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OBJECTIVES

- To solicit feedback from a representative statewide sample of IHSS Consumers on a range of questions relevant to the level and quality of service they receive as participants in the IHSS program.
- To measure IHSS Consumers' perceptions of the IHSS assessment process as it currently operates under the Hourly Task Guidelines (HTG) Initiative

METHODOLOGY

The Consumer Survey was designed as a voluntary, confidential self-report survey of a statewide representative sample of IHSS Consumers on a range of questions pertaining to their perceptions of the IHSS assessment process and the program's overall level of service. The survey mailing consisted of three documents: the survey itself, a cover letter, and an informed consent form. The survey was conducted in two phases: a small-scale pilot study to field test the survey and a larger final phase in which data was collected for the final report.

SURVEY QUESTIONNAIRE

The survey questions and response choices were developed through collaboration between CDSS program staff and the ISR research team. Working drafts of the survey were provided to members of a public stakeholders' group for discussion at periodic stakeholder teleconference meetings. To the extent possible, recommendations made by this group were incorporated into the survey.

Due to the advanced age and functional limitations of some IHSS Consumers, special care was taken to make the survey as user-friendly as possible. For increased readability, ISR retained the services of a reading expert to review the document and to ensure that it was worded as clearly as possible. All documents scored at or below a 9th grade reading level on several standard measures of readability. In addition, 16-point type was used in printing the documents.

ISR obtained translations of the written survey in the following four languages: Spanish, Chinese, Russian, and Armenian. These languages were chosen because they are the four most commonly spoken non-English languages among the IHSS Consumer population (together with English, these languages comprise approximately 85% of the total IHSS Consumer population). The primary language of each survey recipient, as recorded in the Case Management, Information and Payrolling System (CMIPS) database, was determined prior to the survey mailing, and materials were sent to each recipient in the appropriate language. Speakers of languages for which no written translation was available received survey materials in English. To provide access to non-English speakers in languages other than the four translation languages (and to provide support and technical assistance to all non-English speakers), ISR provided a toll-free telephone line that offered live over-the-phone interpretation service in a wider variety of languages.

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Informed Consent and Confidentiality

The survey was designed to be voluntary and confidential. The mail-out packet contained a cover letter that introduced the study, explained that the survey was voluntary and confidential, and provided a toll-free contact number to call for help or to ask questions about the survey. Consumers were provided an opportunity to opt out by returning the survey materials, left blank, in an enclosed postage-paid return envelope. Behind the cover letter was an informed consent form explaining that the survey was voluntary, confidential, and would in no way affect the recipient's IHSS benefits, should they choose to take part or not. A space was provided for the recipient to sign, granting their consent to participate in the survey. Upon receipt of a signed informed consent form and a completed survey, the ISR research team separated these two documents and maintained them in separate, locked files to help protect respondents' confidentiality.

Additional measures were taken to help protect the confidentiality of Consumers who responded to the survey. The copy of the CMIPS database that was used to generate the sample used in this study was scrubbed of personal identifiers such as name, address, and social security number, prior to CDSS releasing it to the ISR research team. A procedure for matching anonymous survey identification numbers with a numeric identifier from the CMIPS database was designed whereby CDSS and their database administrators retained exclusive custody of the names and addresses of potential survey participants. The only piece of personally-identifiable information available to the ISR research team was the respondent's signature on the informed consent. As mentioned above, signed consent forms were separated from survey responses and maintained in a locked file. For cases in which a Consumer who received survey materials chose not to participate, the ISR research team had no access to personally-identifying information. Following this procedure allowed the survey to be mailed out to a large number of IHSS Consumers statewide while maintaining the security of their sensitive personal information.

Pilot Study

Due to the special sensitivity of the IHSS Consumer population (in particular advanced age and functional limitations) and the special confidentiality measures described above, ISR judged that a pilot study would be necessary in order to field test the survey instrument and the protocol for contacting potential respondents. The pilot study was conducted with a statewide random sample size of 1000 Consumers. Pilot study results provided a quantitative basis for estimating likely response rates, and suggested several refinements to the data collection procedures to improve the response rate on the final survey.

Sample Selection

The samples for both the pilot and the final study were drawn from the CMIPS database which contains a complete list of the IHSS Consumer population. The following subgroups of Consumers were excluded from the sampling frame:

1. All minor children (ages 17 and younger)

2. Consumers with severely diminished memory, judgment and orientation
3. Consumers who receive paramedical assistance with Meal Preparation, Eating, and Respiration
4. Consumers who do not receive hours for any of the 12 Hourly Task Guidelines (HTG) tasks
5. In the final study, any Consumer who was sampled in the pilot study

A tabulation of the numbers of Consumers who fall into each of the exclusion categories is presented below (see Table 1.1), along with the percentages that each represents within the total IHSS population. It should be noted that the figures reported below do not represent unduplicated counts; in other words, certain Consumers may belong to more than one of the exclusion categories. In total, 40,014 individuals (10.2% of total IHSS population) were excluded from the sampling frame because they met one or more of the exclusion criteria detailed above. The final sampling frame included the remaining 351,810 individuals in the eligible caseload.

Table 1.1: Categories of IHSS Consumers Excluded From the Sample

	Excluded		Included		Total IHSS Population	
Exclusion Criteria	Count	Percent	Count	Percent	Count	Percent
17 years of age or less	16,327	4.2	375,497	95.8	391,824	100.0
Severely diminished memory, judgment, orientation	23,978	6.1	367,846	93.9	391,824	100.0
Paramedical assistance	3,969	1.0	387,855	99.0	391,824	100.0
No hours for any HTG task	2,874	.7	388,950	99.3	391,824	100.0

From this point forward in this report, references to the total IHSS population should be understood to refer to the subset of 351,810 IHSS Consumers who made up the sampling frame for this study.

For the pilot study, 1,000 cases were selected at random. Each IHSS Consumer in the sampling frame had an equal chance of inclusion in the sample. For the final study, the overall size of the sample was increased to 6500, and was stratified as follows: 5,000 Consumers randomly selected from the general IHSS population, and 1,500 Consumers randomly chosen from within the IHSS-Plus-Waivers (IPW) subpopulation. Consumers who were selected in the pilot were excluded from the sample in the final study to avoid soliciting the same individual on both occasions, as previously mentioned.

Data Collection

The final survey was mailed out to 6,500 IHSS Consumers statewide on March 14, 2008. Data collection continued until May 6, 2008. One thousand one hundred ninety-seven surveys were returned to ISR; of these 1,197 returned surveys, 179 were blank and 1,018 were complete or partially complete. Of the 1,018 Consumers who returned complete or partially complete surveys, 707 also provided explicit consent to participate in the survey (usually by returning a signed informed consent form, and rarely by providing verbal consent over the phone), while 311 did not return a signed informed consent form. Responses from the first mailing yielded a large enough number of completed surveys to go forward with analysis of results at the

planned level of precision without the need for follow-up mailings. Therefore two planned follow-up mailings were cancelled.

The fact that approximately 30% of respondents who returned completed surveys did not return completed informed consent forms presented an unanticipated challenge. While it is likely that a large proportion of respondents in this situation fully intended to give their consent to participate in the study, the ISR research team could not be certain. To ensure that no responses were used where a Consumer did not intend to give consent, the decision was made to exclude these responses from the analysis. In order to assess the impact of this decision on survey results, the response patterns of both groups (completed surveys with consent and completed surveys lacking consent) were compared and found to be equivalent. Therefore, the decision to exclude this subset of responses will not have a measurable effect on the survey results, with the exception that it will lower the reported response rate and estimates of precision somewhat.

Precision of Results and Response Rate

With 707 completed surveys, the results presented in this report can be understood to reflect the true percentages in the total IHSS population within a confidence interval of plus or minus 4 percentage points at the 95% confidence level. This means that if a percentage is reported as 45%, we can be 95% sure that the true percentage in the total IHSS population lies between 41% and 49%. If we were to repeat this survey 100 times, we would be likely to observe a value in the 41 - 49% range 95 times and a value outside that range 5 times.

Very low response rates in the pilot raised the concern that it would be difficult to reach an acceptable level of response from the IHSS Consumer population. Several refinements were made to the mailing strategy in an effort to boost response rates (see discussion above under Pilot Study).

The overall response rate in the final phase was 1197 out of 6,500, or 18%. As mentioned above, this rate was reduced by the decision to exclude the responses of those who returned a completed survey but did not return a signed informed consent. The final sample used for analysis was 707 out of 6,500, or an effective response rate of 11%.

While an 11% response rate was a significant improvement over the pilot study, it is still low. Whenever response rates are low in a survey, the possibility of measurement error due to response bias must be considered. Response bias can occur when the characteristics of the respondents differ systematically from the characteristics in the overall sample. If respondents differ systematically from the overall sample, they may also tend to answer questions differently than those in the entire sample. Unfortunately, it’s impossible to know for sure how Consumers who chose not to participate in the study would have answered the questions. The best we can do to address the question of response bias is to compare certain characteristics of those who participated with the same characteristics of the overall population to assess similarities and differences.

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Comparison of Survey Respondents with the IHSS Consumer population

The CMIPS database contains several demographic variables that permit comparisons to be made between the characteristics of respondents and the characteristics of the overall IHSS population. This is an important analysis -- particularly in this survey with a rate of useable responses of 11% -- because it speaks to how well the current group of survey respondents may represent the overall IHSS population, and, by extension, how well their responses to survey items may generalize to the entire IHSS population.

County

Consumers who completed the survey are distributed proportionally among California's 58 counties in a pattern that is statistically very close to the proportional distribution of the overall IHSS population. The only exception is that Los Angeles County may be slightly underrepresented in the current group of respondents, as compared to the overall IHSS caseload. The small differences observed between the respondent group and the overall population for the remaining 57 counties are within the range expected by chance variation (see Table 1.2).

Table 1.2: Respondents and Population by County

	Respondents		IHSS Population	
	Count	Percent	Count	Percent
Alameda	27	3.8%	14,353	4.1%
Alpine	0	.0%	7	.0%
Amador	1	.1%	142	.0%
Butte	9	1.3%	2,336	.7%
Calaveras	0	.0%	213	.1%
Colusa	0	.0%	147	.0%
Contra Costa	7	1.0%	5,678	1.6%
Del Norte	0	.0%	244	.1%
El Dorado	0	.0%	489	.1%
Fresno	21	3.0%	10,014	2.8%
Glenn	2	.3%	329	.1%
Humboldt	2	.3%	1,401	.4%
Imperial	10	1.4%	4,248	1.2%
Inyo	0	.0%	89	.0%
Kern	13	1.8%	4,503	1.3%
Kings	2	.3%	1,410	.4%
Lake	1	.1%	1,293	.4%
Lassen	0	.0%	233	.1%
Los Angeles	286	40.5%	155,506	44.0%
Madera	1	.1%	1,255	.4%
Marin	1	.1%	1,224	.4%
Mariposa	0	.0%	164	.0%
Mendocino	3	.4%	1,175	.3%
Merced	2	.3%	2,656	.8%
Modoc	2	.3%	92	.0%
Mono	0	.0%	17	.0%
Monterey	5	.7%	2,787	.8%
Napa	0	.0%	558	.2%
Nevada	3	.4%	468	.1%
Orange	30	4.2%	12,449	3.6%
Placer	6	.8%	1,215	.3%
Plumas	0	.0%	232	.1%
Riverside	27	3.8%	11,824	3.4%
Sacramento	25	3.5%	15,961	4.5%
San Benito	0	.0%	290	.1%
San Bernardino	29	4.1%	14,333	4.1%
San Diego	47	6.6%	19,118	5.5%

San Francisco	32	4.5%	17,896	5.1%
San Joaquin	12	1.7%	5,598	1.6%
San Luis Obispo	3	.4%	1,267	.4%
San Mateo	4	.6%	2,035	.6%
Santa Barbara	7	1.0%	2,190	.6%
Santa Clara	28	4.0%	10,967	3.2%
Santa Cruz	3	.4%	1,673	.5%
Shasta	7	1.0%	2,022	.6%
Sierra	0	.0%	32	.0%
Siskiyou	0	.0%	356	.1%
Solano	4	.6%	2,142	.6%
Sonoma	12	1.7%	3,638	1.0%
Stanislaus	14	2.0%	4,983	1.4%
Sutter	2	.3%	572	.2%
Tehama	3	.4%	833	.3%
Trinity	0	.0%	127	.0%
Tulare	5	.7%	2,093	.6%
Tuolumne	2	.3%	262	.1%
Ventura	3	.4%	2,701	.8%
Yolo	4	.6%	1,447	.4%
Yuba	0	.0%	523	.1%
Total	707	100.0%	351,810	100.0%

It is important to note that due to the very unequal distribution of the IHSS caseload across California's 58 counties that the less populous counties tend to be represented by just a handful of respondents in this survey, and some of the least populous counties are not represented at all. For this reason, comparisons between counties will not be made in the analysis below.

Gender

With respect to gender, the proportion of male respondents is larger (46.3%), and the proportion of female respondents smaller (53.7%), than in the overall IHSS population (34.1% male; 65.7% female), and this difference is statistically significant (see Table 1.3). This means that men tended to complete and return the survey more often than did women, and that this difference was not likely simply due to chance. There were still a greater number of women who completed and returned the survey than men; however the difference was not as great as the population proportions would predict.

Table 1.3: Respondents and Population by Gender

	Respondents		IHSS Population	
	Count	Percent	Count	Percent
Female	380	53.7%	231,124	65.7%
Male	327	46.3%	119,969	34.1%
No Data	0	0%	717	.2%
Total	707	100.0%	351,810	100.0%

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Language Group

With respect to primary language, the proportion of Armenian-speaking respondents is smaller (3.0%) and the proportion of Spanish-speaking respondents larger (20.1%) than in the overall IHSS population, and this difference is statistically significant (see Table 1.4). This means that Armenian-speaking Consumers were less likely to complete and return the survey than would be expected by chance, and Spanish-speaking Consumers were more likely to do so than chance would predict.

Table 1.4: Respondents and Population by Language Group

	Respondents		IHSS Population	
	Count	Percent	Count	Percent
English	341	48.2%	173,235	49.2%
Spanish	142	20.1%	50,486	14.4%
Armenian	21	3.0%	27,335	7.8%
Chinese	60	8.5%	26,035	7.4%
Russian	34	4.8%	16,768	4.8%
Other	109	15.4%	57,951	16.5%
Total	707	100.0%	351,810	100.0%

Age

The distribution of survey respondents with respect to age differed somewhat from the age distribution of the overall IHSS population. Specifically, there were fewer respondents in the youngest age category (18-30 years of age), more respondents near the middle of the age range, and fewer respondents in the two most elderly age categories (see Table 1.5). Basically, the youngest and most elderly Consumers are slightly underrepresented in the pool of survey respondents, as compared to the overall IHSS population, and those in the middle of the age distribution are slightly overrepresented.

Table 1.5: Respondents and Population by Age

		Respondents		IHSS Population	
		Count	Percent	Count	Percent
Age (years)	18 - 30	19	2.7%	14,869	4.2%
	31 - 40	27	3.8%	13,956	4.0%
	41 - 50	73	10.3%	29,559	8.4%
	51 - 60	118	16.7%	49,341	14.0%
	61 - 70	147	20.8%	63,995	18.2%
	71 - 80	189	26.7%	93,872	26.7%
	81 - 90	120	17.0%	71,925	20.4%
	91 and above	14	2.0%	14,293	4.1%
	Total	707	100.0%	351,810	100.0%

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Structure of the Analysis

The number and proportion of Consumers endorsing each of the survey response choices for each question on the survey are presented in the tables below. Charts have been included where they are needed to help visualize the trends present in the data.

Responses to open-ended (write-in) questions were content-coded and the frequencies of each code were compiled. A summary of the issues mentioned by respondents in each of the four open-ended questions is provided in narrative format, with emphasis given to the most frequently mentioned themes in Consumers' responses.