

# Appendix:

## Table of Contents

Appendix A: Summary of Consumer Surveys from Around the Nation

Appendix B: List of Stakeholder Group Members

Appendix C: Initial Prioritization Scores of Consumer Survey Questions

Appendix D: Field Test Consumer Survey: DD mail version  
Field Test Consumer Survey: APD mail version

Appendix E: Overview of the Consumer Survey Field Test and Site Responsibilities

Appendix F: Background Form

Appendix G: Consent Form

Appendix H: Feedback Form: Summary of Responses

Appendix I: Loki Results (DD and APD)

Appendix J: Rationale for Recommended Changes to SPD  
Consumer Survey Questions

Appendix K: Recommended Final Version of the Consumer Survey

## Appendix A: Summary of Consumer Surveys from Around the Nation

HSRI gathered information on consumer satisfaction surveys processes in 15 states to learn more about their tools and processes. In seven of these states, we both collected tools and conducted phone interviews of key staff<sup>1</sup>. The following table summarized findings related to this report; this is followed by a description of the process/tool used in each of the seven states, including the state contact person.

State	Survey Name	Sample method	Survey Method	Use of Proxy?
Colorado	CORE Indicators Consumer Survey	random sample	mail	no
Indiana	Quality Improvement Process (QIP)	random sample	completed by case manager on laptop, follow-up with supervisor on phone	if needed
Minnesota	VOICE	random sample	face-to-face	yes
Missouri	MOAIDD (agency who conducts the survey)		face-to-face	yes
New Hampshire	Adult Consumer Outcomes Survey	random sample	face-to-face	yes
Pennsylvania	Independent Monitoring for Quality		face-to-face, mail and phone	no
Wisconsin	Adaptation of the Council's Outcomes Tools	random sample	face-to-face	

---

<sup>1</sup> We looked at tools but did not talk to people from Alaska, Kansas, Maryland, Ohio, South Carolina, Vermont, and Wisconsin.

## Appendix A: Summary of Consumer Surveys from Around the Nation

### **CORE Indicators Consumer Tool**

State: Colorado

Contact: Judy Brown

Phone: 303-866-7450

Email: [judy.brown@state.co.us](mailto:judy.brown@state.co.us)

**Background:** Based on the work done by NASDDDS and HSRI. Also based on COPARS, a tool CO used to use previously. The survey is field-tested. Used since 1986. Do an annual and bi-annual surveys, two page consumer satisfaction. Direct interview. If communication issues not resolvable then other mail-in survey to families. Haven't been doing since 2002. Hired 3rd party surveyors to this for independent review.

Now only do a mail-in survey. Do a different program every year. The questions are different and yet some core questions. In the older approach we would write up a report and meant to be a show piece. A lot of explanations, pictures, and quotes. Advertise to the system how services could be delivered. Reports to the legislature. State interested in the information. This information is complemented by things like waiting lists, etc. Used to counter attacks by splinter groups on other groups. Follow-up the agencies who have a significantly lower rating.

When reading the written in comments we asked them if they felt whether they were able access these services. Health and safety nature goes to program staff for investigation. Do technical assistance – systemic and individual (cell phone example). Concerns go to program quality group and program staff. Ask questions on current issues, e.g., wages for DSP and how it affects families and individuals. Accessibility of services, families not happy with coordinators.

Frequently modified survey, never put it out with a modification every time. Keep them current. Surveyors note difficulties with the instrument and the surveying process. Go through these comments and compile a list of comments. Some questions are in common over years.

#### **Topic Areas**

Satisfaction; involvement in decision-making; participation in community activities; social relationships; employment; restrictions; access to services and involvement in service planning.

#### **Methodology**

Interview a stratified random sample of adults receiving services (10% or 30 adults whichever is greater from major service agencies, e.g., CCBs and Regional Centers). The sample is tested for representativeness of the population from which it was drawn (e.g., age, gender, service program, residential status). Weights are assigned to each agency to combine into the state sample.

Data is collected on a new sample in the first year. In the second year, analyses are conducted on the first year data. Sometimes the data is tracked longitudinally.

Bubble technology. A few problems reading that.

**Proxy:** No proxy

**Analysis:** Aggregation. Significance level of results is at .05 or less.

#### **How Do You Use the Data?**

Compare new service models – compare individualized settings with group settings. Compare things to a performance target. Two general population studies to compare disability results. Did they approve of underlying philosophy for services? Changes over time.

#### **Limitations**

The instrument requires individuals with good communication skills to respond. The different dimensions of decision-making, such as how choices were presented, whether they were unwilling or unable to make choices or whether the choices were responsible ones, are not covered. Insufficient information about satisfaction with their employment.

## Appendix A: Summary of Consumer Surveys from Around the Nation

### **Quality Improvement Process**

Tool(s): QIP through AAA; NCI administered by state staff; PES

Automated program participant experience feedback survey. Part of automated case management assessment and tracking system.

State: Indiana

Contact: Becky Koors

Phone: 317-234-2708

Email: [rKoors@fssa.state.in.us](mailto:rKoors@fssa.state.in.us)

**Background:** A task force consisting of consumers, state agency officials, area agency on aging directors, case managers, and service providers guided the system's design and implementation. Indiana received a grant from RWJ to support systems development. The QIP was pilot tested in four AAA before statewide adoption.

No modification have been made to the tools, but the QIP process was modified. QIP - all the data would come to the state and they would review and then get back with AAA. Now the onus back on the AAA to take care of concerns.

**Topic Areas:** 5 domains: consumer choice, timeliness, respectfulness, consistency and task performance.

### **Methodology**

Random sample. National Core Indicator Project the state staff quality monitors administer the NCI.

QIP - a percentage (10% of the particular waiver.) Some AAA serve medical populations (nursing home level of care) and DD others chose only one population. Done by case manager on laptop at time of annual reassessment. CM Supervisors survey participants about their satisfaction with case managers on the phone. 5 scale instrument: Always, usually, 1/2 the time, occasionally, never. Additionally participant comments can be recorded in a QIP "Notes" section. Each AAA must administer to a sample of at least 5% of all program participants. Case managers enter data into lap top computers during participant home visits. The instrument is administered in person in program participants' homes. QIP majority are done face-to-face at annual reassessment.

PES (20%) used to review folks in the Medical type waivers, administered by state staff.

**Proxy:** If an individual has a legal guardian then we use them. Or other responsible parties. Ask the consumer as much as possible. Yes indicate that info gathered from proxy. Some question geared towards the consumer and others to the guardian.

**Analysis:** If NCI/PES - if CM present then take action right away. If health and safety issue then enter into complaint data base and tracked from there. In the QIP issues are flagged and they have to put special case note issues and it is flagged for the CM's supervisor and only supervisor can check that it was taken care of.

Participant responses are aggregated and summarized and share it with the AAA.

### **How Do You Use the Data?**

Special review cases are flagged when a serious incident is identified or there are negative responses to trustworthiness questions. Case management agency investigates. Once resolved the Special Review Case flag is removed from the database by the case manager supervisor (case managers do not have flag removal privileges within the system). The state agency receives reports on all special review cases. Data is not shared with providers unless there are five or more participants from their agency to protect confidentiality.

**Limitations:** QIP is at the local level so the issues get resolved right away. NCI/PES an outside person going in asking the question. It only gives us aggregate data, not specific data re: Mary Smith. Slice and dicing is difficult. With the QIP process more staff would be better to research and analyze it.

**Things to Consider:** When developing a product or system, make sure it is sufficiently malleable to incorporate modifications - a custom product, not one off the shelf, so that modifications can be easily made. When you go with a standardized questionnaire that is good but when talking to the individual some may be applicable and others not so and don't impact their overall survey results. Watch the phrasing of the questions. Put in time frames such as last 6 months and 1 year, etc. Be familiar with the individual's plan and relate it to the plan. Have a checklist of service delivery issues.

## Appendix A: Summary of Consumer Surveys from Around the Nation

### VOICE

State: Minnesota

Contact: Cindy Ostrowski

Phone: 507-932-0292

Email: [gacommis@rconnect.com](mailto:gacommis@rconnect.com)

#### **Background**

Started out of stakeholder meetings. Some parents and providers got together because of concerns around block grants that were said to come down from the federal level.

In 1995, a stakeholders groups including people with disabilities , family members, legal representatives, advocates, support providers and county staff. This group worked with area legislators to develop a project that could receive state funding. Initially conceived as a quality improvement project, it evolved into an alternative to the state licensing process as the legislature looked for ways to offset existing state costs.

The legislature established the Region 10 Quality Assurance Commission to implement the pilot in counties within Region 10 that chose to participate. Commission members must represent the following 4 groups: advocates; providers; county staff and people receiving supports, their families and legal representatives. The Commission must also have one person from DHS.

Pilot tests of the VOICE review and licensing process occurred between July and November 1998, with implementation starting in December 1998.

Project staff trained volunteer trainers train the review teams.

The stakeholder group kept meeting to discuss key issues and values important to them. One of the issues was quality of services and supports. They got together a group of 40 people which had parents and self advocates and county people and providers at the table. They had good representation from each group. The legislators said they would give them money if they would replace something in the system. So they decided to replace the traditional provider licensure process with VOICE.

It took 1 year to develop and 1 to implement. We wanted person driven, integrated services, looked at the whole life. Look at continuous improvement. We then interviewed self advocates, parents and asked basic questions such as what does quality mean to you? How do you know your child is getting quality care? And came up with the domains.

#### **Topic Areas**

VOICE is a comprehensive quality review of all services for an individual. There are 8 domains of life and service, based on values expressed by people receiving supports, family members and advocates. Based on this preliminary leg work MN came up with these 8 domains which had some sub areas under each - basic assistance, specialized assistance, choice, inclusion, safety and dignity, economic supports, coordination and relationships.

#### **Methodology**

Minnesota legislation requires that at least 5% of the individuals supported by a licensed program (or a minimum of three individuals) must have participated in a VOICE review by the time a provider comes up for relicensing. They use a random sampling process. They send a letter to county and licensed provider to accurately identify the people served. They have their own provider lists which are more current than the states which they update regularly.

It is a person by person process. Two-person volunteer teams perform the reviews to maintain objectivity. They conduct person driven interviews. The team first reviews the information provided by the individual's county case manager. The team then meets with the individual's Quality Circle (planning team), which includes the individual, case manager, all formal providers, and other people involved with the individual's life. The team then meets individually with members of the individuals circle.

Findings scale - For each of the formal or informal providers serving the individual, the providers contribution to that individual's experience of the given domain receives a finding of Exceptional (E), Reasonable (R), Improvement is needed (I), or Concern is expressed that deficiencies may exist (C). A provider gets 60 days to get together to come up with a plan if an *I*. If a *C* it could be a vulnerable adult

## Appendix A: Summary of Consumer Surveys from Around the Nation

issue or just something significant such as what do they need, want, what needs to be provided and how is it provided.

General finding - they try to look through the person's eyes and capture the person's experience in life that way if something is happening with family, community or friends we can highlight too – good or bad.

We develop a earning portrait.

VOICE can be a great resource for people – it does not replace a planning process.

10 hours of interviewing in and then there is paperwork and synthesis and report so it take a total of 20-30 hours per review but we have 30 days to complete it.

We get 3 reviews per year in exchange for training as volunteer reviewers from providers. Stipends are given to self-advocates, parents and community members who are review team members.

Barriers report – once a year or once every two years. Training and education issues. I's and C's aggregated for providers.

### **Proxy**

Yes. Also observe body language of individual.

### **Analysis**

After the interviews the circle meets again. The Circle provides insight into what specifically adds value to that individual's life and what more could be done to increase an individual's quality of life. The circle works together to implement an action plan if any provider receives a finding of C or I for a quality domain.

### **How Do You Use the Data?**

Information generated from the VOICE reviews is brought to a Quality Assurance Review Council, whose members are also drawn from the Stakeholders Group. This Council also receives information from a review of procedural safeguards performed by project staff. The Council makes licensure recommendations to the County Board (or its designee) of the county in which the provider is located, who takes the recommendation to the state DHS. DHS has the ultimate decision regarding the provider's licensure.

### **Limitations**

It seems like it might be a lengthy process.

It mostly provides qualitative information and should therefore be combined with other sources of information.

Keeping up the training up to par is a challenge.

### **Things to Consider**

The grassroots development of the review process was important for obtaining volunteer reviewers because people were invested in the process.

The process gives frontline workers who are interviewed for the reviews and often conduct them, a more significant role in improving quality.

The process is more expensive than the old licensure review process but that may be because this process includes the review of case management and also interviews family members who are often not part of the licensure process.

Annual operational costs per provider was 2,937.

## Appendix A: Summary of Consumer Surveys from Around the Nation

### Missouri Alliance for Individuals with Developmental Disabilities (MOAIDD)

State: Missouri

Contact: Donna Rodriguez

Phone: 417-448-1326

Email: [dolsen@state.pa.us](mailto:dolsen@state.pa.us)

#### **Background**

Its purpose is to review and make recommendations to improve the quality of life of Missouri's citizens with developmental disabilities.

First implemented in 1995. The formalized process is continuing to evolve.

MOAIDD is a volunteer organization - PWD and family volunteers.

#### **Topic Areas**

Section I: Regard for the individual. This section looks at activities that respect and promote the dignity of individuals, and support their involvement in the community. Issues examined include if individual differences are accepted by support staff.

Section II: Personal Growth. This section rates activities to promote personal growth of the individuals. This includes opportunities to increase personal independence, develop personal relationships and hopes, take classes, improve health and fitness, travel and take risks.

Section III: Staff. This section looks at the skills of staff and the way staff interacts with the individuals; if staff is trained, friendly, and supportive; if staff is open to suggestions and genuinely likes the individuals and if staff emphasizes abilities and positive individual qualities, not disabilities.

Section IV: Physical setting. This section includes items related to location of the residence, maintenance of the home's exterior and interior, access to transportation and community resources, warmth and comfort of the environment, furnishings, homey touches, personal space, individuals' taste, and the individuals' personal space.

#### **Methodology**

The process as set up now, agencies certified every 2 years by the state. In the off years MOAIDD goes in provides a family perspective. Accredited agencies are exempt.

Periodic visits to individuals who are receiving residential services through Missouri's Department of Mental Health, Division of Mental Retardation and Developmental Disabilities' Home and Community Based Waiver. MOAIDD volunteers visit at the convenience of the person with a developmental disability and only with his/her and/or the legal guardian's permission. Throughout the process, the focus is on the individual and his/her rights, dignity, and quality of life. The visits are accomplished by a team of volunteer consumers and family members who have been trained to observe and report objectively what they see in the daily life of the individual. Through visits, they will provide information and make recommendations to the individual, provider of services and the Division of MR/DD.

Visit two or three people in an agency no matter the size of the agency. Visit one person in each setting at least e.g., one in group home and one in apartment setting due to shortage of resources. Previously they would interview 2 or 3 people from reach setting.

They have to get release of information from guardian. Coordinator reviews the IP. Then selects the pool of volunteers based on logistics and needs of the individual to be interviewed. They just visit the person and follow a four point talking tool. Volunteers can't have connections with that region/agency.

Visits are guided by observations, interviews, and procedures that ensure the consistent gathering of useful data for enhancing the lives of individuals. Volunteers do not evaluate service programs according to local, state or federal regulations, but instead try to determine if the individual is leading as full a life as possible.

Recommendations have to be supported by fact or observation (this is new). Sometimes may not make recommendation. These get turned to the MOAIDD coordinators and then to the individual/family/guardian, agency, and regional centers. They then go to the person's team and the person

## Appendix A: Summary of Consumer Surveys from Around the Nation

should be involved in implementing the recommendations. We really want to focus on we were there on this day and we recommend something and so they need to recommend an evaluation. Build in resources in the reports.

### **Proxy**

Do it face-to-face always. Staff/family/guardian used as an interpreter not proxy.

### **Analysis**

#### **How Do You Use the Data?**

Volunteers make recommendations per topic area, e.g., provide staff with training around aging issues, sexuality, etc. or staff need to increase communication to better support the individual.

Personal planning team members and regional center quality assurance staff review recommendations and provide a written response to these to the MOAIDD Coordinator.

They also make system recommendations such as Provide training and TA to regional center staff staff and providers on how to create real home environments and Provide staff with training on sexuality issues and policy.

### **Limitations**

Revamp volunteer training, 1 day volunteer training, based on Missouri quality outcomes. Trying to include the self-determination pieces into the volunteer training program.

Volunteers were making recommendations on what they wanted not what the individual wanted.



## Appendix A: Summary of Consumer Surveys from Around the Nation

### New Hampshire Developmental Services Adult Consumer Outcomes Survey

Tool(s): – separate consumer and family/guardian forms.

State: New Hampshire

Contact: Jean Cusson

Phone: 603-271-5143

Email: [JCusson@dhhs.state.nh.us](mailto:JCusson@dhhs.state.nh.us)

#### **Background**

Developed it 10 years ago and doing it for 9 years.

Modified the tool in FY 04. Shortened it, 120 questions to 86. Face-to-face interview. Went to peoples' homes or wherever they want meet with us.

Did a pilot of an earlier version in the North country. This particular version was not piloted.

#### **Topic Areas**

Home, paid work, volunteer activities, community participation, transportation, finance/money, health, assistive technology, service coordination, rights, planning process, and overall comments. The also have comments on each section.

#### **Methodology**

They draw a random sample for a two year period - area agency asks people if they want to participate then if yes we go out and do it. Sometimes names come up again and so they refuse. They draw 30% of people who receive services and from that they get 10%.

They interview the individual and 2 other people who know them well. 3 interviews per individual for about 300 people was very time consuming. They got about as good information as talking to the individual with the interpreter (usually family member) present. Now they do a second interview by phone only if the individual wants it. They put the control with the person using services. They also use the persons' method of communication, therefore the need for an interpreter. In addition to this they send a mail-in family satisfaction survey.

**Proxy**: Sometimes interpreter or guardian answers the questions. They note who, individual or proxy , responded to each question. Two columns the actual answer and who answered the question.

Proxy questions are in the third person.

**Analysis**: NH does state that this is not a scientific tool - if someone needs something to be changed then we have to do it immediately. This is more of a learning tool for both the individual and the staff. They feel it is very hard to draw conclusions through statistical data analysis. But they do send aggregate data to area agencies so they can get a big picture view and make changes where needed.

They analyze the individual and proxy answers separately and then synthesize the answers. Furthermore there is a narrative included in the survey that explains the data. The narrative comes from interviewers observations based on the answers provided (elaborated on by the individual)

#### **How Do You Use the Data?**

Aggregate information is sent to area agencies and they make regional changes. At the state level we might do more training based on what the data tells us. Use it as educational tool for individuals.

#### **Limitations**

They need to look at systemic issues and are doing that now. They are also developing contract outcomes - key areas that they want to measure and focus on, such as employment.

#### **Things to Consider**

There are different levels of QA. Be wary of how you use the stuff. People are satisfied with very little. One tool doesn't do it. They had QA reviewers who would go to a region and stay there for a week and review it. Now they are assigned regions. They know their region well so it makes it more interactive.

## Appendix A: Summary of Consumer Surveys from Around the Nation

### **Independent Monitoring for Quality**

**Tool(s):** About 105 item questionnaire divided into eight sub-sections. In '03-'04 22% relatives home, 12% in own residence and the rest of the majority in residence programs. County programs may have their own satisfaction survey.

**State:** Pennsylvania

**Contact:** Dana Olsen

**Phone:** 717-772-4315

**Email:** [dolsen@state.pa.us](mailto:dolsen@state.pa.us)

**Background:** First began using the tool in 1998. Absolutely independent review of the system. Surveyors make their own judgment about key indicators. Observer agreement process is used during the survey. Pennhurst longitudinal surveys field-tested some of the questions. Reliability and validity may be tested this year but can't say for certain. The process is family or individual based. Modify wording only in the last few years. Otherwise the survey remains the same as the original.

**Topic Areas:** Satisfaction, Dignity Respect and Rights, Choice and Control, Relationships, Inclusion, Monitor's Impressions, Major Concerns, Family/Friends/Guardian Survey

**Methodology:** Essential Data Elements are collected. Eighty questions in the tool for the individual (face-to-face interview) and about 10 or so for guardians/families (telephone surveys). Additionally there is a mail-in NCI family survey.

Three-fourths of the people interviewed live in licensed community residences - they are interviewed once every three years. OMR added people living in their own homes, family homes and institutions as part of the random sample for the NCI project. The sample included at least 30 people served by each county MHMR department. Family/Guardian/Friend Survey completed on the phone with the individual's permission. Independent review teams interview individuals receiving services and their families. The monitoring teams enter the data into HCSIS. Monitor's impressions and major concerns completed by interview team.

**Proxy:** First two sections only answered by the person. No proxy for Satisfaction and Dignity, Respect and Rights Sections of the questionnaire. Communication innovations, such as pictures, communication boards, etc. are used to help people answer the survey. 25-30% non-response.

**Analysis:** The Institute on Disabilities at Temple University analyzes the data – percentages, in aggregate, across provider, county and state.

QM Council receives the data. Data review groups internal to OMR ask the question “What is the story here?” when they review the data. CMS focus areas. Accountability piece is always a challenge.

#### **How Do You Use the Data?**

County level IM4Q data used to monitor county performance (compliance with state and federal regulations). Established an annual process to identify continuous quality improvement initiatives based on IMQ4 and other tools used.

Determines interventions with input from state and national partners, e.g., developing brochures for participants and families informing them about available employment assistance and convening regional focus groups to develop information on best practices to ensure that people's rights are protected, such as privacy rights.

Develop initiatives to support funding people living at home. Drives the way you fund services, e.g., right now PA is considering promoting life sharing situations because through their reviews they found them cost effective. Roommates.

Developing a quality framework. What are the performance measures? Benchmarks. Currently they want to increase the number of people employed by a 1000 people.

#### **Things to Consider**

Be sure the person is there. Show respect. The follow-up question is very important to get a deeper understanding of the situation.

## Appendix A: Summary of Consumer Surveys from Around the Nation

### **Consumer Outcomes Survey**

Tool(s): adaptation of The Council's Outcomes Tool

State: Wisconsin

Contact: Monica Deigan

Phone: 608-261-7807

Email: [deigma@dhfs.statewi.us](mailto:deigma@dhfs.statewi.us)

#### **Background**

Development of the tool included: 1) many stakeholder meetings and work groups; 2) heavy involvement of consumers; and 3) consensus about program participant-defined outcomes driving the system.

#### **Topic Areas**

14 Outcomes and 3 Domains:

Self Determination and Choice Outcomes (e.g., people are treated fairly; people have privacy; people are satisfied with their services)

Community Integration Outcomes (e.g., people choose where and with who they live; people remain connected to informal support networks)

Health and Safety Outcomes (e.g., people are safe; people experience continuity and security; people have the best possible health)

#### **Methodology**

Annual survey of Medicaid HCBS waiver participants enrolled in Wisconsin's Family Care program, a managed long-term approach to providing services for elderly persons with disabilities and individuals with physical or developmental disabilities. Random sample of program participants interviewed. Interviews conducted by Department of Health and Family Services staff.

Interview Process. State staff trained in The Council's process. Interviews conducted face-to-face with the waiver participant, support staff and case manager. Meaning of the outcome is defined by each individual participant. Interviewers determine whether the outcome is in place or not.

#### **Analysis**

An outcomes score is generated, summarizing the percent of outcomes deemed present.

Outcomes score is considered a Quality of Life indicator for the waiver participant.

An support score is generated, summarizing the percent of outcomes for which support is present. Support score considered a measure of the quality of Family Care services/supports.

#### **How Do You Use the Data?**

Data reports and database shared with Care Management Organizations (CMO). CMOs are encouraged to conduct their own analyses on outcomes data. State staff meet with CMOs to discuss baseline results and how to use consumer outcomes information to monitor and improve quality of care. Staff monitors changes over time for entire program for each CMO, between and within CMOs. Goal is to establish standards for CMOs and hold them accountable. Outcome data expected to guide CMO internal quality improvement activities.

#### **Things to Consider**

Brief providers before beginning data collection to reduce their anxiety of being evaluated. Train the staff coordinating and conducting the interviews. Ensure cultural competence. Before the survey is implemented decide who will have access to the information and whether you will be including identifying information.

Appendix B: List of Stakeholder Group Members

<b>Name</b>	<b>Represents</b>
Bill Bullock	Douglas County DD- QA Coordinator
Melinda Compton Cheryl Wells	NorthWest Senior & Disabilities Services
Cindy Helvington	Self Advocates as Leaders
Charles Kurtz	Elder's in Action
Bill Lynch	DD Coalition Staley Implementation Group
Becky Thrash	Oregon Council on DD
Tina Treasure	Oregon State Independent Living Council
Mike Volpe	Home Care Commission OADSAC
May Nelson	Support Service Brokerages

APPENDIX C: Initial Prioritization Scores of Consumer Survey Questions

In the process of developing the draft consumer survey, we worked with the Stakeholder Group to prioritize a larger set of possible questions. At the March 2005 Stakeholder Group meeting, we asked members to identify 15 priority questions and to group these 15 questions into three levels of priority – high (3 points), medium (2 points), and, low (1 point). In the meeting and through later telephone contact, we received responses from 10 APD stakeholders and 6 DD stakeholders. In order to give equal weight to the two groups, we weighted these two groups appropriately (APD \* 6 and DD \*10). We then calculated the total score in two ways -- based on the weighted scores for high, medium and low, and also simply the number of respondents who gave any priority to the question (essentially, each question received 1 point if someone prioritized it as high, medium, or low). We then ordered the questions from highest to lowest score using the total weighted score.

	High	Medium	Low	Total Score	Core	DD Question	APD Question
1. Do you have a person ( <i>outside the service delivery system</i> ) who can advocate on your behalf when needed? ( <i>Choice/Control</i> )	9 DD	2 DD	1 APD	12		✓	
2. Does your plan include things that you need? ( <i>Choice/Control</i> )	9 APD	6 DD 2 APD	-	17	✓		
3. Does your plan include how you will get the things you need? <sup>4</sup> ( <i>Choice/Control</i> )	3 DD	6 DD 2 APD	-	11		✓	
4. Have your rights and responsibilities been explained to you? <sup>+</sup> ( <i>Choice/Control</i> )	-	2 DD 6 APD	-	8	✓ 2 <sup>nd</sup> Level		or ✓
5. Do you understand the risks of your choices? ( <i>Choice/Control</i> )	3 DD 6 APD	2 DD 4 APD	-	15	✓		
6. Do you have people you can talk to about personal things? <sup>1</sup> ( <i>Relationships</i> )	-	4 DD 6 APD	-	10	✓		
7. Do you choose when you want to go out? ( <i>Community Integration</i> ) <i>Combine #7 and #8 into one question.</i>	3 DD	2 DD	2 DD 1 APD	8	✓		
8. Do you choose where you want to go? (e.g., shopping, on errands, entertainment, dinner, religious services, etc.) ( <i>Community Integration</i> )	3 DD	4 DD	1 DD	8	✓		

APPENDIX C: Initial Prioritization Scores of Consumer Survey Questions

	High	Medium	Low	Total Score	Core	DD Question	APD Question
<i>Combine #7 and #8 into one question.</i>							
9. Do you understand the risks to your health? <sup>3</sup> ( <i>Health</i> )	9 DD 3 APD	-	3 APD	15	✓		
10. (If the person takes medication) Do you understand the reason you take medication(s)? <sup>3</sup> ( <i>Health</i> )	-	4 DD 8 APD	-	12	✓		
11. Do you know what to do in the case of an emergency? ( <i>Emergency/Safety Plan</i> )	6 DD 9 APD	2 DD	1 APD	18	✓		
12. Do you have someone who lives nearby you can call during an emergency? ( <i>Emergency/Safety Plan</i> )	6 DD 6 APD	2 DD	-	14	✓		
13. Have you used the services in your emergency back-up/safety plan? ( <i>Emergency/Safety Plan</i> )	3 APD	2 DD 2 APD	2 DD 2 APD	11	✓		
14. Does your Personal Agent/Case Manager give you the help you need? <sup>2</sup> ( <i>Service Delivery Issues</i> )	6 APD	4 DD	-	10	✓		
15. Are you satisfied with the services you currently receive? (if not satisfied ask which ones the individual would like improved?) ( <i>Service Delivery Issues</i> )	3 DD 12 APD	-	2 DD	17	✓		
16. Do you think your service providers have the information and skills to help you in the manner you need? <sup>2,3</sup> ( <i>Service Delivery Issues</i> )	3 DD 3 APD	2 APD	1 DD	9	✓		
17. Do you know what you can do if you are unhappy with your services? <sup>6</sup> ( <i>Service Delivery Issues</i> )	3 APD	4 DD	2 DD	9		✓	



## **Human Services Research Institute**

**7420 SW Bridgeport Rd #210 Portland, OR 97224 · v 503-924-3783 · f 503-924-3789**

---

### **Consumer Satisfaction Survey for People with Developmental Disabilities**

Dear Survey Participant:

The Department of Human Services, Seniors, and People with Disabilities wants to learn about how well services work for people who live with their families or on their own. As part of a contract with Seniors and People with Disabilities, the Human Services Research Institute has written this new consumer satisfaction survey, and we need to learn if the questions are easy to understand and appropriate.

We want to try out the survey on a small number of people before using it with more people who receive in-home services from Seniors and People with Disabilities. Using what we learn from the study we will improve the quality of the questions.

We promise the answers you give us will be kept private. Your name will not be connected to your answers. The answers of everyone in the study

will be put together when we share the results with Seniors and People with Disabilities staff.

Your decision to be part of the study will not affect the services you receive from Seniors and People with Disabilities. If you decide to take part in the survey you can still change your mind at a later time.

The survey has some words in it (e.g., advocate, staff) that you may or may not know. Here is what we mean when we use the words:

1. **Advocate:** a friend or family member who speaks for you when you find it difficult to speak for yourself.
2. **Staff:** are paid people such as, caregivers, home care workers, personal support providers, etc. who come to your home to help you with actions such cooking, bathing, shopping, traveling and other daily tasks. The staff can be hired by the individual receiving services or by an agency and can be self-employed or independent contractors.
3. **Service or Support Plan:** a plan, put together with help from your case manager or personal agent from Seniors and People with Disabilities, that has a list of your needs, preferences, services and supports. Such a plan may be called a Client Plan (Aging and Physical Disabilities) or Individual Support Plan (Developmental Disabilities).



4. **Emergency:** situations that can hurt people, such as earthquakes, fire, car accident, or failure of a service provider to come as planned.
5. **Proxy:** a person who answers the survey questions for the respondent when he or she has difficulty understanding or answering them.

### **How Do I Complete the Survey?**

You can answer the survey on the internet or using a paper and pen.

Internet Survey: We are trying out something new and exciting in this study.

We have put the consumer satisfaction survey on a website so people who want to can answer it on their computers: <http://hsri.loki.ca?c=dd>. We would like to test how answering the survey questions on a website works for people. If you like using a computer, and you have one or can find one to use, please complete the survey on the website so we can test it.

Directions on how to answer the web survey can be found on the website.

Paper and Pen Survey: If you can't or don't want to do the survey on a computer, you can complete the paper version of the survey we have sent you. When you have finished, please mail it back to us in the envelope we sent you with the survey. The envelope has our address on it and is stamped. All you have to do is put your completed survey in the envelope and put it in the mail box.

It should take you about 30 minutes to answer all the questions. If you need help reading the questions, please ask a friend or family member to help you. Each question has 5 responses. Please pick the one that best matches how you feel about the services you receive. If you don't know the answer to a question, check the "don't know" column.





Additionally, please complete the proxy column when answering the survey. On page 2 above, we have given a definition of a proxy response – when someone else answers the question for you, or helps you decide what your answer is. In the proxy column we would like you to mark "I" if you answered the question on your own, or "P" if someone else (for example, a family member or caregiver) answered the question for you or helped you.







We would also like to collect some general information about you in this survey. Please answer the 8 questions at the end of the survey.

**Thank you for helping us!!!**







If you have any questions while answering the survey, please contact Reena Wagle at HSRI, at 503-924-3783 ext. 19.

APPENDIX D: Field Test Consumer Survey: DD mail version





	 Never 1	Rarely 2	 Sometimes 3	Often 4	 Always 5	 Don't Know 6	Who answered? Individual (I) or Proxy (P)
1. Do you have a person who speaks up for you when needed?  (a person such as a friend, family member or an advocate - but not a personal agent, case manager or service provider)	1	2	3	4	5	6	
2. Does your service plan or support plan include the things that you want or need?	1	2	3	4	5	6	
3. Does someone help you understand the risks of your choices?  (choices such as declining services offered, choosing to live in a dangerous neighborhood, etc.)	1	2	3	4	5	6	

	 Never 1	Rarely 2	 Sometimes 3	Often 4	 Always 5	 Don't Know 6	Who answered? Individual (I) or Proxy (P)
 4. Do you have people you can talk to about your personal relationships, thoughts and feelings?	1	2	3	4	5	6	
5. Can you go to the places that you choose when you want to? (such as shopping, entertainment, religious services, etc.)	1	2	3	4	5	6	
 6. Do you know what to do in case of an emergency?  (an emergency such as when your staff person does not show up, a fire, a tsunami, or anything that may hurt you)	1	2	3	4	5	6	





APPENDIX D: Field Test Consumer Survey: DD mail version

	 Never 1	Rarely 2	 Sometimes 3	Often 4	 Always 5	 Don't Know 6	Who answered? Individual (I) or Proxy (P)
 <p>7. Do you have someone you can call to help you during an emergency?</p> <p>(an emergency such as when your staff person does not show up, a fire, a tsunami, or anything that may hurt you)</p>	1	2	3	4	5	6	
 <p>8. Do you understand your health needs?</p> <p>(health needs such as why you take medication, managing conditions like diabetes, the reasons you need to visit your doctor)</p>	1	2	3	4	5	6	

APPENDIX D: Field Test Consumer Survey: DD mail version

	 Never 1	Rarely 2	 Sometimes 3	Often 4	 Always 5	 Don't Know 6	Who answered? Individual (I) or Proxy (P)
9. Are you pleased with the time it took to get services after you asked for them?	1	2	3	4	5	6	
10. When your plan needs to change, does this happen within a reasonable amount of time?	1	2	3	4	5	6	
11. Does your Personal Agent and/or Case Manager give you the help you need?	1	2	3	4	5	6	
12. Are you happy with the services you currently get?	1	2	3	4	5	6	
13. Do you think your staff know how to help you in the way that you need and want?	1	2	3	4	5	6	
14. Do you get the information you need to make choices about your services and supports?	1	2	3	4	5	6	

APPENDIX D: Field Test Consumer Survey: DD mail version

	 Never 1	Rarely 2	 Sometimes 3	Often 4	 Always 5	 Don't Know 6	Who answered? Individual (I) or Proxy (P)
15. Do you decide how you spend your free time? (when you are not working or in school)	1	2	3	4	5	6	
16. Do you feel you have enough staff to help you?	1	2	3	4	5	6	
17. Do you know what to do if you are unhappy with your services?	1	2	3	4	5	6	

Background Information

1. Birth Date: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ / \_\_\_ \_\_\_  
                                  MM   DD   YY
  
2. Gender: \_\_\_ 1 male  
                  \_\_\_ 2 female
  
3. What is your race/ethnicity? (check one)  
   \_\_\_ 1   White  
   \_\_\_ 2   Black or African-American  
   \_\_\_ 3   American Indian and Alaska Native  
   \_\_\_ 4   Asian  
   \_\_\_ 5   Hispanic/Latino origin  
   \_\_\_ 6   Native Hawaiian or Other Pacific Islander
  
4. Where do you live? (check one)  
   \_\_\_ 1   With your family  
   \_\_\_ 2   Independently in your own home  
   \_\_\_ 3   With other unrelated people  
   \_\_\_ 4   Other \_\_\_\_\_ (please specify)
  
5. What county do you live in?  
  
\_\_\_\_\_
  
6. What is your disability? (Check all that apply)  
   \_\_\_ 1   Physical disability  
   \_\_\_ 2   Developmental disability  
   \_\_\_ 3   Disabilities related to age (e.g., dementia, Alzheimer's,  
etc.)  
   \_\_\_ 4   Visual impairment/Blindness



5 Hearing impairment/Deafness

6 Other \_\_\_\_\_ (please specify)

7. How many hours per month of paid support do you now receive?

\_\_\_\_\_

8. What is your main way of talking with other people? (check one)

1 Speaking English

2 Speaking another primary language \_\_\_\_\_  
(please write in which  
language)

3 Using gestures

4 Using sign language or finger spelling

5 Using a communication device

6 Other

9. Who helped you to answer this survey? (check all that apply)

1 No one

2 Family member

3 Caregiver (may be a professional)

4 Friend

5 Other \_\_\_\_\_ (explain)

10. Who do you receive services from?

1 Resource Connections of Oregon (RCO)

2 Full Access Brokerage (FAB)

3 Neither



## **Human Services Research Institute**

**7420 SW Bridgeport Rd #210 Portland, OR 97224 · v 503-924-3783 · f 503-924-3789**

---

### **Consumer Satisfaction Survey for Seniors and People with Physical Disabilities**

Dear Survey Participant:

The Department of Human Services, Seniors and People with Disabilities wants to learn about how well services work for people who live with their families or on their own. As part of a contract with Seniors and People with Disabilities, the Human Services Research Institute has written this new consumer satisfaction survey, and we need to learn if the questions are easy to understand and appropriate.

We want to try out the survey on a small number of people before using it with more people who receive in-home services from Seniors and People with Disabilities. Using what we learn from the study we will improve the quality of the questions.

We promise the answers you give us will be kept private. Your name will not be connected to your answers. The answers of everyone in the study will

be put together when we share the results with Seniors and People with Disabilities staff.

Your decision to be part of the study will not affect the services you receive from Seniors and People with Disabilities. If you decide to take part in the survey you can still change your mind at a later time.

The survey has some words in it (e.g., advocate, staff) that you may or may not know. Here is what we mean when we use the words:

1. **Advocate:** a friend or family member who speaks for you when you find it difficult to speak for yourself.
2. **Staff:** are paid people such as, caregivers, home care workers, personal support providers, etc. who come to your home to help you with actions such as cooking, bathing, shopping, traveling and other daily tasks. The staff can be hired by the individual receiving services or by an agency.
3. **Service or Support Plan:** a plan, put together with help from your case manager from Seniors and People with Disabilities, that has a list of your needs, preferences, services and supports. Such a plan may be called a Client Plan (Aging and Physical Disabilities) or Individual Support Plan (Developmental Disabilities).

4. **Emergency:** situations that can hurt people, such as earthquakes, fire, car accident, or failure of a service provider to come as planned.
5. **Proxy:** a person who answers the survey questions for the respondent when he or she has difficulty understanding or answering them.

### **How Do I Complete the Survey?**

You can answer the survey on the internet or using a paper and pen.

#### Internet Survey

We are trying out something new and exciting in this study. We have put the consumer satisfaction survey on a website so people who want to can answer it on their computers: <http://hsri.loki.ca?c=apd>. We would like to test how answering the survey on a website works for people. If you like using a computer, and you have one or can find one to use, please complete the survey on the website so we can test it. Directions on how to answer the web survey can be found on the website.

#### Paper and Pen Survey

If you can't or don't want to do the survey on a computer, you can complete the paper version of the survey we have sent you. When you have finished, please mail it back to us in the envelope we sent you with the

survey. The envelope has our address on it and is stamped. All you have to do is put your completed survey in the envelope and put it in the mail box.

Completing the survey should take about 30 minutes. If you need help reading the questions please ask a friend or family member to help you. Each question has 5 responses. Please pick the one that best shows us how you feel about the services you receive. If you don't know the answer to a question, check the "don't know" column.

Additionally, please complete the proxy column when answering the survey. On page 2 above, we have given a definition of a proxy response – when someone else answers the question for you, or helps you to decide what your answer is. In the proxy column we would like to mark "I" if you answered the question on your own, or "P" if someone else (for example, a family member or caregiver) answered the question for you or helped you.

We would also like to collect some general information about you in this survey. Please answer the 8 questions at the end of the survey.

**Thank you for helping us!!!**

If you have any questions while answering the survey, please contact Reena Wagle at HSRI, at 503-924-3783 ext. 19.

APPENDIX D: Field Test Consumer Survey: APD mail version

	Never 1	Rarely 2	Sometimes 3	Often 4	Always 5	Don't Know 6	Who answered? Individual (I) or Proxy (P)
<p>1. Do you have a person who speaks up for you/represents your interests when necessary?</p> <p>(a person such as a friend, family member or an advocate - but not case manager or staff)</p>							
<p>2. Does your plan include the things that you want or need?</p>							
<p>3. Does someone help you understand the risks of your choices?</p> <p>(choices such as declining services offered, choosing to live in an unsafe neighborhood, etc.)</p>							
<p>4. Do you have people you can talk to about your personal relationships, thoughts and feelings?</p>							

APPENDIX D: Field Test Consumer Survey: APD mail version

	Never 1	Rarely 2	Sometimes 3	Often 4	Always 5	Don't Know 6	Who answered? Individual (I) or Proxy (P)
<p>5. Can you go to places of your choice when you want to?</p> <p>(such as shopping, entertainment, religious services, etc.)</p>							
<p>6. Do you know what to do in case of an emergency?</p> <p>(an emergency such as when your staff person does not show up, a fire, a tsunami, or anything that may hurt you)</p>							
<p>7. Do you have someone whom you can call to help you during an emergency?</p> <p>(an emergency such as when your staff person does not show up, a fire, a tsunami, or anything that may hurt you)</p>							

APPENDIX D: Field Test Consumer Survey: APD mail version

	Never 1	Rarely 2	Sometimes 3	Often 4	Always 5	Don't Know 6	Who answered? Individual (I) or Proxy (P)
8. Do you understand your health needs?  (health needs such as why you take medication, managing conditions like diabetes, the reasons you need to visit your doctor)							
9. Are you pleased with the time it took to get services after you asked for them?							
10. When your plan needs to change, does this happen within a reasonable amount of time?							
11. Does your Case Manager give you the help you need?							
12. Are you satisfied with the services you currently receive?							



APPENDIX D: Field Test Consumer Survey: APD mail version

	Never 1	Rarely 2	Sometimes 3	Often 4	Always 5	Don't Know 6	Who answered? Individual (I) or Proxy (P)
13. Do you think your staff know how to help you in the way that you need and want?							
14. Do you get the information you need to make choices about your services and supports?							
15. Have your rights and responsibilities been explained to you?							

Background Information

1. Birth Date: \_\_\_ \_\_\_ / \_\_\_ \_\_\_ / \_\_\_ \_\_\_  
                                  MM   DD   YY
  
2. Gender: \_\_\_ 1 male  
              \_\_\_ 2 female
  
3. What is your race/ethnicity? (check one)  
   \_\_\_ 1   White  
   \_\_\_ 2   Black or African-American  
   \_\_\_ 3   American Indian and Alaska Native  
   \_\_\_ 4   Asian  
   \_\_\_ 5   Hispanic/Latino origin  
   \_\_\_ 6   Native Hawaiian or Other Pacific Islander
  
4. Where do you live? (check one)  
   \_\_\_ 1   With your family  
   \_\_\_ 2   Independently in your own home  
   \_\_\_ 3   With other unrelated people  
   \_\_\_ 4   Other \_\_\_\_\_ (please specify)
  
5. What county do you live in? \_\_\_\_\_
  
6. What is your disability? (Check all that apply)  
   \_\_\_ 1   Physical disability  
   \_\_\_ 2   Developmental disability  
   \_\_\_ 3   Disabilities related to age (e.g., dementia, Alzheimer's,  
etc.)  
   \_\_\_ 4   Visual impairment/Blindness  
   \_\_\_ 5   Hearing impairment/Deafness  
   \_\_\_ 6   Other \_\_\_\_\_ (please specify)

7. How many hours per month of paid support do you now receive?

\_\_\_\_\_

8. What is your main way of talking with other people? (check one)

1 Speaking English

2 Speaking another primary language \_\_\_\_\_  
(please specify)

3 Using gestures

4 Using sign language or finger spelling

5 Using a communication device

6 Other

9. Who helped you to answer this survey? (check all that apply)

1 No one

2 Family member

3 Caregiver (may be a professional)

4 Friend

5 Other \_\_\_\_\_ (explain)



## Human Services Research Institute

7420 SW Bridgeport Rd #210 Portland, OR 97224 • v 503-924-3783 • f 503-924-3789

---

### Overview of the Consumer Field Test and Site Responsibilities

Human Services Research Institute (HSRI), in partnership with the Oregon Technical Assistance Corporation (OTAC), is currently under contract to Seniors and People with Disabilities (SPD), Oregon Department of Human Services, to assist with development of a quality assurance system for people receiving waived in-home services. In collaboration with a broad-based Stakeholders Group and with extensive input from other statewide groups of professionals and consumers, the HSRI/OTAC team has designed a consumer survey. This survey will be field tested in several Oregon jurisdictions during August 2005.

The survey process will entail:

- Four field test locations, geographically dispersed; two sites will be designated for APD recipients, and two for DD recipients.
- Sampling of current consumers of waived in-home services who have been receiving services for at least one year.

Sampled individuals will fall into one of four groups: on the DD side, people served by Brokerages and people served through the In-Home Comprehensive program; on the APD side, consumers aged 65 or older, and those who are younger than 65.

- Half of the sample will receive a mail survey, which the individual may complete on paper or on a web site; the other half will be interviewed face-to-face.
- Half of the face-to-face interviews will be conducted by local staff who currently have quality assurance responsibilities; the other half will be done by local volunteers, with support from HSRI/OTAC staff.
- Sample size will be sufficiently large to yield at least 70 face-to-face interviews (10 from the in-home comprehensive program and 20 each from the other 3 groups) and 70 mail surveys.

Each field test site will be asked to assist the HSRI/OTAC team by performing the following tasks:

1. Identify a primary contact person (“coordinator”) for communication with the project team. [early June]

## Appendix E: Overview of the Consumer Survey Field Test and Site Responsibilities

2. Complete a one-page form providing some demographic and diagnostic information on each sampled individual (90-120 people), e.g. age, gender, race/ethnicity, living arrangement, primary language, primary communication method, type of disability, reading ability, number of hours of paid in-home services. [mid June]
3. Contact a smaller sample of recipients (40-60 people) to invite them to participate in a face-to-face interview, and get them to complete a consent form and provide up-to-date contact information and directions to the home. [late June-early July]
4. Identify one or more local staff who will have responsibility to conduct 10-15 face-to-face interviews. [early July]
5. Assist with logistics for a short orientation to the field test for all involved staff, followed by a brief training session for interviewers related to conducting the consumer survey. [late July]
6. Provide the project team with a contact person for the local RSVP program.
7. Distribute mail survey packets (supplied by HSRI) to sampled recipients (40-60), or provide HSRI with mailing addresses. [late July]
8. Local interviewers schedule appointments with assigned recipients, conduct the face-to-face interviews, complete the survey form, and submit it to site coordinator. [August]
9. Coordinator checks documents for completeness and returns all materials to the project team in pre-paid envelopes. [August]
10. Coordinator and interviewers participate in teleconference to debrief about the interview experience. [August]

The HSRI/OTAC project team will keep in regular touch with the site coordinators throughout the field test period, and we will share site-specific results with each site

Appendix F: Background Form

Background Information<sup>2</sup>

1. Birth Date:     /    /      
                  MM  DD  YY

2. Gender:    1 male  
                 2 female

3. What is your race/ethnicity? (check one)

- 1 White
- 2 Black or African-American
- 3 American Indian and Alaska Native
- 4 Asian
- 5 Hispanic/Latino origin
- 6 Native Hawaiian or Other Pacific Islander

4. Where do you live? (check one)

- 1 With your family
- 2 Independently in your own home
- 3 With other unrelated people
- 4 Other \_\_\_\_\_ (please specify)

5. What county do you live in?

\_\_\_\_\_

<sup>2</sup> This is a copy of the DD background form. The only difference between this form and the background form distributed to APD population is the addition of Question #10 on the DD version: "Who do you receive services from?"

Appendix F: Background Form

6. What is your disability? (Check all that apply)

- 1 Physical disability
- 2 Developmental disability
- 3 Disabilities related to age (e.g., dementia, Alzheimer's, etc.)
- 4 Visual impairment/Blindness
- 5 Hearing impairment/Deafness
- 6 Other \_\_\_\_\_ (please specify)

7. How many hours per month of paid support do you now receive? \_\_\_\_\_

8. What is your main way of talking with other people? (check one)

- 1 Speaking English
- 2 Speaking another primary language \_\_\_\_\_  
(which language)
- 3 Using gestures
- 4 Using sign language or finger spelling
- 5 Using a communication device
- 6 Other

9. Who helped you to answer this survey? (check all that apply)

- 1 No one
- 2 Family member
- 3 Caregiver (may be a professional)
- 4 Friend
- 5 Other \_\_\_\_\_ (explain)

10. Who do you receive services from?

- 1 Resource Connections of Oregon (RCO)
- 2 Full Access Brokerage (FAB)
- 3 Neither



## **Human Services Research Institute**

**7420 SW Bridgeport Rd #210 Portland, OR 97224 · v 503-924-3783 · f 503-924-3789**

---

### SPD Consumer Survey Field Test

#### Participant Consent Form

The Human Services Research Institute (HSRI) invites you to be part of a study of a new consumer satisfaction survey. The Oregon state office of Seniors and People with Disabilities (SPD) wants to learn about how well services work for people who live independently. This survey has not been used before, so we need to learn if the questions are clear and appropriate. By participating, you can help us make the survey better.

Being part of this study means we will meet with you to ask you some questions about the services and supports you receive. If you agree to do this, you will be contacted soon by a staff person to schedule a time and place for an interview.

We promise the information you give us will be kept private. Your name will not be connected to your answers, and the results of the study will be presented in aggregate form only.



Appendix G: Consent Form

Your decision about being part of the study will not affect the services you receive from SPD. If you decide to participate, you can still change your mind at a later time if you wish.

If you have any questions, please ask right now. If you have questions later, please contact Reena Wagle at HSRI, at 503-924-3783 ext. 19.

If you want to be part of this study, please sign below and fill out the next page. Also, please take a copy of this form to keep, in case you want to reach us for any reason.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

\_\_\_\_\_

**Your Contact Information:**

Your Name & Address:

\_\_\_\_\_  
Name (please print)

\_\_\_\_\_  
Street Address

\_\_\_\_\_  
City                      State                      Zip

Your Phone Number: \_\_\_\_\_

E-mail: \_\_\_\_\_

How would you like us to contact you?     Phone                       E-mail

Would you prefer that we call a friend or family member to choose a  
time for your interview?                       Yes                       No

If so, please give us your friend or family member's name and phone  
number:

\_\_\_\_\_

\_\_\_\_\_

Friend or family member's name

phone number

**Field test ID number:** \_\_\_\_\_

Appendix H: Feedback Form: Summary of Responses

Questions from feedback form	# Responses	Response
1. Where did you conduct the interview?	38	Home
	1	Car
	1	Shari's Restaurant
2. Who chose the location of the interview?	15	Interviewee
	13	Interviewer and interviewee
	9	Proxy
	3	Interviewer
3. How long did it take to complete the direct interview?	Average 26, minimum 15, maximum 45	
4. Who was present during the interview in addition to the primary consumer and the interviewer? (check all that apply)	21	Parent or Other Relative
	5	Paid Caregiver
	3	Parent/relative AND Paid Caregiver OR Other
	11	No one
5. What was this person's role during the interview?	12	Proxy
	7	Other
	4	Caregiver
	4	Both
	2	Proxy Or Caregiver AND Other
	11	N/A
6. How did the presence of these other people affect the respondent, in terms of answering the questions? Was it helpful to the respondent or a hindrance to the respondent?	20	Helpful
	1	Hindrance
	5	No effect
	1	Helpful and Hindrance
	10	N/A
	3	Missing
7. Describe the respondent's behavior(s) from your observations during the interview? The respondent: (check all that apply)	29	(1) Was communicative
	24	(2) Made consistent eye contact
	5	(3) Avoided eye contact throughout the interview
	11	(4) Was distracted during interview
	25	(5) Answered questions when asked
	13	(6) Other
8. Do you think the respondent had the opportunity to express their feelings and experiences?	29	Yes
	6	No
	4	Don't know
	1	Missing
9. Did the respondent have difficulty understanding any of the questions?	2	All questions
	4	Most questions
	20	A few questions
	14	No trouble

Presented at the October 2005 Stakeholder Group Meeting

Appendix I: Loki Results: DD

**Total Survey Responses: 52 (DD response only)**

**Survey Source**

Internet	Count: 1		2%
In Person	Count: 27		52%
Mail	Count: 24		46%







Score for this question: Not Applicable

**Who Administered Survey**

QA/agency staff	Count: 11		41%
Volunteer	Count: 0		0%
Volunteer with Project staff	Count: 9		33%
Project staff	Count: 7		26%







Score for this question: Not Applicable

**1. Do you have a person who speaks up for you/represents your interests when necessary?**

Never	Count: 2		4%
Rarely	Count: 0		0%
Sometimes	Count: 6		12%
Often	Count: 5		10%
Always	Count: 39		75%
Don't Know	Count: 0		0%







Score for this question: 4.52

**2. Does your plan include the things that you want or need?**

Never	Count: 0		0%
Rarely	Count: 0		0%
Sometimes	Count: 14		27%
Often	Count: 12		24%
Always	Count: 22		43%
Don't Know	Count: 3		6%

Score for this question: 3.92

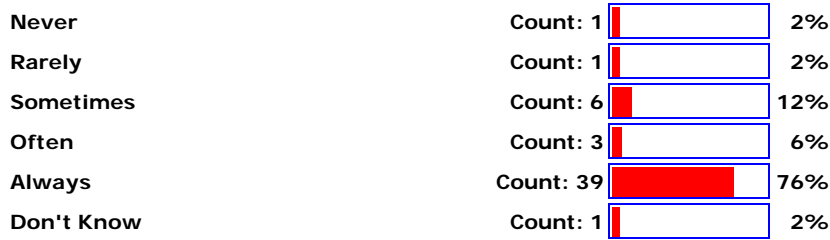
**3. Does someone help you understand the risks of your choices?**

Never	Count: 3		6%
Rarely	Count: 0		0%
Sometimes	Count: 4		8%
Often	Count: 4		8%
Always	Count: 39		76%
Don't Know	Count: 1		2%

Score for this question: 4.43

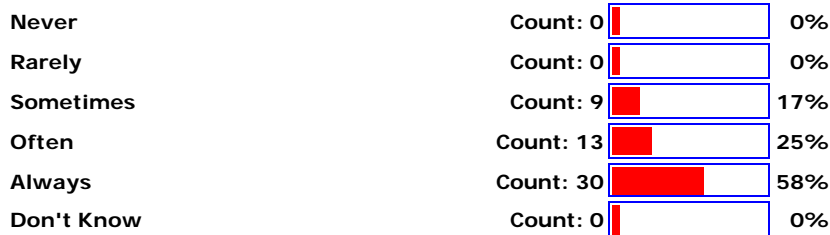
Appendix I: Loki Results: DD

**4. Do you have people you can talk to about your personal relationships, thoughts and feelings?**



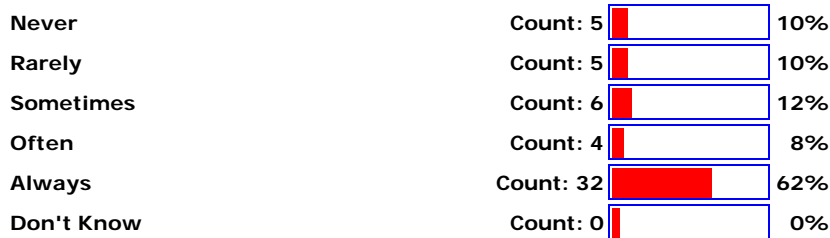
Score for this question: 4.47

**5. Can you go to places of your choice when you want to?**



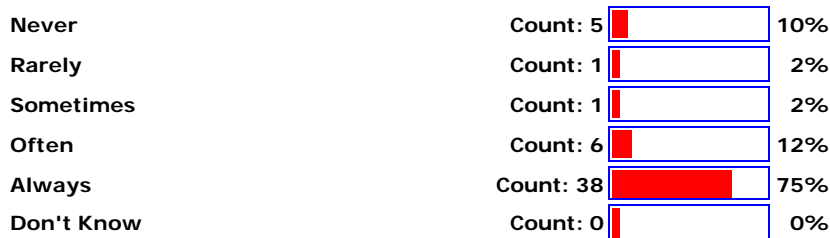
Score for this question: 4.40

**6. Do you know what to do in case of an emergency?**



Score for this question: 4.02

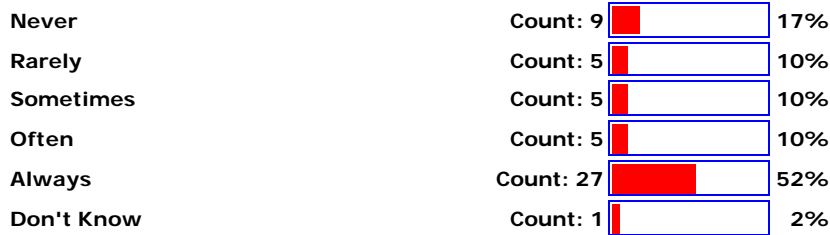
**7. Do you have someone you can call to help you during an emergency?**



Score for this question: 4.39

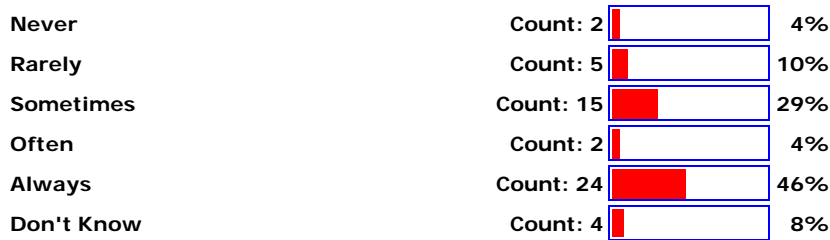
Appendix I: Loki Results: DD

**8. Do you understand your health needs?**



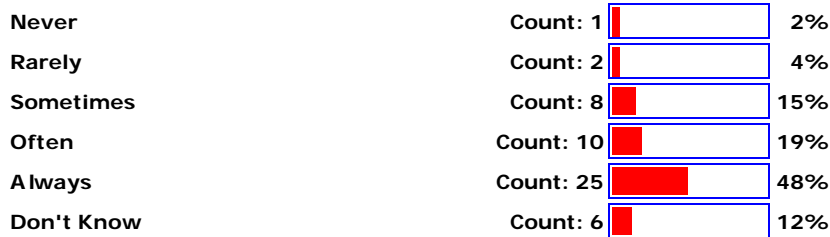
Score for this question: 3.63

**9. Are you pleased with the time it took to get services after you asked for them?**



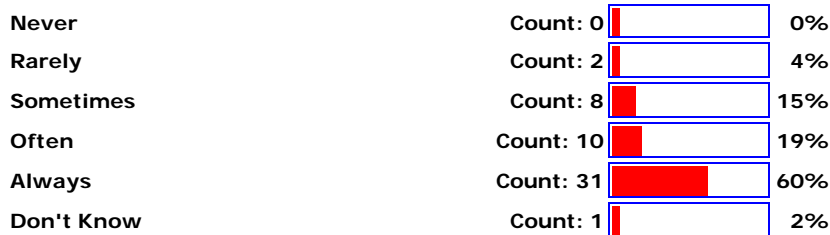
Score for this question: 3.56

**10. When your plan needs to change, does this happen within a reasonable amount of time?**



Score for this question: 3.73

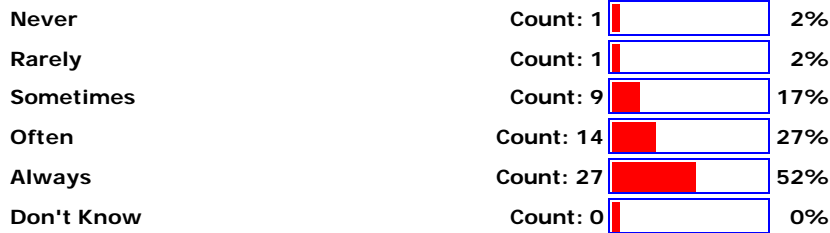
**11. Does your Case Manager give you the help you need?**



Score for this question: 4.29

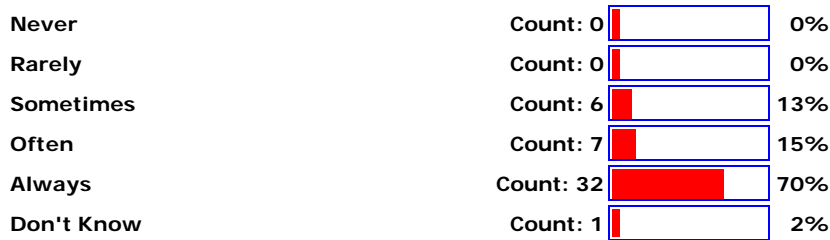
Appendix I: Loki Results: DD

**12. Are you satisfied with the services you currently receive?**



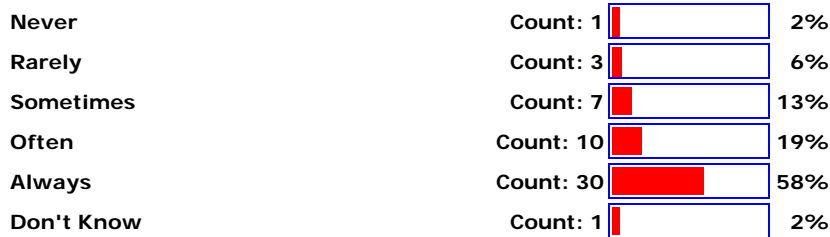
Score for this question: 4.25

**13. Do you think your staff know how to help you in the way that you need and want?**



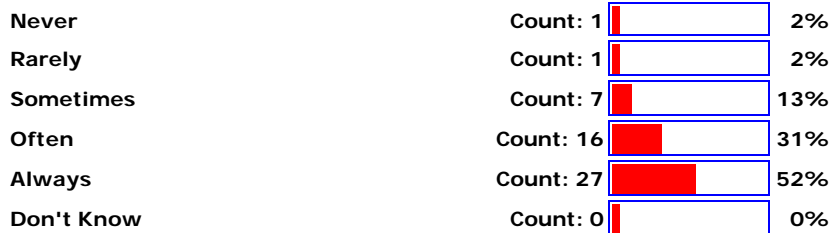
Score for this question: 4.48

**14. Do you get the information you need to make choices about your services and supports?**



Score for this question: 4.19

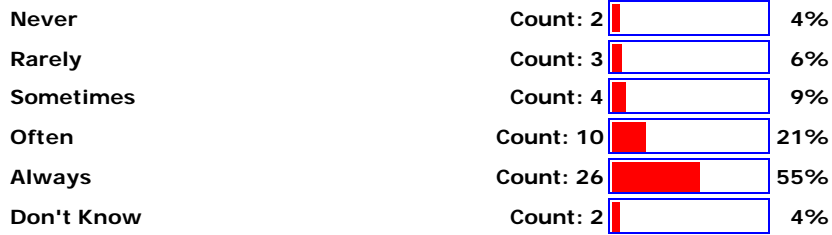
**15. Do you decide how you spend your free time?**



Score for this question: 4.29

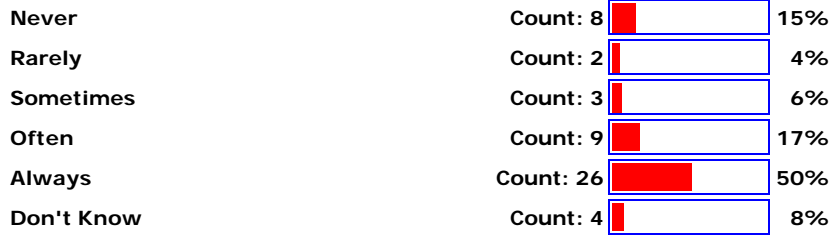
Appendix I: Loki Results: DD

**16. Do you feel you have enough staff to help you?**



**Score for this question: 4.04**

**17. Do you know what to do if you are unhappy with your services?**



**Score for this question: 3.60**

**Gender**



**Score for this question: Not Applicable**

**What is your race/ethnicity?**







**Score for this question: Not Applicable**















## Appendix I: Loki Results: DD

### Where do you live?

With your family	Count: 40		71%
Independently in your own home	Count: 10		18%
With other unrelated people	Count: 2		4%
Other	Count: 4		7%

Score for this question: Not Applicable

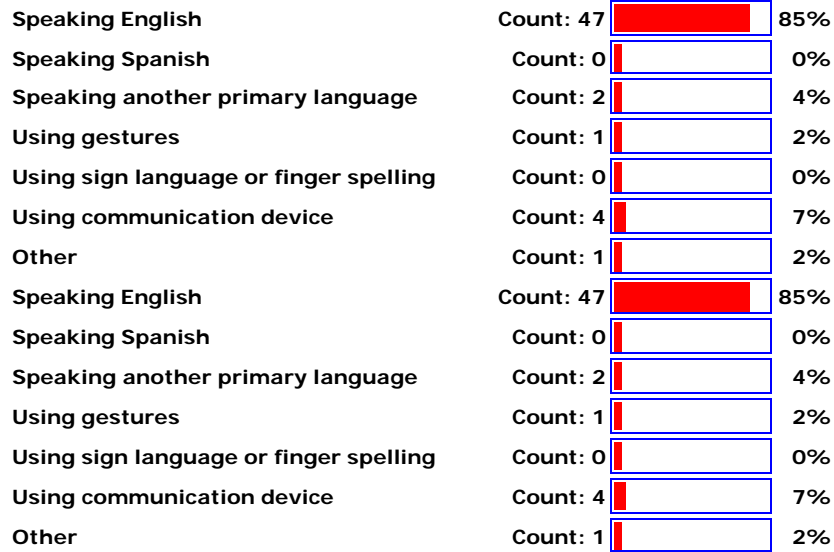
### What is your disability?

Physical disability	Count: 40		55%
Developmental disability	Count: 25		34%
Disabilities related to age	Count: 0		0%
Visual impairment/Blindness	Count: 2		3%
Hearing impairment/Deafness	Count: 1		1%
Other	Count: 5		7%
Physical disability	Count: 40		55%
Developmental disability	Count: 25		34%
Disabilities related to age	Count: 0		0%
Visual impairment/Blindness	Count: 2		3%
Hearing impairment/Deafness	Count: 1		1%
Other	Count: 5		7%

Score for this question: Not Applicable

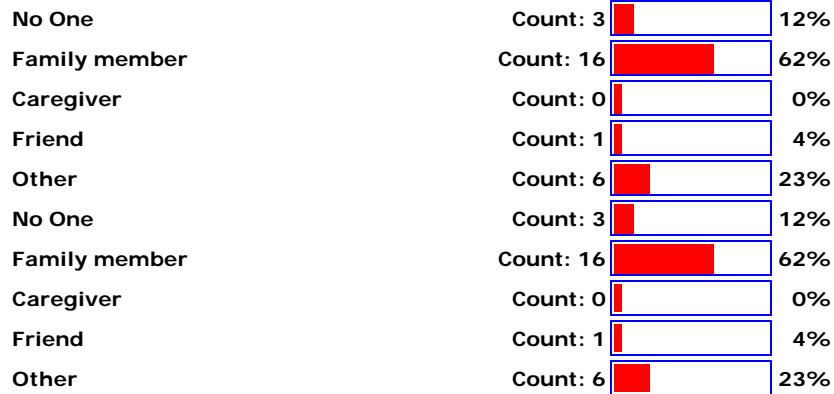
Appendix I: Loki Results: DD

**What is your main way of talking with other people?**



Score for this question: Not Applicable

**Who helped you to answer this survey?**



Score for this question: Not Applicable

**Who do you receive services from?**



Score for this question: Not Applicable

Appendix I: Loki Results: APD

**Total Survey Responses: 83 (APD response only)**

**Survey Source**

Internet	Count: 2		2%
In Person	Count: 23		28%
Mail	Count: 58		70%







Score for this question: Not Applicable

**Who Administered Survey**

QA/agency staff	Count: 8		35%
Volunteer	Count: 1		4%
Volunteer with Project staff	Count: 0		0%
Project staff	Count: 14		61%







Score for this question: Not Applicable

**1. Do you have a person who speaks up for you/represents your interests when necessary?**

Never	Count: 8		10%
Rarely	Count: 3		4%
Sometimes	Count: 14		17%
Often	Count: 11		13%
Always	Count: 45		55%
Don't Know	Count: 1		1%







Score for this question: 3.96

**2. Does your plan include the things that you want or need?**

Never	Count: 0		0%
Rarely	Count: 0		0%
Sometimes	Count: 15		18%
Often	Count: 14		17%
Always	Count: 46		55%
Don't Know	Count: 8		10%

Score for this question: 3.99

**3. Does someone help you understand the risks of your choices?**






Never	Count: 9		11%
Rarely	Count: 4		5%
Sometimes	Count: 8		10%
Often	Count: 14		17%
Always	Count: 44		54%
Don't Know	Count: 3		4%

Score for this question: 3.87

**4. Do you have people you can talk to about your personal relationships, thoughts and feelings?**







Never	Count: 1		1%
-------	----------	---	----

Appendix I: Loki Results: APD

Rarely	Count: 3		4%
Sometimes	Count: 12		14%
Often	Count: 11		13%
Always	Count: 55		66%
Don't Know	Count: 1		1%







Score for this question: 4.36

5. Can you go to places of your choice when you want to?

Never	Count: 2		2%
Rarely	Count: 10		12%
Sometimes	Count: 18		22%
Often	Count: 23		28%
Always	Count: 28		35%
Don't Know	Count: 0		0%







Score for this question: 3.80

6. Do you know what to do in case of an emergency?

Never	Count: 2		3%
Rarely	Count: 1		1%
Sometimes	Count: 4		5%
Often	Count: 11		14%
Always	Count: 60		75%
Don't Know	Count: 2		3%

Score for this question: 4.50

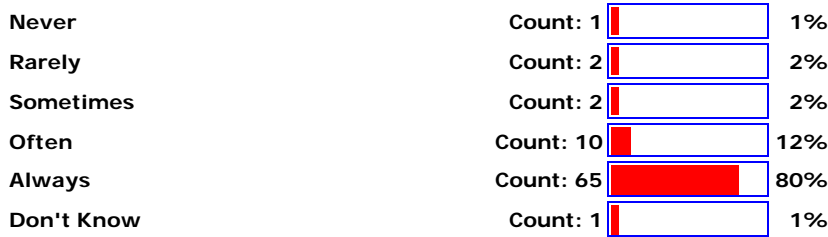
7. Do you have someone you can call to help you during an emergency?

Never	Count: 3		4%
Rarely	Count: 1		1%
Sometimes	Count: 5		6%
Often	Count: 10		12%
Always	Count: 62		77%
Don't Know	Count: 0		0%

Score for this question: 4.57

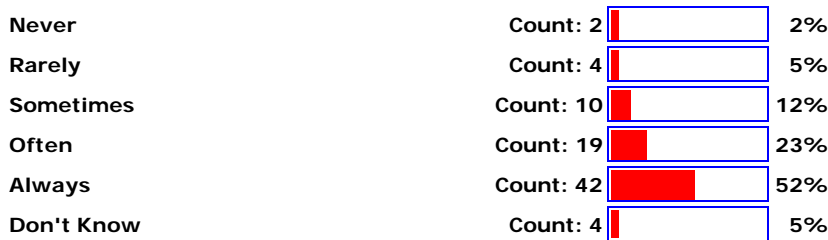
Appendix I: Loki Results: APD

**8. Do you understand your health needs?**



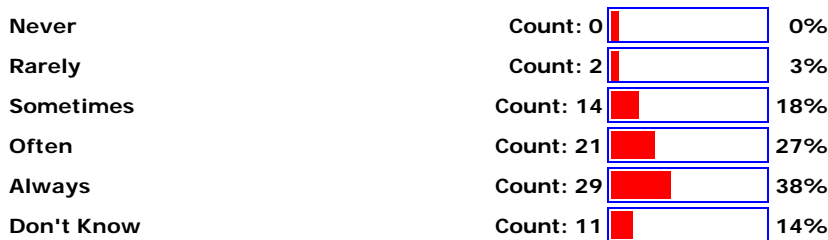
**Score for this question: 4.64**

**9. Are you pleased with the time it took to get services after you asked for them?**



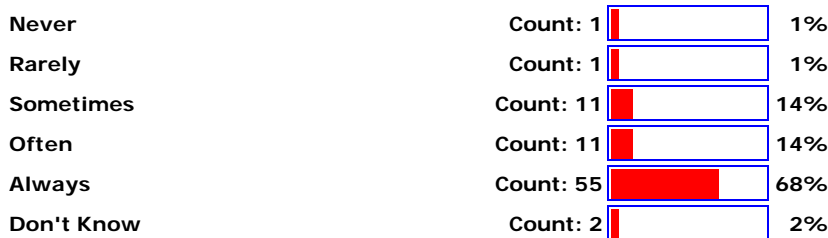
**Score for this question: 4.02**

**10. When your plan needs to change, does this happen within a reasonable amount of time?**



**Score for this question: 3.57**

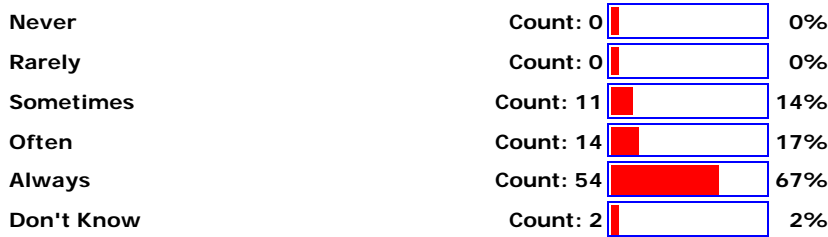
**11. Does your Case Manager give you the help you need?**



**Score for this question: 4.38**

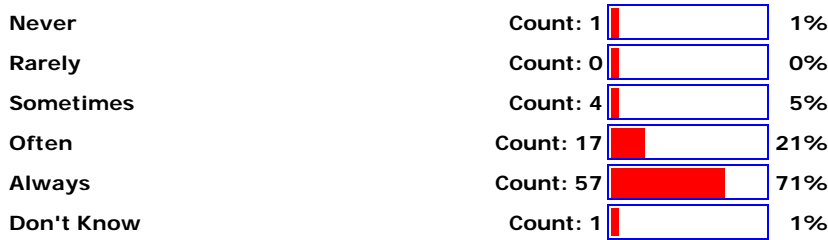
Appendix I: Loki Results: APD

**12. Are you satisfied with the services you currently receive?**



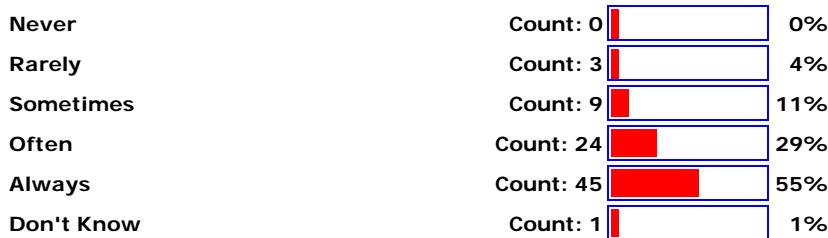
Score for this question: 4.43

**13. Do you think your staff know how to help you in the way that you need and want?**



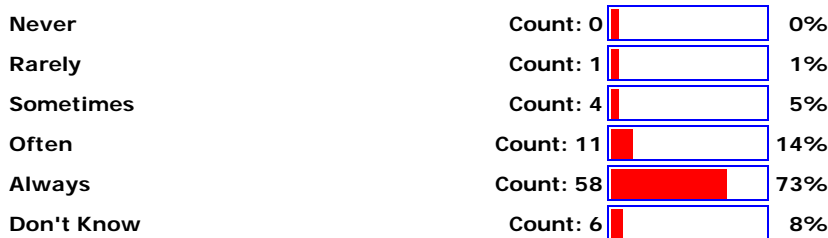
Score for this question: 4.58

**14. Do you get the information you need to make choices about your services and supports?**



Score for this question: 4.32

**15. Have your rights and responsibilities been explained to you?**



Score for this question: 4.35





Appendix I: Loki Results: APD

**Gender**

Male	Count: 23		29%
Female	Count: 56		70%

**Score for this question: Not Applicable**

**Where do you live?**

With your family	Count: 21		27%
Independently in your own home	Count: 44		56%
With other unrelated people	Count: 3		4%
Other	Count: 11		14%





**Score for this question: Not Applicable**

**What is your race/ethnicity?**

White	Count: 71		90%
Black or African-American	Count: 1		1%
American Indian and Alaska Native	Count: 1		1%
Asian	Count: 0		0%
Hispanic/Latino origin	Count: 6		8%
Native Hawaiian or Other Pacific Islander	Count: 0		0%










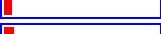


**Score for this question: Not Applicable**

**Where do you live?**

With your family	Count: 21		27%
Independently in your own home	Count: 44		56%
With other unrelated people	Count: 3		4%
Other	Count: 11		14%

**Score for this question: Not Applicable**

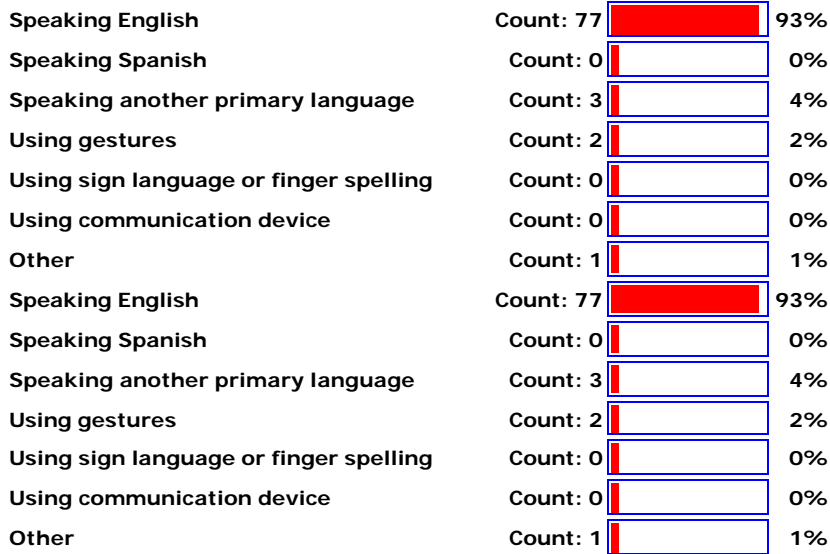
**What is your disability?**

Physical disability	Count: 87		66%
Developmental disability	Count: 3		2%
Disabilities related to age	Count: 12		9%
Visual impairment/Blindness	Count: 7		5%
Hearing impairment/Deafness	Count: 8		6%
Other	Count: 15		11%
Physical disability	Count: 87		66%
Developmental disability	Count: 3		2%
Disabilities related to age	Count: 12		9%
Visual impairment/Blindness	Count: 7		5%
Hearing impairment/Deafness	Count: 8		6%
Other	Count: 15		11%

**Score for this question: Not Applicable**

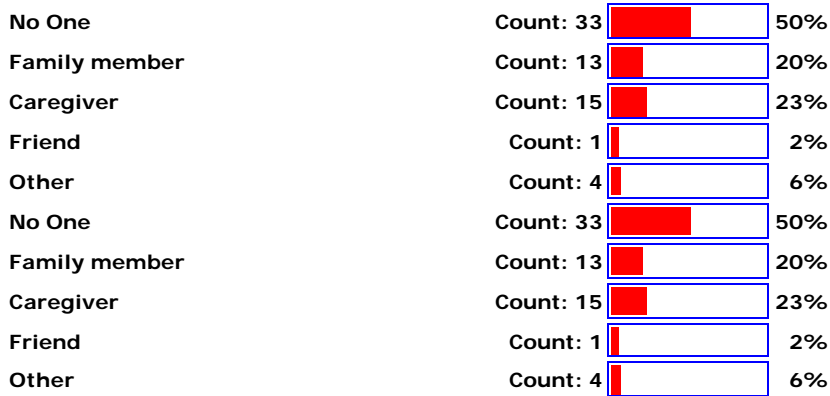
Appendix I: Loki Results: APD

**What is your main way of talking with other people?**



Score for this question: Not Applicable

**Who helped you to answer this survey?**



Score for this question: Not Applicable

**Who do you receive services from?**



Score for this question: Not Applicable



Appendix J:

<p>Rationale for Recommended Changes to SPD Consumer Survey Questions Based on field test findings and Stakeholder Group and SPD feedback.</p>	
Core Questions	Q#2: Modify to say “does your service plan include...
	Q#3: Keep as is; both this item and Q#2 point to difficulties service recipients have with questions in the Choice/Control domain. Recommendation is that case managers/personal agents give more attention to explaining what a plan is and how it is meant to reflect individual wants and needs, and how choice entails risk.
Population Specific Questions	Q#16 DD: This presented problems for respondents and seems to be related to Q#2 and the new Q#9, regarding plan and services reflecting needs. Recommendation is to drop it.
	Q#17 DD: This presented problems for respondents, and did not get at the idea of an appeals process; generally interviewees seemed to say “I talk to my case manager” or the like, so it is not clear that this question is giving anything more than is already captured by Q#11 (help from case manager) or Q#1 (having an advocate). Recommendation is to drop it.
	Q#15 APD: This is the only APD-specific question and was difficult for respondents. Since it does not really assure that the individual understands his/her rights and responsibilities, recommendation is to drop it.
	Q#15 DD: This question did not cause any difficulties but seems to be adequately addressed already by Q#5, so recommendation is to drop it, in the interests of having just a single set of questions for both populations.
DAS-mandated questions:	Q#9: This was designed to address the DAS item on accuracy. Since it encountered problems in both mail survey and face-to-face, and since the DAS question is really about providing services correctly, recommendation is to reword to say “Do you receive the services that you need?”
	Q#10: This was designed to address the DAS item on timeliness. Difficulties responding to this item were due to (a) never needing to change services (recommend using “DK” for such “NA” responses; (b) complex sentence structure (if/then); and (c) not understanding what a plan is (noted above). Recommended rewording: “When you need to change your services, does this happen within a reasonable amount of time?” and use DK for people who have not experienced any need for changes.
	Q#11: This covers the DAS item on helpfulness and is fine as is.
	Q#12: This covers the DAS item on overall service satisfaction. Currently the APD version says “satisfied” while DD version says “happy”. Recommended common wording: “Are you happy/satisfied with the services you currently receive?”
	Q#13: This covers the DAS item on expertise. To address respondent confusion, recommended rewording substitutes “caregiver” for “staff”. Important to note in the discussion of proxy respondents that often the caregiver is the parent, and also serves as the proxy, so this and a few other question become invalid.
	Q#14: This covers the DAS item on information and is fine as is.

Appendix K: Recommended Final Version of Consumer Survey

	<b>Never 1</b>	<b>Rarely 2</b>	<b>Sometimes 3</b>	<b>Often 4</b>	<b>Always 5</b>	<b>Don't Know 6</b>
<p><b>1. Do you have a person who speaks up for you when needed?</b></p> <p><b>(a person such as a friend, family member or an advocate - but not case manager or staff)</b></p>	1	2	3	4	5	6
<p><b>2. Does your service plan include the things that you need?</b></p> <p><b>(a plan is a formal document that lists the services and supports you will receive, often called a Client Plan or Individual Service Plan)</b></p>	1	2	3	4	5	6
<p><b>3. Does someone help you understand the risks of your choices?</b></p> <p><b>(choices such as declining services offered, choosing to live in an unsafe neighborhood, etc.)</b></p>	1	2	3	4	5	6
<p><b>4. Do you have people you can talk to about your personal relationships, thoughts and feelings?</b></p>	1	2	3	4	5	6

Appendix K: Recommended Final Version of Consumer Survey

	<b>Never 1</b>	<b>Rarely 2</b>	<b>Sometimes 3</b>	<b>Often 4</b>	<b>Always 5</b>	<b>Don't Know 6</b>
<b>5. Can you go to the places that you choose when you want to?</b>  <b>(such as shopping, entertainment, religious services, etc.)</b>	1	2	3	4	5	6
<b>6. Do you know what to do in case of an emergency?</b>  <b>(an emergency such as when your staff person does not show up, a fire, a tsunami, or anyone or anything that may hurt you)</b>	1	2	3	4	5	6
<b>7. Do you have someone you can call to help you during an emergency?</b>  <b>(an emergency such as when your staff person does not show up, a fire, a tsunami, or anyone or anything that may hurt you)</b>	1	2	3	4	5	6
<b>8. Do you understand your health needs?</b>  <b>(health needs such as why you take medication, managing conditions like diabetes, the reasons you need to visit your doctor)</b>	1	2	3	4	5	6

Appendix K: Recommended Final Version of Consumer Survey

	<b>Never 1</b>	<b>Rarely 2</b>	<b>Sometimes 3</b>	<b>Often 4</b>	<b>Always 5</b>	<b>Don't Know 6</b>
<b>9. Are services provided in the way you want?</b> <i>DAS- Accuracy</i>	1	2	3	4	5	6
<b>10. Are changes in your services made in a reasonable amount of time when a change is needed?</b> <i>DAS- Timeliness</i>	1	2	3	4	5	6
<b>11. Does your Case Manager and/or Personal Agent give you the help you need?</b> <i>DAS- Helpfulness</i>	1	2	3	4	5	6
<b>12. Are you happy/satisfied with the services you currently receive?</b> <i>DAS- Overall Satisfaction</i>	1	2	3	4	5	6
<b>13. Do you think your paid caregiver knows how to help you in the way that you need and want?</b> <i>DAS- Expertise</i>	1	2	3	4	5	6
<b>14. Do you get the information you need to make choices about your services and supports?</b> <i>DAS- Information</i>	1	2	3	4	5	6