

**SURVEY OF ADULTS RECEIVING
DEVELOPMENTAL DISABILITIES SERVICES
IN VERMONT
SPRING 2011**

Consumer Survey Project

Report Prepared November 2011

For

The Division of Disabilities and Aging Services
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 2011. The coordinating members of the Vermont Consumer Survey Project are:

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FOREWORD

We at the Division of Disabilities and Aging Services 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 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 2008, 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.

Marybeth McCaffrey, Director
Division of Disabilities and Aging Services

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SECTION 1

OVERVIEW

INTRODUCTION

The spring of 2011 marked the first year in the fifth 3-year cycle of satisfaction surveys of adults with developmental disabilities served by the State of Vermont Division of Disabilities and Aging Services. The agencies surveyed in 2011 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 were also invited 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 2008, 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 2008 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 2008.

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 2011. 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 2008 cycle is also included.
- **Consumer Survey 2011 - 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 2008 and 2011 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 2011 survey questions.
- **Participant Profile 2011 - 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 the procedures for collecting survey information and how that information is analyzed for reporting purposes.

SUMMARY OF FINDINGS: STATE OF VERMONT 2011

In the spring of 2011, 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 who have self- or family-managed services were also invited to participate although none completed interviews. 100% of those who are able to respond to the survey at smaller agencies (specialized service agencies and one designated agency) and 50% of those served by the larger designated agencies were invited to be interviewed. Interview times were a little longer than in previous surveys, taking an average of 37 minutes to complete in 2011 and 35 minutes in 2008. As can be seen from Table 1.1, although the response rates for 2011 varied somewhat across agencies, the statewide rate in 2011 was identical to the rate for 2008 (in parentheses).

Table 1.1 – Participants and Types of Interviews Conducted (N=449)

	CCS	HC	NCSS	UVS	Self Managed	Total 2011	(2008)
Interviewed							
Full interview	52%	39%	50%	47%	0%	41%	44%
Picture only	5%	4%	8%	5%	0%	5%	2%
Total interviewed	57%	43%	58%	52%	0%	46%	46%
Not interviewed							
Agency decision	21%	21%	11%	19%	22%	18%	16%
Guardian's decision	2%	1%	5%	2%	7%	3%	2%
Unable to complete	2%	0%	1%	1%	0%	<1%	1%
No Show/Person's choice	16%	19%	8%	10%	68%	19%	22%
Person out of town	0%	2%	2%	1%	3%	2%	<1%
Person incapacitated	0%	9%	8%	14%	0%	8%	11%
Scheduling oversight	2%	1%	2%	0%	0%	1%	<1%
Other	0%	4%	5%	1%	0%	3%	2%
Total not interviewed	43%	57%	42%	48%	100%	54%	54%
Total Participants	44	175	98	91	41	449	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 2008 and 2011.

Table 1.2 – Brief Profile of Consumers Interviewed

	Statewide 2008 (N=181)	Statewide 2011 (N=205)
Age		
Average Age	43	43
Minimum Age	19	20
Maximum Age	89	89
Gender		
Male	56%	56%
Female	44%	44%
Developmental Disability Label		
Mild MR	70%	74%
Moderate MR	16%	16%
Severe MR	4%	2%
Profound MR	1%	0%
Unknown/None Reported	9%	8%
Living Situation		
Provider Home	47%	48%
Family Home	24%	26%
Person's Own Home	22%	20%
Group Living	3%	1%
Staffed Living	0%	1%
Other	4%	4%
Services Received		
Service Coordination	96%	99%
Residential Supports*	57%	55%
Community Supports	67%	68%
Employment	48%	47%
Family Supports - Respite/FFF	52%	49%

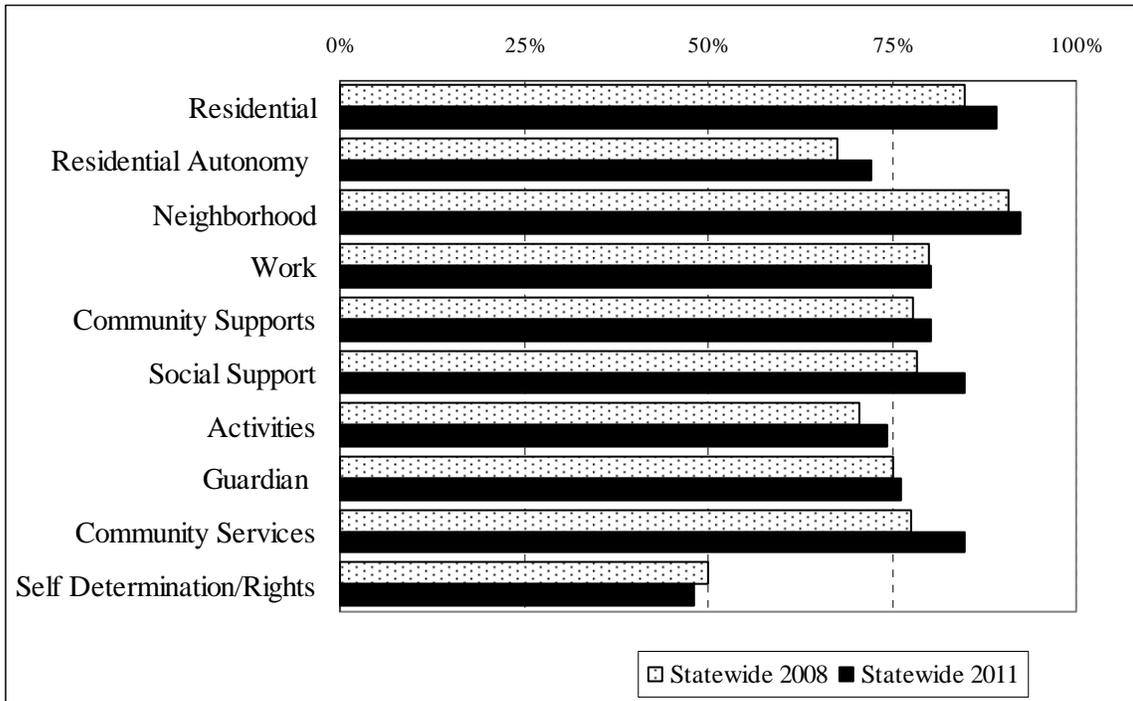
* In Provider Home, Group Living, or Staffed Living

The group profiles of those interviewed in 2011 and those interviewed in 2008 are remarkably similar. This similarity between the groups adds to the validity of any comparative differences found over time.

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).

The 2011 results show increasing satisfaction ratings in eight of the ten domains when compared to the 2008 cycle of surveys, the most marked increases being in the Social Support and Community Services domains. Residential and Residential Autonomy domain ratings were also notably higher. Work satisfaction remained unchanged and satisfaction about Self Determination/Rights was marginally lower. Since the profiles of the respondent groups were so similar in 2011 and 2008, these results would seem to support the trend for an overall increase in life satisfaction among people receiving publicly funded developmental disabilities services over the past three years.

Table 1.3 - Comparative Satisfaction by Domain



SECTION 2

CONSUMER SURVEY 2011

WHAT PEOPLE HAD TO SAY

This Section focuses on how people responded to the consumer survey in 2011. 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 2011 are the same as those visited in 2008, the equivalent year in the previous survey cycle. The selected highlights below include statewide responses from the 2008 surveys 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 2011 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 2008 and 2011. 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 2011, see page 14.

Table 2.1 – Residential

	Statewide 2008	Statewide 2011
• I like where I live	87%	87%
• I cannot think of anywhere better to live	71%	62%
• I'm happy about how I spend my free time	77%	87%
• I'm happy with the chores I do	73%	93%
• I feel safe at home	90%	95%
• I almost always have a way to get to places	86%	84%

Table 2.2 – Residential Autonomy

	Statewide 2008	Statewide 2011
• I had a say in where I live	55%	51%
• I choose what I wear	86%	86%
• I can change the rules at my house	48%	46%
• I can invite friends/family over when I want	79%	93%
• I have privacy when friends/family visit	70%	65%
• I have a say in how I spend my money	91%	99%
• I can stay home alone if I want to when others go out	54%	63%

Table 2.3 – Neighbors/neighborhood

	Statewide 2008	Statewide 2011
• Neighbors are friendly	90%	91%
• I like the neighborhood	84%	90%
• I feel safe in the neighborhood	91%	89%

Table 2.4 – Work

	Statewide 2008	Statewide 2011
• I chose my job	92%	83%
• I like my job	93%	95%
• I work enough hours at my job	48%	56%
• The people I work with respect me	88%	96%
• I chose my job coach	48%	25%
• There's nothing I'd rather do during the day	78%	89%

Table 2.5 – Community Supports (Individual)

	Statewide 2008	Statewide 2011
• I like my (individual) community activities	95%	96%
• I have enough (individual) community activities	55%	53%
• I like the people I spend time with	85%	94%
• I chose my support person	49%	32%
• There's nothing I'd rather do during the day	75%	90%

Table 2.6 - Friends/Social Supports

	Statewide 2008	Statewide 2011
• I have plenty of friends	57%	64%
• I can see my friends when I want	70%	86%
• I have opportunities to meet new people	86%	89%
• I have friends I like to talk/be with (not staff or family)	57%	78%
• I'm not often lonely	52%	51%
• I see my family as much as I want	68%	84%

Table 2.7 – Activities*

	Statewide 2008	Statewide 2011
• I shop as much as I want	55%	57%
• I exercise/play sport as much as I want	55%	58%
• I eat out as much as I want	51%	62%
• I go to entertainment as much as I want	44%	55%
• I go to church/synagogue as much as I want	60%	54%

* 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 2008	Statewide 2011
• I'm happy about my guardian	86%	90%
• I chose my guardian	34%	26%
• I see my guardian whenever I want	81%	82%
• My guardian lets me make my own decisions	62%	57%

Table 2.9 - Community Services

	Statewide 2008	Statewide 2011
• I'm happy with my service agency	79%	88%
• I chose my case manager	34%	32%
• I'm happy with my case manager	82%	89%
• It's easy to contact my case manager	64%	63%
• People listen to me at ISA meetings	92%	87%

Table 2.10 - Self Determination/Rights

	Statewide 2008	Statewide 2011
• I have attended a self advocacy meeting	50%	40%
• I have voted in an election	54%	64%
• I get to learn new things/skills	74%	78%
• I have enough control over my life	75%	75%
• I make all the choices I want	59%	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 2011 are directly comparable to those of 2008. 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 2011 and 2008. The ratings in Table 2.11 below show increased satisfaction ratings across most of the ten domains when compared to the 2008 cycle of surveys. The most significant increases occurred in the Social Support and Community Services domains. Residential and Residential Autonomy domain ratings were also markedly higher. Work satisfaction remained unchanged and satisfaction about Self Determination/Rights was marginally lower. Since the profiles of the respondent groups were so similar in 2011 and 2008, these results suggest an overall increase in life satisfaction among people receiving publicly funded developmental disabilities services over the past three years..

Table 2.11 - Comparative Domain Satisfaction

Domain	Statewide 2008 (N=181)	Statewide 2011 (N=205)
Residential	85%	89%
Residential Autonomy	68%	72%
Neighborhood	91%	92%
Work	80%	80%
Community Supports	78%	80%
Social Support	78%	85%
Activities	71%	74%
Guardian	75%	76%
Community Services	78%	85%
Self Determination/Rights	50%	48%

When further analyses of domain satisfaction by respondent characteristics were completed, significant differences were found in five of the ten domains. First, domain satisfaction was examined by the types of home setting (Table 2.12). This showed that, apart from satisfaction in the Residential Autonomy and Activities domains, the people living in family homes tended to give more favorable satisfaction ratings. People in family homes gave significantly higher ratings than those living semi-independently in the Residential, Guardian and Community Services domains and significantly higher ratings than those in provider homes in the Residential Autonomy and Self Determination/Rights domains. People living semi-independently rated their Residential Autonomy significantly higher than those in provider homes and people in provider homes rated Residential satisfaction significantly higher than those living semi-independently. No statistically significant differences by residential type were found in the other five domains. Similarly, examination of Community Support satisfaction by type of support (individual or group) and Guardian satisfaction by type of guardian showed no significant differences.

Table 2.12 - Domain Satisfaction by Residential Type – 2011

Domain	Family Home (n=54)	Semi-Independent Living (n=42)	Provider Home (n=98)	All Residential Settings (n=169)
* Residential	93%	85%	90%	89%
* Residential Autonomy	76%	81%	67%	72%
Neighborhood	96%	89%	93%	92%
Work	81%	76%	81%	80%
Community Supports	84%	79%	80%	80%
Social Support	86%	86%	84%	85%
Activities	71%	80%	73%	74%
* Guardian	85%	64%	76%	76%
* Community Services	89%	82%	84%	85%
* Self Determination/Rights	53%	51%	44%	48%

SURVEY RESPONSES, 2011: STATEWIDE (N=205)

The following pages provide details of how people across the participating agencies responded to individual questions on the Consumer Survey in the spring of 2011. 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
205	87%	7%	6%

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

RESPONDENTS	SELF	SELF WITH HELP	SOMEONE ELSE
130	9%	42%	49%

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

RESPONDENTS	NO	YES
146	62%	38%

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

RESPONDENTS	LIKE	IN-BETWEEN	NOT LIKE
200	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
147	91%	7%	2%

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

RESPONDENTS	SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
147	86%	10%	4%

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
142	83%	8%	9%

8. Are there any pets at your house?

RESPONSES	YES	NO
184	74%	26%

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

RESPONSES	LIKE	IN-BETWEEN	NOT LIKE
145	89%	1%	10%

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

RESPONSES	NO	SOMETIMES	YES
38	50%	0%	50%

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

RESPONSES	POLITE	SOMETIMES	NOT POLITE
99	93%	7%	0%

12. Tell me how you feel about _____.

RESPONSES	HAPPY	IN-BETWEEN	SAD
113	90%	7%	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?)

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
9	33%	22%	45%

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

RESPONDENTS	NO	YES
75	43%	57%

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? 91

RESPONDENTS	POLITE	SOMETIMES	NOT POLITE
145	92%	7%	1%

16. Tell me how you feel about _____.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
162	91%	8%	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?)

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
29	7%	31%	62%

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

RESPONDENTS	YES	IN-BETWEEN	NO
22	86%	5%	9%

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

RESPONDENTS	NO	IN-BETWEEN	YES
22	77%	5%	18%

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
145	82%	10%	8%

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
181	87%	12%	1 %

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

RESPONDENTS	FUN	IN-BETWEEN	BORED
182	69%	23%	8%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
174	87%	11%	2%

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
139	70%	8%	22%

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

RESPONDENTS	NO	SOMETIMES	YES
141	57%	3%	40%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
158	93%	6%	1%

RULES:

27. Who makes the rules for living here?

RESPONDENTS	SELF	IN-BETWEEN	SOMEONE ELSE
123	2%	3%	95%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
142	80%	14%	6%

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
118	27%	18%	55%

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
168	55%	0%	45%

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

RESPONDENTS	YES	IN-BETWEEN	NO
149	93%	1%	6%

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

RESPONDENTS	SELF	IN-BETWEEN	OTHER
136	27%	27%	46%

PRIVACY:

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

RESPONDENTS	YES ENOUGH	WANT MORE TIME ALONE
149	66%	34%

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

RESPONDENTS	NO	SOMETIMES	YES
144	97%	1%	2%

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

RESPONDENTS	YES	NO/SOME RESTRICTIONS
144	84%	16%

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

RESPONDENTS	HAVE PRIVACY	LISTEN IN
127	94%	6%

37. Can you answer the phone at home?

RESPONDENTS	YES	NO
137	73%	27%

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
131	65%	35%

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

RESPONDENTS	YES	NO
172	27%	73%

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

RESPONDENTS	NO	YES
123	50%	50%

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

RESPONDENTS	YES	NO
46	80%	20%

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

RESPONDENTS	YES, ALLOWED	SOMETIMES	NOT ALLOWED
41	46%	0%	54%

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

RESPONDENTS	NO	SOMETIMES	YES
165	52%	1%	47%

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

RESPONDENTS	YES	NO
157	79%	21%

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
182	89%	11%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
202	95%	4%	1%

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
181	80%	19%	1%

48. Do people steal (take) your money?

RESPONDENTS	NO	YES
183	97%	3%

SAFETY:

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

RESPONDENTS	LEAVE ALONE	TAKE
152	95%	5%

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

RESPONDENTS	YES	SOMETIMES	NO
177	94%	4%	2%

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

RESPONDENTS	YES	SOMETIMES	NO
149	85%	7%	8%

52. Do you feel safe in your home?

RESPONDENTS	YES	IN-BETWEEN	NO
183	95%	3%	2%

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

RESPONDENTS	NO RARELY	IN-BETWEEN	YES MOST OF TIME
181	82%	17%	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
137	63%	0%	37%

55. Do you have a key to your house?

RESPONDENTS	YES	NO
178	62%	38%

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
183	84%	16%	0%

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
180	56%	44%	0%

NEIGHBORHOOD:

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

RESPONDENTS	YES	SOMETIMES	NO
169	91%	6%	3%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
191	88%	10%	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
181	90%	2%	8%

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

RESPONDENTS	YES	IN-BETWEEN	NO
183	90%	7%	3%

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

RESPONDENTS	NO RARELY	IN-BETWEEN	YES, MOST OF TIME
182	88%	10%	2%

WORK

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

RESPONDENTS	YES	NO
184	28%	72%

64. Do you have a job?

RESPONDENTS	YES	NO
184	55%	45%

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

RESPONDENTS	NO	SOMETIMES	YES
82	32%	4%	64%

66. Did you choose to work at _____?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
96	10%	73%	17%

67. Do you like working there?

RESPONDENTS	YES	IN-BETWEEN	NO
101	95%	4%	1%

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

RESPONDENTS	IMPORTANT	NOT IMPORTANT
100	100%	0%

69. Tell me how you feel about your work.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
108	93%	6%	1%

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

RESPONDENTS	ENOUGH	MORE
99	56%	44%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
107	92%	6%	2%

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

RESPONDENTS	VACATION	ALL THE TIME
101	70%	30%

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
79	96%	4%	0%

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
76	5%	20%	75%

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

RESPONDENTS	NO	YES
77	44%	56%

75a. Is that a problem for you?

RESPONDENTS	NO	YES
42	79%	21%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
109	95%	5%	0%

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

RESPONDENTS	RESPECT	IN-BETWEEN	NO RESPECT
100	96%	4%	0%

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

RESPONDENTS	CHOOSE TO GO	HAVE TO GO
97	58%	42%

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

RESPONDENTS	NO	SOMETIMES	YES
96	89%	3%	8%

COMMUNITY ACTIVITIES - INDIVIDUAL SUPPORT

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
137	28%	60%	12%

81. Do you like doing those activities?

RESPONDENTS	LIKE	SOMETIMES	NOT LIKE
142	96%	3%	1%

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

RESPONDENTS	ENOUGH	MORE
137	53%	47%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
161	94%	5%	1%

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

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
143	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
115	9%	23%	68%

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

RESPONDENTS	NO	YES
124	44%	56%

86a. Is that a problem for you?

RESPONDENTS	NO	YES
67	58%	42%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
159	94%	6%	0%

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
142	98%	2%	0%

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

RESPONDENTS	CHOOSE	HAVE TO GO
137	74%	26%

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

RESPONDENTS	NO	SOMETIMES	YES
137	90%	4%	6%

COMMUNITY ACTIVITIES - GROUP SUPPORT

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
18	50%	33%	17%

92. Do you like doing those activities?

RESPONDENTS	YES	IN-BETWEEN	NO
18	94%	6%	0%

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

RESPONDENTS	ENOUGH	MORE
17	24%	76%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
20	100%	0%	0%

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

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
18	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
15	14%	13%	73%

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

RESPONDENTS	NO	YES
15	60%	40%

97a. Is that a problem for you?

RESPONDENTS	NO	YES
7	86%	14%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
20	90%	10%	0%

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
17	100%	0%	0%

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

RESPONDENTS	CHOOSE	HAVE TO GO
17	77%	23%

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

RESPONDENTS	NO	SOMETIMES	YES
17	71%	0%	29%

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
180	92%	8%

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
182	78%	20%	2%

104. Tell me how feel about your friends.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
199	95%	4%	1%

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
181	86%	11%	3%

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

RESPONDENTS	PLENTY	MORE
175	64%	36%

107. Do you have opportunities to meet new people?

RESPONDENTS	YES	NO
176	89%	11%

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

RESPONDENTS	YES	NO
177	92%	8%

109. Does anyone ever ask you to help them?

RESPONDENTS	SOMEONE NAMED	NO ONE NAMED
170	57%	43%

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

RESPONDENTS	NO NOT OFTEN	SOMETIMES	OFTEN LONELY
183	51%	40%	9%

FAMILY:

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

RESPONDENTS	YES	NO
158	98%	2%

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

RESPONDENTS	YES	SOMETIMES	NO
156	84%	13%	3%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
174	84%	14%	2%

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
178	57%	42%	1%

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

RESPONDENTS	NO	YES
-	-	-

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
177	78%	19%	3%

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

RESPONDENTS	NO	YES
-	-	-

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
178	58%	42%	0%

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

RESPONDENTS	NO	YES
-	-	-

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
173	55%	44%	1%

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

RESPONDENTS	NO	YES
6	50%	50%

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
176	63%	37%	0%

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

RESPONDENTS	NO	YES
4	25%	75%

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
76	59%	40%	1%

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

RESPONDENTS	NO	YES
100	50%	50%

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
25	48%	52%	0%

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

RESPONDENTS	NO	YES
152	56%	44%

GUARDIANSHIP

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

RESPONDENTS	YES	MAYBE	NOT SURE
116	97%	0%	3%

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

RESPONDENTS	YES	SOMETIMES	NO
80	82%	14%	4%

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

RESPONDENTS	I CHOSE	SOMEONE ELSE CHOSE
61	26%	74%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
129	90%	8%	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
110	57%	43%

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

RESPONDENTS	NO	YES
111	83%	17%

SELF-ADVOCACY

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

RESPONDENTS	YES	NO
176	40%	60%

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
64	26%	19%	55%	0%

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
97	5%	31%	5%	56%	3%

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

RESPONDENTS	YES	NO
65	80%	20%

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

RESPONDENTS	YES	NO
104	60%	40%

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

RESPONDENTS	YES	NO
180	93%	7%

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

RESPONDENTS	YES	NO
177	66%	34%

VOTING

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

RESPONDENTS	YES	NO
177	76%	24%

134. Have you ever voted in an election?

RESPONDENTS	YES	NO
181	64%	36%

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

RESPONDENTS	YES	NO
111	89%	11%

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

RESPONDENTS	YES	NO
62	58%	42%

SERVICE AGENCY

136 Do you know your service coordinator/case manager?

RESPONDENTS	YES	MAYBE/NOT SURE	NO
182	99%	1%	0%

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

RESPONDENTS	YES	SOMETIMES	NO
178	68%	20%	12%

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

RESPONDENTS	YES	SOMETIMES	NO
179	85%	7%	8%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
203	89%	10%	1%

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
168	11%	20%	69%

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
174	63%	20%	17%

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

RESPONDENTS	NO	YES
171	56%	44%

142a. Is that a problem for you?

RESPONDENTS	NO	YES
75	71%	29%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
202	87%	11%	2%

144. Do you get the services you need?

RESPONDENTS	YES	SOMETIMES	NO
179	90%	7%	3%

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

RESPONDENTS	YES	NO
169	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
150	87%	9%	4%

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

RESPONDENTS	YES	SOMETIMES	NO
147	92%	5%	3%

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

RESPONDENTS	YES	NO
171	89%	11%

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
164	8%	1%	91%

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

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
176	79%	16%	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
180	91%	5%	4%

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
158	99%	1%	0%

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

RESPONDENTS	YES	SOMETIMES	NO
177	78%	10%	12%

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

RESPONDENTS	NO	YES
42	41%	59%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
200	87%	13%	0%

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
175	23%	77%

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
176	23%	77%

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

RESPONDENTS	NO	YES
172	95%	5%

SELF-DETERMINATION

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

RESPONDENTS	ENOUGH	MORE
178	75%	25%

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

RESPONDENTS	NO	YES NOT NAMED	YES NAMED
174	87%	0%	13%

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
171	59%	41%

SECTION 3

PARTICIPANT PROFILE 2011

WHO PARTICIPATED

This Section is intended to give an overall picture of the adults receiving developmental disabilities services statewide. It reports findings from the 2011 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=205)	Not Interviewed (n=244)	All Participants (n=449)
Age			
Average Age	43	40	41
Minimum	20	19	19
Maximum	89	88	89
Gender			
Male	56%	63%	60%
Female	44%	37%	40%
Marital Status			
Single	88%	93%	91%
Married/Civil Union	6%	3%	4%
Married/Civil Union in past	6%	4%	5%
Race			
White	98%	96%	97%
American Indian/Eskimo/Aleut	1%	1%	1%
Black	0%	2%	1%
Asian	1%	<1%	<1%
Other/Unknown	0%	1%	1%
Primary Language			
English	99%	99%	99%
Other/Unknown	1%	1%	1%

Table 3.2 – Legal Factors

	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Guardianship			
No Guardian	33%	28%	30%
Private Guardian	46%	59%	53%
Public Guardian	21%	12%	17%
Unknown	0%	1%	<1%
Payee			
No Payee	17%	15%	16%
Payee	77%	80%	79%
Unknown	6%	5%	5%
Court Restrictions			
No	98%	98%	98%
Yes	2%	1%	2%
Unknown	0%	1%	<1%

Table 3.3 - Family Involvement in People’s Lives

	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Family Involved			
Yes	88%	88%	88%
No	12%	12%	12%
Why Family not Involved	(n=24)	(n=29)	(n=53)
Family gone/not alive/ whereabouts unknown	42%	55%	49%
Family choice	25%	28%	26%
Court restriction	12%	0%	6%
Other	17%	17%	17%
Unknown	4%	0%	2%

COMMUNICATION CAPABILITY

Table 3.4 – Means of Communication

	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Adequate Reliable Speech			
Yes	84%	56%	69%
No	16%	44%	31%
Primary Means of Communication			
Spoken - Understood by familiar listener	91%	74%	82%
Gesture/body language	4%	20%	13%
Sign language/finger spelling	2%	2%	2%
Communication aid/device	2%	2%	2%
Other/Unknown	1%	2%	1%

Table 3.5 – Communication Effectiveness for People with Inadequate Speech

	Interviewed (n=32)	Not Interviewed (n=106)	All Participants (n=138)
Communicate with familiar people			
Yes	100%	91%	93%
No	0%	8%	6%
Unknown	0%	1%	1%
Communicate with unfamiliar people			
Yes	66%	35%	42%
No	34%	62%	56%
Unknown	0%	3%	2%
Communicate beyond basic needs			
Yes	75%	47%	54%
No	25%	50%	44%
Unknown	0%	3%	2%
Communication effectiveness in last year			
More effective	25%	16%	18%
As effective	69%	73%	72%
Health prevents fair assessment	3%	6%	5%
Less effective	0%	1%	1%
Unknown	3%	4%	4%

Table 3.6 – Communication Supports for People with Inadequate Speech

	Interviewed (n=32)	Not Interviewed (n=106)	All Participants (n=138)
Communication addressed in ISA			
Yes	53%	48%	49%
No	47%	51%	50%
Unknown	0%	1%	1%
Communication Supports in Place			
Consistent comm. partners	100%	93%	95%
Team support	100%	97%	98%
Access to comm. aids/devices	63%	54%	56%
Training support for support wkers	81%	86%	85%
Expert consultation/support	47%	48%	48%

MEDICAL/HEALTH ISSUES

Table 3.7 - Developmental Disability

Disability Label	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Mild MR	74%	36%	53%
Moderate MR	16%	23%	20%
Severe MR	2%	11%	7%
Profound MR	0%	9%	5%
Unknown/None reported	8%	21%	15%

Table 3.8 - Other Challenges

Challenge	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
None Reported	14%	11%	12%
Mental Illness	36%	28%	31%
Autism	8%	22%	15%
Cerebral Palsy	13%	10%	11%
Brain Injury	2%	2%	2%
Chemical Dependence	0%	1%	0%
Physical Disability	10%	12%	11%
Hearing	7%	12%	10%
Vision	17%	13%	15%
Seizures	16%	25%	21%
Communication Disorder	7%	1%	4%
Alzheimers Disease	0%	2%	2%
Down Syndrome	13%	15%	14%
Non-Ambulatory	4%	10%	7%
Other	11%	14%	12%

Table 3.9 – Healthcare

	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Last Physical Examination			
In the past year	87%	80%	83%
Over 1 year ago	8%	9%	8%
Unknown	5%	11%	9%
Last Ob/Gyn Examination (female)			
In the past year	51%	50%	51%
Over 1 year ago	12%	20%	16%
Never had an ob/gyn exam	5%	7%	5%
Unknown	32%	23%	28%
Last Dental Examination			
In the past six months	62%	58%	60%
Over 6 months ago	17%	20%	18%
Unknown	21%	22%	22%

Table 3.10 - Health and Lifestyle

	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Medical Care Required			
Less than once/month	87%	81%	84%
At least once/month	9%	12%	11%
At least once/week or more	1%	4%	2%
Unknown	3%	3%	3%
Seizure Frequency			
No seizures	78%	74%	75%
Less than once/month	16%	16%	16%
At least once/month	1%	2%	2%
At least once/week or more	0%	3%	2%
Unknown	5%	5%	5%
Vision			
Sees well (with/without correction)	89%	77%	83%
Vision problems limit activities	7%	14%	10%
Limited or no vision (legally blind)	3%	6%	5%
Unknown	1%	3%	2%
Level of Mobility			
Walks or uses wheelchair	96%	90%	93%
Non-ambulatory needs assistance	4%	10%	7%
Physically Active			
Very physically active	15%	11%	13%
Moderately physically active	65%	62%	63%
Physically inactive	20%	25%	23%
Unknown	0%	2%	1%
Weight concerns			
No weight concerns	58%	62%	61%
Overweight	39%	30%	34%
Underweight	2%	6%	4%
Unknown	1%	2%	1%
Smoke/chew tobacco			
No	91%	92%	91%
Yes	8%	6%	7%
Unknown	1%	2%	2%

RESIDENTIAL INFORMATION

Table 3.11 - Type of Residence

Residential Type	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Provider Home	48%	41%	44%
Family Home	26%	35%	31%
Own Home w/ Housemate	11%	9%	10%
Own Home Lives Alone	10%	11%	10%
Group Living	1%	2%	2%
Staffed Living	1%	0%	<1%
Residential Care Home	1%	0%	<1%
Other/Unknown	2%	2%	2%

Table 3.12 – Respondent Guardianship by Residential Type

Residential Type	No Guardian (n=67)	Private Guardian (n=95)	Public Guardian (n=43)	Total (n=205)
Provider Home	30%	45%	84%	48%
Family Home	24%	40%	0%	26%
Own Home w/ Housemate	24%	4%	5%	11%
Own Home Lives Alone	18%	4%	9%	10%
Group Living	0%	2%	2%	1%
Staffed living	3%	0%	0%	1%
Residential Care Home	0%	3%	0%	1%
Other	1%	2%	0%	2%

Table 3.13 - Residence Characteristics

Residential Characteristic	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Location			
Remote	51%	50%	50%
Walking distance to town	36%	38%	38%
Centrally located in town	13%	11%	12%
Unknown	0%	1%	0%
Ownership/Lease of Home			
Family/guardian	28%	40%	34%
Individual/family person lives with	49%	40%	44%
Provider agency/affiliate	3%	4%	4%
Person rents home	19%	12%	15%
Person owns home	<1	3%	2%
Other/Unknown	<1	1%	1%
Amount of Paid Residential Support			
No on-site support (Indep./family)	29%	31%	30%
24 hour on-site	51%	43%	46%
Daily on-site	8%	14%	12%
Less frequent than daily	8%	7%	7%
As needed	4%	4%	4%
Unknown	0%	1%	1%
Household Composition			
Non-related individuals	55%	42%	48%
Biological/adoptive parents	21%	35%	29%
Lives alone	9%	11%	10%
Spouse/Civil Union	4%	2%	3%
Other relatives	10%	7%	8%
Domestic partner	1%	3%	2%
Living with Others with Developmental Disability			
Yes	24%	28%	26%
No	75%	72%	73%
Unknown	1%	0%	1%
Time in current home/with current provider			
More than 5 years	52%	60%	57%
3-5 years	20%	17%	18%
1-2 years	16%	12%	14%
Less than 1 year	12%	11%	11%

COMMUNITY ACCESS AND BARRIERS

Table 3.14 – Getting to Places beyond Walking Distance

Means of Transport	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Ride from family/friends	60%	61%	61%
Ride in staff member's car	87%	73%	80%
Group transport (provider van)	7%	4%	5%
Public transport	21%	18%	19%
Para transit/volunteer/ride-share	6%	5%	6%
Taxi	10%	5%	7%
Drives self	4%	8%	6%
Other	7%	3%	5%

Table 3.15 – Barriers to More Recreational Activity and Enjoyment

Barrier to more activities	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
No barrier	71%	60%	65%
Behavioral/emotional concerns	17%	20%	19%
Social skills limitations	15%	20%	18%
Health concerns	10%	13%	11%
Money/cost	13%	9%	11%
Inadequate transportation	10%	7%	8%
No chaperone	3%	8%	6%
Recreational activity shortage	6%	2%	4%
Other barrier	2%	1%	1%

SERVICES

Table 3.16 - Types of Services Received

Service Type	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Residential Supports*	50%	44%	47%
Service Coordination	99%	94%	96%
Employment - Individual	47%	32%	39%
Employment - Group	3%	1%	2%
Community Support - Individual	68%	62%	65%
Community Support - Group	17%	8%	12%
Clinical Services	56%	48%	52%
Transportation	54%	50%	52%
Family Supports	49%	58%	54%
Other Supports	6%	5%	6%

Table 3.17 - Self-/Family-Management of Services

	Interviewed (n=205)	Not Interviewed (n=244)	All Participants (n=449)
Management of Services			
Self or Shared with Agency	6%	13%	10%
Family or Shared with Agency	16%	31%	24%
Agency Managed	78%	55%	66%
Unknown	0%	1%	<1%
Individually Negotiated Budget			
Yes	90%	83%	86%
No	10%	16%	13%
Unknown	0%	1%	1%
Individual Support Agreement (ISA)			
Yes	98%	96%	97%
No	2%	4%	3%
Fiscal Intermediary (ISO/private payroll)			
Yes	65%	75%	70%
No	35%	25%	30%
Independent Support Broker (ISB)			
Yes	1%	7%	5%
No	99%	91%	94%
Unknown	0%	2%	1%

SECTION 4

METHODOLOGY

HOW THIS SURVEY IS CONDUCTED

Since the inception of the statewide consumer surveys in 1995, the State Division of Disabilities and Aging Services has taken steps to provide a forum for people receiving developmental disability 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, 2011 marking the first 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 2011, 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 invited to participate. These are the same agencies as those visited in 2008, 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 Services (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, self- or family-management of services 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 Division of Disabilities and Aging Services.

SURVEY ADMINISTRATION

Rosemary Drabing, an independent contractor with extensive experience with the Vermont developmental disabilities service 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 17). The charts appearing in these reports are generated using Excel to format output from the SPSS analysis.

On completion of the interview sessions, the completed Demographic Survey and Consumer Interview questionnaires are returned to the project coordinator for entry into 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 SSPS 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.