

**SURVEY OF ADULTS RECEIVING  
DEVELOPMENTAL SERVICES  
IN VERMONT  
SUMMER 2005**

Consumer Survey Project

Report Prepared February 2006

For

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Vermont Department of Disabilities, Aging and Independent Living  
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This Report describes findings from a survey of adults receiving developmental services across Vermont. The survey was conducted by members of the Vermont Consumer Survey Project in the summer of 2005. The coordinating members of the Vermont Consumer Survey Project are:

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## FOREWORD

We at the Division of Disability and Aging Services are committed to the continual improvement of the developmental services we provide and we believe that a critical part of that commitment is listening to the people we serve. Our first statewide in-depth consumer surveys took place in 1995 using a questionnaire originally developed by Drs Susan Culbert and Sara Burchard from the Psychology Department at the University of Vermont. Over time, this questionnaire has been revised and enhanced in consultation with our consumer advocates. The information from the surveys has not only helped us to gain a clearer picture of who we serve, but to better understand what people feel is important to their quality of life and how we can better support them.

This report contains findings from the second year in the third 3-year cycle of surveys. Those of you who have been reading previous consumer reports will find a number of significant changes in the way in which the information is presented in this 3-year cycle. The reports now include more demographic information, additional findings on Self-Determination and Rights, and perhaps the most significant change, a comparison of information from the previous survey so that you can see how opinion has changed over time.

We hope you find this both informative and helpful.

Theresa A. Wood  
Deputy Commissioner  
Department of Disabilities, Aging and Independent Living

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## **SECTION 1**

### **OVERVIEW**



## INTRODUCTION

The summer of 2005 marked the second year of the third 3-year cycle of satisfaction surveys of adults with developmental disabilities served by the State of Vermont Division of Disability and Aging Services. The same five agencies were surveyed as in 2002: Healthcare and Rehabilitation Services of Southeastern Vermont (HCRS), Howard Center for Human Services (HCHS), Northwestern Counseling and Support Services (NCSS), Sterling Area Services (SAS), and Upper Valley Services (UVS).

In its continuing efforts to provide quality services, the Division has extended the scope of the original demographic and satisfaction surveys used in 1995 to better understand the needs and wishes of people served by developmental service agencies. For example, revisions to the last cycle of surveys started in 2001 included expanded demographic information and new survey questions on self-determination based on input from self-advocates. Work on the survey for this cycle starting in 2004 has included further alignment with questions on the National Core Indicators (NCI) survey to enable comparisons with other states nationally on a greater range of questions. Substantial changes have also been made to the presentation format for the 2004-2006 survey reports: the reports now include more demographic information about the participants, results are presented as percentages, and there are comparisons between this year's findings and those of the previous surveys of the same agencies from 2002. The reports now consist of four major Sections:

- **Overview:** The survey process consists of two parts: a demographics survey and the satisfaction survey itself. This Section is for readers who would like a brief stand-alone summary of survey findings for the summer of 2005. It gives a basic description of the interviews, a brief profile of the respondents, and how they rate their satisfaction in a range of life domains. For comparison purposes, information about people served by the same five agencies in 2002 is also included.
- **Consumer Survey 2005 - What People Had To Say.** This Section is for readers who would like more detail on how people responded to individual questions on the survey. It first gives comparison information from the 2002 and 2005 surveys on selected questions within the life domains. Further detail on domain scores is then given. The final part of this Section includes the full set of responses to the 2005 survey questions.
- **Participant Profile 2005 - Who Participated.** This Section reports the findings from the demographics survey so that each agency can have a clear picture of the population of adults they serve. Each reporting category includes numbers for those interviewed and those not interviewed.
- **Methodology - How This Survey Is Conducted.** This Section describes the procedures for collecting survey information and how that information is analyzed for reporting purposes.

**SUMMARY OF FINDINGS: STATE OF VERMONT 2005**

The selection of adults to participate in the consumer surveys is designed to be representative both within each agency and to be representative of the statewide population of consumers in each year. In the summer of 2005, the independently contracted survey team visited the same five agencies as were surveyed in 2002. 100% of those who are able to respond to the survey at smaller agencies (specialized service agencies) and 50% from the larger designated service agencies were invited to be interviewed. For Howard Center for Human Services a sample of 33% of the current caseload is selected for each year of the 3-year survey cycle. Interviews took an average of 31 minutes to complete in 2005 and 32 minutes in 2002. As can be seen from Table 1.1, the response rate for 2002 (in parentheses) was a little higher than the statewide rate for 2005.

**Table 1.1 – Participants and Types of Interviews Conducted (N=355)**

	NCSS	HCRS	HCHS	SAS	UVS	Total 2005	(2002)
<b>Interviewed</b>							
Full interview	32%	38%	42%	24%	26%	<b>34%</b>	(44%)
Picture only	1%	3%	8%	2%	4%	<b>4%</b>	(6%)
<b>Total Interviewed</b>	<b>33%</b>	<b>41%</b>	<b>50%</b>	<b>26%</b>	<b>30%</b>	<b>38%</b>	(50%)
<b>Not Interviewed</b>							
Agency decision	15%	12%	14%	18%	20%	15%	(14%)
Guardian's decision	7%	0%	0%	0%	0%	1%	(2%)
Unable to complete	1%	6%	7%	8%	7%	6%	(8%)
No Show/Person's choice	27%	37%	21%	16%	16%	24%	(20%)
Person out of town	1%	0%	1%	16%	3%	3%	(0.5%)
Person incapacitated	15%	3%	6%	13%	13%	9%	(0.5%)
Scheduling oversight	0%	1%	0%	0%	0%	0%	(1%)
Other	1%	0%	1%	3%	11%	2%	(4%)
<b>Total not Interviewed</b>	<b>67%</b>	<b>59%</b>	<b>50%</b>	<b>74%</b>	<b>70%</b>	<b>62%</b>	(50%)
<b>Total Participants</b>	<b>75</b>	<b>81</b>	<b>91</b>	<b>38</b>	<b>70</b>	<b>355</b>	(274)

In order to be able to draw valid comparisons between findings at the state and local level it is important that the profile of those giving their opinions about life satisfaction is broadly the same. Table 1.2 compares some of the main demographic characteristics of the people surveyed in 2002 and 2005. More people lived in provider homes and fewer in family homes and more received service coordination in 2005. Otherwise no significant differences were found between the 2002 and 2005 interview groups.

**Table 1.2 – Brief Profile of Consumers Interviewed**

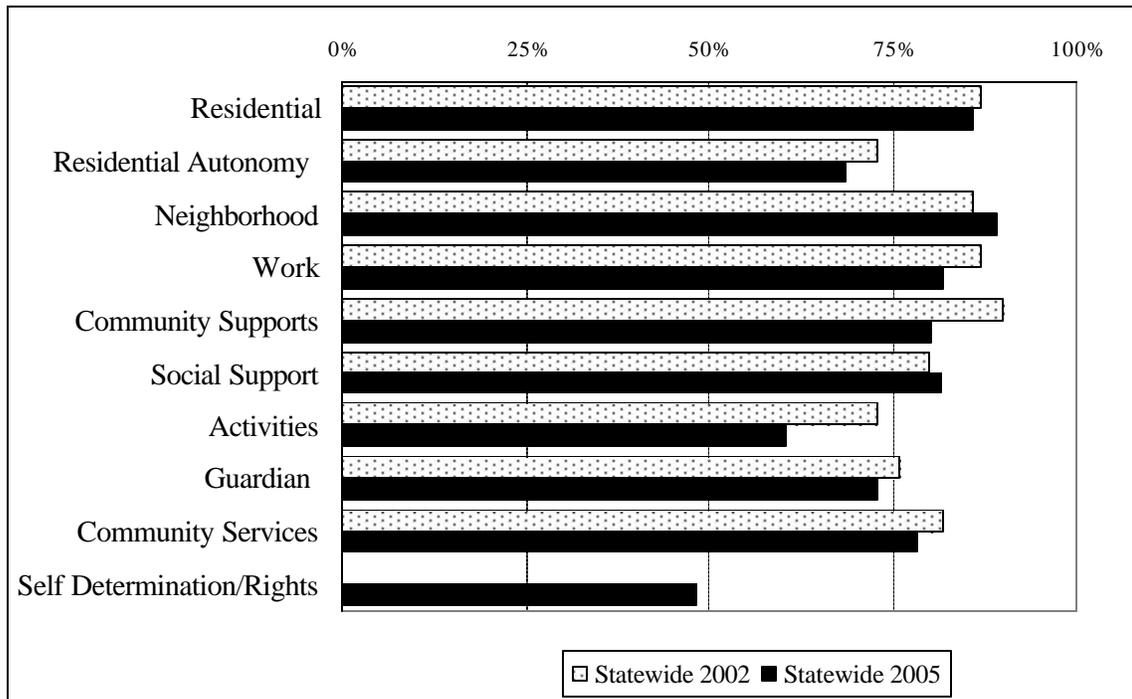
	<b>Statewide 2002 (N=136)</b>	<b>Statewide 2005 (N=134)</b>
<b>Age</b>		
Average Age	41	43
Minimum Age	19	21
Maximum Age	83	86
<b>Gender</b>		
Male	60%	60%
Female	40%	40%
<b>Developmental Disability Label</b>		
Mild MR	80%	73%
Moderate MR	13%	15%
Severe MR	0%	5%
Profound MR	0%	1%
Unknown	7%	6%
<b>Living Situation</b>		
Provider Home	31%	49%
Family Home	31%	25%
Person's Own Home	19%	18%
Group Living	2%	2%
Other	17%	6%
<b>Services Received</b>		
Service Coordination	88%	98%
Residential Supports*	62%	69%
Community Supports	60%	71%
Employment - Individual supported	60%	51%
Family Supports - Respite/FFF	35%	37%

\* In Provider Home, Group Living, or Staffed Living

The analysis of responses to the consumer survey involved grouping responses into scales reflecting a series of life satisfaction domains (Table 1.3). The scales for the 2005 survey are the same as in 2002 with the following exceptions: the Health scale has been dropped and a new Self-determination/Rights scale has been added. Since the Self-determination/Rights scale is based on new or revised questions, a direct comparison of satisfaction in this domain was not possible. It should be noted that community support was formerly called day program.

The 2005 results indicate a general trend toward slightly decreased satisfaction across most domains except for Neighborhood, and Social Support where satisfaction levels were higher. Significantly decreased satisfaction in Community Supports and Activities domains was noted at both state and local levels. In general, more people expressed a wish to take part in more community and social activities than they did in 2002. This may, in fact, be a positive result in that it indicates a desire to have more community and social interaction. Satisfaction in several of the other life domains showed some decreases but none at a significant level.

**Table 1.3 - Comparative Satisfaction by Domain**



Domain	Statewide 2002 (N=136)	Statewide 2005 (N=134)
Residential	87%	86%
Residential Autonomy	73%	69%
Neighborhood	86%	89%
Work	87%	82%
Community Supports	90%	80%
Social Support	80%	82%
Activities	73%	61%
Guardian	76%	73%
Community Services	82%	78%
Self Determination/Rights	-	48%

**SECTION 2**

**CONSUMER SURVEY 2005**

**WHAT PEOPLE HAD TO SAY**



This Section focuses on how people responded to the consumer survey in 2005. The selected highlights also include comparative statewide responses from the survey in 2002. A brief profile of the adults who were interviewed is given in Section 1 and full demographic information on all survey participants for 2005 is available in Section 4.

The method used for collecting survey data is designed to obtain feedback that is broadly representative of consumer opinion statewide each year. In each of the years since 2001, this has been done by interviewing a random selection of consumers from a sampling of agencies based on agency size and regional representation. Consumers from the same five agencies participated in the survey in 2002 and 2005.

### CONSUMER RESPONSE HIGHLIGHTS

Each of the tables below highlights responses that illustrate trends in a given satisfaction domain. For comparison purposes, the tables include the responses the responses of all people interviewed statewide in both 2002 and 2005. The columns show the percentage of respondents whose response agreed with each statement. For full details of how the participants responded to the full set of survey questions in 2005, see page 14.

**Table 2.1 – Residential**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I like where I live	82%	91%
• I cannot think of anywhere better to live	74%	72%
• I'm happy about how I spend my free time	79%	73%
• I'm happy with the chores I do	74%	72%
• I feel safe at home	91%	91%
• I can get to places (like Drs, Agency, shops)	91%	92%

**Table 2.2 – Residential Autonomy**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I had a say in where I live	54%	49%
• I choose what I wear	89%	86%
• I can change the rules at my house	77%	64%
• I can invite friends/family over when I want	85%	79%
• I have privacy when friends/family visit	79%	74%
• I have a say how to spend my money	94%	95%
• I can stay home alone if I want to when others go out	68%	65%

**Table 2.3 – Neighbors/neighborhood**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• Neighbors are friendly	88%	91%
• I like the neighborhood	75%	86%
• I feel safe in the neighborhood	88%	89%

**Table 2.4 – Work**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I chose my job by myself	27%	19%
• I like my job	90%	90%
• I work enough hours at my job	55%	46%
• The people I work with respect me	88%	90%
• I chose my job coach by myself	21%	16%
• There's nothing I'd rather do during the day	85%	69%

**Table 2.5a – Community Supports (Individual)**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I like my (individual) community activities	96%	96%
• I have enough (individual) community activities	58%	54%
• I like the people I spend time with	96%	82%
• I chose my support person by myself	20%	18%
• There's nothing I'd rather do during the day	80%	82%

**Table 2.5b – Community Supports (Group)**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I like my(group) community activities	100%	90%
• I have enough (group) community activities	80%	53%
• I like the people I spend time with	80%	81%
• I chose my support person by myself	21%	6%
• There's nothing I'd rather do during the day	64%	86%

**Table 2.6 - Friends/Social Supports**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I have plenty of friends	74%	74%
• I can see my friends when I want	62%	76%
• I have friends I like to talk/be with (not staff or family)	-	73%
• I'm not often lonely	58%	63%
• I see my family when I want	66%	72%

**Table 2.7 – Activities\***

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I shop as much as I want	79%	57%
• I exercise/play sport as much as I want	81%	59%
• I eat out as much as I want	70%	59%
• I go to church/synagogue as much as I want	70%	62%

\* Activities satisfaction includes those who take part in the activity as much as they want and those who choose not to do so.

**Table 2.8 - Guardianship**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I'm happy about my guardian	81%	86%
• I chose my guardian myself	46%	31%
• I see my guardian whenever I want	82%	85%
• My guardian lets me make my own decisions	72%	63%

**Table 2.9 - Community Services**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I'm happy with my service agency	83%	77%
• I chose my case manager myself	20%	15%
• I'm happy with my case manager	88%	79%
• I can see my case manager whenever I want	82%	80%
• People listen to me at ISA meetings	97%	93%

**Table 2.10 - Self Determination/Rights**

	<b>Statewide 2002</b>	<b>Statewide 2005</b>
• I have attended a self advocacy meeting	25%	48%
• I get to learn new things/skills	57%	68%
• I have enough control over my life	81%	74%
• I make all the choices I want	20%	52%

**DOMAIN SATISFACTION**

In order to obtain a better overall picture of what people who receive our services think, the responses to survey questions are grouped to reflect a range of life satisfaction domains. The questions used to analyze each domain are listed in Section 4.

In the first instance, domain satisfaction was examined across everyone who was interviewed in 2002 and 2005. Table 2.11 shows that, for the most part, people in 2005 responded in similar fashion to people from participating in the 2002 survey. Satisfaction was generally a little lower in 2005 across the domains except for a substantial drop in satisfaction with Community Supports and Activities and a slight increase in the Neighborhood and Social Supports domains. This may, in fact, be a positive result in that it indicates an understanding of choices in the home and a desire to have more community and social interaction.

**Table 2.11 - Comparative Domain Satisfaction**

<b>Domain</b>	<b>Statewide 2002 (N=136)</b>	<b>Statewide 2005 (N=134)</b>
Residential	87%	86%
Residential Autonomy	73%	69%
Neighborhood	86%	89%
Work	87%	82%
Community Supports	90%	80%
Social Support	80%	82%
Activities	73%	61%
Guardian	76%	73%
Community Services	82%	78%
Self Determination/Rights	-	48%

When further analyses of domain satisfaction by respondent characteristics were completed, only one significant difference was found. When domain satisfaction was examined by the types of home setting, it was found that people who lived independently rated their Residential Autonomy significantly higher than those who lived in other residential settings (Table 2.12). There was no significant difference between Residential Autonomy ratings given by people living in family homes and those in provider homes. No statistically significant differences were found on the other domains by residential type. Similarly, examination of community support satisfaction by type of support (individual or group) and guardian satisfaction by type of guardian showed no significant differences.

**Table 2.12 - Domain Satisfaction by Residential Type - 2005**

<b>Domain</b>	<b>Family Home (n=34)</b>	<b>Semi-Independent Living (n=24)</b>	<b>Provider Home (n=66)</b>	<b>All Residential Settings (n=134)</b>
Residential	86%	82%	87%	86%
* Residential Autonomy	65%	88%	62%	69%
Neighborhood	88%	81%	92%	89%
Work	82%	77%	85%	82%
Day Program	82%	76%	80%	80%
Social Support	83%	80%	81%	82%
Activities	66%	59%	58%	61%
Guardian	75%	75%	72%	73%
Community Services	81%	74%	78%	78%
Self Determination/Rights	54%	50%	45%	48%

\*People living semi-independently rated Residential Autonomy significantly higher ( $p < .05$ ) than those in other home types

**SURVEY RESPONSES, 2005: STATEWIDE (N=134)**

The following pages provide details of how people across the five participating agencies responded to individual questions on the Consumer Survey in the summer of 2005. The Vermont Consumer Survey Project is participating in the National Core Indicators (NCI) project. The aim of the project is to establish and validate “core indicators” to serve as benchmarks against which states can examine and evaluate the satisfaction of people receiving developmental services. Questions included in the national project are indicated in the table of results with asterisks (\*). The percentages given in the results below are the percentages of those consumers who answered the question.

**RESIDENTIAL**

\*1. Do you like where you live? Who do you live with?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
133	91%	7%	2%

\*2. Who chose (picked) the place where you live? (Did somebody help you make this choice?)

<b>RESPONDENTS</b>	<b>SELF</b>	<b>SELF WITH HELP</b>	<b>SOMEONE ELSE</b>
110	15%	34%	51%

3. Can you think of a place you would rather live?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES, NOT NAMED</b>	<b>YES, NAMED</b>
116	72%	3%	25%

4. Is the food there pretty good or do you not like the food there?

<b>RESPONDENTS</b>	<b>LIKE</b>	<b>IN-BETWEEN</b>	<b>NOT LIKE</b>
119	96%	3%	1%

5. Show me how you feel about the food at your house.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
129	84%	14%	2%

6. Who decides (picks) what you eat?

<b>RESPONDENTS</b>	<b>SELF</b>	<b>SOMEONE ELSE, I LIKE IT</b>	<b>SOMEONE ELSE, I DON'T LIKE IT</b>
119	56%	41%	3%

7. Who decides (picks) what you wear?

<b>RESPONDENTS</b>	<b>SELF</b>	<b>SOMEONE ELSE, I LIKE IT</b>	<b>SOMEONE ELSE, I DON'T LIKE IT</b>
119	86%	14%	0%

\*8. Who decides when you do things each day (like when to get up, when to eat dinner, what to watch on TV, when to go to bed?)

<b>RESPONDENTS</b>	<b>SELF</b>	<b>SELF WITH HELP</b>	<b>SOMEONE ELSE</b>
117	63%	22%	15%

9a. Do you like or dislike \_\_\_ ? (Average of first three named Family/Housemate responses)

<b>RESPONSES</b>	<b>LIKE</b>	<b>IN-BETWEEN</b>	<b>NOT LIKE</b>
91	89%	6%	5%

9b. Do you like or dislike \_\_\_ ? (Average of first three named Paid Housemate responses)

<b>RESPONSES</b>	<b>LIKE</b>	<b>IN-BETWEEN</b>	<b>NOT LIKE</b>
110	91%	4%	5%

10a. Is \_\_\_ nice and polite to you? (Average of first three named Family/Housemate responses)

<b>RESPONSES</b>	<b>POLITE</b>	<b>SOMETIMES</b>	<b>NOT POLITE</b>
93	89%	4%	7%

\*10b. Is \_\_\_ nice and polite to you? (Average of first three named Paid Housemate responses)

<b>RESPONSES</b>	<b>POLITE</b>	<b>SOMETIMES</b>	<b>NOT POLITE</b>
106	96%	3%	1%

11a. Show me how you feel about \_\_\_ ? (Average of first three named Family/Housemate responses)

<b>RESPONSES</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
99	80%	17%	3%

11b. Show me how you feel about \_\_\_ ? (Average of first three named Paid Housemate responses)

<b>RESPONSES</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
118	84%	9%	7%

\*12. Did you choose (pick) the people you live with?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
63	30%	33%	37%

\*13. Did you choose who helps you at home?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
58	16%	31%	53%

\*14. Have you had a lot of different people support you there?

RESPONDENTS	NO	IN-BETWEEN	YES
65	52%	3%	45%

14a. Is that a problem for you?

RESPONDENTS	NO	IN-BETWEEN	YES
34	85%	3%	12%

15. (For persons living semi-independently with no roommate) Do you like living by yourself?

RESPONDENTS	YES	IN-BETWEEN	NO
15	80%	20%	0%

16. Would you like to have someone live with you?

RESPONDENTS	NO	IN-BETWEEN	YES
15	60%	27%	13%

**THINGS TO DO:**

What do you do for fun when you are at home? (*Not during community or work supports.*)

\*17. Who decides how you spend you free time? (Who decides what you do for fun? Who chooses the activities you do?)

RESPONDENTS	SELF	SELF WITH HELP	SOMEONE ELSE
116	68%	22%	10%

\*18. Do you have enough to do when you're at home or do you sit around with nothing to do?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>IN-BETWEEN</b>	<b>NOTHING</b>
115	70%	16%	14%

\*19. Are you bored when you are at home, or is it fun to be home?

<b>RESPONDENTS</b>	<b>FUN</b>	<b>IN-BETWEEN</b>	<b>BORED</b>
119	57%	25%	18%

20. Show me how you feel about how you spend your free time at home.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
133	73%	23%	4%

**JOBS/CHORES:**

21. Are you told what jobs to do or do you get to pick the jobs/chores you want to do?

<b>RESPONDENTS</b>	<b>PICK</b>	<b>IN-BETWEEN</b>	<b>TOLD</b>
96	76%	6%	18%

22. Would you like to have more jobs/chores to do?

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
100	64%	1%	35%

23. Show me how you feel about the jobs/chores you do around your house.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
108	72%	24%	4%

**RULES:**

24. Who makes the rules for living here?

<b>RESPONDENTS</b>	<b>SELF</b>	<b>SOMEONE ELSE</b>
42	10%	90%

25. Are the rules for living there good rules or are they bad rules?

<b>RESPONDENTS</b>	<b>GOOD</b>	<b>IN-BETWEEN</b>	<b>BAD</b>
42	91%	9%	0%

26. What happens if you don't like a rule? Can you change a rule? (like when you have to go to bed etc.)?

<b>RESPONDENTS</b>	<b>CHANGE IT</b>	<b>IN-BETWEEN</b>	<b>CAN'T CHANGE</b>
39	49%	15%	36%

27. Show me what you think about the rules at your house.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
52	71%	21%	8%

28. What if you want to drink a beer or some wine in your house? Is there no drinking allowed there (at home) or can you have a beer or wine there (at home) if you want?

<b>RESPONDENTS</b>	<b>HAVE A DRINK</b>	<b>IN-BETWEEN</b>	<b>NOT ALLOWED</b>
94	55%	2%	43%

29. Can you invite your friends or your family over to your house whenever you want to?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
114	79%	9%	12%

30. Who decides when you can have friends/family over to visit?

<b>RESPONDENTS</b>	<b>SELF</b>	<b>IN-BETWEEN</b>	<b>OTHER</b>
107	41%	20%	39%

**PRIVACY:**

\*31. Can you be alone if you want to? (Do you have privacy?)

<b>RESPONDENTS</b>	<b>YES ENOUGH</b>	<b>WANT MORE TIME ALONE</b>
115	84%	16%

\*32. (If people get mail) Does anyone ever open your mail without asking you first?

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
97	87%	3%	10%

\*33. Can you use the telephone when you want to?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
116	82%	5%	13%

34. Can you talk on the phone in private or do other people listen in?

RESPONDENTS	HAVE PRIVACY	SOMETIMES	LISTEN IN
105	79	4%	17%

\*35. (If friends come over to visit?) Can you be alone with them, or does someone have to be with you?

RESPONDENTS	HAVE PRIVACY	SOMETIMES	NOT ALONE
90	75%	3%	22%

36. Has anyone ever talked to you about dating? (Having a boyfriend/girlfriend?)

RESPONDENTS	YES	NO
107	33%	67%

37. Do you need to know more about dating? (Having a boyfriend/girlfriend?)

RESPONDENTS	NO	YES
104	71%	29%

38. Do you have a boyfriend/girlfriend?

RESPONDENTS	YES	NO
99	26%	74%

39. Can you have (boyfriend/girlfriend) over to visit whenever you want?

RESPONDENTS	YES	SOMETIMES	NO
24	71%	4%	25%

40. Can (boyfriend/girlfriend) stay overnight at your house if you want, or is (boyfriend/ girlfriend) not allowed to stay overnight?

RESPONDENTS	YES, ALLOWED	SOMETIMES	NOT ALLOWED
26	54%	4%	42%

41. Can you go to (boyfriend/girlfriend)'s house as much as you want?

RESPONDENTS	YES	SOMETIMES	NOT ALLOWED
28	86%	4%	10%

**MONEY:**

42. Can you have your own money whenever you want it or do you have to ask someone for your money?

<b>RESPONDENTS</b>	<b>HAVE IT</b>	<b>ASK FOR IT</b>
115	54%	46%

43. Show me how you feel about (self or other) having your money.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
119	88%	8%	4%

\*44. Do you choose what to buy with your spending money (Did someone else decide how you spend your money?)

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOOSES</b>
115	53%	42%	5%

45. Do people steal (take) your money?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
117	94%	6%

**SAFETY:**

46. Do people in your house take your things or do they leave your stuff alone?

<b>RESPONDENTS</b>	<b>LEAVE ALONE</b>	<b>SOMETIMES</b>	<b>TAKE</b>
111	96%	0%	4%

\*47. Do people let you know before they come to your house?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
116	90%	3%	7%

\*48. Do people let you know before coming into your bedroom?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
118	81%	5%	14%

\*49. Do you feel safe in your home or do you feel afraid (scared) in your home?

<b>RESPONDENTS</b>	<b>SAFE</b>	<b>IN-BETWEEN</b>	<b>AFRAID</b>
118	91%	6%	3%

**COMING AND GOING:**

50. When people in your house go somewhere, do you have to go or can you stay home alone if you want to?

<b>RESPONDENTS</b>	<b>CAN STAY ALONE</b>	<b>IN-BETWEEN</b>	<b>HAVE TO GO</b>
105	55%	10%	35%

51. Do you have a key to your house?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
115	57%	43%

**ACCESS/ TRANSPORTATION**

\*52. When you want to go somewhere, do you have a way to get there?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
108	91%	3%	6%

53. Are there places that you need to go that you can't get to? (Such as to the doctor, the service agency, to go shopping, to the pharmacy, etc.)

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
118	78%	8%	14%

**PETS:**

54. Are there any pets at your house?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
118	75%	0%	25%

55. Do you like having a pet? (Persons with a pet)

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
90	93%	5%	2%

56. Do you want to have a pet? (Persons without a pet)

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
31	48%	7%	45%

**NEIGHBORHOOD:**

57. Are your neighbors/people who live near you friendly toward you?

RESPONDENTS	YES	SOMETIMES	NO
107	91%	4%	5%

58. Are your neighbors/people who live near you mean to you or nice to you?

RESPONDENTS	NICE	IN-BETWEEN	MEAN
105	93%	5%	2%

59. Do you like living in your neighborhood the area where you live or would you like to live in a different neighborhood/area?

RESPONDENTS	LIKE IT	IN-BETWEEN	DIFFERENT PLACE
111	86%	4%	10%

60. Show me how you feel about your neighbors.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
118	75%	19%	6%

\*61. Do you feel safe to be out in your neighborhood/the area near your house, or do you feel afraid to be out in your neighborhood/the area near your house?

RESPONDENTS	SAFE	IN-BETWEEN	AFRAID
112	89%	7%	4%

**WORK**

62. Do you have a job?

RESPONDENTS	YES	NO
116	54%	46%

63. (if q62 = No) Do you want to have a paid job?

RESPONDENTS	NO	SOMETIMES	YES
52	38%	4%	58%

64. Do you like your job or do you dislike your job?

<b>RESPONDENTS</b>	<b>LIKE</b>	<b>SOMETIMES</b>	<b>DISLIKE</b>
62	90%	3%	7%

\*65. Did you choose to work at \_\_\_\_?

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
59	19%	68%	13%

\*66. Do you like working there?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
61	93%	5%	2%

67. Do you work enough hours or do you want to work more hours?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>IN-BETWEEN</b>	<b>MORE</b>
61	46%	3%	51%

68. Is the work you do important work or not important work?

<b>RESPONDENTS</b>	<b>IMPORTANT</b>	<b>IN-BETWEEN</b>	<b>NOT IMPORTANT</b>
59	90%	5%	5%

69. Do you get paid enough for the work you do?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
59	88%	2%	10%

70. Show me how you feel about the money you make from work.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
65	77%	20%	3%

Do you have a job coach/someone/staff who helps you do your job?

\*71. Is \_\_\_\_\_ nice and polite to you?

<b>RESPONDENTS</b>	<b>NICE</b>	<b>IN-BETWEEN</b>	<b>NOT NICE</b>
33	94%	3%	3%

\*72. Did you choose \_\_\_\_\_ to help you at work?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
31	16%	26%	58%

73. Show me how you feel about the other people (co-workers) you work with.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
58	81%	19%	0%

74. Do the people you work with treat you okay, or do they not respect you?

RESPONDENTS	RESPECT	IN-BETWEEN	NO RESPECT
52	90%	6%	4%

75. Do you have to work all the time or do you get a vacation from work?

RESPONDENTS	VACATION	IN-BETWEEN	ALL THE TIME
54	89%	2%	9%

76. Show me how you feel about work.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
63	84%	13%	3%

77. Have you had a lot of different people support you at work?

RESPONDENTS	NO	IN-BETWEEN	YES
42	36%	7%	57%

77a. Is that a problem for you?

RESPONDENTS	NO	IN-BETWEEN	YES
29	83%	3%	14%

78. Is there something else you would rather do during the day?

RESPONDENTS	NO	SOMETIMES	YES
54	68%	6%	26%

79. Do you choose to go to work, or do you have to go?

<b>RESPONDENTS</b>	<b>CHOOSE</b>	<b>SOMETIMES</b>	<b>HAVE TO GO</b>
55	47%	2%	51%

**COMMUNITY ACTIVITIES - INDIVIDUAL SUPPORT**

80. Do you like your community activities or do you not like them?

<b>RESPONDENTS</b>	<b>LIKE</b>	<b>SOMETIMES</b>	<b>NOT LIKE</b>
82	96%	3%	1%

81. Did you choose (pick) your community activities?

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
81	37%	51%	12%

82. Do you like doing those activities?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
82	96%	4%	0%

83. Do you get enough community activities or would you like more?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>SOMETIMES</b>	<b>MORE</b>
81	50%	4%	46%

84. Is (support person) nice and polite to you?

<b>RESPONDENTS</b>	<b>NICE</b>	<b>IN-BETWEEN</b>	<b>NOT NICE</b>
80	95%	3%	2%

85. Did you choose (or pick) who helps you with your community activities?

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
78	18%	31%	51%

86. Show me how you feel about the people you spend time with during the day.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
91	83%	14%	3%

87. Do the people you spend time with during the day treat you okay, or do they not respect you?

RESPONDENTS	RESPECT	IN-BETWEEN	NO RESPECT
82	90%	9%	1%

88. Show me how you feel about your community activities.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
92	83%	14%	3%

89. Have you had a lot of different people support you during the day?

RESPONDENTS	NO	SOMETIMES	YES
77	48%	3%	49%

89a. Is that a problem for you?

RESPONDENTS	NO	SOMETIMES	YES
40	90%	3%	7%

90. Is there something else you would rather do during the day?

RESPONDENTS	NO	SOMETIMES	YES
77	82%	6%	12%

91. Do you choose to go to your community activities, or do you have to go?

RESPONDENTS	CHOOSE	SOMETIMES	HAVE TO GO
81	59%	6%	35%

**COMMUNITY ACTIVITIES - GROUP SUPPORT**

92. Do you like your community activities or do you not like them?

RESPONDENTS	LIKE	SOMETIMES	NOT LIKE
19	90%	5%	5%

93. Did you choose (pick) your community activities?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
19	32%	31%	37%

94. Do you like doing those activities?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
19	95%	0%	5%

95. Do you get enough community activities or would you like more?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>SOMETIMES</b>	<b>MORE</b>
19	53%	0%	47%

96. Is (support person) nice and polite to you?

<b>RESPONDENTS</b>	<b>NICE</b>	<b>IN-BETWEEN</b>	<b>NOT NICE</b>
19	95%	0%	5%

97. Did you choose (or pick) who helps you with your community activities?

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
16	6%	31%	63%

98. Show me how you feel about the people you spend time with during the day.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
21	81%	19%	0%

99. Do the people you spend time with during the day treat you okay, or do they not respect you?

<b>RESPONDENTS</b>	<b><u>RESPECT</u></b>	<b>IN-BETWEEN</b>	<b>NO RESPECT</b>
19	100%	0%	0%

100. Show me how you feel about your community activities.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
22	77%	23%	0%

101. Have you had a lot of different people support you during the day?

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
19	37%	5%	58%

101a. Is that a problem for you?

RESPONDENTS	NO	SOMETIMES	YES
12	92%	0%	8%

102. Is there something else you would rather do during the day?

RESPONDENTS	NO	SOMETIMES	YES
14	86%	14%	0%

103. Do you choose to go to your community activities, or do you have to go?

RESPONDENTS	CHOOSE	SOMETIMES	HAVE TO GO
19	58%	0%	42%

**FRIENDS and SOCIAL SUPPORT**

**FRIENDS:**

\*104. Do you have a best friend or someone you are really close to? (Is there someone you can talk to about personal things?)

RESPONDENTS	YES	NO
116	80%	20%

\*105. Do you have friends you like to talk to or do things with?

RESPONDENTS	YES NOT STAFF OR FAMILY	ALL ARE STAFF OR FAMILY	NO FRIENDS
113	73%	18%	9%

106a. Show me how \_\_\_ usually makes you feel. (Average of first 3 named natural friend responses)

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
86	85%	14%	1%

106b. Show me how \_\_\_ usually makes you feel. (Average of first 3 staff or family friend responses)

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
71	86%	12%	2%

107. Do you have enough friends or do you wish you had more friends?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>MORE</b>
108	59%	41%

\*108. Can you see your friends when you want to see them?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
108	76%	13%	11%

109. Who do you talk to when you need to talk to someone?

<b>RESPONDENTS</b>	<b>SOMEONE</b>	<b>NO ONE</b>
112	95%	5%

110. Does anyone ever ask you to help them?

<b>RESPONDENTS</b>	<b>SOMEONE</b>	<b>NO ONE</b>
114	67%	33%

111. On most days, are you usually happy or sad?

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
114	82%	13%	5%

112. Are you lonely or do you have plenty of friends?

<b>RESPONDENTS</b>	<b>PLENTY</b>	<b>IN-BETWEEN</b>	<b>LONELY</b>
109	74%	14%	12%

\*113. Do you ever feel lonely, like you don't have anyone to talk to?

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
98	63%	34%	3%

**FAMILY:**

\*114. (For those with family they can name) Do you ever get to see your family?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
98	79%	13%	8%

\*115. Can you see your (named) family when you want to?

RESPONDENTS	YES	SOMETIMES	NO
94	72%	12%	16%

116. Show me how you feel about these (named) family members.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
106	81%	17%	2%

### **ACTIVITIES**

What do you do for fun? Can you tell me some things you do for fun?

\*117. Do you ever go shopping?

117a. (If q117=Yes) Do you go to shop as much as you want or do you want to go more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
99	55%	45%

117b. (If q117=No) Do you ever want to go shopping?

RESPONDENTS	NO	YES
6	77%	23%

\*118. Do you ever run errands or go to appointments?

118a. (If q118=Yes) Do you run errands or go to appointments as much as you want or do you want to go more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
102	77%	23%

118b. (If q118=No) Do you ever want to go on errands/appointments?

RESPONDENTS	NO	YES
8	63%	37%

\*119. Do you ever exercise or play sports?

119a. (If q119=Yes) Do you exercise/play sports as much as you want or do you want to do more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
99	59%	41%

119b. (If q119=No) Do you ever want to exercise/play sports?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
13	54%	46%

\*120. Do you ever go out to entertainment?

120a. (If q120=Yes) Do you go out to entertainment as much as you want or do you want more?

<b>RESPONDENTS</b>	<b>AS MUCH AS I WANT</b>	<b>WANT MORE</b>
80	50%	50%

120b. (If q120=No) Do you ever want to go out to entertainment?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
35	46%	54%

\*121. Do you ever go out to eat?

121a. (If q121=Yes) Do you go out to eat as much as you want or do you want to go more?

<b>RESPONDENTS</b>	<b>AS MUCH AS I WANT</b>	<b>WANT MORE</b>
113	63%	37%

121b. (If q121=No) Do you ever want to go out to eat?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
15	27%	73%

\*122. Do you ever go to church or synagogue?

122a. (If q122=Yes) Do you go to church or synagogue as much as you want or do you want to go more?

<b>RESPONDENTS</b>	<b>AS MUCH AS I WANT</b>	<b>WANT MORE</b>
45	67%	33%

122b. (If q122=No) Do you ever want to go to church or synagogue?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
72	57%	43%

\*123. Do you ever go to other community meetings?

123a. (If q123=Yes) Do you go to other community meetings as much as you want or do you want to go more?

<b>RESPONDENTS</b>	<b>AS MUCH AS I WANT</b>	<b>WANT MORE</b>
38	63%	37%

123b. (If q123=No) Do you ever want to other community meetings?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
71	68%	32%

**GUARDIANSHIP**

124. Do you get to see or talk to your guardian when you want to? (Persons with guardianship)

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
74	85%	10	5%

125. Did you get to choose (pick) your guardian, or did someone else choose your guardian?

<b>RESPONDENTS</b>	<b>I CHOSE</b>	<b>SOMEONE ELSE CHOSE</b>
71	31%	69%

126. Show me how you feel about (guardian).

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
88	87%	10%	3%

127. Does your guardian let you make some decisions for yourself or does she/he make decisions for you?

<b>RESPONDENTS</b>	<b>OWN DECISIONS</b>	<b>GUARDIAN DECIDES</b>
71	63%	37%

128. Do you want to change who your guardian is?

<b>RESPONDENTS</b>	<b>NO</b>	<b>MAYBE</b>	<b>YES</b>
71	87%	4%	9%

**SELF-ADVOCACY**

\*129. Have you ever gone to a self-advocacy meeting, conference or event?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
108	48%	52%

130. (If q129=Yes) Why did you go to the self-advocacy meeting, conference, or event?

<b>RESPONDENTS</b>	<b>INFORMATION</b>	<b>SOCIAL OPPORTUNITY</b>	<b>PART OF ADVOCACY MOVEMENT</b>	<b>OTHER</b>
44	46%	29%	7%	18%

\*131. (If q129=No) Why haven't you gone or been able to go?

<b>RESPONDENTS</b>	<b>NO TIME</b>	<b>NOT INTERESTED</b>	<b>NO RIDE</b>	<b>DIDN'T KNOW ABOUT IT</b>	<b>OTHER</b>
49	16%	29%	6%	45%	4%

132a. (If q129=Yes) Do you want to go again to a self-advocacy meeting, conference or event?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
52	75%	25%

132b. (If q129=No) Do you want to go to a self-advocacy meeting, conference or event?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
45	40%	60%

133. Do you see yourself as being a self-advocate?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
103	86%	14%

134. Do you want to know more about self-advocacy?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
103	53%	47%

## **VOTING**

135. Has anyone ever talked to you about voting in elections?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
113	58%	42%

136. Have you ever voted in an election?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
112	55%	45%

137a. (If have voted) Do you want to vote in an election?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
25	96%	4%

137b. (If have not voted) Do you want to vote in an election?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
47	57%	43%

**SERVICE AGENCY**

\*138 Do you know your service coordinator/case manager?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NOT SURE</b>	<b>NO</b>
112	96%	3%	1%

139. Show me how you feel about (your case manager).

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
112	79%	19%	2%

\*140. Did you choose (or pick) (your case manager)?

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
108	15%	16%	69%

141. Do you get to see (your case manager) when you want to?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
111	80%	12%	8%

142. When you want to talk to (your case manager) is it hard or easy to get in touch with him/her?

<b>RESPONDENTS</b>	<b>EASY</b>	<b>IN-BETWEEN</b>	<b>HARD</b>
104	53%	25%	22%

\*143. Does he/she ask you what you want?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
108	75%	13%	12%

\*144. If you ask for something, does he/she help you get you what you need?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
108	93%	2%	5%

145. Have you had a lot of different case managers (service coordinators)?

<b>RESPONDENTS</b>	<b>NO</b>	<b>IN-BETWEEN</b>	<b>YES</b>
105	42%	4%	54%

145a. Is that a problem for you?

<b>RESPONDENTS</b>	<b>NO</b>	<b>IN-BETWEEN</b>	<b>YES</b>
59	80%	1%	19%

146. Show me how you feel about (your service agency).

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
122	77%	20%	3%

147. Did you have a support plan (ISA) meeting this year?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
96	73%	27%

148. When you have your support plan (ISA) meetings, do people listen to what you have to say?

<b>RESPONDENTS</b>	<b>LISTEN</b>	<b>SOMETIMES</b>	<b>NOT LISTEN</b>
71	93%	6%	1%

149. Are the things that are important to you in your support plan (ISA)?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
72	90%	7%	3%

150. Do you have a group of friends or family that you count on to help you make decisions?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
109	76%	6%	18%

151. Do you get the services you need?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
109	94%	4%	2%

\*152. (Waiver or flexible funding consumers only) Do you know how much money the agency has to pay for your worker(s)/services?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
95	10%	7%	83%

153. (Waiver or flexible funding consumers only) When you have your ISA meeting, does your case manager tell you how much money is in your waiver/budget?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
78	44%	6%	50%

154. Do people at (your agency) listen to you or not listen to you?

<b>RESPONDENTS</b>	<b>LISTEN</b>	<b>SOMETIMES</b>	<b>NOT LISTEN</b>
106	82%	11%	7%

155. Are you having trouble getting the help you need from people at (your agency) or are you getting the help you need?

<b>RESPONDENTS</b>	<b>GETTING HELP</b>	<b>SOMETIMES</b>	<b>TROUBLE</b>
107	91%	5%	4%

156. Who would you ask to help you change services or supports you do not like?

<b>RESPONDENTS</b>	<b>NAMED</b>	<b>SOMEONE, BUT DID NOT NAME</b>	<b>NOBODY NAMED</b>
97	74%	8%	18%

\*157. Do people help you do or learn new things?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
104	68%	9%	23%

\*158. Do you want (more) help to do or learn new things?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
88	25%	46%	29%

159. Show me how you feel about the help you get from (your agency).

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
124	84%	13%	3%

160. Have you ever been told about (your agency's) complaint process or are you not aware of (your agency's) complaint process?

<b>RESPONDENTS</b>	<b>TOLD</b>	<b>NOT AWARE</b>
106	36%	64%

161. Have you ever made a formal written complaint to someone at your agency?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
103	85%	15%

162. Have you been told about (your agency's) appeal process or are you not aware of (your agency's) appeal process?

<b>RESPONDENTS</b>	<b>TOLD</b>	<b>NOT AWARE</b>
104	30%	70%

**SELF-DETERMINATION**

163. Do you need to have more control over your life or do you think you have enough control?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>IN-BETWEEN</b>	<b>MORE</b>
106	78%	2%	20%

164. Are there choices you wish you could make that you don't make now?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES NOT NAMED</b>	<b>YES NAMED</b>
103	56%	17%	27%

165. Do you need to know more about how to interview and hire your support staff?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
103	55%	45%



**SECTION 3**

**PARTICIPANT PROFILE 2005**

**WHO PARTICIPATED**



This Section is intended to give an overall picture of the adults receiving developmental services statewide. It reports findings from the 2005 Demographics Survey, including new communication effectiveness and support information as follows:

- **Basic Demographics (Tables 3.1-3.3)** covers Personal Characteristics, Legal Factors, and Family Involvement.
- **Communication Capability (Tables 3.4-3.6)** covers Means of Communication, Communication Effectiveness, and Communication Supports.
- **Medical/Health Issues (Tables 3.7-3.9)** covers Developmental Disability, Other Challenges, and Healthcare and Lifestyle.
- **Residential Information (Tables 3.10-3.12)** covers Type of Residence, Residential Characteristics, and Guardianship by Residential Type.
- **Services (Tables 3.13-3.14)** covers Type of Services Received and Self-Management of Services.

Each of the tables in these reporting categories includes percentages for those interviewed, those not interviewed, and all participants. For ease of reading, the definition of the data reported (left hand column) and the data for all participants served statewide (right hand column) are shown in bold.

### BASIC DEMOGRAPHICS

**Table 3.1 - Personal Characteristics**

Characteristic	Interviewed (n=134)	Not Interviewed (n=221)	All Participants (n=355)
<b>Age</b>			
<b>Average Age</b>	43	40	<b>41</b>
<b>Minimum</b>	21	18	<b>18</b>
<b>Maximum</b>	86	86	<b>86</b>
<b>Gender</b>			
<b>Male</b>	60%	53%	<b>56%</b>
<b>Female</b>	40%	47%	<b>44%</b>
<b>Marital Status</b>			
<b>Single</b>	93%	95%	<b>95%</b>
<b>Married/Civil Union</b>	3%	2%	<b>3%</b>
<b>Single/Married in Past</b>	4%	1%	<b>2%</b>
<b>Unknown</b>	0%	1%	<b>&lt;1%</b>
<b>Race</b>			
<b>White</b>	95%	93%	<b>94%</b>
<b>American Indian/Eskimo/Aleut</b>	2%	1%	<b>2%</b>
<b>Asian</b>	<1%	<1%	<b>&lt;1%</b>
<b>Pacific Islander</b>	0%	<1%	<b>0%</b>
<b>Black</b>	0%	1%	<b>&lt;1%</b>
<b>Other/Unknown</b>	3%	4%	<b>4%</b>
<b>Primary Language</b>			
<b>English</b>	100%	98%	<b>99%</b>
<b>Other</b>	0%	2%	<b>1%</b>

**Table 3.2 - Legal Factors**

	<b>Interviewed (n=134)</b>	<b>Not Interviewed (n=221)</b>	<b>All Participants (n=355)</b>
<b>Guardianship</b>			
<b>No Guardian</b>	30%	21%	<b>24%</b>
<b>Private Guardian</b>	40%	52%	<b>48%</b>
<b>Public Guardian</b>	30%	24%	<b>26%</b>
<b>Unknown</b>	0%	3%	<b>2%</b>
<b>Payee</b>			
<b>No Payee</b>	16%	21%	<b>18%</b>
<b>Payee</b>	80%	74%	<b>77%</b>
<b>Unknown</b>	4%	5%	<b>5%</b>
<b>Court Restrictions</b>			
<b>No</b>	89%	84%	<b>86%</b>
<b>Yes</b>	10%	13%	<b>12%</b>
<b>Unknown</b>	1%	3%	<b>2%</b>

**Table 3.3 - Family Involvement in People's Lives**

	<b>Interviewed (n=134)</b>	<b>Not Interviewed (n=221)</b>	<b>All Participants (n=355)</b>
<b>Family Involved</b>			
<b>Yes</b>	89%	84%	<b>86%</b>
<b>No</b>	10%	13%	<b>12%</b>
<b>Unknown</b>	1%	3%	<b>2%</b>
<b>Why Family not Involved</b>	<b>(n=15)</b>	<b>(n=32)</b>	<b>(n=47)</b>
<b>Family gone/not alive/     whereabouts unknown</b>	33%	38%	<b>36%</b>
<b>Family choice</b>	27%	25%	<b>26%</b>
<b>Other</b>	40%	12%	<b>21%</b>
<b>Unknown</b>	0%	25%	<b>17%</b>

**COMMUNICATION CAPABILITY**

**Table 3.4 – Means of Communication**

	<b>Interviewed (n=134)</b>	<b>Not Interviewed (n=221)</b>	<b>All Participants (n=355)</b>
<b>Adequate Reliable Speech</b>			
<b>Yes</b>	86%	53%	<b>66%</b>
<b>No</b>	14%	46%	<b>34%</b>
<b>Unknown</b>	0%	1%	<b>1%</b>
<b>Primary Means of Communication</b>			
<b>Spoken - Understood by     familiar listener</b>	96%	70%	<b>80%</b>
<b>Gesture/body language</b>	2.0%	18%	<b>12%</b>
<b>Sign language/finger spelling</b>	0.0%	3%	<b>2%</b>
<b>Communication aid/device</b>	2.0%	2%	<b>2%</b>
<b>Other</b>	<1%	5%	<b>3%</b>
<b>Unknown</b>	0.0%	2%	<b>1%</b>

**Table 3.5 – Communication Effectiveness for People with Inadequate Speech**

	<b>Interviewed (n=18)</b>	<b>Not Interviewed (n=103)</b>	<b>All Participants (n=121)</b>
<b>Communicate with familiar people</b>			
<b>Yes</b>	100%	88%	<b>90%</b>
<b>No</b>	0%	10%	<b>8%</b>
<b>Unknown</b>	0%	2%	<b>2%</b>
<b>Communicate with unfamiliar people</b>			
<b>Yes</b>	72%	30%	<b>36%</b>
<b>No</b>	28%	65%	<b>60%</b>
<b>Unknown</b>	0%	5%	<b>4%</b>
<b>Communicate beyond basic needs</b>			
<b>Yes</b>	67%	40%	<b>44%</b>
<b>No</b>	33%	56%	<b>53%</b>
<b>Unknown</b>	0%	4%	<b>3%</b>
<b>Communication effectiveness in last year</b>			
<b>More effective</b>	33%	15%	<b>18%</b>
<b>As effective</b>	50%	67%	<b>64%</b>
<b>Less effective</b>	11%	6%	<b>7%</b>
<b>Unknown</b>	6%	12%	<b>11%</b>

**Table 3.6 – Communication Supports for People with Inadequate Speech**

	<b>Interviewed (n=18)</b>	<b>Not Interviewed (n=103)</b>	<b>All Participants (n=121)</b>
<b>Communication addressed in ISA</b>			
<b>Yes</b>	53%	40%	<b>42%</b>
<b>No</b>	47%	55%	<b>54%</b>
<b>Unknown</b>	0%	5%	<b>4%</b>
<b>Communication Supports in Place</b>			
<b>Consistent comm. partners</b>	100%	86%	<b>88%</b>
<b>Team support</b>	100%	91%	<b>93%</b>
<b>Access to comm. aids/devices</b>	67%	34%	<b>39%</b>
<b>Training support for support wkers</b>	78%	64%	<b>66%</b>
<b>Expert consultation/support</b>	67%	38%	<b>42%</b>

**MEDICAL/HEALTH ISSUES**

**Table 3.7 - Developmental Disability**

<b>Disability Label</b>	<b>Interviewed (n=134)</b>	<b>Not Interviewed (n=221)</b>	<b>All Participants (n=355)</b>
<b>Mild MR</b>	73%	45%	<b>55%</b>
<b>Moderate MR</b>	15%	23%	<b>20%</b>
<b>Severe MR</b>	5%	14%	<b>11%</b>
<b>Profound MR</b>	1%	8%	<b>5%</b>
<b>Unknown</b>	1%	5%	<b>4%</b>
<b>Not reported</b>	5%	5%	<b>5%</b>

**Table 3.8 - Other Challenges**

<b>Challenge</b>	<b>Interviewed (n=134)</b>	<b>Not Interviewed (n=221)</b>	<b>All Participants (n=355)</b>
<b>Mental Illness</b>	24%	23%	<b>24%</b>
<b>Autism</b>	4%	11%	<b>8%</b>
<b>Cerebral Palsy</b>	4%	19%	<b>12%</b>
<b>Brain Injury</b>	1%	3%	<b>2%</b>
<b>Chemical dependence</b>	2%	0%	<b>1%</b>
<b>Physical disability</b>	5%	15%	<b>10%</b>
<b>Hearing</b>	6%	16%	<b>11%</b>
<b>Vision</b>	20%	21%	<b>20%</b>
<b>Seizures</b>	13%	32%	<b>23%</b>
<b>Communication disorder</b>	0%	14%	<b>7%</b>
<b>Alzheimers disease</b>	1%	2%	<b>1%</b>
<b>Down Syndrome</b>	7%	14%	<b>10%</b>
<b>Non-Ambulatory</b>	4%	17%	<b>10%</b>
<b>Other</b>	10%	17%	<b>13%</b>

**Table 3.9 - Healthcare and Lifestyle**

	<b>Interviewed (n=134)</b>	<b>Not Interviewed (n=221)</b>	<b>All Participants (n=355)</b>
<b>Last Physical Examination</b>			
<b>In the past year</b>	87%	75%	<b>80%</b>
<b>Over 1 year ago</b>	8%	10%	<b>9%</b>
<b>Unknown</b>	5%	15%	<b>11%</b>
<b>Last Dental Examination</b>			
<b>In the past six months</b>	69%	47%	<b>55%</b>
<b>Over 6 months ago</b>	14%	27%	<b>22%</b>
<b>Unknown</b>	17%	26%	<b>23%</b>
<b>Medical Care Required</b>			
<b>Less than once/month</b>	84%	75%	<b>79%</b>
<b>At least once/month</b>	10%	9%	<b>9%</b>
<b>At least once/week or more</b>	2%	4%	<b>3%</b>
<b>Unknown</b>	4%	12%	<b>9%</b>
<b>Seizure Frequency</b>			
<b>No seizures</b>	83%	75%	<b>78%</b>
<b>Less than once/month</b>	11%	13%	<b>12%</b>
<b>At least once/month</b>	1%	3%	<b>2%</b>
<b>At least once/week or more</b>	1%	4%	<b>3%</b>
<b>Unknown</b>	4%	5%	<b>5%</b>
<b>Vision</b>			
<b>Sees well (with/without correction)</b>	90%	81%	<b>85%</b>
<b>Vision problems limit activities</b>	8%	10%	<b>9%</b>
<b>Limited or no vision (legally blind)</b>	2%	6%	<b>4%</b>
<b>Unknown</b>	0%	3%	<b>2%</b>
<b>Level of Mobility</b>			
<b>Walks or uses wheelchair</b>	95%	84%	<b>88%</b>
<b>Non-ambulatory needs assistance</b>	5%	14%	<b>11%</b>
<b>Unknown</b>	0%	2%	<b>1%</b>
<b>Physically Active</b>			
<b>Very physically active</b>	25%	19%	<b>21%</b>
<b>Moderately physically active</b>	59%	55%	<b>57%</b>
<b>Physically inactive</b>	16%	23%	<b>20%</b>
<b>Unknown</b>	0%	3%	<b>2%</b>
<b>Weight concerns</b>			
<b>No weight concerns</b>	60%	61%	<b>60%</b>
<b>Overweight</b>	34%	28%	<b>31%</b>
<b>Underweight</b>	4%	7%	<b>6%</b>
<b>Unknown</b>	2%	4%	<b>3%</b>
<b>Smoke/chew tobacco</b>			
<b>No</b>	90%	90%	<b>90%</b>
<b>Yes</b>	9%	5%	<b>7%</b>
<b>Unknown</b>	1%	5%	<b>3%</b>

**RESIDENTIAL INFORMATION**

**Table 3.10 - Type of Residence**

<b>Residential Type</b>	<b>Interviewed (n=134)</b>	<b>Not Interviewed (n=221)</b>	<b>All Participants (n=355)</b>
<b>Provider Home</b>	49%	47%	<b>48%</b>
<b>Family Home</b>	25%	36%	<b>32%</b>
<b>Person's Own Home</b>	18%	10%	<b>13%</b>
<b>Group Living</b>	2%	1%	<b>1%</b>
<b>Staffed Living</b>	1%	2%	<b>2%</b>
<b>Residential Care Home</b>	2%	0%	<b>1%</b>
<b>Nursing facility</b>	1%	2%	<b>1%</b>
<b>Other/Unknown</b>	2%	2%	<b>2%</b>

**Table 3.11 – Respondent Guardianship by Residential Type**

<b>Residential Type</b>	<b>No Guardian (n=40)</b>	<b>Private Guardian (n=53)</b>	<b>Public Guardian (n=41)</b>	<b>Total (n=134)</b>
<b>Provider Home</b>	23%	45%	80%	<b>49%</b>
<b>Family Home</b>	30%	41%	0%	<b>25%</b>
<b>Person's Own Home</b>	40%	8%	10%	<b>18%</b>
<b>Group Living</b>	0%	2%	3%	<b>2%</b>
<b>Staffed Living</b>	0%	0%	2%	<b>1%</b>
<b>Residential Care Home</b>	2%	2%	3%	<b>2%</b>
<b>Nursing facility</b>	0%	0%	2%	<b>1%</b>
<b>Other/Unknown</b>	5%	2%	0%	<b>2%</b>

**Table 3.12 - Residence Characteristics**

<b>Residential Characteristic</b>	<b>Interviewed (n=134)</b>	<b>Not Interviewed (n=221)</b>	<b>All Participants (n=355)</b>
<b>Location</b>			
<b>Remote</b>	45%	52%	<b>49%</b>
<b>Walking distance to town</b>	33%	30%	<b>31%</b>
<b>Centrally located in town</b>	22%	15%	<b>18%</b>
<b>Unknown</b>	0%	3%	<b>2%</b>
<b>Ownership/Lease of Home</b>			
<b>Family/guardian</b>	29%	34%	<b>32%</b>
<b>Individual/family person lives with</b>	44%	48%	<b>46%</b>
<b>Provider agency/affiliate</b>	4%	2%	<b>3%</b>
<b>Person rents home</b>	18%	8%	<b>12%</b>
<b>Person owns home</b>	2%	2%	<b>2%</b>
<b>Unknown</b>	1%	4%	<b>3%</b>
<b>Other</b>	2%	2%	<b>2%</b>
<b>Amount of Paid Residential Support</b>			
<b>No on-site support (Indep./family)</b>	28%	32%	<b>30%</b>
<b>24 hour on-site</b>	52%	52%	<b>52%</b>
<b>Daily on-site</b>	10%	8%	<b>9%</b>
<b>Less frequent than daily</b>	8%	6%	<b>6%</b>
<b>As needed</b>	2%	2%	<b>2%</b>
<b>Unknown</b>	0%	<1%	<b>&lt;1%</b>
<b>Household Composition</b>			
<b>Non-related individuals</b>	53%	53%	<b>53%</b>
<b>Biological/adoptive parents</b>	22%	34%	<b>30%</b>
<b>Lives alone</b>	13%	5%	<b>8%</b>
<b>Spouse/Civil Union</b>	2%	2%	<b>2%</b>
<b>Minor children only</b>	0%	1%	<b>&lt;1%</b>
<b>Other relatives</b>	8%	3%	<b>5%</b>
<b>Other/Unknown</b>	2%	2%	<b>2%</b>
<b>Time in current home/with current provider</b>			
<b>More than 5 years</b>	51%	61%	<b>57%</b>
<b>3-5 years</b>	15%	17%	<b>16%</b>
<b>1-2 years</b>	16%	12%	<b>14%</b>
<b>Less than 1 year</b>	14%	8%	<b>10%</b>
<b>Unknown</b>	4%	2%	<b>3%</b>

**SERVICES**

**Table 3.13 - Types of Services Received**

Service Type	Interviewed (n=134)	Not Interviewed (n=221)	All Participants (n=355)
<b>Residential Supports*</b>	69%	60%	<b>64%</b>
<b>Service Coordination</b>	98%	88%	<b>92%</b>
<b>Employment - Individual supported</b>	51%	28%	<b>37%</b>
<b>Employment - Group</b>	3%	2%	<b>2%</b>
<b>Community Support - Individual</b>	71%	56%	<b>62%</b>
<b>Community Support - Group</b>	19%	8%	<b>12%</b>
<b>Clinical Services</b>	57%	45%	<b>49%</b>
<b>Transportation</b>	53%	43%	<b>47%</b>
<b>Family supports - Respite/FFF</b>	37%	46%	<b>43%</b>
<b>Other Supports</b>	7%	8%	<b>8%</b>

\* In Provider Home, Group Living, or Staffed Living

**Table 3.14 - Self-Management of Services**

	Interviewed (n=134)	Not Interviewed (n=221)	All Participants (n=355)
<b>Management of Services</b>			
<b>Self or Shared with Agency</b>	8%	4%	<b>6%</b>
<b>Family or Shared with Agency</b>	8%	13%	<b>11%</b>
<b>Agency Managed</b>	84%	79%	<b>81%</b>
<b>Unknown</b>	0%	4%	<b>2%</b>
<b>Individually Negotiated Budget</b>			
<b>Yes</b>	85%	81%	<b>83%</b>
<b>No</b>	10%	15%	<b>13%</b>
<b>Unknown</b>	5%	4%	<b>4%</b>
<b>Individual Support Agreement (ISA)</b>			
<b>Yes</b>	98%	86%	<b>90%</b>
<b>No</b>	1%	12%	<b>8%</b>
<b>Unknown</b>	1%	2%	<b>2%</b>
<b>Fiscal Intermediary (ISO/private payroll)</b>			
<b>Yes</b>	43%	53%	<b>49%</b>
<b>No</b>	53%	43%	<b>47%</b>
<b>Unknown</b>	4%	4%	<b>4%</b>
<b>Independent Support Broker (ISB)</b>			
<b>Yes</b>	10%	6%	<b>7%</b>
<b>No</b>	87%	90%	<b>89%</b>
<b>Unknown</b>	3%	4%	<b>4%</b>

## **SECTION 4**

### **METHODOLOGY**

#### **HOW THIS SURVEY IS CONDUCTED**



Since the inception of the statewide consumer surveys in 1995, the State Division of Disability and Aging Services has taken steps to provide a forum for people receiving developmental services to express their own point of view while eliminating possible bias or influence. For this reason, the surveys have always been administered by an independently contracted team. Originally, this work was contracted to a team from the University of Vermont. Since 2003, survey administration and data entry has been coordinated by Rosemary Drabing, M.S.W. and Janet Bramley Ph.D. has been responsible for survey analysis and reporting. Survey responses remain confidential and personally identifying data are removed before the survey responses are analyzed.

The Vermont Consumer Survey is conducted statewide over a 3 year period, 2005 marking the second year of the third such 3-year cycle. Within each year, a sample of adults receiving developmental services is surveyed. This Section describes the methodology used to obtain and analyze information for the 2005-2006 Vermont Consumer Survey. The information in this Section covers:

- **Participant Selection:** How people are chosen to take part in the survey to obtain a fair representation of the adults receiving developmental services in the state of Vermont and their views in a variety of life satisfaction domains.
- **The Survey Instruments:** A brief description of the questionnaires used to obtain demographic and satisfaction information.
- **Survey Administration:** A description of how demographic information is collected and the participant interview procedure.
- **Survey Analysis and Reporting:** A description of the analytical procedures used to derive the findings presented in this report.

## **PARTICIPANT SELECTION**

The selection of adults to participate in the consumer survey is designed to be representative both within each agency and to be representative of the statewide population receiving developmental services in each year. Five or six agencies are chosen each year. In the summer of 2005, the independently contracted survey interviewers visited the same five agencies as were surveyed in 2002; the agencies visited in 2004 were the same as those in 2001 and likewise, those visited in 2006 will be the same as those in 2003.

The selection of participants is the first stage of the survey process each year. During springtime, a random sample based on the size of agency and regional representation is drawn from the list of people currently served by the agency. These are the potential survey participants for that summer. The percentage of individuals served by each agency who are invited to participate is shown in Table 4.1.

**Table 4.1 –Sample Size by Agency as a Percentage of Adults Served**

Agency	2004	2005	2006
Champlain Vocational Services (CVS)	100%		
Community Access Program (RMHS - CAP)			50%
Community Associates (CSAC - CA)	50%		
Community Developmental Services (WCMH - CDS)			50%
Health Care and Rehabilitation Services of Southeastern Vermont (HCRS)		50%	
Howard Center for Human Services (HCHS)	33%	33%	33%
Lamoille County Mental Services (LCMH)			100%
Lincoln Street Incorporated (LSI)			100%
Northeast Kingdom Human Services (NKHS)	50%		
Northwestern Counseling and Support Services (NCSS)		50%	
Specialized Community Care (SCC)	100%		
Sterling Area Services (SAS)		100%	
Upper Valley Services (UVS)		50%	
United Counseling Service (UCS)	50%		

The Demographic Survey is used to collect information about all participants. The agency then makes a determination as to which people can also participate in satisfaction interviews. While it is recognized that not all participants are able or willing to be interviewed, the aim is to interview 60% of participants.

### **THE SURVEY INSTRUMENTS**

Two survey instruments are used: the Demographic Survey and the Consumer Interview. These instruments were developed and extensively field-tested for reliability by Susan Culbert, Ph.D., and Sara Burchard, Ph.D. during the early 1990s. The format and questions had been reviewed and approved by a variety of stakeholders including self-advocates, family members, service providers, and representatives from the State Division of Developmental Services, prior to the survey instruments' first statewide use in 1995.

Since the first 3-year cycle of surveys, a number of questions have been changed or added to the original survey instruments. For the second cycle of surveys, questions addressing knowledge of services and self-determination were added to the Consumer Interview in response to consumer advocacy requests. It was at this time also that the State started submitting survey data to the National Core Indicators (NCI) project. This project currently includes 21 states and provides an annual comparative 'report card' on services for adults receiving developmental services. For the current cycle of surveys, the Demographic Survey, in particular, has been further enhanced. This has been partly to include more questions on communication capabilities and services to inform the current communication

initiative, and partly to align more closely with questions with the National Core Indicators (NCI) project to enable more cross state comparisons. Revisions to the current consumer interview have been primarily clarifications and matching up to the NCI survey wording rather than additional questions.

The Demographic Survey is filled out by case managers at the participating agencies prior to the interviews with the people receiving services. The information gathered can be used in the first instance by the interviewers to inform and facilitate the interview process. It has also proved over the last decade to be valuable resource for obtaining a comprehensive ongoing picture of the population of adults receiving developmental services here in Vermont. The Demographic Survey consists of sections covering general demographics, communication capabilities and services, medical and health information, behavioral challenges, residential characteristics, services, and self management and self determination. The information from the Demographic Survey is reported in section 3 of this Report.

The structured Consumer Interview consists of 165 questions designed to measure how satisfied people receiving developmental services are in a variety of life domains: how they feel about their residential living, work and/or community activities, community services, and activities. It also obtains information on other valued outcomes, such as social support, neighbors, leisure activities, degree of independence, opportunities for growth and change, self-advocacy, and self-determination. Each question on the survey has a high value of 2 (positive response) and a low of 0 (negative response). The values for 'Not Applicable', 'Refused' or 'Unclear/unknown' are excluded from the analysis. On average, the direct interviews will take between 30 and 35 minutes to complete. For people who have difficulty with verbal communication, there is an abbreviated version of the Consumer Interview covering the same satisfaction domains, in which picture cards ('Happy', 'In-between' and 'Sad') are used for respondents to indicate their answers. The information from the Consumer Interview is reported in section 2 of this Report.

Copies of the survey instruments may be requested from the Division of Disability and Aging Services.

## **SURVEY ADMINISTRATION**

Rosemary Drabing, an independent contractor with extensive experience with the Vermont developmental service system, took over project coordination in 2003, the last year of the previous cycle of surveys. In each year, field interviewers are hired and trained to complete the consumer interviews. Typically, interviewers have included graduate students, teaching and human services professionals, and consumers of developmental services.

Once the participant pool has been selected (see page 49), the project coordinator meets with service coordinators at the participating agencies and distributes copies of the Demographic Survey to be filled out before the interviews. It is at this time that a determination will be made by the agencies as to which of the randomly selected adults can also participate in direct interviews. Arrangements are then made for the direct interviews to take place usually at agency offices.

Generally, the participants are interviewed alone at the agency offices to allow them to express their opinions freely. However, accommodations are made as necessary, for example, if the individual wants someone present or an interpreter is needed or the individual cannot get to the office. The interview questions are read by the interviewer and the answers are recorded on the questionnaire forms. Not all survey questions are applicable for every person, and not all people will answer all of the questions in their interviews. On a few occasions, it will be clear that the person has difficulty with the questions and cannot complete the interview. Should this happen, the interviewer may switch to the picture version of the survey, or the interview will be respectfully terminated and the responses will not be included in the survey analysis.

## **SURVEY ANALYSIS**

All data entry and analysis is performed using standard SPSS™ statistical software (Version 10.0.7) and the charts appearing in these reports are generated using Microsoft Excel™ to format output from the SPSS analysis.

On completion of the interview sessions, the completed Demographic Survey and Consumer Interview questionnaires are returned to the project coordinator for entry into an SPSS database. Each participant is identified by agency and a survey number; no personally identifying information is entered into this database. The database is then submitted to the Evaluator for analysis. Janet Bramley, the Evaluator for this project has been connected with the Consumer Survey Project first as an interviewer and later as an evaluator since 1995.

The analysis of responses to the two survey instruments involves two stages. In the first instance, simple descriptive cross-tabulation statistics are used to generate data for the tables in Sections 2 (Interview responses) and Section 3 (Demographic Survey findings) of this Report.

The second stage involves grouping responses to the Consumer Survey into life satisfaction domains. Table 4.2 below indicates which questions were used for each of these domains. The valid responses to these questions are a high value of 2 (positive response) through a low value of 0 (negative response). The values for 'Not Applicable', 'Refused' or 'Unclear/unknown' are excluded from the analysis. For each domain the mean of the valid responses to the indicated questions is divided by 2 and multiplied by 100 to give a percentage satisfaction rate. These percentage rates are then further analyzed using Analysis of Variance (ANOVA) procedures to determine whether there were significant differences between different groups of people (Domain Satisfaction, page 6, and pages 12-13)

**Table 4.2 – Survey Questions Used for Generating Domain Satisfaction Scores\***

<b>Domain</b>	<b>Survey Questions Used for Domain Scores</b>
Residential	1, 3, 4, 5, mean9, mean10, mean11, 14, 15, 16, 18, 19, 20 22, 23, 25, 27, 43, 45, 46, 47, 48, 49,52, 53, 55, 56
Residential Autonomy	2, 6, 7, 8, 12, 13, 17, 21, 24, 26, 28, 29, 30, 31, 32, 33, 34, 35, 39, 40, 41, 42, 44, 50, 51
Neighborhood	57, 58, 59, 60, 61
Work	64, 65, 66, 67, 68, 69, 70, 71, 72, 73, 74, 76
Community Supports	80, 81, 82, 83, 84, 85, 86, 87, 88, 92, 93, 94, 95, 96, 97, 98, 99, 100
Social Support	104, 105, mean106, 107, 108, 109, 110, 111, 112, 113, 114, 115, 116
Activities	117a, 118a, 119a, 120a, 121a, 122a, 123a, 117b, 118b, 119b, 120b, 121b, 122b, 123b
Guardian	124, 125, 126, 127
Community Services	139, 140, 141, 142, 144, 145, 146, 147, 148, 149, 150, 154, 155, 156, 157, 159
Self Determination/Rights	129, 136, 152, 153, 160, 162, 163, 164, 165

\*Note: The Self Determination/Rights scale is new and based on questions added to the survey in accordance with the National Core Indicators and in response to feedback from advocates. The Health Satisfaction from previous surveys is no longer examined as those questions were removed from the survey. However, full demographic information on Healthcare and Lifestyle scale is shown in Table 3.9.