

**SURVEY OF ADULTS RECEIVING
DEVELOPMENTAL DISABILITIES SERVICES
IN VERMONT
SPRING 2013**

Consumer Survey Project

Report Prepared July 2013

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 2013. 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 third year in the fifth 3-year cycle of surveys. The demographic and satisfaction information collected and analyzed for this report is the same as for the previous cycle of surveys completed during the period 2008-2010.

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 2010, 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 2013 marked the third year in the fifth 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 2013 were: Health Care and Rehabilitation Services of Southeastern Vermont (HCRS), Lincoln Street Incorporated (LSI), Rutland Mental Health Services – Community Access Program (RMHS), Specialized Community Care (SCC) and United Counseling Service (UCS). 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 five agencies surveyed this year are the same as those visited in 2010, 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 2010 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 2010.

The evolution of the demographic and satisfaction surveys from their original form in 1995 reflects the Division's commitment to continuous quality improvement and its mission to better understand and respond to the needs and wishes of people served by Vermont's developmental disabilities service agencies. For example, the survey cycle started in 2001 included more demographic information and added survey questions on self-determination based on input from self-advocates. The cycle starting in 2004 expanded further on demographics and included substantial changes and additions to the survey report presentation format. The last round of surveys starting in 2008 featured changes based on input from a range of stakeholders; information on access and barriers to community activities were added and some questions were rephrased for easier understanding. The format of the 2008-2010 surveys has been retained for the current survey cycle. As before, the reports consist of four major Sections:

- **Overview:** This Section provides a brief stand-alone summary of findings for spring 2013. 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 2010 survey is also included.
- **Consumer Survey 2013 - 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 2010 and 2013 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 2013 survey questions.
- **Participant Profile 2013 - 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 2013

In the spring of 2013, the independently contracted survey team visited five agencies; Health Care and Rehabilitation Services of Southeastern Vermont (HCRS), Lincoln Street Incorporated (LSI), Rutland Mental Health Services – Community Access Program (RMHS), Specialized Community Care (SCC) and United Counseling Service (UCS). 100% of those who are able to respond to the survey at smaller agencies (LSI and SCC) and 50% of those at the larger designated agencies were invited to be interviewed. Interview times remain similar to earlier surveys, taking an average of 33 minutes to complete in 2013 and 36 minutes in 2010. As can be seen from Table 1.1, the response rates for 2013 varied considerably across agencies, and the statewide rate in 2013 was marginally higher than the rate for 2010 (in parentheses).

Table 1.1 – Participants and Types of Interviews Conducted (N=391)

	HCRS	LSI	RMHS	SCC	UCS	Total 2013	(2010)
Interviewed							
Full interview	27%	57%	43%	16%	62%	41%	41%
Picture only	3%	6%	4%	3%	4%	4%	2%
Total interviewed	30%	63%	47%	19%	66%	45%	43%
Not interviewed							
Agency decision	12%	15%	24%	33%	12%	18%	24%
Guardian's decision	14%	0%	7%	0%	0%	7%	<1%
Unable to complete	0%	0%	2%	0%	1%	1%	1%
No Show/Person's choice	30%	13%	11%	39%	12%	19%	24%
Person out of town	2%	2%	2%	3%	1%	2%	<1%
Person incapacitated	9%	5%	6%	6%	3%	6%	6%
Scheduling oversight	0%	0%	0%	0%	2%	0%	0%
Other	3%	2%	1%	0%	3%	2%	1%
Total not interviewed	70%	37%	53%	81%	34%	55%	57%
Total Participants	115	46	128	36	68	393	391

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 2010 and 2013.

Table 1.2 – Brief Profile of Consumers Interviewed

	Statewide 2010	Statewide 2013
	(N=169)	(N=176)
Age		
Average Age	42	42
Minimum Age	20	19
Maximum Age	85	88
Gender		
Male	54%	57%
Female	46%	43%
Developmental Disability Label		
Mild MR	67%	67%
Moderate MR	24%	16%
Severe MR	4%	4%
Profound MR	0%	3%
Unknown/None Reported	5%	10%
Living Situation		
Provider Home	49%	42%
Family Home	27%	27%
Person's Own Home	14%	23%
Group Living	5%	3%
Staffed Living	1%	2%
Other	4%	3%
Services Received		
Service Coordination	95%	94%
Residential Supports*	55%	47%
Community Supports	56%	51%
Employment	48%	44%
Family Supports - Respite/FFF	51%	50%

* In Provider Home, Group Living, or Staffed Living

The group profiles of those interviewed in 2013 and those interviewed in 2010 are remarkably similar in terms of age gender and disability level. The last three years have, however, seen a rise in the numbers living in their own homes and a reduction in residential, community and employment supports for those in the agencies surveyed this year.

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 2008-2010 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 2013 satisfaction ratings are similar to those from 2010. Higher scores were given to Residential Autonomy, Community Supports, and Activities. These increases, particularly in Residential Autonomy satisfaction may be attributable to the higher numbers of people in this year's sample who are living semi-independently.

Table 1.3 - Comparative Satisfaction by Domain

Domain	Statewide 2010	Statewide 2013
	(N=169)	(N=176)
Residential	90%	89%
*Residential Autonomy	66%	75%
Neighborhood	93%	94%
Work	77%	78%
Community Supports	78%	82%
Social Support	85%	86%
Activities	73%	76%
Guardian	73%	68%
Community Services	87%	85%
Self Determination/Rights	45%	46%

SECTION 2

CONSUMER SURVEY 2013

WHAT PEOPLE HAD TO SAY

This Section focuses on how people responded to the consumer survey in 2013. 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 2013 are the same as those visited in 2010, the equivalent year in the previous survey cycle. The selected highlights below include statewide responses from the 2010 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 2013 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 2010 and 2013. 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 2013, see page 14.

Table 2.1 – Residential

	Statewide 2010	Statewide 2013
• I like where I live	94%	89%
• I cannot think of anywhere better to live	73%	76%
• I'm happy about how I spend my free time	87%	84%
• I'm happy with the chores I do	89%	93%
• I feel safe at home	96%	96%
• I almost always have a way to get to places	82%	81%

Table 2.2 – Residential Autonomy

	Statewide 2010	Statewide 2013
• I had a say in where I live	50%	38%
• I choose what I wear	79%	92%
• I can change the rules at my house	46%	49%
• I can invite friends/family over when I want	84%	89%
• I have privacy when friends/family visit	52%	65%
• I have a say in how I spend my money	96%	95%
• I can stay home alone if I want to when others go out	54%	61%

Table 2.3 – Neighbors/neighborhood

	Statewide 2010	Statewide 2013
• Neighbors are friendly	92%	91%
• I like the neighborhood	89%	90%
• I feel safe in the neighborhood	88%	94%

Table 2.4 – Work

	Statewide 2010	Statewide 2013
• I chose my job	72%	87%
• I like my job	92%	91%
• I work enough hours at my job	52%	55%
• The people I work with respect me	98%	97%
• I chose my job coach	23%	31%
• There's nothing I'd rather do during the day	77%	88%

Table 2.5 – Community Supports (Individual)

	Statewide 2010	Statewide 2013
• I like my (individual) community activities	97%	93%
• I have enough (individual) community activities	47%	71%
• I like the people I spend time with	99%	92%
• I chose my support person	18%	25%
• There's nothing I'd rather do during the day	89%	90%

Table 2.6 - Friends/Social Supports

	Statewide 2010	Statewide 2013
• I have plenty of friends	63%	66%
• I can see my friends when I want	83%	87%
• I have opportunities to meet new people	88%	82%
• I have friends I like to talk/be with (not staff or family)	83%	85%
• I'm not often lonely	44%	57%
• I see my family as much as I want	80%	91%

Table 2.7 – Activities*

	Statewide 2010	Statewide 2013
• I shop as much as I want	53%	55%
• I exercise/play sport as much as I want	53%	57%
• I eat out as much as I want	50%	58%
• I go to entertainment as much as I want	55%	54%
• I go to church/synagogue as much as I want	56%	63%

* 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 2008 – 2010 survey.

Table 2.8 - Guardianship

	Statewide 2010	Statewide 2013
• I'm happy about my guardian	94%	91%
• I chose my guardian	12%	15%
• I see my guardian whenever I want	86%	90%
• My guardian lets me make my own decisions	59%	35%

Table 2.9 - Community Services

	Statewide 2010	Statewide 2013
• I'm happy with my service agency	88%	88%
• I chose my case manager	23%	23%
• I'm happy with my case manager	93%	91%
• It's easy to contact my case manager	69%	72%
• People listen to me at ISA meetings	92%	89%

Table 2.10 - Self Determination/Rights

	Statewide 2010	Statewide 2013
• I have attended a self advocacy meeting	43%	45%
• I have voted in an election	54%	59%
• I get to learn new things/skills	86%	82%
• I have enough control over my life	76%	78%
• I make all the choices I want	75%	85%

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 2013 are directly comparable to those of 2010. 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 2013 and 2010. Table 2.11 below shows a significantly increased satisfaction in comparison with the 2010 survey results in only one domain, Residential Autonomy. This may be due to more respondents living semi-independently in this year’s sample. However, there were also small increases in satisfaction in 2013 across six of the other nine domains. Since similar increases were noted in 2011 and 2012, the other years in this survey cycle, these results may suggest a general trend towards increased life satisfaction among people receiving publicly funded developmental disabilities services over the past three years.

Table 2.11 - Comparative Domain Satisfaction

Domain	Statewide 2010	Statewide 2013
	(N=169)	(N=176)
Residential	90%	89%
*Residential Autonomy	66%	75%
Neighborhood	93%	94%
Work	77%	78%
Community Supports	78%	82%
Social Support	85%	86%
Activities	73%	76%
Guardian	73%	68%
Community Services	87%	85%
Self Determination/Rights	45%	46%

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 provider homes. No statistically significant differences by residential type were found in the other domains. Examination of satisfaction by legal status (Table 12b) showed that legally independent respondents were significantly more satisfied with their Residential Autonomy than those who have a private or publicly appointed guardian. Those with a private guardian rated their Community Services significantly higher than the legally independent respondents. Although, legally independent respondents appeared to rate their Self-Determination Rights than those with guardians the difference failed to reach statistical significance because of the wide variation in responses. No other statistically significant differences by legal status were found in the other domains.

Table 2.12a - Domain Satisfaction by Residential Type – 2013

Domain	Family Home (n=48)	Semi-Independent Living (n=40)	Provider Home (n=74)	All Residential Settings (n=176)
Residential	90%	88%	91%	89%
* Residential Autonomy	74%	92%	68%	75%
Neighborhood	96%	92%	95%	94%
Work	76%	79%	78%	78%
Community Supports	79%	88%	82%	82%
Social Support	88%	85%	87%	86%
Activities	73%	81%	76%	76%
Guardian	64%	64%	72%	68%
Community Services	85%	83%	87%	85%
Self Determination/Rights	44%	51%	45%	46%

* People living semi-independently rated Residential Autonomy higher (p<.05) than those in other home types
 * People living with their family rated Residential Autonomy higher (p<.05) than those in provider homes

Table 2.12b - Domain Satisfaction by Legal Status – 2013

Domain	Independent (n=49)	Private Guardian (n=66)	Public Guardian (n=61)	All Residential Settings (n=176)
Residential	88%	91%	89%	89%
* Residential Autonomy	84%	73%	69%	75%
Neighborhood	93%	97%	92%	94%
Work	79%	78%	77%	78%
Community Supports	85%	83%	79%	82%
Social Support	85%	88%	85%	86%
Activities	79%	76%	73%	76%
Guardian	-	67%	69%	68%
*Community Services	81%	89%	84%	85%
Self Determination/Rights	51%	44%	44%	46%

* Legally independent people rated Residential Autonomy higher (p<.05) than those with private or public guardians
 People with private guardians rated Community Services higher (p<.05) than legally independent respondents

SURVEY RESPONSES: STATEWIDE 2013 (N=176)

The following pages provide details of how people across the participating agencies responded to individual questions on the Consumer Survey in the spring of 2013. 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?

RESPONDENTS	YES	IN-BETWEEN	NO
176	89%	4%	7%

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

RESPONDENTS	SELF	SELF WITH HELP	SOMEONE ELSE
137	12%	26%	62%

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

RESPONDENTS	NO	YES
160	76%	24%

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

RESPONDENTS	LIKE	IN-BETWEEN	NOT LIKE
176	96%	3%	1%

5. Who usually decides (picks) what you eat?

RESPONDENTS	SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
159	97%	2%	1%

6. Who usually decides (picks) what you wear?

RESPONDENTS	SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
160	92%	8%	0%

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?)

RESPONDENTS	SELF	SELF WITH HELP	SOMEONE ELSE
149	90%	5%	5%

8. Are there any pets at your house?

RESPONSES	YES	NO
158	71%	29%

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

RESPONSES	LIKE	IN-BETWEEN	NOT LIKE
113	94%	3%	3%

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

RESPONSES	NO	SOMETIMES	YES
43	56%	5%	39%

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

RESPONSES	POLITE	SOMETIMES	NOT POLITE
75	91%	9%	0%

12. Tell me how you feel about _____.

RESPONSES	HAPPY	IN-BETWEEN	SAD
88	86%	12%	2%

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?)

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
7	17%	17%	66%

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

RESPONDENTS	NO	YES
6	33%	67%

14a. Is that a problem for you?

RESPONDENTS	NO	YES
4	75%	25%

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

RESPONDENTS	POLITE	SOMETIMES	NOT POLITE
116	92%	8%	0%

16. Tell me how you feel about _____.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
128	92%	5%	3%

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?)

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
14	21%	43%	36%

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

RESPONDENTS	YES	IN-BETWEEN	NO
26	85%	15%	0%

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

RESPONDENTS	NO	IN-BETWEEN	YES
25	56%	20%	24%

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?)

RESPONDENTS	SELF	SELF WITH HELP	SOMEONE ELSE
149	90%	7%	3%

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

RESPONDENTS	ENOUGH	IN-BETWEEN	NOTHING
150	81%	15%	4%

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

RESPONDENTS	FUN	IN-BETWEEN	BORED
159	66%	26%	8%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
175	84%	13%	3%

JOBS/CHORES:

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

RESPONDENTS	PICK	IN-BETWEEN	TOLD
152	81%	5%	14%

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

RESPONDENTS	NO	SOMETIMES	YES
157	70%	4%	26%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
168	93%	5%	2%

RULES:

27. Who makes the rules for living here?

RESPONDENTS	SELF	IN-BETWEEN	SOMEONE ELSE
111	5%	11%	84%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
128	83%	12%	5%

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

RESPONDENTS	CHANGE	IN-BETWEEN	CAN'T CHANGE
108	33%	16%	51%

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?

RESPONDENTS	HAVE A DRINK	IN-BETWEEN	NOT ALLOWED
80	70%	0%	30%

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

RESPONDENTS	YES	IN-BETWEEN	NO
155	89%	1%	10%

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

RESPONDENTS	SELF	IN-BETWEEN	OTHER
153	43%	12%	45%

PRIVACY:

33. Can you be alone if you want to? (Do you have privacy?)

RESPONDENTS	YES ENOUGH	WANT MORE TIME ALONE
129	67%	33%

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

RESPONDENTS	NO	SOMETIMES	YES
155	94%	2%	4%

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

RESPONDENTS	YES	NO/SOME RESTRICTIONS
152	93%	7%

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

RESPONDENTS	HAVE PRIVACY	LISTEN IN
140	95%	5%

37. Can you answer the phone at home?

RESPONDENTS	YES	NO
146	77%	23%

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

RESPONDENTS	HAVE PRIVACY	NOT ALONE
116	65%	35%

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

RESPONDENTS	YES	NO
149	38%	62%

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

RESPONDENTS	NO	YES
64	67%	33%

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

RESPONDENTS	YES	NO
54	83%	17%

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

RESPONDENTS	YES, ALLOWED	SOMETIMES	NOT ALLOWED
50	56%	0%	44%

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

RESPONDENTS	NO	SOMETIMES	YES
144	49%	0%	51%

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

RESPONDENTS	YES	NO
140	74%	26%

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
157	85%	15%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
172	86%	9%	5%

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
159	75%	20%	5%

48. Do people steal (take) your money?

RESPONDENTS	NO	YES
158	99%	1%

SAFETY:

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

RESPONDENTS	LEAVE ALONE	TAKE
133	98%	2%

50. Do people let you know before they come to your house?

RESPONDENTS	YES	SOMETIMES	NO
157	94%	3%	3%

51. Do people let you know before coming into your bedroom?

RESPONDENTS	YES	SOMETIMES	NO
125	93%	2%	5%

52. Do you feel safe in your home?

RESPONDENTS	YES	IN-BETWEEN	NO
154	96%	2%	2%

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

RESPONDENTS	NO RARELY	IN-BETWEEN	YES MOST OF TIME
160	86%	13%	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?

RESPONDENTS	CAN STAY ALONE	IN-BETWEEN	HAVE TO GO
128	61%	0%	39%

55. Do you have a key to your house?

RESPONDENTS	YES	NO
157	57%	43%

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?)

RESPONDENTS	ALMOST ALWAYS	IN-BETWEEN	ALMOST NEVER
158	81%	18%	1%

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.)

RESPONDENTS	NO	SOMETIMES	YES
157	66%	32%	2%

NEIGHBORHOOD:

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

RESPONDENTS	YES	SOMETIMES	NO
155	91%	5%	4%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
167	91%	7%	2%

60. 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
159	90%	5%	5%

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

RESPONDENTS	YES	IN-BETWEEN	NO
159	94%	5%	1%

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

RESPONDENTS	NO RARELY	IN-BETWEEN	YES, MOST OF TIME
159	90%	9%	1%

WORK

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

RESPONDENTS	YES	NO
159	26%	74%

64. Do you have a job?

RESPONDENTS	YES	NO
160	51%	49%

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

RESPONDENTS	NO	SOMETIMES	YES
78	27%	4%	69%

66. Did you choose to work at _____?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
78	8%	79%	13%

67. Do you like working there?

RESPONDENTS	YES	IN-BETWEEN	NO
80	91%	6%	3%

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

RESPONDENTS	IMPORTANT	NOT IMPORTANT
797	96%	4%

69. Tell me how you feel about your work.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
83	88%	11%	1%

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

RESPONDENTS	ENOUGH	MORE
78	55%	45%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
83	93%	6%	1%

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

RESPONDENTS	VACATION	ALL THE TIME
79	68%	32%

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

73. Is _____ nice and polite to you?

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
70	100%	0%	0%

74. Did you choose _____ to help you at work?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
67	10%	21%	69%

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

RESPONDENTS	NO	YES
66	54%	46%

75a. Is that a problem for you?

RESPONDENTS	NO	YES
33	73%	27%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
82	94%	6%	0%

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

RESPONDENTS	RESPECT	IN-BETWEEN	NO RESPECT
785	97%	3%	0%

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

RESPONDENTS	CHOOSE TO GO	HAVE TO GO
77	40%	60%

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

RESPONDENTS	NO	SOMETIMES	YES
78	88%	4%	8%

COMMUNITY ACTIVITIES - INDIVIDUAL SUPPORT

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
76	43%	40%	17%

81. Do you like doing those activities?

RESPONDENTS	LIKE	SOMETIMES	NOT LIKE
76	93%	7%	0%

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

RESPONDENTS	ENOUGH	MORE
75	71%	29%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
89	93%	6%	1%

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

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
77	96%	3%	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?)

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
73	8%	17%	75%

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

RESPONDENTS	NO	YES
73	59%	41%

86a. Is that a problem for you?

RESPONDENTS	NO	YES
30	70%	30%

87. Tell me how you feel about the people you spend time with during the day.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
89	92%	7%	1%

88. 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
76	94%	5%	1%

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

RESPONDENTS	CHOOSE	HAVE TO GO
73	78%	22%

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

RESPONDENTS	NO	SOMETIMES	YES
70	90%	6%	4%

COMMUNITY ACTIVITIES - GROUP SUPPORT

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
10	40%	40%	20%

92. Do you like doing those activities?

RESPONDENTS	YES	IN-BETWEEN	NO
10	90%	10%	0%

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

RESPONDENTS	ENOUGH	MORE
10	40%	60%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
11	91%	9%	0%

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

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
10	100%	0%	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?)

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
10	10%	20%	70%

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

RESPONDENTS	NO	YES
10	50%	50%

97a. Is that a problem for you?

RESPONDENTS	NO	YES
5	80%	20%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
11	91%	0%	9%

99. 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
10	100%	0%	0%

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

RESPONDENTS	CHOOSE	HAVE TO GO
10	70%	30%

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

RESPONDENTS	NO	SOMETIMES	YES
10	70%	10%	20%

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?)

RESPONDENTS	YES	NO
158	94%	6%

103. 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
156	85%	15%	0%

104. Tell me how feel about your friends.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
171	99%	1%	0%

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

RESPONDENTS	YES	SOMETIMES	NO
157	87%	9%	4%

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

RESPONDENTS	PLENTY	MORE
158	66%	34%

107. Do you have opportunities to meet new people?

RESPONDENTS	YES	NO
157	82%	18%

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

RESPONDENTS	YES	NO
155	94%	6%

109. Does anyone ever ask you to help them?

RESPONDENTS	SOMEONE NAMED	NO ONE NAMED
154	60%	40%

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

RESPONDENTS	NO NOT OFTEN	SOMETIMES	OFTEN LONELY
157	57%	33%	10%

FAMILY:

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

RESPONDENTS	YES	NO
143	94%	6%

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

RESPONDENTS	YES	SOMETIMES	NO
141	91%	8%	1%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
152	80%	15%	5%

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?

RESPONDENTS	ENOUGH	WANT MORE	RATHER NOT GO
154	54%	45%	1%

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

RESPONDENTS	NO	YES
5	60%	40%

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?

RESPONDENTS	ENOUGH	WANT MORE	RATHER NOT GO
148	77%	23%	0%

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

RESPONDENTS	NO	YES
8	50%	50%

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?

RESPONDENTS	ENOUGH	WANT MORE	RATHER NOT GO
149	60%	40%	0%

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

RESPONDENTS	NO	YES
10	10%	90%

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
141	55%	45%	0%

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

RESPONDENTS	NO	YES
16	44%	56%

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
150	59%	41%	0%

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

RESPONDENTS	NO	YES
9	56%	44%

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
55	53%	47%	0%

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

RESPONDENTS	NO	YES
102	69%	31%

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
39	49%	51%	0%

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

RESPONDENTS	NO	YES
112	67%	33%

GUARDIANSHIP

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

RESPONDENTS	YES	MAYBE	NOT SURE
110	98%	0%	2%

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

RESPONDENTS	YES	SOMETIMES	NO
109	90%	8%	2%

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

RESPONDENTS	I CHOSE	SOMEONE ELSE CHOSE
105	15%	85%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
121	91%	7%	2%

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

RESPONDENTS	OWN DECISIONS	GUARDIAN DECIDES
103	35%	65%

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

RESPONDENTS	NO	YES
105	81%	19%

SELF-ADVOCACY

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

RESPONDENTS	YES	NO
153	45%	55%

128. (If q127=Yes) Why did you go to the self-advocacy meeting, conference, or event?

RESPONDENTS	INFORMATION	SOCIAL OPPORTUNITY	PART OF ADVOCACY MOVEMENT	OTHER
51	23%	16%	51%	10%

129. (If q127=No) Why haven't you gone or been able to go?

RESPONDENTS	NO TIME	NOT INTERESTED	NO RIDE	DIDN'T KNOW ABOUT IT	OTHER
50	14%	42%	0%	40%	4%

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

RESPONDENTS	YES	NO
66	77%	23%

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

RESPONDENTS	YES	NO
83	59%	41%

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

RESPONDENTS	YES	NO
156	96%	4%

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

RESPONDENTS	YES	NO
153	63%	37%

VOTING

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

RESPONDENTS	YES	NO
154	71%	29%

134. Have you ever voted in an election?

RESPONDENTS	YES	NO
153	59%	41%

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

RESPONDENTS	YES	NO
88	94%	6%

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

RESPONDENTS	YES	NO
62	53%	47%

SERVICE AGENCY

136 Do you know your service coordinator/case manager?

RESPONDENTS	YES	MAYBE/NOT SURE	NO
150	98%	1%	1%

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

RESPONDENTS	YES	SOMETIMES	NO
150	60%	16%	24%

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

RESPONDENTS	YES	SOMETIMES	NO
151	87%	6%	7%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
163	91%	8%	1%

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
146	13%	10%	77%

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
144	72%	16%	12%

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

RESPONDENTS	NO	YES
149	60%	40%

142a. Is that a problem for you?

RESPONDENTS	NO	YES
59	64%	36%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
170	88%	10%	2%

144. Do you get the services you need?

RESPONDENTS	YES	SOMETIMES	NO
156	91%	6%	3%

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

RESPONDENTS	YES	NO
146	89%	11%

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

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
130	89%	9%	2%

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

RESPONDENTS	YES	SOMETIMES	NO
124	88%	9%	3%

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

RESPONDENTS	YES	NO
151	92%	8%

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
123	4%	0%	96%

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

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
156	83%	12%	5%

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
155	91%	4%	5%

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
141	96%	1%	3%

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

RESPONDENTS	YES	SOMETIMES	NO
152	82%	4%	14%

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

RESPONDENTS	NO	YES
31	48%	52%

154. Tell me how you feel about the help you get from (your agency).

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
169	89%	10%	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?

RESPONDENTS	TOLD	NOT AWARE
153	25%	75%

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

RESPONDENTS	TOLD	NOT AWARE
153	25%	75%

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

RESPONDENTS	NO	YES
150	99%	1%

SELF-DETERMINATION

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

RESPONDENTS	ENOUGH	MORE
153	78%	22%

159. Are there decisions (choices) you wish you could make that you don't make now?

RESPONDENTS	NO	YES NOT NAMED	YES NAMED
151	85%	1%	14%

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?)

RESPONDENTS	NO	YES
145	39%	61%

SECTION 3

PARTICIPANT PROFILE 2013

WHO PARTICIPATED

This Section is intended to give an overall picture of the adults receiving developmental disabilities services statewide. It reports findings from the 2013 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 Developmental 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)**, a new category, covers Getting to Places and Barriers to More Recreational Activity and Enjoyment.
- **Services (Tables 3.16-3.17)** covers Type of Services Received and Self-/Family Management of Services.

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=176)	Not Interviewed (n=217)	All Participants (n=393)
Age			
Average Age	42	43	43
Minimum	19	19	19
Maximum	88	87	88
Gender			
Male	57%	57%	57%
Female	43%	43%	43%
Marital Status			
Single	90%	94%	92%
Married/Civil Union	4%	2%	3%
Married/Civil Union in past	6%	2%	4%
Unknown	0%	2%	1%
Race			
White	95%	97%	96%
Asian	2%	1%	1%
Pacific Islander	1%	0%	1%
Black/African American	1%	1%	1%
Other/Unknown	1%	1%	1%
Primary Language			
English	99%	100%	100%
Other Language	1%	0%	<1%

Table 3.2 – Legal Factors

	Interviewed (n=176)	Not Interviewed (n=217)	All Participants (n=393)
Guardianship			
No Guardian	28%	14%	20%
Private Guardian	37%	55%	47%
Public Guardian	35%	30%	32%
Unknown	0%	1%	1%
Payee			
No Payee	13%	13%	13%
Payee	85%	80%	82%
Unknown	2%	7%	5%
Court Restrictions			
No	95%	96%	96%
Yes	4%	2%	3%
Unknown	1%	2%	1%

Table 3.3 - Family Involvement in People’s Lives

	Interviewed (n=176)	Not Interviewed (n=217)	All Participants (n=393)
Family Involved			
Yes	88%	83%	85%
No	11%	16%	14%
Unknown	1%	1%	1%
Why Family not Involved	(n=20)	(n=34)	(n=54)
Family gone/not alive/ whereabouts unknown	57%	56%	56%
Family choice	33%	29%	31%
Court restriction	5%	3%	4%
Other	5%	0%	2%
Unknown	0%	12%	7%

COMMUNICATION CAPABILITY

Table 3.4 – Means of Communication

	Interviewed (n=176)	Not Interviewed (n=217)	All Participants (n=393)
Adequate Reliable Speech			
Yes	86%	51%	67%
No	14%	49%	33%
Primary Means of Communication			
Spoken - Understood by familiar listener	95%	67%	80%
Gesture/body language	2%	28%	16%
Sign language/finger spelling	1%	3%	2%
Communication aid/device	2%	1%	1%
Other/Unknown	0%	1%	1%

Table 3.5 – Communication Effectiveness for People with Inadequate Speech

	Interviewed (n=24)	Not Interviewed (n=106)	All Participants (n=130)
Communicate with familiar people			
Yes	83%	36%	45%
No	17%	60%	52%
Unknown	0%	4%	3%
Communicate with unfamiliar people			
Yes	83%	36%	45%
No	17%	60%	52%
Unknown	0%	4%	3%
Communicate beyond basic needs			
Yes	83%	41%	49%
No	17%	58%	50%
Unknown	0%	1%	1%
Communication effectiveness in last year			
More effective	21%	16%	17%
As effective	67%	70%	69%
Health prevents fair assessment	8%	7%	8%
Less effective	0%	3%	2%
Unknown	4%	4%	4%

Table 3.6 – Communication Supports for People with Inadequate Speech

	Interviewed (n=24)	Not Interviewed (n=106)	All Participants (n=130)
Communication addressed in ISA			
Yes	48%	47%	47%
No	48%	49%	49%
Unknown	4%	4%	4%
Communication Supports in Place			
Consistent comm. partners	88%	87%	87%
Team support	100%	98%	99%
Access to comm. aids/devices	58%	55%	55%
Training support for support wkers	63%	70%	68%
Expert consultation/support	50%	58%	57%

MEDICAL/HEALTH ISSUES

Table 3.7 - Developmental Disability

Disability Label	Interviewed (n=176)	Not Interviewed (n=217)	All Participants (n=393)
Mild MR	67%	39%	51%
Moderate MR	16%	20%	18%
Severe MR	4%	12%	9%
Profound MR	3%	14%	9%
Unknown/None reported	10%	15%	13%

Table 3.8 - Other Challenges

Challenge	Interviewed	Not Interviewed	All Participants
	(n=176)	(n=217)	(n=393)
None Reported	15%	13%	14%
Mental Illness	49%	46%	47%
Autism	15%	18%	17%
Cerebral Palsy	7%	13%	11%
Brain Injury	3%	3%	3%
Chemical Dependence	1%	0%	1%
Physical Disability	7%	16%	12%
Hearing	8%	10%	9%
Vision	15%	17%	16%
Seizures	21%	24%	23%
Communication Disorder	3%	13%	8%
Alzheimers Disease	1%	0%	1%
Down Syndrome	10%	7%	8%
Non-Ambulatory	3%	13%	9%
Prader Willi Syndrome	0%	0%	0%
Other	11%	11%	11%

Table 3.9 – Healthcare

	Interviewed	Not Interviewed	All Participants
	(n=176)	(n=217)	(n=393)
Last Physical Examination			
In the past year	88%	82%	85%
Over 1 year ago	7%	7%	7%
Unknown	5%	11%	8%
Last Ob/Gyn Examination (female)			
In the past year	62%	29%	44%
Over 1 year ago	17%	27%	22%
Never had an ob/gyn exam	5%	12%	9%
Unknown	16%	32%	25%
Last Dental Examination			
In the past six months	67%	55%	60%
Over 6 months ago	19%	25%	22%
Unknown	14%	20%	18%

Table 3.10 - Health and Lifestyle

	Interviewed (n=176)	Not Interviewed (n=217)	All Participants (n=393)
Medical Care Required			
Less than once/month	85%	82%	83%
At least once/month	9%	7%	8%
At least once/week or more	4%	3%	4%
Unknown	2%	8%	5%
Seizure Frequency			
No seizures	80%	70%	75%
Less than once/month	14%	17%	15%
At least once/month	<1%	3%	2%
At least once/week or more	1%	5%	3%
Unknown	5%	5%	5%
Vision			
Sees well (with/without correction)	88%	76%	81%
Vision problems limit activities	10%	7%	9%
Limited or no vision (legally blind)	2%	12%	7%
Unknown	<1%	5%	3%
Level of Mobility			
Walks or uses wheelchair	97%	85%	90%
Non-ambulatory needs assistance	3%	13%	9%
Unknown	0%	2%	1%
Physically Active			
Very physically active	15%	14%	15%
Moderately physically active	66%	50%	57%
Physically inactive	18%	31%	25%
Unknown	1%	5%	3%
Weight concerns			
No weight concerns	55%	65%	61%
Overweight	38%	23%	30%
Underweight	4%	6%	5%
Unknown	3%	6%	4%
Smoke/chew tobacco			
No	88%	91%	89%
Yes	11%	6%	9%
Unknown	1%	3%	2%

RESIDENTIAL INFORMATION

Table 3.11 - Type of Residence

Residential Type	Interviewed (n=176)	Not Interviewed (n=217)	All Participants (n=393)
Provider Home	42%	52%	47%
Family Home	27%	33%	30%
Own Home w/ Housemate	8%	4%	6%
Own Home Lives Alone	15%	7%	10%
Group Living	3%	0%	2%
Staffed Living	2%	1%	2%
Residential Care Home	1%	0%	<1%
Other/Unknown	2%	3%	3%

Table 3.12 – Respondent Guardianship by Residential Type

Residential Type	No Guardian (n=49)	Private Guardian (n=66)	Public Guardian (n=61)	Total (n=176)
Provider Home	10%	41%	69%	42%
Family Home	33%	48%	0%	27%
Own Home w/ Housemate	18%	3%	3%	8%
Own Home Lives Alone	31%	6%	13%	15%
Group Living	0%	2%	7%	3%
Staffed living	0%	0%	5%	2%
Residential Care Home	2%	0%	0%	1%
Other	6%	0%	3%	2%

Table 3.13 - Residence Characteristics

Residential Characteristic	Interviewed (n=176)	Not Interviewed (n=217)	All Participants (n=393)
Location			
Remote	42%	50%	47%
Walking distance to town	34%	29%	31%
Centrally located in town	23%	18%	20%
Unknown	1%	3%	2%
Ownership/Lease of Home			
Family/guardian	30%	34%	32%
Individual/family person lives with	42%	50%	47%
Provider agency/affiliate	4%	4%	4%
Person rents home	19%	11%	14%
Person owns home	2%	0%	1%
Other/Unknown	3%	1%	2%
Amount of Paid Residential Support			
No on-site support (Indep./family)	34%	29%	31%
24 hour on-site	50%	58%	54%
Daily on-site	4%	3%	4%
Less frequent than daily	9%	8%	9%
As needed	3%	2%	3%
Household Composition			
Non-related individuals	50%	54%	52%
Biological/adoptive parents	24%	30%	27%
Lives alone	16%	7%	11%
Spouse/Civil Union	3%	1%	2%
Other relatives	5%	5%	5%
Domestic partner	2%	2%	2%
Other/Unknown	<1%	1%	1%
Living with Others with Developmental Disability			
Yes	98%	97%	97%
No	2%	3%	3%
Time in current home/with current provider			
More than 5 years	51%	64%	59%
3-5 years	22%	16%	18%
1-2 years	16%	10%	13%
Less than 1 year	10%	7%	8%
Unknown	1%	3%	2%

COMMUNITY ACCESS AND BARRIERS

Table 3.14 – Getting to Places beyond Walking Distance

Means of Transport	Interviewed	Not Interviewed	All Participants
	(n=176)	(n=217)	(n=393)
Ride from family/friends	60%	51%	55%
Ride in staff member's car	81%	71%	76%
Group transport (provider van)	4%	5%	5%
Public transport	24%	9%	16%
Para transit/volunteer/ride-share	1%	1%	1%
Taxi	7%	2%	4%
Drives self	5%	10%	8%
Other	3%	6%	4%

Table 3.15 – Barriers to More Recreational Activity and Enjoyment

Barrier to more activities	Interviewed	Not Interviewed	All Participants
	(n=176)	(n=217)	(n=393)
No barrier	68%	66%	67%
Behavioral/emotional concerns	14%	16%	15%
Social skills limitations	6%	18%	13%
Health concerns	6%	13%	10%
Money/cost	17%	8%	12%
Inadequate transportation	10%	6%	8%
No chaperone	3%	4%	4%
Recreational activity shortage	5%	6%	6%
Other barrier	1%	1%	1%

SERVICES

Table 3.16 - Types of Services Received

Service Type	Interviewed	Not Interviewed	All Participants
	(n=176)	(n=217)	(n=393)
Residential Supports*	47%	53%	50%
Service Coordination	94%	92%	93%
Employment - Individual	44%	29%	36%
Employment - Group	1%	0%	1%
Community Support - Individual	51%	61%	56%
Community Support - Group	14%	3%	8%
Clinical Services	48%	48%	48%
Transportation	28%	28%	28%
Family Supports	50%	50%	50%
Other Supports	1%	1%	1%

* In Provider Home, Group Living, or Staffed Living

Table 3.17 - Self-/Family-Management of Services

	Interviewed	Not Interviewed	All Participants
	(n=176)	(n=217)	(n=393)
Management of Services			
Self or Shared with Agency	21%	20%	20%
Family or Shared with Agency	23%	21%	22%
Agency Managed	56%	59%	58%
Individually Negotiated Budget			
Yes	85%	80%	82%
No	15%	20%	18%
Individual Support Agreement (ISA)			
Yes	95%	91%	93%
No	5%	9%	7%
Fiscal Intermediary (ISO/private payroll)			
Yes	59%	64%	62%
No	41%	35%	38%
Independent Support Broker (ISB)			
Yes	0%	1%	1%
No	99%	99%	99%
Unknown	1%	0%	<1%

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, 2013 marking the third year of the fifth 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 2011 - 2013 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 2008-2010 survey cycle. In the spring of 2013, the independently contracted survey interviewers visited the following agencies: Health Care and Rehabilitation Services of Southeastern Vermont (HCRS), Lincoln Street Incorporated (LSI), Rutland Mental Health Services – Community Access Program (RMHS), Specialized Community Care (SCC) and United Counseling Service (UCS). These are the same agencies as those visited in 2010, 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 2011-2013 survey cycle.

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

Agency	2011	2012	2013
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. The last round of surveys starting in 2008 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. As of 2008, Vermont ceased participation in the NCI project due to budget constraints.

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 a 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, medical and health information, behavioral challenges, residential characteristics, services, and self-/family management and self-determination. 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.