

**SURVEY OF ADULTS RECEIVING  
DEVELOPMENTAL DISABILITIES SERVICES  
IN VERMONT  
SPRING 2014**

Consumer Survey Project

Report Prepared August 2014

For

The Developmental Disabilities Services Division  
Vermont Department of Disabilities, Aging and Independent Living  
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This Report describes findings from a survey of adults receiving developmental disabilities services across Vermont. The survey was conducted by members of the Vermont Consumer Survey Project in the spring of 2014. The coordinating members of the Vermont Consumer Survey Project are:

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## **FOREWORD**

We at the Developmental Disabilities Services Division are committed to quality improvement. We continually monitor, and seek ways we can improve, the developmental disabilities services provided here in Vermont. A critical component of that quality improvement effort is input from 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 on the basis of findings from the surveys and in consultation with our consumer advocates. The information from the surveys has not only helped us to develop a profile of the people we serve, but to better understand what people feel is important to their quality of life and how we can provide the best support possible.

This report contains findings from the first year in the sixth 3-year cycle of surveys. The demographic portion of the survey has undergone some minor modifications for this cycle of surveys in order to better track, in particular, further health and healthcare issues. The satisfaction information collected and analyzed for this report is the same as for the previous cycle of surveys completed during the period 2011-2013.

Each year, the participants include consumers from a subset of the publicly-funded agencies in Vermont that provide developmental disabilities services. This subset is selected to be representative of the whole state in any given year. So that you can see how opinion has changed over time, this report also includes comparisons with the statewide responses from 2011, the last time that people from the same subset of agencies was surveyed.

We hope you find this both informative and helpful in planning and evaluating services provided for people with developmental disabilities.

Camille George, Director  
DAIL/Developmental Disabilities Services Division

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## **SECTION 1**

### **OVERVIEW**



## INTRODUCTION

The spring of 2014 marked the first year in the sixth 3-year cycle of satisfaction surveys of adults with developmental disabilities served by the State of Vermont Developmental Disabilities Services Division. The agencies surveyed in 2014 were: Champlain Community Services (CCS), HowardCenter (HC), Northwestern Counseling and Support Services (NCSS), and Upper Valley Services (UVS); adults from across the state who have self- or family-managed services also received personal invitations to participate. As in the past, respondent selection is designed to be representative both within each agency and across the statewide population of developmental disabilities service recipients. The agencies surveyed this year are the same as those visited in 2011, the equivalent year in the previous cycle of surveys. The statewide report compares the responses from this year's interviews to consumer responses from the 2011 surveys to give a fair reflection of overall change over time. Likewise, individual agency reports contain comparisons with the responses from that particular agency in 2011.

The evolution of the demographic and satisfaction surveys from their original form in 1995 reflects the Division's commitment to continuous quality improvement. Over the years, both surveys have undergone changes that help the Division to better understand and respond to the current needs and wishes of people receiving developmental disabilities services. In 2001, demographic information collection was expanded and satisfaction survey questions on self-determination were added based on input from self-advocates. The 2004 survey featured extra questions on communication skills and services and substantial changes and additions to the survey report presentation format. In 2008, based on input from a range of stakeholders, questions on access and barriers to community activities were added to the demographic survey and some satisfaction questions were rephrased for easier understanding. For the current survey cycle, there are some revisions to the demographic survey, particularly relating to health and healthcare. The format of the satisfaction questions remains the same. As before, the reports consist of four major Sections:

- **Overview:** This Section provides a brief stand-alone summary of findings for spring 2014. 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 respondents participating in the 2011 survey is also included.
- **Consumer Survey 2014 - What People Had To Say.** This Section provides more detail on how people responded to individual questions on the survey. It first gives comparison information from the 2011 and 2014 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 2014 survey questions.
- **Participant Profile 2014 - Who Participated.** This Section reports on findings from the demographics survey to provide a clear picture of the consumer population served. Each table includes numbers for those interviewed and those not interviewed.
- **Methodology - How This Survey Is Conducted.** This Section describes procedures for collecting survey information and how that information is analyzed for reporting purposes.

**SUMMARY OF FINDINGS: STATE OF VERMONT 2014**

In the spring of 2014, the independently contracted survey team visited four agencies; Champlain Community Services (CCS), HowardCenter (HC), Northwestern Counseling and Support Services (NCSS), and Upper Valley Services (UVS); adults from across the state who have self- or family-managed services were also invited to participate. 50% of those at the larger designated agencies (HC, NCSS and UVS) and 100% of those served by CCS and those with self- or family-managed services were invited to be interviewed. Interview duration times were shorter this year, an average of 31 minutes 2014 compared to 37 minutes in 2011. As can be seen from Table 1.1, the response rates for 2014 varied considerably across the participant groups. The response rate across the designated agencies was 45% in 2014. However, as in 2011, the lack of responses from the people with self- or family-managed services had the effect of depressing the overall response rate statewide by 5%. Nevertheless, the statewide rate in 2014 was somewhat lower than the rate for 2011 (in parentheses).

**Table 1.1 – Participants and Types of Interviews Conducted (N=558)**

	CCS	HC	NCSS	UVS	Self Managed	Total 2014	(2011)
<b>Interviewed</b>							
Full interview	44%	40%	46%	42%	1%	37%	41%
Picture only	8%	1%	5%	3%	0%	3%	5%
<b>Total interviewed</b>	<b>52%</b>	<b>41%</b>	<b>51%</b>	<b>45%</b>	<b>1%</b>	<b>40%</b>	<b>46%</b>
<b>Not interviewed</b>							
Agency decision	16%	19%	21%	18%	13%	18%	18%
Guardian's decision	0%	0%	4%	1%	0%	1%	3%
Unable to complete	2%	0%	1%	0%	0%	<1%	<1%
No Show/Person's choice	18%	28%	15%	21%	51%	26%	19%
Person out of town	0%	2%	0%	0%	1%	1%	2%
Person incapacitated	8%	8%	6%	13%	7%	8%	8%
Scheduling oversight	0%	0%	2%	0%	0%	1%	1%
Other	4%	2%	0%	2%	26%	5%	3%
<b>Total not interviewed</b>	<b>48%</b>	<b>59%</b>	<b>49%</b>	<b>55%</b>	<b>99%</b>	<b>60%</b>	<b>54%</b>
<b>Total Participants</b>	<b>50</b>	<b>239</b>	<b>122</b>	<b>77</b>	<b>70</b>	<b>558</b>	<b>449</b>

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 2011 and 2014.



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

	<b>Statewide 2011 (N=205)</b>	<b>Statewide 2014 (N=220)</b>
<b>Age</b>		
Average Age	43	42
Minimum Age	20	19
Maximum Age	89	89
<b>Gender</b>		
Male	56%	58%
Female	44%	42%
<b>Intellectual Disability (ID)</b>		
Mild ID	74%	63%
Moderate ID	16%	18%
Severe ID	2%	3%
Profound ID	0%	1%
Unknown/None Reported	8%	15%
<b>Living Situation</b>		
Shared Home (home of paid provider)	48%	48%
Family Home	26%	27%
Person's Own Home	20%	21%
Group Living	1%	2%
Other/Unknown	5%	2%
<b>Services Received</b>		
Service Coordination	99%	100%
Residential Supports*	55%	50%
Community Supports	68%	70%
Employment	47%	48%
Family Supports - Respite/FFF	49%	47%

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

The group profiles of those interviewed in 2014 and those interviewed in 2011 are remarkably similar which would suggest that direct comparisons in the analysis of responses to satisfaction questions are appropriate.

The analysis of responses to the consumer survey involves grouping responses into scales reflecting a series of life satisfaction domains (Table 1.3). The domains examined remain the same as for the 2011-2013 cycle of surveys and the domain ratings are directly comparable. (Caution should be taken when comparing current satisfaction ratings in the Activities

domain with ratings from survey cycles prior to 2008; certain response options and hence potential scores were changed starting in 2008).

In general, the 2014 satisfaction ratings are similar to those from 2011. Overall, there has been an upward trend in satisfaction scores since 2011 with seven of ten domains receiving higher ratings. Noticeably higher scores (3% or more) were given for Residential Autonomy, Neighborhood, Activities and Self/Determination Rights and a much lower score for Guardian satisfaction. These increases might suggest that the respondents this year felt more empowered.

**Table 1.3 – Comparative Satisfaction by Domain**

<b>Domain</b>	<b>Statewide 2011 (N=205)</b>	<b>Statewide 2014 (N=220)</b>
Residential	89%	90%
Residential Autonomy	72%	77%
Neighborhood	92%	95%
Work	80%	80%
Community Supports	80%	82%
Social Support	85%	85%
Activities	74%	78%
Guardian	76%	70%
Community Services	85%	86%
Self Determination/Rights	48%	51%

## **SECTION 2**

### **CONSUMER SURVEY 2014**

#### **WHAT PEOPLE HAD TO SAY**



This Section focuses on how people responded to the consumer survey in 2014. 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. The agencies visited in 2014 are the same as those visited in 2011, the equivalent year in the previous survey cycle. The selected highlights below include statewide responses from the 2011 survey for comparison over time. A brief profile of the adults who were interviewed is given in Section 1 and full demographic information on all survey participants for 2014 is available in Section 3.

### 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 of all people interviewed statewide in 2011 and 2014. 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 2014, see page 14.

**Table 2.1 – Residential**

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I like where I live	89%	90%
• I cannot think of anywhere better to live	76%	74%
• I'm happy about how I spend my free time	84%	83%
• I'm happy with the chores I do	93%	91%
• I feel safe at home	96%	96%
• I almost always have a way to get to places	81%	86%

**Table 2.2 – Residential Autonomy**

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I had a say in where I live	38%	48%
• I choose what I wear	92%	87%
• I can change the rules at my house	49%	46%
• I can invite friends/family over when I want	89%	90%
• I have privacy when friends/family visit	65%	67%
• I have a say in how I spend my money	95%	91%
• I can stay home alone if I want to when others go out	61%	69%

**Table 2.3 – Neighbors/neighborhood**

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• Neighbors are friendly	91%	91%
• I like the neighborhood	90%	93%
• I feel safe in the neighborhood	94%	94%

**Table 2.4 – Work**

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I chose my job	87%	82%
• I like my job	91%	97%
• I work enough hours at my job	55%	54%
• The people I work with respect me	97%	98%
• I chose my job coach	31%	13%
• There's nothing I'd rather do during the day	88%	91%

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

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I like my (individual) community activities	93%	97%
• I have enough (individual) community activities	71%	59%
• I like the people I spend time with	92%	99%
• I chose my support person	25%	32%
• There's nothing I'd rather do during the day	90%	96%

**Table 2.6 - Friends/Social Supports**

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I have plenty of friends	66%	63%
• I can see my friends when I want	87%	80%
• I have opportunities to meet new people	82%	76%
• I have friends I like to talk/be with (not staff or family)	85%	81%
• I'm not often lonely	57%	56%
• I see my family as much as I want	91%	89%

**Table 2.7 – Activities\***

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I shop as much as I want	55%	64%
• I exercise/play sport as much as I want	57%	56%
• I eat out as much as I want	58%	68%
• I go to entertainment as much as I want	54%	62%
• I go to church/synagogue as much as I want	63%	64%

\* Includes those who take part in the activity as much as they want and those who choose not to do so. Note that response options for Activities satisfaction were expanded for the surveys from 2008 onward.

**Table 2.8 - Guardianship**

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I'm happy about my guardian	91%	89%
• I chose my guardian	15%	20%
• I see my guardian whenever I want	90%	89%
• My guardian lets me make my own decisions	35%	35%

**Table 2.9 - Community Services**

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I'm happy with my service agency	88%	90%
• I chose my case manager	23%	22%
• I'm happy with my case manager	91%	94%
• It's easy to contact my case manager	72%	73%
• People listen to me at ISA meetings	89%	93%

**Table 2.10 - Self Determination/Rights**

	<b>Statewide 2011</b>	<b>Statewide 2014</b>
• I have attended a self advocacy meeting	45%	49%
• I have voted in an election	59%	61%
• I get to learn new things/skills	82%	72%
• I have enough control over my life	78%	81%
• I make all the choices I want	85%	87%

**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 derivation of the domains examined remains the same as in the last survey cycle. Thus, the domain ratings for 2014 are directly comparable to those of 2011. 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 2014 and 2011. Table 2.11 below shows increased satisfaction scores in seven of the ten domains. There was significantly increased satisfaction in comparison with the 2011 survey results in Residential Autonomy and scores increased also by 3% or more in the Neighborhood, Activities and Self/Determination Rights domains. Increases in these domains might suggest that the respondents this year felt more empowered. Only Guardian satisfaction had decreased. This continuing upward trend in satisfaction scores (also noted the last 3-year survey cycle) is encouraging and may indicate that publicly funded developmental disabilities services are contributing to the general feelings of wellbeing amongst the people receiving them.

**Table 2.11 - Comparative Domain Satisfaction**

Domain	Statewide 2011	Statewide 2014
	(N=205)	(N=220)
Residential	89%	90%
Residential Autonomy	72%	77%
Neighborhood	92%	95%
Work	80%	80%
Community Supports	80%	82%
Social Support	85%	85%
Activities	74%	78%
Guardian	76%	70%
Community Services	85%	86%
Self Determination/Rights	48%	51%

When further analyses of domain satisfaction by respondent characteristics were completed, significant differences were found both by residential type and by legal status. First, domain satisfaction was examined by the types of home setting (Table 2.12a). People living semi-independently rated their Residential Autonomy significantly higher than those in other home types. People in family homes gave significantly higher ratings in the Residential Autonomy domain than their peers in shared homes, and significantly higher ratings than those living semi-independently for their Neighborhood. No statistically significant differences by residential type were found in the other domains. Examination of satisfaction by legal status (Table 12b) showed that those with a private guardian rated their Residential significantly higher than those who have a publicly appointed guardian. Legally independent respondents were significantly more satisfied with their Residential Autonomy than those with private or publicly appointed guardians. Both legally independent people and those with



a private guardian rated their Social Supports significantly higher than those who have a publicly appointed guardian. No other statistically significant differences by legal status were found in the other domains.

**Table 2.12a - Domain Satisfaction by Residential Type – 2014**

Domain	Family Home (n=60)	Semi-Independent Living (n=46)	Shared Home (n=105)	All Residential Settings (n=220)
Residential	93%	88%	90%	90%
* Residential Autonomy	74%	93%	72%	77%
**Neighborhood	97%	92%	95%	95%
Work	82%	77%	81%	80%
Community Supports	85%	82%	81%	82%
Social Support	88%	83%	83%	85%
Activities	82%	79%	75%	78%
Guardian	72%	74%	67%	70%
Community Services	88%	85%	86%	86%
Self Determination/Rights	51%	54%	49%	51%

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

\*People living with their families rated Residential Autonomy higher (p<.05) than those in shared homes

\*\*People living with their families rated their Neighborhood higher (p<.05) than those living semi-independently

**Table 2.12b - Domain Satisfaction by Legal Status – 2014**

Domain	Independent No Guardian (n=87)	Private Guardian (n=100)	Public Guardian (n=33)	All Respondents (n=220)
*Residential	89%	92%	86%	90%
** Residential Autonomy	83%	73%	71%	77%
Neighborhood	94%	95%	93%	95%
Work	80%	81%	78%	80%
Community Supports	80%	84%	81%	82%
***Social Support	85%	86%	76%	84%
Activities	80%	78%	72%	78%
Guardian	-	69%	68%	69%
Community Services	85%	88%	85%	86%
Self Determination/Rights	52%	51%	47%	51%

\*People with private guardians rated Residential satisfaction higher (p<.05) than those with public guardians

\*\*People with no guardian rated Residential Autonomy higher (p<.05) than those with private or public guardians

\*\*\*People with private or no guardians rated their Social Supports higher (p<.05) than those with public guardians

**SURVEY RESPONSES: STATEWIDE 2014 (N=220)**

The following pages provide details of how people across the participating agencies responded to individual questions on the Consumer Survey in the spring of 2014. The percentages given in the results below are the percentages of those consumers who answered the question. The notation ‘-’ indicates there were too few responses to be meaningful and ‘NR’ indicates that no-one answered this 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>
220	90%	5%	5%

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>
172	11%	37%	52%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
203	74%	26%

4. Tell me how you feel about the food at your house.

<b>RESPONDENTS</b>	<b>LIKE</b>	<b>IN-BETWEEN</b>	<b>NOT LIKE</b>
216	98%	1%	1%

5. Who usually 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>
197	97%	2%	1%

6. Who usually 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>
198	87%	11%	2%

7. 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>
191	90%	7%	3%

8. Are there any pets at your house?

<b>RESPONSES</b>	<b>YES</b>	<b>NO</b>
205	78%	22%

9. (If has pet) Do you like having a pet?

<b>RESPONSES</b>	<b>LIKE</b>	<b>IN-BETWEEN</b>	<b>NOT LIKE</b>
153	96%	1%	3%

10. (If has no pet) Do you want to have a pet? If "YES", what kind?

<b>RESPONSES</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
53	55%	6%	39%

11. (For persons with paid helper(s) in home) Are/is \_\_\_\_\_ nice and polite to you?

<b>RESPONSES</b>	<b>POLITE</b>	<b>SOMETIMES</b>	<b>NOT POLITE</b>
105	91%	7%	2%

12. Tell me how you feel about \_\_\_\_\_.

<b>RESPONSES</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
112	88%	9%	3%

13. Did you choose (pick) who helps you at home? (Did you get to interview/hire them? Did you get to meet other people or was someone assigned to you?)

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
6	67%	0%	33%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
5	0%	100%

14a. Is that a problem for you?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
6	83%	17%

15. (For persons living with unpaid others) Are/is the other people/person nice and polite to you?

<b>RESPONDENTS</b>	<b>POLITE</b>	<b>SOMETIMES</b>	<b>NOT POLITE</b>
152	90%	9%	1%

16. Tell me how you feel about \_\_\_\_\_.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
165	95%	4%	1%

17. Did you choose (pick) the people you live with? (Did anyone ask who you'd like to live with? Were you given choices? Did you get to interview people?)

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
18	17%	55%	28%

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

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
28	79%	21%	0%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>IN-BETWEEN</b>	<b>YES</b>
28	68%	11%	21%

**THINGS TO DO:**

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

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

<b>RESPONDENTS</b>	<b>SELF</b>	<b>SELF WITH HELP</b>	<b>SOMEONE ELSE</b>
194	87%	10%	3%

21. 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>
205	82%	13%	5%

22. 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>
204	70%	22%	8%

23. Tell 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>
219	83%	14%	3%

**JOBS/CHORES:**

24. 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>
193	73%	8%	19%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
195	79%	2%	19%

26. Tell 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>
210	91%	7%	2%

**RULES:**

27. Who makes the rules for living here?

<b>RESPONDENTS</b>	<b>SELF</b>	<b>IN-BETWEEN</b>	<b>SOMEONE ELSE</b>
95	4%	8%	88%

28. Tell me what you think about the rules at your house.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
107	82%	9%	9%

29. 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</b>	<b>IN-BETWEEN</b>	<b>CAN'T CHANGE</b>
85	32%	14%	54%

30. 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>
123	74%	0%	26%

31. 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>
199	90%	2%	8%

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

<b>RESPONDENTS</b>	<b>SELF</b>	<b>IN-BETWEEN</b>	<b>OTHER</b>
192	41%	16%	43%

**PRIVACY:**

33. 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>
168	80%	20%

34. (If people get mail) Do people read your mail or email asking you first?

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
194	92%	3%	5%

35. Can you use the telephone when you want to?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO/SOME RESTRICTIONS</b>
185	94%	6%

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

<b>RESPONDENTS</b>	<b>HAVE PRIVACY</b>	<b>LISTEN IN</b>
174	96%	4%

37. Can you answer the phone at home?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
186	81%	19%

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

<b>RESPONDENTS</b>	<b>HAVE PRIVACY</b>	<b>NOT ALONE</b>
137	67%	33%

39. Do you have a boyfriend/girlfriend? What is his/her first name?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
193	34%	66%

40. (If no) Do you want to have a boyfriend/girlfriend?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
123	54%	46%

41. (If yes) Can you see (boyfriend/girlfriend) as much as you want?

RESPONDENTS	YES	NO
62	73%	27%

42. (If yes) Can you be with (boyfriend/girlfriend) alone in your bedroom

RESPONDENTS	YES, ALLOWED	SOMETIMES	NOT ALLOWED
60	50%	2%	48%

43. Would you like to know more about dating? (Having a boyfriend/girlfriend?)

RESPONDENTS	NO	SOMETIMES	YES
186	61%	0%	39%

44. Do you have someone to talk to about dating? (Having a boyfriend/girlfriend?)

RESPONDENTS	YES	NO
177	81%	19%

**MONEY:**

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

RESPONDENTS	HAVE IT	ASK FOR IT
199	86%	14%

46. Tell me how you feel about (self or other) having your money.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
216	90%	7%	3%

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOOSES
200	75%	22%	3%

48. Do people steal (take) your money?

RESPONDENTS	NO	YES
201	98%	2%



**SAFETY:**

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

<b>RESPONDENTS</b>	<b>LEAVE ALONE</b>	<b>TAKE</b>
168	95%	5%

50. Do people let you know before they come to your house? (Knock first/ask permission?)

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
200	95%	2%	3%

51. Do people let you know before coming into your bedroom? (Knock first/ask permission?)

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
143	86%	7%	7%

52. Do you feel safe in your home?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
204	96%	2%	2%

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

<b>RESPONDENTS</b>	<b>NO RARELY</b>	<b>IN-BETWEEN</b>	<b>YES MOST OF TIME</b>
202	80%	19%	1%

**ACCESS/ TRANSPORTATION**

54. 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>
165	69%	1%	30%

55. Do you have a key to your house?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
198	59%	41%

56. When you want to go somewhere, do you have a way to get there? (Can you get a ride when you need one or is it hard to get a ride?)

<b>RESPONDENTS</b>	<b>ALMOST ALWAYS</b>	<b>IN-BETWEEN</b>	<b>ALMOST NEVER</b>
204	86%	11%	3%

57. 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>
199	66%	30%	4%

**NEIGHBORHOOD:**

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

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
191	91%	6%	3%

59. Tell me how you feel about your neighbors/people who live near you

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
214	87%	10%	3%

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

<b>RESPONDENTS</b>	<b>LIKE IT</b>	<b>IN-BETWEEN</b>	<b>DIFFERENT PLACE</b>
203	93%	3%	4%

61. Do you feel safe to be out in your neighborhood/the area near your house?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
205	94%	5%	1%

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

<b>RESPONDENTS</b>	<b>NO RARELY</b>	<b>IN-BETWEEN</b>	<b>YES, MOST OF TIME</b>
205	93%	6%	1%

**WORK**

63. Do you volunteer? Do something that you are not paid for that is helpful to others?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
202	24%	76%

64. Do you have a job?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
205	60%	40%

65. (if q65 = No) Do you want to have a paid job?

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
82	33%	5%	62%

66. 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>
118	8%	74%	18%

67. Do you like working there?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
122	97%	1%	2%

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

<b>RESPONDENTS</b>	<b>IMPORTANT</b>	<b>NOT IMPORTANT</b>
121	97%	3%

69. Tell me how you feel about your work.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
125	92%	7%	1%

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

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>MORE</b>
121	54%	46%

71. Tell me how you feel about the amount of money you make from work

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
125	90%	8%	2%

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

<b>RESPONDENTS</b>	<b>VACATION</b>	<b>ALL THE TIME</b>
122	71%	29%

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

73. Is \_\_\_\_\_ nice and polite to you?

<b>RESPONDENTS</b>	<b>NICE</b>	<b>IN-BETWEEN</b>	<b>NOT NICE</b>
89	99%	0%	1%

74. Did you choose \_\_\_\_\_ to help you at work?

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
80	6%	6%	88%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
87	41%	59%

75a. Is that a problem for you?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
51	84%	16%

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

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
123	95%	5%	0%

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

<b>RESPONDENTS</b>	<b>RESPECT</b>	<b>IN-BETWEEN</b>	<b>NO RESPECT</b>
120	98%	2%	0%

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

<b>RESPONDENTS</b>	<b>CHOOSE TO GO</b>	<b>HAVE TO GO</b>
119	60%	40%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
119	91%	4%	5%

**COMMUNITY ACTIVITIES - INDIVIDUAL SUPPORT**

80. 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>
137	42%	48%	10%

81. Do you like doing those activities?

<b>RESPONDENTS</b>	<b>LIKE</b>	<b>SOMETIMES</b>	<b>NOT LIKE</b>
139	97%	1%	2%

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

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>MORE</b>
135	59%	41%

83. Tell me how you feel about your community activities.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
152	95%	4%	1%

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

<b>RESPONDENTS</b>	<b>NICE</b>	<b>IN-BETWEEN</b>	<b>NOT NICE</b>
139	97%	2%	1%

85. Did you choose (or pick) \_\_\_\_\_ to help you with your community activities? (Did you get to interview/hire him/her? Did you choose or was he/she assigned to you?)

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
124	11%	20%	69%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
133	53%	47%

86a. Is that a problem for you?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
61	75%	25%

87. Tell 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>
150	99%	1%	0%

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

<b>RESPONDENTS</b>	<b>RESPECT</b>	<b>IN-BETWEEN</b>	<b>NO RESPECT</b>
138	96%	4%	0%

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

<b>RESPONDENTS</b>	<b>CHOOSE</b>	<b>HAVE TO GO</b>
129	74%	26%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
133	96%	2%	2%

**COMMUNITY ACTIVITIES - GROUP SUPPORT**

91. 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>
6	50%	50%	0%

92. Do you like doing those activities?

<b>RESPONDENTS</b>	<b>YES</b>	<b>IN-BETWEEN</b>	<b>NO</b>
8	100%	0%	0%

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

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>MORE</b>
8	62%	38%

94. Tell me how you feel about your community activities.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
8	100%	0%	0%

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

<b>RESPONDENTS</b>	<b>NICE</b>	<b>IN-BETWEEN</b>	<b>NOT NICE</b>
8	87%	13%	0%

96. Did you choose (or pick) \_\_\_\_\_ to help you with your community activities? (Did you get to interview/hire him/her? Did you choose or was he/she assigned to you?)

<b>RESPONDENTS</b>	<b>YES WITHOUT HELP</b>	<b>YES WITH HELP</b>	<b>NO SOMEONE ELSE CHOSE</b>
6	0%	33%	67%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
6	50%	50%

97a. Is that a problem for you?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
3	33%	67%

98. Tell 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>
7	86%	14%	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>RESPECT</b>	<b>IN-BETWEEN</b>	<b>NO RESPECT</b>
7	100%	0%	0%

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

<b>RESPONDENTS</b>	<b>CHOOSE</b>	<b>HAVE TO GO</b>
7	57%	43%

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

<b>RESPONDENTS</b>	<b>NO</b>	<b>SOMETIMES</b>	<b>YES</b>
8	75%	12%	13%

**FRIENDS and SOCIAL SUPPORT**

FRIENDS:

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

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
200	90%	10%

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

<b>RESPONDENTS</b>	<b>YES NOT STAFF OR FAMILY</b>	<b>ALL ARE STAFF OR FAMILY</b>	<b>NO FRIENDS</b>
196	81%	15%	4%

104. Tell me how feel about your friends.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
207	96%	2%	2%



105. Can you see your friends when you want to see them? (Can you make plans with your friends when you want to?)

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
189	80%	18%	2%

106. Do you have plenty of friends or do you wish you had more friends?

<b>RESPONDENTS</b>	<b>PLENTY</b>	<b>MORE</b>
191	63%	37%

107. Do you have opportunities to meet new people?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
202	76%	24%

108. Do you have someone you trust to talk to when you need to talk to someone?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
200	93%	7%

109. Does anyone ever ask you to help them?

<b>RESPONDENTS</b>	<b>SOMEONE NAMED</b>	<b>NO ONE NAMED</b>
194	68%	32%

110. Do you ever feel lonely? (Does that happen a lot?)

<b>RESPONDENTS</b>	<b>NO NOT OFTEN</b>	<b>SOMETIMES</b>	<b>OFTEN LONELY</b>
203	56%	34%	10%

**FAMILY:**

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

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
178	93%	7%

112. Can you see your (named) family when you want to?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
170	89%	8%	3%

113. Tell me how you feel about these (named) family members.

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
183	89%	10%	1%

**ACTIVITIES**

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

114. Do you ever go shopping?

114a. (If q114=Yes) Do you go to shop as much as you want or do you want to go more?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>WANT MORE</b>	<b>RATHER NOT GO</b>
196	64%	35%	1%

114b. (If q114=No) Do you ever want to go shopping?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
4	50%	50%

115. Do you ever run errands or go to appointments?

115a. (If q115=Yes) Do you run errands or go to appointments as much as you want or do you want to go more?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>WANT MORE</b>	<b>RATHER NOT GO</b>
195	80%	19%	1%

115b. (If q115=No) Do you ever want to go on errands/appointments?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
7	86%	14%

116. Do you ever exercise or play sports?

116a. (If q116=Yes) Do you exercise/play sports as much as you want or do you want to do more?

<b>RESPONDENTS</b>	<b>ENOUGH</b>	<b>WANT MORE</b>	<b>RATHER NOT GO</b>
195	56%	44%	0%

116b. (If q116=No) Do you ever want to exercise/play sports?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
5	20%	80%

117. Do you ever go out to entertainment?

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

RESPONDENTS	ENOUGH	WANT MORE	RATHER NOT GO
178	66%	34%	0%

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

RESPONDENTS	NO	YES
23	39%	61%

118. Do you ever go out to eat?

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

RESPONDENTS	ENOUGH	WANT MORE	RATHER NOT GO
195	68%	32%	0%

118b. (If q118=No) Do you ever want to go out to eat?

RESPONDENTS	NO	YES
5	40%	60%

119. Do you ever go to church or synagogue?

119a. (If q119=Yes) Do you go to church or synagogue as much as you want or do you want to go more?

RESPONDENTS	ENOUGH	WANT MORE	RATHER NOT GO
77	61%	39%	0%

119b. (If q119=No) Do you ever want to go to church or synagogue?

RESPONDENTS	NO	YES
120	68%	32%

120. Do you ever go to other community meetings?

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

RESPONDENTS	ENOUGH	WANT MORE	RATHER NOT GO
42	62%	38%	0%

120b. (If q120=No) Do you ever want to other community meetings?

RESPONDENTS	NO	YES
157	62%	38%

**GUARDIANSHIP**

121. Do you know who your guardian is? (Persons with guardianship)

<b>RESPONDENTS</b>	<b>YES</b>	<b>MAYBE</b>	<b>NOT SURE</b>
112	97%	1%	2%

122. Do you get to see or talk to your guardian when you want to?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
110	89%	6%	5%

123. 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>
108	20%	80%

124. Tell me how you feel about (guardian).

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
125	89%	9%	2%

125. 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>
108	35%	65%

126. Do you want to change who your guardian is? (Have a different guardian/Not have a guardian?)

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
109	88%	12%

**SELF-ADVOCACY**

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

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
199	49%	51%

128. (If q127=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>
82	18%	34%	39%	9%

129. (If q127=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>
63	13%	36%	3%	48%	0%

130a. (If q127=Yes) Do you want to go (go again) to a self-advocacy meeting, conference or event?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
96	63%	37%

130b. (If q127=No) Do you want to go to a self-advocacy meeting, conference or event?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
96	47%	53%

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

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
198	90%	10%

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

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
193	57%	43%

**VOTING**

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

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
195	72%	28%

134. Have you ever voted in an election?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
196	61%	39%

135a. (If have voted) Do you want to vote in an election?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
118	91%	9%

135b. (If have not voted) Do you want to vote in an election?

<b>RESPONDENTS</b>	<b>YES</b>	<b>NO</b>
74	45%	55%

**SERVICE AGENCY**

136 Do you know your service coordinator/case manager?

<b>RESPONDENTS</b>	<b>YES</b>	<b>MAYBE/NOT SURE</b>	<b>NO</b>
200	99%	0%	1%

137. Does he/she ask you what you want?

<b>RESPONDENTS</b>	<b>YES</b>	<b>SOMETIMES</b>	<b>NO</b>
195	71%	12%	17%

138. 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>
197	86%	8%	6%

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

<b>RESPONDENTS</b>	<b>HAPPY</b>	<b>IN-BETWEEN</b>	<b>SAD</b>
214	94%	5%	1%

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
185	12%	10%	78%

141. Is it easy or is it hard to get in touch with (your case manager) when you want to?

RESPONDENTS	EASY	IN-BETWEEN	HARD
194	73%	12%	15%

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

RESPONDENTS	NO	YES
191	52%	48%

142a. Is that a problem for you?

RESPONDENTS	NO	YES
89	70%	30%

143. Tell me how you feel about (your service agency).

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
211	90%	8%	2%

144. Do you get the services you need?

RESPONDENTS	YES	SOMETIMES	NO
198	90%	8%	2%

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

RESPONDENTS	YES	NO
196	93%	7%

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

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
181	93%	4%	3%

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

RESPONDENTS	YES	SOMETIMES	NO
177	95%	2%	3%

148. Do you have a friend or family member that you count on to help you make decisions?

RESPONDENTS	YES	NO
193	94%	6%

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

RESPONDENTS	YES	MAYBE/NOT SURE	NO
187	6%	2%	92%

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

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
195	85%	11%	4%

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

RESPONDENTS	GETTING HELP	SOMETIMES	HAVING TROUBLE
193	90%	7%	3%

152. Is there someone at (your agency) you can ask to help you change services or supports you do not like?

RESPONDENTS	SOMEONE NAMED	SOMEONE NOT NAMED	NO-ONE
173	98%	1%	1%

153. Do people help you do or learn new things?

RESPONDENTS	YES	SOMETIMES	NO
192	72%	8%	20%

153a. (if 153= No or Sometimes) Do you want [more] help to do or learn new things?

RESPONDENTS	NO	YES
54	35%	65%



154. Tell 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>
211	90%	9%	1%

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

<b>RESPONDENTS</b>	<b>TOLD</b>	<b>NOT AWARE</b>
194	33%	67%

156. 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>
194	33%	67%

157. Have you ever made a formal grievance (complaint) or appeal to someone at your agency?

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
194	98%	2%

**SELF-DETERMINATION**

158. 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>MORE</b>
193	80%	20%

159. Are there decisions (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>
193	87%	3%	10%

160. Do you need to know more about how to choose who helps you? (Do you need to learn how to interview and hire your support workers?)

<b>RESPONDENTS</b>	<b>NO</b>	<b>YES</b>
190	56%	44%



## **SECTION 3**

### **PARTICIPANT PROFILE 2014**

#### **WHO PARTICIPATED**



This Section gives an overall picture of the adults receiving developmental disabilities services statewide. It reports findings from the 2014 Demographics Survey 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 3.7-3.10)** covers Intellectual Disability, Other Challenges, Healthcare and Health, and Lifestyle.
- **Residential Information (Tables 3.11-3.13)** covers Type of Residence, Residential Characteristics, and Guardianship by Residential Type.
- **Community Access and Barriers (Tables 3.14-3.15)** covers Getting to Places and Barriers to More Recreational Activity and Enjoyment.
- **Services (Table 3.16)** covers Type of Services Received

Each of the tables 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=220)	Not Interviewed (n=338)	All Participants (n=558)
<b>Age</b>			
<b>Average Age</b>	42	40	<b>41</b>
<b>Minimum</b>	19	19	<b>19</b>
<b>Maximum</b>	89	84	<b>89</b>
<b>Gender</b>			
<b>Male</b>	58%	64%	<b>61%</b>
<b>Female</b>	42%	36%	<b>39%</b>
<b>Marital Status</b>			
<b>Single</b>	89%	90%	<b>90%</b>
<b>Married/Civil Union</b>	4%	7%	<b>6%</b>
<b>Married/Civil Union in past</b>	7%	2%	<b>4%</b>
<b>Unknown</b>	0%	1%	<b>&lt;1%</b>
<b>Race</b>			
<b>White</b>	96%	85%	<b>89%</b>
<b>American Indian/Eskimo/Aleut</b>	1%	<1%	<b>1%</b>
<b>Black</b>	0%	1%	<b>1%</b>
<b>Asian</b>	1%	1%	<b>1%</b>
<b>Other/Unknown</b>	2%	13%	<b>8%</b>
<b>Speaks English</b>			
<b>Yes</b>	100%	99%	<b>99%</b>
<b>No</b>	<1%	1%	<b>1%</b>

**Table 3.2 – Legal Factors**

	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Guardianship</b>			
<b>No Guardian</b>	40%	29%	<b>33%</b>
<b>Private Guardian</b>	45%	56%	<b>52%</b>
<b>Public Guardian</b>	15%	13%	<b>14%</b>
<b>Unknown</b>	0%	2%	<b>1%</b>
<b>Payee</b>			
<b>No Payee</b>	20%	17%	<b>18%</b>
<b>Payee</b>	79%	66%	<b>71%</b>
<b>Unknown</b>	1%	17%	<b>11%</b>
<b>Court Restrictions</b>			
<b>No</b>	97%	96%	<b>97%</b>
<b>Yes</b>	2%	2%	<b>2%</b>
<b>Unknown</b>	1%	2%	<b>1%</b>

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

	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Family Involved</b>			
<b>Yes</b>	90%	90%	<b>90%</b>
<b>No</b>	10%	9%	<b>9%</b>
<b>Unknown</b>	0%	1%	<b>1%</b>
<b>Why Family not Involved</b>	<b>(n=21)</b>	<b>(n=31)</b>	<b>(n=52)</b>
<b>Family gone/not alive/     whereabouts unknown</b>	38%	42%	<b>40%</b>
<b>Family choice</b>	43%	42%	<b>42%</b>
<b>Other</b>	5%	3%	<b>4%</b>
<b>Unknown</b>	14%	13%	<b>14%</b>

**COMMUNICATION CAPABILITY**

**Table 3.4 – Means of Communication**

	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Adequate Reliable Speech</b>			
<b>Yes</b>	84%	60%	<b>69%</b>
<b>No</b>	16%	39%	<b>30%</b>
<b>Unknown</b>	0%	1%	<b>1%</b>
<b>Primary Means of Communication</b>			
<b>Spoken - Understood by familiars</b>	95%	75%	<b>83%</b>
<b>Gesture/body language</b>	1%	15%	<b>10%</b>
<b>Sign language/finger spelling</b>	2%	3%	<b>2%</b>
<b>Communication aid/device</b>	1%	4%	<b>3%</b>
<b>Other/Unknown</b>	1%	3%	<b>2%</b>

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

	<b>Interviewed (n=36)</b>	<b>Not Interviewed (n=133)</b>	<b>All Participants (n=169)</b>
<b>Communicate with familiar people</b>			
<b>Yes</b>	100%	94%	<b>95%</b>
<b>No</b>	0%	5%	<b>4%</b>
<b>Unknown</b>	0%	1%	<b>1%</b>
<b>Communicate with unfamiliar people</b>			
<b>Yes</b>	80%	36%	<b>46%</b>
<b>No</b>	17%	59%	<b>50%</b>
<b>Unknown</b>	3%	5%	<b>4%</b>
<b>Communicate beyond basic needs</b>			
<b>Yes</b>	80%	36%	<b>46%</b>
<b>No</b>	17%	59%	<b>50%</b>
<b>Unknown</b>	3%	5%	<b>4%</b>
<b>Communication effectiveness in last year</b>			
<b>More effective</b>	33%	13%	<b>17%</b>
<b>As effective</b>	59%	69%	<b>67%</b>
<b>Less effective</b>	8%	7%	<b>7%</b>
<b>Unknown</b>	0%	11%	<b>9%</b>

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

	<b>Interviewed (n=36)</b>	<b>Not Interviewed (n=133)</b>	<b>All Participants (n=169)</b>
<b>Communication addressed in ISA</b>			
<b>Yes</b>	42%	48%	<b>47%</b>
<b>No</b>	58%	47%	<b>50%</b>
<b>Unknown</b>	0%	5%	<b>3%</b>
<b>Communication Supports in Place</b>			
<b>Consistent comm. partners</b>	94%	84%	<b>86%</b>
<b>Team support</b>	100%	95%	<b>96%</b>
<b>Access to comm. aids/devices</b>	53%	53%	<b>53%</b>
<b>Training support for support wkers</b>	53%	68%	<b>64%</b>
<b>Expert consultation/support</b>	22%	35%	<b>32%</b>

**MEDICAL/HEALTH ISSUES**

**Table 3.7 - Intellectual Disability**

<b>Disability Level</b>	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Mild ID</b>	63%	46%	<b>53%</b>
<b>Moderate ID</b>	18%	17%	<b>17%</b>
<b>Severe ID</b>	3%	9%	<b>7%</b>
<b>Profound ID</b>	1%	9%	<b>5%</b>
<b>Unknown/None reported</b>	15%	19%	<b>18%</b>



**Table 3.8 - Other Challenges**

Challenge	Interviewed (n=220)	Not Interviewed (n=338)	All Participants (n=558)
None Reported	12%	13%	<b>12%</b>
Mental Illness	46%	34%	<b>39%</b>
Autism	20%	22%	<b>21%</b>
Cerebral Palsy	8%	11%	<b>10%</b>
Brain Injury	2%	4%	<b>3%</b>
Seizures	12%	22%	<b>18%</b>
Chemical Dependence	0%	1%	<b>1%</b>
Vision	12%	11%	<b>11%</b>
Hearing	10%	10%	<b>10%</b>
Physical Disability	8%	12%	<b>10%</b>
Communication Disorder	3%	9%	<b>7%</b>
Alzheimers Disease	3%	4%	<b>4%</b>
Down Syndrome	7%	11%	<b>10%</b>
Non-Ambulatory	1%	5%	<b>3%</b>
Other	9%	14%	<b>12%</b>

**Table 3.9 – Healthcare**

	Interviewed (n=220)	Not Interviewed (n=338)	All Participants (n=558)
<b>Medical Care Required</b>			
Less than once/month	89%	75%	<b>81%</b>
At least once/month	8%	14%	<b>11%</b>
At least once/week or more	3%	3%	<b>3%</b>
Unknown	0%	8%	<b>5%</b>
<b>Last Physical Examination</b>			
In the past year	87%	74%	<b>79%</b>
Over 1 year ago	12%	13%	<b>13%</b>
Unknown	1%	13%	<b>8%</b>
<b>Last Ob/Gyn Examination (female)</b>			
In the past year	56%	31%	<b>42%</b>
Over 1 year ago	20%	22%	<b>21%</b>
Never had an ob/gyn exam	11%	10%	<b>10%</b>
Unknown	13%	37%	<b>27%</b>
<b>Last Dental Examination</b>			
In the past six months	53%	29%	<b>39%</b>
6 - 12 months ago	29%	23%	<b>25%</b>
Over 1 year ago	9%	13%	<b>12%</b>
Unknown	9%	35%	<b>24%</b>

**Table 3.10 - Health and Lifestyle**

	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Overall Health</b>			
Excellent or very good	36%	29%	<b>32%</b>
Fairly good	59%	54%	<b>56%</b>
Poor	5%	14%	<b>10%</b>
Unknown	0%	3%	<b>2%</b>
<b>Physically Active</b>			
Very physically active	20%	15%	<b>17%</b>
Moderately physically active	67%	58%	<b>62%</b>
Physically inactive	13%	25%	<b>20%</b>
Unknown	0%	2%	<b>1%</b>
<b>Level of Mobility</b>			
Moves without aids	87%	79%	<b>82%</b>
Moves with aids or uses wheelchair	12%	16%	<b>14%</b>
Non-ambulatory	1%	4%	<b>3%</b>
Unknown	0%	1%	<b>1%</b>
<b>Vision</b>			
Sees well (with/without correction)	87%	84%	<b>85%</b>
Vision problems limit activities	11%	8%	<b>9%</b>
Limited or no vision (legally blind)	2%	3%	<b>3%</b>
Unknown	0%	5%	<b>3%</b>
<b>Hearing</b>			
Hears well (with/without correction)	93%	85%	<b>88%</b>
Hearing problems limit activities	5%	6%	<b>6%</b>
Limited or no vision (deaf)	2%	4%	<b>3%</b>
Unknown	0%	5%	<b>3%</b>
<b>Weight concerns</b>			
No weight concerns	57%	58%	<b>57%</b>
Overweight	39%	28%	<b>33%</b>
Underweight	4%	4%	<b>4%</b>
Unknown	0%	10%	<b>6%</b>
<b>Smoke/chew tobacco</b>			
Yes	11%	6%	<b>9%</b>
No	88%	85%	<b>86%</b>
Unknown	1%	9%	<b>5%</b>
<b>Drink alcohol</b>			
Yes, in excess	1%	1%	<b>1%</b>
Yes, occasionally	19%	8%	<b>12%</b>
No	75%	75%	<b>75%</b>
Unknown	5%	16%	<b>12%</b>
<b>Take Psych Medications</b>			
Yes	56%	48%	<b>51%</b>
No	44%	41%	<b>42%</b>
Unknown	0%	11%	<b>7%</b>

**RESIDENTIAL INFORMATION**

**Table 3.11 - Type of Residence**

<b>Residential Type</b>	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Shared Home</b>	48%	33%	<b>39%</b>
<b>Family Home</b>	27%	40%	<b>35%</b>
<b>Own Home</b>	21%	22%	<b>21%</b>
<b>Group Living</b>	2%	3%	<b>3%</b>
<b>Other/Unknown</b>	2%	2%	<b>2%</b>

**Table 3.12 – Respondent Guardianship by Residential Type**

<b>Residential Type</b>	<b>No Guardian (n=87)</b>	<b>Private Guardian (n=100)</b>	<b>Public Guardian (n=33)</b>	<b>Total (n=220)</b>
<b>Shared Home</b>	40%	42%	85%	<b>48%</b>
<b>Family Home</b>	21%	42%	0%	<b>27%</b>
<b>Own Home</b>	36%	11%	12%	<b>21%</b>
<b>Group Living</b>	0%	4%	3%	<b>2%</b>
<b>Other/Unknown</b>	3%	1%	0%	<b>2%</b>

**Table 3.13 - Residence Characteristics**

<b>Residential Characteristic</b>	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Time in current home/with current provider</b>			
More than 5 years	50%	62%	<b>58%</b>
3-5 years	18%	13%	<b>15%</b>
1-2 years	18%	11%	<b>14%</b>
Less than 1 year	14%	10%	<b>11%</b>
Unknown	0%	4%	<b>2%</b>
<b>Location</b>			
Remote	47%	45%	<b>46%</b>
Walking distance to town	33%	34%	<b>34%</b>
Centrally located in town	20%	19%	<b>19%</b>
Unknown	0%	2%	<b>1%</b>
<b>Ownership/Lease of Home</b>			
Family/guardian	28%	42%	<b>37%</b>
Individual/family person lives with	47%	33%	<b>38%</b>
Provider agency/affiliate	3%	4%	<b>3%</b>
Person rents home	19%	17%	<b>18%</b>
Person owns home	2%	2%	<b>2%</b>
Other/Unknown	1%	2%	<b>2%</b>
<b>Household Composition</b>			
Non-related individuals	51%	35%	<b>41%</b>
Biological/adoptive parents	25%	37%	<b>32%</b>
Lives alone	12%	13%	<b>13%</b>
Spouse/Civil Union	3%	5%	<b>4%</b>
Other relatives	9%	9%	<b>9%</b>
Domestic partner	0%	1%	<b>1%</b>
<b>Amount of Paid Residential Support</b>			
No on-site support (Indep./family)	26%	32%	<b>29%</b>
24 hour on-site	44%	42%	<b>43%</b>
Daily on-site	11%	9%	<b>10%</b>
Less frequent than daily	12%	13%	<b>13%</b>
As needed	7%	4%	<b>5%</b>

**COMMUNITY ACCESS AND BARRIERS**

**Table 3.14 – Getting to Places beyond Walking Distance**

<b>Means of Transport</b>	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Ride from family/friends</b>	62%	62%	<b>62%</b>
<b>Ride in staff member's car</b>	86%	73%	<b>78%</b>
<b>Group transport (provider van)</b>	5%	4%	<b>4%</b>
<b>Public transport</b>	24%	21%	<b>22%</b>
<b>Para transit/volunteer/ride-share</b>	5%	3%	<b>4%</b>
<b>Taxi</b>	10%	5%	<b>7%</b>
<b>Drives self</b>	5%	11%	<b>9%</b>
<b>Other</b>	2%	2%	<b>2%</b>

**Table 3.15 – Barriers to More Recreational Activity and Enjoyment**

<b>Barrier to more activities</b>	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>No barrier</b>	66%	58%	<b>61%</b>
<b>Behavioral/emotional concerns</b>	8%	18%	<b>14%</b>
<b>Social skills limitations</b>	12%	18%	<b>16%</b>
<b>Health concerns</b>	4%	12%	<b>9%</b>
<b>Money/cost</b>	15%	11%	<b>13%</b>
<b>Inadequate transportation</b>	5%	7%	<b>6%</b>
<b>No chaperone</b>	8%	9%	<b>9%</b>
<b>Recreational activity shortage</b>	2%	6%	<b>4%</b>
<b>Other barrier</b>	3%	1%	<b>2%</b>

**SERVICES**

**Table 3.16 - Types of Services Received**

<b>Service Type</b>	<b>Interviewed (n=220)</b>	<b>Not Interviewed (n=338)</b>	<b>All Participants (n=558)</b>
<b>Residential Supports*</b>	50%	26%	<b>42%</b>
<b>Service Coordination</b>	100%	93%	<b>96%</b>
<b>Employment - Individual</b>	48%	31%	<b>38%</b>
<b>Community Support - Individual</b>	70%	58%	<b>63%</b>
<b>Community Support - Group</b>	15%	8%	<b>11%</b>
<b>Clinical Services</b>	55%	39%	<b>45%</b>
<b>Transportation</b>	43%	39%	<b>41%</b>
<b>Family Supports</b>	47%	52%	<b>50%</b>
<b>Other Supports</b>	7%	8%	<b>8%</b>

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

## **SECTION 4**

### **METHODOLOGY**

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





Since the inception of the statewide consumer surveys in 1995, the State Developmental Disabilities Services Division has taken steps to provide a forum for people receiving developmental disabilities 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, 2014 marking the first year of the sixth such 3-year cycle. Within each year, a sample of adults receiving developmental disabilities services is surveyed. This Section describes the methodology used to obtain and analyze information for the 2014 - 2016 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 disabilities 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 aims to be representative both within each agency and across the statewide population receiving developmental disabilities services in each year. Five agencies are chosen each year. The order in which agencies are visited is the same as for the 2011-2013 survey cycle. In the spring of 2014, the independently contracted survey interviewers visited the following agencies: Champlain Community Services (CCS), HowardCenter (HC), Northwestern Counseling and Support Services (NCSS), and Upper Valley Services (UVS); adults from across the state who have self- or family-managed services were also personally invited to participate. These are the same agencies as those visited in 2011, the equivalent year in the previous cycle of surveys.

Participant selection is the first stage of the survey process. In the winter, a random sample based on agency size and regional representation is drawn from the list of people currently served. These are the potential survey participants for that year. Table 4.1 shows the percentage of individuals served by each agency who will be invited to participate and the order of agency visits in the 2014-2016 survey cycle.

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

<b>Agency</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>
Champlain Community Services (CCS)	100%		
Counseling Service of Addison County - Community Associates (CSAC)		50%	
Health Care and Rehabilitation Services of Southeastern Vermont (HCRS)			50%
HowardCenter (HC)	50%		
Lamoille County Mental Health (LCMH)		100%	
Lincoln Street Incorporated (LSI)			100%
Northeast Kingdom Human Services (NKHS)		50%	
Northwestern Counseling and Support Services (NCSS)	50%		
Rutland Mental Health Services - Community Access Program (RMHS)			50%
Specialized Community Care (SCC)			100%
Sterling Area Services (SAS)		100%	
Upper Valley Services (UVS)	50%		
United Counseling Service (UCS)			50%
Washington County Mental Health Services - Community Developmental Services (WCMH)		50%	
Self-/Family-Management (T-II)	100%		

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 Disabilities 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 multi-state

project provides an annual comparative ‘report card’ on services for adults receiving developmental disabilities services. For the 2004 – 2006 survey cycle, the Demographic Survey, in particular, was further enhanced. This was partly to include more on communication capabilities and services to inform the statewide communication initiative, and partly to align more closely with questions with the National Core Indicators (NCI) project to enable more cross state comparisons. Vermont ceased participation in the NCI project in 2008 due to budget constraints; plans to resume participation are in progress. The 2008 survey featured changes based on input from a range of stakeholders; information on access and barriers to community activities were added and a number of questions were rephrased for easier understanding. The Demographic Survey has undergone minor revisions and reordering of questions for the current survey cycle. The satisfaction survey remains unchanged.

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 disabilities services here in Vermont. The Demographic Survey consists of sections covering general demographics, communication capabilities and services, health and lifestyle information, residential characteristics, services, and behavioral support needs. The information from the Demographic Survey is reported in section 3 of this Report.

The structured Consumer Interview consists of 160 questions designed to measure how satisfied people receiving developmental disabilities 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 Developmental Disabilities Services Division.

## **SURVEY ADMINISTRATION**

Rosemary Drabing, an independent contractor with extensive experience with the Vermont developmental disabilities services system, took over project coordination in 2003. 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 disabilities services.

Once the participant pool has been selected (see page 54), 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**

Initially survey data is entered onto Microsoft Excel™ worksheets and then analysis is performed using standard SPSS™ statistical software (PASW Version 20). The charts appearing in these reports are generated using Excel (Microsoft Office 2010) 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 Excel worksheets. Each participant is identified by agency and a survey number; no personally identifying information is entered into this database. The worksheets are then submitted to the Evaluator for conversion to SPSS format and 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\***

Domain	Survey Questions used for Domain Scores
Residential	q1, q3, q4, q9, q10, q11, q12, q14a, q15, q16, q18, q19, q21, q22, q23, q25, q26, q28, q46, q48, q49, q50, q51, q52, q53, q56, q57
Residential Autonomy	q2, q5, q6, q7, q13, q17, q20, q24, q27, q29, q30, q31, q32, q33, q34, q35, q36, q37, q38, q41, q42, q45, q47, q54, q55
Neighborhood	q58, q59, q60, q61, q62
Work	q66, q67, q68, q69, q70, q71, q72, q73, q74, q75a, q76, q77, q78, q79
Day Program	q80, q81, q82, q83, q84, q85, q86a, q87, q88, q89, q90, q91, q92, q93, q94, q95, q96, q97a, q98, q99, q100, q101
Social Support	q102, q103, q104, q105, q106, q107, q108, q109, q110, q111, q112, q113
Activities	q114yes, q115yes, q116yes, q117yes, q118yes, q119yes, q120yes, q114no, q115no, q116no, q117no, q118no, q119no, q120no
Guardian	q122, q123, q124, q125, q126
Community Services	q137, q138, q139, q140, q141, q142a, q143, q144, q145, q146, q147, q148, q150, q151, q152, q153a, q154
Self Determination and Rights	q127, q134, q149, q155, q156, q158, q159, q160

\*Notes:

1. The Self Determination/Rights scale was added in 2004 and is based on questions added to the survey in response to feedback from advocates.
2. The Health Satisfaction scale from surveys prior to 2004 is no longer examined as those questions were removed from the survey in 2004. However, full demographic information on Healthcare and Lifestyle scale is shown in Tables 3.9 and 3.10.
3. Questions used for the Activities scale since 2008 offer three response options instead of the two response options in previous surveys.