

SURVEY OF ADULT CONSUMERS OF DEVELOPMENTAL SERVICES

STATE OF VERMONT – 2002 Report

Report of Satisfaction or Positive Responses on
Residence, Employment, Day Activities & Services

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PURPOSE

This survey was conducted as part of the State of Vermont's Quality Assurance procedures. The structured interview obtained consumer information on satisfaction with residential living, work and/or day activities, community services, and case management. It also obtained 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. Susan Culbert, Ph.D., and Sara Burchard, Ph.D., developed the interview and field-tested it extensively. The format and questions were reviewed and approved by a variety of stakeholders which included family members, service providers, consumers, and representatives from the State Division of Developmental Services. A number of questions have been added to the original survey in order to include the survey results in the National Core Indicators Project, a project including 18 states that provides a 'report card' on services for adults receiving developmental services. Additional questions have been included for the State Division of Developmental Services to provide information on consumer knowledge of services. Copies of the surveys can be found attached to this report.

This report contains the results of the consumer survey for 274 adult consumers of developmental services from the State of Vermont during the summer and fall of 2002. The five agencies include Northwestern Counseling and Support Services (NCSS), Health Care and Rehabilitation Services of Southeastern Vermont (HCRS), Howard Community Services (HCS), Sterling Area Services (SAS), and Upper Valley Services (UVS). Those agencies were chosen to provide a regional representation of consumers throughout Vermont and a representation of size of developmental services agencies in Vermont. The results are reported showing aggregated consumer responses to individual questions and questions grouped by content area. Comparisons are made across types of residence and types of work and day activity on consumer satisfaction.

PROJECT STAFF

In order to obtain the consumer's own point of view and to eliminate possible bias or influence, the State Division of Developmental Services contracted with psychologists affiliated with the University of Vermont to act as an independent group to coordinate and implement the collection of consumer satisfaction interviews on a statewide basis. Drs. Culbert and Burchard, the project coordinators, hired and trained eight field interviewers to complete the consumer interviews. The interviewers included one psychology graduate student, two consumers of developmental services, and five advanced undergraduates.

PROCEDURE

The procedure for selecting survey participants was changed from prior years. Interviews conducted from 1995-1999 were statewide by random selection of a certain percentage of consumers within each agency over the course of the four years (there were no interviews during 1996). . At the request of the agency directors, the sampling was changed for 2001-2003 from statewide, random sampling to sampling based upon size of agency and regional representation. In addition, all interviews will be conducted over the course of three years instead of four years. Such sampling will allow agency participation to be completed in one year rather than over four years for all but the largest agency (at their request, random sampling will be completed over the course of three years).

During the summer/fall of 2002, Project staff went to the 5 agency sites to gather demographic information on all consumers and to conduct direct interviews with the sample of consumer participants. The interview questions were read by the interviewer and the consumers' answers were recorded. Not all survey questions were applicable for every consumer, and not all consumers answered all of the questions in their interviews.

PARTICIPANTS

There were 274 survey participants this year. For all of the participants, demographic information was collected. For 136 of the participants, direct interviews were also conducted. Table 1 on page 4 shows the type of interview completed. There were 121 consumers that were able to participate in the full self-report interview and 15 that could participate in the picture only sections of the interview. 91 consumers were scheduled to have demographic data only collected, there were 12 people who could not complete the interview for communication reasons, 9 people who refused after meeting the interviewer, and 26 people that did not show up for the interview. For these 47 people were an interview was at least scheduled only demographic data was collected, thus the demographic only is comprised of a 138 individuals. The interviews took an average of 34 minutes to complete during the summer of 2002.

Table 1 - Types of Interviews Conducted (n=274)

	NCSS	HCS	SAS	HCRS	UVS	Total
Full Interview	24	45	5	19	28	121
Picture only	4	3	0	0	8	15
No Show	12	4	1	3	6	26
Unable to complete	3	4	2	0	12	21
Person's choice	3	9	2	0	2	16
Person Incapacitated	1	0	0	0	0	1
Person out of town	0	1	0	0	0	1
Agency's decision	5	27	9	0	12	53
Guardian's decision	2	0	3	0	0	5
Scheduling	0	1	1	0	1	3
Other	4	2	4	0	2	12
Total	58	96	27	22	71	274

Table 2 below shows the living situations for the 274 participants. Table 3 on page 5 shows the developmental disability as noted in their record for the 274 participants.

Table 2- Number of Consumers by Residential Type and Year

Residential Type	2002 Interviews	2002 Demographics Only	2002 All
ICF / Nursing	2	3	5
Group Home	3	8	11
Staffed Residence	4	0	4
DH/Family	19	67	86
DH/Roommate	23	17	40
DH/Unidentified	0	1	1
Family Home	42	23	65
Semi-independent	26	10	36
RCH	7	2	9
Other	8	6	14
Missing	2	1	3
<i>Total</i>	136	138	274

ICF/Nursing = Intermediate Care Facilities/Nursing Facilities

During 2001 and 2002 Developmental Home types were divided into Developmental Homes with Families (DH/Family), Developmental Homes with Paid Roommates (DH/Roommate), and Developmental Homes with Neighbor Support (DH/Neighbor). RCH = Residential Care Homes

Table 3 – Developmental Disability Label

	2002 Consumers Interviewed (n=136)	2002 Demographic only (n=138)	2002 Demographic Information All (n=274)
Mild MR	109	54	163
Moderate MR	17	28	45
Severe MR	0	22	22
Profound MR	0	22	22
Unspecified MR	2	2	4
Autism	0	2	2
Asperger's Syndrome	1	1	2
Rett's Disorder	1	1	2
Missing Data	6	6	12

Table 4 below shows the number of participants who experience additional challenges. A number of consumers in the interview, as well as the demographic only group had additional challenges and overall 159 of the 274 consumers (58%) had one or more additional challenges.

Table 4 - Number of Individuals with a Particular Challenge

	2002 Consumers Interviewed (n=136)	2002 Demographic only (n=138)	2002 Demographic Information All (n=274)
Cerebral Palsy	13	20	33
Brain Injury	4	8	12
Chemical Dependence	1	1	2
Mental Illness	31	24	55
Medically Fragile	10	14	24
Physically Challenged (other than mobility)	4	5	9
Hearing	7	6	13
Seizures	12	28	40
Other	21	32	53
Non-Ambulatory	10	20	30
Uses Cane, Walker, or Wheelchair	23	34	57

The 274 consumers who participated were between the ages of 19 and 89 years with a median age of 42 years. There were 128 females, 145 males, and one person with gender information missing.

Seventy-three of the participants were independent of a guardian. There were 116 people who had private guardians, 80 who had Guardianship Services, and 5 people had missing data.

Demographic data collected included the locations of the consumers' residences. In 2002, there were 73 consumers that lived in a town or village, 65 that lived within walking distance of a town or village, 133 that lived in rural areas, and 3 people that had missing data.

Other demographic data collected included information about court ordered restrictions (e.g., Act 248, probation, etc.), annual physicals, and family involvement. There were 12 individuals in this sample that had court ordered restrictions. There were 228 consumers that had seen a doctor within the last year, and 214 that had family involved in their lives. Case managers reported that the family members of the other 60 consumers were not involved because they were deceased, not in the area, or chose not to be involved.

Table 5 below displays the numbers of individuals receiving the different types of services available in Vermont. There were 228 people who received home and community based waiver funded services. There were 23 consumers who "self manage" their services, 13 of whom provided direct consumer interview information. Ten consumers who were managing at least some of their own services were involved in the hiring of support staff.

Table 5 - Number of Individuals Receiving Services

	2002 Consumers Interviewed (n=136)	2002 Demographic only Group (n=138)	2002 Totals (n=274)
Case Management	118	131	249
Home Support	60	97	157
Employment Support	65	31	96
Community Support	81	101	182
Family Respite	47	72	119
Clinical Intervention	60	75	135
Crisis Services	39	56	95
Transportation	55	58	113
Other	10	21	31

Of the total number of participants, 115 had some form of paid work. Table 6 below displays a breakdown of the type of work consumers were doing and the number of hours consumers were working each week. On average, consumers that were working were working approximately 12 hours a week. The two categories of employment were independent competitive employment with follow along support only (54% of those working) and individually supported employment (46% of those working).

Table 6 - Type and Number of Hours of Employment

	Competitive Employment	Supported Employment	Total/ Mean
<i>Number of People (Demographic Only)</i>	16	25	41
<i>Mean Number of Hours per Week</i>	10	8	9
<i>Number of People (Full Interview)</i>	45	29	74
<i>Mean Number of Hours per Week</i>	15	9	13
<i>Number of People (Total)</i>	61	54	115
<i>Mean # of Hours (Total)</i>	14	9	12

Of the 274 participants, 154 (or 56%) had daytime activities. Table 7 below shows a breakdown of the types of daytime support received and the average hours per week that consumers were receiving such support. On average, consumers received 16 hours of daytime support per week. The types of support were individualized, group activities, both group and individual support and PASARR activities.

Table 7 – Type and Number of Hours for Daytime Activities

	Individualized & Companionship	Group	PASARR	Both Individual and Group	Total/ Mean
Number of People (Survey Group)	52	8	2	8	70
Mean Number of Hours	15	9	6	25	16
Number of People (Demographic Group)	61	15	2	6	84
Mean Number of Hours	19	15	5	7	18
Number of People (Total)	113	23	4	14	154
Mean # of Hours (Total)	17	13	3	17	16

- PASARR is specific community supports to people who are in nursing facilities.

RESULTS

Table 8 below shows the demographics and residential living situation of the 2001 sample of 253 consumers compared to the 2002 sample of 136 consumers. As shown in Table 8, the 136 consumers who participated in 2002 did not differ from the statewide consumer sample in age, gender, level of developmental disability, living situation, or number of identified challenges in addition to their identified level of developmental disability. Table 9 on page 10 displays the level of cognitive challenge by living situation.

Table 8 -Comparing Sample Characteristics from the 2002 and 2001 Sample

	2001 Sample (n=253)	2002 Sample (N=136)	Significance
Gender			
Male	140	76	X ² =.033,df=1, p=.47, ns
Female	113	60	
Age			
Mean	40	43	t=-.382,df=385, p=.703,ns
Median	39	42	
Minimum	18	19	
Maximum	87	89	
Developmental Disability Label			
Mild MR	188	109	X ² =11.37, df=8, p=.181
Moderate MR	45	17	
Severe MR	7	0	
Unspecified MR	1	2	
Asperger's Syndrome	1	1	
Autism	1	0	
Living Situation			
ICF / Nursing	5	2	X ² =.702, df=2, p=.704, ns
Group Home	14	3	
Staffed Residence	7	4	
DH/Family	65	19	
DH/Roommate	14	23	
DH/Neighbor	1	0	
Family Home	74	42	
Semi-independent	59	26	
RCH	9	7	
Other	5	8	
<i>Total</i>	253	134	
Number of Additional Challenges			
No Additional Challenges	164	66	t= 1.13,df=316, p=.259, ns
One Additional Challenge	72	41	
Two Additional Challenges	14	21	
Three or more Additional Challenges	3	7	

Table 9- Living Situation by Disability Label for 136 Consumers

<i>Residential Type</i>	<i>Mild MR</i>	<i>Moderate MR</i>	<i>Unspecified MR</i>	<i>Asperger's Disorder</i>	<i>Missing</i>	<i>Totals</i>
ICF / Nursing	4	2	0	0	0	6
Group Home	3	0	0	0	0	3
Staffed Residence	3	1	0	0	0	4
DH/Family	16	1	2	0	0	19
DH/Roommate	17	4	0	1	1	23
Family Home	34	5	1	0	0	40
Semi-independent	25	1	0	0	0	26
RCH	5	1	0	0	1	7
Other/Unknown	2	2	0	0	4	8
<i>Total</i>	109	17	2	1	6	136

The remainder of this report will provide information regarding the results of the 136 direct consumer interviews. The results from all 136 consumers to the 160 individual survey questions are found in Appendix C. The following are selected findings from the questions.

RESIDENTIAL

- 113 consumers were happy where they were living, 18 consumers wanted to live somewhere else, and 5 people were in-between
- 100 consumers felt that where they lived was a good place to live, 14 consumers felt they lived in an in-between place, and 8 felt it was a bad place
- 29 people said there was a better place and named it, 2 people said there was a better place to live but could not name it, and 89 people said there was not a better place to live
- 23 people were happy about living alone, 1 person was in-between, and 2 people were sad about living alone
- 103 consumers were happy about their free time spent at home, 20 were in-between, and 8 people were sad
- 68 consumers felt that there were fun things to do at home, 39 people were in-between, and 13 people were bored at home

- 22 people wanted more chores at home, 4 people sometimes would like more chores, and 88 people had enough chores
- 62 consumers felt the rules at their homes were good rules, 9 consumers felt the rules were in-between, and 6 felt like the rules were bad
- 72 of 117 people said that someone had talked to them about dating
- 13 people reported that people enter their home without asking and 107 people said it did not happen
- 21 consumers reported that people enter their bedrooms without asking

AUTONOMY

- 60 people reported having a choice in where they lived, 52 people felt they did not have a say
- 29 people said that someone else picked what they eat, but they liked it, 16 said someone else picked what they eat and they did not like it, and 73 people picked what they ate
- 32 of 43 consumers felt they had no say about with whom they live
- 48 consumers reported that someone else makes the rules for living at their house; 31 consumers reported making their own rules
- 95 consumers reported that they were allowed to invite friends and family over when they wanted to, 7 people could sometimes invite friends or family over, and 10 consumers could not
- 63 consumers said they make decisions about visits, and 47 people reported someone else makes decisions
- 82 of 104 consumers said they have privacy when their friends visit
- 69 consumers have their own money, and 45 consumers have to ask for their money
- 101 consumers decide how they spend their money, and 16 consumers said someone else decides
- 59 of 119 consumers said that they cannot go out whenever they want, they had to wait for someone to take them

NEIGHBORS/NEIGHBORHOOD

- 100 people said the neighbors were friendly, 7 people said they were sometimes friendly and 7 people said they were not
- 22 individuals wanted to live in a different neighborhood that they named, 6 people wanted to live in a different neighborhood but could not name it, and 85 people were happy with their neighborhoods
- 103 consumers feel safe in their neighborhood, and 14 consumers felt unsafe

WORK

- 74 consumers did some form of paid work: 45 had independent competitive jobs with follow-along support only, 29 had individually supported jobs
- 19 of 29 individuals that were not working indicated that they wanted a job
- Work hours ranged from 3 to 40 hours per week (median = 11 hrs./wk)
- 63 people reported that the place where they worked was a good place to work, 6 people were in-between, and 1 person said it was a bad place
- 66 were happy with their jobs, 9 people were in-between and 2 people were sad
- 31 of 69 people would like to work more hours
- 62 respondents indicated that people at work treat them with respect, 7 people were in-between, and 1 person did not feel respected by co-workers
- 8 people chose their job coach with assistance, 9 consumers made the choice unassisted and 25 people reported that someone else chose

DAYTIME ACTIVITIES

- 70 people interviewed participated in daytime activities, 52 people had individual daytime activities, 8 people had group daytime activities, 8 people had both individual and group activities, and 2 person received PASAAR services
- Daytime activity hours ranged from 2 to 40 hours per week (median 14 hrs./wk.)
- 65 of 67 people reported they liked with their daytime activities programs
- 28 consumers reported wanting more hours of daytime activities

- 26 consumers engaged in volunteer work activities on a regular basis which involved from 1 to 25 hours per week (median = 6 hrs./wk.)
- 5 of 24 people wanted more hours to volunteer
- 21 people reported they were happy with their volunteer activities, and one person was in-between

FRIENDS/SOCIAL SUPPORT

- 72 people indicated that they had enough friends, and 46 people indicated wanted more friends
- 109 of 119 respondents indicated that if they need help there is someone to help them, and 10 people said there was no one to help
- 77 of 115 individuals said they had a best friend
- 19 people felt like there was no one to talk to, 30 people were sometimes lonely, and 68 people were not lonely
- 66 people see their family members as much as they want while 31 consumer do not and 3 consumers were in-between

COMMUNITY SERVICES

- 104 people indicated that they were happy with their services agency, 15 people were in-between, and 7 people was sad about the help he/she received
- 105 people were happy with their case managers, 13 people were in-between, and 1 person was sad about his/her case manager
- 62 people said someone else chose their case managers, 23 people choose their case manager with help, and 21 people chose unassisted
- 87 individuals could see their case managers when they wanted, 7 could sometimes see their case manager when they wanted, and 12 people could not see their case mangers when they wanted
- 62 people said it was easy to reach their case mangers, 26 people were in-between, and 16 people said it was hard to reach their case managers
- 83 people were happy with their guardians, 13 people were in-between, and 7 people were sad about their guardians

- 52 people indicated that their guardians let them make some decisions for themselves and 20 people said their guardian made all the decisions
- 90 consumers felt listened to at their ISA meetings and 2 people felt sometimes listened to
- 29 people had been told about their agency complaint process, and 86 people were not aware of their agency complaint process

ACTIVITIES

- Many people participated in the activities they wanted to
- Of those individuals 26% wanted to do the activities more often
- Some of the activities people wanted to do more were: going out for entertainment, going to church or synagogue, playing sports, and visiting friends and family.

OPPORTUNITIES

- 28 people had attended a self-advocacy meeting, primarily to get information or for the social opportunities it presented; and 83 people indicated they had never attended a self-advocacy meeting, primarily because they did not know about it or were not interested.
- 43 people would like to know more about self-advocacy/determination
- 87 of 112 individuals saw themselves as self-advocates
- 79 people indicated that they get to learn new things/skills and 31 people said they do not ever get to learn new things/skills

SUBSCALE RESULTS

The interview questions were organized by their content into subscales (groups of related questions combined). The subscale scores are reported as percent satisfaction with Residence, Neighborhood, Work, Daytime Activities, Social Support, Community Services, Guardian, and Activities. The subscale of Autonomy is presented as the average percent of positive responses, reflecting independence and choice. The questions that make up these subscales are shown in Appendix B. A copy of the 2002 survey is found in Appendix A and responses to each question of the 160 questions are found in Appendix C.

The results of the satisfaction survey for consumers are presented by Type of Residence, Type of Employment, and Type of Day Activity. Consumers are included in the type of residence analyses if they live in a Developmental Home, Family Home or Supervised Independent Living situations, as these are the largest categories of living situations and best suited for more detailed analysis. The results of Employment Satisfaction and Day Activity Satisfaction are reported for those consumers with those services and a completed interview. These results are presented first by percent satisfaction or percent of positive responses for subscales of satisfaction. Where satisfaction differences were found between types of residence, employment, or day activities on a subscale of satisfaction, then the individual questions in that scale were further examined for differences.

Satisfaction and Autonomy by Type of Residence

To determine whether there were any differences in satisfaction between consumers in Developmental Homes, Family Homes, and Semi-Independent living situations, statistical analyses were performed on satisfaction subscales. Since the numbers of consumers in the other living situations were relatively small they were not included in the statistical analyses. However, their responses are included in the average satisfaction for all persons. First, we compared the different types of Developmental Homes to ensure that these categories could be collapsed. Comparisons between Developmental Homes with Families and Developmental Homes with roommates showed no differences. These results of this analysis are shown in Appendix D. Therefore, the two categories of Developmental Homes were collapsed into one for comparison with Family Homes and Semi-independent living. Table 10 on page 16 shows satisfaction subscales by residential type and for the entire sample.

The primary analyses used were one-way analyses of variance (ANOVAs) and t-tests. In general, there must be a large difference in mean scores and little variability among scores within a group for a statistically significant difference. There may be instances where the percentages seem quite different but are not statistically different due to a small sample size, a large range or variability between scores within a group, or a combination of the two. The overall subscale differences by residential type were as follows (see Figure 1):

- Persons in Semi-Independent living situations were significantly more autonomous than persons living in Developmental Home or Family Home living situations
- Individuals in Family Homes did not differ on autonomy from individuals in Developmental Homes (see Figure 1 for graphic presentation of significant differences)
- Individual in Family Homes and Semi-Independent living situations were significantly more satisfied with their guardianship than people living in Developmental Homes

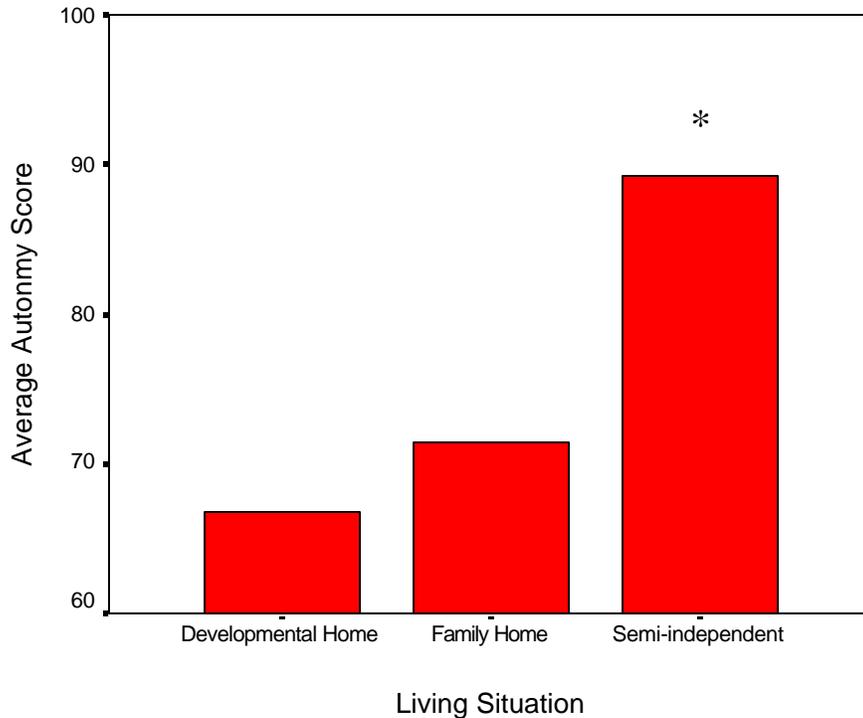
Table 10 - Subscales and Total Satisfaction By Residential Type
(2002)

Reported as Average Percent Satisfied or Percent Positive

Subscale	Family Home	Semi-Independent Living	All DH	Mean for three types of residence	Mean for all individuals surveyed
Number People	42	26	42	110	136
Residential	86	91	89	88	87
* Autonomy	71 ^a	89 ^b	67 ^a	74	73
Neighborhood	87	87	90	88	86
Work	84	91	87	87	87
Day Program	91	94	91	91	90
Social Support	78	83	80	80	80
Activities	74	75	72	73	73
* Guardian	82 ^a	90 ^a	69 ^b	78	76
Community Services	80	82	81	81	82
Health	89	91	92	91	90

** indicates a significant difference for the given subscale ($p < .05$). Superscripts (a, b) indicate which groups differ. Groups with the same superscript do not differ from each other and groups with no superscripts do not differ from any other group.*

Figure 1- Average Autonomy Score by Residential Type (n=110)



* Indicates a significant effect at $p < .05$

The individual questions which make up the subscales where significant differences between living situations were found were also examined for differences between residence types using chi-square analyses. These analyses compare the responses between consumers living in Developmental Homes, Family Homes, and Semi-Independent living situations. In order to do the analyses, consumers' negative and in-between responses were combined. This allowed for an examination of more complete data tables. The consumers' original responses, however, are provided in Table 11 beginning on page 18. The other living arrangements had too few persons to be included in these comparisons.

There were many differences in Autonomy between the three living situations. Persons in Semi-Independent living situations generally reported more autonomy than persons living in Family Home, or Developmental Home living situations, however, this was not always the case. Each question in the Autonomy scale was tested with chi square to determine if there were differences in choice between the three residential settings. There were significant differences in 10 out of 30 questions on that subscale.

For six questions regarding deciding what to eat, making rules, deciding on visits, going places, and coming home (Question #6, 30, 36 41, 57 & 58)

- Persons in Semi-Independent living situations were more autonomous than persons living in Family Home or Developmental Home living situations

For one question in regards to people opening your mail (Question # 38)

- Persons in Semi-Independent living situations and Developmental Homes were more autonomous than persons in Family Home living situations

For one question in regards to choosing a place to live (Question 3).

- Persons in Developmental Home living situations were more autonomous than person in Family Home or Semi Independent living situation.

For one question in regards to choosing fun things to do at home (Question 22)

- Persons in Semi Independent or Family Homes living situations were more autonomous than persons in Developmental Homes living situation

For one question in regards to having a key to the house (Question 60)

- Person in Semi Independent living situation were more autonomous than people in Family Home living situations
- Persons in Family Home living situations were more autonomous than person in Developmental Home living situations
- Person in Semi Independent living situation were more autonomous than people in Developmental Home living situations

Table 11 - Residential Autonomy by Residence Type

3. Did you have any say choosing that place to live?

	Family Home ^a	Semi-Independent ^a	Developmental Home ^b
NO	21	11	12
YES	13	13	25

6. Who decides (picks) what you eat?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
SELF	19	22	20
OTHER, LIKE IT	10	1	12
OTHERS, DON'T LIKE IT	9	1	5

22. Do you choose or pick the things you do for fun?

	Family Home ^a	Semi-Independent ^a	Developmental Home ^b
YES, WITHOUT HELP	35	24	23
YES, WITH HELP	3	0	10
NO, SOMEONE ELSE CHOOSES	1	1	3

30. Who makes the rules for living here?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
SELF	9	7	9
OTHERS	19	2	19

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

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
SELF	17	20	19
OTHERS	19	2	16

38. Does anyone open your mail without asking you first?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^a
YES	8	2	2
NO	24	23	35

41. When you have friends over, can you be alone with them, or does someone have to be with you?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
HAVE PRIVACY	24	21	26
NOT ALONE	10	0	6

57. Can you go out whenever you want to or do you have to wait for someone to take you?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
WAIT	21	6	23
WHEN WANT	18	19	14

58. Do you have to wait for someone to bring you home or can you come home when you want to?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
WAIT	20	6	20
WHEN WANT	18	19	16

60. Do you have a key to your house?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^c
YES	23	25	16
NO	14	0	22

Superscripts (a, b, c) indicate which groups differ. Groups with the same superscript do not differ from each other and groups with no superscripts do not differ from any other group.

Satisfaction and Type of Employment

The results of the interview questions which make up the Work Satisfaction subscale are presented in Table 12 broken down by type of employment. To determine whether there were any real differences in satisfaction, a t-test was performed between persons with Independent Competitive Employment and persons with Individual Supported Employment. There were too few persons working in the other employment situations to be examined, however, their responses are included in the total for all persons.

- There was no difference in Work satisfaction between those with Independent Competitive Jobs and those with Individual Supported Jobs

**Table 12 - Work Satisfaction By
Type of Employment**
Reported as Average Percent Satisfied

	Competitive Employment	Supported Employment	Total/ Mean
<i>Number of People (2002)</i>	45	27	72
Work Satisfaction (2002)	89	86	88

- *Consumers worked between 3 and 40 hours a week (median = 11 hours/week)*
 - *Responses in 2002 categorized as competitive employment included follow along support only, while supported employment was used for individuals who receive ongoing assistance at work.*
- Discrepancies in Number of Respondents in Table 6 and Table 12 are due to not all consumers completing the Day Satisfaction portion of the survey.*

Satisfaction and Type of Day Activities

The results of the interview questions on Day Activity satisfaction are presented in Table 13 as the average percent satisfaction by type of day activity of a group.

- There was no difference in Day Activity satisfaction between those with Individualized supports, Group supports, or a combination of the two

**Table 13 Day Activity Satisfaction By
Type of Day Activities**

Reported as Average Percent Satisfied

	Individualized & Companionship	Group	PASARR	Both Individualized & Group	Total/ Mean
Number of People (2002)	48	7	NA	8	63
Day Program Satisfaction (2002)	90	86	NA	93	90

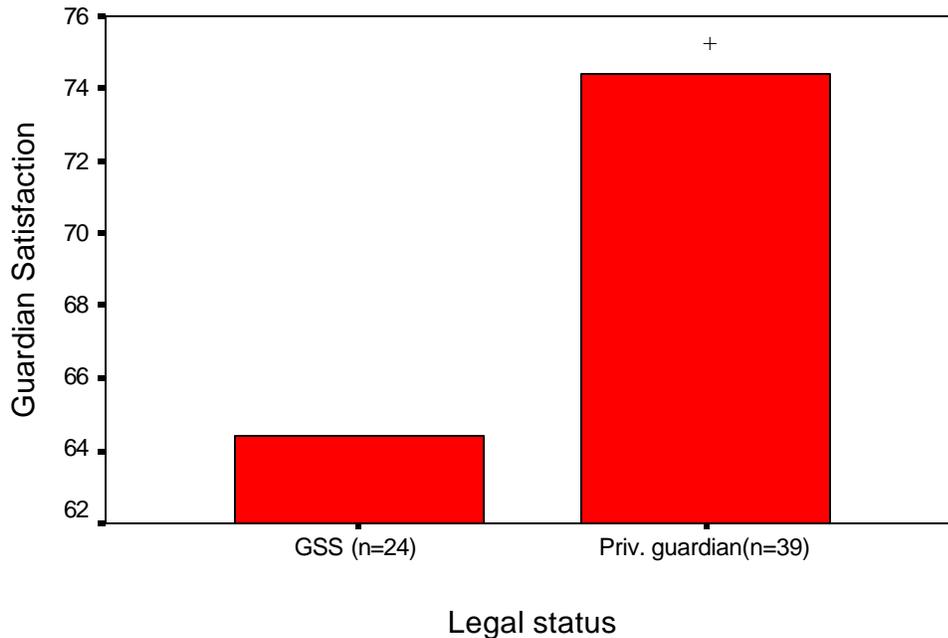
- NA represents cases where 3 or fewer consumers responded. These percentages are not included to maintain consumer anonymity

- Consumers were involved with day activities between 2 and 40 hours a week (median = 14 hours/ week)
- Discrepancies in Number of Respondents in Table 7 and Table 13 are due to not all consumers completing the Day Satisfaction portion of the survey.
- PASARR is specific community supports to people who are in nursing facilities.

Guardian Satisfaction by Guardian Type

In order to obtain a fair comparison of guardian satisfaction only individuals with private guardians and those with guardianship services were compared. Individuals who were their own guardian were excluded from this analysis because they are only asked: Are you happy/in-between or sad about being your own guardian?

Figure 2 - Guardian Satisfaction by
type of Guardian (n=63)



+ Indicate trend level difference $p < .1$.

- Individuals with state appointed guardians (Guardianship Services Specialists or GSS) and private guardians did not differ on any subscale.
- There was a trend for people that answered the Guardian Satisfaction questions, for those with Private Guardians to be more satisfied than those with Guardianship services. This trend persisted for persons in supervised living and DH homes when persons in Family Homes, who live with their private guardian, are removed from the analysis.
- People who do not have a guardian were more autonomous than those that had assigned guardianship. These individuals were also more likely to live in semi-independent living situations. Table 14 displays Guardian status by living situation.

Table 14 – Type of Guardian by Living Situation

Residential type	GSS	Private guardian	Independent	Total
Group Home	2	1	0	3
Staffed Residence	0	3	1	4
DH- Family	7*	9*	2	18
DH-Professional Roommate	11*	6*	6	23
Family Home	1*	21*	19	41
Semi Independent	5*	7*	14	26
Residential care home	2	4	1	7
Nursing facility	1	1	4	6
Other	1	0	3	4
Total	30	52	50	132

** Data used in Guardian Satisfaction analysis*

APPENDIX A
SATISFACTION SCALE SUPPLEMENT



Consumer ID# _____ Agency ID# _____ (Location: _____)
Agency #2 ID# _____ (Location: _____)

DATE of Interview: _____

Interviewer: _____ 2nd Interviewer: _____

If person was NOT scheduled for interview, check primary reason for why:

- Person's choice – declined opportunity for interview
- Person out of town
- Person incapacitated
- Agency decision – person has insufficient ability to reliably communicate to interview
- Agency scheduling oversight
- Guardian's decision
- Reason unknown
- Other (please specify): _____

GENDER: Male _____ Female: _____

DOB: _____ AGE: _____

RACE (check one): {OPTIONAL}

- American Indian/ Eskimo/ Aleut
- Asian/ Pacific Islander
- Black
- White
- Mixed Race
- Other/ Unknown

ETHNICITY (check one): {OPTIONAL}

- Hispanic
- Non-Hispanic

LEGAL Status: G.S.S. _____ Private Guardian _____ Independent _____

Average Annual Income (including SS, SSI, VA Benefits, work earnings, etc.):

___ < \$8,000/yr. ___ \$8,000-11,000/Yr. ___ > \$11,000.

Does the person have a payee or someone who manages his/her money? Yes _____ No _____

MARITAL Status:

- Never Married
- Live-in partner
- Married now
- Married in past, single now

Does this person have any court-ordered restrictions (i.e., probation, parole, furlough, Act 248)?

- Yes; please list _____
- No

Does the person have any family that is involved in his/her life? Yes No

If NO, please check why not:

- Family gone/ no longer alive/ unknown
- Family's choice not to be in touch
- Court-ordered restrictions
- Other: _____

Has the person had a physical exam? Yes No

If YES, please check when:

- Within the past year
- Over 1 year ago

How is this person currently labeled in his/her records?

- Mild MR (317) Moderate MR (318.0) Severe MR (318.1)
- Profound MR (318.2) Unspecified MR (319)

And/or

- Autistic Disorder Asperger's Disorder Rett's Disorder
- Childhood Disintegrative Disorder PDD, NOS

Challenges other than MR? (Check all that apply.)

- cerebral palsy
- brain injury/ neurological problems
- chemical dependency
- mental illness/ psychiatric diagnosis (other than PDD or MR)
- medically fragile
- physically challenged other than mobility
- hard of hearing/ deaf
- Seizures
- other (please specify) _____

Primary language:

- Speaks English
- Other primary language (please specify): _____

Does this person have adequate, reliable speech, which is understood by others (strangers) and allows himself/herself full expression? Yes No

If NO, what other means of communication does the person use?

- Spoken – understood by familiar listeners only
- Gestures/ body language
- Eye gaze
- Sign language or finger spelling
- Communication board/ book
- Electronic communication device
- Facilitated communication
- Other (please specify): _____

Mobility:

- Walks (ambulatory)
- Non-ambulatory

Does this person use assistive devices, such as a cane, walker or wheelchair?

- Yes
- No

Does this person require mobility assistance of another person?

- No, or almost never
- Occasionally needs help of another person
- Always requires help of another person

Vision:

- Sees well, with or without corrective lenses
- Vision problems limit activities, such as reading or travel
- Limited or no vision (legally blind)

Behavioral Challenges:

Self-Injury: Does this person ever cause injury to him/herself, for example by hitting self, biting, banging head, scratching or puncturing skin?

- No Yes
- If yes, about how often does this behavior occur?*
- less than once/month
- once/month
- 1-3 times/month
- 1-6 times/week
- 1-10 times/day
- one or more times/ hour

Disruptive Behavior: Does this person ever interfere with the activities of others, for example, by starting fights, laughing or crying without reason, yelling or screaming?

No Yes

If yes, about how often does this behavior occur?

- less than once/month
- once/month
- 1-3 times/month
- 1-6 times/week
- 1-10 times/day
- one or more times/ hour

Uncooperative Behavior: Does this person ever engage in "uncooperative" behavior, for example, breaking rules or laws, cheating, acting defiant, or stealing?

No Yes

If yes, about how often does this behavior occur?

- less than once/month
- once/month
- 1-3 times/month
- 1-6 times/week
- 1-10 times/day
- one or more times/ hour

Paid Services - Provider/Agency #1

What supports does the person receive from service provider? (Indicate if a different agency provides support)

- Service Coordination/ Case Management
- Home Supports
- Employment Supports
- Community Supports
- Family Respite
- Clinical Intervention
- Crisis Services
- Transportation
- Other (please specify): _____

Paid Services - Provider/Agency #2

- Service Coordination/ Case Management
- Home Supports
- Employment Supports
- Community Supports
- Family Respite
- Clinical Intervention
- Crisis Services
- Transportation

Residential

What amount of residential support does s/he receive? (Check one of the four categories below.)

- A) 24-hour on-site support and/or supervision (i.e., people living with, or being available in his/her home during any hours that s/he is home)
- B) daily on-site support (i.e., for a limited number of hours-per-day; not round-the-clock)
- C) less frequent than daily support
- D) on-call only
- E) none

How might this living arrangement best be categorized?

- A) Intermediate Care Facility (ICF) - medical support
- B) group home
- C) staffed apartment
- D) developmental home (family care home)
- E) developmental home (professional roommate)
- F) developmental home (neighbor support)
- G) parents' or family member's home
- H) supervised living (living semi-independently)
- I) residential care home (community care home)
- J) nursing facility
- K) other (please specify)

Who own or leases the place where this person lives?

- A) Person rents home (name is on the lease)
- B) Person owns home (name is on the title)
- C) Family, guardian, or friend
- D) Individual/ family with whom the person lives
- E) Provider agency/ affiliate
- F) State or County agency (not mental health)
- G) Don't know
- H) Other (please specify) _____

Primary household composition:

- A) lives alone
- B) spouse/ domestic partner
- C) spouse/ domestic partner and minor child(ren)
- D) minor child(ren)
- E) biological/ adoptive parent(s)
- F) other relative(s)
- G) non-related individual(s)

Location of Residence:

- A) Residence is physically remote; not within walking distance to town or to public transportation.
- B) Residence located within walking distance to town/city (within 1/2 mile).
- C) Residence centrally located within city, town, or village center (within block or so of downtown).

How many people live in this household?

- With Developmental Disabilities (including consumer) receiving DS services
- Without Developmental Disabilities

How many different places has this person lived within the past year? (Count one for present home.) _____

How many moves are with the same provider? _____

Non-Residential Activities

Please answer the following questions about this person's major activities outside of the home.

(Note: For most people, this would be their job or daytime program.)

Does the person participate in an unpaid day program on a regular basis?

No Got to item #8. If "yes", check all that apply.

- A) receives group day activity support
- B) receives individual day activity support
- C) companionship
- D) other, please specify in detail: _____

What kinds of things do they do?

	Group	Individual	Companionship	Other
Hours/week				

Does this person perform paid work on a regular basis?

No Go to item #9. If "yes", check the item below that best describes that work.

- A) independent work (follow-along support only)
- B) individual supported work
- C) enclave or work crew
- D) sheltered workshop
- E) other work (please specify)_____

What kinds of things do they do?

Does this person do volunteer work on a fairly regular basis? Y / N

What kinds of things do they do?

For those work/volunteer activities that he/she does outside the home, fill in the chart below.

Leave blank those questions that do not apply.

a. How much does he/she work or spend time volunteering?

DO NOT include travel time.

	Paid Work	Volunteer Work
Hours/week		

Additional Services

Does this person receive Home and Community Based Waiver Services?

- Yes
- No
- Don't know

Does this person self-manage his/her services?

- Yes, all services
- Yes, some services
- No

Does this person hire their case manager?

- Yes
- No

Support staff (day)?

- Yes, all
- Yes, some
- No

Additional Information to Assist Interviewer

Service Plan: What is the annual service plan called in your organization - by what term would this person best know this document? (To assist interviewer)

Please list below first names only of live-in roommates/household members (to assist interviewer with interview): Indicate the name and the role of each person listed (i.e., housemate, home provider, spouse/partner, parent, sibling, spouse or child of care-provider, etc.).

<u>First Name</u>	<u>Role</u>
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Please list below first names only of regular staff members with whom the interviewee has contact (to assist the interviewer with the interview). Indicate the name and the staff role (i.e., job coach (JC); case manager (CM); residence staff (RS); Day Program (DP); guardian (GSS); etc.).

<u>First Name</u>	<u>Role</u>
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

ID# _____
Agency _____
Date _____
Int. _____
Time _____

SELF-PERCEIVED SATISFACTION SCALE



A. RESIDENTIAL

Where do you live? How do you like living there?

1. ___ Are you happy living there or would you like to live somewhere else?
HAPPY=2; IN-BETWEEN=1; SOMEWHERE ELSE=0
2. ___ Is that a bad place to live or a good place to live? GOOD=2; IN-BETWEEN=1; BAD=0
3. ___ Did you have any say in choosing that place to live?
YES=2; NO=0
4. ___ Can you think of a better place to live?
NO=2;
(If "YES," ask next two questions before scoring.)
Where would that be?

Why would you like to live there?

IF BOTH FOLLOW-UP QUESTIONS ARE ANSWERED, SCORE=0; IF NOT SCORE=1.

5. ___ Is the food there pretty bad or do you like the food there?
LIKE=2; IN-BETWEEN=1; DISLIKE=0
6. ___ Show me how you feel about the food at your house. (Show pictures of faces and describe each one.) HAPPY=2; IN-BETWEEN=1; SAD=0
7. ___ Who decides (picks) what you eat?
SELF=2
(If "OTHER", Ask "Do you have to eat things you don't like?")
NO=1; YES=0

8. ___ Who decides (picks) what you wear?

SELF=2

(If "OTHER", Ask "Do you like what you wear?")

YES=1; NO=0

9. ___ Do you choose the times you do things each day, like when to get up, when to eat dinner, when to do laundry...? (Do you decide when you watch TV, when to go to bed?)

(If "YES", Did someone help you with this choice?.)

YES, WITHOUT HELP=2; YES, WITH HELP=1,

NO, SOMONE ELSE CHOOSES=0

IF PERSON LIVES ALONE, GO TO NUMBER 19.

PEOPLE THEY LIVE WITH:

Who do you live with there? (Include as many as 6 names of people who live in the household.

Add names of those not given that live there. Write names in chart below.)

(Repeat questions 10-12 for every person listed alternating the order of nice/mean for question

#11. Use chart below.)

Names	10. Do you like living with ___? YES=2 SOMETIMES=1 NO=0	11. Is ___ mean to you or is ___ nice to you? (alternate wording) NICE=2; IN-BETWEEN=1; MEAN=0	12. Show me how you feel about ___. HAPPY=2; IN-BETWEEN=1; SAD=0

13. ___ (Ask this question if not living with own family)

Did you have any say about who lives there with you? NO=0, GO TO #14.

(If "YES", Ask, Who did you choose to live with you?).

IF FOLLOW-UP QUESTION IS ANSWERED, SCORE=2. IF NOT, SCORE=1.

STAFF/SUPPORT PEOPLE:

Who are the staff or support people who work there? (List first names of regular/residential staff. This section is for residential staff only. Make sure you are NOT asking about day activities staff, work staff, etc.)

(Repeat questions 14-16 for every person listed alternating the order of forced choice options for question #14. Use chart below.)

Names	14. Do you like or dislike ___? (alternate wording) LIKE=2 IN-BETWEEN=1 DISLIKE=0	15. Is ___ nice to you and polite? YES=2; SOMETIMES=1 NO=0	16. Show me how you feel about __. HAPPY=2 IN-BETWEEN=1 SAD=0

17. ___ Did you have any choice in hiring (did you pick) who works at your house?
NO=0;
(If “YES”, Ask, “Who did you pick?”).

IF FOLLOW-UP QUESTION IS ANSWERED, SCORE=2. IF NOT, SCORE=1.

18. ___ Have you had a lot of different people support you there?
NO=2
(If “YES”, Ask “Is that a problem for you?”)
NO=1; YES=0

COMPLETE ITEMS 19-21 IF PERSON LIVES ALONE.

19. ___ Do you like living by yourself? YES=2; NO=0

20. ___ Would you like to have someone live with you? NO=2 (then ask question 21)
(If “YES”, Ask, “Who would you like to live with you? Why?”).

IF BOTH FOLLOW-UP QUESTIONS ARE ANSWERED, SCORE 0; IF NOT, SCORE 1

21. ___ Show me how you feel about living alone. (Show picture of faces.)
HAPPY=2; IN-BETWEEN=1; SAD=0

THINGS TO DO:

What do you do for fun when you are at home? (Try to elicit a couple of responses.)

22. ___ Do you choose or pick the things you do for fun? ? Examples: Whether to take a walk, play a game, watch TV, select what’s on TV, etc Y/N (If Yes, Do you choose how you spend your weekends or time off?; If No, Who chooses the activities you do

(If "YES", Did someone help you with this choice?.)
YES, WITHOUT HELP=2; YES WITH HELP=1;
NO, SOMEONE ELSE CHOOSES=0

23. ___ Do you have enough to do when you're at home or do you sit around with nothing to do?
ENOUGH=2; IN-BETWEEN=1; NOTHING=0
24. ___ Are you bored when you are at home, or is it fun to be home?
FUN=2; IN-BETWEEN=1; BORED=0
25. ___ Show me how you feel about how you spend your free time at home. (Show pictures of faces.)
HAPPY=2; IN-BETWEEN=1; SAD=0

JOBS/CHORES:

What are some of the chores/jobs you do at home? (Try to elicit a couple of responses, such as making the bed, doing dishes, setting the table, doing laundry, etc.)

26. ___ Are you told what jobs to do or do you get to pick the jobs/chores you want to do?
PICK=2; IN-BETWEEN=1; TOLD=0
27. ___ Do you have to work too hard there (at home)?
NO=2; SOMETIMES=1; YES=0
28. ___ Would you like to have more jobs/chores to do?
NO=2; SOMETIMES=1; YES=0

29. ___ Show me how you feel about the jobs/chores you do around your house. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0

RULES:

What are the rules for living in that house? (Give examples only if necessary: Can you go to bed whenever you want? Can you watch TV whenever you want to? Can you smoke in the house?)

DO NOT INCLUDE LANDLORD RULES IN THE SCORING OF THIS SECTION.

(If "NO RULES", skip to #33 and then ask #35)

(If consumer does not know what rules are skip section except questions 33, 35, & 36.)

30. ___ Who makes the rules for living there?

SELF=2; OTHER=0

31. ___ Are the rules for living there good rules or are they bad rules?

GOOD=2; IN-BETWEEN=1; BAD=0

32. ___ What happens if you don't like a rule? Can you change a rule (like when you have to go to bed, etc.)? COMPROMISE=2; NOTHING=0

33. ___ 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? HAVE DRINK=2; NOT ALLOWED=0; MEDICAL REASON/NOT OF LEGAL AGE=30

34. ___ Show me what you think about the rules at your house. (Show pictures of faces.)

HAPPY=2; IN-BETWEEN=1; SAD=0

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

YES=2; SOMETIMES=1; NO=0 (If "sometimes," query further about who can/cannot visit.)

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

SELF=2; OTHER=0

PRIVACY and DATING:

37. ___ Can you be by yourself as much as you want to? (Do you have enough time to yourself, enough private time?) YES=2; IN-BETWEEN=1; NO=0

38. ___ Do you ever get mail? If YES, Follow up:

Does anyone ever open your mail without asking you first? NO=2; YES=0

39. ___ Can you use the telephone when you want to? YES=2; SOMETIMES=1; NO=0

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

PRIVATE=2; SOMETIMES=1; LISTEN=0

41. ___ When you have friends over, can you be alone with them, or does someone have to be with you?
HAVE PRIVACY=2; SOMETIMES=1; NOT ALONE=0

42. ___ Has anyone ever talked to you about dating? (Having a boyfriend/girlfriend?)
YES=2; NO=0

43. ___ Do you need to know more about dating? (Having a boyfriend/girlfriend?)
NO=2; YES=0

Do you have a boy/girl friend? What is (his/her) first name? (If not or married/living with significant other, go on to #48.)

44. ___ Can you have ___ over to visit whenever you want? YES=2; NO=0

45. ___ Can ___ stay overnight at your house if you want, or is ___ not allowed to stay overnight?
ALLOWED=2; SOMETIMES=1; NOT ALLOWED=0

46. ___ Do other people have to be with you when ___ is at your house, or can you be alone at your house with ___ if you want? ALONE=2; SOMETIMES=1; OTHER PEOPLE=0

47. ___ Can you spend time at ___'s house whenever you want or are you not allowed to go over to her/his house? YES=2; SOMETIMES=1; NOT ALLOWED=0

MONEY:

Let's talk about money. Who has your money? Does someone help you with your money?

48. ___ Can you have your own money whenever you want it or do you have to ask someone for your money? HAVE=2; ASK=0

49. ___ Show me how you feel about (self or other) having your money. (Show pictures of faces.)
HAPPY=2; IN-BETWEEN=1; SAD=0

50. ___ Can you buy the things you want to buy or does someone else decide how you spend your money? SELF=2; SOMEONE ELSE=0

51. ___ Do people steal (take) your money? NO=2; YES=0

SAFETY:

52. ___ Do people in your house take your things or do they leave your stuff alone?
LEAVE ALONE=2; TAKE=0

53. ___ Do people go into your house without asking?
NO=2; YES=0

54. ___ Does anyone go into your bedroom without asking? NO=2; SOMETIMES=1; YES=0

55. ___ Do people go into your house and take your things? NO=2; (IF YES, ASK FOLLOW-UP)
What kind of things do they take?

IF FOLLOW-UP IS ANSWERED, SCORE=0; IF NOT, SCORE=1.

56. ___ Do you feel safe in your home or do you feel afraid (scared) in your home?
SAFE=2; IN-BETWEEN=1; AFRAID=0
If person does not feel safe in their house, Ask "Why not?"

* If person is "Afraid" for a reason that indicates they are in immediate danger or risk of serious harm SEE PROTOCOL.

COMING AND GOING:

Do you like to go out? (Go downtown, to the neighbors, to the stores, to someone else/s house?)
Where do you like to go? REFER TO PICTURES IF NECESSARY

57. ___ Can you go out whenever you want to or do you have to wait for someone to take you?
WHEN WANT=2; WAIT=0 (If "WAIT", try to determine whether the person
can go when they want and need a ride or if they must wait until it is
"convenient" for someone else.) How come you have to wait?

58. ___ Do you have to wait for someone to bring you home or can you go home when you
want to? WHEN WANT=2; WAIT=0 (If "WAIT", try to determine whether the
person can go when they want and need a ride or if they must wait until it is
"convenient" for someone else.) How come you have to wait?

59. ___ When people in your house go somewhere, do you have to go or can you stay home alone
if you want to? STAY ALONE=2; SOMETIMES=1; GO=0

60. ___ Do you have a key to your house? YES=2; NO=0 (If "NO," go to next section)

61. ___ Do you use your key whenever you want to or do you have to ask to use your key?
FREELY=2; ASK=0

ACCESS/ TRANSPORTATION:

62. ___ When you want to go somewhere, do you have a way to get there?
YES=2; SOMETIMES=1; NO=0.

63. ___ Are there places that you need to go to that you can't get to? (Such as to the doctor, the
service agency, to go shopping, to the pharmacy, etc.) NO=2; YES=0

64. ___Are the places where you go for services or support easy to get to? YES=2; NO=0
(e.g. to the doctor, the service agency, to go shopping, to the pharmacy, etc.)

PETS:

Are there any pets at your house? Y/N (If "YES," what kind? Then ask #65 and skip #66 & #67)
(If "NO," skip #65 and ask #66 & #67)

65. ___Do you like having a pet? IF YES, SCORE=2; IF NO, SCORE=0; IN-BETWEEN=1

66. ___Do you want to have a pet? What kind of pet? NO=2; YES=0 (If, "YES", ask #67. If, "NO", skip #67.)

67. ___Can you have a pet at your house if you want to or are no pets allowed? YES=2; NO=0

Is there anything else that you want to tell me about where you live that we haven't already talked about; such as, things you like?

Things you don't like?

Things you want changed or fixed?

B. NEIGHBORHOOD

Do you know any of the neighbors? If yes, can you tell me their first names? (List)

68. ___Are the neighbors friendly toward you? YES=2; SOMETIMES=1; NO=0

69. ___Are the neighbors mean to you or nice to you? NICE=2; IN-BETWEEN=1; MEAN=0

70. ___Do you like living in your neighborhood or would you like to live in a different neighborhood? LIKE=2
(If ELSEWHERE, Ask, "Where would that be?").

IF ANSWER, SCORE=0; IF NO ANSWER, SCORE=1

71. ___Do your neighbors ignore you (pretend you're not there) or do they talk to you?
TALK=2; SOMETIMES=1; IGNORE=0

72. ___Show me how you feel about your neighbors. (Show pictures of faces.)
HAPPY=2; IN-BETWEEN=1; SAD=0

73. __ Do you feel safe and happy to walk around in your neighborhood near your house, or do you feel afraid to walk around your neighborhood? SAFE/HAPPY=2; NOT=0

Is there anything else that you want to tell me about your neighbors/neighborhood that we haven't already talked about; such as, Things you like?

Things you don't like?

Things you want changed or fixed?

C. EMPLOYMENT

Do you have a job? (If "YES", Ask about job and then begin with #75. If "NO", Ask #74 and move to next section.)

(Ask only if consumer does not have a job, then skip Employment section if "YES")

74. __ Do you want to have a paid job? NO=2; YES=0

75. __ Do you like your job or do you dislike your job? LIKE=2; IN-BETWEEN=1; DISLIKE=0

76. __ Did you choose to work at _____? Y / N (If "YES", Did someone help you with this choice.)

YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0

77. __ Is that a bad place to work or a good place to work? GOOD=2; IN-BETWEEN=1; BAD=0

78. __ Do you like the hours you work? YES=2; IN-BETWEEN=1; NO=0

79. __ Do you work enough hours or do you want to work more hours? ENOUGH=2; MORE=0

80. __ Is the work you do important work or not important work?
IMPORTANT=2; IN-BETWEEN=1; NOT IMPORTANT=0

81. __ Do you get paid fairly for the work you do? YES=2; IN-BETWEEN=1; NO=0

82. __ Show me how you feel about the money you make from work. (Show pictures of faces.)
HAPPY=2; IN-BETWEEN=1; SAD=0

83. __ Are the people at work mean to you or are people at work nice to you?
NICE=2; IN-BETWEEN=1; MEAN=0

84. __ If you had a problem at work or needed help, is there someone at work who helps you or is there no one to help you? SOMEONE=2; NO ONE=0

85. __ Do you have a job coach? Y/N (If "YES", ask follow-up questions. If "NO", mark as 8 "Non Applicable" and go to #86) If "YES", Did you choose (or pick) your job coach (the person who helps you)? Y/N (If "YES", Did someone help you with this choice?.)
 YES, WITHOUT HELP=2; YES, WITH HELP=1;
 NO, SOMEONE ELSE CHOSE=0
86. __ Show me how you feel about the people you work with. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0
87. __ Do the people you work with treat you okay, or do they not respect you?
 RESPECT=2; IN-BETWEEN=1; NO RESPECT=0
88. __ Do you have to work all the time or do you get a vacation from work?
 VACATION=2; ALL THE TIME=0
89. __ Show me how you feel about work. (Show pictures of faces.)
 HAPPY=2; IN-BETWEEN=1; SAD=0
90. __ Have you had a lot of different people support you at work?
 NO=2
 (If "YES", Ask "Is that a problem for you?")
 NO=1; YES=0
91. __ Is there something else you would rather do during the day?
 Please list:

 NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0
92. __ Do you choose to go to your worksite, or do you have to go?
 CHOOSE=2; SOMETIMES=1; HAVE TO GO=0

Is there anything else that you want to tell me about your job that we haven't already talked about such as; things you like?

Things you don't like?

Things you want changed or fixed?

D. DAYTIME ACTIVITIES - GROUP

What do you do during the daytime?

(Be clear that you are asking about group daytime activities only, NOT residential free time, and use program or staff names throughout the section so the consumer is clear about exactly what you are asking.)

- 75a. ___ Do you like your daytime activities at _____ or do you dislike them? LIKE=2; DISLIKE=0
- 76a. ___ Did you choose to go to _____? (Did you look at more than one day program?) Y/N
(If "YES", Did someone help you with this choice?.)
YES, WITHOUT HELP=2; YES, WITH HELP=1;
NO, SOMEONE ELSE CHOSE=0
- 77a. ___ Is that a bad place to go or a good place to go? GOOD=2; IN-BETWEEN=1; BAD=0
- 78a. ___ Do you like the hours of your day activities? YES=2; IN-BETWEEN=1; NO=0
- 79a. ___ Do you get enough hours at _____ or would you like more hours?
ENOUGH=2; MORE=0
- 83a. ___ Are the people you spend time with at _____ mean to you or nice to you?
NICE=2; IN-BETWEEN=1; MEAN=0
- 85a. ___ Did you choose (or pick) who helps you at _____? Y / N
(If "YES", Did someone help you with this choice?.)
YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0
- 86a. ___ Show me how you feel about the people you spend time with during the day at _____.
(Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0
- 87a. ___ Do the people you spend time with at _____ during the day treat you okay, or do they not respect you? RESPECT=2; IN-BETWEEN; NO RESPECT=0
- 89a. ___ Show me how you feel about your daytime activities at _____. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0
- 90a. ___ Have you had a lot of different people support you during the day?
NO=2
(If "YES", Ask "Is that a problem for you?")
NO=1; YES=0
- 91a. ___ Is there something else you would rather do during the day?
Please list:

NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0
- 92a. ___ Do you choose to go to your daytime activities, or do you have to go?
CHOOSE=2; SOMETIMES=1; HAVE TO GO=0

E. DAYTIME ACTIVITIES – INDIVIDUAL SUPPORT / COMPANIONSHIP

Do you have a support person who does things with you? Who is that person? What kinds of things do you do with _____?

- 75b. ___ Do you like your daytime activities or do you dislike them? LIKE=2; DISLIKE=0

- 78b. ___ Do you like the hours of your day activities? YES=2; IN-BETWEEN=1; NO=0
- 79b. ___ Do you get enough hours of daytime support with _____ or would you like more hours? ENOUGH=2; MORE=0
- 83b. ___ Are the people you spend time with during the day mean to you or nice to you? NICE=2; IN-BETWEEN=1; MEAN=0
- 85b. ___ Did you choose (or pick) who helps or supports you during the day?
Y / N (If "YES", Did someone help you with this choice?.)
YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0
- 86b. ___ Show me how you feel about the people you spend time with during the day. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0
- 87b. ___ Do the people you spend time with during the day treat you okay, or do they not respect you? RESPECT=2; IN-BETWEEN=1; NO RESPECT=0
- 89b. ___ Show me how you feel about what you do with _____. (Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0
- 90b. ___ Have you had a lot of different people support you during the day?
NO=2
(If "YES", Ask "Is that a problem for you?")
NO=1; YES=0
- 91b. ___ Is there something else you would rather do during the day?
Please list:

NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0
- 92b. ___ Do you choose to go out with _____, or do you have to go?
CHOOSE=2; SOMETIMES=1; HAVE TO GO=0

Is there anything else you want to tell me about your daytime activities that we haven't talked about, such as, things you like?

Things you don't like?

Things you want changed or fixed?

F. VOLUNTEER ACTIVITIES

What do you do when you volunteer? Do you have a support person who helps you? Y / N
(Be clear that you are asking about volunteer activities only and use the support person's name or the volunteer job site throughout the section)

75c. ___ Do you like your volunteer activities or do you dislike them? LIKE=2; DISLIKE=0

76c. ___ Did you choose to go to (volunteer site)? Y / N (If "YES", Did someone help you with this

choice?.)

YES, WITHOUT HELP=2; YES, WITH HELP=1;

NO, SOMEONE ELSE CHOSE=0

77c. ___ Is that a bad place to go or a good place to go? GOOD=2; IN-BETWEEN=1; BAD=0

78c. ___ Do you like the hours of your volunteer activities? YES=2; IN-BETWEEN=1; NO=0

79c. ___ Do you get enough hours of volunteer time or would you like more hours?

ENOUGH=2; MORE=0

83c. ___ Are the people you spend time with when you volunteer mean to you or nice to you?

NICE=2; IN-BETWEEN=1; MEAN=0

85c. ___ Do you have someone who helps you at your volunteer site? (If "YES", ask follow-up questions. If "NO", go to #86c) Did you choose (or pick) who helps you at your volunteer site? Y/N (If "YES", Did someone help you with this choice?.)

YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0

86c. ___ Show me how you feel about the people you spend time with when you volunteer.

(Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0

87c. ___ Do the people you spend time with when you volunteer treat you okay, or do they not respect you? RESPECT=2; IN-BETWEEN=1; NO RESPECT=0

89c. ___ Show me how you feel about your volunteer activities. (Show pictures of faces.)

HAPPY=2; IN-BETWEEN=1; SAD=0

Is there anything else you want to tell me about your volunteer activities that we haven't talked about, such as, things you like?

Things you don't like?

Things you want changed or fixed?

G. SOCIAL SUPPORT

FRIENDS:

Do you have friends that you like to be with? Y / N Who are your friends?

LIST NAMES IN THE CHART BELOW

(If necessary, use the following questions to generate names, list them in the chart below)

(If she/he asks answers "yes" ask who the friends are and try to determine if they are

family, staff, roommates, co-workers, etc.)

YES, FRIENDS NOT STAFF OR FAMILY=2

YES, FRIENDS WHO ARE STAFF, CARE-GIVERS, OR FAMILY=1

(Repeat #93 for every person listed in the chart below.)

Names	Type	93. Show me how __ usually makes you feel. (Show faces)

94. __ Do you have enough friends or do you wish you had more friends? ENOUGH=2; MORE=0

95. __ Do you hardly ever get to see your friends or do you see your friends when you want to see them? If hardly ever, why not or how come you don't see them much? (Please indicate below)

(Try to determine if there are restrictions on when he/she can see friends. Try to

factor

out situations where the friends are unavailable – this is not the issue.)

WHENEVER=2; HARDLY EVER=0

96. __ Who do you talk to when you need to talk to someone? SOMEONE=2; NO ONE=0

97. __ Do you have any best friends? (Is there someone you tell personal things to?)

YES=2; NO=0

98. __ If you need help, who do you ask to help you? SOMEONE=2; NO ONE=0

99. __ Does anyone ask you to help them? SOMEONE=2; NO ONE=0

100.__ On most days, are you usually happy or sad? HAPPY=2; SAD=0

101.__ Are you lonely or do you have plenty of friends? PLENTY=2; LONELY=0

102.__ Do you ever feel lonely, like you don't have anyone to talk to?
NO=2; SOMETIMES=1; YES=0

FAMILY:

Let's talk about your family members that you don't live with. Do you have family that you see? Who is in your family? (List)

103.__ Do these family members (family members listed above) make you upset or happy?
HAPPY=2; IN-BETWEEN=1; UPSET=0

104.__ Do you get to see these family members (family members listed above) as much as you want? YES =2; NO=0
(If "NO", try to determine if there are any restrictions placed on the consumer.)

105.__ Show me how you feel about these family members (family members listed above).
(Show pictures of faces.) HAPPY=2; IN-BETWEEN=1; SAD=0

Is there anything else you want to tell me about your friends or family that we haven't already talked about, such as, things you like?

Things you don't like?

Things you want changed or fixed?

H. ACTIVITIES

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

(Ask the following questions about each activity listed below beginning with those listed by the interviewee. *If the consumer is unable to respond to the “follow-up” questions, please put a check in the appropriate YES/NO column.*)

	YES	NO
<u>Activity</u> Do you ever...	If answer is yes, then alternating the order each time, ask: Do you go (do___) as much as you want or do you hardly ever get to go (do)? AS MUCH AS=2; HARDLY EVER=0	If answer is no, then ask: Do you want to go to (do) ___? NO=2; YES=0
106. go shopping(e.g., groceries, clothing, housewares, CDs)		
107. go out on errands or appointments (e.g., doctor, bank, post office, hair stylist)		
108. go out for exercise (e.g., walking, biking, aerobics, etc.)		
109. play any sports (e.g., bowling, skating, fishing, swimming, playing sports, etc.)		
110. go out for entertainment (e.g., movies, concerts, plays, bars, parties, sporting events)		
111. go out to eat		
112. go to church/synagogue		
113. stay home and do fun things (e.g., watch videos, play cards or games, work on puzzles or craft projects)		
114. visit friends/family		

I. GUARDIANSHIP

Do you have a guardian?

If yes, what is his/her name? (If "no," then go to next section)

115. ___ Do you get to see or talk to your guardian when you want to? YES=2; SOME=1; NO=0

116. ___ Did you get to choose (pick) your guardian, or did someone else choose your guardian?
I CHOSE=2; SOMEONE ELSE CHOSE=0

117. ___ Show me how you feel about (guardian). (Show pictures of faces)
HAPPY=2; IN-BETWEEN=1; SAD=0

118. ___ Does your guardian let you make some decisions for yourself or does she/he make all
your decisions for you? MAKE OWN DECISIONS=2; GUARDIAN=0

Is there anything else you want to tell me about your guardian that we haven't already talked
about, such as, things you like?

Things you don't like?

Things you want changed or fixed?

J. SERVICE AGENCY

(Be clear that you are referring to the consumer's case worker and not home provider, day service provider, etc. Make sure you are aware of the agency name and of the service plan term the consumer is familiar with. Use these names/terms throughout the following sections.)

Let's talk about your case manager (service coordinator). Who is your case manager (service coordinator)?

119. ___ Show me how you feel about your case manager (service coordinator). (Show pictures of faces) HAPPY=2; IN-BETWEEN=1; SAD=0

120. __ Did you choose (or pick) your case manager? Y / N
(If "YES", Did someone help you with this choice?.)
YES, WITHOUT HELP=2; YES, WITH HELP=1; NO, SOMEONE ELSE CHOSE=0
Who helped you make this choice?

121. __ Do you get to see your case manager when you want to? YES=2; SOMETIMES=1;
NO=0

122. __ When you want to talk to (case manager/service coordinator) is it hard or easy to get in
touch with him/her? EASY=2; IN-BETWEEN=1; HARD=0

123. __ When you ask _____ for help, does he/she get you what you need?
YES=2; SOMETIMES=1; NO=0

124. __ Have you had a lot of different case managers?
NO=2
(If "YES", Ask "Is that a problem for you?")
NO=1; YES=0

Now let's talk about other services.

125. __ Show me how you feel about (your service agency). (Show pictures of faces)
HAPPY=2; IN-BETWEEN=1; SAD=0

126. __ Did you have a support plan / ISA (IPP) meeting this year? YES=2; NO=0

127. __ When you have your support plan / ISA (IPP) meetings, do people listen to what you
have to say? LISTEN=2; SOMETIMES=1; DON'T LISTEN=0

128. __ Did you get what you wanted in your support plan / ISA (IPP)? YES=2;
SOMEWHAT=1; NO=0

129. __ Are the things that are important to you in your support plan / ISA (IPP)?
YES=2; SOME=1; NO=0

130. __ Do you have a group of friends and family that you count on to help you make
decisions? (Like the types of support you need, where to live, how to get places?)
YES=2; NO=0

131. __ Tell me what agency services are available to you at _____ (Service agency)?

Please list: _____

NAMED=2; COULD NOT NAME=0

132. ___ Are there other supports and services you wish you had that you don't have now?

Please list:_____

NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0

133. ___ Do you know how much money from (your agency) you have to spend on services? (Do you know how much your budget is?) YES, GIVES FIGURE=2; YES, DID NOT GIVE FIGURE=1; NO=0

134. ___ Do you know how you can use your money/budget from _____(service agency) for services?

Please list:_____

YES, NAMED=2; YES, BUT DID NOT NAME=1; NO=0

(If Yes to either 133 or 134, then ask question 135, if both questions are no skip 135.)

135. ___ Who do you ask for help with using your money/budget to get services?

Please list:_____

YES, NAMED=2; YES, BUT DID NOT NAME=1; NO=0

136. ___ Have you ever been told about (your agency's) complaint process or are you not aware of (your agency's) complaint process? TOLD=2; NOT AWARE=0

137. ___ Have you ever made a formal written complaint to someone at your agency? NO=2; YES=0

138. ___ Have you been told about (your agency's) appeal process or are you not aware of (your agency's) appeal process? TOLD=2; NOT AWARE=0

139. ___ Do people at (your agency) listen to you or not listen to you? LISTEN=2; SOMETIMES=1; NOT LISTEN=0

140. ___ Do you have trouble changing the things you don't like or do people at (your agency) help change things you don't like? HELP CHANGE=2; TROUBLE CHANGING=0

141. ___ Are you having trouble getting the help you need or are you getting the help you need? (Such as transportation, job coaching, taking a class, taking a vacation, getting medical care, etc.) GET HELP=2; TROUBLE=0

142. ___ Who would you ask to help you change services or supports you do not like?

Please list:_____

NAMED=2; SOMEONE, BUT DID NOT NAME=1; NOBODY NAMED=0

143. ___ Do you ever get to learn new things (skills)? (Do people help you learn new things?)

Y/N What are they?_____

NAMED=2; YES, BUT DID NOT NAME=1; NO=0.

144. ___ Show me how you feel about the help you get from (your agency).

HAPPY=2; IN-BETWEEN=1; SAD=0

K. HEALTH CARE

SCORE HAPPY=2; IN-BETWEEN=1; SAD=0 FOR QUESTIONS 145-149 THAT USE FACES (*).

145. ___Do you get to see your doctor when you want/need to? YES=2; NO=0

*146. ___Show me how you feel about the doctor you see when you are sick or when you have checkups. HAPPY=2; IN-BETWEEN=1; SAD=0

147. ___Do you get to see your dentist when you want/need to? YES=2; NO=0

*148. ___Show me how you feel about your dentist. HAPPY=2; IN-BETWEEN=1; SAD=0

149. ___Are there any other health services that you want/need to have?

Please list:_____

NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0

L. VOTING

150. ___Has anyone ever talked to you about voting in elections? YES=2; NO=0.

151. ___ (*First Ask*) Do you want to vote in elections or do you not want to vote in elections? Y/N

If "NO", then ask, Do you vote in elections? NO=2; YES=0

If "YES", then ask, Do you vote in elections? YES=2; NO=0

M. SELF-ADVOCACY

Do you know what a self-advocate is? (*Provide an explanation if person is uncertain.*)
(Self-advocacy means speaking up for yourself, telling people what you want, advocating for your rights/what you need?)

152. ___ Have you gone to a self-advocacy meeting or conference, or have you not been able to go? GONE=2; If "NOT GONE, then ask follow-up question before scoring
Do you want to go to a self-advocacy meeting, conference, or event? NO=2; YES=0

(If "GONE", then ask #153 and skip to #155)
(If "NOT GONE", then SKIP TO #154)

153. ___ Why did you go to the self-advocacy meeting, conference, or event? (Check primary reason)

___ To get information for self/others
___ To see/meet people – social opportunity
___ To be part of the self-advocacy movement
___ Support
___ Other (please specify) _____

154. ___ Why haven't gone or been able to go? (Check primary reason)

___ Not enough time
___ Not interested
___ Can't get a ride
___ Didn't know about it
___ Other (please specify) _____

155. ___ Do you see yourself as being a self-advocate? YES=2; NO=0

156. ___ Do you want to know more about self-advocacy or do you know enough about it?
ENOUGH=2; MORE=0.

N. SELF-DETERMINATION

157. ___ Do you need to have more control over your life or do you think you have enough control? (Such as control over where you live, what you do during the day, how to spend your money) ENOUGH=2; MORE=0

158. __ Are there choices you wish you could make that you don't make now?

Please list: _____

NO=2; YES, BUT DID NOT NAME=1; YES, NAMED=0

159. __ Were you involved in the interviewing and hiring of any of your support staff or were they assigned to you? INVOLVED, NAMED=2; INVOLVED, NOT

NAMED=1

ASSIGNED=0

(If "YES", Ask who.)

160. __ Do you need to know more about how to interview and hire your support staff?

NO=2; YES=0

Is there anything else you want to tell me that we haven't talked about already today?



APPENDIX B:

Factors Included in Each Subscale Based on 2002 Survey (2002)

From the Self-Perceived Satisfaction Scale:

- RESIDENTIAL SATISFACTION – Includes the following questions: q1,q2,q4,q5,q6, mean of q10-q12, mean of q14-q16, q18,q19,q20,q21,q23,q24,q25,q27,q28,q29,q31,q34,q65,q67,q49,q51,q52,q53,q54,q55, q56,q62,q63,q64,q65,q66
- RESIDENTIAL AUTONOMY – Includes the following questions: q3,q7,q8,q9,q13,q17,q22,q26,q30,q32,q33,q35,q36,q37,q38,q39,q40,q41,q48,q50,q57,q58,q59,q60,q61,q67
- NEIGHBOR SATISFACTION – Includes Neighborhood questions q68- q73
- WORK SATISFACTION – Includes Employment questions(q75,q76,q77,q78,q79,q80,q81,q82,q83,q84, q86,q87,q88,q89)
- DAY PROGRAM SATISFACTION – Includes Daytime Activities questions (q75a,q76a,q77a,q78a,q79a,q83a,q86a,q87a,q89a,q75b,q78b,q79b,q83b, q86b,q87b,q89b,q75c,q76c,q77c,q79c,q83c, q86c,q87c,q89c)
- SOCIAL SUPPORT SATISFACTION – Includes Friends, Social Support, and Family questions (mean of q93,q94,q95,q96,q97,q98,q99,q100,q101,q102,q103,q104,q105)
- ACTIVITIES AND OPPORTUNITIES SATISFACTION – Questions (q106-q114)
- GUARDIAN SATISFACTION – Includes all Guardianship questions (q115,q116,q117,q118)
- SERVICE SATISFACTION – Includes questions (q119,q120,q121,q122,q123,q124,q125,q126,q127,q128,q129,q130, q139,q140,q141,q142,q143,q144)
- HEALTH SATISFACTION – (q145,q146,q147,q148,q149)
- *Additional questions for the full self-report have been added since the 1997 interview in accordance with the Federal Core Indicators Project, and at the request of the Division of Developmental Services. These questions are not included in the subscales, so that comparisons can be made across years. However, response to these questions and all other questions can be found in Appendix A.*

APPENDIX C: SELF-PERCEIVED SATISFACTION SCALE, 2002

STATE OF VERMONT (N=136)

The Vermont Consumer Survey Project is participating in a national Core Indicators Project sponsored by the Board of Directors of the National Association of State Directors of Developmental Disabilities Services. The aim of the project is to establish and validate “core indicators” which would serve as benchmarks against which states could examine and evaluate consumer outcomes for their citizens. The consumer questions that have been included in the national project as key consumer outcomes are indicated in the table of results with asterisks (*). When national data become available against which to compare local and state results, that information will be included in our reports.

RESIDENTIAL

* 1. Are you happy living there or would you like to live somewhere else?

HAPPY	IN-BETWEEN	SOMEWHERE ELSE
113	5	18

2. Is that a bad place to live or a good place to live?

GOOD	IN-BETWEEN	BAD
100	14	8

* 3. Did you have any say in choosing that place to live?

YES	NO
60	52

4. Can you think of a better place to live?

NO	YES, COULD NOT NAME	YES, NAMED PLACE
89	2	29

5. Is the food there pretty bad or do you like the food there?

LIKE	IN-BETWEEN	DISLIKE
114	4	2

6. Show me how you feel about the food at your house.

SELF	IN-BETWEEN	NO, DON'T HAVE TO EAT
115	13	5

7. Who decides (picks) what you eat?

SELF	SOMEONE ELSE, LIKE IT	SOMEONE ELSE, DON'T LIKE IT
73	29	16

8. Who decides (picks) what you wear?

SELF	OTHER
107	13

* 9. Do you choose the times you do things each day, like when to get up, when to eat dinner, when to do laundry...?

YES, WITHOUT ASSISTANCE	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
86	23	7

Do you like living with ___ ? (Housemates 1 through 6)

12. Show me how you feel about ___ . (Housemates 1 through 6)

HOUSEMATE	HAPPY	IN-BETWEEN	SAD
1.	23	4	0
2.	20	7	0
3.	23	6	3
4.	16	1	1
5.	7	1	2

(Ask this question if not living with family)

* 13. Did you have any say about who lives there with you?

YES	NO
12	32

STAFF/SUPPORT PEOPLE:

Do you like ___ ? (Staff or support people 1 through 4)

16. Point to the face which shows how you feel about ___ .
(Staff or support people 1 through 4)

STAFF	HAPPY	IN-BETWEEN	SAD
1.	16	0	0
2.	16	0	0
3.	20	1	1
4.	4	0	0

* 17. Did you have any choice in hiring (did you pick) who works at your house?

YES, SOMEONE NAMED	NO
5	11

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

NO	YES, NOT A PROBLEM	YES, IT HAS BEEN A PROBLEM
4	11	1

For persons living semi-independently with no roommate:

19. Do you like living by yourself?

YES	NO
21	1

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

NO	YES, FOLLOW UP NOT ANSWERED	YES, FOLLOW UP ANSWERED
19	1	2

21. Show me how you feel about living alone.

HAPPY	IN-BETWEEN	SAD
23	1	2

THINGS TO DO:

* 22. Do you choose or pick the things you do for fun?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
93	18	7

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

ENOUGH	IN-BETWEEN	NOTHING
83	23	10

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

FUN	IN-BETWEEN	BORED
68	39	13

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

HAPPY	IN-BETWEEN	SAD
103	20	8

JOBS/CHORES:

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

PICK	IN-BETWEEN	TOLD
89	8	14

27. Do you have to work too hard there (at home)?

NO	SOMETIMES	YES
96	6	11

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

NO	SOMETIMES	YES
88	4	22

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

HAPPY	IN-BETWEEN	SAD
92	29	3

RULES:

30. Who makes the rules for living here?

SELF	SOMEONE ELSE
31	48

31. Are the rules for living there good rules or are they bad rules?

GOOD	IN-BETWEEN	BAD
62	9	6

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

COMPROMISE	NOTHING
56	17

33. 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?

HAVE A DRINK	NO DRINKING ALLOWED	MEDICAL REASONS
51	24	37

34. Show me what you think about the rules at your house.

HAPPY	IN-BETWEEN	SAD
56	20	9

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

YES	SOMETIMES	NO
95	7	10

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

SELF	OTHER
63	47

PRIVACY:

* 37. Can you be by yourself as much as you want to? (Do you have enough time to yourself, enough private time?)

YES	IN-BETWEEN	NO
94	7	17

38. Does anyone ever open your mail without asking you first?

NO	YES
95	16

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

YES	SOMETIMES	NO
100	7	11

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

PRIVATE	SOMETIMES	LISTEN
97	5	9

* 41. When you have friends over, can you be alone with them, or does someone have to be with you?

HAVE PRIVACY	SOMETIMES	NOT ALONE
82	6	16

42. Has anyone ever talked to you about dating? (Having a boyfriend/girlfriend?)

YES	NO
45	72

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

NO	YES
85	31

44. Can you have (boyfriend/girlfriend) over to visit whenever you want?

YES	NO
24	5

45. Can (boyfriend/girlfriend) stay overnight at your house if you want, or is (boyfriend/girlfriend) not allowed to stay overnight?

YES, ALLOWED	SOMETIMES	NOT ALLOWED
13	2	13

46. Do other people have to be with you when (boyfriend/girlfriend) is at your house, or can you be alone at you house with (boyfriend/girlfriend) if you want?

NO, CAN BE ALONE	SOMETIMES	YES, OTHER PEOPLE
18	1	6

47. Can you spend time at (boyfriend/girlfriend)'s house whenever you want or are you not allowed to go over to her/his house?

YES	SOMETIMES	NOT ALLOWED
22	1	3

MONEY:

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

HAVE	ASK
69	45

49. Show me how you feel about (self or other) having your money.

HAPPY	IN-BETWEEN	SAD
96	18	7

* 50. Can you buy the things you want to buy or does someone else decide how you spend your money?

SELF	SOMEONE ELSE
101	16

51. Do people steal (take) your money?

NO	YES
108	9

SAFETY:

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

LEAVE ALONE	SOMETIMES	TAKE
103	2	5

* 53. Do people go into your house without asking?

NO	SOMETIMES	YES
107	0	13

* 54. Does anyone go into your bedroom without asking?

NO	SOMETIMES	YES
98	5	16

55. Do people go into your house and take your things?

NO	YES, FOLLOW UP NOT ANSWERED	YES, FOLLOW UP ANSWERED
113	2	4

* 56. Do you feel safe in your home or do you feel afraid (scared) in your home?

SAFE	IN-BETWEEN	AFRAID
107	6	5

COMING AND GOING:

57. Can you go out whenever you want to or do you have to wait for someone to take you?

WHEN WANT	SOMETIMES	WAIT
60	0	59

58. Do you have to wait for someone to bring you home or can you come home when you want to?

WHEN WANT	SOMETIMES	WAIT
62	0	55

59. When people in your house go somewhere, do you have to go or can you stay home alone if you want to?

CAN STAY ALONE	SOMETIMES	HAVE TO GO
66	4	27

60. Do you have a key to your house?

YES	NO
74	44

61. Do you use your key whenever you want to or do you have to ask to use your key?

FREELY	ASK
71	3

ACCESS/ TRANSPORTATION

* 62. When you want to go somewhere, do you have a way to get there?

YES	SOMETIMES	NO
109	6	6

63. Are there services or supports that you need that you can't get to? (Such as to the doctor, the service agency, to go shopping, to the pharmacy, etc.)

NO	SOMETIMES	YES
96	1	22

64. Are the places where you go for services or support easy to get to? (e.g., to the doctor, the service agency, to go shopping, to the pharmacy, etc.)

YES	IN-BETWEEN	NO
108	3	8

PETS:

65. Do you like having a pet? (Persons with a pet)

YES	IN-BETWEEN	NO
82	2	4

66. Do you want to have a pet? (Persons without a pet)

NO	IN-BETWEEN	YES
21	1	13

67. Can you have a pet in this house if you want to or are no pets allowed? (Persons without a pet)

ALLOWED	IN-BETWEEN	NO PETS ALLOWED
17	1	11

NEIGHBORHOOD

68. Are the neighbors friendly toward you?

YES	SOMETIMES	NO
100	7	7

69. Are the neighbors mean to you or are the neighbors nice to you?

NICE	IN-BETWEEN	MEAN
103	6	3

70. Do you like living in your neighborhood or would you like to live in a different neighborhood?

LIKE	DIFFERENT, NOT NAMED	DIFFERENT, NAMED
85	6	22

71. Do your neighbors ignore you (pretend you're not there) or do they talk to you?

TALK	SOMETIMES	IGNORE
92	10	12

72. Show me how you feel about your neighbors.

HAPPY	IN-BETWEEN	SAD
100	15	9

* 73. Do you feel safe and happy to walk around in your neighborhood near your house, or do you feel afraid to walk around your neighborhood?

SAFE	IN-BETWEEN	NOT SAFE
103	5	9

EMPLOYMENT

74. Do you want to have a paid job?

YES	NO
19	10

75. Do you like your job or do you dislike your job?

LIKE	IN-BETWEEN	DISLIKE
63	3	3

* 76. Did you choose to work at _____?

YES UNASSISTED	YES WITH ASSISTANCE	SOMEONE ELSE CHOOSES
18	37	11

* 77. Is that a bad place to work or a good place to work?

GOOD	IN-BETWEEN	BAD
63	6	1

78. Do you like the hours you work?

YES	IN-BETWEEN	NO
66	1	3

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

ENOUGH	MORE
38	31

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

IMPORTANT	IN-BETWEEN	NOT IMPORTANT
59	3	6

81. Do you get paid fairly for the work you do?

YES	IN-BETWEEN	NO
61	3	4

82. Show me how you feel about the money you make from work.

HAPPY	IN-BETWEEN	SAD
65	9	2

* 83. Are the people at work mean to you or are people at work nice to you?

NICE	IN-BETWEEN	MEAN
63	5	2

84. If you had a problem at work or needed help, is there someone at work who helps you or is there no one to help you?

SOMEONE	SOMETIMES	NO ONE
67	0	2

* 85. Did you choose (or pick) your job coach (the person who helps you)?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO
9	8	25

86. Show me how you feel about the people you work with.

HAPPY	IN-BETWEEN	SAD
66	8	3

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

RESPECT	IN-BETWEEN	NO RESPECT
62	7	1

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

VACATION	IN-BETWEEN	ALL THE TIME
62	0	6

89. Show me how you feel about work.

HAPPY	IN-BETWEEN	SAD
66	9	2

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

NO	YES, NOT A PROBLEM	YES, IT HAS BEEN A PROBLEM
14	34	6

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

NO	YES, BUT DID NOT NAME	YES, NAMED
58	1	9

92. Do you choose to go to your worksite, or do you have to go?

CHOOSE	SOMETIMES	HAVE TO GO
45	0	25

DAYTIME ACTIVITIES- GROUP

75a. Do you like your daytime activities at _____ or do you dislike them?

LIKE	DISLIKE
15	0

76a. Did you choose to go to _____?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
9	5	0

* 77a. Is that a bad place to go or a good place to go?

GOOD	IN-BETWEEN	BAD
14	0	1

78a. Do you like the hours of your day activities?

YES	IN-BETWEEN	NO
13	2	0

* 79a. Do you get enough hours of daytime support or would you like more hours?

ENOUGH	IN-BETWEEN	MORE
12	0	3

83a. Are people you spend time with during the day mean to you or nice to you?

NICE	IN-BETWEEN	MEAN
12	2	1

* 85a. Did you choose (or pick) who helps you at your day program site?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
3	7	4

86a. Show me how you feel about the people you spend time with during the day.

HAPPY	IN-BETWEEN	SAD
12	1	2

87a. Do the people you spend time with during the day treat you okay, or do they not respect you?

RESPECT	IN-BETWEEN	NO RESPECT
14	1	0

89a. Show me how you feel about your daytime activities.

HAPPY	IN-BETWEEN	SAD
13	2	1

90a. Have you had a lot of different people support you at your day program?

NO	YES, NOT A PROBLEM	YES, IT HAS BEEN A PROBLEM
5	9	1

91a. Is there something else you would rather do during the day?

NO	YES, BUT DID NOT NAME	YES, NAMED
9	1	4

92a. Do you choose to go to your daytime activities, or do you have to go?

CHOOSE	SOMETIMES	HAVE TO GO
12	0	2

DAY ACTIVITIES-INDIVIDUAL

75b. Do you like your daytime activities or do you dislike them?

LIKE	DISLIKE
57	2

78b. Do you like the hours of your day activities?

YES	IN-BETWEEN	NO
57	1	1

79b. Do you get enough hours of daytime support with _____ or would you like more hours?

ENOUGH	MORE
34	25

83b. Are the people you spend time with during the day mean to you or nice to you?

NICE	IN-BETWEEN	MEAN
58	2	0

85b. Did you choose (or pick) who helps or supports you during the day?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
12	19	28

86b. Show me how you feel about the people you spend time with during the day?

HAPPY	IN-BETWEEN	SAD
55	7	2

87b. Do the people you spend time with during the day treat you okay, or do they not respect you?

RESPECT	IN-BETWEEN	NO RESPECT
58	0	0

89b. Show me how you feel about what you do with _____.

HAPPY	IN-BETWEEN	SAD
57	6	1

90b. Have you had a lot of different people support you during the day?

NO	YES, NO PROBLEM	YES, IT IS A PROBLEM
28	21	8

91b. Is there something else you would rather do during the day?

NO	YES, NOT NAMED	YES, NAMED
44	3	8

92b. Do you choose to go out with _____, or do you have to go?

CHOOSE	SOMETIMES	HAVE TO GO
36	2	19

VOLUNTEER ACTIVITIES

75c. Do you like your volunteer activities or do you dislike them?

LIKE	DISLIKE
24	0

76c. Did you choose to go to _____?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
10	11	3

77c. Is that a bad place to go or a good place to go?

GOOD	IN-BETWEEN	BAD
24	0	0

78c. Do you like the hours of your volunteer activities?

YES	IN-BETWEEN	NO
23	0	0

79c. Do you get enough hours of volunteer time or would you like more hours?

ENOUGH	IN-BETWEEN	MORE
19	0	5

83c. Are people you spend time with when you volunteer mean to you or nice to you?

NICE	IN-BETWEEN	MEAN
22	1	1

85c. Did you choose (or pick) who helps you at your volunteer site?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
5	7	3

86c. Show me how you feel about the people you spend time with when you volunteer.

HAPPY	IN-BETWEEN	SAD
21	0	1

87c. Do the people you spend time with when you volunteer treat you okay, or do they not respect you?0.

RESPECT	IN-BETWEEN	NO RESPECT
23	1	0

89c. Show me how you feel about your volunteer activities.

HAPPY	IN-BETWEEN	SAD
21	1	0

FRIENDS and SOCIAL SUPPORT

Do you have friends you like to be with?

* 93. Show me how Friend's name usually makes you feel. (Friends 1-5)

FRIENDS	HAPPY	IN-BETWEEN	SAD
1	99	7	2
2	78	6	1
3	50	1	4
4	31	1	0
5	17	0	1

94. Do you have enough friends or do you wish you had more friends?

ENOUGH	IN-BETWEEN	MORE
72	0	46

* 95. Do you hardly ever get to see your friends, or do you see your friends when you want to see them?

WHENEVER	SOMETIMES	HARDLY EVER
70	6	37

96. Who do you talk to when you need to talk to someone?

SOMEONE NAMED	NO ONE
115	5

* 97. Do you have any best friends? (Is there someone you tell personal things too?)

SOMEONE NAMED	NO ONE
77	38

98. If you need help, who do you ask to help you?

SOMEONE NAMED	SOMEONE, NO NAME	NO ONE
109	0	10

99. Does anyone ask you to help them?

SOMEONE NAMED	SOMEONE, NO NAME	NO ONE
81	0	37

100. On most days, are you usually happy or sad?

HAPPY	IN-BETWEEN	SAD
96	17	6

101. Are you lonely or do you have plenty of friends?

PLENTY	IN-BETWEEN	LONELY
93	5	19

* 102. Do you ever feel lonely, like you don't have anyone to talk to?

NO	SOMETIMES	YES
68	30	19

FAMILY:

103. Does your family make you upset or happy?

HAPPY	IN-BETWEEN	UPSET
85	12	3

* 104. Do you get to see your family as much as you want?

YES	IN-BETWEEN	NO
66	3	31

105. Show me how you feel about your family.

HAPPY	IN-BETWEEN	SAD
95	13	3

ACTIVITIES

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

Activity Do you ever...	If answer is yes, then alternating the order each time, ask: Do you go/do as much as you want or do you hardly ever get to go?		If answer is no, then ask: Do you want to go to ___?	
	AS MUCH AS=2	HARDLY EVER=0	NO=2	YES=0
*106. go shopping	86	22	4	2
*107. go out on errands or appointments	80	18	8	6
*108. go out for exercise	77	17	14	4
*109. play any sports	58	21	19	14
110. go out for entertainment	62	28	12	13
*111. go out to eat	78	29	2	6
*112. go to church/synagogue	35	14	46	20
113. stay home and do fun things	99	12	2	1
114. visit friends/family	74	26		10

GUARDIANSHIP

115. Do you get to see or talk to your guardian when you want to? (Persons with guardianship)

YES	SOMETIMES	NO
60	5	8

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

CHOSE	IN-BETWEEN	SOMEONE ELSE CHOSE
31	1	41

117. Show me how you feel about (guardian).

HAPPY	IN-BETWEEN	SAD
83	13	7

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

OWN DECISIONS	GUARDIAN
52	20

SERVICE AGENCY

119. Show me how you feel about your caseworker.

HAPPY	IN-BETWEEN	SAD
105	13	1

* 120. Did you choose (or pick) your caseworker?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
21	23	62

121. Do you get to see your caseworker when you want to?

YES	SOMETIMES	NO
87	7	12

122. When you want to talk to (case worker) is it easy or hard to get in touch with him/her?

EASY	IN-BETWEEN	HARD
62	26	16

* 123. When you ask _____ for help, does he/she get you what you need?

YES	SOMETIMES	NO
98	2	4

124. Have you had a lot of different case managers?

NO	YES, NO PROBLEM	YES, IT IS A PROBLEM
47	34	23

125. Show me how you feel about (your service agency).

HAPPY	IN-BETWEEN	SAD
104	15	7

126. Did you have a service plan meeting this year?

YES	NO
87	15

127. When you have your ISA (IPP/ISP) meetings, do people listen to what you have to say?

LISTEN	SOMETIMES	DON'T LISTEN
90	2	0

128. Did you get what you wanted in your ISA (IPP/ISP)?

YES	SOMEWHAT	NO
77	10	3

129. Are the things that are important to you in your ISA (IPP/ISP)?

YES	SOMEWHAT	NO
83	2	4

130. Do you have a group of friends and family that you count on to help you make decisions?

YES	NO
91	24

131. Tell me what agency services are available to you?

NAMED	COULD NOT NAME
37	70

132. Are there other supports and services you wish you had that you don't have now?

NO	YES, BUT DID NOT NAME	YES, NAMED
84	5	15

133. Do you know how much money from (your agency) you have to spend on services?
(Do you know how much your budget is?)

YES, GIVES FIGURE	YES, DID NOT GIVE FIGURE	NO
4	9	97

134. Do you know how you can use your money/budget for services?

YES, NAMED	YES, BUT DID NOT NAME	NO
12	6	78

135. Who do you ask for help with using your money/budget to get services?

YES, NAMED	YES, BUT DID NOT NAME	NO
30	3	6

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

TOLD	NOT AWARE
29	86

137. Have you ever made a formal written complaint to someone at your agency?

NO	YES
97	16

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

TOLD	NOT AWARE
16	96

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

LISTEN	SOMETIMES	NOT LISTEN
104	10	3

140. Do you have trouble changing the things you don't like or do people at (your agency) help change things you don't like?

HELP CHANGE	TROUBLE CHANGING
83	16

141 Are you having trouble getting the help you need or are you getting the help you need?

GET HELP	TROUBLE
104	4

142. Who would you ask to help you change services or supports you do not like?

NAMED	SOMEONE, BUT DID NOT NAME	NOBODY NAMED
90	2	18

143. Do you ever get to learn new things (skills)? (Do people help you learn new things?)
 Y/N What are they? _____

NAMED	YES, BUT DID NOT NAME	NO
63	16	31

144. Show me how you feel about the help you get from (your agency).

HAPPY	IN-BETWEEN	SAD
108	12	5

HEALTH CARE

145. Do you get to see your doctor when you want to?

YES	NO
109	6

146. Show me how you feel about the doctor you see when you are sick or when you have checkups.

HAPPY	IN-BETWEEN	SAD
107	12	8

147. Do you get to see your dentist when you want/need to?

YES	NO
99	13

148. Show me how you feel about your dentist.

HAPPY	IN-BETWEEN	SAD
91	14	9

149. Are there any other health services that you would like to have?

NO	YES, NOT NAMED	YES, NAMED
104	3	3

VOTING

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

YES	NO
57	59

151.(First Ask) Do you want to vote in elections or do you not want to vote in elections?

If “NO”, then ask, Do you vote in elections?

If “YES”, then ask, Do you vote in elections?

YES	NO
93	21

SELF-ADVOCACY

* 152. Have you gone to a self-advocacy meeting or conference, or have you not been able to go)?

GONE	NOT GONE
28	83

153. Why did you go to the self-advocacy meeting, conference, or event? (Check primary reason)

INFORMATION	SOCIAL OPPORTUNITY	PART OF SELF ADVOCACY MOVEMENT	OTHER
16	8	2	5

- Why haven't gone or been able to go? (Check primary reason)

NOT ENOUGH TIME	NOT INTERESTED	NO RIDE	DID NOT KNOW ABOUT IT	OTHER
7	24	8	29	6

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

YES	NO
87	25

156. Do you want to know more about self-advocacy or do you know enough about it?

ENOUGH	MORE
68	43

SELF-DETERMINATION

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

ENOUGH	MORE
95	22

158. Are there choices you wish you could make that you don't make now?

YES, NAMED	YES, NOT NAMED	NO
74	13	22

159. Were you involved in the interviewing and hiring of any of your support staff or were they assigned to you?

INVOLVED	ASSIGNED
17	82

160. Do you need to know more about how to interview and hire your support staff?

NO	YES
72	30

APPENDIX D:

Satisfaction and Type of Developmental Home
(STATE 2002)

During the summer of 2002 interview sessions, consumers living in Development Homes were divided into Developmental Homes with Families and Developmental Homes with Paid Roommates. To determine if the type of Developmental Home living situation made a significant difference in satisfaction across the state, t-test comparisons for satisfaction subscales were made between consumers living in Developmental Homes with a Family and consumers living in Developmental Homes with a Paid Roommate. There were no differences in satisfaction on any subscale. Since the two Developmental Home living situations were similar in all other outcomes for the 2002 survey they were combined for further analyses at the agency level.

Subscales and Total Satisfaction by Developmental Home Residential Type
(STATE 2002)

Reported as Average Percent Satisfied or Percent Positive

Subscale	DH Roommate	DH Family	Mean For All Persons
Number People	23	19	42
Residential	87	90	89
Autonomy	66	67	67
Neighborhood	88	91	90
Work	85	91	87
Day Program	89	93	91
Social Support	80	78	79
Activities	69	76	72
Guardianship	67	70	69
Services	82	79	81
Health	90	94	92

Note: There were no differences between types of developmental home on any subscale (for p < .05).