

**SURVEY OF ADULTS RECEIVING
DEVELOPMENTAL SERVICES
IN VERMONT
SPRING 2008**

Consumer Survey Project

Report Prepared September 2008

For

The Division of Disability and Aging Services
Vermont Department of Disabilities, Aging and Independent Living
103 South Main Street
Waterbury, VT 05671-1601

This Report describes findings from a survey of adults receiving developmental services across Vermont. The survey was conducted by members of the Vermont Consumer Survey Project in the spring of 2008. The coordinating members of the Vermont Consumer Survey Project are:

June Bascom, M.Ed. - Project Director
Rosemary Drabing, M.S.W. - Survey administration and data entry.
Janet Bramley, Ph.D. - Data analysis and report preparation.

For questions about this report or requests for further copies, please contact:

June Bascom
The Division of Disability and Aging Services
Vermont Department of Disabilities, Aging and Independent Living
103 South Main Street
Waterbury, VT 05671-1601

FOREWORD

We at the Division of Disability and Aging Services are committed to quality improvement. We continually monitor, and seek ways we can improve, the developmental 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 fourth 3-year cycle of surveys. Each year, we include consumers from a subset of the agencies in Vermont who provide developmental 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 the last completed cycle of surveys. In addition, in keeping with our efforts for continuing improvement, new information has been added on how people are able to get to places that are beyond walking distance, and on barriers that may prevent them from participating in more community activities and enjoyment.

We hope you find this both informative and helpful.

Lorraine Wargo, Director
Division of Disability and Aging Services

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SECTION 1

OVERVIEW

INTRODUCTION

The spring of 2008 marked the start of the fourth 3-year cycle of satisfaction surveys of adults with developmental disabilities served by the State of Vermont Division of Disability and Aging Services. The agencies surveyed in 2008 were: Northwestern Counseling and Support Services (NCSS), HowardCenter (HC), Upper Valley Services (UVS), and Champlain Community Services (CCS); adults from across the state who are self- or family-managing 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 consumers. It should be noted that the order in which agencies are visited has changed for this survey cycle, partly due to demographic changes since the inception of these surveys, and partly to make the scheduling and completion of the interview process more efficient. This change, along with having a year without a survey (2007), results in the first cycle having some agencies visited sooner than three years and some others longer than three years. For this reason, the statewide report compares the responses from this year's interviews to consumer responses from all agencies over the last completed survey cycle (2004 - 2006) to give a fair reflection of overall change over time. Individual agency reports will continue as before to contain comparisons with the responses from the year that particular agency was last visited.

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 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 last cycle starting in 2004 expanded further on demographics included substantial changes and additions to the survey report presentation format and further alignment with the National Core Indicators (NCI) survey. This latest round of surveys starting in 2008 features changes based on input from a range of stakeholders; information on access and barriers to community activities has been added and a number of questions have been rephrased for easier understanding and further alignment with the NCI survey. As for the last survey cycle, the reports consist of four major Sections:

- **Overview:** This Section provides a brief stand-alone summary of findings for spring 2008. 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 2004 - 2006 cycle is also included.
- **Consumer Survey 2008 - 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 2004 - 2006 survey cycle and 2008 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 2008 survey questions.

- **Participant Profile 2008 - 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 2008

In the spring of 2008, the independently contracted survey team visited four agencies; Northwestern Counseling and Support Services (NCSS), HowardCenter (HC), Upper Valley Services (UVS), Champlain Community Services (CCS); adults who are self-/family-managing 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 the larger designated agencies were invited to be interviewed. Interviews took an average of 35 minutes to complete in 2008 and 31 minutes in 2004 - 2006. As can be seen from Table 1.1, the response rate for 2008 was somewhat higher than the statewide rate for 2004 – 2006 (in parentheses).

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

	NCSS	HC	UVS	CCS	Self-Family Managed	Total 2008	(2004-2006)
Interviewed							
Full interview	45%	49%	52%	44%	0%	44%	(35%)
Picture only	1%	3%	1%	2%	0%	2%	(5%)
Total Interviewed	46%	52%	53%	47%	0%	46%	(40%)
Not Interviewed							
Agency decision	22%	14%	11%	22%	23%	16%	(17%)
Guardian's decision	5%	2%	1%	2%	3%	2%	(2%)
Unable to complete	0%	2%	3%	5%	0%	1%	(4%)
No Show/Person's choice	20%	22%	14%	13%	68%	22%	(23%)
Person out of town	1%	1%	1%	0%	0%	<1%	(2%)
Person incapacitated	5%	5%	16%	11%	0%	11%	(8%)
Scheduling oversight	1%	0%	0%	0%	0%	<1%	(1%)
Other	1%	2%	1%	0%	6%	2%	(3%)
Total not Interviewed	54%	48%	47%	53%	100%	54%	(60%)
Total Participants	78	163	74	45	31	391	(1188)

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 2004 - 2006 and 2008.

Table 1.2 – Brief Profile of Consumers Interviewed

	Statewide 2004 - 2006 (N=475)	Statewide 2008 (N=181)
Age		
Average Age	42	43
Minimum Age	19	19
Maximum Age	86	89
Gender		
Male	58%	56%
Female	42%	44%
Developmental Disability Label		
Mild MR	71%	70%
Moderate MR	20%	16%
Severe MR	4%	4%
Profound MR	0%	1%
Unknown	5%	9%
Living Situation		
Provider Home	43%	47%
Family Home	27%	24%
Person's Own Home	22%	22%
Group Living	4%	3%
Other	4%	4%
Services Received		
Service Coordination	95%	96%
Residential Supports*	61%	57%
Community Supports	59%	67%
Employment - Individual supported	51%	48%
Family Supports - Respite/FFF	43%	52%

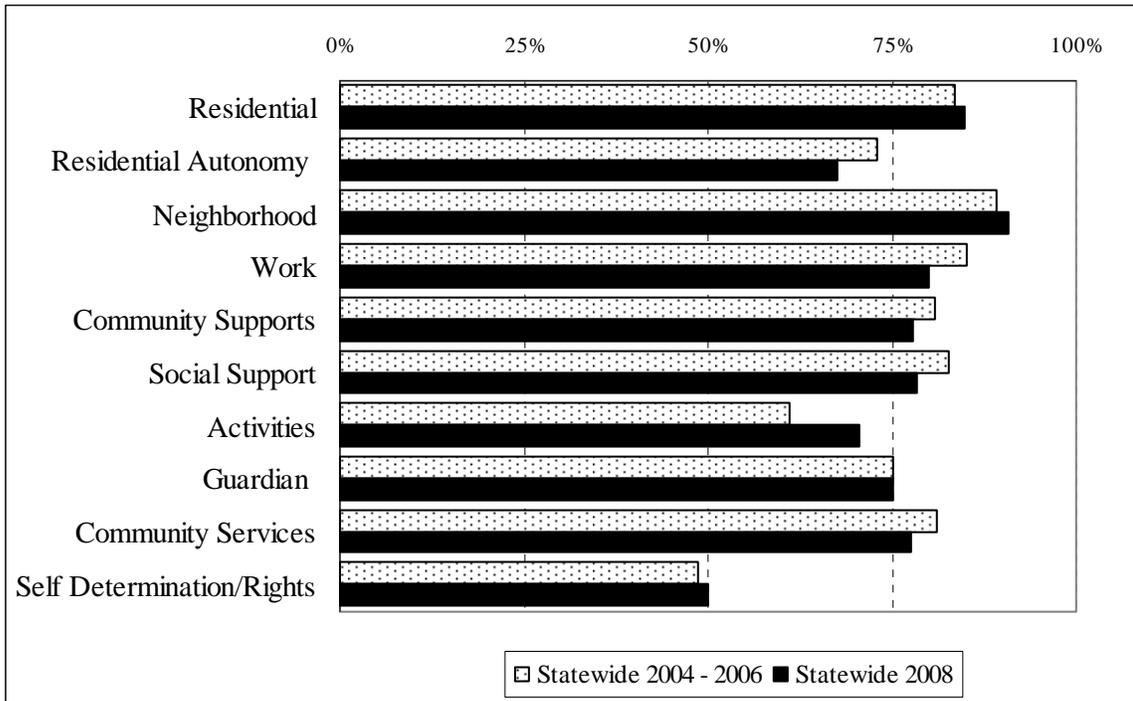
* In Provider Home, Group Living, or Staffed Living

In general the profiles are similar. As a higher percentage of the 2008 interview group live in developmental homes than in 2004 - 2006, it is to be expected that utilization percentages are higher for certain services in 2008.

The analysis of responses to the consumer survey involves grouping responses into scales reflecting a series of life satisfaction domains (Table 1.3). While the revisions to the survey necessitated some regrouping of responses for the scales, the domains examined remain the same as for the previous survey cycle. The ratings for all but one of the domains are directly comparable to previous years. Response options for questions relating to participation in activities have been changed to help providers see what activities consumers would like more opportunities to enjoy or would rather not participate in at all. The effect of this has been to increase the overall Activities satisfaction rating. This is further discussed on page 12.

The 2008 results indicate generally similar levels of satisfaction with only some slight differences in ratings within the different domains, some caused in part by revisions to the survey. For example, the apparent increase in satisfaction with community activities is due to increased response options available for activity satisfaction questions. Small decreases were noted in Residential Autonomy, Work, and Social Support ratings. This may be partly a result of more people living in provider homes rather than with their family, or an indication of greater understanding of choices and expectations in the home and work and a desire to have more community and social opportunities.

Table 1.3 - Comparative Satisfaction by Domain



SECTION 2

CONSUMER SURVEY 2008

WHAT PEOPLE HAD TO SAY

This Section focuses on how people responded to the consumer survey in 2008. 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. Since the order of visiting agencies has been revised to better reflect the demographic composition of the consumer base in Vermont, the selected highlights also include comparative statewide responses from all of the 2004 – 2006 surveys rather than the equivalent year from that cycle. A brief profile of the adults who were interviewed is given in Section 1 and full demographic information on all survey participants for 2008 is available in Section 4.

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 the period 2004 – 2006 and 2008. 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 2008, see page 14.

Table 2.1 – Residential

	Statewide 2004 - 2006	Statewide 2008
• I like where I live	91%	87%
• I cannot think of anywhere better to live	67%	71%
• I'm happy about how I spend my free time	74%	77%
• I'm happy with the chores I do	72%	73%
• I feel safe at home	93%	90%
• I can get to places (like Drs, Agency, shops)	92%	86%

Table 2.2 – Residential Autonomy

	Statewide 2004 - 2006	Statewide 2008
• I had a say in where I live	43%	55%
• I choose what I wear	84%	86%
• I can change the rules at my house	54%	48%
• I can invite friends/family over when I want	87%	79%
• I have privacy when friends/family visit	73%	70%
• I have a say in how I spend my money	94%	91%
• I can stay home alone if I want to when others go out	59%	54%

Table 2.3 – Neighbors/neighborhood

	Statewide 2004 - 2006	Statewide 2008
• Neighbors are friendly	91%	90%
• I like the neighborhood	78%	84%
• I feel safe in the neighborhood	93%	91%

Table 2.4 – Work

	Statewide 2004 - 2006	Statewide 2008
• I chose my job	89%	92%
• I like my job	95%	93%
• I work enough hours at my job	61%	48%
• The people I work with respect me	92%	88%
• I chose my job coach	61%	48%
• There's nothing I'd rather do during the day	65%	78%

Table 2.5 – Community Supports (Individual)

	Statewide 2004 - 2006	Statewide 2008
• I like my (individual) community activities	97%	95%
• I have enough (individual) community activities	52%	55%
• I like the people I spend time with	83%	85%
• I chose my support person	57%	49%
• There's nothing I'd rather do during the day	73%	75%

Table 2.6 - Friends/Social Supports

	Statewide 2004 - 2006	Statewide 2008
• I have plenty of friends	59%	57%
• I can see my friends when I want	83%	70%
• I have opportunities to meet new people	-	86%
• I have friends I like to talk/be with (not staff or family)	73%	57%
• I'm not often lonely	62%	52%
• I see my family as much as I want	79%	68%

Table 2.7 – Activities*

	Statewide 2004 - 2006	Statewide 2008
• I shop as much as I want	56%	55%
• I exercise/play sport as much as I want	56%	55%
• I eat out as much as I want	56%	51%
• I go to entertainment as much as I want	52%	44%
• I go to church/synagogue as much as I want	62%	60%

* 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 [see page 12 for details on how this affected measurement of overall satisfaction with activities.]

Table 2.8 - Guardianship

	Statewide 2004 - 2006	Statewide 2008
• I'm happy about my guardian	85%	86%
• I chose my guardian	40%	34%
• I see my guardian whenever I want	89%	81%
• My guardian lets me make my own decisions	67%	62%

Table 2.9 - Community Services

	Statewide 2004 - 2006	Statewide 2008
• I'm happy with my service agency	83%	79%
• I chose my case manager	45%	34%
• I'm happy with my case manager	86%	82%
• It's easy to contact my case manager	57%	64%
• People listen to me at ISA meetings	93%	92%

Table 2.10 - Self Determination/Rights

	Statewide 2004 - 2006	Statewide 2008
• I have attended a self advocacy meeting	41%	50%
• I have voted in an election	48%	54%
• I get to learn new things/skills	77%	74%
• I have enough control over my life	81%	75%
• I make all the choices I want	62%	59%

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. Due to some item changes in the survey instrument for the 2008 – 2010, there have been some minor changes to the construction of the life domain scales. However, the domains examined remain the same as in the last survey cycle. The ratings for all but one of the domains are directly comparable to previous years. Questions relating to participation in activities have been changed to allow three rather than just two response options. This will help providers not only see which activities consumers feel they do enough, but also which activities they would like more opportunities to enjoy, or would rather not participate in at all. The effect of this has been to increase the overall Activities satisfaction rating. 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 2008 and 2004 - 2006. Table 2.11 shows that, for the most part, people in 2008 responded in similar fashion to people from participating in the 2004 - 2006 survey cycle. The increase in satisfaction with community activities is attributable to the revisions to the survey. The slight decreases noted in Residential Autonomy, Work, Community Support and Social Support ratings may be partly a result of more people living in provider homes rather than with their family, or an indication of greater understanding of choices in the home and work and a desire to have more community and social opportunities.

Table 2.11 - Comparative Domain Satisfaction

Domain	Statewide 2004 - 2006 (N=475)	Statewide 2008 (N=181)
Residential	84%	85%
Residential Autonomy	73%	68%
Neighborhood	89%	91%
Work	85%	80%
Community Supports	81%	78%
Social Support	83%	78%
Activities	61%	71%
Guardian	75%	75%
Community Services	81%	78%
Self Determination/Rights	49%	50%

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

group) and guardian satisfaction by type of guardian showed no significant differences. (While it may seem that Guardianship ratings given by people who lived independently were high, there were too few independently living respondents with guardians for this to be statistically significant.)

Table 2.12 - Domain Satisfaction by Residential Type – 2008

Domain	Family Home (n=44)	Semi-Independent Living (n=40)	Provider Home (n=85)	All Residential Settings (n=181)
Residential	86%	84%	85%	85%
* Residential Autonomy	67%	85%	59%	68%
Neighborhood	95%	88%	91%	91%
Work	80%	81%	81%	80%
Day Program	81%	81%	76%	78%
Social Support	81%	79%	78%	78%
Activities	69%	75%	69%	71%
Guardian	77%	89%	72%	75%
Community Services	81%	76%	77%	78%
Self Determination/Rights	52%	55%	46%	50%

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

SURVEY RESPONSES, 2008: STATEWIDE (N=181)

The following pages provide details of how people across the participating agencies responded to individual questions on the Consumer Survey in the spring of 2008. The Vermont Consumer Survey Project is participating in the National Core Indicators (NCI) project. The aim of the project is to establish and validate “core indicators” to serve as benchmarks against which states can examine and evaluate the satisfaction of people receiving developmental services. Questions included in the national project are indicated in the table of results with asterisks (*). The percentages given in the results below are the percentages of those consumers who answered the question. The notation ‘-’ indicates there were too few responses to preserve anonymity 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
179	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
134	17%	38%	45%

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

RESPONDENTS	NO	YES
143	71%	29%

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

RESPONDENTS	LIKE	IN-BETWEEN	NOT LIKE
177	88%	10%	2%

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

RESPONDENTS	SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
157	48%	51%	1%

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

RESPONDENTS	SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
169	86%	13%	1%

*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
135	63%	25%	12%

8. Are there any pets at your house?

RESPONSES	YES	NO
173	65%	35%

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

RESPONSES	LIKE	IN-BETWEEN	NOT LIKE
106	92%	5%	3%

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

RESPONSES	NO	SOMETIMES	YES
58	47%	6%	47%

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

RESPONSES	POLITE	SOMETIMES	NOT POLITE
93	91%	9%	0%

12. Tell me how you feel about _____.

RESPONSES	HAPPY	IN-BETWEEN	SAD
98	87%	12%	1%

*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
79	18%	38%	44%

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

RESPONDENTS	NO	YES
76	29%	71%

14a. Is that a problem for you?

RESPONDENTS	NO	YES
51	88%	12%

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

RESPONSES	POLITE	SOMETIMES	NOT POLITE
85	89%	11%	0%

16. Tell me how you feel about ____.

RESPONSES	HAPPY	IN-BETWEEN	SAD
91	86%	12%	2%

*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
61	15%	24%	61%

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

RESPONDENTS	YES	IN-BETWEEN	NO
19	79%	5%	16%

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

RESPONDENTS	NO	IN-BETWEEN	YES
18	67%	11%	22%

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
164	68%	25%	7%

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
166	77%	13%	10%

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

RESPONDENTS	FUN	IN-BETWEEN	BORED
169	63%	27%	10%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
174	77%	20%	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
121	63%	13%	24%

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

RESPONDENTS	NO	SOMETIMES	YES
124	53%	6%	41%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
128	73%	22%	5%

RULES:

27. Who makes the rules for living here?

RESPONDENTS	SELF	IN-BETWEEN	SOMEONE ELSE
95	11%	8%	81%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
91	66%	24%	10%

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 IT	IN-BETWEEN	CAN'T CHANGE
84	29%	19%	52%

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
88	52%	0%	48%

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

RESPONDENTS	YES	IN-BETWEEN	NO
130	79%	11%	10%

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

RESPONDENTS	SELF	IN-BETWEEN	OTHER
118	33%	23%	44%

PRIVACY:

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

RESPONDENTS	YES ENOUGH	WANT MORE TIME ALONE
144	83%	17%

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

RESPONDENTS	NO	SOMETIMES	YES
133	82%	7%	11%

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

RESPONDENTS	YES	NO/SOME RESTRICTIONS
141	79%	21%

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

RESPONDENTS	HAVE PRIVACY	LISTEN IN
121	79%	21%

37. Can you answer the phone at home?

RESPONDENTS	YES	NO
127	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
105	70%	30%

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

RESPONDENTS	YES	NO
150	31%	69%

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

RESPONDENTS	NO	YES
99	46%	54%

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

RESPONDENTS	YES	NO
46	78%	22%

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

RESPONDENTS	YES	SOMETIMES	NO
44	43%	7%	50%

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

RESPONDENTS	YES, ALLOWED	SOMETIMES	NOT ALLOWED
135	40%	6%	54%

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

RESPONDENTS	YES	NO
133	67%	33%

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
160	56%	44%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
154	75%	19%	6%

*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
160	56%	35%	9%

48. Do people steal (take) your money?

RESPONDENTS	NO	YES
164	93%	7%

SAFETY:

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

RESPONDENTS	LEAVE ALONE	TAKE
155	94%	6%

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

RESPONDENTS	YES	SOMETIMES	NO
166	82%	10%	8%

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

RESPONDENTS	YES	SOMETIMES	NO
152	74%	8%	18%

52. Do you feel safe in your home?

RESPONDENTS	YES	IN-BETWEEN	NO
169	90%	6%	4%

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

RESPONDENTS	NO RARELY	IN-BETWEEN	YES MOST OF TIME
169	82%	14%	4%

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
129	54%	13%	33%

55. Do you have a key to your house?

RESPONDENTS	YES	NO
159	60%	40%

*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	86%	8%	6%

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
152	80%	11%	9%

NEIGHBORHOOD:

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

RESPONDENTS	YES	SOMETIMES	NO
154	90%	6%	4%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
159	79%	18%	3%

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

RESPONDENTS	LIKE IT	IN-BETWEEN	DIFFERENT PLACE
166	84%	4%	12%

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

RESPONDENTS	YES	IN-BETWEEN	NO
166	91%	7%	2%

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

RESPONDENTS	NO RARELY	IN-BETWEEN	YES, MOST OF TIME
168	90%	9%	1%

WORK

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

RESPONDENTS	YES	NO
165	60%	40%

64. Do you have a job?

RESPONDENTS	YES	NO
166	55%	45%

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

RESPONDENTS	NO	SOMETIMES	YES
74	38%	3%	59%

*66. Did you choose to work at _____?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
88	24%	68%	8%

*67. Do you like working there?

RESPONDENTS	YES	IN-BETWEEN	NO
91	93%	6%	1%

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

RESPONDENTS	IMPORTANT	NOT IMPORTANT
91	92%	8%

69. Tell me how you feel about your work.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
94	92%	6%	2%

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

RESPONDENTS	ENOUGH	MORE
90	48%	52%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
93	83%	12%	5%

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

RESPONDENTS	VACATION	ALL THE TIME
86	78%	22%

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
68	96%	1%	3%

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
65	11%	37%	52%

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

RESPONDENTS	NO	YES
62	24%	76%

75a. Is that a problem for you?

RESPONDENTS	NO	YES
47	87%	13%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
86	90%	9%	1%

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

RESPONDENTS	RESPECT	IN-BETWEEN	NO RESPECT
85	88%	10%	2%

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

RESPONDENTS	CHOOSE TO GO	HAVE TO GO
83	68%	32%

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

RESPONDENTS	NO	SOMETIMES	YES
81	78%	9%	13%

COMMUNITY ACTIVITIES - INDIVIDUAL SUPPORT

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
109	29%	58%	13%

81. Do you like doing those activities?

RESPONDENTS	LIKE	SOMETIMES	NOT LIKE
110	95%	4%	1%

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

RESPONDENTS	ENOUGH	MORE
110	55%	45%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
115	90%	7%	3%

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

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
107	92%	7%	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
96	17%	32%	51%

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

RESPONDENTS	NO	YES
99	35%	65%

86a. Is that a problem for you?

RESPONDENTS	NO	YES
62	77%	23%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
107	85%	10%	5%

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
106	88%	8%	4%

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

RESPONDENTS	CHOOSE	HAVE TO GO
106	73%	27%

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

RESPONDENTS	NO	SOMETIMES	YES
96	75%	2%	23%

COMMUNITY ACTIVITIES - GROUP SUPPORT

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
11	27%	55%	18%

92. Do you like doing those activities?

RESPONDENTS	YES	IN-BETWEEN	NO
11	73%	18%	9%

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

RESPONDENTS	ENOUGH	MORE
11	73%	27%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
15	87%	13%	0%

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

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
11	91%	9%	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
11	36%	9%	55%

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

RESPONDENTS	NO	YES
11	64%	36%

97a. Is that a problem for you?

RESPONDENTS	NO	YES
4	50%	50%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
14	79%	14%	7%

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	90%	10%	0%

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

RESPONDENTS	CHOOSE	HAVE TO GO
10	60%	40%

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

RESPONDENTS	NO	SOMETIMES	YES
10	83%	9%	8%

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
162	88%	12%

*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
164	57%	37%	6%

104. Tell me how feel about your friends.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
161	92%	5%	3%

*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
150	70%	21%	9%

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

RESPONDENTS	PLENTY	MORE
153	57%	43%

107. Do you have opportunities to meet new people?

RESPONDENTS	YES	NO
161	86%	14%

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

RESPONDENTS	YES	NO
162	94%	6%

109. Does anyone ever ask you to help them?

RESPONDENTS	SOMEONE NAMED	NO ONE NAMED
159	57%	43%

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

RESPONDENTS	NO NOT OFTEN	SOMETIMES	OFTEN LONELY
162	52%	31%	17%

FAMILY:

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

RESPONDENTS	YES	NO
145	86%	14%

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

RESPONDENTS	YES	SOMETIMES	NO
132	68%	19%	13%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
142	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
147	56%	39%	5%

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

RESPONDENTS	NO	YES
9	33%	67%

*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	61%	26%	13%

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

RESPONDENTS	NO	YES
9	67%	33%

*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
133	53%	43%	4%

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

RESPONDENTS	NO	YES
22	64%	36%

*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
114	45%	52%	3%

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

RESPONDENTS	NO	YES
39	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
124	54%	40%	6%

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

RESPONDENTS	NO	YES
37	41%	59%

*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
79	52%	44%	4%

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

RESPONDENTS	NO	YES
79	66%	34%

*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
36	44%	42%	14%

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

RESPONDENTS	NO	YES
107	72%	28%

GUARDIANSHIP

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

RESPONDENTS	YES	MAYBE	NOT SURE
107	94%	3%	3%

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

RESPONDENTS	YES	SOMETIMES	NO
101	81%	15%	4%

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

RESPONDENTS	I CHOSE	SOMEONE ELSE CHOSE
82	34%	66%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
105	86%	13%	1%

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

RESPONDENTS	OWN DECISIONS	GUARDIAN DECIDES
93	62%	38%

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

RESPONDENTS	NO	YES
100	83%	17%

SELF-ADVOCACY

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

RESPONDENTS	YES	NO
154	50%	50%

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
65	52%	23%	20%	5%

*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
75	9%	25%	8%	52%	6%

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

RESPONDENTS	YES	NO
76	71%	29%

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

RESPONDENTS	YES	NO
70	43%	57%

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

RESPONDENTS	YES	NO
155	77%	23%

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

RESPONDENTS	YES	NO
153	58%	42%

VOTING

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

RESPONDENTS	YES	NO
160	69%	31%

134. Have you ever voted in an election?

RESPONDENTS	YES	NO
165	54%	46%

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

RESPONDENTS	YES	NO
69	81%	19%

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

RESPONDENTS	YES	NO
70	51%	49%

SERVICE AGENCY

*136 Do you know your service coordinator/case manager?

RESPONDENTS	YES	MAYBE/NOT SURE	NO
165	96%	3%	1%

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

RESPONDENTS	YES	SOMETIMES	NO
160	70%	13%	17%

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

RESPONDENTS	YES	SOMETIMES	NO
161	83%	12%	5%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
172	82%	14%	4%

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

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
159	11%	23%	66%

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
156	64%	19%	17%

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

RESPONDENTS	NO	YES
151	38%	62%

142a. Is that a problem for you?

RESPONDENTS	NO	YES
91	71%	29%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
173	79%	14%	7%

144. Do you get the services you need?

RESPONDENTS	YES	SOMETIMES	NO
165	89%	5%	6%

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

RESPONDENTS	YES	NO
142	54%	46%

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

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
87	92%	3%	5%

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

RESPONDENTS	YES	SOMETIMES	NO
92	87%	5%	8%

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

RESPONDENTS	YES	NO
157	86%	14%

*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
121	12%	7%	81%

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

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
162	80%	11%	9%

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
157	85%	5%	10%

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
145	60%	19%	21%

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

RESPONDENTS	YES	SOMETIMES	NO
160	74%	8%	18%

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

RESPONDENTS	YES	NO
47	55%	45%

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

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
163	84%	10%	6%

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	33%	67%

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
152	37%	63%

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

RESPONDENTS	NO	YES
153	92%	8%

SELF-DETERMINATION

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

RESPONDENTS	ENOUGH	MORE
157	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
147	59%	20%	21%

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
143	71%	29%

SECTION 3

PARTICIPANT PROFILE 2008

WHO PARTICIPATED

This Section is intended to give an overall picture of the adults receiving developmental services statewide as reported via surveys conducted by case managers. It reports findings from the 2008 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 in these reporting categories includes percentages for those interviewed, those not interviewed, and all participants. For ease of reading, the definition of the data reported (left hand column) and the data for all participants served statewide (right hand column) are shown in bold.

BASIC DEMOGRAPHICS

Table 3.1 – Personal Characteristics

Characteristic	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Age			
Average Age	43	39	41
Minimum	19	18	18
Maximum	89	85	89
Gender			
Male	56%	60%	58%
Female	44%	40%	42%
Marital Status			
Single	90%	96%	93%
Married/Civil Union	4%	3%	4%
Married/Civil Union in past	6%	1%	3%
Race			
White	96%	93%	94%
American Indian/Eskimo/Aleut	1%	1%	1%
Asian	<1%	1%	1%
Black	<1%	1%	1%
Other/Unknown	2%	4%	3%
Primary Language			
English	99%	99%	99%
Other	1%	1%	1%

Table 3.2 – Legal Factors

	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Guardianship			
No Guardian	35%	24%	29%
Private Guardian	44%	57%	51%
Public Guardian	21%	18%	19%
Unknown	0%	1%	1%
Payee			
No Payee	18%	21%	19%
Payee	78%	73%	76%
Unknown	4%	6%	5%
Court Restrictions			
No	99%	97%	98%
Yes	1%	2%	<2%
Unknown	0%	1%	<1%

Table 3.3 - Family Involvement in People's Lives

	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Family Involved			
Yes	87%	89%	88%
No	13%	11%	12%
Why Family not Involved	(n=23)	(n=25)	(n=62)
Family gone/not alive/ whereabouts unknown	35%	56%	46%
Family choice	44%	24%	33%
Other	17%	12%	15%
Unknown	4%	8%	6%

COMMUNICATION CAPABILITY

Table 3.4 – Means of Communication

	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Adequate Reliable Speech			
Yes	82%	57%	68%
No	18%	43%	31%
Unknown	<1%	0%	<1%
Primary Means of Communication			
Spoken - Understood by familiar listener	94%	76%	84%
Gesture/body language	1%	21%	12%
Sign language/finger spelling	<1%	1%	1%
Communication aid/device	3%	<1%	2%
Other/Unknown	2%	1%	1%

Table 3.5 – Communication Effectiveness for People with Inadequate Speech

	Interviewed (n=32)	Not Interviewed (n=90)	All Participants (n=122)
Communicate with familiar people			
Yes	97%	96%	96%
No	3%	4%	4%
Communicate with unfamiliar people			
Yes	81%	47%	56%
No	16%	51%	42%
Unknown	3%	2%	2%
Communicate beyond basic needs			
Yes	81%	48%	56%
No	19%	51%	43%
Unknown	0%	1%	1%
Communication effectiveness in last year			
More effective	22%	12%	15%
As effective	63%	76%	72%
Health prevents fair assessment	9%	2%	4%
Less effective	0%	3%	2%
Unknown	6%	7%	7%

Table 3.6 – Communication Supports for People with Inadequate Speech

	Interviewed (n=32)	Not Interviewed (n=90)	All Participants (n=122)
Communication addressed in ISA			
Yes	53%	42%	45%
No	44%	51%	49%
Unknown	3%	7%	6%
Communication Supports in Place			
Consistent comm. partners	100%	93%	95%
Team support	100%	97%	98%
Access to comm. aids/devices	59%	51%	53%
Training support for support wkers	78%	73%	75%
Expert consultation/support	66%	47%	52%

MEDICAL/HEALTH ISSUES

Table 3.7 - Developmental Disability

Disability Label	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Mild MR	70%	42%	55%
Moderate MR	16%	22%	19%
Severe MR	4%	10%	7%
Profound MR	1%	6%	4%
Unknown/None reported	9%	20%	15%

Table 3.8 - Other Challenges

Challenge	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Mental Illness	25%	17%	21%
Autism	10%	14%	12%
Cerebral Palsy	9%	14%	12%
Brain Injury	4%	2%	3%
Chemical dependence	1%	0%	1%
Physical disability	12%	16%	14%
Hearing	4%	12%	8%
Vision	15%	16%	16%
Seizures	12%	23%	18%
Communication disorder	4%	10%	7%
Alzheimers disease	1%	1%	1%
Prader Willi Syndrome	0%	1%	1%
Down Syndrome	15%	14%	15%
Non-Ambulatory	3%	6%	5%
Other	13%	12%	12%

Table 3.9 – Healthcare

	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Last Physical Examination			
In the past year	84%	78%	81%
Over 1 year ago	9%	7%	8%
Unknown	7%	15%	11%
Last Ob/Gyn Examination (female)			
In the past year	51%	41%	46%
Over 1 year ago	19%	19%	19%
Never had an ob/gyn exam	1%	7%	4%
Unknown	29%	33%	31%
Last Dental Examination			
In the past six months	57%	53%	55%
Over 6 months ago	18%	23%	21%
Unknown	25%	24%	24%

Table 3.10 - Health and Lifestyle

	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Medical Care Required			
Less than once/month	83%	83%	83%
At least once/month	8%	9%	9%
At least once/week or more	4%	1%	2%
Unknown	5%	7%	6%
Seizure Frequency			
No seizures	83%	73%	78%
Less than once/month	15%	15%	15%
At least once/month	0%	4%	2%
At least once/week or more	1%	3%	2%
Unknown	1%	5%	3%
Vision			
Sees well (with/without correction)	88%	81%	84%
Vision problems limit activities	7%	13%	10%
Limited or no vision (legally blind)	3%	3%	3%
Unknown	2%	3%	3%
Level of Mobility			
Walks or uses wheelchair	96%	84%	95%
Non-ambulatory needs assistance	3%	6%	5%
Unknown	1%	0%	<1%
Physically Active			
Very physically active	13%	13%	13%
Moderately physically active	66%	63%	64%
Physically inactive	21%	21%	21%
Unknown	<1%	3%	2%
Weight concerns			
No weight concerns	53%	60%	57%
Overweight	42%	33%	37%
Underweight	3%	5%	4%
Unknown	2%	2%	2%
Smoke/chew tobacco			
No	90%	91%	91%
Yes	9%	6%	7%
Unknown	1%	3%	2%

RESIDENTIAL INFORMATION

Table 3.11 - Type of Residence

Residential Type	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Provider Home	47%	40%	43%
Family Home	24%	35%	30%
Own Home w/ Housemate	12%	10%	11%
Own Home Lives Alone	10%	12%	11%
Group Living	3%	1%	2%
Residential Care Home	1%	2%	2%
Nursing facility	1%	0%	0%
Other/Unknown	2%	0%	1%

Table 3.12 – Respondent Guardianship by Residential Type

Residential Type	No Guardian (n=63)	Private Guardian (n=80)	Public Guardian (n=38)	Total (n=181)
Provider Home	35%	43%	76%	47%
Family Home	17%	41%	0%	24%
Own Home w/ Housemate	22%	6%	5%	12%
Own Home Lives Alone	19%	5%	8%	10%
Group Living	2%	3%	5%	3%
Residential Care Home	2%	1%	0%	1%
Nursing Facility	0%	0%	3%	1%
Other	3%	1%	3%	2%

Table 3.13 - Residence Characteristics

Residential Characteristic	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Location			
Remote	45%	49%	47%
Walking distance to town	36%	29%	32%
Centrally located in town	17%	20%	19%
Unknown	2%	2%	2%
Ownership/Lease of Home			
Family/guardian	25%	43%	34%
Individual/family person lives with	48%	37%	42%
Provider agency/affiliate	2%	3%	3%
Person rents home	19%	15%	17%
Person owns home	3%	1%	2%
Unknown	1%	0%	1%
Other	2%	1%	1%
Amount of Paid Residential Support			
No on-site support (Indep./family)	21%	26%	24%
24 hour on-site	50%	45%	48%
Daily on-site	15%	13%	14%
Less frequent than daily	7%	8%	7%
As needed	6%	7%	6%
Unknown	1%	1%	1%
Household Composition			
Non-related individuals	54%	43%	48%
Biological/adoptive parents	22%	34%	28%
Lives alone	10%	10%	10%
Spouse/Civil Union	5%	2%	3%
Minor children only	1%	1%	1%
Other relatives	7%	8%	8%
Other/Unknown	1%	2%	2%
Time in current home/with current provider			
More than 5 years	48%	66%	58%
3-5 years	19%	14%	16%
1-2 years	19%	9%	14%
Less than 1 year	12%	8%	10%
Unknown	2%	3%	2%

COMMUNITY ACCESS AND BARRIERS

Table 3.14 – Getting to Places beyond Walking Distance

Means of Transport	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Ride from family/friends	56%	64%	61%
Ride in staff member's car	82%	80%	81%
Group transport (provider van)	4%	4%	4%
Public transport	27%	21%	24%
Para transit/volunteer/ride-share	10%	5%	7%
Taxi	13%	6%	9%
Drives self	3%	4%	3%
Other	3%	5%	4%

Table 3.15 – Barriers to More Recreational Activity and Enjoyment

Barrier to more activities	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
No barrier	71%	57%	63%
Behavioral/emotional concerns	13%	21%	17%
Social skills limitations	14%	20%	17%
Health concerns	12%	10%	11%
Money/cost	9%	9%	9%
Inadequate transportation	5%	6%	6%
No chaperone	4%	7%	5%
Recreational activity shortage	1%	4%	2%
Other barrier	1%	2%	2%

SERVICES

Table 3.16 - Types of Services Received

Service Type	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Residential Supports*	57%	47%	52%
Service Coordination	96%	93%	95%
Employment - Individual supported	48%	31%	39%
Employment - Group	4%	1%	3%
Community Support - Individual	67%	64%	66%
Community Support - Group	13%	12%	13%
Clinical Services	54%	51%	53%
Transportation	50%	45%	48%
Family Supports	52%	54%	53%
Other Supports	6%	8%	7%

* In Provider Home, Group Living, or Staffed Living

Table 3.17 - Self-/Family-Management of Services

	Interviewed (n=181)	Not Interviewed (n=210)	All Participants (n=391)
Management of Services			
Self or Shared with Agency	7%	13%	10%
Family or Shared with Agency	9%	19%	14%
Agency Managed	83%	65%	74%
Unknown	1%	3%	2%
Individually Negotiated Budget			
Yes	73%	82%	77%
No	27%	16%	21%
Unknown	<1%	2%	2%
Individual Support Agreement (ISA)			
Yes	96%	94%	95%
No	4%	6%	5%
Fiscal Intermediary (ISO/private payroll)			
Yes	61%	68%	65%
No	39%	31%	35%
Unknown	<1%	<1%	<1%
Independent Support Broker (ISB)			
Yes	2%	10%	6%
No	97%	85%	91%
Unknown	1%	5%	3%

SECTION 4

METHODOLOGY

HOW THIS SURVEY IS CONDUCTED

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

The Vermont Consumer Survey is conducted statewide over a 3 year period, 2008 marking the first year of the fourth such 3-year cycle. Within each year, a sample of adults receiving developmental services is surveyed. This Section describes the methodology used to obtain and analyze information for the 2008-2010 Vermont Consumer Survey. The information in this Section covers:

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

PARTICIPANT SELECTION

The selection of adults to participate in the consumer survey aims to be representative both within each agency and across the statewide population receiving developmental services in each year. Five agencies are chosen each year. The order in which agencies are visited has remained unchanged over the previous three survey cycles. On the basis of a re-examination of current statewide demographics, the order and thus ‘mix’ of agencies visited each year has been changed to better represent the current profile of consumers served statewide. In the spring of 2008, the independently contracted survey interviewers visited the following agencies: Northwestern Counseling and Support Services (NCSS), HowardCenter (HC), Upper Valley Services (UVS), and Champlain Community Services (CCS); adults from across the state who are self-/family-managing services were also invited to participate.

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 2008-2010 survey cycle.

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

Agency	2008	2009	2010
Champlain Community Services (CCS)	100%		
Community Access Program (RMHS - CAP)			50%
Community Associates (CSAC - CA)		50%	
Community Developmental Services (WCMH - CDS)		50%	
Health Care and Rehabilitation Services of Southeastern Vermont (HCRS)			50%
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%		
Specialized Community Care (SCC)			100%
Sterling Area Services (SAS)		100%	
Upper Valley Services (UVS)	50%		
United Counseling Service (UCS)			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 Services, prior to the survey instruments’ first statewide use in 1995.

Since the first 3-year cycle of surveys, a number of questions have been changed or added to the original survey instruments. For the second cycle of surveys, questions addressing knowledge of services and self-determination were added to the Consumer Interview in response to consumer advocacy requests. It was at this time also that the State started

submitting survey data to the National Core Indicators (NCI) project. This project currently includes 31 states and provides an annual comparative 'report card' on services for adults receiving developmental services. For the 2004 - 2006 survey cycle, the Demographic Survey, in particular, was further enhanced. This was done partly to include more questions 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. This latest round of surveys starting in 2008 features changes based on input from a range of stakeholders; information on access and barriers to community activities has been added and a number of questions have been rephrased for easier understanding and further alignment with the NCI survey.

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 services here in Vermont. The Demographic Survey consists of sections covering general demographics, communication capabilities and services, medical and health information, behavioral challenges, residential characteristics, services, and self-/family management and self-determination. The information from the Demographic Survey is reported in section 3 of this Report.

The structured Consumer Interview consists of 160 questions designed to measure how satisfied people receiving developmental services are in a variety of life domains: how they feel about their residential living, work and/or community activities, community services, and activities. It also obtains information on other valued outcomes, such as social support, neighbors, leisure activities, degree of independence, opportunities for growth and change, self-advocacy, and self-determination. Each question on the survey has a high value of 2 (positive response) and a low of 0 (negative response). The values for 'Not Applicable', 'Refused' or 'Unclear/unknown' are excluded from the analysis. On average, the direct interviews will take between 30 and 35 minutes to complete. For people who have difficulty with verbal communication, there is an abbreviated version of the Consumer Interview covering the same satisfaction domains, in which picture cards ('Happy', 'In-between' and 'Sad') are used for respondents to indicate their answers. The information from the Consumer Interview is reported in section 2 of this Report.

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

SURVEY ADMINISTRATION

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

Once the participant pool has been selected (see page 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

All data entry and analysis is performed using standard SPSS™ statistical software (Version 15) and the charts appearing in these reports are generated using Microsoft Excel™ to format output from the SPSS analysis.

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

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

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

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

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 accordance with the National Core Indicators and 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 Table 3.9.
3. Questions used for the Activities scale for the 2008 – 2010 survey cycle offer three response options instead of the two response options in previous surveys. For discussion of the impact of this change see page 12.