

**SURVEY OF ADULT CONSUMERS OF DEVELOPMENTAL
SERVICES**

STATE OF VERMONT – 2003 REPORT

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

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Consumer Survey Project
Waterbury, Vermont

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 (NCI) project, a project including 21 states that provides a 'report card' on services for adults receiving developmental services. Additional questions have also 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 355 adult consumers of developmental services from five agencies in the State of Vermont during the summer of 2003. The five agencies include Community Access Program (CAP) in Rutland County, Howard Community Services (HCS) in Chittenden County, Lamoille County Mental Health Services (LCMH), Lincoln Street Incorporated (LSI) in Southeast Vermont, and Community Developmental Services (CDS) in Washington County. 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, types of work and day activity, and types of guardianship on consumer satisfaction.

PROJECT STAFF

Since the inception of the statewide consumer surveys in 1995, the State Division of Developmental Services has taken steps to obtain the consumer's own point of view and to eliminate possible bias or influence. Prior to 2003, the Division contracted with Drs. Culbert and Burchard as independent psychologists affiliated with the University of Vermont to coordinate and implement the collection of consumer satisfaction interviews on a statewide basis. Rosemary Drabing, an independent contractor with extensive experience with the Vermont developmental service system, took over project coordination in 2003, while Drs. Culbert and Burchard provided consultation services during the 2003 project setup. Six field interviewers were hired and trained to complete the consumer interviews. The interviewers in summer 2003 included two psychology Ph.D. students, one teacher, a former UVM staff member and two consumers of developmental services. Rosemary Drabing took responsibility for survey data entry and then passed the de-identified data for analysis to Janet Bramley of the Research and Statistics Unit of the Department of Developmental and Mental Health Services.

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, based on the size of 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 a sampling of selected agencies, based upon size of agency and regional representation. In addition, all interviews have been conducted over the course of three years instead of four years. Such sampling allows agency participation to be completed in one year rather than over four years for all but the largest agency (at their request, random sampling has been completed over the course of three years).

During the summer of 2003, project staff went to the 5 agency sites to gather demographic information on selected participants 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 355 survey participants in 2003. Demographic information about all participants was collected, and 167 participated in direct interviews. Table 1 on page 3 shows the type of interview completed. There were 145 consumers who were able to participate in the full self-report interview and 22 who could participate in the picture only sections of the interview. Added to the 95 consumers who were scheduled to have demographic data only collected, there were 9 people who could not complete the interview, 60 who chose not to participate (either by a direct refusal or two no shows), 4 who could not get to the interview and 20 who did not participate for other reasons. This left a total of 188 people for whom demographic information only was collected. The interviews took an average of 44 minutes to complete during the summer of 2003.

Table 1 below shows how many consumers completed interviews and the type of interview completed for all five agencies. Table 2 shows the living situations for the participants in the interview group and the group for whom only demographic data were collected. The majority lived in a family-type setting: 185 (52%) lived in a developmental home with a family and 75 lived with their own families ((21%). Fifty-four (15%) were living semi-independently, receiving regularly scheduled or intermittent hourly supervised supports rather than full 24 hour residential supports. Twenty-six (7%) lived in a staffed setting and 14 (4%) in developmental home with a professional roommate.

Table 1 - Types of Interviews Conducted (N=355)

	Agency					Total
	CAP	HCS	LCMH	LSI	CDS-WCMH	
Interview						
Full interview	31	35	23	25	31	145
Picture only	7	2	5	2	6	22
Total Interviews	38	37	28	27	37	167
Demographics Only						
Agency decision	41	6	3	15	26	91
Guardian's decision	1	0	0	0	3	4
Unable to complete	4	1	2	0	2	9
Person's choice	19	9	4	1	27	60
Person out of town	0	2	1	0	0	3
Person incapacitated	0	1	0	0	0	1
Scheduling oversight	1	0	0	0	2	3
Other	5	5	1	1	5	17
Total Demographics Only	71	24	11	17	65	188
Total Participants	109	61	39	44	102	355

Table 2 - Number of Consumers by Residential Type*

Residential Type	Consumer Interviews	Demographics Only	All Consumers
DH- Family	86	99	185
DH-Roommate	5	9	14
Family Home	38	37	75
Semi-independent	33	21	54
ICF/Nursing	1	2	3
Group Home	1	12	13
Staffed Residence	1	0	1
RCH	1	5	6
Nursing facility	1	2	3
Other	0	1	1
Total	167	188	355

* ICF/Nursing = Intermediate Care Facilities/Nursing Facilities

During 2003 two Developmental Home types were reported:

DH/Family = Developmental Homes with Families

DH/Roommate = Developmental Homes with Paid Roommates

RCH = Residential Care Homes

Table 3 shows the developmental disability as noted in their record for the 355 participants, and Table 4 shows how many participants experience additional challenges. Many consumers in the interview, as well as the demographic only group had additional challenges. Overall 276 (78%) participants had one or more additional challenges.

Table 3 – Developmental Disability Label

Disability Label	Consumers Interviewed (n=167)	Demographics Only (n=188)	All Consumers (n=355)
Mild MR	108	67	175
Moderate MR	39	26	65
Severe MR	8	40	48
Profound MR	3	38	41
Unspecified MR	1	6	7
Autism*	0	4	4
Aspergerger's Syndrome	3	2	5
PDDNOS	1	1	2
Missing Data	4	4	8
Total	167	188	355

* Seven of those interviewed and five of those not interviewed this year had an autism diagnosis in addition to an MR label and are listed only under the MR disability in Table 3.

Table 4 - Number of Individuals with a Particular Challenge

Challenge	Consumers Interviewed (n=167)	Demographics Only (n=188)	All Consumers (n=355)
Cerebral Palsy	11	28	39
Brain Injury	6	6	12
Chemical Dependence	3	3	6
Mental Illness	60	64	124
Medically Fragile	3	8	11
Physically Challenged (other than mobility)	3	4	7
Hearing	16	20	36
Seizures	42	50	92
Other	59	82	141
Non-Ambulatory	10	34	44
Uses Cane, Walker, or Wheelchair	22	53	75

Table 5 shows the level of communication reported for the 355 participants: adequate reliable speech, spoken communication that is understood by those who are familiar with the individual, and non-verbal which includes methods such as gestures, signing, picture boards, electronic communication, facilitated communication, etc.

Table 5 - Communication Methods Used by Participants

Level of Communication	Consumers Interviewed (n=167)	Demographics Only (n=188)	All Consumers (n=355)
Adequate, Reliable Speech	140	78	218
Spoken (Familiar Only)	13	21	34
Non-Verbal Communication	14	71	85
None Reported	0	18	18
Total	167	188	355

The 355 consumers who participated were between the ages of 18 and 87 years with a median age of 42 years. There were 172 females and 183 males. Sixty-three of the participants were independent of a guardian. There were 158 people who had private guardians and 134 who had public Guardianship Services.

Demographic data collected included the consumers’ residential locations. There were 71 consumers who lived in a town or village, 95 who lived within walking distance of a town or village, 189 who lived in rural areas, and 3 people had missing data. Other demographic data collected included information about court ordered restrictions (e.g., Act 248, probation, etc.), annual physicals, and family involvement. Seven individuals in this sample had court ordered restrictions. There were 273 consumers that had seen a doctor within the last year, and 291 that had family involved in their lives. Case managers reported that the family members of the other 64 consumers were not involved because they were deceased, not in the area, or chose not to be involved.

Table 6 shows how many individuals received the different types of services available in Vermont. There were 296 people who received home and community based waiver funded services. There were 44 who “self manage” their services, 22 of whom provided direct consumer interview information. Sixteen consumers who were managing at least some of their own services were involved in the hiring of support staff.

Table 6 - Number of Individuals Receiving Services

Service Type	Consumers Interviewed (n=167)	Demographics Only (n=188)	All Consumers (n=355)
Case management	153	166	319
Home Support	102	117	219
Employment Support	76	36	112
Community Support	86	108	194
Family Respite	73	80	153
Clinical Intervention	54	67	121
Crisis Services	57	52	109
Transportation	62	64	126
Other	13	25	38

Of the total number of participants, 136 had some form of paid work. Table 7 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 14 hours a week. The two main categories of employment were independent competitive employment with follow along support only (49% of those working) and individually supported employment (48% of those working).

Table 7 - Type and Number of Hours of Employment

Employment Type	Consumers Interviewed (n=167)		Demographics Only (n=188)		All Consumers (n=355)	
	People	Mean Hours	People	Mean Hours	People	Mean Hours
Competitive Employment	46	15	21	20	67	17
Supported Employment	43	12	22	10	65	11
Enclave	2	20	1	12	3	17
Unknown	1	8	0	0	1	8
Total	92	14	44	15	136	14

Of the 355 participants, 220 (62%) had daytime activities. Table 8 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 19 hours of daytime support per week. The types of support were individualized, group activities, both group and individual support, and PASARR activities. Individualized support, the main day program type, was received by 189 (86%) of the 220 participating in daytime activities.

Table 8 – Type and Number of Hours for Daytime Activities

Day Program Type	Consumers Interviewed (n=167)		Demographics Only (n=188)		All Consumers (n=355)	
	People	Mean Hours	People	Mean Hours	People	Mean Hours
Individualized and/or Companionship	85	17	104	20	189	19
Group Activity	3	20	4	9	7	14
PASARR*	0	0	1	30	1	30
Both Individualized and Group	10	18	13	22	23	20
Total	98	17	122	20	220	19

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

RESULTS

Table 9 below shows basic demographics and the residential living situation of the consumers who completed the 2001, 2002 and 2003 surveys.

Table 9 - Respondent Profiles 2001, 2002, and 2003

	2001 Sample (N=253)		2002 Sample (N=136)		2003 Sample (N=167)	
Age						
Mean	40		43		42	
Median	39		42		42	
Minimum	18		19		18	
Maximum	87		89		84	
Gender	Number	Percent	Number	Percent	Number	Percent
Male	140	55%	76	56%	85	51%
Female	113	45%	60	44%	82	49%
Developmental Disability Label	Number	Percent	Number	Percent	Number	Percent
Mild MR	188	74%	109	80%	108	65%
Moderate MR	45	18%	17	13%	39	23%
Severe MR	7	3%	0	0%	8	5%
Profound MR	0	0%	0	0%	3	2%
Unspecified MR	1	0.4%	2	1%	1	1%
Asperger's Syndrome	1	0.4%	1	1%	3	2%
Autism *	1	0.4%	0	0%	0	0%
PDD NOS	0	0%	0	0%	1	1%
Unknown	10	4%	7	5%	4	2%
Living Situation	Number	Percent	Number	Percent	Number	Percent
DH/Family	65	26%	19	14%	86	51%
DH/Roommate	14	6%	23	17%	5	3%
DH/Neighbor	1	0.4%	0	0%	0	0%
Family Home	74	29%	42	31%	38	23%
Semi-independent	59	23%	26	19%	33	20%
ICF / Nursing	5	2%	2	1%	1	1%
Group Home	14	6%	3	2%	1	1%
Staffed Residence	7	3%	4	3%	1	1%
RCH	9	4%	7	5%	1	1%
Other	5	2%	8	6%	1	1%

* Of those completing interviews, there were 5 people in 2001, 1 person in 2002, and 7 people in 2003 who had an MR label and who also had a diagnosis of autism.

Table 10 shows the living situation of the consumers who completed interviews together with their level of cognitive challenge.

Table 10 - Living Situation by Disability Label for 167 Respondents

Residential Type	Mild MR	Moderate MR	Severe MR	Profound MR	Unspecified MR	Autism*	Aspergerger's Syndrome	PDDNOS	Missing Data
DH- Family	44	31	5	3	1	0	1	1	0
DH-Roommate	4	0	1	0	0	0	0	0	0
Family Home	28	7	1	0	0	0	0	0	2
Semi-independent	29	1	1	0	0	0	2	0	0
ICF/Nursing	1	0	0	0	0	0	0	0	0
Group Home	0	0	0	0	0	0	0	0	1
Staffed Residence	1	0	0	0	0	0	0	0	0
RCH	1	0	0	0	0	0	0	0	0
Nursing facility	0	0	0	0	0	0	0	0	1
Total	108	39	8	3	1	0	3	1	4

* Of those completing interviews, there were 5 people living in Developmental Homes with Families, and 2 people living with their natural families who had an MR label and who also had a diagnosis of autism.

Table 11 shows the living situation of the consumers who completed interviews together with their guardianship status: public guardianship services, private guardianship or independent of guardianship.

Table 11 - Living Situation by Guardianship Status for 167 Respondents

Residential Type	Guardianship Services Specialist (GSS)	Private Guardian	Independent	Total
DH- Family	49	32	5	86
DH-Roommate	2	2	1	5
Family Home	0	27	11	38
Semi-independent	3	10	20	33
ICF/Nursing	1	0	0	1
Group Home	0	1	0	1
Staffed Residence	1	0	0	1
RCH	1	0	0	1
Nursing facility	0	1	0	1
				0
Total	57	73	37	167

Selected Findings from Direct Consumer Interviews

The remaining sections of this report focus on findings from the 167 direct consumer interviews. The responses of all 167 consumers to the 160 individual survey items are found in Appendix C. The following are selected findings from those responses.

RESIDENTIAL

- 134 consumers were happy where they were living, 21 consumers wanted to live somewhere else, and 11 people were in-between
- 124 consumers felt that where they lived was a good place to live, 13 consumers felt they lived in an in-between place, and 6 felt it was a bad place
- 33 people said there was a better place to live and named it, 2 people said there was a better place to live but could not name it, and 104 people said there was not a better place to live
- 16 who live semi-independently felt happy living alone and 2 felt in-between. Of these, 6 said they would like to have someone live with them, 4 naming who they would like to live with
- 123 consumers were happy about their free time spent at home, 28 were in-between, and 13 people were sad
- 93 consumers felt that there were fun things to do at home, 31 people were in-between, and 18 people were bored at home
- 39 people wanted more chores at home, 6 people sometimes would like more chores, and 92 people had enough chores
- 91 consumers felt the rules at their homes were good rules, 11 consumers felt the rules were in-between, and 5 felt like the rules were bad
- 55 of 139 people said that someone had talked to them about dating and 53 need to know more about dating
- 9 people reported that people enter their home without asking and 137 people said it did not happen
- 13 consumers reported that people enter their bedrooms without asking

AUTONOMY

- 68 people reported having a choice in where they lived, and 68 people felt they did not have a say
- 57 people said that someone else picked what they eat, but they liked it, 15 said someone else picked what they eat and they did not like it, and 70 people picked what they ate

- 55 of 70 consumers felt they had no say about with whom they live
- 89 consumers reported that someone else makes the rules for living at their house; 18 consumers reported making their own rules
- 110 consumers reported that they were allowed to invite friends and family over when they wanted to, 4 people could sometimes invite friends or family over, and 23 consumers could not
- 49 consumers said they make decisions about visits, and 76 people reported someone else makes decisions
- 81 consumers said they have privacy when their friends visit, 11 said sometimes and 37 said they could not be alone when their friends visit
- 72 consumers have their own money, and 71 consumers have to ask for their money
- 105 consumers decide how they spend their money, and 34 consumers said someone else decides
- 92 of 143 consumers said that they cannot go out whenever they want, they had to wait for someone to take them

NEIGHBORS/NEIGHBORHOOD

- 112 people said the neighbors were friendly, 4 people said they were sometimes friendly and 9 people said they were not
- 18 individuals wanted to live in a different neighborhood that they named, 9 people wanted to live in a different neighborhood but could not name where, and 109 people liked their neighborhoods
- 122 consumers feel safe in their neighborhood, and 11 consumers felt unsafe

WORK

- 92 consumers did some form of paid work: 46 had independent competitive jobs with follow-along support only, and 43 had individually supported jobs
- 9 of 43 individuals who were not working indicated that they wanted a job
- Work hours ranged from .5 to 40 hours per week (median = 11 hrs./wk)

- 76 people reported that the place where they worked was a good place to work, 4 people were in-between, and 1 person said it was a bad place
- 82 were happy with their jobs, 9 people were in-between and 2 people were sad
- 31 of 82 people said they would like to work more hours
- 76 respondents indicated that people at work treat them with respect, 3 people were in-between, and 2 did not feel respected by co-workers
- 20 people chose their job coach with assistance, 6 consumers made the choice unassisted and 22 people reported that someone else chose
- 24 named something else they would rather do during the day, 3 could not name it and 53 did not want to do something different

DAYTIME ACTIVITIES

- 98 people interviewed participated in daytime activities, 85 people had individual daytime activities, 3 people had group daytime activities, and 10 people had both individual and group activities
- Daytime activity hours ranged from 1 to 40 hours per week (median 17 hrs./wk.)
- 8 consumers were happy with their group daytime activities, 3 were in-between and 1 was sad. 11 felt it was a good place to go
- 4 named something else they would rather do than their group activity during the day, 2 could not name it and 4 did not want to do something different
- 73 of 74 people reported they liked their individual daytime activities programs
- 45 consumers felt they had enough hours of daytime activities and 31 reported wanting more
- 12 chose their individual day program support person unassisted, 22 with assistance and 36 reported someone else chose their support person
- 43 consumers engaged in volunteer work activities on a regular basis which involved from 1 to 20 hours per week (median = 4 hrs./wk.)
- 14 of 36 people wanted more hours to volunteer
- 36 people reported they were happy with their volunteer activities, 3 were in-between and 3 were sad

FRIENDS/SOCIAL SUPPORT

- 83 people indicated that they had enough friends, and 55 people indicated wanted more friends
- 133 respondents indicated that if they need help there is someone to help them, and 6 people said there was no one to help
- 90 of 138 individuals said they had a best friend and 48 said they did not
- 17 people felt like there was no one to talk to, 42 people were sometimes lonely, and 78 people were not lonely
- 82 people said they see their family members as much as they want while 40 consumers said they did not

COMMUNITY SERVICES

- 138 people indicated that they were happy with their services agency, and 18 people felt in-between about the help he/she received
- 138 people were happy with their case managers, 13 people were in-between, and 1 person was sad about his/her case manager
- 84 people said someone else chose their case managers, 39 people chose their case manager with help, and 7 people chose unassisted
- 111 individuals could see their case managers when they wanted, 14 could sometimes see their case manager when they wanted, and 9 people could not see their case managers when they wanted
- 88 people said it was easy to reach their case managers, 22 people were in-between, and 20 people said it was hard to reach their case managers
- 60 of 128 consumers said they had had a lot different case managers. 39 did not feel this was a problem and 21 said it was a problem
- 111 people were happy with their guardians, 10 people were in-between, and 4 people were sad about their guardians
- 52 people indicated that their guardians let them make some decisions for themselves and 47 people said their guardian made all the decisions
- 101 consumers felt listened to at their ISA meetings and 2 people felt sometimes listened to and 2 said they were not listened to

- 59 people had been told about their agency complaint process, and 77 people were not aware of their agency complaint process

ACTIVITIES

- Most people participated in the activities they wanted to
- The major activities people said they wanted to do more were: going to church or synagogue (23%), going out for entertainment (16%), visiting friends and family (12%), and playing sports (9%)

OPPORTUNITIES

- 111 people had made their own choice about voting, either wanting to vote and voting, or not wanting to vote and not voting
- 89 people had made their own choice about attending a self-advocacy meeting, either wanting to go and attending, or not wanting to go and not attending
- The primary reasons consumers cited for going to a self-advocacy meeting were to get information or for the social opportunities it presented; the primary reasons consumers cited for not going were because they did not know about it, they were not interested, or they did not have enough time
- 82 felt they knew enough about self-advocacy/determination and 46 people would like to know more
- 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
- 25 said they need to have more control over their life and 107 said they had enough control
- 44 said there are choices they wish they could make that could not make now and 31 could name those choices

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. For a copy of the 2003 survey see Appendix A; for the questions that make up the subscales, see Appendix B; for responses to each of the 160 questions see Appendix C.

The results of the satisfaction survey for consumers are presented by Type of Residence, Type of Employment, Type of Day Activity, and Type of Guardianship. 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. The main overall finding was that more Autonomy satisfaction was reported by those living semi-independently, in competitive work and independent of guardianship.

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. In this sample there were 86 respondents living in Developmental Homes with Families and only 5 in Developmental Homes with roommates. The results of this analysis are shown in Appendix D. The analysis showed that those living with a roommate tended to be less satisfied on all subscales other than autonomy where their satisfaction was higher. Only the Health subscale scores were statistically significantly different. Since healthcare is not a primary focus of the survey, the two categories of Developmental Homes were collapsed into one for comparison with Family Homes and Semi-independent living. Table 12 on page 15 shows satisfaction subscales by residential type and for all respondents.

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

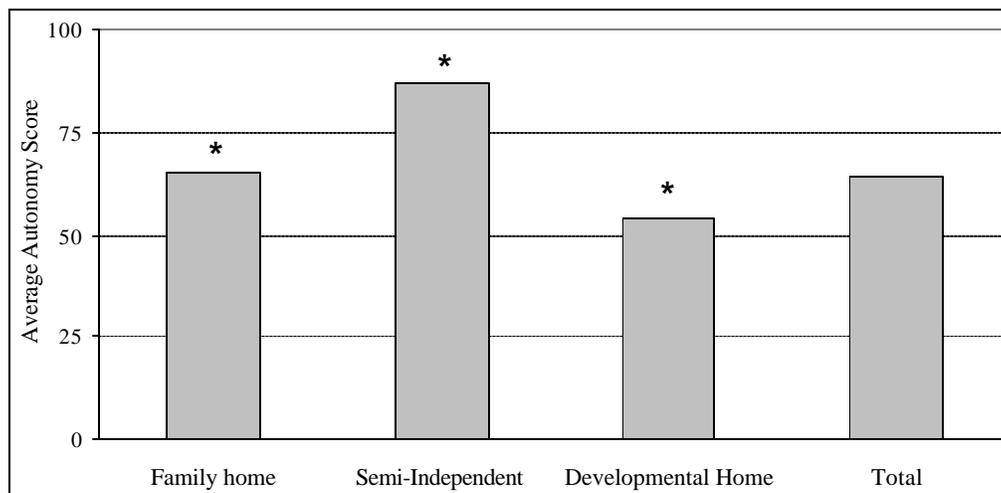
combination of the two. Autonomy was the only factor where a significant difference in satisfaction was found between persons living in different types of residence. Persons in Semi-Independent living situations scored significantly higher on the autonomy subscale than persons living in Developmental Homes or their Family Home. Furthermore, individuals in Family Homes differed significantly on the autonomy subscale from individuals in Developmental Homes (see Figure 1 for graphic presentation of significant differences).

**Table 12 - Subscales and Total Satisfaction By Residential Type
(Reported as Average Percent Satisfied or Percent Positive)**

Subscale	Family Home	Semi-Independent Living	All Developmental Homes	Mean for Three Types of Residence	Mean for all Individuals Surveyed
Number of People	38	33	91	162	167
Residential	88%	89%	87%	87%	87%
* Autonomy	65% ^b	87% ^a	54% ^c	64%	64%
Neighborhood	91%	86%	85%	87%	87%
Work	92%	89%	89%	90%	90%
Day Program	90%	93%	88%	89%	89%
Social Support	82%	81%	79%	80%	80%
Activities	77%	82%	77%	78%	78%
Guardian	79%	76%	68%	71%	71%
Community Services	84%	80%	85%	84%	83%
Health	90%	92%	88%	89%	89%

* 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 - Autonomy Satisfaction By Residential Type



* Indicates a significant difference $p < .05$

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. For a 'positive' versus 'not positive' analysis, consumers' negative and in-between responses were combined. This allowed for an examination of more complete data tables. These analyses compare the responses between consumers living in Developmental Homes, Family Homes, and Semi-Independent living situations. The other living arrangements had too few persons to be included in these comparisons. The consumers' original responses to those items where significant differences were found are listed beginning on this page.

A number of differences in Autonomy between the three living situations were found. Generally, persons in Semi-Independent living situations reported more autonomy and those in Developmental Home living situations reported less autonomy, but 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 statistically significant differences in 21 out of 30 questions on that subscale.

For six questions about when to do things, what chores to do, making rules, deciding on visits, having their own money, and coming home (Questions #9, 26, 30, 36, 48 and 57):

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

For four questions about picking what to wear, private time, using the telephone, and using their own house key (Questions # 8, 37, 38 and 61):

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

For two questions about picking what to eat, and coming home (Questions # 7 and 58):

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

For eight questions about choosing who they live with, what to do for fun, having a beer, inviting friends and family, telephone privacy, being alone with guests, being able to be home alone and having a door key (Questions # 13, 22, 33, 35, 40, 41, 59 and 60):

- Persons in Semi-Independent living situations were more autonomous than persons living in Developmental Homes but not statistically different from persons living in Family Homes

For one question about choosing the place to live (question #3)

- Persons in Developmental Homes were more autonomous than persons in Family Homes

Individual Item Responses - Residential Autonomy by Residence Type

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

	Family Home ^b	Semi-Independent	Developmental Home ^a
YES	11	13	44
NO	23	17	25

7. Who decides (picks) what you eat?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^c
SELF	20	29	20
OTHER, LIKE IT	15	2	37
OTHERS, DON'T LIKE IT	2	0	13

8. Who decides (picks) what you wear?

	Family Home ^a	Semi-Independent ^a	Developmental Home ^b
SELF	34	30	51
OTHER, LIKE IT	3	1	20
OTHERS, DON'T LIKE IT	0	0	2

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

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
YES WITHOUT ASSISTANCE	22	28	41
YES WITH ASSISTANCE	11	1	14
NO SOMEONE ELSE CHOOSES	3	1	16

13. Did you have any say about who lives there with you? (if not living with family)

	Family Home	Semi-Independent ^a	Developmental Home ^b
YES ANSWERED WHO	N/A	5	8
YES DID NOT KNOW WHO	N/A	1	0
NO	N/A	2	44

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

	Family Home	Semi-Independent ^a	Developmental Home ^b
YES WITHOUT ASSISTANCE	27	29	48
YES WITH ASSISTANCE	6	1	18
NO SOMEONE ELSE CHOOSES	1	1	6

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

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
PICK	21	30	50
IN-BETWEEN	6	1	4
TOLD	5	0	12

30. Who makes the rules for living here?

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
SELF	3	12	3
OTHERS	24	8	52

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?

	Family Home	Semi-Independent ^a	Developmental Home ^b
HAVE A DRINK	13	16	16
NO DRINKING ALLOWED	12	3	21

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

	Family Home	Semi-Independent ^a	Developmental Home ^b
YES	26	27	54
SOMETIMES	1	0	2
NO	7	0	15

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

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
SELF	9	22	17
OTHER	24	3	47

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

	Family Home ^a	Semi-Independent ^a	Developmental Home ^b
YES	33	28	52
IN-BETWEEN	3	1	7
NO	0	1	15

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

	Family Home ^a	Semi-Independent ^a	Developmental Home ^b
YES	30	30	44
SOMETIMES	2	1	5
NO	3	0	24

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

	Family Home	Semi-Independent ^a	Developmental Home ^b
PRIVATE	22	27	35
SOMETIMES	5	3	6
LISTEN	5	0	15

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

	Family Home	Semi-Independent ^a	Developmental Home ^b
HAVE PRIVACY	20	27	34
SOMETIMES	3	2	5
NOT ALONE	9	1	25

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

	Family Home ^b	Semi-Independent ^a	Developmental Home ^b
HAVE	18	27	25
ASK	18	4	47

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
WHEN WANT	13	25	31
WAIT	23	6	59

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 ^c
WHEN WANT	15	25	15
WAIT	20	6	57

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

	Family Home	Semi-Independent ^a	Developmental Home ^b
CAN STAY ALONE	24	12	32
SOMETIMES	5	0	6
HAVE TO GO	6	3	34

60. Do you have a key to your house?

	Family Home	Semi-Independent ^a	Developmental Home ^b
YES	23	26	23
NO	12	5	48

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

	Family Home ^a	Semi-Independent ^a	Developmental Home ^b
FREELY	23	24	15
ASK	2	0	7

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 items that make up the Work Satisfaction subscale are presented in Table 13 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 for comparison. 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 13)
- Residential Autonomy was the only subscale where significant differences were found. Those in competitive employment were significantly more autonomous than those in supported employment (Figure 2). This is expected since those living semi-independently were more likely to be in competitive employment and those in Developmental Homes were more likely to be in supported employment.

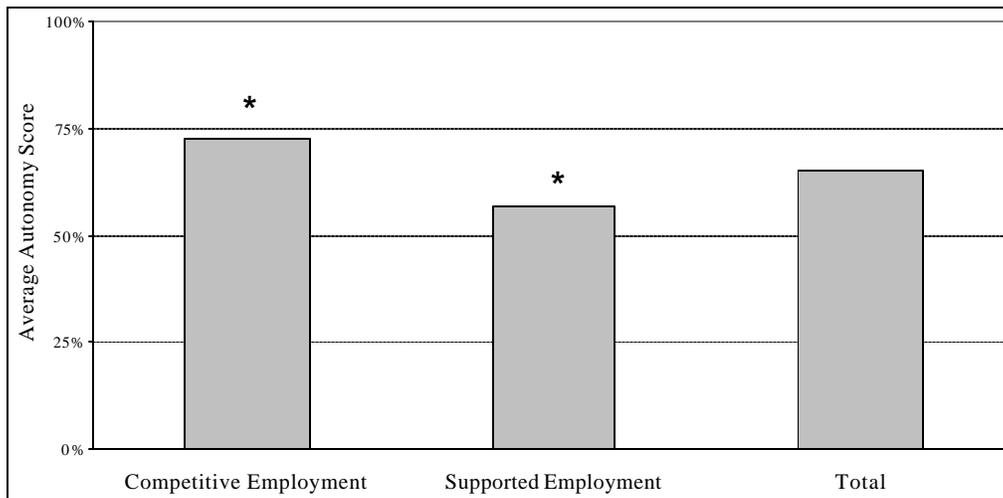
Table 13 - Work Satisfaction By Type of Employment
(Reported as Average Percent Satisfied or Percent Positive)

	Competitive Employment	Supported Employment	Mean for all Employed
Number of People	46	43	92
Work Satisfaction	89%	89%	90%

Consumers worked between .5 and 40 hours a week (median = 11 hours/ week). All individuals in paid work completed the work satisfaction portion of the survey.

Responses in 2003 categorized as competitive employment included follow along support only, while supported employment was used for individuals who receive ongoing assistance at work.

Figure 2 - Autonomy Satisfaction By Type of Employment



* Indicates a significant difference $p < .05$

Satisfaction and Type of Day Activities

The results of the interview questions on Day Activity satisfaction are presented in Table 14 as the average percent satisfaction by type of day activity of a group.

For analysis purposes, satisfaction was examined by the responses of two groups: those receiving Individualized supports only, and those participating in Group supports or a combination of the Individualized and Group supports. (There were 10 consumers with a combination of the Individualized and Group supports and just 3 who had Group activities only). To determine whether there were any real differences in satisfaction, a t-test was performed between persons in these two groups.

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

**Table 14 - Day Activity Satisfaction By Type of Day Activities
(Reported as Average Percent Satisfied or Percent Positive)**

	Individualized and Companionship	Individualized and Group (10) or Group Only (3)	Mean for All Consumers in Day Programs
Number of People	83	12	95
Day Program Satisfaction	90%	87%	89%

Consumers were involved with day activities between .5 and 40 hours a week (median = 11 hours/ week). Discrepancies in the number of respondents reported in Table 8 and Table 14 are due to not all consumers completing the Day Satisfaction portion of the survey.

Satisfaction and Type of Guardianship

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?

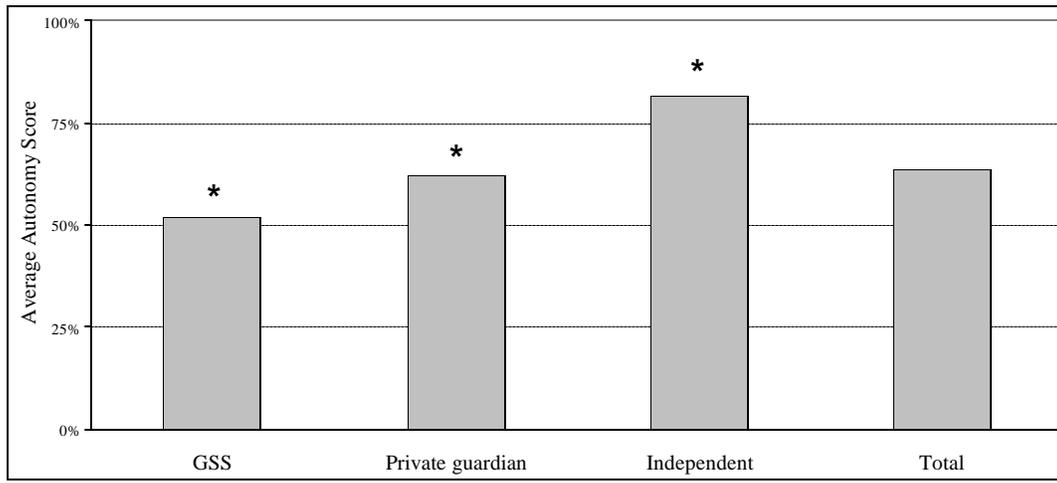
- Individuals with state appointed guardians (Guardianship Services Specialists or GSS) and private guardians did not differ on the Guardian satisfaction subscale (Table 15).
- Residential Autonomy was the only subscale where significant differences were found between the different guardianship status groups. People who do not have a guardian were significantly more autonomous than those that had assigned guardianship. Also people with private guardians were significantly more autonomous than those with public guardians (Figure 3). This is expected since a higher percentage of those living semi-independently had no guardian and a higher percentage of those living in Developmental Homes had a public guardian.

**Table 15 - Guardian Satisfaction By Type of Guardianship
(Reported as Average Percent Satisfied or Percent Positive)**

	Guardianship Services Specialist (GSS)	Private Guardian	Mean for all Guardianship types
Number of People	53	70	123
Guardian Satisfaction	67%	74%	71%

Discrepancies in the number of respondents reported in Table 11 and Table 15 are due to not all consumers completing the Guardian Satisfaction portion of the survey.

Figure 3 - Autonomy Satisfaction by Type of Guardianship



* Indicates significant difference $p < .05$.

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 2003 Survey

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, 54,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, 2003

STATE OF VERMONT (N=167)

The Vermont Consumer Survey Project is participating in a National Core Indicators (NCI) 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” to 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.

Note: For a few questions where there were only two response alternatives, the interviewee gave an ‘in-between’ response. For consistent analysis, these responses were reported as one of the permitted alternatives appropriate to the context of the question. In nearly every instance, only one consumer had given the ‘in-between’ response. A double asterisk (**) shows where these responses have been incorporated.

RESIDENTIAL

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

HAPPY	IN-BETWEEN	SOMEWHERE ELSE
134	11	21

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

GOOD	IN-BETWEEN	BAD
124	13	6

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

YES**	NO
69	68

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

NO	YES, COULD NOT NAME	YES, NAMED PLACE
104	2	33

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

LIKE	IN-BETWEEN	DISLIKE
132	9	3

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

HAPPY	IN-BETWEEN	SAD
139	13	5

7. Who decides (picks) what you eat?

SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
70	57	15

8. Who decides (picks) what you wear?

SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
116	26	2

* 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
92	28	21

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.	121	18	5
2.	92	16	10
3.	54	14	3
4.	22	3	4
5.	7	1	2
6.	2	0	0

(Ask this question if not living with family)

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

YES, ANSWERED WHO	YES, DID NOT KNOW WHO	NO
13	2	55

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.	2	2	0
2.	2	2	0
3.	4	0	0
4.	1	0	0

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

YES, SOMEONE NAMED	NO
1	4

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

NO	YES, NOT A PROBLEM	YES, IT HAS BEEN A PROBLEM
2	0	2

For persons living semi-independently with no roommate:

19. Do you like living by yourself?

YES	NO
17	0

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

NO	YES, FOLLOW UP NOT ANSWERED	YES, FOLLOW UP ANSWERED
11	2	4

21. Show me how you feel about living alone.

HAPPY	IN-BETWEEN	SAD
16	2	0

THINGS TO DO:

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

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
105	27	9

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
101	23	16

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

FUN	IN-BETWEEN	BORED
93	31	18

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

HAPPY	IN-BETWEEN	SAD
123	28	13

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
103	11	17

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

NO	SOMETIMES	YES
115	10	9

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

NO	SOMETIMES	YES
92	6	39

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

HAPPY	IN-BETWEEN	SAD
112	28	10

RULES:

30. Who makes the rules for living here?

SELF	SOMEONE ELSE
18	89

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

GOOD	IN-BETWEEN	BAD
91	11	5

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
69	29

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	NO, FOR MEDICAL REASONS
46	36	50

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

HAPPY	IN-BETWEEN	SAD
100	23	6

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

YES	SOMETIMES	NO
110	4	23

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

SELF	OTHER
49	76

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
114	11	19

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

NO	YES
101	26

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

YES	SOMETIMES	NO
107	8	28

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

PRIVATE	SOMETIMES	LISTEN
85	14	22

* 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
81	11	37

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

YES	NO
55	84

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

NO	YES**
87	53

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

YES	NO
24	9

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
11	1	18

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
15	1	12

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
21	4	7

MONEY:

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

HAVE	ASK
72	71

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

HAPPY	IN-BETWEEN	SAD
134	17	8

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

SELF**	SOMEONE ELSE
105	34

51. Do people steal (take) your money?

NO	YES
137	7

SAFETY:

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

LEAVE ALONE	TAKE
128	9

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

NO	YES
134	6

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

NO	SOMETIMES	YES
116	13	13

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

NO	YES, FOLLOW UP NOT ANSWERED	YES, FOLLOW UP ANSWERED
134	0	8

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

SAFE	IN-BETWEEN	AFRAID
133	2	9

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	WAIT
51	92

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

WHEN WANT	WAIT
57	86

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
69	11	46

60. Do you have a key to your house?

YES	NO
73	68

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

FREELY	ASK
62	10

ACCESS/ TRANSPORTATION

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

YES	SOMETIMES	NO
119	9	14

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	YES
103	31

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**	NO
127	13

PETS:

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

YES	IN-BETWEEN	NO
103	4	2

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

NO	YES
21	14

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

ALLOWED	NO PETS ALLOWED
16	11

NEIGHBORHOOD

68. Are the neighbors friendly toward you?

YES	SOMETIMES	NO
112	4	9

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

NICE	IN-BETWEEN	MEAN
110	9	5

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

LIKE	DIFFERENT, NOT NAMED	DIFFERENT, NAMED
109	9	18

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

TALK	SOMETIMES	IGNORE
104	13	7

72. Show me how you feel about your neighbors.

HAPPY	IN-BETWEEN	SAD
110	24	10

* 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	NOT SAFE
122	11

EMPLOYMENT

74. Do you want to have a paid job?

YES	NO
9	34

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

LIKE	IN-BETWEEN	DISLIKE
74	5	2

* 76. Did you choose to work at ____?

YES UNASSISTED	YES WITH ASSISTANCE	SOMEONE ELSE CHOOSES
19	41	21

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

GOOD	IN-BETWEEN	BAD
76	4	1

78. Do you like the hours you work?

YES	IN-BETWEEN	NO
78	2	2

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

ENOUGH	MORE
51	31

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

IMPORTANT	IN-BETWEEN	NOT IMPORTANT
70	4	3

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

YES	IN-BETWEEN	NO
79	1	2

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

HAPPY	IN-BETWEEN	SAD
83	7	2

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

NICE	IN-BETWEEN	MEAN
74	8	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	NO ONE
78	4

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

YES, UNASSISTED	YES, WITH ASSISTANCE	NO
6	20	22

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

HAPPY	IN-BETWEEN	SAD
79	10	1

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

RESPECT	IN-BETWEEN	NO RESPECT
76	3	2

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

VACATION	ALL THE TIME
75	5

89. Show me how you feel about work.

HAPPY	IN-BETWEEN	SAD
82	9	1

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

NO	YES, NOT A PROBLEM	YES, IT HAS BEEN A PROBLEM
24	49	2

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

NO	YES, BUT DID NOT NAME	YES, NAMED
53	3	24

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

CHOOSE	SOMETIMES	HAVE TO GO
36	1	43

DAYTIME ACTIVITIES- GROUP

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

LIKE	DISLIKE
11	0

76a. Did you choose to go to ____?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
2	3	6

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

GOOD	IN-BETWEEN	BAD
11	0	0

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

YES	IN-BETWEEN	NO
10	0	1

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

ENOUGH	MORE
5	6

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

NICE	IN-BETWEEN	MEAN
10	0	1

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

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
1	2	8

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

HAPPY	IN-BETWEEN	SAD
11	1	0

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
9	1	1

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

HAPPY	IN-BETWEEN	SAD
8	3	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
6	2	1

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

NO	YES, BUT DID NOT NAME	YES, NAMED
4	2	4

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

CHOOSE	SOMETIMES	HAVE TO GO
2	0	8

DAY ACTIVITIES-INDIVIDUAL

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

LIKE	DISLIKE
73	1

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

YES	IN-BETWEEN	NO
69	3	4

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

ENOUGH	MORE
45	31

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

NICE	IN-BETWEEN	MEAN
74	2	1

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

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
12	22	36

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

HAPPY	IN-BETWEEN	SAD
82	7	4

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
71	3	2

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

HAPPY	IN-BETWEEN	SAD
81	8	4

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

NO	YES, NO PROBLEM	YES, IT IS A PROBLEM
39	29	6

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

NO	YES, NOT NAMED	YES, NAMED
48	4	17

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

CHOOSE	SOMETIMES	HAVE TO GO
36	1	35

VOLUNTEER ACTIVITIES

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

LIKE	DISLIKE
33	4

76c. Did you choose to go to ____?

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
11	14	8

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

GOOD	IN-BETWEEN	BAD
36	0	2

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

YES	IN-BETWEEN	NO
36	0	2

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

ENOUGH	MORE
22	14

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

NICE	IN-BETWEEN	MEAN
34	0	2

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

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
2	11	12

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

HAPPY	IN-BETWEEN	SAD
36	3	2

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

RESPECT	IN-BETWEEN	NO RESPECT
34	0	2

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

HAPPY	IN-BETWEEN	SAD
33	6	3

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	130	7	5
2	102	9	2
3	61	7	0
4	33	3	2
5	18	2	0

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

ENOUGH	MORE
83	55

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

WHENEVER	HARDLY EVER
93	35

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

SOMEONE	NO ONE
134	8

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

YES	NO
90	48

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

SOMEONE	NO ONE
133	6

99. Does anyone ask you to help them?

SOMEONE**	NO ONE
102	40

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

HAPPY**	SAD
118	18

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

PLENTY**	LONELY
113	25

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

NO	SOMETIMES	YES
78	42	17

FAMILY:

103. Does your family make you upset or happy?

HAPPY	IN-BETWEEN	UPSET
99	13	12

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

YES	NO
82	40

105. Show me how you feel about your family.

HAPPY	IN-BETWEEN	SAD
117	19	8

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	105**	23	3	9
*107. go out on errands or appointments	111	20	2	4
*108. go out for exercise	105	18	7	12
*109. play any sports	75	32	19	14
110. go out for entertainment	72	33	9	21
*111. go out to eat	95	32	2	11
*112. go to church/synagogue	28	17	61	31**
113. stay home and do fun things	119	14	2	1
114. visit friends/family	88	27	6	16

GUARDIANSHIP

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

YES**	SOMETIMES	NO
89	11	8

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

CHOSE	SOMEONE ELSE CHOSE
37	63

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

HAPPY	IN-BETWEEN	SAD
111	10	4

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	47

SERVICE AGENCY

119. Show me how you feel about your caseworker.

HAPPY	IN-BETWEEN	SAD
138	13	1

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

YES, UNASSISTED	YES, WITH ASSISTANCE	NO, SOMEONE ELSE CHOOSES
7	39	84

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

YES	SOMETIMES	NO
111	14	9

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
88	22	20

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

YES	SOMETIMES	NO
119	9	2

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

NO	YES, NO PROBLEM	YES, IT IS A PROBLEM
68	39	21

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

HAPPY	IN-BETWEEN	SAD
133	26	3

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

YES	NO
93	26

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

LISTEN	SOMETIMES	DON'T LISTEN
101	2	2

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

YES	SOMEWHAT	NO
89	8	5

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

YES	SOMEWHAT	NO
90	6	4

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

YES	NO
110	23

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

NAMED	COULD NOT NAME
39	94

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
90	5	29

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
3	3	122

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

YES, NAMED	YES, BUT DID NOT NAME	NO
7	4	116

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

YES, NAMED	YES, BUT DID NOT NAME	NO
17	1	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	NOT AWARE
59	77

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

NO	YES
117	17

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
58	76

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

LISTEN	SOMETIMES	NOT LISTEN
120	9	8

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
115	9

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

GET HELP	TROUBLE
122	8

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

NAMED	SOMEONE, BUT DID NOT NAME	NOBODY NAMED
114	4	14

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
67	29	36

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

HAPPY	IN-BETWEEN	SAD
138	18	0

HEALTH CARE

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

YES	NO
131	7

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

HAPPY	IN-BETWEEN	SAD
131	21	6

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

YES	NO
119	13

148. Show me how you feel about your dentist.

HAPPY	IN-BETWEEN	SAD
113	21	11

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

NO	YES, NOT NAMED	YES, NAMED
118	3	8

VOTING

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

YES	NO
76	60

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

VOTED & I WANTED TO / DID NOT VOTE & I DID NOT WANT TO	VOTED & I DID NOT WANT TO/ DID NOT VOTE & I WANTED TO
111	25

SELF-ADVOCACY

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

DID GO AND I WANTED TO / DID NOT GO AND I DID NOT WANT TO	DID GO AND DID NOT WANT TO/ DID NOT GO AND WANTED TO
89	36

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

INFORMATION	SOCIAL OPPORTUNITY	PART OF SELF ADVOCACY MOVEMENT	SUPPORT	OTHER
28	4	1	1	8

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

NOT ENOUGH TIME	NOT INTERESTED	NO RIDE	DID NOT KNOW ABOUT IT	OTHER
9	15	1	34	2

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

YES	NO
101	24

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

ENOUGH	MORE
82	46

SELF-DETERMINATION

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

ENOUGH	MORE**
107	25

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

NO	YES, NOT NAMED	YES, NAMED
80	13	31

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

INVOLVED, NAMED	INVOLVED, DID NOT NAME	ASSIGNED
13	6	57

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

NO	YES
52	28

APPENDIX D:

Satisfaction and Type of Developmental Home

During the summer of 2003 interview sessions, consumers living in Developmental Homes were divided into Developmental Homes with Families (N=86) and Developmental Homes with Paid Roommates (N=5). To determine if the type of Developmental Home living situation made a significant difference in satisfaction across the state, ttest 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 was a significant difference in scores on the Health subscale but no differences in satisfaction on any of the other subscales. Since healthcare is not the primary focus for the survey, and the two Developmental Home living situations were similar in all other domains for the 2003 survey, they were combined for further analyses at the agency level.

**Subscales and Total Satisfaction by Developmental Home Residential Type
(Reported as Average Percent Satisfied or Percent Positive)**

Subscale	Developmental Home Family	Developmental Home Roommate	All Developmental Homes
Number of People	86	5	91
Residential	87%	80%	87%
Autonomy	53%	64%	54%
Neighborhood	85%	80%	85%
Work	90%	78%	89%
Day Program	88%	79%	88%
Social Support	79%	77%	79%
Activities	77%	68%	77%
Guardian	68%	66%	68%
Community Services	85%	83%	85%
* Health	89% ^a	66% ^b	88%

* 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.