

NOT THE FULL REPORT
Interview Questions and Demographic Survey ONLY

**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
103 South Main Street
Waterbury, VT 05671-1601

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 your 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 wkrs	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	50%	50%	47%
Walking distance to town	29%	29%	31%
Centrally located in town	18%	18%	20%
Unknown	3%	3%	2%
Ownership/Lease of Home			
Family/guardian	34%	34%	32%
Individual/family person lives with	42%	50%	47%
Provider agency/affiliate	4%	4%	4%
Person rents home	11%	11%	14%
Person owns home	0%	0%	1%
Other/Unknown	1%	1%	2%
Amount of Paid Residential Support			
No on-site support (Indep./family)	34%	29%	20%
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	54%	54%	52%
Biological/adoptive parents	30%	30%	27%
Lives alone	6%	7%	11%
Spouse/Civil Union	1%	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	65%	64%	59%
3-5 years	16%	16%	18%
1-2 years	10%	10%	13%
Less than 1 year	7%	7%	8%
Unknown	3%	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%

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.