
SPD Consumer Survey
for Use with Recipients of In-Home Services:
Survey Development and Field Test Report

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March, 2006

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I. INTRODUCTION

In May 2004, the Oregon Department of Human Services, Division of Seniors and People with Disabilities (SPD) contracted with Human Services Research Institute (HSRI) to assist in improving the processes for assuring quality in SPD in-home waiver services. With funding from Oregon's Real Choices Systems Change grant from the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS), the project focuses on in-home services provided to three populations -- people with developmental disabilities, people with physical disabilities, and seniors. The services are provided through three Oregon Medicaid waiver programs – the In-home Comprehensive Services program, the Support Services Brokerages, and the Client-Employed Provider program. The project, running from May 2004 through September 2006, gives particular attention to the areas of recipient safety, health and service satisfaction.

One of the major contract tasks for the HSRI team¹ was development of a consumer survey process applicable to all three populations served by SPD's in-home waiver programs. Between December 2004 and July 2005, the study team worked closely with SPD and with a group of stakeholders to develop the consumer survey instrument and methodology. During the summer of 2005, we conducted a field test of the tool and process. This report describes the development and field test of the consumer survey, and provides recommendations regarding both the survey questions and survey administration.

II. INITIAL DEVELOPMENT OF CONSUMER SURVEY

The HSRI team conducted an initial exploration of consumer surveys, learning about approaches used in other states and more closely examining current SPD practice. Drawing from HSRI's knowledge and experience in quality assurance, we identified a number of states which have been particularly successful in conducting consumer surveys. We gathered materials from these states and followed up with telephone interviews with key staff. In these interviews, we sought to more fully understand the context and development process which led to states' decisions about survey domains, methodology, analysis, and other relevant aspects. Appendix A contains details about what we learned.

At the same time, the project team explored in more detail what is currently happening in Oregon around consumer surveys. We conducted telephone interviews with a number of key informants in SPD and in the field, including representatives from agencies serving people with developmental disabilities (henceforth called the "DD" population) and agencies serving seniors and/or people with physical disabilities (henceforth called the "APD" population). In particular, we spoke with staff in each Brokerage to understand how they implement their survey and what methodological variations exist among the Brokerages' approaches.

¹ HSRI worked in collaboration with the Oregon Technical Assistance Corporation (OTAC) and Loki Innovations.

With this information as a foundation, we began to work on two parallel tracks: design of a consumer survey instrument and development of the methodology for implementing the survey instrument. A central participant in this ongoing process was the project Stakeholder Group, composed of representatives of governmental, advocacy and consumer groups involved with in-home service provision for the three populations (see Appendix B for a list of the Stakeholder Group members). The Stakeholder Group meets monthly to brainstorm about project tasks and to review draft materials; the group provided regular input during the development of the consumer survey.

A. Design of Draft Consumer Survey Instrument

Based on our research and stakeholder input, the project team set out to develop a core set of questions that would be common to both DD and APD populations, as well as a few program/population specific questions. Our initial goal was to keep the number of core questions to 10, and the total number of questions to 15. In February and March 2005, the project team developed several initial drafts of the survey, built around seven domains derived from what we learned in other states. The domains include choice/control, relationships, community integration, health, emergency/safety planning, service delivery, and satisfaction.

A key consideration in designing this consumer survey instrument is Oregon's 2005-07 Budget Instructions requiring all state agencies to develop performance measures around customer satisfaction. The Department of Administrative Services (DAS) mandated the inclusion of six specific questions in any customer surveys implemented by state agencies². The DAS goal was to have a baseline of consumer survey data established by Spring 2006, with findings available for a report to the 2007 legislature. For this reason, the mandated questions need to be incorporated into the survey tool developed by this project.

We presented the draft survey instruments to the project Stakeholder Group. The stakeholders first discussed whether the domains were appropriate and covered all their areas of concern, and then reviewed the preliminary questions that were developed for each domain. In a subsequent Stakeholder Group meeting, we offered a draft with 44 questions (including the six questions mandated by DAS). Each member had the opportunity to identify their top priority questions and to group those into three levels of priority – high, medium and low. We aggregated their responses, distinguishing the responses of APD representatives from those of DD representatives. (See Appendix C for results of prioritization).

The resulting draft survey instruments reflect the priorities of the two groups of stakeholders. Several questions stood out as receiving the highest scores from both groups; these became core questions. Coincidentally, these core questions covered five of the seven domains; for the other two domains, community integration and health, the Stakeholder Group advised merging the draft questions into one new question on community integration and one on health. We also included six modified questions to address all of the DAS-mandated areas.

² Recommended Statewide Customer Service Performance Measure Guidance, prepared by the Oregon Progress Board, June 2005.

Several questions received much higher prioritization from one population than the other, indicating population-specific issues. These questions were attached to the appropriate survey, DD or APD. As a result, we had two versions for the field test, one for DD (including the 10 core questions, 4 added DAS items, and 3 population-specific questions) and one for APD (10 core, 4 DAS, and 1 population-specific item).

In addition to the population specific questions, one more distinction exists between the DD and APD surveys. At the request of some Stakeholder Group members representing the DD population, we also added “smiley faces” above the response columns on each page of the DD survey and several other graphics to some questions; these Stakeholder Group representatives felt the graphics would improve the reliability of responses. In the field test, we did not explicitly test whether the “smiley faces” improved response rates and reliability. Stakeholder Group members continue to hold mixed views about the use of the graphic, suggesting that SPD will benefit from having further discussions among involved parties to determine whether the “smiley faces” should be used.

The field test versions of the mail survey (both DD and APD-specific versions) are included in Appendix D.

B. Development of Survey Methodology

Building on our interviews with other states, the project team identified six major methodological considerations pertinent to conducting a consumer survey. After a series of discussions with the Stakeholder Group as well as SPD staff, we reached consensus on these issues, as described below. These decisions informed the final design of the field test.

1. *Purpose of the Survey*: Should the survey provide information on how the system is working as a whole, or how individuals receiving services are faring?

Aggregate/system level data from consumer surveys is used by a number of states³ to drive policy and practice at the system level, to identify areas for training or technical assistance at various levels of the system, and to develop performance measures.

However, Stakeholder Group members were concerned that if a serious risk to health and safety is identified at the individual case level, this information must not be ignored – in this case, the individual identified as being at risk should be approached in some fashion. In addition, there was clear support for having the ability to identify specific caregivers serving multiple people with serious risk situations.

Consensus: The primary purpose of the consumer survey should be to provide the state with a system perspective on quality in the areas of health and safety; ideally, it would also have the capacity to identify individuals who, through the survey, appear to be at risk for an identified health or safety issue. It may be helpful to also be able to disaggregate the results by locality (county, agency) and perhaps even by case manager/personal agent.

The field test was consequently designed to offer a systems perspective, with questions addressing all the relevant domains of the consumer experience in in-home

³ Including Colorado, Indiana, Pennsylvania and Wisconsin

services. Because of the small sample size, we did not attempt to flag any individual-level responses. (see next discussion regarding confidentiality).

2. *Confidentiality*: The issue of using survey data to identify individual cases at risk raises concerns around confidentiality. In order to obtain honest responses to survey questions, the survey must give respondents assurance that confidentiality will be maintained. In most of the states we examined, respondents are guaranteed confidentiality immediately prior to answering the survey questions. If any of the respondent's answers are going to be shared, as when a serious risk is identified, then the respondent must authorize release of that specific information.

States deal with this in a variety of ways. In the Indiana Quality Improvement Process, responses are monitored for specific questions which raise flags; this process is used to create a complaint data base of special review cases. In New Hampshire, individual-level responses are used as a problem solving/education instrument for the individual. Issues that are raised during the review are addressed through technical assistance to providers or by helping individuals become more sophisticated users of services. Minnesota uses individual-level data to identify providers who receive multiple negative responses in areas of concern, but individual cases are not identified. In Colorado, the respondent is assured confidentiality, but the individual gives consent to release confidentiality on certain issues/questions, allowing the respondent to maintain anonymity on other questions. (See Appendix A for more detail about these state processes.)

Consensus: Confidentiality is key to obtaining valid responses. For certain questions, SPD may want to gain individual consent to release the information, but it may be best to segregate the individual-level problem-solving activities from the consumer survey process in order to assure confidentiality of survey responses without losing the vital information when an individual is at imminent risk. The best approach might be some type of automatic risk flagging combined with individual consent to sharing the risk information.⁴

The field test design offered a limited opportunity to learn about this issue. As part of the training process, the interviewers were alerted to the possibility that a respondent could reveal an immediate risk situation; however, no interviewers encountered this situation during the actual field test. This issue will need to be addressed by SPD as part of discussions regarding the final implementation of the consumer survey.

3. *Sampling Frame*: Several considerations arise regarding the sample of people to be surveyed. Most important are (a) criteria for inclusion in the survey sample, (b) sample size and stratification, and (c) timing for the sampling process.

(a) Should the sample include all people receiving in-home supports through one of the waivers? It may be desirable to restrict respondents depending on the *length of*

⁴ A telephone survey process could automatically generate a risk flag whenever a respondent hits a critical threshold (e.g. two key questions about current health/safety are answered negatively). This would alert the telephone interviewer to ask the respondent if he/she would like to have a follow-up call from someone in an official capacity; if agreeable, the respondent would provide his/her name and contact information. This information would be emailed automatically to a designated staff person; the survey responses would not be shared. Such an approach could be used for telephone surveys or face-to-face interviews.

time they have been receiving services or the type and amount of services they receive. People who have just begun to receive services may have a fairly limited exposure to aspects of the program, and/or may still be in transition from their prior living situation. In addition, people who are receiving only a small amount of services (e.g. 40 hours per month or less) may have a perspective that is based on fairly few interactions with the caregiver, relative to other people in the respondent's life, making their view distinctly different.

Consensus: The Stakeholder Group voiced support for restricting the sample to people with at least one year of experience receiving in-home services. We were able to adopt this suggestion for the field test, by requesting that the sample from SPD include only those people who had received services for at least a year, although the structure of the SPD data system made this more difficult than expected.⁵

The concern regarding the amount of services received per month appeared to be a more salient issue for the APD population; these representatives on the Stakeholder Group felt that some minimal number of hours of service would be an appropriate criterion – something between 20 and 40 hours per month. However, neither the state, nor local agencies, nor individual survey respondents were able to provide an accurate number of hours of services received.⁶ If we had eliminated from our analysis all the surveys where respondents received less than 40 hours per month (26 cases) or where there was no response to the question (19), we would have had lost one third of our survey data for the field test. Therefore, we chose not to use this as a criterion in the data analysis. If this is a factor SPD would like to use in analysis of future survey findings, they will need to identify a more reliable method of collecting hours of service per month.

(b) The question of *sample size and stratification* depends on the level of disaggregation desired. One consideration in deciding whether to use a random sample or to stratify by sub-groups of interest is whether the sub-groups are sufficiently large to avoid under-representation in the statewide sample. In general, a 5% sample is sufficient, but there should be at least 25-50 people in each sub-group for which results will be tabulated. In order to assure that the findings are not simply due to chance, several states we spoke with distribute their customer survey to a statewide random sample of service recipients⁷, particularly if they are using mail surveys.

For this SPD survey of in-home service recipients, simple random sampling might result in sample sizes that are too small for analysis at the program level (e.g. CEP vs. In-Home Comprehensive recipients). As noted above (#1), stakeholders expressed interest in having information at least at the Brokerage/agency level.

⁵ The in-home data system is based on when invoices are paid, rather than when services are received, making it difficult to learn how long someone had been receiving services.

⁶ Agencies had to estimate the number of hours and individuals often left this field blank or provided an unrealistic number: the range was from 4 hours to 672 hours per month (with an average of 116 hours per month). That this is problematic is not completely surprising given the flexibility of in-home supports – hours are not tracked by service recipient as they are for fee-for-service supports.

⁷ See Appendix A for more details.

This suggests that stratification of the sample may be needed – taking a random sample of X number of people from each program type, which would represent a different percentage sample from each group.

Consensus: The sample should be stratified by the following areas: APD vs. DD; within APD, seniors vs. people with physical disabilities; within DD, recipients of In-home Comprehensive vs. Brokerage services. For the field test, we set a goal of receiving completed surveys from 40 individuals receiving services through the Brokerages, 20 individuals receiving services through the In-Home Comprehensive Services program, 40 seniors receiving services through the Client-Employed Provider program (CEP) administered by an Area Agency on Aging (AAA), and 40 people with physical disabilities receiving services through CEP and administered by a Disability Services Office. This ensured representation from each of the populations receiving waiver in-home supports. With statewide implementation, the survey could be expanded to additional SPD programs, and findings could also be stratified by adults vs. children and by waiver program.

- (c) There appear to be two options regarding *timing of the survey*: at a single point in time (annually, quarterly, etc) or on a rolling schedule with the survey administration tied to a standard event in each case such as an annual reassessment (Indiana’s Quality Improvement Process uses this method). The latter would provide a cumulative sample throughout the year, but it requires more resources and coordination on part of the case managers.

Consensus: The group expressed a strong preference for the point-in-time option, using several survey points spread out across a year. The rolling date would not work because there are already too many activities happening at the time of the annual reassessment. The field test explicitly tested a survey distributed at one point in time.

4. Survey Method: Several different methods are available to administer a consumer satisfaction survey including face-to-face interviews, telephone interviews, web-based and mail-in surveys. The availability of resources, the ability of the respondents and the purpose of the survey all influence the choice of method to be used. Below we discuss some pros and cons of the four survey methods.

(a) Face-to-Face: Several of the states we contacted use the face-to-face method. These states found that individuals with developmental disabilities and seniors find it easier to express themselves in person than through a written survey or over the telephone. Face-to-face interviews provide an opportunity for the interviewer to establish rapport with the individual, perhaps yielding more complete interviews, and to clarify ambiguous responses as needed. However, face-to-face interviews are more time-consuming and expensive.

(b) Telephone: Another option is the telephone interview. Telephone interviews are most effective when the data collection instrument is short. Some states use telephone interviews for only a part of their survey, e.g. for questions related to consumers’ satisfaction with their case manager. In addition, scheduling a telephone interview may be easier than arranging a face-to-face visit because

telephone interviews require less logistical planning and seem less intrusive. Technologies such as the Interactive Voice Response (IVR) system can be used to enhance data collection via the telephone by allowing people to complete the survey over the phone, with results automatically entered into a database. However, this approach is not viable for people who do not have phones or who have trouble hearing on the telephone.

- (c) Web-based: The main advantage of a web-based survey is convenience for respondents who regularly use the Internet. The technology is easily set up, and offers the potential for quick aggregation of data. One obvious drawback to this approach is that many individuals receiving in-home supports may not be able to complete a survey on-line. However, the system could also be set up to be used by whomever administers the survey, allowing people in the field to quickly input respondents' answers and thus make the information immediately available in the survey database.
- (d) Mail-in: A few states we spoke with use a mail-in methodology. While this method is inexpensive and can reach a larger number of people than face-to-face or telephone interviews, literacy issues and physical limitations may create difficulties in completing a mail-in survey. In general, the response rate tends to be lower for mail surveys than for face-to-face or telephone interviews.

Consensus: A combination of methods seems to be the best approach; this addresses the differing needs and preferences of SPD populations. The Stakeholder Group expressed particular interest in face-to-face and mail surveys, with much less support voiced for telephone interviews. The mail survey method could include the options of completing the survey in writing and mailing it back, or using the web to complete the form. The field test thus expressly tested three methods -- face-to-face interviews and mail surveys, with the option to complete the mail survey on-line.

- 5. Data Collection Responsibility: Where face-to-face or telephone interviews are used, a critical issue is who conducts the interview. In selecting an interviewer, it is important to consider the nature of the questions being asked, to avoid any conflict of interest or undue influence over the respondent. For example, if the survey includes questions regarding satisfaction with one's case manager and services, the interviewer would need to be someone not directly involved with the respondent's services. Several options are described below:

- (a) Quality Assurance Staff: The advantage to this option is that QA staff are already engaged in similar individual-level review tasks and have the needed skills. Since they are not directly responsible for assuring a recipient receives appropriate services, they would not necessarily have a conflict of interest. Confidentiality and anonymity of the individual could be assured.
- (b) Case Manager/Service Coordinator/Personal Agent: The advantage of using case managers is their ongoing connection with recipients, making it easier to schedule the interview and have rapport with the respondent. However, the proposed survey instrument includes questions about the consumer's satisfaction with their case manager/personal agent. Having the case manager/personal agent conduct the survey would likely inhibit an honest response from the interviewee and

would violate confidentiality. To avoid such a conflict, some questions could be moved to a separate survey conducted by a third-party, but this would require extra time and resources to conduct a second interview.

(c) *Third-party (volunteer, peer)*: Many states use volunteers to interview program participants regarding their satisfaction with services. These volunteers undergo comprehensive training including careful review of the interview protocol, good interview techniques, and technical issues such as observer agreement and how to record the data and their observations. This method is particularly useful in a situation with limited staff resources, but does require significant training, support and oversight of the non-professional interviewers.

Consensus: The Stakeholder Group agreed that, when conducting face-to-face or telephone interviews, it is important for an independent party to administer the survey. The field test was designed explicitly to examine the differential effect of different types of interviewers: we recruited agency staff (both QA staff and case managers) as well as several third-party volunteers to conduct the interviews; we also used project staff to assist the third-party volunteers as needed.

6. *Use of Proxy Respondents*: The issue of the use of proxy respondents emerges regardless of the survey method. *Proxy* is the use of another individual (e.g., family member, caregiver, friend, etc.) to answer survey questions when the individual is unable to speak for himself or herself. In our examination of how other states address the use of proxies, we found significant variation. Some states argue that using a proxy in situations where an individual's communication is difficult to understand provides a valid method of interviewing the participant. Other states feel that other individuals should be used as interpreters only, because the proxy respondent may not accurately reflect the perspective of the interviewee. In situations where proxy answers are considered legitimate, several additional questions need to be considered: who can provide the proxy response, whether the proxy can be used for all or only for some questions, and whether the proxy responses should be separately analyzed.

Consensus: The Stakeholder Group was unable to come to an agreement on how to address the use of a proxy; we decided to wait for the results of the field test to gain insight into whether the use of proxy respondents impact survey results. The field test survey tool included several questions about the extent of reliance on the proxy respondent, which allows us to examine the data for any systematic bias.

III. FIELD TEST OF CONSUMER SURVEY

The project team spent the summer of 2005 planning and conducting a field test of the consumer survey. The field test was designed to offer insight into the clarity of the survey questions and the viability of the survey methods. Although we had considerable input from the Stakeholder Group and SPD during the development of the survey, it was nonetheless important to formally test our proposed survey on people who would be receiving the survey during any statewide implementation. The field test enabled us to identify specific difficulties people had in answering the questions. Further, it allowed us

to see how well the survey as a whole yielded a composite view of the service experience of a small group of individuals receiving SPD in-home supports. The field test process is described below.

A. Recruiting Field Test Sites

In June of 2005, SPD staff approached several agencies serving the DD and APD populations to ask for their participation in the consumer survey field test. Five agencies agreed to participate: Resource Connections of Oregon (a Brokerage serving the Salem area), Full Access Brokerage (serving a multi-county area), Lane and Clackamas County In-Home Comprehensive programs, and Northwest Senior & Disability Services (serving the mid-Willamette Valley and Tillamook County). These sites were asked to be involved in several activities of the field test: provide background information on clients identified in the SPD sample, approach individuals to invite them to participate in the face-to-face interviews, attend the training on the interview process, conduct some face-to-face interviews, and coordinate the collection of all materials related to the survey. The five sites were also responsible for distributing the mail survey to a specified sample of clients. Appendix E contains a complete list of site responsibilities and tasks. By participating, the field test sites had a unique opportunity to provide feedback on the survey instrument and process prior to statewide implementation.

B. Obtaining Sample from SPD

In July 2005, SPD staff extracted a list of qualified service recipients in the five field test sites. Specifically, the project team requested a complete list of individuals who met the following criteria: currently receiving in-home Waiver services, 18 years of age or older, and receiving services for at least a year. Across the five field test sites, 365 individuals were identified as potential survey respondents.

In obtaining the sample, the project team encountered several challenges. First, it was difficult to compile a list of individuals who fit our description. SPD had to pull information from different databases and integrate it. Second, we mistakenly assumed the sites had easy access to certain descriptive information on their service recipients, which would enable them to quickly and easily complete the background form (described next) and to send out the mail surveys. In the end, the data system limitations at both the state and site levels made the initial stages of the field test more difficult than anticipated.

Recommendation: SPD will need to develop a process to identify individuals to sample for this survey and pull as much data on these individuals as possible. Without developing a method to streamline this process, the level of effort involved in this activity will be daunting for local agencies. From the perspective of the field test sites, simply providing addresses (in the form of mailing labels) would significantly reduce the level of effort required to distribute the mail survey.

C. Background Forms

Once SPD had created a list of the entire population of people matching the survey criteria, it was necessary to gather additional information on these individuals to determine who should receive a face-to-face interview and who should get a mail survey. We wanted to identify individuals who would need more assistance in completing a survey and assure that they received a face-to-face interview. We also did not want to

send a mail survey to someone with a visual impairment. The sites were thus asked to complete a background form for each individual in the sample.

While many questions were asked on the background form, we eventually used only two pieces of information to determine which type of survey an individual was to receive: type of disability (i.e. visual impairment) and method of communication. We also used the method of communication item to determine whether the individual speaks another primary language (see next discussion). The other questions which were included on the background form were useful in the analysis of the survey data, but were very difficult for the field test sites to easily provide.

Some confusion also arose concerning the race/ethnicity element: there was a discrepancy between the categories we had on the background form, what was in local agency systems, and what was in the SPD data systems. It was suggested that we simply use Census Bureau categories or the SPD categories.

Recommendation: Given the level of effort needed on the part of pilot sites to complete the background form and the limited amount of information the project team used to determine survey method, we recommend that the information obtained from the SPD data systems and local agencies should include only information needed to make the decision on which type of survey an individual should receive. Additional demographic information can be collected directly from the survey respondent through background forms attached to the survey instrument. Appendix F contains the modified background form distributed with the surveys; it uses race/ethnicity categories consistent with the U.S. Census Bureau categories.

D. Spanish Versions of the Survey

After finalizing the field test tool, the project team had all materials translated into Spanish to distribute as needed. We had the survey instrument and related materials reviewed for cultural appropriateness by the director of Juntos Podemos, a Salem family center for Latino families who have children with developmental disabilities. We then used the information from the background form to identify sampled individuals whose primary language was Spanish, and provided them with the Spanish version of the survey; four APD respondents received the Spanish version of the mail survey and one face-to-face APD interview was conducted in Spanish (by a project team member). In the final tally, we received completed surveys from all but one of these individuals.

The Spanish versions of the materials were used to their full extent. Due to the extremely small sample of Spanish surveys, we were unable to do any separate analysis of these surveys, but feel the overall effort to involve Spanish-speaking service recipients was successful. SPD will need to decide whether additional language translations would be useful; the background information from the original SPD sample indicated several APD individuals had as their primary language Russian (4 individuals), Vietnamese (1 individual), Cambodian (1 individual), or Dutch (1 individual).

E. Implementing Face-to-Face Interviews and Mail Surveys

As described in Section II.B.4 above, one intent of the field test was to explore the use of face-to-face interviews vs. mail surveys as a method of administering this consumer

survey. The following section provides an overview of the process used to implement these two methods as well as recommendations based on the field test findings.

1. Face-to-Face Interviews: The goal of the field test was to complete 70 face-to-face interviews. To achieve this goal, the team decided to pursue face-to-face interviews with twice that number of individuals, 140 individuals, to protect against having as little as a 50% completion rate.

- (a) Identifying Interviewers: Each field test site was asked to identify individuals who could conduct the face-to-face interviews -- agency staff, advocates, and independent volunteers. To encourage the participation of advocates and volunteers, the project team offered a stipend of \$25/interview. We ended up with a combination of interviewers in each site, engaging QA staff, case managers, personal agents, volunteers from Self Advocates As Leaders (SAAL), and a volunteer who advocates for people with physical disabilities. HSRI/OTAC staff also participated in a number of interviews, providing support to the SAAL volunteers and completing interviews that could not be done by others due to time constraints (see Table 4 in Section IV.C below for more detail).
- (b) Training: In September 2005, the project team conducted a two-hour training for all interviewers. The training reviewed the survey tool question-by-question, described the logistics of setting up interviews, and discussed general interviewing techniques. A follow-up training was conducted with the SAAL volunteers to provide additional coaching.

Recommendation: If both agency staff and third-party volunteers are used to administer the face-to-face survey, we would recommend holding two training sessions, one for agency staff and one for volunteers. The volunteers had many questions and would benefit from more role-playing, while agency staff could have a shorter version of the training, focusing on the logistics and a quick discussion of the intent of questions. It might also be useful to have more follow-up sessions with volunteers.

- (c) Consent form: We asked the field site coordinators to contact each individual in the face-to-face sample, to request their participation in the survey and have them sign a consent form (see Appendix G). The field test coordinators found it very time-consuming to get the consent forms signed in person prior to conducting the interview; this required additional arrangements to meet with the individual simply to sign the form. In an effort to streamline this effort, two sites gained verbal consent over the phone, and then the individual signed the consent form when the interview was conducted.

Recommendation: As long as each agency's confidentiality agreement allows this, we recommend simply gaining verbal consent prior to the interview and written consent during the interview; this procedure improved the consent form process considerably.

- (d) Conducting interviews: As consent forms were received, HSRI assigned interviewers to contact the survey recipients and schedule the interview. Following the completion of each interview, the interviewers filled out a feedback

form which indicated how the interview went and allowed interviewees to tell us if particular questions were difficult for respondents. Appendix H provides a summary of responses from the feedback form. Completed interview materials were returned to OTAC/HSRI staff for data entry.

- (e) *Overall level of effort:* The level of effort for the face-to-face interviews was significant. Project staff spent quite a bit of time scheduling and tracking interviews, and collecting completed materials. Agency staff spent a lot of time coordinating the consent forms, scheduling and conducting interviews; field test coordinators reported that the whole process was very labor intensive and turnaround times were unrealistic. It is estimated that each interview took about two hours work for a 20-minute interview.

Recommendation: The face-to-face interview process was made more difficult by the involvement of an outside party – HSRI/OTAC. For example, because of issues of confidentiality, when we asked sites to complete background forms, we provided them a list of individuals identified only with a unique field test code but no names included (we did not have the names). Sites then had to match the individual's identification number to the individual's name before gathering the background information, a step in the process that would have been avoided if SPD was giving the sample list directly to the local entities. When the consumer survey is conducted statewide, issues like this will be avoided.

2. *Mail Survey:* In initial discussions about the field test, the project team set a goal of collecting 70 mail surveys; we distributed three times that number of surveys in order to assure that we achieved our goal.

The mail survey was mailed from HSRI on September 6, 2005. Survey packets included the survey instrument, the background form, instructions for completing the forms, and a web address if survey participants wanted to complete the survey on line. The packet also included a self-addressed stamped envelope for returning the completing survey to HSRI.

Analysis of the findings on face-to-face vs. mail survey methods is presented in Section IV.C below.

F. Data Collection

Staff from Loki Innovations developed a website to assist in data collection. The website offered the opportunity for people to complete the survey on-line (three respondents chose to do so), as well as a method of easy data entry. All completed surveys, both face-to-face and mail, were returned to HSRI where they were input into the web-based data system -- this process proved to be extremely useful. This web-based application allows for the possibility of entering data remotely and for the reporting of results in "real-time". Loki has the ability to develop an interface that would enable a user to view findings at several levels (local agency, APD vs. DD, statewide, and other groupings of interest such

as demographic information) and to see the results by survey question. Appendix I contains a sample report of field test findings generated by the website⁸.

IV. FINDINGS AND RECOMMENDATIONS FROM FIELD TEST

The field test was designed to provide guidance on a number of aspects of survey methodology, particularly focusing on the issues discussed earlier in this report. The field test yielded a sufficient number of completed surveys to enable the project team to present results for some population subgroups, and to provide specific policy and methodology recommendations regarding potential future use of the consumer survey.

Before examining the data more closely, it is important to note that the information presented in this section provides an analysis of the data gathered through a field test conducted in only the five pilot sites. The responses to individual questions are not a representative sample of the local entities or the state as a whole. However, the data does provide us with a large enough sample that we are able to examine trends in responses, which allows us to identify factors which may affect future applications of the survey.

A. Who Participated in the Survey?

When developing the survey process, the project team set the goal of receiving 70 surveys completed through face-to-face interviews and 70 mail surveys. Table 1 shows the extent to which we achieved those goals, with mixed results: face-to-face surveys fell short of the desired number, in both the APD and DD arenas; but mail surveys exceeded our goal, due to particularly high numbers in the APD site. The following section discusses response rates and possible explanations for the variations; we present the survey numbers here to establish the numeric baseline for all survey results presented in this section.

Table 1: Consumer Surveys Received							
	<i>Face-to-Face</i>				<i>Mail</i>		
	<i># in Sample</i>	<i>Consents Rec'd</i>	<i>Goal</i>	<i>Received</i>	<i># in Sample</i>	<i>Goal</i>	<i>Received (mail + internet)</i>
Brokerage	47	22	20	15	35	20	24+1
In-home Comp	20	11	10	11	9	10	
DSO	40	17	20	11	70	20	59+2
AAA	34	14	20	12	44	20	
<i>TOTAL</i>	<i>141</i>	<i>64</i>	<i>70</i>	<i>49</i>	<i>158</i>	<i>70</i>	<i>86</i>

⁸ In reviewing this document, please bear in mind that the findings do not represent the entire survey population; rather, this document illustrates how survey findings could be reported.

Among the 135 survey respondents were people of both genders, people with various racial/ethnic identities, and people residing in different types of living arrangement. Table 2 shows this variability. It provides some context for understanding the differences between the DD and the APD responses, and also offers an opportunity for examining how well these two groups surveyed in the field test represent the larger populations of people receiving in-home supports. However, the project team was unable to obtain comparable information for the entire population of individuals receiving SPD in-home waiver supports. The population figures will be important to have, before SPD decides a sampling framework for future surveys.

Table 2: Demographics of Survey Respondents			
<i>Gender:</i>			
- DD:	61% Male,	39% Female	
- APD:	29% Male,	71% Female	
<i>Race:</i>			
- DD:	88% White,	8% African American,	4% combination of other races
- APD:	90% White,	8% Hispanic/Latino,	2% combination of other races
<i>Living Situation</i>			
	With Family	Independently	Other
- DD:	72%	16%	12%
- APD	28%	55%	17%
<i>Average Age:</i>			
- DD:	33 years		
- Physical Disability	54 years		
- Seniors:	73 years		

B. How was the Survey Administered?

The field test explored the best method to have the surveys completed, using face-to-face interviews or mail surveys⁹. Our discussions with other states indicated that some individuals with developmental disabilities and most seniors find it easier to complete the survey if there is someone to assist them in the process (see II.B.4a). However, this method is labor-intensive and resource-intensive, compared to mail surveys. The field test utilized both methods to determine whether there was an advantage to using one over the other. We wanted to explore whether survey methods impacted response rates by population, and whether the nature of the response varied depending on survey method.

As shown in Table 1 above, the overall response rates can come close or exceeded our goal: 86 mail surveys were received (54% response rate) and 49 surveys were completed

⁹ In this analysis, mail and internet response are grouped as one.

through a face-to-face interview (35% response rate). At the time of scheduling the face-to-face interviews, it appeared that we would reach our desired level of completed surveys, but we lost 25% of these individuals after the consents were signed. When the interviewer called to set up the interview, the individuals declined to participate, either not returning phone calls or stating they were no longer interested in participating. By contrast, the response rate for the mail surveys was higher than expected; generally, mail surveys have response rates well under 50%. It is also important to note that we did not send any notification or reminders to the mail survey recipients either before or after the mail survey was distributed; the 54% response rate was achieved with very little effort on the part of the project team.

We explored the hypothesis that face-to-face interviews would provide more complete survey responses because the interviewer can help the individual with questions which might be less clear. Table 3 shows that both mail surveys and face-to-face interviews resulted in questions with missing responses, but there was no clear trend in mail surveys providing less complete survey data.

Table 3: Mail versus Face-to-Face: Questions with Low Response Rates	
<i>Question</i>	<i>% with missing responses</i> ¹⁰
2. Does your plan include the things that you want or need?	Mail survey: 14%
10. When your plan needs to change, does this happen within a reasonable amount of time?	Face-to-face survey: 22% Mail survey: 14%
13. Do you think your staff know how to help you in the way that you need and want?	Face-to-face survey: 12%
16. Do you feel you have enough staff to help you? (DD only)	Face-to-face survey: 19%
17. Do you know what to do if you are unhappy with your services? (DD only)	Mail survey: 17%
15APD. Have your rights and responsibilities been explained to you? (APD only)	Face-to-face survey: 17%

We also examined responses to the 14 core survey questions to see whether the two survey methods elicited different response patterns. One might expect that face-to-face interviews would result in more positive responses to the more personally-sensitive questions. However, our analysis revealed no notable differences¹¹ between mail and

¹⁰ Questions were noted when more than 10% of the responses were ‘don’t know’ and/or missing.

¹¹ A difference was noted when one group answered positively or negatively by more than 20% above the percentage for the other group. For example if for a particular question, 50% of the mail surveys received a positive response while 75% of the face-to-face surveys received a positive response, we would note a difference.

face-to-face survey responses. This indicates that survey method does not lead to a systematic bias in responses to individual questions.

Recommendation: While we might have expected the face-to-face interviews to provide us with more complete survey responses, and perhaps indicate different levels of satisfaction, the field test revealed very little difference in response patterns overall or for individual questions. Therefore, in determining a preferred method of survey implementation, both methods should be considered equally. The decision should be based on organizational/policy preferences, along with logistical and resource considerations. SPD should consider using a combination of methods, perhaps routinely distributing mail surveys to all individuals in a sample, and supplement with a smaller sample of face-to-face interviews concentrated in a different geographic area each cycle.

C. Who Administered the Survey?

The field test included two types of interviewers – professional staff from the participating agencies (“agency staff”) and volunteers, including those from local advocacy groups (“third-party”). Examining face-to-face survey results for respondents interviewed by agency staff, compared to those interviewed by a third-party, we can gain insight into the interviewer’s impact on the interviewee – whether independence (any third-party) and peer identification (a self-advocate) leads to more varied responses and/or more complete surveys. If no substantial differences are found between responses from the two groups, SPD would be able to fully consider both interviewer options, weighing implementation considerations such as cost and ease of administration.

For the face-to-face interviews in the field test, the project team utilized three types of individuals as interviewers: five staff from the local agencies participating in the field test (some were QA staff, others personal agents/case managers¹²), four volunteers from local advocacy groups (three members of SAAL), and two HSRI/OTAC project staff. Table 4 below shows the number of interviews completed by each group of interviewers. For analytic purposes, we grouped the data according to whether the surveys were administered by professional agency staff or by third-party volunteers (including volunteers alone, project staff alone, or the two together as a team).

Table 4: Types of Interviewers			
<i>Type of Interviewer (# of interviewers)</i>	<i>DD</i>	<i>APD</i>	<i>Grouping used for analysis</i>
Agency staff (5)	9	11	20
Project staff alone (2)	7	4	29
Volunteer alone (1)	0	8	
Volunteer with project staff (3 teams)	10	0	

¹² It is important to note that personal agents/case managers who conducted face to face interviews did not interview people on their own caseload.

In testing the hypothesis that a third-party interviewer will evoke more varied responses from interviewees, we compared the two groups' responses on the 14 core survey questions. Table 5 below indicates four areas with notable differences.¹³

Table 5: Areas of Contrast Among Interviewer Groups		
	<i>Agency staff</i>	<i>Third-party</i>
3. Does someone help you understand the risks of your choices? (n=45)	100% positive	73% positive
4. Do you have people you can talk to about your personal relationships, thoughts and feelings? (n=47)	90% positive	70% positive
5. Can you go to places of your choice when you want to? (n=49)	50% positive	79% positive
8. Do you understand your health needs? (n=48)	95% positive	68% positive
9. Are you pleased with the time it took to get services? (n=45)	0% negative	20% negative
<i>Bold indicate the group that responded more positively</i>		

We found that respondents who spoke with agency staff tended to respond more favorably on 4 of the 14 core questions; by contrast, people interviewed by a third-party responded more positively on only one question. However, it is interesting to note that most of the questions answered more positively in the presence of agency staff were not related to the service/support the individual receives, questions on which one might expect to see an influence. And, conversely, several other survey questions where one might have expected to see the influence of an agency-affiliated staff person showed no difference between the two groups: “11. Does your personal agent/case manager give you the help you need?” and “12. Are you happy with the services you currently get?”

Recommendation: While the type of person who administers the survey does appear to elicit some different survey responses, the absence of effect on expected questions leads to the conclusion that the nature of the interviewer does not systematically bias the results. Therefore, we recommend that both agency staff and third-party volunteers could be used to conduct the interviews, thus allowing logistical and resource considerations to determine the matter. It is important to note, however, that successful use of third-party interviewers requires substantial support. In particular, careful consideration should be given to training, ongoing support during interviews, and financial compensation.¹⁴

¹³ A contrast is noted when either group gave 20% or more positive or negative responses than did the other group.

¹⁴ Several states including Oregon have implemented the Advocates Involved in Monitoring (AIM) program which uses volunteers to make monitoring visits to group homes; extensive materials have been developed to train and support this labor-intensive and highly regarded process.

D. Who Responded to the Survey Questions ?

During initial conversations on survey development, the project team discussed the issue of proxy responses (see Section II.B.6). One goal of the field test was to determine how often proxies were used and whether proxy responses vary significantly from individual responses; the hypothesis is that responses from a proxy representative would be different than those from the individual service recipient.

In the field test, we included a number of questions to identify whether the survey responses represent the respondent's or a proxy's opinion. We anticipated being able to obtain this information on a question-by-question basis. We also asked a more general question on both the mail and face-to-face survey about who, if anyone, helped the individual to complete the survey. In examining the survey data, we learned that it is very difficult to get a clear sense of when a proxy responds and how much that response reflects the target individual's views. The effort to get this information on a question-by-question basis proved futile; for many of the surveys, the information was missing or only partially completed. Therefore, we had to rely on the more general question about the overall use of a proxy, in terms of the individual receiving help to answer the questions. Even with this data, we needed to make some judgments about whether the responses truly reflected the opinions of the individual. For example, we found six cases where respondents completed the survey on their own, but someone else was present and their presence was considered 'helpful'; for analysis purposes, we considered these surveys to be completed by the individual.

The use of proxy respondents seemed to appropriately reflect population characteristics. Overall, 47% of survey respondents completed the survey by themselves, while 53% relied on proxy assistance. Individuals doing face-to-face interviews were more reliant on proxies than those completing mail surveys (55% vs. 42% respectively); this is not surprising since we targeted the face-to-face interviews to those who needed more assistance. We also found that people with developmental disabilities were more reliant on the use of proxies than seniors or people with physical disabilities (84% developmental disabilities vs. 39% seniors, 29% physical disabilities). These overall findings support the conclusion that many individuals being served by in-home waivers do need assistance in completing a consumer survey; proxy respondents will always be necessary.

In examining the influence of a proxy respondent, the findings offered some support for our hypothesis of a difference between the two groups. Table 6 identifies four core questions, as well as one population-specific question on the DD survey, where a difference of more than 20% was evident in positive responses. In questions #1 and #3, proxies more often indicated that the individual is being adequately represented; it may be the case that the proxy is the person who provides that help. Further, questions #6 and #8 indicate that proxy respondents are less sanguine about the individual's understanding of health needs and emergency situations. However, we did not find this effect across all questions in the survey. If we accept the hypothesis that proxies represent their own opinions, we would have also expected to see more positive responses by proxies on questions such as 'do you have people you can talk to about your personal relationship, thoughts and feelings?' (#4): we did not find a notable difference on this question. This

suggests that, while our hypothesis is supported in some cases, proxy responses do not systematically bias the survey results.

<i>Question</i>	<i>Individual</i>	<i>Proxy</i>
1. Do you have a person who speaks up for you when needed? (n=131)	60% positive	87% positive
3. Does someone help you understand the risks of your choices? (n=127)	62% positive	93% positive
6. Do you know what to do in case of an emergency? (n=128)	95% positive	73% positive
8. Do you understand your health needs? (n=129)	97% positive	71% positive
16. DD Do you feel you have enough staff to help you ? (n=42)	57% positive	83% positive
<i>Bold percentages indicate the group that responded more positively</i>		

It is also interesting to note that there was no difference in response rates to individual questions depending on whether an individual or proxy was completing the survey; proxies were no more able to complete questions than were individuals.

Recommendations: Because the use of proxy respondents appears to be a necessary part of any SPD consumer survey, there does need to be some mechanism to determine whether the survey was completed by individual or proxy. Clearly, while the best option would be to ask this on a question-by-question basis, the field test suggests this is not feasible. Therefore, we recommend using a single question asking ‘who helped you answer this survey’ which will allow SPD to look for proxy bias.

Since the findings suggest that proxy respondents do exert influence on some survey answers, it will be important for SPD to periodically conduct an analysis of proxy bias. The bias cannot be avoided without substantially increasing survey sample size and cost; many individuals need the assistance of a proxy and would otherwise be unable to complete the survey. However, it will be important to note which questions are most often answered by proxy, and then examine the differences between the groups’ responses.

E. Were Some Questions More Difficult than Others?

Designing a survey for the diverse populations served by SPD in-home waiver programs is challenging. The potential survey respondents vary both in experience and concerns, as well as in cognitive ability and the language used when describing services received (i.e. case manager vs. personal agent). For this reason, the process of developing the consumer survey required compromise and prioritization in order to accommodate the interests of all stakeholders. The final version of the field test survey (included in Appendix D) included 14 core questions for both the DD and APD population; an additional three population-specific questions were include on the DD survey and one question on the

APD survey in order to address the differing concerns of these groups. One of the main goals of the field test was to identify specific questions which were particularly difficult to answer, due to their wording or concept, either between populations or across the entire survey population.

As Table 7 indicates, several questions appear to be difficult for survey respondents to answer. Four of the core questions received a notable number of missing responses, as well as three of the four questions population-specific questions.

Table 7: Questions with low response rates		
2. Does your plan include the things that you need? (n=135)	11 Don't Know 1 Missing	9%
9. Are you pleased with the time it took to get services? (n=135)	8 Don't Know 2 Missing	7%
10. When your plan needs to change, does this happen in a reasonable amount of time? (n=135)	17 Don't Know 6 Missing	17%
13. Do you think your staff know how to help you in the way that you need and want? (n=135)	2 Don't Know 9 Missing	8%
15. (APD). Have your rights and responsibilities been explained to you? (n=84)	6 Don't Know 3 Missing	11%
16. (DD). Do you feel you have enough staff to help you? (n=51)	2 Don't Know 5 Missing	14%
17. (DD). Do you know what to do if you are unhappy with your services? (n=51)	4 Don't Know	8%

The concerns about these particular questions were echoed by the people conducting the face-to-face interviews. As previously mentioned, following each face-to-face interview, we asked the interviewers to complete a feedback form regarding their experience administering the survey. In particular, we asked for feedback on each question which a respondent found difficult to answer. All of the questions included in Table 7 were identified on the feedback forms as causing confusion, usually in terms of the wording of the question. In some cases, the difficulty was caused by a particular word (i.e. 'plan' or 'staff'), while in other cases the problem was that the questions were too abstract (i.e. 'pleased with the time it took', 'a reasonable amount of time'). One additional question which received comments from a number of interviewers was #3: 'Does someone help you understand the risks of your choices?' – respondents reportedly had difficulty understanding the word 'risk'.

Recommendation: In response to the low response rate and the interviewers' comments, the project team has edited the survey to clarify the questions which appeared more problematic. We believe that the revised questions (see Appendix J) will result in better response rates on the questions individuals found difficult to understand during the field test. We recommend that SPD continue to review survey results over time to identify particular questions with which respondents are having difficulty and to respond accordingly.

F. How Well Did the Required DAS Questions Work?

As described in Section II.A., part of the impetus for the development of this consumer survey was changes made to the DAS 2005-07 budget instructions, which direct each state agency to incorporate consumer satisfaction measures into their mandated activities. As a result, DAS identified six questions (see Table 8 below) which are now required to be included in consumer surveys administered by each state agency.

In the initial stages of survey development, the project team incorporated these questions into our draft survey. We clarified with DAS that, while the main idea of the six questions is mandated, the actual wording may vary from survey to survey, if a defensible argument can be made for the modified wording. Thus, we proposed wording that is more appropriate for SPD's target audience. We then asked Stakeholder Group members to prioritize all of the questions in the survey (as described in Section II.A) in order to determine which questions are most important to the constituency of this group. It is noteworthy that the DAS mandatory questions did not receive high prioritization: only two of the six questions were identified as core questions (#11 and #14), and even these fell at the low end of the prioritization scale. Additionally, in examining the finding from the field test, several of the DAS questions also received a relatively low response rate or were biased by who conducted the face-to-face surveys (see Table 8, below).

One more issue regarding the DAS questions is the scale used for the survey responses. The DAS question format includes a 4-point scale. However, to accommodate the cognitive limitations present in some of the SPD population and to enhance the reliability of responses, the project team adopted a 5-point scale for all questions. The responses cannot be easily translated into the 4-point scale desired by DAS; however, it would be possible to recast the data using four points on a continuum, using interpolation techniques.¹⁵

¹⁵ This would require a major statistical assumption – that the response options (both the 4-point and the 5-point) constitute an interval or continuous variable rather than representing ordinal values.

Table 8: DAS Questions			
<i>DAS Question</i>	<i>Field Test Survey Question</i>	<i>Issues</i>	<i>Low Priority</i>
1. TIMELINESS: How would you rate the timeliness of the services provided by (insert agency name)?	10. When your plan needs to change, does this happen in a reasonable amount of time?	Poor response rate (23 of 135)	✓
2. ACCURACY: How would you rate the ability of (insert agency name) to provide services correctly the first time?	9. Are you pleased with the time it took to get services?	Poor response rate (10 of 135); answered more positively by agency staff	✓
3. HELPFULNESS: How would you rate the helpfulness of (insert agency name)'s employees?	11. Does your Case Manager give you the help you need?		
4. EXPERTISE: How would you rate the knowledge and expertise of (insert agency name)'s employees?	13. Do you think your staff know how to help you in the way that you need and want?	Poor response rate (11 of 135)	✓
5. INFORMATION: How would you rate the availability of information at (insert agency name)?	14. Do you get the information you need to make choices about your services and supports?		
6. OVERALL: How do you rate the overall quality of services provided by (insert agency name)?	12. Are you happy/satisfied with the services you currently receive?		✓

Recommendation: Modifications to the DAS questions are suggested in the next section; these modifications ensure that the mandated questions are consistently asked through this survey process, but are asked in a way that addresses the issues faced by the SPD population.

G. Recommendations for Changes in the Survey Instrument

Based on the field test findings discussed above, the project team realized the need to edit several survey questions. We focused on questions where feedback forms (from face-to-face interviews suggested respondents had difficulty with the question, and/or individual questions received high numbers of “don’t know”. Modifications to these questions are included in Table 9 below. We recommend dropping the four population-specific

questions (#15-17 on DD survey and #15 on ADP survey). We found that we received a low response rate for all but one of these questions, indicating that these questions were difficult for respondents. Further, in designing the survey and conducting the field test, we found that using a DD and an APD version of the survey became more logistically complicated when making changes and distributing the survey. Thus, we recommend using a single survey, changing the wording of several questions to incorporate the language of both the DD and APD populations. The survey now consists of 14 core questions, to be used for both population groups. Appendix J provides the rationale for some of the changes made, and Appendix K contains the final recommended version of the survey.

Table 9: Revisions to Consumer Survey Questions, Based on Finding From Field Test

Original Survey Questions	Revised Survey Questions
<p><u>DD</u> 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 case manager or staff)</p> <p><u>APD</u> 1. Do you have a person who speaks up for you/represents your interests when necessary? (a person such as a friend, family member or an advocate - but not case manager or staff)</p>	<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 case manager or staff)</p>
<p><u>DD</u> 2. Does your service plan or support plan include the things that you want or need?</p> <p><u>APD</u> 2. Does your plan include the things that you want or need?</p>	<p>2. Does your service plan include the things that you need? (A plan is a formal document that lists the services and supports you will receive, often called a Client Plan or Individual Service Plan)</p>
<p>3. Does someone help you understand the risks of your choices? (choices such as declining services offered, choosing to live in an unsafe neighborhood, etc.)</p>	<p>No change</p>
<p>4. Do you have people you can talk to about your personal relationships, thoughts and feelings?</p>	<p>No change</p>

Table 9: Revisions to Consumer Survey Questions, Based on Finding From Field Test

Original Survey Questions	Revised Survey Questions
<p><u>DD</u> 5. Can you go to the places that you choose when you want to? (such as shopping, entertainment, religious services, etc.)</p> <p><u>APD</u> 5. Can you go to places of your choice when you want to? (such as shopping, entertainment, religious services, etc.)</p>	<p>5. Can you go to the places that you choose when you want to? (such as shopping, entertainment, religious services, etc.)</p>
<p>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)</p>	<p>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 anyone or anything that may hurt you)</p>
<p>7. Do you have someone whom you can call to help you during an emergency? (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? (an emergency such as when your staff person does not show up, a fire, a tsunami, or anyone or anything that may hurt you)</p>
<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)</p>	<p>No change</p>
<p>9. Are you pleased with the time it took to get services after you asked for them?</p>	<p>9. Are services provided in the way you want?</p>
<p>10. When your plan needs to change, does this happen within a reasonable amount of time?</p>	<p>10. Are changes in your services made in a reasonable amount of time when a change is needed?</p>
<p><u>DD</u> 11. Does your Personal Agent and/or Case Manager give you the help you need?</p> <p><u>APD</u> 11. Does your Case Manager give you the help you need?</p>	<p>11. Does your Case Manager and/or Personal Agent give you the help you need?</p>
<p><u>DD</u> 12. Are you happy with the services you currently get?</p> <p><u>APD</u> 12. Are you satisfied with the services you currently</p>	<p>12. Are you happy/satisfied with the services you currently receive?</p>

Table 9: Revisions to Consumer Survey Questions, Based on Finding From Field Test	
Original Survey Questions	Revised Survey Questions
receive?	
13. Do you think your staff know how to help you in the way that you need and want?	13. Do you think your paid caregiver knows 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?	No change
<u>APD</u> 15. Have your rights and responsibilities been explained to you?	Deleted – obtained through other SPD efforts
<u>DD</u> 15. Do you decide how you spend your free time?	Deleted -- covered by #5
<u>DD</u> 16. Do you feel you have enough staff to help you?	Deleted – covered by #2
<u>DD</u> 17. Do you know what to do if you are unhappy with your services?	Deleted – difficult to answer and interpret

V. NEXT STEPS

The field test experience proved to be extremely valuable in providing the project team with a vast amount of information on which to base recommendations regarding the consumer survey tool and implementation process. With this report, HSRI has provided SPD with electronic versions of all materials used in the field test, including a single version of the survey tool with final recommended changes. With this information, SPD can begin to make final implementation decisions, such as which survey method to use, how often to survey, data collection responsibilities, etc. SPD will also have to make some decisions regarding issues which were not addressed by the field test: proportion of SPD population to sample, how to address concerns about individual risks identified through survey responses, distribution of survey finding to local entities, reporting findings to DAS, etc.

To accompany this report, HSRI has prepared an Executive Summary of the field test experience. SPD may choose to distribute this Executive Summary to interested parties, especially members of the Stakeholder Group and the pilot sites who participated in the field test. HSRI has also prepared a site-specific report for each of the pilot sites, providing them with site-level data compared to the entire population of the field test; this will give them with some insight into their own service population and may also stimulate support for ongoing use of the consumer survey.