, Minnesota, Montana, Illinois and Utah are currently on hiatus. South Dakota, South Carolina, and Maine signed on in 2002. In Phase V, twenty-one states participated in NCI, plus the local DD authority in Orange County, CA. State participation in NCI is entirely voluntary.

This report summarizes both "first cycle" data (submitted prior to February 28, 2003) and "second cycle" data (submitted between March 1, 2003 and June 30, 2003) of Phase V (i.e., the fifth year) of NCI. A total of seventeen states plus Orange County are included in this final report.

The Indicators

The survey instrument is designed specifically to measure certain core indicators. Most indicators correspond to single survey items. A few indicators are referenced to clusters of related items. Table 1 presents a crosswalk between core indicators³ collected using the Consumer Survey Version 2002-2003 and their corresponding survey item(s).

Table 1. Crosswalk of Core Indicators and Survey Questions: Consumer Survey Version 2002-2003

Key to codes:	
BI = background information question	
Q = consumer interview question (bold indicates question allows consumer responses only)	
S = Day/Vocational/Educational Supplement	
Question:	Refers to Core Indicator:
BI-17	The proportion of people taking medications for mood, anxiety, or behavior problems.
BI-20	The proportion of people who have had a physical exam in the past year.
BI-21	The proportion of women who have had a GYN exam in the past year.
BI-22	The proportion of people who have had a routine dental exam in the past six months.
Q1	The proportion of people who are satisfied with their job or day program.
Q2, Q8	The proportion of people indicating that most support staff treat them with respect.
Q4	The proportion of people satisfied with where they live.
Q5	The proportion of people who report satisfaction with the amount of privacy they have.
Q6, Q7	The proportion of people who report that they feel safe in their home and neighborhood.
Q9, Q10, Q45-Q47	The proportion of people whose basic rights are respected by others.
Q12	The proportion of people who have friends and caring relationships with people other than support staff and family members.
Q13	The proportion of people who have a close friend, someone they can talk to about personal things.
Q14, Q16	The proportion of people who are able to see their families and friends when they want.
Q15	The proportion of people who feel lonely.

³ Wording has been updated to reflect Revised Phase V Indicators (in draft).

Q17	The proportion of people who know their service coordinators.
Q18	The proportion of people reporting that service coordinators help them get what they need.
Q19	The proportion of people who report that their service coordinators asked about their preferences.
Q20	The proportion of people who have an advocate or someone who speaks on their behalf.
Q21	The proportion of people reporting that they received support to learn or do something new in the past year.
Q22	The proportion of people who report having adequate transportation when they want to go somewhere.
Q26-Q31, Q33	The proportion of people who participate in everyday activities in their communities.
Q34, Q36- Q40, Q42- Q44	The proportion of people who make choices about their everyday lives.
Q35, Q41	The proportion of people who report having been provided options about where to live and work.
Q48	The proportion of people who have participated in activities of self-advocacy groups or other groups that address rights.
Q49	The rate at which people report that "needed" services were not available.
S1-S6	The average monthly earnings of people who have jobs in the community.
S1-S6	The average number of hours worked per month for people with jobs in the community.
S1-S6	The percent of people earning at or above the state minimum wage.
S9	Of people who have a job in the community, the percent who were continuously employed during the previous year.
S10	Of people who have a job in the community, the percent who receive job benefits.
S11	Of people who have a job in the community, the average length of time people have been working at their current job.

III. Consumer Survey

The National Core Indicators Consumer Survey was initially developed by a 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 over half of the original 60 core indicators. Many questions were drawn from survey instruments already in use in the field; other questions were developed specifically for NCI. NCI staff have tested and refined the instrument each year based on feedback from interviewers.

Organization of the Survey

The Consumer Survey is composed of a pre-survey form and three sections.

- THE PRE-SURVEY FORM collects 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 “case manager” or 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 requests data that would most likely be found in agency records or information systems. In some states, case managers complete this section at the same time the pre-survey form is completed. In other states, surveyors complete the section during the direct interview.
- SECTION I of the survey, which concerns questions aimed at obtaining expressions of satisfaction and opinions from each individual, may be completed only through a direct interview with the individual; proxy responses are not acceptable.
- SECTION II questions are to be answered by the individual if possible. If the person is unable to respond, an advocate is asked to answer.
- The last page of the survey is the SURVEYOR FEEDBACK SHEET. Surveyors are asked to record the length of the interview with the individual and describe any problematic questions.
- The DAY/VOCATIONAL/EDUCATIONAL SUPPLEMENT is an optional add-on to the survey instrument. These data are generally collected at the same time the background information section is completed.

IV. Methods

Criteria for Exclusion of Responses

All persons selected in the survey sample are given an opportunity to respond to questions in a face-to-face interview. There is no pre-screening procedure. Exclusion of responses is done at the time of data analysis, based on specific criteria described below.

The total number of surveys administered in **Phase V** was **9552**. Section I is administered only to **the person receiving services**. A person's responses are excluded if any of the following criteria are met:

- ◆ The consumer responded to less than half of the questions in Section I.
- ◆ The interviewer recorded that the person did not understand the questions being asked
- ◆ The interviewer recorded that the person gave inconsistent responses.

After excluding incomplete and inconsistent responses, the number of valid respondents to Section I = **6239**. Overall, **65% (6239/9552)** of consumers in the total sample were able to respond to Section I of the direct interview. The “**% Consumer Respondents Section I**” column in Table 2 indicates the percentage of consumers who were able to respond to Section I, by state.

Section II allows multiple respondents. The “**% Consumer Respondents Section II**” column in Table 2 indicates that a consumer was **one of the respondents** to Section II. Other informants (e.g., family, friend, support worker) may have provided answers to some of the questions. In the final analysis, if a respondent is excluded from Section I, his or her responses are also excluded from Section II. Otherwise, **all responses to questions in Section II are included in the analysis**, regardless of how many questions were answered. Thus, the consumer response rate to Section I may be lower than the response rate to Section II due to stricter criteria for including Section I responses. The number of responses to Section II = **8986**. Overall, **64% (5755/8986)⁴** of responses to Section II included consumer responses.

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, 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 number of surveys completed and response rates to each section, by state.

⁴ This figure does not include Maine.

Table 2. Valid Number of Surveys and Response Rates, By State

State	Valid N	% Consumer Respondents Section I	% Consumer Respondents Section II
AL Alabama	297	71%	67%
RCOC California – Regional Center of Orange County	599	78%	72%
CT Connecticut	406	72%	65%
DE Delaware	290	49%	36%
HI Hawaii	487	52%	53%
IN Indiana	795	79%	62%
IA Iowa	820	78%	79%
KY Kentucky	512	68%	70%
ME Maine	417	43%	not available
NC North Carolina	674	63%	69%
OK Oklahoma	407	46%	40%
PA Pennsylvania	1349	74%	71%
RI Rhode Island	406	64%	69%
SC South Carolina	582	44%	52%
SD South Dakota	534	68%	70%
VT Vermont ⁵	274	50%	50%
WV West Virginia	297	57%	53%
WY Wyoming	406	72%	69%
TOTAL	9552	65%	64%

Administration

Most participating states used the basic survey tool developed by the project. Vermont and Pennsylvania include NCI items in their own statewide survey tools. States used a variety of types of surveyors, including: consumers and families, university students, and state personnel. 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 caseload⁶.

⁵ The State of Vermont used a survey tool called the *Self-Perceived Satisfaction Scale*, developed by Susan Culbert, Ph.D. and Sara Burchard, Ph.D. of the University of Vermont. The survey has been in use for several years and has been adapted to align with the NCI Consumer Survey. There are some differences in sampling and survey methods used in Vermont vs. other NCI states. For example, Vermont only allows the interview to be completed by individuals receiving supports. Surrogate responses are not accepted. For those individuals who do not complete the survey for whatever reason, demographic information only is collected. Vermont's sample included a total of 274 individuals, 136 who responded to the survey and 138 for whom demographic information only was collected. The response rate of 50% reported here is calculated by dividing the number of survey respondents (136) by the total number of individuals in the sample (274).

⁶ The State of Maine is transitioning from a previously established Quality of Life survey process to the NCI survey process. The interviewers are assigned differently and may include individuals' case managers or provider staff.

Training

“Train-the-trainer” sessions were provided to the lead agencies from each state. These trainings were conducted by conference call. The first part of the training reviewed the survey tool in detail, question by question. The second part reviewed general interviewing techniques. The participants, or “trainers” from each state, then conducted training with the actual interviewers. NCI 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.

V. Data Analysis

NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state, and files are submitted to HSRI for analysis. All data files received are reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. An outcome adjustment procedure is performed on selected outcomes. See Appendix A for specific rules used to recode, collapse, and adjust outcome variables.

Outcome Adjustment

Outcome adjustment or “risk adjustment” is a statistical process used to control for differences in the individual characteristics of people interviewed across states. This method effectively “levels the playing field” across states. It is necessary to perform this analysis because a state that has a broad eligibility definition (i.e., serves people with autism, brain injury, or other developmental disability) will probably have a sample that looks slightly different from a state that only serves people diagnosed with MR. Other reasons, such as sampling biases, may also affect the nature of the sample.

Only those indicators that are likely to be affected by individual characteristics are adjusted; the rest are not adjusted. For example, a person who has limited mobility and frequent seizures might be less likely to participate in shopping or other community activities. On the other hand, such characteristics should not affect whether a person has friends or has contact with his or her service coordinator. Items are “adjusted” using a logistic regression model. Earlier in NCI, a detailed analysis involving ICAP⁷ data determined a number of individual characteristics that were found to predict outcomes on the Consumer Survey. These individual characteristics are used as regression variables and include: age, gender, legal status, level of MR label, other diagnoses, primary means of expression, and vision⁸.

The predicted values created by the logistic regression represent the “adjusted mean proportion” for each state. Essentially, the predicted value represents what one would expect the outcome to be if all factors were equal across samples. For outcomes that are adjusted, the column heading in the data table will read “Adjusted Mean Proportion.” The types of outcomes that are subject to adjustment include: Community Inclusion, Choice and Decision-making, some Access items, and some Rights items. Appendix A, Table A1 indicates the specific variables that are adjusted.

⁷ The Inventory for Client and Agency Planning is a tool that measures a variety of functional and behavioral characteristics.

⁸ The following items were not included in the outcome adjustment procedure this year due to missing data in a number of states: mobility, frequency of seizures, frequency of medical care required, and the presence of problem behavior.

Scale Development

For the sub-domains of Community Inclusion, Choice and Decision-making, and Service Coordination, we were able to combine certain items into reliable scales. There are a total of four scales. The Community Inclusion scale and the two Choice scales were created using adjusted figures. The Service Coordination scale uses unadjusted figures. The scale scores are computed by averaging the values of a number of items. In order for a score to be computed, the person (or a proxy respondent) must have answered a minimum number of questions. Each scale is described in further detail in the results section of this report.

A scale can be considered a reliable measure if its internal consistency is ≥ 0.70 . The statistic that assesses the scale's reliability is called Cronbach's alpha. In other words, if the alpha is ≥ 0.70 , we can be fairly confident that items are measuring the same dimension. Alpha scores are also included in the results sections.

Significance Testing

All four scales were tested for significant differences across states, and between each state and the national average. Each state's scale score was compared with the average scale score across all other states (not including that state). A conservative cutoff point ($p \geq 0.01$) was used to determine significant differences. These results are displayed below in table and map formats.

Analysis of variance is a collection of techniques used to test for differences among more than two groups. Post hoc (multiple comparison) tests provide information about which groups are different from each other. One such analysis, called Tukey's test, was performed to determine "homogeneous subsets" of results, i.e., groups of states that are not significantly different from one another. Subsets are arranged by column and labeled with a number at the top of each column. Scores that fall in the same subsets are not significantly different.

VI. Results: Demographic Characteristics of Respondents

First, we present descriptive information about the sample of respondents. Seventeen states plus the Regional Center of Orange County administered the consumer survey in the first cycle of 2002-2003 and together conducted a total of 9552 interviews. The participating states represented are: AL, CA – Regional Center Orange County (RCOC), CT, DE, HI, IA, IN, KY, ME, NC, OK, PA, RI, SC, SD, VT, WV and WY. Respondent characteristics are summarized in the following tables.

Table 3. Gender

	<i>N</i>	<i>% Male</i>	<i>% Female</i>
AL	295	55.9	44.1
RCOC	597	57.8	42.2
CT	405	55.3	44.7
DE	290	47.2	52.8
HI	487	51.7	48.3
IN	789	53.1	46.9
IA	819	55.7	44.3
KY	510	56.1	43.9
ME	414	51.7	48.3
NC	664	54.8	45.2
OK	407	59.0	41.0
PA	1342	51.6	48.4
RI	406	56.4	43.6
SC	582	59.8	40.2
SD	533	57.2	42.8
VT	273	53.1	46.9
WV	278	47.5	52.5
WY	406	56.2	43.8
TOTAL	9497	54.6	45.4

Table 4. Race

	<i>N</i>	% <i>American Indian or Alaska Native</i>	% <i>Asian</i> ⁹	% <i>Black or African American</i>	% <i>Native Hawaiian & Other Pacific Islander</i>	% <i>White</i>	% <i>Other</i>	% <i>Mixed Race</i>	% <i>Don't Know</i>
AL	295	0.0	0.7	33.6	0.0	64.7	0.3	0.0	0.7
RCOC	599	1.0	8.7	2.7	0.8	65.6	19.0	1.3	0.8
CT	405	0.0	0.2	10.4	0.2	82.0	5.9	1.2	0.0
DE	290	0.0	0.3	24.8	0.0	71.0	3.4	0.3	0.0
HI	487	0.2	-	1.2	57.9	16.2	4.3	19.7	0.4
IN	792	0.8	0.1	1.6	2.0	94.1	1.0	0.1	0.3
IA	819	0.6	0.1	8.7	0.1	89.4	0.7	0.4	0.0
KY	510	0.0	0.8	7.8	0.0	90.8	0.2	0.4	0.0
ME				Not available					
NC	664	1.2	0.8	34.9	0.0	61.4	1.1	0.6	0.0
OK	407	6.6	-	10.1	0.4	81.6	0.2	1.0	0.0
PA	1347	0.7	0.4	4.5	0.3	92.8	0.6	0.4	0.4
RI	406	2.2	0.2	5.2	0.2	89.7	1.2	0.7	0.5
SC	581	0.0	0.2	47.5	0.0	50.1	1.0	0.9	0.3
SD	533	12.9	0.2	0.4	0.0	85.7	0.8	0.0	0.0
VT	272	0.4	0.0	0.4	0.0	98.2	0.4	0.4	0.4
WV	291	0.3	0.7	3.8	0.0	94.2	0.0	0.7	0.3
WY	406	3.9	0.2	0.2	0.5	94.8	0.2	0.0	0.0
TOTAL	9104	1.7	3.7	11.0	0.6	78.7	2.4	1.5	0.2

⁹ Hawaii and Oklahoma used the 2000 version of the survey, which combined "Asian" and "Pacific Islander" into one category. Their percentages for "Asian/Pacific Islander" are reported under "Native Hawaiian& Other Pacific Islander."

Table 5. Ethnicity

	<i>N</i>	<i>% Hispanic</i>	<i>% Non-Hispanic</i>	<i>% Don't Know</i>
AL	294	96.3	2.0	1.7
RCOC	599	81.6	17.0	1.3
CT	404	91.3	8.4	0.2
DE	290	95.2	3.8	1.0
HI	487	96.9	1.8	1.2
IN	786	37.8	60.7	1.5
IA	819	98.7	1.3	0.0
KY	511	98.8	0.8	0.4
ME		Not available		
NC	660	98.9	0.9	0.2
OK	407	97.1	2.9	0.0
PA	1341	97.6	2.1	0.3
RI	406	96.3	2.5	1.2
SC	579	98.3	1.4	0.3
SD	533	99.6	0.4	0.0
VT	274	97.4	0.7	1.8
WV	291	94.2	1.4	4.5
WY	406	93.8	6.2	0.0
TOTAL	9087	91.0	8.3	0.7

Table 6. Level of MR

	<i>N</i>	<i>% Had No MR label</i>	<i>% Mild</i>	<i>% Moderate</i>	<i>% Severe</i>	<i>% Profound</i>	<i>% Unspecified or Unknown</i>
AL	295	1.0	24.1	28.1	23.1	22.7	1.0
RCOC	598	10.5	43.8	23.1	13.5	7.9	1.2
CT	406	2.0	44.1	28.1	12.8	11.8	1.2
DE	290	0.7	25.5	29.7	21.0	20.0	3.1
HI	487	0.8	19.5	31.6	20.9	21.1	6.0
IN	784	3.6	39.8	28.2	9.8	11.9	6.8
IA	818	1.7	41.3	20.4	15.9	17.2	3.4
KY	504	2.4	29.8	30.8	19.4	13.3	4.4
ME	417	1.0	38.4	24.5	14.1	11.3	10.8
NC	642	4.0	35.5	24.9	18.5	15.6	1.4
OK	407	0.2	32.7	19.2	16.2	31.0	0.7
PA	1340	0.5	40.7	29.1	16.5	11.3	1.8
RI	406	4.4	32.0	26.8	19.7	11.3	5.7
SC	580	22.9	31.0	21.2	11.6	9.5	3.8
SD	533	6.4	37.7	23.6	12.4	19.7	0.2
VT	264	3.0	61.7	17.0	8.3	8.3	1.5
WV	291	5.5	30.9	33.0	16.5	7.2	6.9
WY	406	8.4	48.8	18.0	9.6	14.3	1.0
TOTAL	9468	4.4	37.1	25.6	15.4	14.3	3.3

Table 7. Other Disabilities (Duplicated Counts)

	<i>N</i>	% <i>Mental illness</i>	% <i>Cerebral palsy</i>	% <i>Brain injury</i>	% <i>Autism</i>	% <i>Chem- ical depend- ency</i>	% <i>Seizure disorder</i>	% <i>Vision or hearing impair- ment</i>	% <i>Commun- ication disorder</i>	% <i>Physical disability</i>	% <i>Alz- heimer's disease</i>	% <i>Down Syn- drome</i>	% <i>Other Dis- ability</i>
AL	297	13.5	13.4	1.2	2.9	0.4	28.6	8.5	4.0	10.1	0.4	N/A	2.9
RCOC	599	18.2	24.1	1.2	7.5	1.0	26.1	7.9	0.2	0.8	0.2	6.8	4.8
CT	406	32.6	11.6	2.0	5.9	0.5	20.7	26.4	13.6	17.3	0.7	8.9	17.8
DE	290	19.4	10.1	1.4	11.1	0.7	26.0	22.9	13.2	17.0	1.4	9.4	22.6
HI	487	9.0	6.6	0.4	2.7	0.2	29.2	16.8	7.2	9.4	0.4	N/A	16.8
IN	795	25.4	11.7	4.2	6.9	1.1	21.5	16.6	17.4	12.5	0.7	12.1	29.5
IA	820	29.0	12.7	2.7	7.7	1.3	25.6	17.2	8.3	12.8	0.6	7.6	33.7
KY	512	47.0	18.8	3.6	7.3	1.8	31.3	18.9	16.6	14.7	1.1	N/A	27.7
ME	417	16.1	10.6	0.7	3.8	1.2	18.9	10.1	2.4	0.2	0.0	7.7	0.2
NC	674	37.0	15.4	3.8	6.9	2.7	23.3	13.4	9.5	10.2	0.9	7.5	17.9
OK	407	24.6	21.4	1.5	4.4	0.2	38.7	32.7	17.2	30.5	0.7	9.3	44.1
PA	1349	33.8	14.4	2.9	4.5	0.3	25.0	15.8	10.3	13.9	0.8	9.7	16.6
RI	406	29.8	13.3	3.4	6.4	1.0	25.1	18.5	15.8	17.2	2.2	3.7	27.6
SC	582	27.6	12.4	2.9	13.0	2.0	25.8	31.7	29.3	24.5	1.4	N/A	31.9
SD	534	37.3	13.7	14.1	8.1	1.7	33.4	7.5	27.4	61.4	0.9	11.0	9.2
VT	274	22.4	12.1	4.4	0.7	0.7	N/A	4.8 ¹⁰	20.3	3.3	N/A	N/A	19.6
WV	297	30.9	16.5	8.9	10.7	1.4	32.6	20.6	0.0	19.9	4.5	11.3	17.5
WY	406	33.7	11.1	0.0	4.4	2.5	18.5	4.9	N/A	39.9	0.0	7.9	42.6
Total	9552	28.3	14.0	3.3	6.4	1.2	25.4	16.4	12.4	17.2	0.9	8.7	22.0

¹⁰ Includes hearing impairment only.

Table 8. Type of Residence

	<i>N</i>	% <i>Specialized Facility</i>	% <i>Group Home</i>	% <i>Apartment Program</i>	% <i>Independent Home or Apartment</i>	% <i>Parent or Relative's Home</i>	% <i>Foster Care or Host Home</i>	% <i>Nursing Facility</i>	% <i>Other</i>	% <i>Don't Know</i>
AL	295	4.1	44.7	2.4	3.1	43.4	1.0	0.0	1.0	0.3
RCOC	597	11.2	32.7	1.5	14.9	38.7	0.3	0.3	0.3	0.0
CT	405	3.7	36.5	6.2	19.3	25.7	5.7	1.0	2.0	0.0
DE	290	17.9	30.3	6.6	2.4	26.2	15.2	0.0	1.4	0.0
HI	487	0.6	20.9	0.6	4.9	40.9	31.2	0.2	0.6	0.0
IN	792	21.2	9.6	8.0	38.3	18.3	0.0	0.5	4.0	0.1
IA	816	11.3	20.1	6.7	30.5	22.8	4.8	2.2	1.6	0.0
KY	509	13.8	8.3	13.8	7.5	31.4	10.8	2.2	12.4	0.0
ME	Not available									
NC	660	12.0	25.9	3.8	8.9	36.5	3.3	1.8	7.7	0.0
OK	407	17.4	10.3	0.5	62.7	1.7	6.6	0.0	0.7	0.0
PA	1344	3.5	34.2	1.6	10.0	39.0	4.9	0.7	5.9	0.2
RI	406	1.2	59.9	4.7	18.2	13.3	0.5	0.2	2.0	0.0
SC	564	2.8	12.4	6.0	11.3	58.9	2.8	1.1	4.4	0.2
SD	533	0.0	47.7	24.6	20.3	7.1	0.4	0.0	0.0	0.0
VT	274	0.7	4.0	1.5	13.1	23.7	46.4	1.1	8.4	1.1
WV	289	3.1	7.3	4.8	19.7	57.1	3.8	0.3	3.5	0.3
WY	406	5.7	55.4	6.7	14.0	14.8	3.0	0.5	0.0	0.0
TOTAL	9074	8.1	26.9	5.8	18.1	29.9	6.6	0.8	3.6	0.1

Table 9. Age

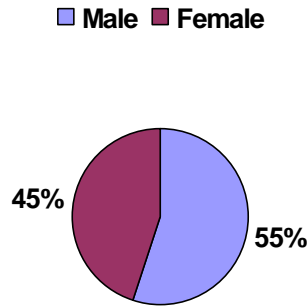
	<i>N</i>	<i>MEAN</i>	<i>MIN</i>	<i>MAX</i>
AL	291	41	18	98
RCOC	599	38	19	88
CT	403	46	19	93
DE	287	44	21	84
HI	486	43	19	95
IN	787	41	18	80
IA	808	44	20	86
KY	502	41	19	77
ME	402	46	19	86
NC	650	39	19	69
OK	407	39	20	76
PA	1319	42	18	92
RI	406	46	20	90
SC	399	40	18	81
SD	533	43	19	83
VT	264	44	20	90
WV	288	40	19	80
WY	405	42	22	83
TOTAL	9236	42	18	98

Demographic Profile of Sample

This section summarizes selected demographic characteristics of the overall sample.

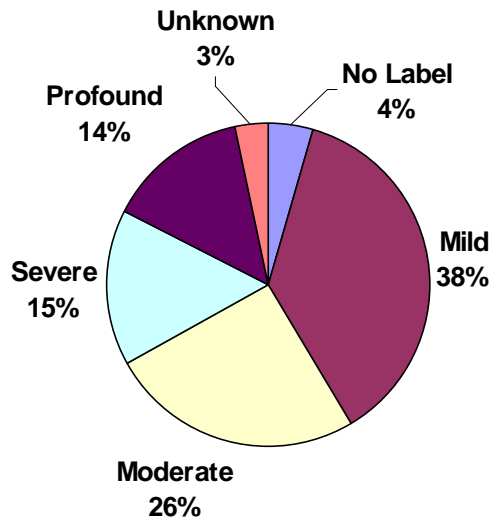
- » Most states had a slightly higher percentage of males in their samples. Overall, the total sample was 55% male and 45% female.

Figure 1. Gender (N=9497)



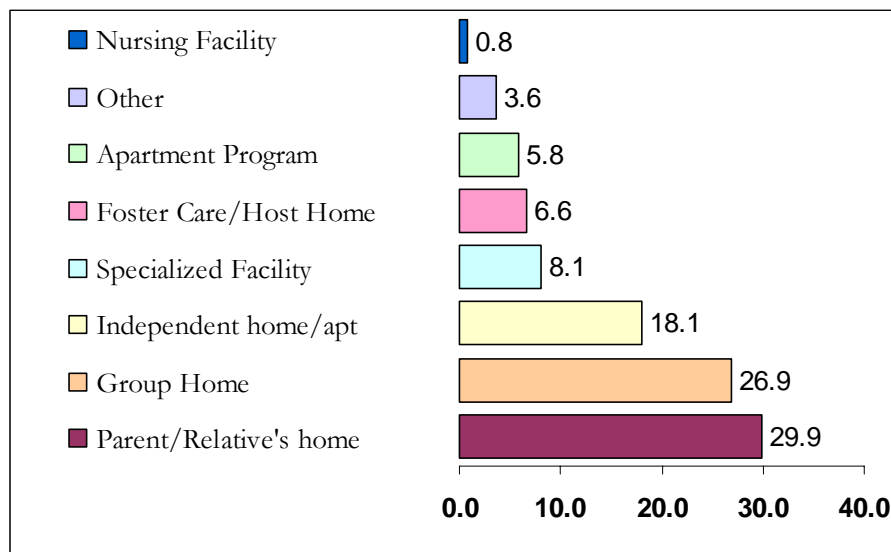
- » The average age of respondents was 42 years old, with a range of ages from 18 to 98.
- » The reported levels of mental retardation among respondents varied by state. Overall, about 64% of the sample had a diagnosis of “mild” or “moderate” MR, and 29% had a diagnosis of “severe” or “profound” MR.

Figure 2. Level of MR (N=9468)



- » 17% 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 included slightly higher minority participation than in previous years. The breakdown was as follows: 11% identified their race as Black or African American (compared with 8% in 2002); 4% reported their race as Asian, Native Hawaiian, or Other Pacific Islander; and 2% reported their race as American Indian or Alaska Native. Another 4% reported their race as “Other” or “Mixed Race.” 8% reported their ethnicity as Hispanic (compared with 5% in 2002).
- » Overall, 30% of the total respondents live with their families, although this figure varies by state. The percent of respondents living in other types of homes is shown in the table below.

Figure 3. Type of Residence (N=9074)



- » Overall, 28% of the total respondents also were reported to have a mental illness/psychiatric diagnosis, and 25% had a diagnosis of seizure disorder or other neurological problem.
- » The types of day/employment services and supports received by respondents varied by state. Overall, about 19% receive supported employment services, 9% receive group employment services, 38% receive facility-based vocational services, and 35% receive non-vocational day services.
- » 61% of respondents in the overall sample receive Home and Community Based Waiver Services; 17% receive ICF/MR funding.

Additional Outcome Adjustment Variables

Several variables related to individual characteristics are used to “adjust” certain consumer outcome results. The adjustment variables include demographic information such as age, gender, level of MR, and other disabilities diagnosed. Additional adjustment factors are displayed in the following tables, by state and for the sample as a whole.

Table 10. Consumer Legal Status

	<i>N</i>	<i>% Legally Competent Adult</i>	<i>% Private Guardian</i>	<i>% State/County Guardian</i>	<i>% Don't Know or Never Evaluated</i>
AL	295	77.3	22.4	0.0	0.3
RCOC	598	89.3	9.9	0.8	0.0
CT	402	35.3	60.7	0.7	3.2
DE	290	53.1	27.2	7.2	12.4
HI	487	29.6	40.5	30.0	0.0
IN	781	50.2	45.8	1.2	2.8
IA	818	61.1	34.1	2.9	1.8
KY	506	33.2	47.2	16.4	3.2
ME	417	29.0	44.8	15.8	10.3
NC	655	39.2	48.5	8.2	4.0
OK	407	36.4	57.0	4.4	2.2
PA	1335	74.4	10.9	1.6	13.0
RI	406	75.4	22.7	0.5	1.5
SC	557	57.8	34.5	2.0	5.7
SD	532	33.5	55.1	10.7	0.8
VT	273	26.7	42.5	29.3	1.5
WV	291	44.0	50.9	2.4	2.7
WY	406	29.6	70.4	0.0	0.0
TOTAL	9456	51.9	37.3	6.4	4.3

Table 11. Primary Means of Expression

	<i>N</i>	<i>% Speaks English</i>	<i>% Speaks Other Primary Language</i>	<i>% Uses Gestures</i>	<i>% Uses Sign Language</i>	<i>% Uses Communication Device</i>	<i>% Other</i>	<i>% Don't Know</i>
AL	295	72.2	0.3	22.0	1.0	0.3	3.4	0.7
RCOC	597	61.3	4.0	33.5	0.0	0.2	0.5	0.5
CT	406	78.3	0.7	14.0	1.7	1.0	3.9	0.2
DE	289	67.1	1.0	19.0	2.4	2.1	8.3	0.0
HI	487	63.9	1.2	16.4	2.1	0.4	14.0	2.1
IN	790	81.3	0.4	9.0	0.8	1.0	7.3	0.3
IA	815	79.1	0.4	11.5	1.5	1.0	6.3	0.2
KY	509	75.0	0.4	16.7	1.0	0.6	5.5	0.8
ME	417	65.5	0.0	14.1	1.2	2.2	0.2	16.8
NC	658	78.6	0.6	11.7	1.2	1.2	5.9	0.8
OK	406	64.0	0.0	14.0	2.0	0.7	19.2	0.0
PA	1347	79.1	0.2	14.3	1.9	1.2	2.8	0.5
RI	406	79.1	0.7	11.6	2.7	1.2	4.4	0.2
SC	574	86.1	0.3	8.2	0.9	0.3	4.0	0.2
SD	533	72.4	0.2	10.9	2.6	4.5	9.2	0.2
VT	270	72.2	N/A	N/A	N/A	N/A	27.8	0.0
WV	291	78.0	0.3	12.0	1.0	1.4	4.8	2.4
WY	406	80.5	0.2	9.6	2.0	1.0	6.7	0.0
TOTAL	9496	75.2	0.6	13.9	1.4	1.1	5.7	1.2

Table 12. Vision

	<i>N</i>	<i>% Sees Well</i>	<i>% Vision Problems Limit Activities</i>	<i>% Limited or No Vision/Legally Blind</i>	<i>% Don't Know</i>
AL	295	92.5	4.7	1.4	1.4
RCOC	597	88.8	3.4	7.5	0.3
CT	406	83.7	9.1	6.4	0.7
DE	290	82.8	9.7	6.2	1.4
HI	486	86.0	8.2	5.6	0.2
IN	788	87.9	6.7	3.7	1.6
IA	817	90.8	4.8	4.3	0.1
KY	509	80.9	11.8	4.5	2.8
ME	417	95.4	0.7	3.8	0.0
NC	586	83.1	7.8	6.8	2.2
OK	407	88.5	5.4	5.9	0.2
PA	1345	87.3	5.9	5.1	1.7
RI	406	85.7	7.6	6.2	0.5
SC	573	86.7	4.7	5.4	3.1
SD	533	87.4	8.1	4.5	0.0
VT	271	91.9	4.8	3.3	0.0
WV	291	83.2	9.6	4.5	2.7
WY	406	85.5	10.6	3.9	0.0
TOTAL	9423	87.2	6.7	5.0	1.1

VII. Results: Core Indicator Outcomes and Comparisons across States

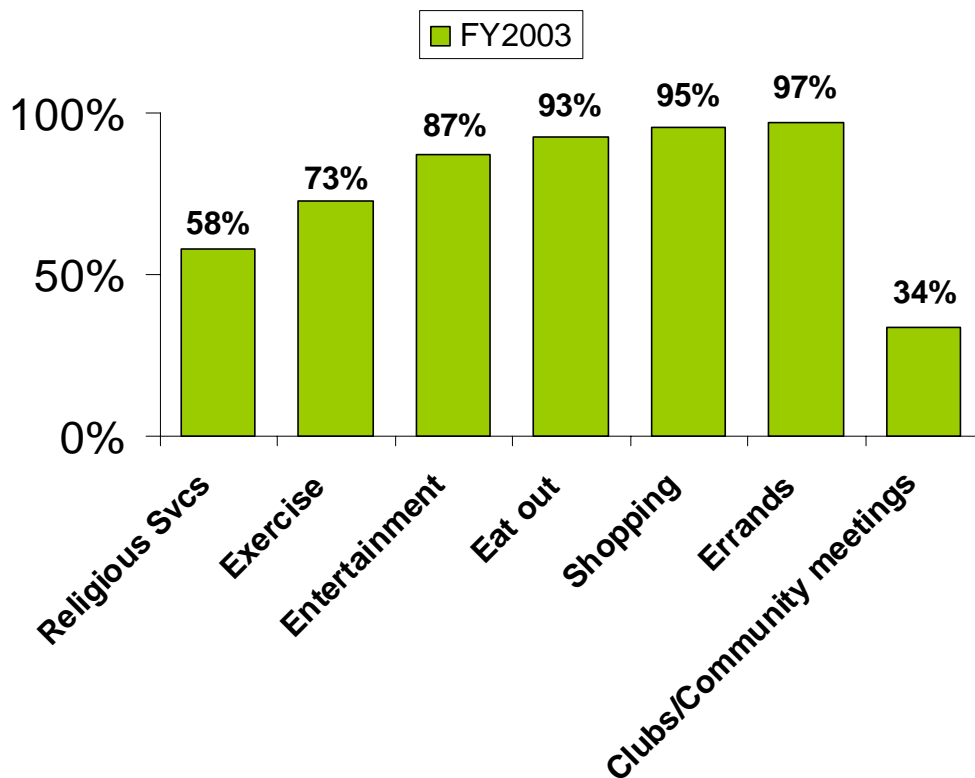
The data from the Consumer Survey were analyzed to assess core indicator outcomes for the sample as a whole and separately by state. The following brief summary highlights national results from FY2003 NCI data. Notable changes from FY2002 are indicated.

Summary of Aggregate Results

Community Inclusion

- » For most types of community activities asked about in the survey, participation was high, ranging from 73% to 97%. Two activities had lower participation: 58% attended religious services, and 34% reported belonging to clubs or community organizations.

Figure 4. Community Inclusion – Adjusted Results for Total Sample



Respect and Rights

- » 91% of all respondents report that they have enough privacy.
- » 31% of all respondents reported having attended a self-advocacy group meeting or event, compared with 28% in FY2002.
- » Across the board, most respondents report that residential support staff (88%) and day support staff (94%) treat them with respect.

Service Coordination

- » 84% of respondents report that they know their service coordinators, compared with 88% in FY2002.
- » 79% of all respondents report that service coordinators get them what they need, compared with 77% in FY2002.
- » 65% report that service coordinators ask them what is important, compared with 69% in FY2002.

Access

- » 82% of respondents reported that they almost always have a way to get where they want to go.

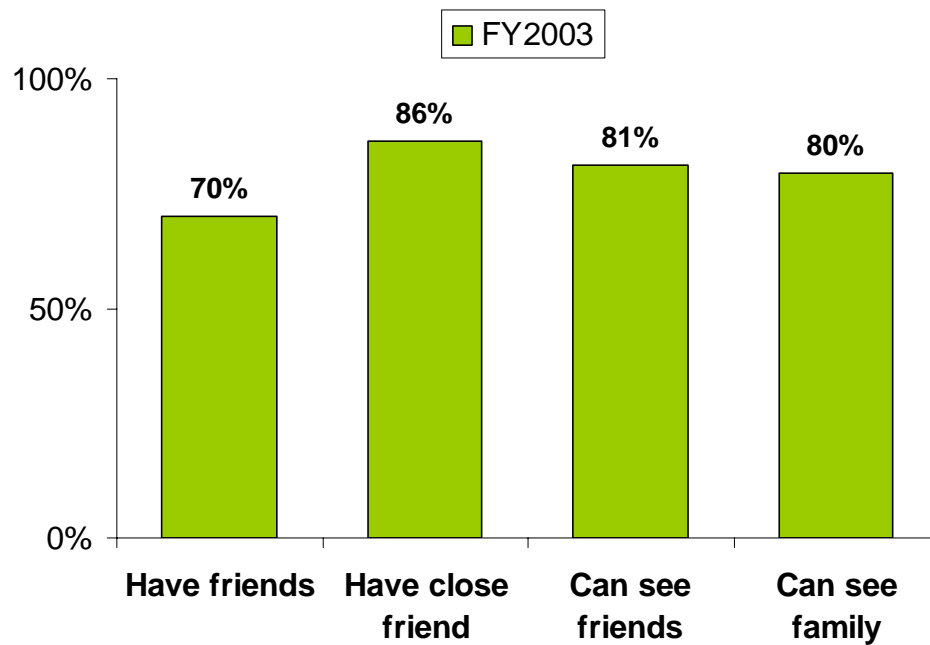
Satisfaction

- » Satisfaction with home was 87% (compared with 94% in FY2002) and satisfaction with work/day program was 90% (compared with 96% in FY2002).

Relationships

- » The majority of respondents report having friends other than family and staff (72%), best friends (85%), and being able to see their friends (79%) and family (77%) when they want to.
- » About half of the respondents (50%) reported “sometimes” or “always” feeling lonely.

Figure 5. Relationships – Results for Total Sample



Safety

- » 81% of respondents reported feeling safe in their homes, and 81% reported feeling safe in their neighborhood.

Health

- » Across the board, women’s access to yearly GYN exams continues to be low (only 53% had an exam in the past year and 7% have never had one).

Figure 6. Time of Last Physical Exam

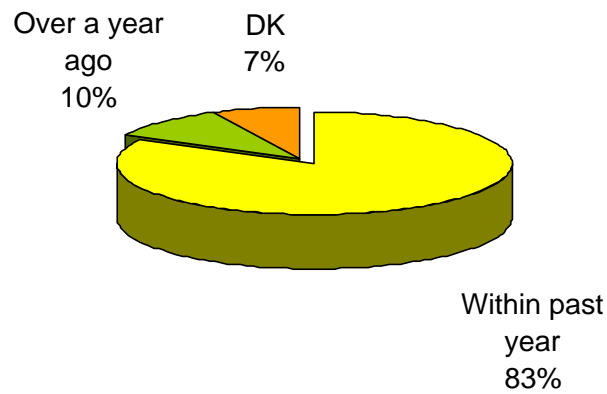


Figure 7. Time of Last Dental Exam

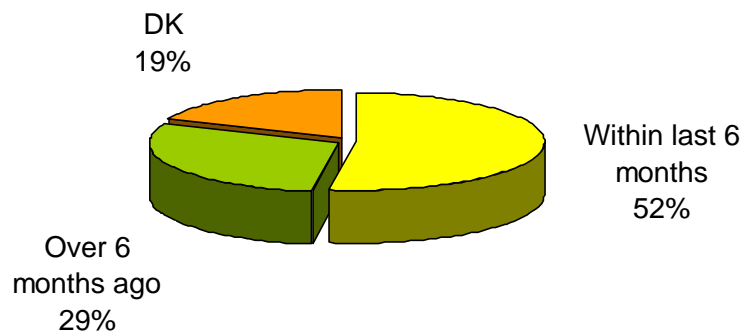
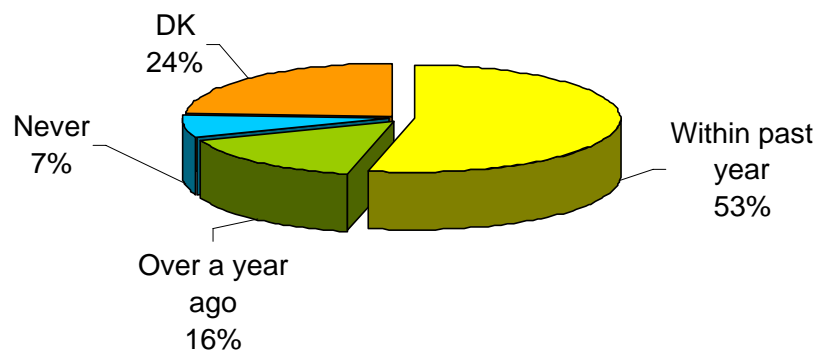


Figure 8. Time of Last GYN Visit



Presentation of Detailed Results by State

The results are organized according to the current list of Core Indicators¹¹. Each section represents one Sub-domain and contains the following information:

- Concern statement for the Sub-domain
- Indicators in that Sub-domain measured by the Consumer Survey
- Statistics provided for **all** indicators:
 - ♦ **Mean proportion** (either adjusted or non-adjusted) for each state and for the total sample
 - ♦ Two “summary” measures are displayed. (1) The “TOTAL” row is simply the aggregate of all responses across all states. This measure does not take into account the different state sample sizes. (2) The “STATE AVERAGE” row represents the mean across all states. Thus, all states are equally represented in this measure, regardless of sample size.
 - ♦ **Valid N** for each state and for the total sample
- Additional statistics provided **only for scale scores** (Community Inclusion, Supports-Related Choices, Personal Choices, and Service Coordination):
 - ♦ Significance testing for **each state vs. the national average**
 - ♦ Significant differences **among states** (Tukey’s test)
- The results for the states are indicated by the two letter abbreviations.
- Tables that display “adjusted” results are so noted. For these indicators, the sample sizes may be 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.
- Broadly, the “STATE AVERAGE” figures constitute benchmarks for comparing states. For example, when a particular state’s mean score is appreciably higher than the cross-state average, the quality or characteristic is better reflected in the state’s system than in others.
- On the other hand, in states where the mean score is appreciably lower than the cross-state average, then there is a valid basis for stakeholders to probe further.

¹¹ The current version is Phase V Core Indicators (in draft).

- In no instance should the cross-state averages be interpreted as necessarily defining “acceptable” levels of performance or satisfaction. Instead, they are a multi-state “norms” that describe present levels of performance or satisfaction across the participating 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 average level) in one or two states, the levels of satisfaction achieved there might define a level of performance that may serve as a guidepost for other states.

- Phase IV (FY2002) data are not presented in this report. **At this stage of NCI, comparisons of results from year to year should be made with caution**, for three reasons: (1) even slight changes in wording or response options of certain questions may affect comparability of results from one year to the next; (2) the mix of participating states differs slightly each year and may affect the “total sample” results; and (3) the states draw new samples each year rather than following the same group of individuals. **Appendix D includes a crosswalk of consumer survey questions from year to year, and indicates item comparability across years.**

Consumer Outcomes: Work

The Work Sub-domain has the following concern statement: “People have support to find and maintain community integrated employment.” There are six work indicators measured using the supplement to the Consumer Survey:

1. The average monthly earnings of people who have jobs in the community.
2. The average number of hours worked per month for people with jobs in the community.
3. The percent of people earning at or above the state minimum wage.¹²
4. Of people who have a job in the community, the percent who were continuously employed during the previous year.
5. Of people who have a job in the community, the percent who receive job benefits.
6. Of people who have a job in the community, the average length of time people have been working at their current job.

IMPORTANT NOTE ABOUT THE DATA SOURCE

A review of previous data collection efforts concluded that the most preferable way to collect the employment data was through the Consumer Survey supplement, *unless* a state already had a good system in place for obtaining the information from providers (e.g., Vermont, Washington, Wyoming). Massachusetts decided to create a new reporting system (adapted from the original Provider Survey protocol) that would require provider agencies by contract to report employment information on an annual basis. One advantage to using the Consumer Survey supplement is the potential ability to link the employment information with other person-level data collected in the survey. The major drawback at this time is that the information is only collected on a sample of the service population (usually about 400 individuals), and once the data is broken down by type of employment, the Ns are very small in some categories.

The current version of the supplement form is entitled “Day/Vocational/Educational Support” and expands on the basic survey by requesting additional information about competitive employment, enrollment in public school, funding streams, job benefits, and length of employment in the community.

In Phase V, eight states collected data using the Consumer Survey supplement (CA – RCOC, CT, IA, IN, NC, OK, PA, SD) and four states submitted data from their own systems (MA, VT, WA, WY). Data extracted from state systems are from FY2002. Data collected using the Consumer Survey supplement are from FY2003.

¹² Not reported for Phase V.

Table 13. Earnings and Hours Worked Per Month, By State (Source: Consumer Survey Supplement FY2003)

State	Category of employment	Average Monthly wage	MIN	MAX	N of Consumers	Average Monthly Hours Worked	MIN	MAX	N of Consumers
RCOC	Competitive	\$599.60	\$48.00	\$1,425.60	23	76.7	8	173	27
	Individual supported	\$508.04	\$28.00	\$1,200.00	51	75.5	4	168	57
	Group Supported	\$254.92	\$6.58	\$1,212.60	60	76.2	6	160	62
	Facility Based Work Program	\$97.63	\$0.00	\$795.06	68	79.6	4	160	75
	Facility Based Non Work Activities					83.3	6	160	78
	Community Based Non Work Activities					83.9	4	186	73
CT	Competitive	\$667.02	\$1.00	\$2,000.00	30	80.1	4	160	32
	Individual supported	\$375.68	\$80.40	\$1,068.00	20	48.2	12	156	23
	Group Supported	\$266.92	\$8.00	\$800.00	54	78.3	15	165	66
	Facility Based Work Program	\$166.91	\$1.00	\$650.00	30	72.3	12	140	32
	Facility Based Non Work Activities					74.7	12	173	57
	Community Based Non Work Activities					78.1	4	150	49
IA	Competitive	\$393.06	\$8.00	\$1,543.25	36	54.7	10	162	45
	Individual supported	\$254.55	\$5.90	\$786.50	41	40.2	1	120	43
	Group Supported	\$127.23	\$1.12	\$433.19	20	46.0	4	200	22
	Facility Based Work Program	\$87.43	\$0.00	\$609.33	209	67.6	1	150	202
	Facility Based Non Work Activities					60.9	1	150	98
	Community Based Non Work Activities					20.1	1	104	42

Table 14. Earnings and Hours Worked Per Month, By State – Continued (Source: Consumer Survey Supplement FY2003)

State	Category of employment	Average Monthly wage	MIN	MAX	N of Consumers	Average Monthly Hours Worked	MIN	MAX	N of Consumers
IN	Competitive	\$355.77	\$20.00	\$939.00	39	61.9	4	160	42
	Individual supported	\$217.94	\$40.00	\$573.55	33	52.5	8	131	38
	Group Supported	\$166.28	\$0.56	\$800.00	24	62.8	11	160	25
	Facility Based Work Program	\$96.68	\$0.00	\$2,416.00	357	74.8	1	160	364
	Facility Based Non Work Activities					75.3	1	200	244
	Community Based Non Work Activities					23.1	1	150	200
NC	Competitive	\$388.09	\$25.00	\$1,080.33	40	68.6	1	177	44
	Individual supported		Data not displayed where n<5			42.6	1	140	62
	Group Supported	\$121.86	\$2.51	\$466.16	17	56.8	1	120	21
	Facility Based Work Program	\$68.92	\$0.00	\$567.79	142	58.0	3	200	143
	Facility Based Non Work Activities					72.7	3	200	131
	Community Based Non Work Activities					56.4	1	184	71
OK	Competitive	\$340.18	\$38.05	\$1,120.00	30	63.2	8	160	33
	Individual supported	\$28.00	\$850.00	\$269.23	49	86.5	5	160	54
	Group Supported	\$304.26	\$6.18	\$824.00	48	95.4	6	160	55
	Facility Based Work Program	\$83.16	\$0.00	\$600.00	145	85.2	13	140	145
	Facility Based Non Work Activities					50.2	8	120	30
	Community Based Non Work Activities					40.7	6	180	33

Table 15. Earnings and Hours Worked Per Month, By State – Continued (Source: Consumer Survey Supplement FY2003)

State	Category of employment	Average Monthly wage	MIN	MAX	N of Consumers	Average Monthly Hours Worked	MIN	MAX	N of Consumers
PA	Competitive	\$431.68	\$20.60	\$1,692.60	52	64.5	4	160	64
	Individual supported	\$252.84	\$6.00	\$1,027.50	40	58.3	1	200	48
	Group Supported	\$210.33	\$7.50	\$840.00	42	81.1	1	160	41
	Facility Based Work Program	\$99.30	\$0.00	\$2,098.00	342	83.0	2	185	399
	Facility Based Non Work Activities					84.6	1	180	348
	Community Based Non Work Activities					43.2	0.5	161	198
SD	Competitive	\$258.29	\$4.00	\$1,080.00	63	58.8	8	160	62
	Individual supported	\$59.55	\$2.00	\$196.00	92	49.1	4	152	98
	Group Supported	\$44.74	\$1.00	\$246.00	100	59.8	4	173	113
	Facility Based Work Program	\$103.42	\$0.00	\$983.00	326	80.4	4	173	326
	Facility Based Non Work Activities					73.6	4	165	393
	Community Based Non Work Activities					17.8	4	22	12

Table 16. Summary of Monthly Earnings, All States (Source: Consumer Survey Supplement FY2003)

Category of Employment	Mean Monthly Earnings for Total Sample	National Average
Competitive	\$403.44	\$429.21
Individual supported	\$244.87	\$241.46
Group Supported	\$181.88	\$187.79
Facility Based Work Program	\$96.30	\$101.13

Table 17. Summary of Monthly Hours Worked, All States (Source: Consumer Survey Supplement FY2003)

Category of Employment	Mean Hours per Month for Total Sample	National Average
Competitive	64.7	66.1
Individual supported	57.0	56.7
Group Supported	71.9	70.1
Facility Based Work Program	77.1	75.4
Facility Based Non-Work Activities	76.0	72.1
Community Based Non-Work Activities	44.0	45.4

Because the median values for combined wages are lower than the mean values, the mean value can be misleading. Percentiles are displayed in the table below in order to show what the income distribution looks like. For example, in CT, 50% of people make \$257 or less per month (all work activities combined). In Indiana, 50% of people make \$69 or less per month.

Table 18. Total Monthly Wages, All Work Activities Combined, by State (Source: Consumer Survey Supplement FY2003)

RCOC	Valid N	199	CT	Valid N	132	IA	Valid N	274
Mean		\$310	Mean		\$356	Mean		\$166
Median		\$156	Median		\$257	Median		\$78
Min		\$0	Min		\$1	Min		\$0
Max		\$1,426	Max		\$2,000	Max		\$2,149
Percentiles	25	\$51	Percentiles	25	\$90	Percentiles	25	\$21
	50	\$156		50	\$257		50	\$78
	75	\$500		75	\$518		75	\$218
IN	Valid N	395	NC	Valid N	198	OK	Valid N	260
Mean		\$145	Mean		\$153	Mean		\$193
Median		\$69	Median		\$50	Median		\$109
Min		\$0	Min		\$0	Min		\$0
Max		\$2,416	Max		\$1,416	Max		\$1,120
Percentiles	25	\$20	Percentiles	25	\$20	Percentiles	25	\$28
	50	\$69		50	\$50		50	\$109
	75	\$200		75	\$200		75	\$316
PA	Valid N	463	SD	Valid N	420	All States	Valid N	2341
Mean		\$163	Mean		\$143	Mean		\$182
Median		\$84	Median		\$81	Median		\$90
Min		\$0	Min		\$0	Minimum		\$0
Max		\$2,098	Max		\$1,326	Max		\$2,416
Percentiles	25	\$34	Percentiles	25	\$21	Percentiles	25	\$29
	50	\$84		50	\$81		50	\$90
	75	\$200		75	\$179		75	\$243

Table 19. Competitive Employment Wages, by State (Source: Consumer Survey Supplement FY2003)

RCOC	Valid N	23	CT	Valid N	30	IA	Valid N	36
	Mean	\$600		Mean	\$667		Mean	\$393
	Median	\$500		Median	\$549		Median	\$314
	Minimum	\$48		Minimum	\$1		Minimum	\$8
	Maximum	\$1,426		Maximum	\$2,000		Maximum	\$1,543
	Percentiles			Percentiles			Percentiles	
		25		25	\$280		25	\$92
		50		50	\$500		50	\$314
		75		75	\$928		75	\$500
IN	Valid N	39	NC	Valid N	40	OK	Valid N	30
	Mean	\$356		Mean	\$388		Mean	\$340
	Median	\$300		Median	\$294		Median	\$340
	Minimum	\$20		Minimum	\$25		Minimum	\$38
	Maximum	\$939		Maximum	\$1,080		Maximum	\$1,120
	Percentiles			Percentiles			Percentiles	
		25		25	\$180		25	\$118
		50		50	\$300		50	\$340
		75		75	\$468		75	\$439
SD	Valid N	63	PA	Valid N	52			
	Mean	\$258		Mean	\$432			
	Median	\$198		Median	\$333			
	Minimum	\$4		Minimum	\$21			
	Maximum	\$1,080		Maximum	\$1,693			
	Percentiles			Percentiles				
		25		25	\$85			
		50		50	\$198			
		75		75	\$374			

Table 20. Individual Supported Employment Wages, by State (Source: Consumer Survey Supplement FY2003)

RCOC	Valid N	51	CT	Valid N	20	IA	Valid N	41
	Mean	\$508		Mean	\$376		Mean	\$255
	Median	\$516		Median	\$270		Median	\$209
	Minimum	\$28		Minimum	\$80		Minimum	\$6
	Maximum	\$1,200		Maximum	\$1,068		Maximum	\$787
	Percentiles			Percentiles			Percentiles	
		25		25	\$124		25	\$66
		50		50	\$270		50	\$209
		75		75	\$590		75	\$444
IN	Valid N	27	OK	Valid N	49	PA	Valid N	40
	Mean	\$212		Mean	\$269		Mean	\$253
	Median	\$197		Median	\$200		Median	\$200
	Minimum	\$40		Minimum	\$28		Minimum	\$6
	Maximum	\$574		Maximum	\$850		Maximum	\$1,028
	Percentiles			Percentiles			Percentiles	
		25		25	\$105		25	\$72
		50		50	\$200		50	\$200
		75		75	\$408		75	\$347
SD	Valid N	92						
	Mean	\$60						
	Median	\$51						
	Minimum	\$2						
	Maximum	\$196						
	Percentiles							
		25						
		50						
		75						

Table 21. Facility-Based Work Program Wages, by State (Source: Consumer Survey Supplement FY2003)

RCOC	Valid N	68	CT	Valid N	30	IA	Valid N	209	
	Mean	\$98		Mean	\$167		Mean	\$87	
	Median	\$60		Median	\$60		Median	\$60	
	Minimum	\$0		Minimum	\$1		Minimum	\$0	
	Maximum	\$795		Maximum	\$650		Maximum	\$609	
	Percentiles	25	\$31	Percentiles	25	\$30	Percentiles	25	\$18
		50	\$60		50	\$60		50	\$60
		75	\$109		75	\$364		75	\$121
IN	Valid N	331	NC	Valid N	142	OK	Valid N	145	
	Mean	\$102		Mean	\$69		Mean	\$83	
	Median	\$50		Median	\$33		Median	\$40	
	Minimum	\$0		Minimum	\$0		Minimum	\$0	
	Maximum	\$2,416		Maximum	\$568		Maximum	\$600	
	Percentiles	25	\$15	Percentiles	25	\$17	Percentiles	25	\$13
		50	\$50		50	\$33		50	\$40
		75	\$125		75	\$76		75	\$101
PA	Valid N	342	SD	Valid N	326				
	Mean	\$99		Mean	\$103				
	Median	\$60		Median	\$53				
	Minimum	\$0		Minimum	\$0				
	Maximum	\$2,098		Maximum	\$983				
	Percentiles	25	\$25	Percentiles	25	\$14			
		50	\$60		50	\$53			
		75	\$121		75	\$136			

Table 22. Total Hours Worked, All Work Activities Combined, by State (Source: Consumer Survey Supplement FY2003)

RCOC	Valid N	216	CT	Valid N	149	IA	Valid N	266
Mean		79	Mean		75	Mean		69
Median		80	Median		80	Median		69
Minimum		4	Minimum		4	Minimum		1
Maximum		176	Maximum		165	Maximum		170
Percentiles	25	36	Percentiles	25	40	Percentiles	25	36
	50	80		50	80		50	69
	75	120		75	100		75	100
IN	Valid N	410	NC	Valid N	257	OK	Valid N	274
Mean		78	Mean		58	Mean		89
Median		80	Median		48	Median		91
Minimum		0.25	Minimum		1.00	Minimum		5
Maximum		180	Maximum		200	Maximum		160
Percentiles	25	32	Percentiles	25	20	Percentiles	25	60
	50	80		50	48		50	91
	75	120		75	89		75	120
PA	Valid N	533	SD	Valid N	406	All States	Valid N	2511
Mean		81	Mean		92	Mean		79
Median		80	Median		95	Median		80
Minimum		1	Minimum		4	Minimum		0
Maximum		185	Maximum		199	Maximum		200
Percentiles	25	42	Percentiles	25	52	Percentiles	25	40
	50	80		50	95		50	80
	75	120		75	130		75	120

Table 23. Total Hours Spent in Non-Work Activities, by State (Source: Consumer Survey Supplement FY2003)

RCOC	Valid N	138	CT	Valid N	99	IA	Valid N	122
Mean		91	Mean		82	Mean		56
Median		108	Median		100	Median		46
Minimum		4	Minimum		4	Minimum		0.5
Maximum		186	Maximum		173	Maximum		150
Percentiles	25	60	Percentiles	25	39	Percentiles	25	19
	50	108		50	100		50	46
	75	120		75	110		75	94
IN	Valid N	289	NC	Valid N	170	OK	Valid N	53
Mean		74	Mean		73	Mean		54
Median		68	Median		51	Median		40
Minimum		0.5	Minimum		1	Minimum		6
Maximum		200	Maximum		200	Maximum		180
Percentiles	25	26	Percentiles	25	30	Percentiles	25	36
	50	68		50	51		50	40
	75	120		75	120		75	72.5
PA	Valid N	471	SD	Valid N	394	All States	Valid N	1736
Mean		80	Mean		74	Mean		76
Median		96	Median		65	Median		75
Minimum		0.5	Minimum		4	Minimum		0.5
Maximum		188	Maximum		174	Maximum		200
Percentiles	25	30	Percentiles	25	22	Percentiles	25	30
	50	96		50	65		50	75
	75	120		75	130		75	120

Table 24. Community Employment Indicators, by State (Source: Consumer Survey Supplement FY2003)

	Continuous employment				Benefits				Years at current job			
	% Yes	% No	% N/A	Tot N	% Yes	% No	% N/A	Tot N	Mean	MIN	MAX	Tot N
RCOC	23.6	36.9	39.5	564	7.8	46.4	45.8	565	3.7	1 mo.	27 yrs.	152
CT	45.0	36.2	18.8	260	22.4	52.8	24.8	254	6.0	2 mo.	33 yrs.	42
IA	26.9	50.6	22.5	360	14.5	45.6	39.8	344	4.4	2 mo.	36 yrs.	97
IN	10.0	9.5	80.5	907	3.0	12.6	84.4	765	3.7	1 mo.	24 yrs.	94
NC	21.2	38.2	40.7	519	4.9	47.5	47.7	514	3.4	1 mo.	29 yrs.	140
OK	71.6	15.4	13.0	162	71.2	16.0	12.9	163	2.8	1 mo.	17 yrs.	131
PA	9.7	43.6	46.7	1129	2.4	32.8	64.9	247	2.5	1 mo.	30 yrs.	71
SD	28.7	59.0	59.0	485	4.6	57.7	37.7	501	5.2	3 mo.	27 yrs.	220

Table 25. Percent of Respondents Enrolled in Public School, by State (Source: Consumer Survey Supplement FY2003)

	% Yes	% No	Tot N
RCOC	13.7	86.3	564
CT	3.3	96.7	307
IA	4.1	95.9	439
IN	1.7	98.3	819
NC	8.1	91.9	582
OK	3.2	96.8	407
PA	8.0	92.0	1285
SD	0.0	100.0	533

Table 26. Funding Sources of Day/Vocational Services Received, by State (Source: Consumer Survey Supplement FY2003)

	% HCBS Waiver Program	% State MR/DD Agency	% Voc Rehab Agency	% PAS/IRWE	% Other	% N/A
RCOC	19.1	46.8	31.6	1.2	5.1	23.7
CT	40.9	61.2	3.6	0.4	4.0	16.1
IA	18.4	13.8	4.8	99.8	50.5	16.4
IN	27.7	44.9	4.5	0.0	5.9	15.8
NC	27.0	34.5	9.8	0.0	16.0	21.4
OK	29.5	27.3	0.2	0.0	10.8	33.7
PA	54.5	13.8	1.1	0.2	13.6	18.7
SD	93.8	0.0	0.8	0.9	3.8	2.1

The following table displays employment indicators for the four states that submitted state data system information.
Note: these data are from FY2002.

Table 27. Average Monthly Earnings and Average Hours Worked per Month, by State (Source: State Data Systems FY2002)

State	Category of employment	Average Monthly Wage	Average Hours Worked per Month	N of Consumers
MA	Facility Based Work Program	\$76.32	54.42	3110
	Group Supported	\$162.83	44.11	1549
	Individual Supported	\$382.47	58.40	1573
	Overall	\$195.87	59.14	5571
<i>Source: Massachusetts Provider Survey FY 2002</i>				
VT	Facility Based Work Program	\$54.71	47.99	25
	Group Supported	\$350.82	71.60	14
	Individual Supported ^a	\$383.66	54.65	719
	Overall	\$382.80	56.46	747
<i>Source: Vermont FY 2002 Survey of Employment/Vocational Services</i>				
WA	Facility Based Work Program	\$117.08	64.77	1208
	Group Supported	\$284.86	74.64	1011
	Individual Supported	\$699.35	83.16	1870
	Overall ^b	\$424.85	75.62	4089
<i>Source: Washington Division of Developmental Disabilities Cost Benefit Analysis Report June 2002</i>				
WY	Facility Based Work Program	\$172.37	53.83	194
	Group Supported	None	None	None
	Individual Supported	\$319.13	71.38	128
	Competitive	\$210.34	48.26	139
	Overall	\$224.57	57.02	461
<i>Source: Wyoming Division of Developmental Disabilities FY 2002</i>				
^a For VT, the "Individual Supported" line includes both categories "Competitive" and "Individual Supported" employment.				
^b Overall figures for WA may include duplicate counts for people who receive more than one type of employment support.				

Consumer Outcomes: Community Inclusion

The Community Inclusion Sub-domain has the following concern statement: “People use integrated community services and participate in everyday community activities.” There is one indicator listed:

1. The proportion of people who participate in everyday integrated activities in their communities.

Seven items from the consumer survey are grouped together to create a composite “scale score” for Community Inclusion. All of these items are first “risk adjusted” using a logistic regression model to control for differences in respondent characteristics (e.g., level of MR, age, etc.) across states. The predicted values created by the logistic regression represent the “adjusted mean proportion” for each state. A separate regression analysis is performed for each item. The scale score is then computed by averaging the predicted values of all seven items. In order for a score to be computed, the person (or a proxy respondent) must have answered at least five out of seven questions. The seven items look at whether or not people:

- Go shopping
- Go out on errands or appointments
- Go out for entertainment
- Go out to eat
- Go to religious services
- Go to clubs or community meetings
- Exercise or play sports

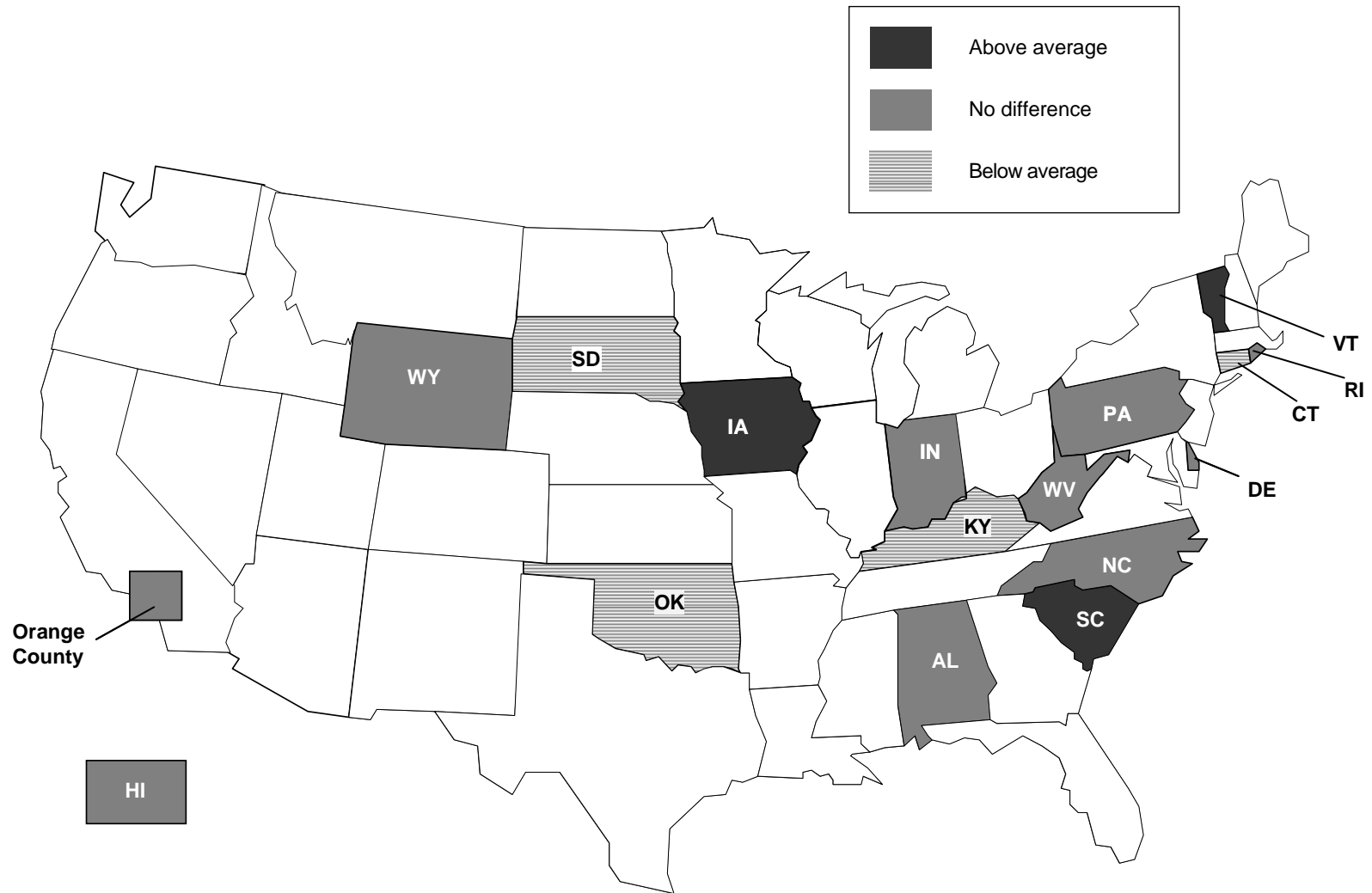
A scale can be considered a reliable measure if its internal consistency is ≥ 0.70 . The statistic that assesses the scale’s reliability is called Cronbach’s alpha. An internal reliability test of the Community Inclusion scale resulted in a Cronbach’s alpha = **0.76**. This result attests to the reliability of the scale. In other words, we can be fairly confident that all items are measuring the same dimension.

Each state’s scale score was compared with the average scale score across all other states (not including that state). The table on the right displays each state’s scale score compared with the average across all other states, and the last column indicates whether or not the state’s score was significantly different from the average. A conservative cutoff point ($p \geq 0.01$) was used to determine significant differences. Figure 9 on the next page displays state performance on the Community Inclusion scale in a map format. Those states colored in dark grey performed above average, those with horizontal stripes performed below average, and those in light grey were no different from the average.

Table 28. Community Inclusion Scale Scores by State, Compared to National Average

	State Scale Score	Average Across All Other States	Sig. at $p \geq 0.01$
VT	0.898	0.527	Yes
SC	0.564	0.530	Yes
IA	0.547	0.530	Yes
WV	0.540	0.531	No
PA	0.538	0.530	No
AL	0.537	0.531	No
RCOC	0.533	0.531	No
WY	0.524	0.532	No
NC	0.524	0.532	No
IN	0.523	0.532	No
HI	0.517	0.532	No
DE	0.516	0.532	No
RI	0.516	0.532	No
KY	0.514	0.532	Yes
SD	0.513	0.533	Yes
CT	0.510	0.532	Yes
OK	0.505	0.533	Yes

Figure 9. Community Inclusion: State Scale Scores Compared with National Average



Analysis of variance is a collection of techniques used to test for differences among more than two groups. Post hoc (multiple comparison) tests provide information about which groups are different from each other. One such analysis, called Tukey's test, was performed to determine "homogeneous subsets" of results, i.e., groups of states that are not significantly different from one another. The following table displays the results of the Tukey's test. Subsets are arranged by column and labeled with a number at the top of each column. Scores that fall in the same subsets are not significantly different. For example: Alabama's score of 0.54 spans across subsets 2, 3, and 4. Therefore, Indiana's result is not significantly different from any of the other states that fall in subsets 2, 3, or 4. It is, however, significantly different from Oklahoma (which only falls in subset 1), and Vermont (which only falls in subset 5). Another way to interpret these results is to use the minimum significant difference, which is estimated at **0.03** for the Community Inclusion scale. Using the Alabama example, any state with a score less than 0.51 or greater than 0.57 would be significantly different from Alabama.

Table 29. Community Inclusion Scale Scores, by Subsets of States

State	N	Subset for alpha = .05				
		1	2	3	4	5
OK	389	0.51				
CT	371	0.51	0.51			
SD	497	0.51	0.51			
KY	371	0.51	0.51			
RI	372	0.52	0.52	0.52		
DE	236	0.52	0.52	0.52		
HI	447	0.52	0.52	0.52		
IN	756	0.52	0.52	0.52		
NC	457	0.52	0.52	0.52		
WY	398	0.52	0.52	0.52		
RCOC	547	0.53	0.53	0.53	0.53	
AL	200		0.54	0.54	0.54	
PA	1057		0.54	0.54	0.54	
WV	232		0.54	0.54	0.54	
IA	597			0.55	0.55	
SC	299				0.56	
VT	85					0.90

The following seven tables display the results for each item that comprises the Community Inclusion Scale. Results are ordered from highest to lowest scores by state. The “adjusted” mean proportions are displayed. **“State average”** represents the average score across states. This figure is computed by adding the adjusted mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 99-102 of Appendix C.

Table 30. Proportion of people who go shopping

State	Valid N	Adjusted Mean Proportion
VT	85	97%
WY	398	96%
IA	597	96%
SC	299	96%
WV	232	96%
NC	457	95%
ME	315	95%
CT	371	95%
KY	371	95%
OK	389	95%
IN	756	95%
SD	497	95%
HI	447	95%
PA	1057	95%
RCOC	547	95%
DE	236	95%
RI	372	95%
AL	200	94%
State Average		95%
Total	7626	95%

Table 31. Proportion of people who go out on errands or appointments

State	Valid N	Adjusted Mean Proportion
VT	85	98%
WY	398	98%
WV	232	98%
NC	457	97%
IA	597	97%
KY	371	97%
SD	497	97%
SC	299	97%
OK	389	97%
CT	371	97%
IN	756	97%
RCOC	547	97%
HI	447	97%
DE	236	97%
PA	1057	97%
RI	372	97%
AL	200	96%
State Average		97%
Total	7311	97%

Table 32. Proportion of people who go out for entertainment

State	Valid N	Adjusted Mean Proportion
OK	389	89%
WY	398	88%
VT	85	88%
IA	597	88%
NC	457	88%
KY	371	88%
HI	447	88%
WV	232	88%
SD	497	88%
SC	299	87%
IN	756	87%
RCOC	547	87%
AL	200	87%
CT	371	87%
DE	236	87%
PA	1057	86%
RI	372	86%
State Average		87%
Total	7311	87%

Table 33. Proportion of people who go out to eat

State	Valid N	Adjusted Mean Proportion
VT	85	95%
SC	299	94%
WV	232	93%
IA	597	93%
PA	1057	93%
WY	398	93%
CT	371	93%
ME	315	93%
SD	497	93%
IN	756	93%
NC	457	93%
RI	372	93%
KY	371	93%
RCOC	547	92%
AL	200	92%
DE	236	92%
HI	447	92%
OK	389	91%
State Average		93%
Total	7626	93%

Table 34. Proportion of people who go to religious services

State	Valid N	Adjusted Mean Proportion
VT	85	60%
ME	315	60%
AL	200	60%
HI	447	59%
IA	597	59%
WV	232	59%
PA	1057	58%
SC	299	58%
DE	236	58%
CT	371	58%
RI	372	58%
RCOC	547	58%
IN	756	58%
NC	457	57%
SD	497	57%
WY	398	57%
KY	371	57%
OK	389	56%
State Average		58%
Total	7626	58%

Table 35. Proportion of people who go to clubs or community meetings

State	Valid N	Adjusted Mean Proportion
SC	299	39%
PA	1057	38%
RCOC	547	38%
AL	200	37%
RI	372	36%
IN	756	34%
DE	236	34%
IA	597	33%
WV	232	32%
NC	457	31%
CT	371	31%
KY	371	30%
SD	497	30%
OK	389	30%
HI	447	30%
WY	398	29%
State Average		33%
Total	7226	34%

Table 36. Proportion of people who exercise or play sports

State	Valid N	Adjusted Mean Proportion
WY	398	75%
IA	597	74%
WV	232	74%
NC	457	74%
HI	447	74%
KY	371	73%
SD	497	73%
SC	299	73%
OK	389	73%
ME	315	73%
CT	371	73%
IN	756	72%
AL	200	72%
DE	236	72%
RCOC	547	72%
PA	1057	71%
RI	372	71%
State Average		73%
Total	7541	73%

Consumer Outcomes: Choice and Decision-Making

The Choice and Decision-Making Sub-domain has the following concern statement: “People make choices about their lives and are actively engaged in planning their services and supports.” The two indicators listed are:

1. The proportion of people who make choices about their everyday lives.
2. The proportion of people who report having been provided options about where to live and work.

The Consumer Survey includes eleven choice items. Two scales were created using the adjusted mean proportions of nine items. These two scales measure the first indicator. The first scale, called “Support-Related Choices,” is composed of five items. These items indicate whether people chose (or had some input in choosing):

- Place where they live (if not living with family)
- Staff who help at home
- Work or day activity
- Staff who help at work
- Case manager/service coordinator

In order for a score to be computed, the person (or a proxy respondent) must have answered at least four out of five questions. Internal consistency of the Supports-Related Choices scale was high, with a Cronbach’s alpha of **0.92**.

The second scale, called “Personal Choices,” includes four items. These items indicate whether people choose (or have some input in choosing):

- People they live with (if not living with family)
- Daily schedule
- How to spend free time
- What to buy with spending money

In order for a score to be computed, the person (or a proxy respondent) must have answered at least three out of four questions. Internal consistency of the Personal Choices scale was high, with a Cronbach’s alpha of **0.96**.

Each state’s scale score was compared with the average scale score across all other states (not including that state). The tables below display each state’s scale score compared with the average across all other states, and the last column indicates whether or not the state’s score was significantly different from the average. A conservative cutoff point ($p \geq 0.01$) was used to determine significant differences.

Figures 10 and 11 on the following pages display state performance on the Supports-Related Choices and Personal Choices scales in a map format. Those states colored in dark grey performed above average, those with horizontal stripes performed below average, and those in light grey were no different from the average.

Table 37. Supports-Related Choices Scale Scores by State, Compared to National Average

	State Scale Score	Average Across All Other States	Sig. at p>=0.01
VT	0.841	0.653	Yes
SC	0.715	0.653	Yes
WY	0.714	0.652	Yes
IA	0.699	0.652	Yes
WV	0.681	0.655	No
CT	0.675	0.655	No
RCOC	0.674	0.654	No
PA	0.667	0.654	No
IN	0.653	0.656	No
SD	0.651	0.656	No
RI	0.640	0.656	No
NC	0.639	0.657	No
KY	0.626	0.657	No
AL	0.593	0.657	Yes
DE	0.591	0.658	Yes
OK	0.585	0.660	Yes
HI	0.581	0.660	Yes

Table 38. Personal Choices Scale Scores by State, Compared to National Average

	State Scale Score	Average Across All Other States	Sig. At p>=0.01
VT	0.911	0.743	Yes
SC	0.825	0.741	Yes
PA	0.783	0.738	Yes
RCOC	0.780	0.742	Yes
IA	0.771	0.742	Yes
WY	0.766	0.744	No
RI	0.754	0.744	No
WV	0.754	0.744	No
CT	0.748	0.745	No
IN	0.748	0.744	No
SD	0.725	0.746	No
AL	0.722	0.745	No
NC	0.712	0.747	Yes
KY	0.700	0.747	Yes
DE	0.699	0.746	Yes
HI	0.663	0.750	Yes
OK	0.647	0.750	Yes

Figure 10. Support-Related Choices: State Scale Scores Compared with National Average

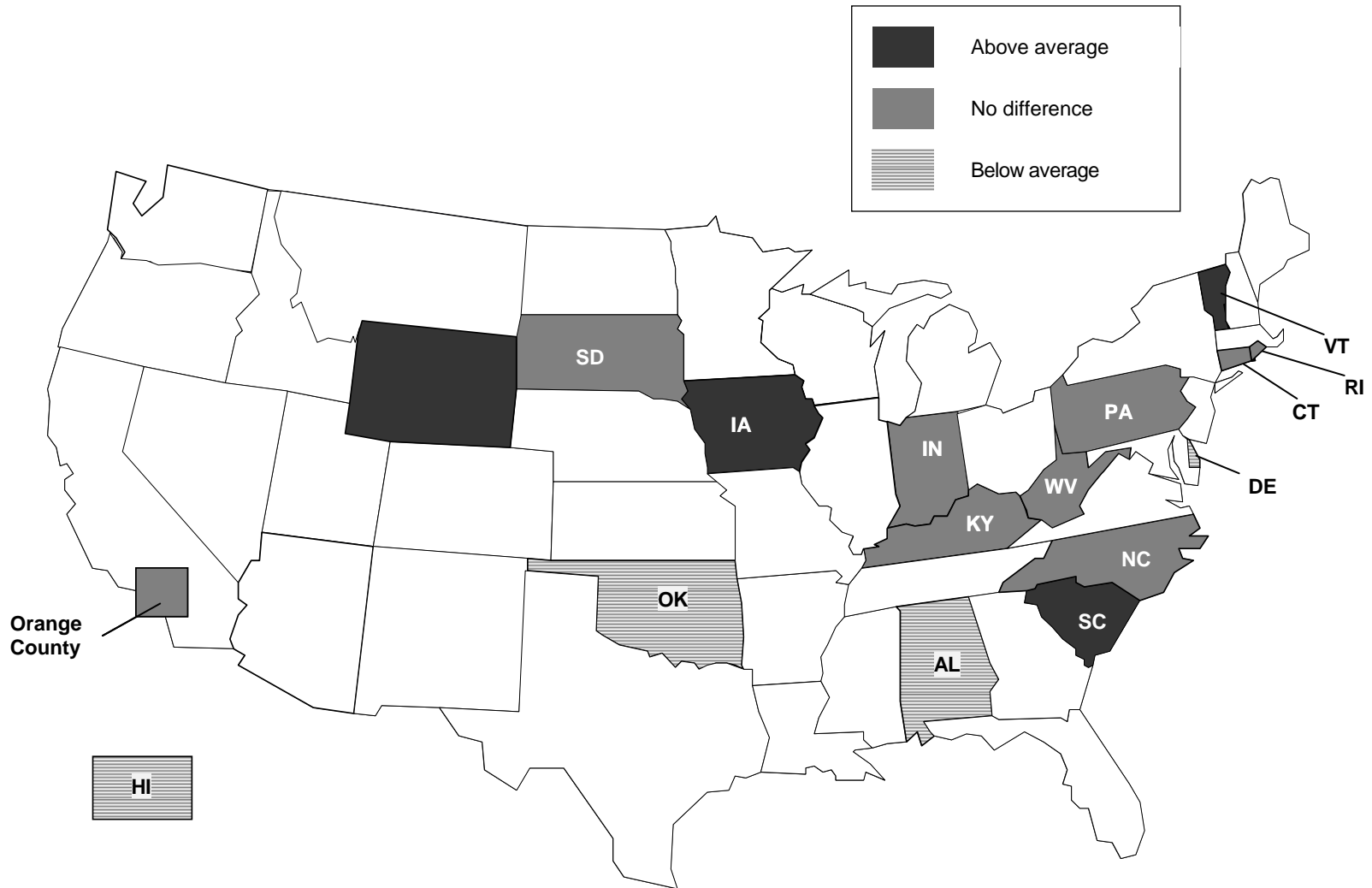
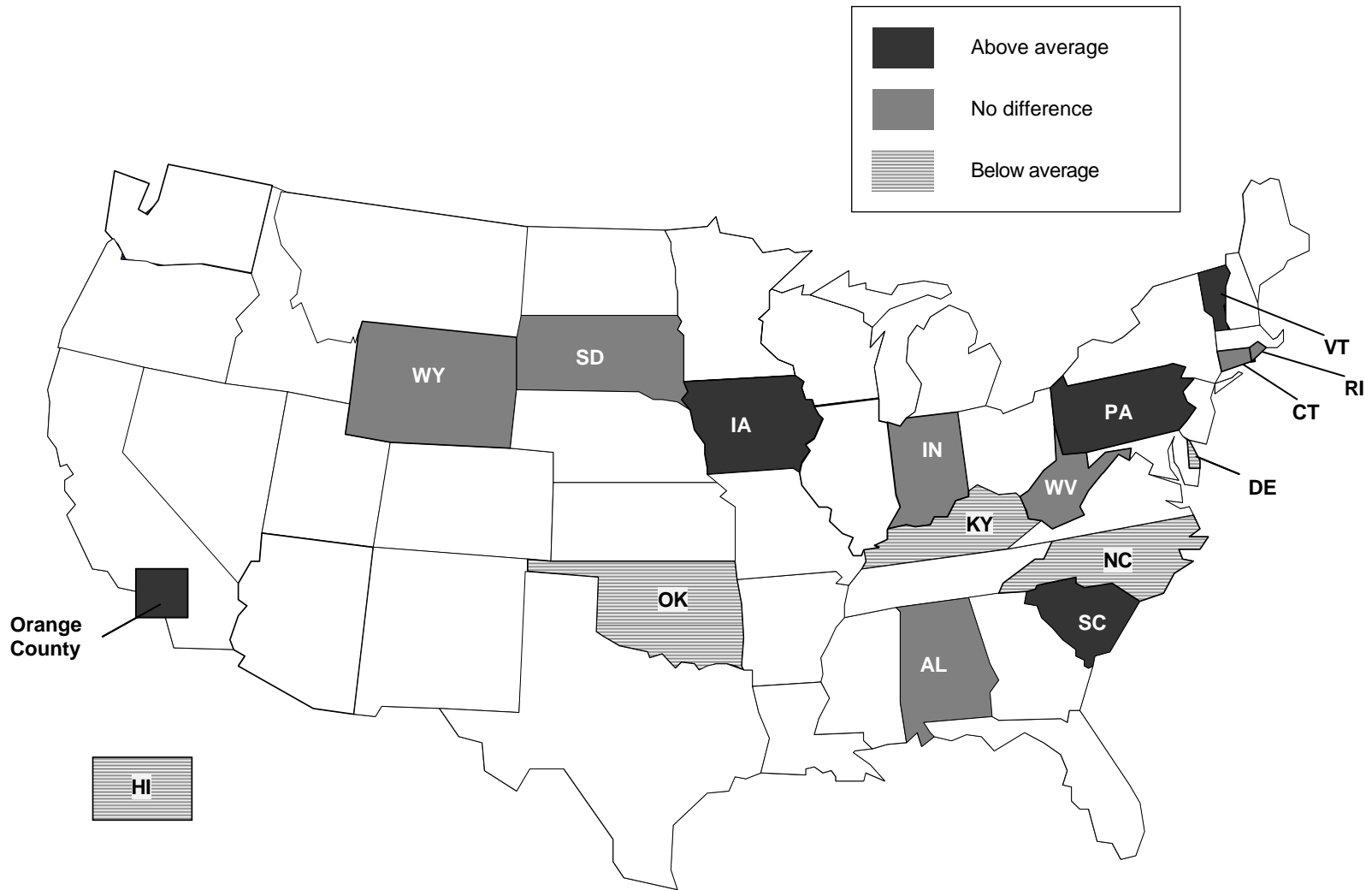


Figure 11. Personal Choices: State Scale Scores Compared with National Average



Tukey's tests were also performed to determine which states were significantly different from one another on each scale. Scores that fall into the same subsets are not significantly different. For the Support-Related Choices scale, the minimum significant difference is estimated at **0.08**. For the Personal Choices scale, the minimum significant difference is estimated at **0.07**.

Table 39. Support-Related Choices Scale Scores, by Subsets of States

State	N	Subset for alpha = .05				
		1	2	3	4	5
HI	447	0.58				
OK	389	0.58				
DE	236	0.59				
AL	200	0.59				
KY	371	0.63	0.63			
NC	457	0.64	0.64	0.64		
RI	372	0.64	0.64	0.64		
SD	497	0.65	0.65	0.65	0.65	
IN	756	0.65	0.65	0.65	0.65	
PA	1057		0.67	0.67	0.67	
RCOC	547		0.67	0.67	0.67	
CT	371		0.67	0.67	0.67	
WV	232		0.68	0.68	0.68	
IA	597			0.70	0.70	
WY	398				0.71	
SC	299				0.71	
VT	85					0.84

Table 40. Personal Choices Scale Scores, by Subsets of States

State	N	Subset for alpha = .05						
		1	2	3	4	5	6	7
OK	389	0.65						
HI	447	0.66	0.66					
DE	236	0.70	0.70	0.70				
KY	371	0.70	0.70	0.70				
NC	457	0.71	0.71	0.71	0.71			
AL	200		0.72	0.72	0.72	0.72		
SD	497		0.73	0.73	0.73	0.73		
IN	756			0.75	0.75	0.75		
CT	371			0.75	0.75	0.75		
WV	232			0.75	0.75	0.75		
RI	372			0.75	0.75	0.75		
WY	398			0.77	0.77	0.77	0.77	
IA	597				0.77	0.77	0.77	
RCOC	547				0.78	0.78	0.78	
PA	1057					0.78	0.78	
SC	299						0.82	
VT	85							0.91

The following eleven tables display the results for each choice item. The items that comprise the two choice scales are listed first. The last two items are not included in the scales, but relate to the second choice indicator. These two items are:

- Person looked at more than one home
- Person looked at more than one job

Results are ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the adjusted mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 103-108 of Appendix C.

Table 41. Proportion of people who chose place where they live

State	Valid N	Adjusted Mean Proportion
VT	85	66%
SC	299	56%
RCOC	547	56%
PA	1057	54%
IA	597	54%
WY	398	53%
CT	371	52%
WV	232	52%
IN	756	51%
RI	372	51%
SD	497	50%
NC	457	49%
AL	200	49%
KY	371	48%
DE	236	47%
OK	389	45%
HI	447	44%
State Average		52%
Total	7311	51%

Table 42. Proportion of people who choose staff who help them at home

State	Valid N	Adjusted Mean Proportion
VT	85	66%
WY	398	63%
SC	299	62%
IA	597	62%
WV	232	62%
CT	371	61%
NC	457	60%
IN	756	60%
SD	497	60%
KY	371	60%
OK	389	59%
PA	1057	59%
RI	372	59%
RCOC	547	59%
HI	447	58%
DE	236	58%
AL	200	57%
State Average		60%
Total	7311	60%

Table 43. Proportion of people who chose place of work or day activity

State	Valid N	Adjusted Mean Proportion
VT	85	74%
SC	299	68%
RCOC	547	65%
PA	1057	65%
WY	398	64%
IA	597	64%
RI	372	62%
WV	232	62%
CT	371	62%
IN	756	62%
SD	497	60%
NC	457	59%
AL	200	59%
KY	371	59%
DE	236	57%
OK	389	56%
HI	447	55%
State Average		62%
Total	7311	62%

Table 44. Proportion of people who choose staff who help them at work or day activity

State	Valid N	Adjusted Mean Proportion
SC	299	67%
WY	398	66%
WV	232	66%
CT	371	66%
IA	597	65%
SD	497	65%
NC	457	64%
KY	371	64%
HI	447	64%
IN	756	64%
DE	236	63%
RI	372	63%
RCOC	547	63%
OK	389	63%
PA	1057	63%
AL	200	62%
State Average		64%
Total	7226	64%

Table 45. Proportion of people who chose case manager/service coordinator

State	Valid N	Adjusted Mean Proportion
VT	85	57%
WY	398	53%
IA	597	52%
WV	232	51%
CT	371	51%
SD	497	51%
NC	457	50%
KY	371	50%
SC	299	50%
HI	447	49%
IN	756	49%
RCOC	547	49%
OK	389	49%
PA	1057	48%
RI	372	48%
DE	236	47%
AL	200	47%
State Average		50%
Total	7311	50%

Table 46. Proportion of people who choose people they live with

State	Valid N	Adjusted Mean Proportion
VT	85	58%
SC	299	51%
PA	1057	50%
RCOC	547	50%
IA	597	49%
WV	232	48%
WY	398	48%
CT	371	47%
AL	200	47%
RI	372	47%
IN	756	47%
SD	497	46%
DE	236	45%
NC	457	45%
HI	447	43%
KY	371	43%
OK	389	42%
State Average		47%
Total	7311	47%

Table 47. Proportion of people who choose daily schedule

State	Valid N	Adjusted Mean Proportion
VT	85	92%
SC	299	88%
PA	1057	86%
RCOC	547	85%
WY	398	85%
IA	597	85%
RI	372	84%
WV	232	84%
IN	756	84%
CT	371	84%
SD	497	83%
AL	200	83%
NC	457	82%
KY	371	81%
DE	236	81%
HI	447	79%
OK	389	78%
State Average		84%
Total	7311	84%

Table 48. Proportion of people who choose how to spend free time

State	Valid N	Adjusted Mean Proportion
VT	85	97%
SC	299	94%
WY	398	93%
IA	597	93%
CT	371	93%
PA	1057	92%
WV	232	92%
ME	315	92%
RCOC	547	92%
RI	372	92%
IN	756	92%
SD	497	92%
NC	457	91%
KY	371	91%
AL	200	91%
DE	236	91%
HI	447	90%
OK	389	89%
State Average		92%
Total	7626	92%

Table 49. Proportion of people who choose what to buy with spending money

State	Valid N	Adjusted Mean Proportion
VT	85	96%
SC	299	93%
PA	1057	91%
WY	398	90%
RCOC	547	90%
RI	372	90%
IA	597	90%
WV	232	89%
CT	371	89%
IN	756	89%
ME	315	88%
KY	371	87%
SD	497	87%
AL	200	87%
NC	457	87%
DE	236	86%
HI	447	84%
OK	389	84%
State Average		89%
Total	7626	89%

Table 50. Proportion of people who looked at more than one home

State	Valid N	Mean Proportion (%)
RCOC	257	56.0
OK	231	43.3
AL	115	40.9
CT	232	40.5
IA	538	37.5
IN	474	36.9
KY	305	36.4
SD	418	34.2
NC	285	34.0
SC	185	30.3
WY	333	27.9
WV	100	27.0
HI	209	23.4
RI	252	22.6
PA	1019	16.3
DE	153	10.5
State Average		32.8
Total	5106	30.9

Table 51. Proportion of people who looked at more than one job

State	Valid N	Mean Proportion (%)
OK	218	53.2
RCOC	367	46.0
CT	277	36.8
KY	381	34.6
DE	199	33.7
SD	418	32.5
HI	309	31.7
IN	518	31.7
SC	299	31.4
IA	587	30.3
AL	167	29.3
RI	243	26.3
WY	335	24.2
WV	173	17.3
PA	1065	16.3
State Average		31.7
Total	5967	29.4

Consumer Outcomes: Relationships

The Relationships Sub-domain has the following concern statement: “People have friends and relationships.” There are four indicators listed in this sub-domain:

1. The proportion of people who have friends and caring relationships with people other than support staff and family members.
2. The proportion of people who have a close friend, someone they can talk to about personal things.
3. The proportion of people who are able to see their families and friends when they want.
4. The proportion of people who feel lonely.

Results are presented below for each indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 109-111 of Appendix C.

Table 52. Proportion of people who report having friends and caring relationships with people other than support staff and family members

State	Valid N	Mean Proportion (%)
RI	250	89.6
DE	139	88.5
OK	179	86.6
VT	108	83.3
CT	284	81.3
RCOC	466	78.1
IA	609	74.5
NC	414	72.9
SC	251	72.5
KY	344	72.4
AL	206	72.3
IN	628	70.7
WV	163	69.9
WY	290	62.8
PA	940	61.0
SD	353	56.7
ME	179	52.0
HI	250	46.8
State Average		71.8
Total	6053	70.1

Table 53. Proportion of people who report having a close friend

State	Valid N	Mean Proportion (%)
WY	260	94.6
HI	225	93.8
KY	319	92.5
AL	180	92.2
OK	169	91.7
PA	818	90.3
RI	236	90.3
WV	140	90.0
SC	229	90.0
ME	169	89.3
NC	365	85.8
SD	331	85.5
IA	568	85.4
IN	547	84.6
CT	255	82.7
RCOC	407	80.3
VT	115	67.0
DE	131	39.7
State Average		84.8
Total	5464	86.4

Table 54. Proportion of people who are able to see their families when they want to

State	Valid N	Mean Proportion (%)
ME	179	94.4
PA	812	91.9
RI	219	87.2
SD	345	85.2
AL	199	83.4
SC	244	83.2
IN	559	80.0
HI	228	78.9
IA	568	78.7
NC	388	76.5
KY	330	75.8
WY	274	73.4
CT	253	71.9
WV	151	71.5
RCOC	439	69.9
OK	165	69.7
VT	100	66.0
DE	115	51.3
State Average		77.2
Total	5568	79.5

Table 55. Proportion of people who are able to see their friends when they want to

State	Valid N	Mean Proportion (%)
ME	165	95.2
SD	341	90.3
KY	315	87.6
OK	176	86.9
RI	224	86.6
WY	264	85.2
CT	256	84.4
IN	546	83.3
PA	821	82.8
IA	584	82.7
AL	182	81.3
HI	230	80.4
SC	231	79.7
NC	360	79.2
RCOC	405	71.6
WV	146	69.9
VT	113	61.9
DE	122	39.3
State Average		79.4
Total	5481	81.4

Table 56. Proportion of people who feel lonely

State	Valid N	Mean Proportion (%)
HI	243	36.6
DE	124	39.5
SD	334	43.7
CT	270	45.2
IN	609	46.5
PA	924	46.8
WY	280	49.6
AL	197	51.8
SC	251	52.2
RCOC	454	52.2
OK	170	52.4
NC	406	52.5
KY	341	52.8
WV	158	53.8
VT	117	58.1
RI	239	63.2
IA	598	70.6
State Average		51.0
Total	5715	51.0

Consumer Outcomes: Satisfaction

The Satisfaction Sub-domain has the following concern statement: “People are satisfied with the services and supports received.” The indicators measured by the Consumer Survey are:

1. The proportion of people satisfied with where they live.
2. The proportion of people who are satisfied with their job or day program.

Results are presented below for each item, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on p. 112 of Appendix C.

Table 57. Proportion of people who report satisfaction with where they live

State	Valid N	Mean Proportion (%)
SD	360	97.2
NC	423	96.5
HI	250	96.4
IN	633	96.1
RCOC	468	95.7
WY	292	95.2
IA	613	94.9
SC	256	94.5
AL	210	94.3
RI	257	94.2
WV	168	94.0
PA	991	93.9
DE	141	93.6
CT	291	93.5
KY	346	93.4
OK	184	90.8
VT	136	86.8
ME	179	79.3
State Average		93.3
Total	6198	94.2

Table 58. Proportion of people who report satisfaction with their work/day program

State	Valid N	Mean Proportion (%)
VT	74	98.6
WY	267	98.5
HI	216	97.2
DE	139	97.1
IN	521	96.9
IA	523	96.7
NC	323	96.6
OK	147	96.6
WV	117	96.6
CT	260	96.5
RI	231	96.1
SD	333	96.1
ME	179	95.5
PA	845	94.7
SC	229	93.9
RCOC	397	93.2
KY	309	92.9
AL	177	91.5
State Average		95.9
Total	5287	95.6

System Performance: Service Coordination

The Service Coordination Sub-domain has the following concern statement: “Service Coordinators are accessible, responsive, and support the person’s participation in service planning.” The Consumer Survey measures three indicators related to service coordination:

1. The proportion of people reporting that service coordinators help them get what they need.
2. The proportion of people who know their service coordinators.
3. The proportion of people who report that their service coordinators asked about their preferences.

A scale was created using the three items that measure the indicators above. In order for a score to be computed, the person must have answered at least two out of three questions. Internal consistency of the Service Coordination scale was good, with a Cronbach’s alpha of **0.82**.

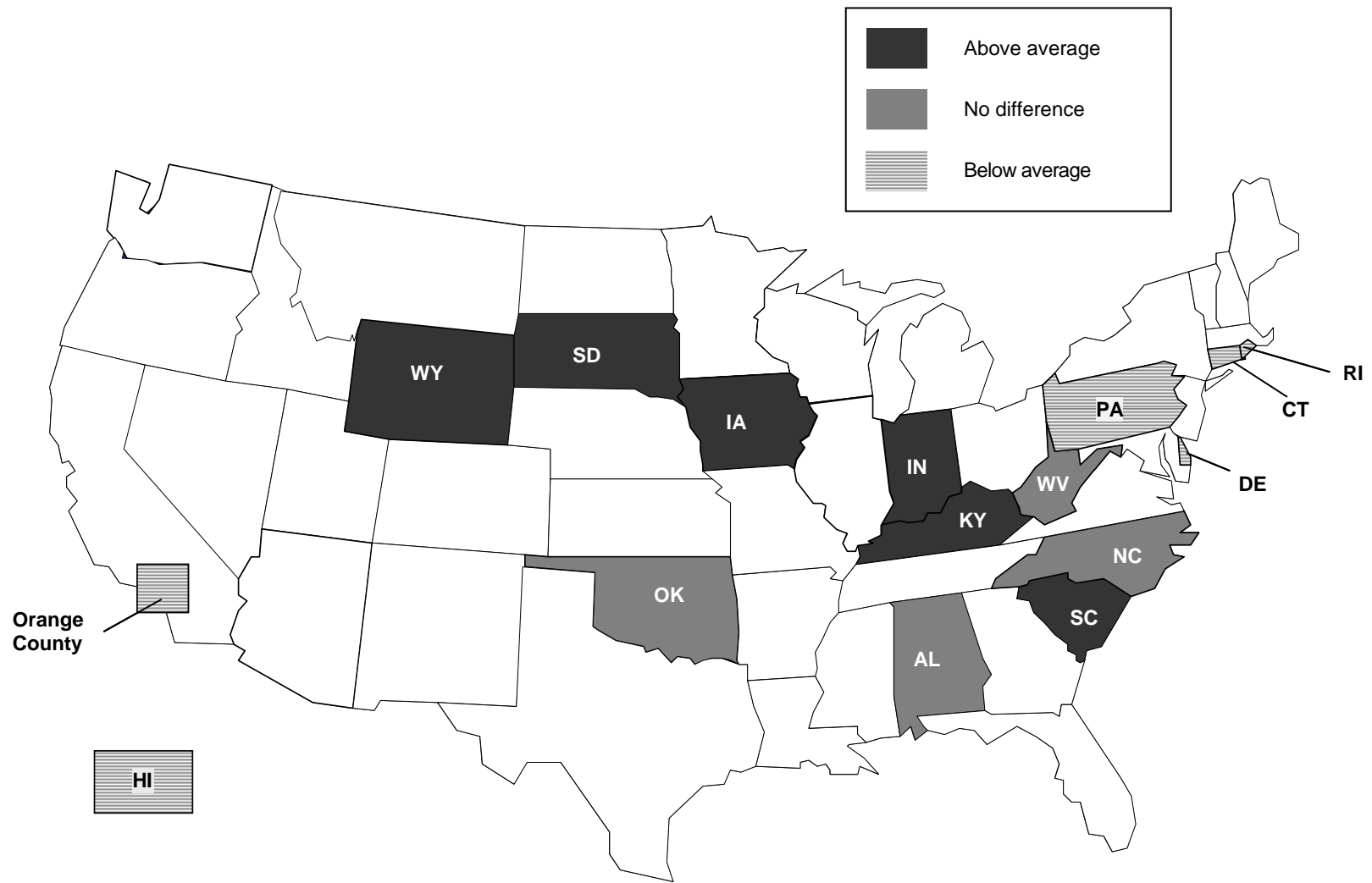
Each state’s scale score was compared with the average scale score across all other states (not including that state). The tables below display each state’s scale score compared with the average across all other states, and the last column indicates whether or not the state’s score was significantly different from the average. A conservative cutoff point ($p \geq 0.01$) was used to determine significant differences.

Figure 12 on the following page displays state performance on the Service Coordination scale in a map format. Those states colored in dark grey performed above average, those with horizontal stripes performed below average, and those in light grey were no different from the average.

Table 59. Service Coordination Scale Scores by State, Compared to National Average

	State Scale Score	Average Across All Other States	Sig. at $p \geq 0.01$
SD	0.953	0.828	Yes
WY	0.941	0.830	Yes
SC	0.909	0.833	Yes
IN	0.897	0.831	Yes
IA	0.886	0.830	Yes
KY	0.879	0.833	Yes
NC	0.865	0.834	No
OK	0.863	0.835	No
AL	0.863	0.835	No
WV	0.821	0.837	No
PA	0.805	0.842	Yes
CT	0.778	0.839	Yes
RCOC	0.775	0.842	Yes
RI	0.703	0.842	Yes
HI	0.675	0.844	Yes
DE	0.547	0.843	Yes

Figure 12. Service Coordination: State Scale Scores Compared with National Average



Tukey's tests were also performed to determine which states were significantly different from one another on each scale. Scores that fall into the same subsets are not significantly different. For the Service Coordination scale, the minimum significant difference is estimated at **0.09**.

Table 60. Service Coordination Scale Scores, by Subsets of States

State	N	Subset for alpha = .05							
		1	2	3	4	5	6	7	8
DE	123	0.55							
HI	244		0.67						
RI	237		0.70	0.70					
RCOC	438			0.77	0.77				
CT	277			0.78	0.78				
PA	868				0.81	0.81			
WV	129				0.82	0.82	0.82		
AL	193					0.86	0.86	0.86	
OK	172					0.86	0.86	0.86	
NC	391					0.87	0.87	0.87	
KY	328					0.88	0.88	0.88	0.88
IA	566					0.89	0.89	0.89	0.89
IN	418						0.90	0.90	0.90
SC	245							0.91	0.91
WY	280							0.94	0.94
SD	359								0.95

Results are presented below for each Service Coordination item, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 113-115 of Appendix C.

Table 61. Proportion of people who report that their service coordinators help them get what they need

State	Valid N	Mean Proportion (%)
SD	355	97.2
VT	104	94.2
WY	281	91.8
SC	249	90.4
IN	415	87.2
AL	189	86.2
KY	327	84.4
IA	557	83.3
NC	386	82.1
OK	168	79.2
WV	120	79.2
CT	266	72.9
RCOC	426	72.5
RI	234	70.1
PA	830	69.8
HI	243	60.1
DE	89	33.7
State Average		78.5
Total	5239	79.4

Table 62. Proportion of people who report that they know their case manager

State	Valid N	Mean Proportion (%)
SD	352	99.1
IA	568	98.1
OK	182	97.3
WY	281	96.1
IN	430	93.0
KY	340	92.9
NC	394	92.9
WV	134	91.0
SC	252	90.5
AL	199	88.4
PA	924	86.1
RCOC	451	85.8
CT	278	85.6
RI	240	74.2
HI	246	73.2
DE	140	70.7
State Average		88.4
Total	5411	89.4

Table 63. Proportion of people who report that their case manager asks them what's important

State	Valid N	Mean Proportion (%)
WY	276	89.9
SD	351	86.6
IN	413	80.9
AL	184	78.8
KY	317	76.0
NC	379	73.1
IA	545	71.4
PA	843	69.4
WV	124	66.9
CT	265	64.9
RCOC	427	64.4
OK	165	63.6
RI	226	61.1
HI	242	58.7
DE	117	27.4
State Average		68.9
Total	4874	71.2

System Performance: Access

The Access Sub-domain has the following concern statement: “Publicly-funded services are readily available to individuals who need and qualify for them.” There are three Access indicators measured by the Consumer Survey:

1. The proportion of people reporting that they received support to learn or do something new in the past year.
2. The proportion of people who report having adequate transportation when they want to go somewhere.
3. The rate at which people report that “needed” services were not available.

Results are presented below for each indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 116-118 of Appendix C.

Table 64. Proportion of people reporting that they received help to reach goals

State	Valid N	Adjusted Mean Proportion
HI	238	76%
VT	85	75%
WY	290	75%
OK	184	75%
IA	464	75%
AL	170	75%
KY	259	75%
SD	361	75%
NC	330	75%
IN	595	75%
CT	273	74%
WV	146	74%
DE	123	74%
RCOC	454	74%
RI	244	74%
SC	206	73%
PA	832	73%
State Average		75%
Total	5254	75%

Table 65. Proportion of people who report having adequate transportation when they want to go somewhere

State	Valid N	Adjusted Mean Proportion
HI	238	83%
AL	170	82%
NC	330	82%
KY	259	82%
IA	464	82%
IN	595	82%
OK	184	82%
SD	361	81%
DE	123	81%
WY	290	81%
CT	273	81%
WV	146	81%
RI	244	81%
SC	206	81%
VT	85	81%
PA	832	81%
RCOC	454	80%
State Average		81%
Total	5254	81%

Table 66. Proportion of people who report that needed services were not available

State	Valid N	Mean Proportion (%)
SD	496	6.9
WY	402	8.5
OK	402	12.7
AL	236	13.1
IA	758	13.7
CT	390	15.1
IN	799	15.4
VT	101	19.8
RCOC	541	20.5
NC	578	22.0
PA	1267	22.3
SC	535	22.6
HI	478	23.0
KY	490	23.3
RI	389	25.4
ME	321	25.9
DE	275	26.2
WV	285	53.0
State Average		20.5
Total	8743	19.7

Health, Welfare, and Rights: Safety

The Safety Sub-domain has the following concern statement: “People are safe from abuse, neglect, and injury.” There is one Safety indicator measured with the Consumer Survey:

1. The proportion of people who report that they feel safe in their home and neighborhood.

Results are presented below for the two items related to this indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on p. 119 of Appendix C.

Table 67. Proportion of people who report that they feel safe in their home

State	Valid N	Mean Proportion (%)
ME	179	96.1
DE	141	91.5
VT	118	90.7
RI	246	84.6
NC	412	82.3
HI	248	81.0
IN	617	80.9
WY	284	80.6
SD	345	80.6
RCOC	461	79.4
OK	179	79.3
CT	285	79.3
PA	937	79.2
IA	604	76.7
WV	163	75.5
KY	341	71.8
AL	203	70.9
SC	250	69.6
State Average		80.6
Total	6013	79.6

Table 68. Proportion of people who report that they feel safe in their neighborhood

State	Valid N	Mean Proportion (%)
VT	112	92.0
ME	179	89.9
WY	283	86.9
RI	242	84.7
PA	916	83.4
NC	406	82.3
AL	197	82.2
WV	163	82.2
SD	340	81.2
IN	615	80.3
OK	177	79.7
HI	247	78.9
CT	281	78.6
DE	132	78.0
IA	603	76.5
RCOC	459	73.0
KY	339	70.8
SC	247	70.0
State Average		80.6
Total	5938	80.0

Health, Welfare & Rights: Health

The Health Sub-domain has the following concern statement: “People secure needed health services.” There are three Health indicators collected with the Background Information section of the Consumer Survey:

1. The proportion of people who have had a physical exam in the past year.
2. The proportion of women who have had a GYN exam in the past year.
3. The proportion of people who have had a routine dental exam in the past six months.

Results are presented below for each indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 120-121 of Appendix C.

Table 69. Proportion of people who had a physical exam in the past year

State	Valid N	Mean Proportion (%)
SD	530	99.8
OK	407	97.8
IN	817	96.0
WV	291	94.2
AL	294	93.2
RI	406	91.4
PA	1343	89.1
CT	401	88.8
KY	504	88.1
NC	660	85.6
VT	269	84.8
IA	788	84.6
DE	289	80.6
SC	548	79.0
WY	406	60.3
HI	487	48.7
RCOC	598	39.3
State Average		82.4
Total	9038	82.6

Table 70. Proportion of people who had a gynecological exam in the past year

State	Valid N	Mean Proportion (%)
RI	173	71.1
DE	149	69.8
OK	166	68.7
IN	356	64.6
CT	174	64.4
NC	291	63.6
SD	224	60.7
WV	145	57.9
PA	639	57.4
KY	215	57.2
IA	360	55.0
SC	210	44.8
AL	125	43.2
WY	157	39.5
HI	230	17.8
RCOC	240	14.2
State Average		53.1
Total	3854	53.5

Table 71. Proportion of people who had a routine dental exam in the past six months

State	Valid N	Mean Proportion (%)
SD	531	90.6
RI	406	73.4
CT	400	70.0
IA	785	63.2
WY	406	62.8
IN	815	61.3
DE	290	57.6
OK	407	56.8
WV	289	53.3
PA	1333	51.2
KY	499	46.9
AL	293	45.4
NC	660	42.3
SC	487	38.8
HI	487	16.2
RCOC	598	13.9
State Average		52.7
Total	8686	52.3

Health, Welfare & Rights: Medications

The Medications Sub-domain has the following concern statement: “Medications are managed effectively and appropriately.” There is one indicator collected using the Background Information section of the Consumer Survey:

1. The proportion of people taking medications for mood, anxiety, or behavior problems.

Results are presented below for this indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on p. 122 of Appendix C.

Table 72. Proportion of people receiving psychotropic¹³ medications

State	Valid N	Mean Proportion (%)
RI	406	55.2
OK	407	50.6
KY	512	48.8
IN	820	47.2
AL	297	46.5
WV	297	46.1
WY	406	44.6
IA	795	42.6
PA	1349	40.5
SD	534	38.6
NC	674	37.8
CT	406	35.0
DE	290	34.8
RCOC	599	32.4
SC	582	31.1
HI	487	23.2
State Average		40.9
Total	9552	37.7

¹³ Results include medication taken for mood, anxiety or behavioral problems.

Health, Welfare & Rights: Respect/Rights

The Respect/Rights Sub-domain has the following concern statement: “People receive the same respect and protections as others in the community.” There are five indicators measured by the Consumer Survey:

1. The proportion of people who have an advocate or someone who speaks on their behalf.
2. The proportion of people whose basic rights are respected by others.
3. The proportion of people who have participated in activities of self-advocacy groups or other groups that address rights.
4. The proportion of people who report satisfaction with the amount of privacy they have.
5. The proportion of people indicating that most support staff treat them with respect.

Results are presented below for each indicator, ordered from highest to lowest scores by state. **“State average”** represents the average score across states. This figure is computed by adding the mean proportion scores and dividing by the number of states. The **“Total”** figure represents all cases aggregated across all states. When making comparisons, it is preferable to use the State average, since this figure accounts for differences in sample size. Unadjusted, raw data frequencies for these items are displayed on pp. 123-128 of Appendix C.

Table 73. Proportion of people reporting that they have an advocate or someone who speaks on their behalf

State	Valid N	Mean Proportion (%)
OK	118	94.9
IA	452	94.9
IN	317	90.5
NC	314	89.8
SD	252	89.3
KY	215	88.4
HI	214	87.9
RI	188	87.2
WY	222	85.1
WV	90	82.2
VT	73	82.2
AL	160	78.1
CT	169	78.1
DE	110	76.4
SC	211	65.4
RCOC	267	51.7
State Average		82.6
Total	3372	83.5

Table 74. Proportion of people reporting that their mail is opened without permission

State	Valid N	Adjusted Mean Proportion
VT	85	15%
WY	398	18%
CT	371	19%
SC	299	19%
IA	597	19%
SD	497	19%
WV	232	20%
IN	756	20%
PA	1057	20%
RI	372	20%
KY	371	20%
NC	457	20%
RCOC	547	21%
DE	236	22%
OK	389	22%
HI	447	22%
AL	200	22%
State Average		20%
Total	7311	20%

Table 75. Proportion of people who report that they have some restrictions on being alone with guests

State	Valid N	Adjusted Mean Proportion
RCOC	547	16%
PA	1057	17%
VT	85	17%
AL	200	18%
RI	372	18%
CT	371	19%
SC	299	19%
IN	756	19%
DE	236	19%
IA	597	20%
SD	497	20%
WV	232	20%
HI	447	21%
NC	457	21%
WY	398	21%
KY	371	22%
OK	389	23%
State Average		19%
Total	7311	19%

Table 76. Proportion of people reporting that there are restrictions on their use of the phone

State	Valid N	Adjusted Mean Proportion
SC	299	11%
RCOC	547	12%
PA	1057	12%
VT	85	12%
RI	372	12%
AL	200	12%
IN	756	12%
DE	236	13%
IA	597	13%
ME	315	13%
CT	371	13%
WV	232	13%
WY	398	14%
NC	457	14%
SD	497	14%
HI	447	15%
OK	389	15%
KY	371	15%
State Average		13%
Total	7626	13%

Table 77. Proportion of people reporting that other people enter their home without permission

State	Valid N	Adjusted Mean Proportion
RCOC	454	10%
VT	85	11%
DE	123	11%
PA	832	11%
IA	464	11%
AL	170	11%
OK	184	11%
SC	206	12%
RI	244	12%
WY	290	12%
IN	595	12%
SD	361	12%
WV	146	12%
NC	330	12%
HI	238	12%
CT	273	12%
KY	259	13%
State Average		12%
Total	5254	12%

Table 78. Proportion of people report that other people enter their bedroom without permission

State	Valid N	Adjusted Mean Proportion
RCOC	454	18%
SC	206	18%
OK	184	18%
PA	832	18%
IN	595	18%
RI	244	19%
VT	85	19%
WY	290	19%
IA	464	19%
AL	170	19%
DE	123	19%
WV	146	19%
SD	361	19%
NC	330	19%
KY	259	19%
CT	273	19%
HI	238	20%
State Average		19%
Total	5254	19%

Table 79. Proportion of people who have attended activities of self-advocacy groups

State	Valid N	Adjusted Mean Proportion
VT	85	35%
WY	398	32%
CT	371	31%
IA	597	31%
ME	315	31%
SD	497	30%
WV	232	30%
KY	371	30%
SC	299	30%
IN	756	30%
NC	457	29%
OK	389	29%
PA	1057	29%
HI	447	29%
RI	372	29%
RCOC	547	29%
AL	200	28%
DE	236	27%
State Average		30%
Total	7626	30%

Table 80. Proportion of people reporting they can be alone (have privacy)

State	Valid N	Adjusted Mean Proportion
AL	170	92%
RCOC	454	92%
DE	123	92%
SC	206	91%
PA	832	91%
RI	244	91%
ME	133	91%
IN	595	91%
HI	238	91%
OK	184	91%
IA	464	91%
CT	273	91%
VT	85	91%
NC	330	91%
SD	361	91%
WV	146	91%
KY	259	90%
WY	290	90%
State Average		91%
Total	5378	91%

Table 81. Proportion of people reporting that most day support staff treat them with respect

State	Valid N	Mean Proportion (%)
AL	178	98.3
SD	324	97.5
RI	226	96.0
NC	296	95.9
WY	254	95.7
DE	133	95.5
RCOC	366	94.5
OK	126	94.4
CT	229	93.9
ME	179	93.9
WV	112	93.8
HI	214	93.0
IA	477	91.6
SC	229	90.8
KY	303	90.8
IN	508	90.6
PA	684	90.1
VT ¹⁴	70	90.0
State Average		93.7
Total	4908	93.2

Table 82. Proportion of people reporting that most residential support staff treat them with respect

State	Valid N	Mean Proportion (%)
SD	323	96.3
RI	237	96.2
OK	178	93.3
IN	471	93.2
NC	303	91.7
PA	515	90.9
HI	114	90.4
IA	536	90.3
CT	232	89.7
RCOC	278	87.1
AL	159	85.5
WY	254	85.0
WV	79	84.8
KY	248	84.3
DE	76	84.2
VT	10	80.0
SC	201	73.1
State Average		88.0

¹⁴ Includes work supports only, not day activity.

Total	4214	89.6
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Appendix A: Rules for Recoding and Combining Variables to
Compute Core Indicators

Table A1. Background Information Variables Used to Adjust Outcomes

<i>BI Item #</i>	<i>Variable Name</i>	<i>Recode or Collapse?</i>
BI-4	AGE	As is
BI-5	GENDER	As is
BI-8	LGLSTAT	Collapse codes 2 + 3 = Not independent
BI-11	LEVELMR	Collapse into 3 categories: a) No MR + Mild ; b) Moderate ; c) Severe + Profound
BI-12	DXMIPD, DXAUTISM, DXCP, DXCHEMPD, DXSENSE, DXPHYSCL, DXCOMM, DXALZHEM, DXOTHER	Use each disability as separate adjustment variable. 1= Does not have disability ; 2= Has disability
	DXBI, DXNEURO	Create a new variable DXBINEUR to indicate presence of any one of the three diagnoses: seizure disorder, brain injury, or neurological problems.
BI-13	EXPRESS	Collapse into 2 categories: a) verbal = 1 + 2; and b) non-verbal = 3 + 4 + 5 + 6
BI-14	MOBILITY	As is
BI-15	VISION	Collapse 2 + 3 = has vision problems
BI-18	SEIZURES	Collapse 2 + 3 + 4 = frequent seizures
BI-19	MEDCARE	Collapse 2 + 3 + 4 + 5 = requires frequent medical care
BI-31 through 33	(SELFINJ) <u>SIFREQ</u>, (DISBEH) <u>DBFREQ</u>, (UNCPBEH) <u>UBFREQ</u>	Create a new variable BEHAVIOR to indicate the presence of any one of the three behaviors.

Table A2. Outcome Variables -- Rules for Analysis

Survey Item #	Variable Name	Recode or Collapse?	Risk Adjust?
Q1	LIKEWORK	Collapse <i>In-between</i> (1) and <i>Yes</i> (2)	
Q2	STAFNICE	Collapse <i>In-between</i> (1) and <i>No</i> (0)	
Q4	LIKEHOME	Collapse <i>Yes</i> (2) and <i>In-between</i> (1)	
Q5	BEALONE	As is	YES
Q6	AFRAIDHM	Collapse <i>Sometimes</i> (1) and <i>Yes</i> (2)	
Q7	AFRAIDNH	Collapse <i>Sometimes</i> (1) and <i>Yes</i> (2)	
Q8	HOMESTAF	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q9-10	ENTERHM, ENTERBRM	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	YES
Q12	HASFRNDS	Collapse <i>No</i> (0) and <i>Yes - staff or family</i> (1)	
Q13	BESTFRND	As is	
Q14	SEEFRNDS	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q15	LONELY	Collapse <i>Sometimes</i> (1) and <i>Always</i> (0)	
Q16	SEEFAMILY	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q17	KNOWSCM	Collapse <i>Maybe</i> (1) and <i>Yes</i> (2)	
Q18	HELPSGET	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q19	ASKIMPOR	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	
Q20	HASADVOC	Collapse <i>Maybe</i> (1) and <i>No</i> (0)	
Q21	HELPGOAL	Collapse <i>Sometimes</i> (1) and <i>No</i> (0)	YES
Q22	TRANSPOR	Collapse <i>No</i> (0) and <i>Sometimes</i> (1)	YES

<i>Survey Item #</i>	<i>Variable Name</i>	<i>Recode or Collapse?</i>	<i>Risk Adjust?</i>
Q26-33	SHOPPING, ERRANDS, ENTERTAN, EATOUT, RELIGION, CLUBS, SPORTS	As is	YES
Q34, Q36-Q40, Q42-Q44	CHOSHOME, ROOMATES, CHSSTAFF, SCHEDULE, FREETIME, CHOOSJOB, CHSJBSTF, CHOOSBUY, CHOOSCM	Collapse <i>Person had some input</i> (1) and <i>Person chose without help</i> (2)	YES
Q35, Q41	NUMHOME, NUMJOBS	Collapse <i>Visited one place only</i> (1) and <i>Did not visit</i> (0)	
Q45-47	MAIOPEN, ALONEGST, USEPHONE	Collapse <i>Sometimes restricted</i> (1) and <i>Not restricted</i> (2)	YES
Q48	SELSADVO	Collapse <i>Yes</i> (2) and <i>Had opportunity but chose not to</i> (1)	YES
Q49	SERVED	Collapse <i>No</i> (0) and <i>Sometimes</i> (1)	

Appendix B: Services and Supports Received

State	AL	RCOC	CT	DE	HI	IA	IN	KY	ME	NC	OK	PA	RI	SC	SD	VT	WV	WY	State Avg	Total
Service coordination or case management																				
N	289	599	402	290	487	772	816	507	417	635	407	1343	406	563	533	274	292	406		9438
%No	2.1	0.8	0.5	0.7	1.4	10.2	7.0	2.4	5.3	7.2	0.2	0.5	6.7	7.3	0.0	8.4	17.8	0.0	4.4	4.1
%Yes	97.6	99.0	99.5	99.3	98.6	89.0	92.3	96.8	83.5	92.4	99.8	99.5	93.1	92.0	100.0	90.9	81.2	100.0	94.7	95.1
%DK	0.3	0.2	0.0	0.0	0.0	0.8	0.7	0.8	11.3	0.3	0.0	0.0	0.2	0.7	0.0	0.7	1.0	0.0	1.0	0.8
Vocational services - supported employment																				
N	196	590	339	290	487	724	815	464	N/A	535	407	1264	406	553	533	268	292	406		8569
%No	94.9	79.2	77.3	79.7	97.5	71.5	85.5	82.1	N/A	74.6	83.8	88.9	72.7	80.3	58.7	79.9	91.8	72.9	80.7	80.7
%Yes	4.6	19.3	22.1	19.7	2.1	28.0	14.0	16.4	N/A	25.4	16.2	9.7	27.3	18.8	41.3	20.1	7.5	27.1	18.8	18.7
%DK	0.5	1.5	0.6	0.7	0.4	0.4	0.5	1.5	N/A	0.0	0.0	1.4	0.0	0.9	0.0	0.0	0.7	0.0	0.5	0.6
Vocational services - group employment																				
N	194	591	343	290	487	719	815	458	N/A	506	405	1250	406	554	533	268	292	406		8517
%No	97.4	83.1	74.1	87.6	97.7	85.0	95.5	92.4	N/A	91.9	87.4	94.7	91.6	85.7	79.4	100.0	97.3	97.3	90.5	90.4
%Yes	2.1	14.6	25.7	12.4	1.8	14.0	3.7	5.9	N/A	7.5	12.6	3.5	7.9	13.5	20.6	0.0	2.1	2.7	8.9	8.8
%DK	0.5	2.4	0.3	0.0	0.4	1.0	0.9	1.7	N/A	0.6	0.0	1.8	0.5	0.7	0.0	0.0	0.7	0.0	0.7	0.9
Vocational services - facility based employment																				
N	215	591	335	290	487	750	816	483	N/A	547	405	1281	406	548	533	268	292	406		8653
%No	67.0	77.3	77.6	55.2	96.7	36.3	42.4	51.3	N/A	61.6	63.7	61.0	51.0	60.4	17.6	100.0	86.3	65.3	63.0	59.5
%Yes	32.1	21.0	22.1	44.1	3.1	63.6	57.4	47.4	N/A	38.0	36.3	37.5	49.0	38.5	49.7	0.0	13.0	34.7	34.6	37.8
%DK	0.9	1.7	0.3	0.7	0.2	0.1	0.2	1.2	N/A	0.4	0.0	1.6	0.0	1.1	32.6	0.0	0.7	0.0	2.5	2.6
Non-vocational day services																				
N	268	590	340	290	487	723	816	472	N/A	529	405	1280	406	551	533	255	292	406		8643
%No	20.1	80.8	67.4	56.6	20.1	80.9	56.9	44.5	N/A	64.3	93.3	63.5	70.2	81.1	49.7	38.0	63.4	65.3	59.8	62.0
%Yes	79.1	17.1	32.1	43.1	79.7	18.4	42.2	54.2	N/A	35.2	6.7	34.6	29.6	18.0	17.6	62.0	36.3	34.7	37.7	35.2
%DK	0.7	2.0	0.6	0.3	0.2	0.7	1.0	1.3	N/A	0.6	0.0	1.9	0.2	0.9	32.6	0.0	0.3	0.0	2.6	2.8
Community participation																				
N	283	590	356	290	487	736	815	476	N/A	551	406	1271	406	545	523	274	292	406		8707
%No	9.9	64.1	36.8	50.7	74.9	41.8	23.8	39.5	N/A	34.3	79.3	50.0	31.5	71.9	10.1	32.8	55.5	0.0	41.6	42.6
%Yes	89.4	30.7	62.9	45.5	24.6	54.9	75.2	58.6	N/A	62.6	20.7	47.4	68.2	22.8	89.5	66.4	43.8	100.0	56.7	55.4
%DK	0.7	5.3	0.3	3.8	0.4	3.3	1.0	1.9	N/A	3.1	0.0	2.7	0.2	5.3	0.4	0.7	0.7	0.0	1.7	2.0
Assistive technology																				
N	200	590	332	290	487	720	816	459	N/A	503	407	1264	406	554	512	N/A	292	406		8238
%No	95.0	90.0	81.9	62.1	97.1	79.0	75.0	80.0	N/A	80.3	66.8	86.5	86.7	74.2	75.8	N/A	84.2	98.3	82.1	82.0
%Yes	4.0	7.8	16.9	35.2	2.5	18.5	23.4	15.0	N/A	17.9	33.2	10.7	13.1	24.5	24.0	N/A	15.1	1.7	16.5	16.3
%DK	1.0	2.2	1.2	2.8	0.4	2.5	1.6	5.0	N/A	1.8	0.0	2.8	0.2	1.3	0.2	N/A	0.7	0.0	1.5	1.7

State	AL	RCOC	CT	DE	HI	IA	IN	KY	ME	NC	OK	PA	RI	SC	SD	VT	WV	WY	State Avg	Total
Clinical services																				
N	241	590	359	290	487	748	816	473	N/A	536	407	1264	406	558	533	274	292	406		8680
%No	67.6	68.6	39.8	35.5	95.1	42.4	38.8	39.3	N/A	44.4	16.0	59.9	34.2	52.0	45.4	50.0	41.4	77.3	49.9	50.7
%Yes	31.5	29.3	59.1	62.1	4.5	54.1	58.9	58.8	N/A	53.9	84.0	37.0	65.3	46.4	54.6	49.3	56.5	22.7	48.7	47.6
%DK	0.8	2.0	1.1	2.4	0.4	3.5	2.2	1.9	N/A	1.7	0.0	3.1	0.5	1.6	0.0	0.7	2.1	0.0	1.4	1.7
Transportation																				
N	280	591	383	289	487	758	816	489	417	562	407	1292	406	557	533	274	292	406		9239
%No	8.6	25.2	14.4	11.1	87.1	18.1	14.1	16.4	10.8	30.6	3.2	33.5	14.5	47.4	87.1	58.0	26.0	0.5	28.1	29.3
%Yes	91.1	73.1	85.1	88.9	12.5	80.1	85.5	82.2	76.3	69.2	96.8	63.9	85.5	49.2	12.9	41.2	73.3	99.5	70.4	69.1
%DK	0.4	1.7	0.5	0.0	0.4	1.8	0.4	1.4	12.9	0.2	0.0	2.6	0.0	3.4	0.0	0.7	0.7	0.0	1.5	1.6
Respite																				
N	205	590	340	290	487	718	816	471	417	523	407	1264	406	548	533	274	292	406		8987
%No	98.0	79.0	84.1	75.5	90.1	84.8	90.3	63.9	74.6	72.8	96.8	76.0	93.6	75.0	96.8	55.8	74.0	98.5	82.2	82.1
%Yes	1.0	19.5	14.7	23.1	9.4	11.6	9.1	35.0	13.4	25.4	3.2	20.9	5.9	24.3	3.2	43.4	25.7	1.5	16.1	16.0
%DK	1.0	1.5	1.2	1.4	0.4	3.6	0.6	1.1	12.0	1.7	0.0	3.1	0.5	0.7	0.0	0.7	0.3	0.0	1.7	1.8
Enrolled in school system																				
N	N/A	589	342	290	N/A	315	816	N/A	N/A	508	406	1285	406	N/A	509	N/A	292	406		6164
%No	N/A	84.2	93.9	97.2	N/A	95.6	98.2	N/A	N/A	90.2	97.3	92.0	99.0	N/A	97.8	N/A	93.5	98.8	94.8	94.3
%Yes	N/A	14.1	5.8	2.1	N/A	4.1	1.8	N/A	N/A	9.6	2.7	8.0	0.7	N/A	2.2	N/A	6.5	1.2	4.9	5.5
%DK	N/A	1.7	0.3	0.7	N/A	0.3	0.0	N/A	N/A	0.2	0.0	0.0	0.2	N/A	0.0	N/A	0.0	0.0	0.3	0.3
Home and community based waiver, ICF/MR, or other funding																				
N	290	595	363	218	487	777	815	499	N/A	539	406	1290	382	571	533	274	292	406		8737
%ICF	0.0	15.5	9.9	24.3	0.0	31.3	45.4	0.0	N/A	15.0	17.5	11.5	0.0	55.0	0.0	0.0	9.9	4.2	14.1	16.6
%HCB	91.4	46.6	71.3	57.8	78.4	55.7	30.9	22.8	N/A	41.4	78.8	58.1	100.0	44.5	100.0	83.2	41.1	95.8	64.6	60.7
%DK	2.1	34.1	8.3	17.9	0.2	13.0	23.7	3.6	N/A	16.9	2.7	4.3	0.0	0.5	0.0	0.7	14.4	0.0	8.4	9.1
%Other	6.6	3.9	10.5	0.0	21.4	0.0	0.0	73.5	N/A	26.7	1.0	26.1	0.0	0.0	0.0	16.1	34.6	0.0	13.0	13.5
Other services and supports																				
N	206	582	222	234	487	567	816	332	N/A	382	404	1032	406	519	533	274	292	406		7694
%No	95.1	78.2	77.9	71.4	80.9	78.1	97.2	77.4	N/A	68.6	50.2	76.7	93.3	65.9	0.6	88.0	77.4	15.5	70.1	70.0
%Yes	3.9	12.5	14.9	4.7	18.7	13.9	2.7	15.1	N/A	20.9	49.8	14.1	5.4	29.3	99.4	11.3	14.7	84.5	24.5	24.9
%DK	1.0	9.3	7.2	23.9	0.4	7.9	0.1	7.5	N/A	10.5	0.0	9.2	1.2	4.8	0.0	0.7	7.9	0.0	5.4	5.1

State	AL	RCOC	CT	DE	HI	IA	IN	KY	ME	NC	OK	PA	RI	SC	SD	VT	WV	WY	State Avg	Total
Individually-negotiated budget																				
N	294	596	400	289	487	786	814	497	N/A	624	407	1334	N/A	555	532	N/A	292	406		8313
% No	99.3	99.7	78.0	49.8	94.9	24.9	12.0	28.2	N/A	47.8	21.4	50.1	N/A	50.3	14.5	N/A	64.4	4.2	49.3	46.3
% Yes	0.0	0.2	21.3	48.4	4.9	69.8	85.1	67.6	N/A	45.2	76.7	45.7	N/A	43.6	84.4	N/A	34.6	95.8	48.2	50.7
% DK	0.7	0.2	0.8	1.7	0.2	5.2	2.8	4.2	N/A	7.1	2.0	4.2	N/A	6.1	1.1	N/A	1.0	0.0	2.5	3.0
Person-centered planning																				
N	294	596	398	290	487	776	815	503	417	643	407	1335	N/A	570	532	N/A	292	406		8761
%No	93.5	0.3	58.3	16.9	24.4	13.5	7.5	15.3	15.8	10.9	9.6	37.9	N/A	27.5	10.3	N/A	96.6	0.0	27.4	23.9
%Yes	5.8	99.7	40.7	82.4	75.4	85.2	90.7	83.1	72.7	87.6	90.4	59.0	N/A	71.9	89.7	N/A	2.4	100.0	71.0	74.4
%DK	0.7	0.0	1.0	0.7	0.2	1.3	1.8	1.6	11.5	1.6	0.0	3.1	N/A	0.5	0.0	N/A	1.0	0.0	1.6	1.7
Fiscal Intermediary																				
N	295	596	399	290	487	762	815	485	N/A	607	404	1326	N/A	568	523	N/A	292	406		8255
%No	99.3	99.8	85.2	96.6	99.8	88.1	98.4	90.3	N/A	86.7	100.0	92.1	N/A	88.0	97.9	N/A	98.6	100.0	94.7	94.0
%Yes	0.0	0.2	14.0	2.4	0.2	3.5	1.2	3.9	N/A	5.6	0.0	3.9	N/A	4.4	1.5	N/A	0.3	0.0	2.8	2.9
%DK	0.7	0.0	0.8	1.0	0.0	8.4	0.4	5.8	N/A	7.7	0.0	4.0	N/A	7.6	0.6	N/A	1.0	0.0	2.5	3.1
Microboard to manage funds																				
N	295	596	398	290	487	764	815	487	N/A	612	404	1324	N/A	566	N/A	N/A	292	406		7736
%No	99.3	100.0	98.2	98.6	100.0	94.0	99.5	95.1	N/A	93.5	100.0	95.5	N/A	91.9	N/A	N/A	98.6	100.0	97.4	96.9
%Yes	0.0	0.0	0.5	0.3	0.0	0.3	0.0	0.2	N/A	1.6	0.0	1.2	N/A	1.8	N/A	N/A	0.0	0.0	0.4	0.5
%DK	0.7	0.0	1.3	1.0	0.0	5.8	0.5	4.7	N/A	4.9	0.0	3.2	N/A	6.4	N/A	N/A	1.4	0.0	2.1	2.5
Support broker																				
N	295	596	398	290	487	762	815	487	N/A	610	404	1322	N/A	567	523	N/A	292	406		8254
%No	99.3	100.0	89.9	98.6	100.0	92.3	97.7	93.4	N/A	91.3	100.0	94.9	N/A	91.9	98.7	N/A	98.6	100.0	96.4	96.0
%Yes	0.0	0.0	9.5	0.3	0.0	1.0	2.0	2.1	N/A	4.1	0.0	1.8	N/A	1.6	1.1	N/A	0.3	0.0	1.6	1.7
%DK	0.7	0.0	0.5	1.0	0.0	6.7	0.4	4.5	N/A	4.6	0.0	3.3	N/A	6.5	0.2	N/A	1.0	0.0	2.0	2.4

Appendix C: Item-by-Item Survey Results

Notes about item-by-item survey results:

- The tables contained in this Appendix are grouped by sub-domain (e.g., Community Inclusion).
- Each table displays data for **one** survey item.
- The title of each table contains the question number and wording as it appears on the NCI Consumer Survey.
- Results are listed **alphabetically** by state.
- The data presented are **unadjusted**, basic frequencies of responses.
- All valid response categories are broken out.
- For most items, “not applicable” and “no response” are considered “missing” data and therefore are not included in these tables.
- The “state average” represents the sum of all scores in the column divided by the number of states. This figure is preferred because it takes into account differences in sample sizes across states.
- The “total” line represents the results of the entire national sample (all states, all cases). This aggregate figure is **not adjusted for sample size**; therefore, some states may be under- or over-represented in the total.
- Only items that provided data for the indicators are listed. Probe questions and consistency checks are not included.
- **Q1 - Q22** are Section I questions, which **only allow consumer responses**.
- **Q26 - Q49** are Section II questions, which **allow other informants to respond** (except in the state of Vermont).
- Some states had missing data due to variations on survey questions and response options. Missing data is indicated as “Not available.”

Community Inclusion

Q26. Do you go shopping?

States	% No	% Yes	Total
AL	8.1	91.9	248
RCOC	7.6	92.4	563
CT	4.8	95.2	392
DE	9.1	90.9	285
HI	4.5	95.5	486
IA	4.0	96.0	776
IN	3.4	96.6	815
KY	6.5	93.5	505
ME	2.3	97.7	384
NC	7.6	92.4	593
OK	1.5	98.5	402
PA	5.7	94.3	1294
RI	4.0	96.0	404
SC	8.5	91.5	544
SD	1.4	98.6	497
VT	5.2	94.8	116
WV	5.6	94.4	287
WY	2.0	98.0	402
State average	5.1	94.9	
Total	5.1	94.9	8993

Q27. Do you go out on errands or appointments?

State	% No	% Yes	Total
AL	17.1	82.9	251
RCOC	3.0	97.0	561
CT	2.5	97.5	393
DE	5.9	94.1	287
HI	0.8	99.2	487
IA	2.8	97.2	775
IN	2.1	97.9	815
KY	3.6	96.4	507
ME	Not available		
NC	5.4	94.6	590
OK	0.7	99.3	403
PA	2.1	97.9	1270
RI	2.7	97.3	401
SC	3.8	96.2	546
SD	1.2	98.8	497
VT	12.2	87.8	115
WV	1.0	99.0	287
WY	0.7	99.3	402
State Average	4.0	96.0	
Total	3.1	96.9	8587

Q28. Do you go out for entertainment?

State	% No	% Yes	Total
AL	18.5	81.5	249
RCOC	11.6	88.4	562
CT	7.9	92.1	394
DE	7.3	92.7	287
HI	19.4	80.6	484
IA	8.9	91.1	777
IN	9.7	90.3	812
KY	11.6	88.4	499
ME	Not available		
NC	17.4	82.6	591
OK	2.2	97.8	403
PA	23.6	76.4	1299
RI	9.0	91.0	398
SC	15.2	84.8	547
SD	5.6	94.4	498
VT	23.9	76.1	117
WV	24.5	75.5	286
WY	10.2	89.8	401
State Average	13.3	86.7	
Total	13.6	86.4	8604

Q29. Do you always eat at home, or do you sometimes go out to eat?

State	% Always Eats At Home	% Sometimes Eats Out	Total
AL	14.5	85.5	249
RCOC	10.2	89.8	560
CT	9.5	90.5	391
DE	18.1	81.9	287
HI	7.2	92.8	486
IA	9.7	90.3	770
IN	6.5	93.5	813
KY	8.9	91.1	505
ME	0.0	100.0	361
NC	10.0	90.0	590
OK	7.7	92.3	401
PA	6.0	94.0	1292
RI	4.5	95.5	401
SC	0.0	100.0	470
SD	4.8	95.2	500
VT	7.5	92.5	134
WV	7.8	92.2	115
WY	5.6	94.4	395
State Average	7.7	92.3	
Total	7.4	92.6	8869

Q30. Do you go to religious services?

State	% No	% Yes	Total
AL	19.1	80.9	246
RCOC	45.1	54.9	554
CT	55.6	44.4	383
DE	35.1	64.9	285
HI	58.6	41.4	469
IA	45.6	54.4	769
IN	39.1	60.9	804
KY	39.7	60.3	489
ME	10.9	89.1	293
NC	28.3	71.7	584
OK	35.6	64.4	396
PA	43.9	56.1	1274
RI	59.4	40.6	397
SC	23.8	76.2	541
SD	47.4	52.6	481
VT	57.4	42.6	115
WV	40.6	59.4	283
WY	56.0	44.0	393
State Average	41.2	58.8	
Total	41.5	58.5	8756

Q31. Do you go to clubs or other community meetings?

State	% No	% Yes	Total
AL	62.6	37.4	235
RCOC	69.5	30.5	548
CT	66.3	33.7	380
DE	88.5	11.5	287
HI	95.2	4.8	483
IA	76.5	23.5	761
IN	71.3	28.8	800
KY	83.5	16.5	490
ME	Not available		
NC	76.5	23.5	578
OK	77.5	22.5	400
PA	11.1	88.9	1251
RI	82.0	18.0	383
SC	59.8	40.2	535
SD	70.5	29.5	488
VT	Not available		
WV	78.9	21.1	285
WY	80.5	19.5	399
State Average	71.9	28.1	
Total	65.9	34.1	8303

Q33. Do you exercise or play sports?

State	% No	% Yes, In Non-integrated Setting	% Yes, In Community Setting	Total
AL	28.5	36.8	34.7	239
RCOC	28.5	42.9	28.6	555
CT	32.3	29.0	38.7	393
DE	55.7	21.6	22.6	287
HI	26.7	31.5	41.8	486
IA	26.7	31.0	42.3	771
IN	28.2	33.8	38.0	811
KY	35.7	31.9	32.3	504
ME	9.5	0.0	90.5	305
NC	27.6	38.2	34.2	587
OK	32.5	41.8	25.8	400
PA	29.6	30.5	39.9	1306
RI	20.0	31.9	48.1	395
SC	27.7	16.4	55.9	542
SD	18.3	42.4	39.4	493
VT		Not available		
WV	45.3	23.9	30.9	285
WY	0.0	44.4	55.6	403
State Average	27.8	31.1	41.1	
Total	27.6	31.8	40.6	8762

Choice and Decision-making

Q34. Who chose the place where you live?

State	% Someone Else Chose	% Person Had Some Input	% Person Chose Without Help	Total
AL	43.3	38.0	18.7	150
RCOC	37.3	50.5	12.2	327
CT	51.0	32.6	16.3	288
DE	66.3	29.2	4.5	178
HI	79.1	16.7	4.3	282
IA	36.9	45.4	17.7	623
IN	46.6	39.1	14.3	614
KY	39.8	43.6	16.7	342
ME	N/A	N/A	N/A	N/A
NC	42.1	44.4	13.5	363
OK	48.7	38.4	12.9	372
PA	67.7	23.8	8.5	1222
RI	50.2	24.0	25.9	313
SC	42.4	32.3	25.3	198
SD	38.9	40.5	20.6	452
VT	46.4	Not available	53.6	112
WV	45.1	38.1	16.8	113
WY	34.5	40.7	24.8	339
State Average	48.0	36.1	18.0	
Total	49.7	34.7	15.6	6288

Q37. Do you choose who helps you at home?

State	% No, Someone Else Chooses	% Person Can Request A Change	% Yes, Person Chooses	Total
AL	33.8	52.0	14.2	148
RCOC	24.4	61.4	14.3	308
CT	53.7	28.8	17.5	285
DE	31.1	57.9	11.1	190
HI	75.1	18.8	6.1	277
IA	45.0	47.1	7.9	662
IN	28.9	60.6	10.6	606
KY	21.9	61.1	17.0	329
ME		Not available		
NC	49.2	35.9	14.9	423
OK	49.6	32.7	17.6	391
PA	78.1	13.6	8.3	744
RI	42.4	38.4	19.2	349
SC	18.2	36.0	45.8	203
SD	17.4	70.4	12.1	453
VT	68.8	6.3	25.0	16
WV	35.2	52.5	12.3	122
WY	11.0	78.4	10.7	347
State Average	40.2	44.2	15.6	
Total	41.5	45.0	13.5	5853

Q40. Who chose the place where you work (or go during the day)?

State	% Someone Else Chose	% Person Had Some Input	% Person Chose Without Help	Total
AL	46.4	38.8	14.8	196
RCOC	36.2	50.8	13.0	431
CT	39.6	44.3	16.1	341
DE	63.6	30.0	6.4	250
HI	61.3	24.1	14.6	398
IA	33.0	51.3	15.7	651
IN	35.2	47.5	17.3	631
KY	34.5	41.6	23.9	394
ME		Not available		
NC	44.1	42.6	13.2	408
OK	29.8	51.6	18.6	285
PA	38.8	40.6	20.7	1075
RI	42.1	28.0	29.9	328
SC	29.6	39.9	30.5	321
SD	35.1	38.3	26.6	447
VT	16.7	56.1	27.3	66
WV	39.6	47.3	13.2	182
WY	20.8	45.8	33.4	332
State Average	38.0	42.3	19.7	
Total	38.3	42.1	19.5	6736

Q42. Do you choose who helps you at work?

State	% No, Someone Else Chooses	% Person Can Request A Change	% Yes, Person Chooses	Total
AL	26.6	54.8	18.6	188
RCOC	21.1	67.8	11.1	422
CT	58.3	31.0	10.7	300
DE	16.5	79.7	3.8	261
HI	37.8	52.3	10.0	400
IA	41.4	45.4	13.2	613
IN	18.0	74.0	8.0	616
KY	13.0	72.3	14.8	393
ME		Not available		
NC	42.4	46.9	10.7	375
OK	61.6	24.8	13.6	258
PA	71.6	15.0	13.4	971
RI	63.3	22.0	14.8	305
SC	0.0	49.3	50.7	282
SD	18.0	68.4	13.6	455
VT		Not available		
WV	37.1	56.2	6.7	178
WY	4.4	85.9	9.7	319
State Average	33.2	52.9	14.0	
Total	36.2	50.4	13.4	6336

Q44. Did you choose your case manager/service coordinator?

State	% No, Someone Else Chose	% Can Request A Change	% Yes, Person Chose	Total
AL	43.4	50.9	5.8	226
RCOC	21.3	72.9	5.9	527
CT	67.6	27.0	5.3	374
DE	99.0	1.0	0.0	286
HI	24.0	73.5	2.5	480
IA	53.3	37.2	9.5	683
IN	31.1	17.7	51.2	541
KY	23.7	60.3	16.0	481
ME		Not available		
NC	57.5	37.1	5.3	544
OK	77.6	12.9	9.5	388
PA	93.4	4.1	2.5	1197
RI	63.1	23.3	13.6	360
SC	9.9	65.6	24.5	506
SD	32.6	58.9	8.5	494
VT	58.5	21.7	19.8	106
WV	46.5	50.0	3.5	226
WY	18.7	42.8	38.5	390
State Average	48.3	38.7	13.1	
Total	50.2	37.2	12.6	7809

Q36. Did you choose the people you live with (or to live by yourself)?

State	% No, Someone Else Chose	% Chose Some People or Had Input	% Yes, Chose Who to Live With	Total
AL	63.3	12.2	24.5	139
RCOC	57.9	14.8	27.4	318
CT	61.7	11.3	27.1	266
DE	72.4	22.1	5.5	181
HI	78.7	10.8	10.5	286
IA	44.6	24.3	31.1	592
IN	52.6	19.0	28.5	601
KY	38.7	31.5	29.7	333
ME		Not available		
NC	62.5	16.9	20.6	349
OK	46.3	16.8	36.9	369
PA	75.5	8.3	16.2	588
RI	51.7	13.6	34.8	302
SC	38.8	21.8	39.4	188
SD	39.9	20.0	40.1	451
VT	72.7	2.3	25.0	44
WV	42.9	13.4	43.8	112
WY	54.6	24.6	20.8	337
State Average	56.2	16.7	27.2	
Total	55.1	17.8	27.1	5456

Q38. Who decides your daily schedule?

State	% Someone Else Decides	% Person Has Help Deciding	% Person Decides	Total
AL	28.8	32.1	39.2	240
RCOC	16.5	33.5	50.0	564
CT	22.2	28.8	49.0	392
DE	16.0	69.0	15.0	287
HI	26.1	32.7	41.2	486
IA	16.9	37.4	45.8	771
IN	20.5	38.6	40.9	814
KY	18.3	24.7	57.1	503
ME		Not available		
NC	22.1	36.5	41.4	587
OK	20.4	33.2	46.4	401
PA	15.3	32.3	52.5	1304
RI	8.1	25.4	66.5	394
SC	31.7	22.4	45.8	539
SD	8.2	32.8	59.0	497
VT	6.0	19.8	74.1	116
WV	23.1	34.3	42.7	286
WY	1.0	39.2	59.8	403
State Average	17.7	33.7	48.6	
Total	18.0	33.7	48.3	8584

Q39. Who decides how you spend your free time?

State	% Someone Else Decides	% Person Has Help Deciding	% Person Decides	Total
AL	13.0	30.9	56.1	246
RCOC	7.3	26.9	65.8	562
CT	9.4	27.8	62.8	392
DE	5.9	24.4	69.7	287
HI	21.2	37.2	41.6	486
IA	4.0	23.0	73.0	771
IN	13.5	31.4	55.1	813
KY	12.4	23.3	64.3	502
ME	2.5	0.0	97.5	358
NC	8.9	29.0	62.0	582
OK	11.0	22.5	66.5	400
PA	6.5	23.7	69.8	1302
RI	3.8	19.7	76.5	391
SC	27.3	19.1	53.6	539
SD	0.8	11.2	88.0	498
VT	5.9	15.3	78.8	118
WV	10.6	32.7	56.7	284
WY	0.0	18.2	81.8	402
State Average	9.1	23.1	67.8	
Total	9.2	23.8	67.0	8933

Q43. Do you choose what you buy with your spending money?

State	% No, Someone Else Chooses	% Person Has Help Choosing	% Yes, Person Chooses	Total
AL	10.2	33.2	56.6	244
RCOC	9.7	32.1	58.1	554
CT	12.9	31.9	55.3	389
DE	23.3	65.2	11.5	287
HI	26.7	37.7	35.6	486
IA	8.7	41.5	49.8	771
IN	8.0	41.4	50.6	812
KY	12.3	23.0	64.7	504
ME	11.1	0.0	88.9	359
NC	11.8	36.4	51.8	585
OK	18.5	35.8	45.8	400
PA	9.5	21.6	68.9	1280
RI	14.1	33.1	52.8	396
SC	28.0	14.7	57.3	529
SD	8.4	37.5	54.1	499
VT	17.9	0.7	81.3	134
WV	13.6	0.8	85.6	118
WY	0.0	35.0	65.0	403
State Average	13.6	29.0	57.4	
Total	12.6	31.6	55.7	8895

Q35. How many places did you visit before moving here?

State	% Did Not Visit Before Moving In	% One Place Only	% Looked At More Than One	Total
AL	23.5	35.7	40.9	115
RCOC	18.3	25.7	56.0	257
CT	23.7	35.8	40.5	232
DE	33.3	56.2	10.5	153
HI	60.8	15.8	23.4	209
IA	16.9	45.5	37.5	538
IN	14.1	48.9	36.9	474
KY	20.3	43.3	36.4	305
ME		Not available		
NC	35.4	30.5	34.0	285
OK	23.8	32.9	43.3	231
PA	73.2	10.5	16.3	1019
RI	55.6	21.8	22.6	252
SC	24.3	45.4	30.3	185
SD	40.2	25.6	34.2	418
VT		Not available		
WV	30.0	43.0	27.0	100
WY	0.0	72.1	27.9	333
State Average	30.8	36.8	32.4	
Total	35.5	33.6	30.9	5106

Q41. How many places did you visit before working [at your job or day activity]?

State	% Did Not Visit Beforehand	% One Place Only	% Looked At More Than One Place	Total
AL	28.1	42.5	29.3	167
RCOC	22.3	31.6	46.0	367
CT	24.9	38.3	36.8	277
DE	24.6	41.7	33.7	199
HI	44.0	24.3	31.7	309
IA	25.4	44.3	30.3	587
IN	18.3	50.0	31.7	518
KY	16.3	49.1	34.6	381
ME		Not available		
NC		Not available		
OK	24.8	22.0	53.2	218
PA	68.4	15.3	16.3	1065
RI	56.8	16.9	26.3	243
SC	25.4	43.1	31.4	299
SD	45.9	21.5	32.5	418
VT		Not available		
WV	26.0	56.6	17.3	173
WY	14.9	60.9	24.2	335
State Average	31.1	37.2	31.7	
Total	35.5	35.1	29.4	5967

Relationships

Q12. Do you have friends you like to talk to or do things with?

State	% No	% Yes – Staff Or Family	% Yes - Not Staff Or Family	Total
AL	9.2	18.4	72.3	206
RCOC	10.1	11.8	78.1	466
CT	6.3	12.3	81.3	284
DE	2.9	8.6	88.5	139
HI	6.4	46.8	46.8	250
IA	3.1	22.3	74.5	609
IN	9.4	19.9	70.7	628
KY	6.7	20.9	72.4	344
ME	5.6	42.5	52.0	179
NC	9.7	17.4	72.9	414
OK	3.4	10.1	86.6	179
PA	11.5	27.6	61.0	940
RI	2.8	7.6	89.6	250
SC	8.4	19.1	72.5	251
SD	4.0	39.4	56.7	353
VT	0.0	16.7	83.3	108
WV	9.2	20.9	69.9	163
WY	6.2	31.0	62.8	290
State Average	6.4	21.8	71.8	
Total	7.3	22.5	70.1	6053

Q13. Do you have a best friend, or someone you are really close to?

State	% No	% Yes	Total
AL	7.8	92.2	180
RCOC	19.7	80.3	407
CT	17.3	82.7	255
DE	60.3	39.7	131
HI	6.2	93.8	225
IA	14.6	85.4	568
IN	15.4	84.6	547
KY	7.5	92.5	319
ME	10.7	89.3	169
NC	14.2	85.8	365
OK	8.3	91.7	169
PA	9.7	90.3	818
RI	9.7	90.3	236
SC	10.0	90.0	229
SD	14.5	85.5	331
VT	33.0	67.0	115
WV	10.0	90.0	140
WY	5.4	94.6	260
State Average	15.2	84.8	
Total	13.6	86.4	5464

Q14. Can you see your friends when you want to see them?

State	% No	% Sometimes	% Yes	Total
AL	6.0	12.6	148	182
RCOC	6.2	22.2	290	405
CT	4.3	11.3	216	256
DE	0.0	60.7	48	122
HI	1.7	17.8	185	230
IA	3.9	13.4	483	584
IN	4.6	12.1	455	546
KY	4.1	8.3	276	315
ME	4.8	0.0	157	165
NC	3.6	17.2	285	360
OK	1.1	11.9	153	176
PA	4.3	12.9	680	821
RI	4.9	8.5	194	224
SC	4.8	15.6	184	231
SD	1.5	8.2	308	341
VT	32.7	5.3	70	113
WV	6.8	23.3	102	146
WY	4.9	9.8	225	264
State Average	5.6	15.1	81.4	
Total	4.7	14.0	4459	5481

Q16. Can you see your family when you want to?

State	% No	% Sometimes	% Yes	Total
AL	7.0	9.5	83.4	199
RCOC	9.1	21.0	69.9	439
CT	9.5	18.6	71.9	253
DE	0.9	47.8	51.3	115
HI	5.3	15.8	78.9	228
IA	5.6	15.7	78.7	568
IN	4.5	15.6	80.0	559
KY	10.0	14.2	75.8	330
ME	5.6	0.0	94.4	179
NC	4.9	18.6	76.5	388
OK	5.5	24.8	69.7	165
PA	3.9	4.2	91.9	812
RI	1.4	11.4	87.2	219
SC	7.0	9.8	83.2	244
SD	3.8	11.0	85.2	345
VT	31.0	3.0	66.0	100
WV	6.0	22.5	71.5	151
WY	13.1	13.5	73.4	274
State Average	7.4	15.4	77.2	
Total	6.5	14.0	79.5	5568

Q15. Do you ever feel lonely?

State	% Always Or Often	% Sometimes	% Never	Total
AL	48.2	34.0	17.8	197
RCOC	47.8	37.7	14.5	454
CT	54.8	34.8	10.4	270
DE	60.5	32.3	7.3	124
HI	63.4	28.0	8.6	243
IA	29.4	39.3	31.3	598
IN	53.5	34.8	11.7	609
KY	47.2	39.6	13.2	341
ME		Not available		
NC	47.5	38.7	13.8	406
OK	47.6	35.9	16.5	170
PA	53.2	41.6	5.2	924
RI	36.8	51.5	11.7	239
SC	47.8	32.3	19.9	251
SD	56.3	34.1	9.6	334
VT	58.1	25.6	16.2	117
WV	46.2	38.0	15.8	158
WY	50.4	29.3	20.4	280
State Average	49.9	35.7	14.3	
Total	48.9	37.0	14.1	5715

Satisfaction

Q1. Do you like working at [your job or day activity]?

State	% No	% In-Between	% Yes	Total
AL	8.5	1.7	89.8	177
RCOC	6.8	4.8	88.4	397
CT	3.5	5.0	91.5	260
DE	2.9	15.1	82.0	139
HI	2.8	4.6	92.6	216
IA	3.3	8.8	88.0	523
IN	3.1	5.8	91.2	521
KY	7.1	3.2	89.6	309
ME	4.5	0.0	95.5	179
NC	3.4	5.6	91.0	323
OK	3.4	3.4	93.2	147
PA	5.3	5.7	89.0	845
RI	3.9	4.3	91.8	231
SC	6.1	6.1	87.8	229
SD	3.9	3.6	92.5	333
VT	1.4	9.5	89.2	74
WV	3.4	6.0	90.6	117
WY	1.5	4.5	94.0	267
State Average	4.1	5.4	90.4	
Total	4.4	5.4	90.3	5287

Q4. Do you like your home or where you live?

State	% No	% In-Between	% Yes	Total
AL	5.7	5.7	88.6	210
RCOC	4.3	5.8	90.0	468
CT	6.5	4.8	88.7	291
DE	6.4	13.5	80.1	141
HI	3.6	5.6	90.8	250
IA	5.1	8.0	86.9	613
IN	3.9	6.2	89.9	633
KY	6.6	3.8	89.6	346
ME	20.7	9.5	69.8	179
NC	3.5	5.4	91.0	423
OK	9.2	5.4	85.3	184
PA	6.1	6.2	87.8	991
RI	5.8	5.4	88.7	257
SC	5.5	9.8	84.8	256
SD	2.8	4.7	92.5	360
VT	13.2	3.7	83.1	136
WV	6.0	5.4	88.7	168
WY	4.8	5.8	89.4	292
State Average	6.7	6.4	87.0	
Total	5.8	6.2	88.0	6198

Service Coordination

Q18. If you ask for something, does [your case manager/service coordinator] help you get what you need?

State	% No	% Sometimes	% Yes	Total
AL	7.4	6.3	86.2	189
RCOC	14.8	12.7	72.5	426
CT	14.7	12.4	72.9	266
DE	48.3	18.0	33.7	89
HI	28.0	11.9	60.1	243
IA	4.8	11.8	83.3	557
IN	6.0	6.7	87.2	415
KY	7.0	8.6	84.4	327
ME		Not available		
NC	6.0	11.9	82.1	386
OK	9.5	11.3	79.2	168
PA	13.9	16.4	69.8	830
RI	26.9	3.0	70.1	234
SC	4.0	5.6	90.4	249
SD	1.4	1.4	97.2	355
VT	3.8	1.9	94.2	104
WV	11.7	9.2	79.2	120
WY	3.2	5.0	91.8	281
State Average	12.4	9.1	78.5	
Total	10.7	9.9	79.4	5239

Q17. Do you know your case manager/service coordinator?

State	% No	% Maybe	% Yes	Total
AL	11.6	6.0	82.4	199
RCOC	14.2	7.5	78.3	451
CT	14.4	9.4	76.3	278
DE	29.3	0.7	70.0	140
HI	26.8	2.4	70.7	246
IA	1.9	2.6	95.4	568
IN	7.0	6.3	86.7	430
KY	7.1	3.2	89.7	340
ME		Not available		
NC	7.1	6.3	86.5	394
OK	2.7	2.2	95.1	182
PA	13.9	3.1	83.0	924
RI	25.8	1.3	72.9	240
SC	9.5	5.6	84.9	252
SD	0.9	2.0	97.2	352
VT		Not available		
WV	9.0	9.7	81.3	134
WY	3.9	1.4	94.7	281
State Average	11.6	4.4	84.1	
Total	10.6	4.3	85.2	5411

Q19. Does [your case manager/service coordinator] ask you what you want?

State	% No	% Sometimes	% Yes	Total
AL	8.7	12.5	78.8	184
RCOC	24.1	11.5	64.4	427
CT	19.6	15.5	64.9	265
DE	41.0	31.6	27.4	117
HI	30.2	11.2	58.7	242
IA	12.8	15.8	71.4	545
IN	6.5	12.6	80.9	413
KY	12.3	11.7	76.0	317
ME		Not available		
NC	9.8	17.2	73.1	379
OK	11.5	24.8	63.6	165
PA	18.3	12.3	69.4	843
RI	32.7	6.2	61.1	226
SC		Not available		
SD	6.3	7.1	86.6	351
VT		Not available		
WV	16.1	16.9	66.9	124
WY	5.4	4.7	89.9	276
State Average	17.0	14.1	68.9	
Total	15.8	13.0	71.2	4874

Access

Q21. Do people help you do new things you want to do?

State	% No	% Sometimes	% Yes	Total
AL	8.5	17.5	74.0	200
RCOC	7.5	28.6	64.0	455
CT	4.0	17.7	78.3	277
DE	6.3	53.6	40.2	112
HI	4.1	20.8	75.1	245
IA	3.3	16.9	79.8	604
IN	4.2	21.0	74.8	595
KY	5.8	24.2	70.0	330
ME		Not available		
NC	5.5	24.7	69.8	397
OK	4.5	21.3	74.2	178
PA	5.6	24.5	69.8	905
RI	0.9	4.8	94.4	231
SC	7.5	22.1	70.4	253
SD	2.3	7.8	89.8	344
VT ¹⁵	28.2	14.5	57.3	110
WV	5.0	31.9	63.1	160
WY	4.6	6.4	89.0	281
State Average	6.3	21.1	72.6	
Total	5.4	20.6	74.0	5677

¹⁵ Source: Culbert et al. (2002). Page 86. Results based on question, "Do you ever get to learn new things?" [If yes: What are they?]. Response options differ slightly: Yes – named, Yes – but did not name, No.

Q22. When you want to go somewhere, do you always have a way to get there?

State	% Almost Never	% Sometimes	% Almost Always	Total
AL	7.2	16.4	76.3	207
RCOC	4.1	19.4	76.5	459
CT	3.2	16.2	80.6	284
DE	1.6	31.0	67.4	129
HI	0.8	6.5	92.7	246
IA	4.0	25.6	70.4	601
IN	2.7	15.5	81.8	620
KY	5.5	16.9	77.6	344
ME		Not available		
NC	4.6	20.5	74.9	415
OK	3.4	5.0	91.6	179
PA	2.9	14.0	83.1	995
RI	4.2	8.8	87.0	238
SC	5.9	14.5	79.6	255
SD	1.4	7.5	91.1	360
VT	5.0	5.0	90.1	121
WV	4.8	20.2	75.0	168
WY	2.4	8.0	89.6	288
State Average	3.7	14.8	81.5	
Total	3.6	15.5	80.9	5909

Q49. Do you get the services you need?

State	% No	% Sometimes	% Yes	Total
AL	6.8	6.4	86.9	236
RCOC	7.4	13.1	79.5	541
CT	3.6	11.5	84.9	390
DE	3.3	22.9	73.8	275
HI	13.0	10.0	77.0	478
IA	4.6	9.1	86.3	758
IN	4.0	11.4	84.6	799
KY	12.2	11.0	76.7	490
ME	25.9	0.0	74.1	321
NC	9.5	12.5	78.0	578
OK	10.0	2.7	87.3	402
PA	7.7	14.5	77.7	1267
RI	23.7	1.8	74.6	389
SC	8.8	13.8	77.4	535
SD	2.6	4.2	93.1	496
VT ¹⁶	14.9	5.0	80.2	101
WV	41.8	11.2	47.0	285
WY	0.7	7.7	91.5	402
State Average	11.1	9.4	79.5	
Total	9.5	10.2	80.3	8743

¹⁶ Source: Culbert et al. (2002). Page 84. Results based on question, “Are there other supports and services you wish you had that you don’t have now?” [If yes: Please list.] Response options differ slightly: Yes – named, Yes – but did not name, No.

Safety

Q6. Are you ever afraid or scared when you are at home?

State	% Rarely	% Sometimes	% Most Of The Time	Total
AL	70.9	21.2	7.9	203
RCOC	79.4	15.8	4.8	461
CT	79.3	15.8	4.9	285
DE	91.5	6.4	2.1	141
HI	81.0	9.3	9.7	248
IA	76.7	19.4	4.0	604
IN	80.9	15.2	3.9	617
KY	71.8	20.8	7.3	341
ME	96.1	0.0	3.9	179
NC	82.3	13.3	4.4	412
OK	79.3	16.8	3.9	179
PA	79.2	17.5	3.3	937
RI	84.6	12.2	3.3	246
SC	69.6	19.6	10.8	250
SD	80.6	15.1	4.3	345
VT	90.7	5.1	4.2	118
WV	75.5	21.5	3.1	163
WY	80.6	14.4	4.9	284
State Average	80.6	14.4	5.0	
Total	79.6	15.6	4.8	6013

Q7. Are you ever afraid or scared when you are out in your neighborhood?

State	% Rarely	% Sometimes	% Most Of The Time	Total
AL	82.2	9.6	8.1	197
RCOC	73.0	21.6	5.4	459
CT	78.6	13.5	7.8	281
DE	78.0	18.2	3.8	132
HI	78.9	11.3	9.7	247
IA	76.5	17.9	5.6	603
IN	80.3	14.3	5.4	615
KY	70.8	20.1	9.1	339
ME	89.9	0.0	10.1	179
NC	82.3	11.1	6.7	406
OK	79.7	12.4	7.9	177
PA	83.4	13.8	2.8	916
RI	84.7	8.7	6.6	242
SC	70.0	18.6	11.3	247
SD	81.2	11.8	7.1	340
VT	92.0	0.0	8.0	112
WV	82.2	15.3	2.5	163
WY	86.9	8.8	4.2	283
State Average	80.6	12.6	6.8	
Total	80.0	13.8	6.2	5938

Health

BI-20. When was his/her last physical exam?

State	% Within Past Year	% Over A Year Ago	% Don't Know	Total
AL	93.2	4.4	2.4	294
RCOC	39.3	29.4	31.3	598
CT	88.8	4.7	6.5	401
DE	80.6	3.5	15.9	289
HI	48.7	40.5	10.9	487
IA	84.6	8.2	7.1	788
IN	96.0	2.6	1.5	817
KY	88.1	5.6	6.3	504
ME		Not available		
NC	85.6	8.9	5.5	660
OK	97.8	1.0	1.2	407
PA	89.1	4.8	6.2	1343
RI	91.4	4.2	4.4	406
SC	79.0	14.6	6.4	548
SD	99.8	0.2	0.0	530
VT	84.8	6.7	8.6	269
WV	94.2	3.4	2.4	291
WY	60.3	34.2	5.4	406
State Average	82.4	10.4	7.2	
Total	82.6	10.2	7.2	9038

BI-21. If female, when was her last OB/GYN exam?

State	% Within Past Year	% Over A Year Ago	% Never Had An Exam	% Don't Know	Total
AL	43.2	21.6	5.6	29.6	125
RCOC	14.2	13.8	1.7	70.4	240
CT	64.4	14.4	5.2	16.1	174
DE	69.8	9.4	2.7	18.1	149
HI	17.8	34.3	1.3	46.5	230
IA	55.0	13.1	5.3	26.7	360
IN	64.6	12.9	5.6	16.9	356
KY	57.2	11.6	2.8	28.4	215
ME		Not available			
NC	63.6	13.1	7.2	16.2	291
OK	68.7	9.0	6.0	16.3	166
PA	57.4	9.4	7.7	25.5	639
RI	71.1	11.6	4.0	13.3	173
SC	44.8	19.0	23.8	12.4	210
SD	60.7	27.7	3.1	8.5	224
VT		Not available			
WV	57.9	17.9	17.9	6.2	145
WY	39.5	32.5	7.6	20.4	157
State Average	53.1	17.0	6.7	23.2	
Total	53.5	15.8	6.6	24.2	3854

BI-22. When was his/her last dentist visit?

State	% Within Last Six Months	% Over Six Months Ago	% Don't Know	Total
AL	45.4	28.7	25.9	293
RCOC	13.9	39.5	46.7	598
CT	70.0	17.0	13.0	400
DE	57.6	16.2	26.2	290
HI	16.2	52.6	31.2	487
IA	63.2	20.0	16.8	785
IN	61.3	30.8	7.9	815
KY	46.9	30.7	22.4	499
ME		Not available		
NC	42.3	45.3	12.4	660
OK	56.8	36.1	7.1	407
PA	51.2	26.3	22.5	1333
RI	73.4	12.1	14.5	406
SC	38.8	35.1	26.1	487
SD	90.6	9.0	0.4	531
VT		Not available		
WV	53.3	33.2	13.5	289
WY	62.8	29.1	8.1	406
State Average	52.7	28.9	18.4	
Total	52.3	29.1	18.6	8686

Medications

BI-17. Does this person currently take medications for...?¹⁷

State	Mood Disorders		Anxiety		Behavior	
	N	% Yes	N	% Yes	N	% Yes
AL	294	27.6	289	14.9	291	33.3
RCOC	598	18.2	597	10.2	595	21.0
CT	390	28.2	375	14.9	388	18.3
DE	290	22.4	289	16.6	290	23.8
HI	487	8.2	487	8.8	487	18.5
IA	767	31.6	739	19.4	739	21.0
IN	817	34.8	817	24.0	816	30.8
KY	485	35.5	467	21.6	474	24.9
ME			Not available			
NC	225	82.2	172	20.3	220	39.1
OK	407	31.7	407	25.1	407	36.4
PA	1316	30.1	1295	19.3	1291	20.3
RI	406	34.7	406	33.7	405	25.7
SC	553	19.2	551	9.6	561	22.1
SD	526	29.1	516	16.3	512	21.1
VT			Not available			
WV	291	37.8	291	29.2	291	22.3
WY	406	32.8	406	22.4	406	25.6
State Average		31.5		19.2		25.3
Total	8258	29.7	8104	18.9	8173	24.2

¹⁷ Due to a coding error, medication taken for behavior problems is not reported.

Respect and Rights

Q20. Do you know who your advocate or guardian is?

State	% No	% Maybe, Not Sure	% Yes	Total
AL	16.9	5.0	78.1	160
RCOC	39.0	9.4	51.7	267
CT	12.4	9.5	78.1	169
DE	22.7	0.9	76.4	110
HI	6.1	6.1	87.9	214
IA	2.0	3.1	94.9	452
IN	5.0	4.4	90.5	317
KY	6.5	5.1	88.4	215
ME		Not available		
NC	5.4	4.8	89.8	314
OK	4.2	0.8	94.9	118
PA		Not available		
RI	11.2	1.6	87.2	188
SC	25.1	9.5	65.4	211
SD	5.2	5.6	89.3	252
VT ¹⁸	11.0	6.8	82.2	73
WV	11.1	6.7	82.2	90
WY	12.2	2.7	85.1	222
State Average	12.2	5.1	82.6	
Total	11.4	5.1	83.5	3372

¹⁸ Source: Culbert et al. (2002). Page 85. Results based on question, "Who would you ask to help you change services or supports you do not like?" Response options differ slightly: Named, Someone – but did not name, Nobody named.

Q45. Do people read your mail without your permission?

State	% Yes	% Some Mail	% No	Total
AL	70.3	13.3	16.4	195
RCOC	83.7	7.3	8.9	504
CT	74.1	11.7	14.2	324
DE	94.3	3.1	2.6	227
HI	71.8	9.8	18.4	450
IA	47.7	3.8	48.5	744
IN	90.7	4.3	5.0	742
KY	86.4	3.5	10.1	455
ME		Not available		
NC	85.8	6.7	7.6	541
OK	79.2	5.6	15.1	390
PA	69.4	6.5	24.2	1155
RI	90.8	2.4	6.8	382
SC	88.5	3.4	8.2	417
SD	96.6	1.7	1.7	477
VT ¹⁹	85.6	Not available	14.4	111
WV	67.7	12.5	19.8	263
WY	95.4	3.3	1.3	394
State Average	81.1	6.7	12.3	
Total	79.2	5.842	14.927	7771

¹⁹ Source: Culbert et al. (2002). Page 84. Results based on question, "Does anyone ever open your mail without asking you first?" Response options only include: Yes, No.

Q46. Can you be alone with [guests], or does someone have to be with you?

State	% No, Someone Always Present	% Some Restrictions	% Yes, Can Be Alone With Guests	Total
AL	10.5	17.3	72.3	191
RCOC	5.2	15.0	79.8	346
CT	9.7	14.4	75.9	278
DE	12.0	6.5	81.5	108
HI	14.9	9.1	76.0	242
IA	1.8	25.5	72.6	654
IN	10.0	9.8	80.2	520
KY	7.2	7.4	85.4	377
ME		Not available		
NC	5.2	10.7	84.1	421
OK	7.4	8.2	84.4	352
PA	5.5	8.0	86.5	1245
RI	3.1	4.6	92.3	324
SC	38.1	13.0	48.9	378
SD	8.2	9.7	82.0	401
VT	15.4	5.8	78.8	104
WV	9.0	11.5	79.5	200
WY	5.9	16.3	77.7	337
State Average	9.9	11.3	78.7	
Total	8.7	11.7	79.6	6478

Q47. Are you allowed to use the phone when you want to?

State	% Not Allowed	% Some Restrictions	% Can Use Anytime	Total
AL	13.4	16.8	69.8	202
RCOC	2.5	13.3	84.2	480
CT	2.3	11.6	86.0	301
DE	0.5	8.5	91.0	199
HI	6.9	10.8	82.2	259
IA	1.6	8.7	89.8	703
IN	1.3	9.7	89.0	637
KY	8.9	11.7	79.4	403
ME	12.3	0.0	87.7	367
NC	2.7	11.8	85.5	476
OK	0.0	7.9	92.1	316
PA	2.7	9.0	88.4	1005
RI	0.3	3.8	95.9	345
SC	2.4	3.8	93.9	425
SD	1.0	8.9	90.1	393
VT	9.3	5.9	84.7	118
WV	2.9	11.1	86.0	207
WY	1.2	11.8	87.0	346
State Average	4.0	9.2	86.8	
Total	3.4	9.1	87.5	7182

Q9. Do people (including staff) let you know before they come into your home?

State	% No	% Sometimes	% Yes	Total
AL	10.0	7.5	82.6	201
RCOC	4.4	6.1	89.5	458
CT	7.6	8.4	84.0	263
DE	7.8	4.7	87.6	129
HI	4.3	4.3	91.3	115
IA	10.0	6.5	83.5	569
IN	6.7	4.2	89.1	613
KY	6.0	3.9	90.1	335
ME		Not available		
NC	6.7	6.2	87.2	406
OK	4.5	10.8	84.7	176
PA	7.5	5.5	87.0	930
RI	1.7	6.4	91.9	234
SC	4.0	7.6	88.4	250
SD	1.1	3.4	95.5	352
VT	10.8	Not available	89.2	120
WV	5.6	6.7	87.6	89
WY	3.1	6.9	89.9	288
State Average	6.0	5.8	88.2	
Total	6.2	5.8	88.0	5528

Q10. Do people (including staff) ask permission before coming into your bedroom?

State	% No	% Sometimes	% Yes	Total
AL	17.0	14.0	69.0	200
RCOC	9.8	11.4	78.8	457
CT	12.0	11.6	76.4	259
DE	14.1	7.1	78.8	99
HI	16.7	2.6	80.7	114
IA	7.3	10.3	82.5	565
IN	6.0	8.4	85.7	621
KY	12.1	7.4	80.5	338
ME		Not available		
NC	12.2	10.2	77.6	402
OK	9.0	6.2	84.8	178
PA	11.6	9.7	78.6	782
RI	4.9	2.7	92.4	223
SC	7.1	9.1	83.8	253
SD	6.5	3.4	90.1	352
VT	13.4	4.2	82.4	119
WV	14.1	7.6	78.3	92
WY	18.8	9.1	72.1	287
State Average	11.3	7.9	80.7	
Total	10.4	8.7	81.0	5341

Q48. Have you ever participated in a self-advocacy group, meeting, conference, or event?

State	% No	% Had Opportunity But Chose Not To	% Yes	Total
AL	62.4	2.5	35.0	197
RCOC	71.4	3.6	25.0	507
CT	69.0	6.4	24.6	345
DE	82.2	0.7	17.1	281
HI	66.7	Not available	33.3	12
IA	58.3	4.1	37.6	686
IN	65.9	8.3	25.8	604
KY	77.2	3.1	19.7	351
ME	10.3	33.5	56.2	370
NC	67.1	2.7	30.1	511
OK	52.6	11.6	35.7	361
PA	83.2	Not available	16.8	1240
RI	61.5	8.2	30.3	366
SC	56.7	3.1	40.1	446
SD	51.2	13.1	35.7	443
VT	74.8	Not available	25.2	111
WV	71.1	3.3	25.6	90
WY	59.7	1.8	38.5	390
State Average	63.4	7.1	30.7	
Total	64.5	5.9	29.6	7311

Q5. Can you be alone if you want to?

State	% No	% Yes	Total
AL	18.9	81.1	190
RCOC	9.3	90.7	419
CT	7.9	92.1	253
DE	5.6	94.4	126
HI	6.4	93.6	235
IA	18.3	81.7	508
IN	7.4	92.6	565
KY	5.6	94.4	337
ME	6.7	93.3	179
NC	7.0	93.0	388
OK	12.6	87.4	175
PA	5.5	94.5	891
RI	4.6	95.4	197
SC	11.2	88.8	242
SD	6.1	93.9	263
VT	15.3	84.7	111
WV	6.4	93.6	140
WY	11.2	88.8	277
State Average	9.2	90.8	
Total	8.9	91.1	5496

Q2. Is [staff who helps you at job/day activity] nice and polite to you?

State	% No	% Sometimes	% Yes	Total
AL	0.0	1.7	98.3	178
RCOC	1.4	4.1	94.5	366
CT	0.4	5.7	93.9	229
DE	0.8	3.8	95.5	133
HI	0.0	7.0	93.0	214
IA	1.7	6.7	91.6	477
IN	1.8	7.7	90.6	508
KY	2.3	6.9	90.8	303
ME	6.1	0.0	93.9	179
NC	1.4	2.7	95.9	296
OK	1.6	4.0	94.4	126
PA	2.5	7.5	90.1	684
RI	0.4	3.5	96.0	226
SC	2.2	7.0	90.8	229
SD	0.9	1.5	97.5	324
VT ²⁰	2.9	7.1	90.0	70
WV	2.7	3.6	93.8	112
WY	1.2	3.1	95.7	254
State Average	1.7	4.6	93.7	
Total	1.7	5.2	93.2	4908

Q8. Is [staff who helps you at home] nice and polite to you?

State	% No	% Sometimes	% Yes	Total
AL	11.9	2.5	85.5	159
RCOC	7.2	5.8	87.1	278
CT	3.9	6.5	89.7	232
DE	1.3	14.5	84.2	76
HI	2.6	7.0	90.4	114
IA	2.1	7.6	90.3	536
IN	2.8	4.0	93.2	471
KY	10.5	5.2	84.3	248
ME		Not available		
NC	5.3	3.0	91.7	303
OK	1.7	5.1	93.3	178
PA	1.6	7.6	90.9	515
RI	0.8	3.0	96.2	237
SC	17.4	9.5	73.1	201
SD	0.3	3.4	96.3	323
VT	10.0	10.0	80.0	10
WV	10.1	5.1	84.8	79
WY	6.3	8.7	85.0	254
State Average	5.6	6.4	88.0	
Total	4.6	5.9	89.6	4214

²⁰ Includes work supports only, not day activity.

Appendix D: Comparability of Questions Across Past Versions

NCI Consumer Survey -- Comparability of Questions Across Past Versions

Codes:

	O.K. for longitudinal analysis
	questionable, may have comparability problems
	not comparable, do not use

Question/Number	Phase V	Phase IV	Phase III	Phase II	Comments
	FY03 data	FY02 data	FY01 data	FY00 data	
	V.2002	V.2001	V.2000	V.2 (1999)	
taking meds for mood, anxiety, or behavior	BI-17	BI-17	BI-17	BI-19	DK code changed from 9 to 3 in 2001. In 1999, all three in one category.
had physical exam in past year	BI-20	BI-20	BI-20	BI-22	"n/a in records" added to DK response in 2001
had GYN exam in past year	BI-21	BI-21	BI-21	BI-23	"n/a in records" added to DK response in 2001
had routine dental exam in past 6 months	BI-22	BI-22	BI-22	BI-24	"n/a in records" added to DK response in 2001
type of residence	BI-24	BI-24	BI-24	BI-26	demographic
who owns or leases residence	BI-25	BI-25	BI-25	BI-27	demographic
receives HCBS funding	BI-29	BI-29	BI-29	BI-31	demographic
has individually-negotiated budget	BI-30	BI-30	BI-30	n/a	
has person-centered plan	BI-30	BI-30	BI-30	n/a	
uses FI or ISO	BI-30	BI-30	BI-30	n/a	
microboard manages funds	BI-30	BI-30	BI-30	n/a	
has support broker or personal agent	BI-30	BI-30	BI-30	n/a	
satisfied with job or day program	1	1	1	1&6	day and work separated in 1999
day staff nice (treat with respect)	2	2	2	4&8	day and work separated in 1999
<i>consistency check</i>	3	3	8		
satisfied with home	4	4	13	19	
can be alone, have privacy	5	5	14	21	wording of question changed
afraid at home	6	6	15	22	y/n codes reversed in V.2000 - should not affect outcome but may have caused data entry errors. 1999 wording different

Question/Number	Phase V	Phase IV	Phase III	Phase II	Comments
	FY03 data	FY02 data	FY01 data	FY00 data	
	V.2002	V.2001	V.2000	V.2 (1999)	
					y/n codes reversed in V.2000 - should not affect outcome but may have caused data entry errors. 1999 wording different
afraid in neighborhood	7	7	16	22	
home staff nice (treat with respect)	8	8	17	25	slightly re-phrasing of question; probably O.K.
people ask before entering home	9	9	48	59	moved from Section II to Section 1. Also wording of question reversed in V.2000.
people ask before entering room	10	10	49	60	moved from Section II to Section 1. Also wording of question reversed in V.2000.
<i>consistency check</i>	11	11	12		
has friends	12	12	5	11	
has best friend	13	13	6	12	
can see friends	14	14	7	13	
					y/n codes were reversed prior to 2002 - should not affect outcome but may have caused data entry errors
lonely	15	15	9	15	
can see family	16	16	11	17	
know case manager	17	17	19	n/a	
case manager helps get what they need	18	18	21	29	
case manager asks what they want	19	19	22	n/a	wording change from "...what's important to you" to "...what you want"
has an advocate	20	20	23	31	wording change from "do you have..." to "do you know..."
					wording change from "did anyone help you learn to do something new this year" to "...reach your goals" to "...do new things you want to do"
received support to do new things	21	21	24	36	
has transportation	22	22	53	63	moved from Section II to Section 1
<i>section completed</i>	23	23	25	37	
<i>did person understand</i>	24	24	26	38	
<i>did person give consistent and valid responses</i>	25	25	27		
shopping	26	26	28	39	

Question/Number	Phase V	Phase IV	Phase III	Phase II	Comments
	FY03 data	FY02 data	FY01 data	FY00 data	
	V.2002	V.2001	V.2000	V.2 (1999)	
errands	27	27	29	40	
entertainment	28	28	31	42	
eat out	29	29	32	43	
religious activity	30	31	33	44	
clubs or community orgs	31	31	n/a	n/a	
sports or exercise	32	33	30	41	added "1-yes in non-integrated setting" code in V.2001
chose home	33	34	36	46	wording change from "did you choose" to "who chose"
looked at more than one home	34	35	n/a	n/a	
chose roommate	35	36	37	47	
chooses home staff	36	37	43	52	
chooses schedule	37	38	38	48	wording change from "do you choose the times you do things..." to "who decides your daily schedule"
chooses free time	38	39	39	49	wording change from "do you choose..." to "who decides...". Also 1999 version uses phrase "for fun" instead of "in free time".
chose job	39	40	42	51	wording change from "did you choose" to "who chose"
looked at more than one job	40	41	n/a	n/a	
chose job staff	41	42	44	53	V.1999 and V.2000 refer to job only
chooses what to buy	42	43	41	56	
chose case manager	43	44	45	54	
mail opened without permission	44	45	46	57	V.2000 question more complex
can be alone with guests	45	46	47	58	
can use phone	46	47	50	61	
attended self-advocacy	47	48	51	n/a	added definition and response choices "n/a" and "1"
gets needed services	48	49	52	62	wording of question reversed in V.2000

[LAST PAGE]