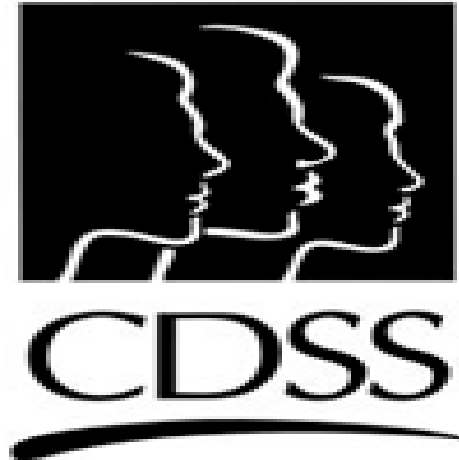


ANALYSIS OF STATEWIDE CDSS IN-HOME SUPPORTIVE SERVICES (IHSS) 2010 CONSUMER SURVEY



Prepared for the California Department of Social Services
Adult Programs Division

By

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IHSS 2010 CONSUMER SURVEY

KEY FINDINGS

- When asked if the IHSS program meets their needs, about nine out of ten (91%) of Consumers responded that it does - an increase of nearly 10 percentage points compared to the results of the last Consumer Survey in 2008.
- The proportion of Consumers reporting a decrease in their hours at reassessment more than doubled from 15.3% in 2008 to 33.6% in 2010. Among Consumers reporting a decrease in hours, 51.2% attributed the decrease to a change in the program rules (up from 18.6% in 2008).
- The majority of Consumers (about 60% to 75%, depending on the task) feel that their hours are about right, while a minority (about 20% to 40%) feels that their hours are not enough.
- Among the 25.1% of Consumers who requested additional hours from their county, 40.2% received additional hours, while the remainder did not. Stated differently, about 11% of Consumers asked for, and received, additional hours.
- Few Consumers (2.8%) requested a fair hearing to appeal the number of approved hours.
- The overwhelming majority (92.9%) of Consumers report that their social worker either fully or mostly explained the IHSS program to them, and answered their questions.
- Common themes in Consumers' responses to the open-ended question "How could the IHSS program better meet your needs?" included:
 - Praise and gratitude for the program
 - Requests for additional hours and services
 - Concern over the California State budget and its effect on IHSS hours and services – in particular the recent 3.6% across-the-board cut in hours
 - Better pay and benefits for providers

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BACKGROUND

The California Department of Social Services (CDSS) In-Home Supportive Services (IHSS) Program helps California's elderly, blind, and disabled to remain safely in their own homes by paying for in-home care providers to assist Consumers with certain personal care, domestic, and paramedical tasks.

Enactment of Senate Bill 1104 (2004)—the Quality Assurance Initiative—directed CDSS to implement a variety of oversight and program integrity measures within the IHSS program. Among those measures were a set of regulation changes collectively known as Hourly Task Guidelines (HTGs). Implemented in September of 2006, HTGs sought to increase uniformity in the IHSS assessment process across the state by specifying ranges of authorized hours thought to be appropriate for each of twelve selected IHSS tasks. In an effort to evaluate the impact of HTG implementation on individual Consumers, and to assess Consumer perceptions of the IHSS program, CDSS has undertaken two statewide random-sample surveys of IHSS Consumers.

The initial statewide Consumer Survey was developed jointly by CDSS and a panel of stakeholders through a collaborative stakeholder process. The survey was initially sent out in spring of 2008 and this 2010 survey is its second administration.

METHODOLOGY

The 2010 Consumer Survey was mailed to 8,355 randomly-selected Consumers across California in November of 2010. This number was based on the assumption that about 1 in 7 Consumers would return the survey, and would produce the approximately 1,200 surveys needed for the analysis. Three attempts were made to contact Consumers by mail and invite their participation. A toll-free phone number was provided to accommodate Consumers who preferred to participate by phone. Written materials were provided in English, Spanish, Russian, Chinese, and Armenian. An over-the-phone interpreter service was available to Consumers who spoke languages for which written translations were not provided.

The research team was pleasantly surprised when 3,373 completed surveys were returned, for a response rate of 40 percent. Consumer participation improved significantly compared to the 2008 administration, in which 707 responses were received and the response rate was 11 percent.

Most of the survey questions provided categorical (check-the-box) response options. Results from the categorical questions are provided in the tables below. Results from the 2008 administration are also included in the tables for ease of comparison.

The survey also contained four write-in questions. Open-ended questions help enrich quantitative data by providing contextual explanations for Consumer opinions, and often uncover information that may not otherwise be shared. The responses can give insight and clarity, and detail useful information in trying to understand how to meet the needs of IHSS Consumers. Write-in question results are presented below as a discussion of

common themes and unique outliers that were found in Consumer responses. Themes for each question are listed and discussed according to the frequency with which they were mentioned.

FINDINGS

Question 1: How helpful are the pamphlets, booklets, and forms that you received about the IHSS program?

Most Consumers (84.1%) found the written materials provided by the IHSS program to be helpful (see Table 1.1).

- 56.3% of Consumers reported that the written materials were very helpful
- 27.8% reported that the materials were somewhat helpful
- 2.3% reported that the materials were not helpful
- 10.1% indicated they did not receive written materials
- 3.5% reported receiving written materials in a language that they do not read

Table 1.1. Question 1: How helpful are the pamphlets, booklets, and forms that you received about the IHSS program?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
How helpful are the pamphlets, booklets, and forms that you received about the IHSS program?	Very helpful	363	53.5%	1,809	56.3%	2.8%
	Somewhat helpful	182	26.8%	892	27.8%	1.0%
	Not Helpful	15	2.2%	73	2.3%	0.1%
	I did not receive any	100	14.7%	326	10.1%	-4.6%
	They were in a language I do not read	19	2.8%	114	3.5%	0.7%
Total		679	100.0%	3,214	100.0%	

Question 2A: Have you had a reassessment?

Results were little changed from 2008. Nearly three-quarters of those surveyed had received at least one reassessment, while slightly more than one-quarter had never received a reassessment.

- 71.8% of Consumers indicated that they had received a reassessment
- 28.2% reported that they had not been reassessed

Table 1.2. Question 2A: Have you had a reassessment?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
Have you had a reassessment?	Yes	466	71.1%	2,182	71.8%	0.7%
	No	189	28.9%	857	28.2%	-0.7%
Total		655	100.0%	3,039	100.0%	

Question 2B: Did your hours change based on your last reassessment?

Among Consumers who reported a change in their hours as a result of their most recent assessment, those reporting a decrease in hours (33.6%) slightly outnumbered those reporting an increase in hours (31.8%). This constitutes a significant change since the 2008 administration of the survey, in which Consumers experiencing increases outnumbered those experiencing decreases by nearly 3-to-1 (see Table 1.3). Because the 2010 survey mailings took place at about the same time that 3.6 percent across-the-board reductions in hours were being implemented, it is likely that the effects of these cuts are reflected here in the survey results.

In the 2010 administration:

- 31.8% reported hours went up
- 33.6% reported hours went down
- 29.4% reported no change in hours
- 5.1% did not know if hours were changed

Among Consumers who reported an increase in hours at their last assessment, eight hours per month was the median (the midpoint) reported increase. Among Consumers who reported a decrease in hours at their last assessment, four hours per month was the median reported decrease.

Table 1.3. Question 2B: Did your hours change based on your last reassessment?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
Did your hours change based on your last reassessment?	My hours went up by (blank) hours per month.	214	45.0%	760	31.8%	-13.2%
	My hours went down by (blank) hours per month.	73	15.3%	804	33.6%	18.3%
	My hours did not change.	163	34.2%	703	29.4%	-4.8%
	I don't know whether my hours changed.	26	5.5%	123	5.1%	-0.4%
Total		476	100.0%	2,390	100.0%	

Note: Percentages may not sum to 100 percent due to rounding.

Question 2C: What was the main reason you were given for the change in your hours?

As in 2008, the most commonly reported reason given for a change in hours was a change in the Consumers' health situation. However, the proportion of Consumers indicating that program rule changes were the reason for their change in hours increased significantly—about a six-fold increase compared with 2008 (see Table 1.4). Here again, the change is likely attributable to the recent 3.6 percent across-the-board reduction in hours.

In the 2010 administration:

- 46.2% reported a change in their health situation
- 4.4% reported a change in their home situation
- 25.5% reported a change in the program rules
- 15.7% reported a change in hours without a reason being given
- 8.3% reported some other reason

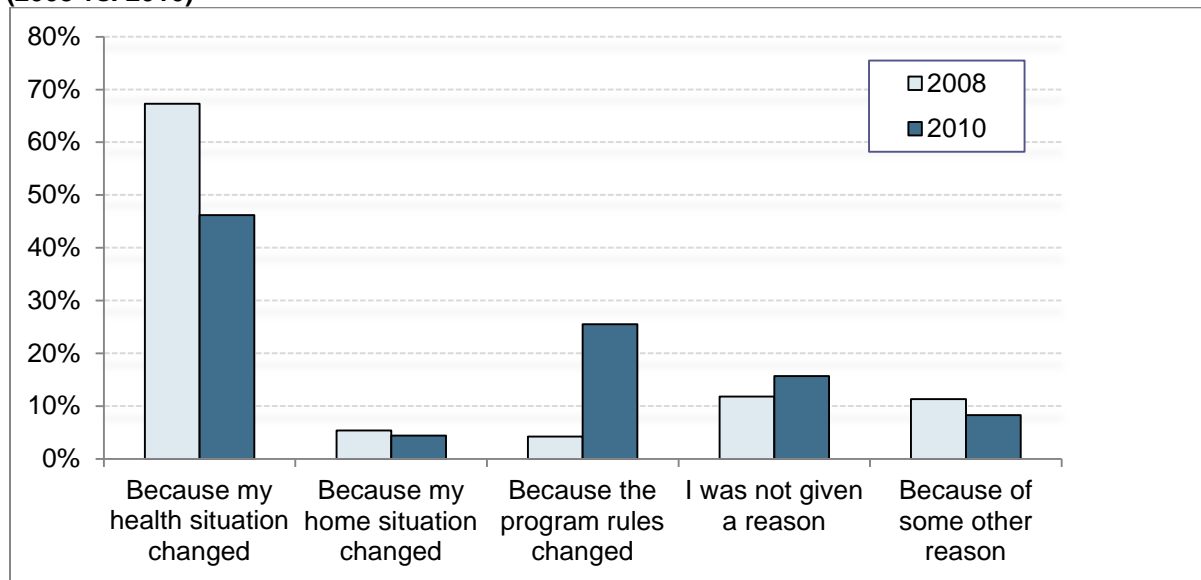
Table 1.4. Question 2C: What was the main reason you were given for the change in your hours?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
What was the main reason you were given for the change in your hours?	Because my health situation changed	239	67.3%	802	46.2%	-21.1%
	Because my home situation changed	19	5.4%	76	4.4%	-1.0%
	Because the program rules changed	15	4.2%	443	25.5%	21.3%
	I was not given a reason	42	11.8%	272	15.7%	3.9%
	Because of some other reason	40	11.3%	144	8.3%	-3.0%
Total		355	100.0%	1,737	100.0%	

Note: Percentages may not sum to 100 percent due to rounding.

The large increase in Consumers reporting program rule changes as the reason for their changes in hours is seen clearly in Figure 1.1:

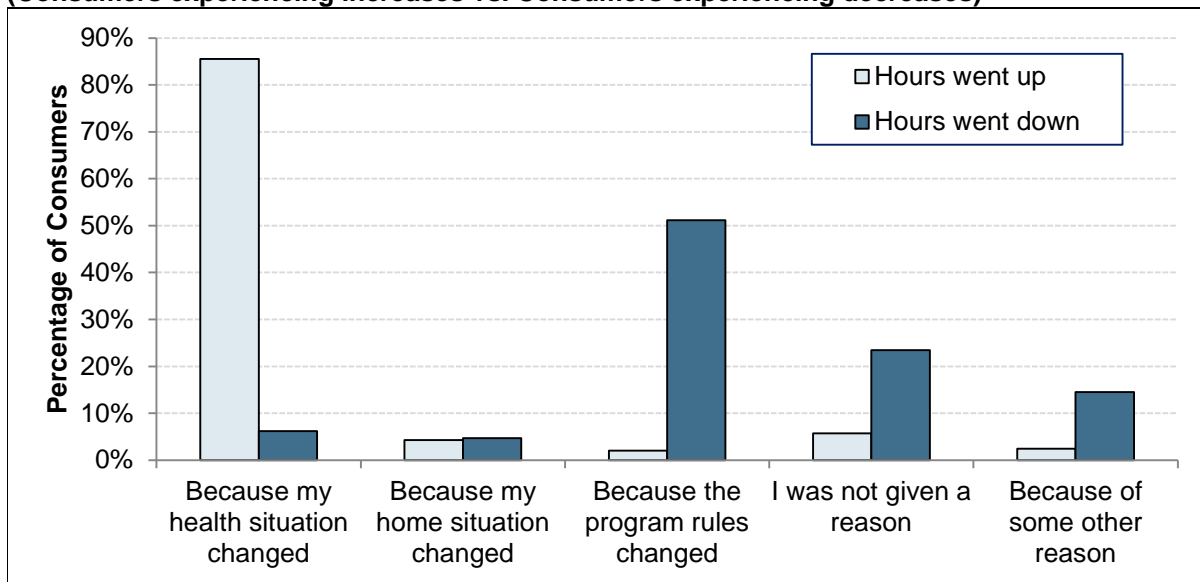
Figure 1.1. Question 2C: What was the main reason you were given for the change in your hours? (2008 vs. 2010)



There was a significantly different response pattern for those Consumers whose hours had increased as a result of their most recent assessment, compared with those whose hours had decreased. (These patterns are illustrated in Figure 1.2.)

- Consumers who had an **increase** in hours tended more often to report a change in health situation as the primary reason for the change (85.5% of those experiencing an increase vs. 6.2% of those experiencing a decrease).
- Consumers who had a **decrease** in hours were more likely to report a change in the program's rules as the reason for the change (51.2% of those experiencing a decrease vs. less than 2.0% of those experiencing an increase).
- Consumers who had a **decrease** in hours tended to report more often that they were not given a reason for the change (23.4% of those experiencing a decrease vs. 5.7% of those experiencing an increase).

**Figure 1.2. Question 2C: What was the main reason you were given for the change in your hours?
(Consumers experiencing increases vs. Consumers experiencing decreases)**



Consumers who reported that their change in hours was due to “some other reason” were provided space to write in the reason they were given. There were 458 write-in responses¹:

Across-the-Board Reduction in Hours—204 comments

The most frequent explanation Consumers received regarding their change in hours was attributed to the new state law Assembly Bill (AB) 1612 (Chapter 725, Statutes of 2010) which reduced hours by 3.6 percent. Typically, Consumers described the reasons behind their reduction in hours with comments such as, “*budget cuts,*” the “*new state law,*” or simply, “*reduced 3.6 percent.*” Quite a few Consumers noted that their appeals for more hours were denied due to a lack of funds in the current California budget. One respondent summarized a common rationale associated with these denials by simply stating, “*The government has no money.*” A few Consumers mentioned that they had been given an increase of hours, but the recent 3.6 percent reduction nullified that benefit, as described by the following comment: “*Now my hours are going down by 3.6 percent in February. So my hours went up due to health and then down due to Notice of Action/Rule Change.*” Additionally, comments such as, “*I understand it is the economic crisis facing our state and country US,*” expressed an understanding and sensitivity to current budget constraints.

¹ Totals given reflect the number of Consumers providing write-in responses and may not balance with the sum total of comments under the thematic subheadings. This is because some Consumer comments may reflect more than one content theme.

Increased Needs–81 comments

Several Consumers explained that their hours had been increased in an effort to address a worsening health condition. Quite frequently respondents gave detailed accounts of their medical circumstance when accounting for the added hours, as typified in this response: *“Because I have cancer of the tongue, breast, and lung.”* However, not all respondents gave worsening medical conditions as reasons for obtaining additional hours, as typified by this response, *“Not enough hours given before to do the work necessary to keep up with having enough clean clothes and a clean house.”*

Reiteration and Expansion of Existing Response Choices–55 comments

Consumers sometimes simply reiterated the response choices for the question. A common example of this can be seen when respondents simply write in comments like *“Health”* or *“Program changed.”* There were instances when respondents checked one or more of the categorical options and also wrote in the write-in space to further their explanation. For example, some respondents who checked both *“Because my health situation changed”* and *“Because my home situation changed,”* used the write-in space to explain how relatives had moved in or out, or that the Consumers themselves had moved to another location in an effort to receive better care.

Decreased Hours–56 comments

Several participants expressed dissatisfaction with IHSS reducing Consumer hours when the provider was known to be a spouse or a live-in relative. The following comment is a good example of Consumer frustration on the issue: *“When a family member cares for a disabled member of the family, less hours are allowed. It’s not really right, but we were told those are the rules.”* Some Consumers simply stated that their hours had been decreased without further explanation, while others provided more concrete examples to justify the reduction in hours, such as, *“Don’t need help getting to the bathroom.”* A few respondents mentioned gaining an increase in their overall health which decreased their need for extensive hours of care. One Consumer attributed the decrease in her hours to having transitioned to adult daycare instead of IHSS.

Request More Hours of Service–44 comments

Instead of discussing the reasons behind a change in allocated hours, some Consumers used this open-ended question as an opportunity to petition for more hours. A typical comment that provides an example of these kinds of comments is simply, *“I’m sick and need more hours.”*

Procedural Problems–20 comments

Some Consumers felt that the reassessment process had some troubling issues associated with it. Most notably, respondents felt their assessment was not done properly or thoroughly, possibly due to a lack of training on the part of the assessment worker. *“My hours were reduced. Two years ago an untrained worker did not do a*

thorough evaluation,” says one Consumer who provided a typical comment that reflects this theme. A few Consumers reported that they were still waiting for a notification of the outcome of their reassessment. One Consumer noted that a change in hours can occur relocating to a different county, even when health needs remain the same.

Miscellaneous–2 comments

One Consumer mentioned that a difference in hours could be the difference between remaining at home and having to be moved to a convalescent facility: *“Assessments should be based on whether a totally disabled person may remain at home with the maximum hours allowed versus sending him/her to a convalescent facility.”* And, one Consumer noted that the rising cost of medications is challenging.

Question 3: For each IHSS service in the table below, please indicate whether your current authorized hours are not enough, about right, or too many.

A majority of Consumers indicated their hours are about right. Further, the responses given by Consumers regarding their allotment of hours for specific HTG tasks shows a consistent pattern across all twelve tasks (see Table 1.5).

- A majority of Consumers reported that their hours are about right on all twelve tasks, with percentages ranging from a low of 58.9% (Meal Preparation) to a high of 77.6% (Menstrual Care).
- A minority of Consumers reported that their hours are not enough on all twelve tasks, with percentages ranging from a low of 21.9% (Menstrual Care) to a high of 40.9% (Meal Preparation).
- Less than 1% reported receiving too many hours.

Table 1.5. Question 3: For each IHSS service in the table below, please indicate whether your current authorized hours are not enough, about right, or too many

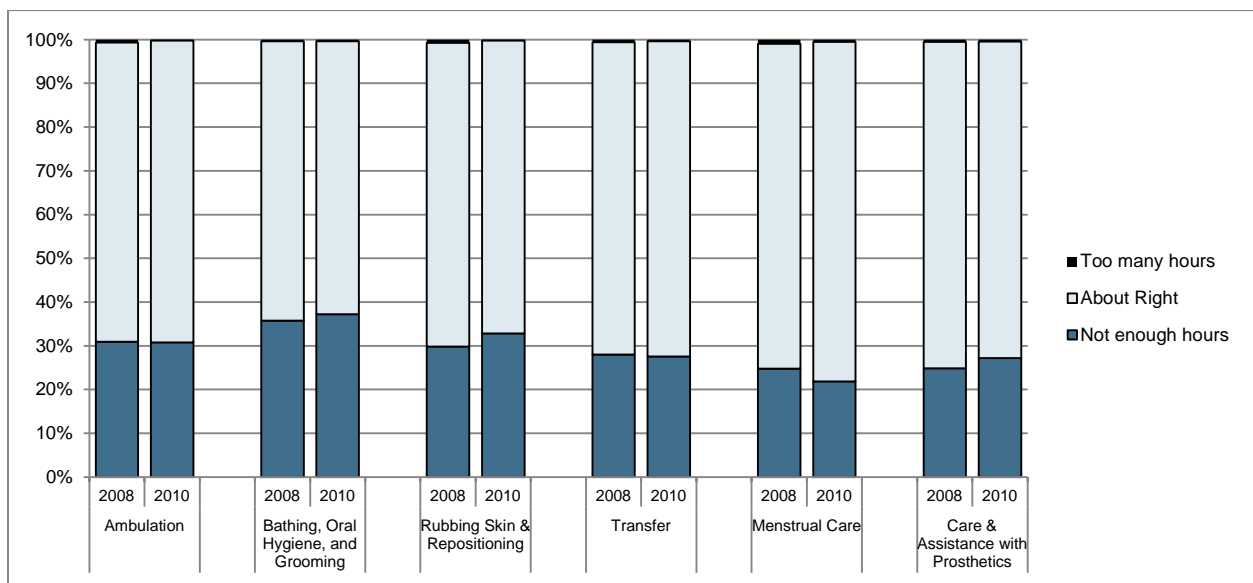
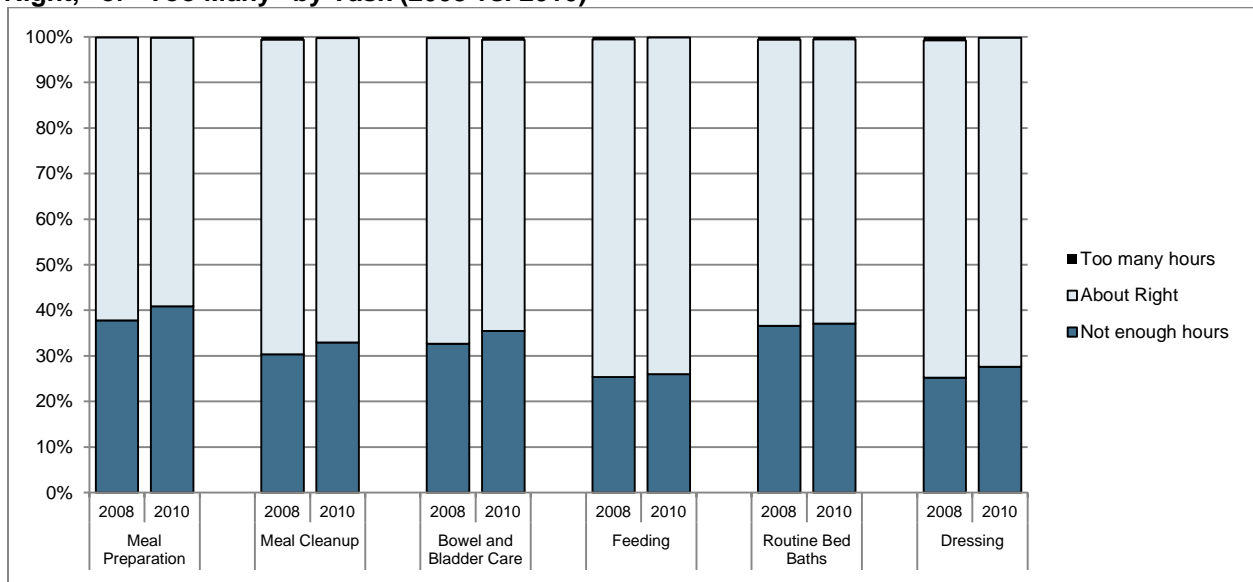
		Not enough hours		About right		Too many hours		Total	
		Count	Percent	Count	Percent	Count	Percent	Count	Percent
Meal Preparation	2008	223	37.8%	366	62.0%	1	0.2%	590	100.0%
	2010	1,187	40.9%	1,709	58.9%	6	0.2%	2,902	100.0%
Meal Cleanup	2008	178	30.3%	405	69.0%	4	0.7%	587	100.0%
	2010	961	32.9%	1,948	66.8%	9	0.3%	2,918	100.0%
Bowel and Bladder Care	2008	120	32.7%	246	67.0%	1	0.3%	367	100.0%
	2010	599	35.5%	1,078	63.9%	11	0.7%	1,688	100.0%
Feeding	2008	89	25.4%	260	74.1%	2	0.6%	351	100.0%
	2010	431	26.0%	1,224	73.8%	3	0.2%	1,658	100.0%
Routine Bed Baths	2008	113	36.6%	194	62.8%	2	0.6%	309	100.0%
	2010	602	37.1%	1,010	62.3%	10	0.6%	1,622	100.0%
Dressing	2008	129	25.2%	379	74.0%	4	0.8%	512	100.0%
	2010	685	27.6%	1,790	72.1%	6	0.2%	2,481	100.0%
Ambulation	2008	133	30.9%	294	68.4%	3	0.7%	430	100.0%
	2010	665	30.8%	1,489	68.9%	6	0.3%	2,160	100.0%
Bathing, Oral Hygiene, and Grooming	2008	189	35.7%	338	63.9%	2	0.4%	529	100.0%
	2010	968	37.3%	1,620	62.3%	11	0.4%	2,599	100.0%
Rubbing Skin & Repositioning	2008	120	29.9%	279	69.4%	3	0.7%	402	100.0%
	2010	583	32.8%	1,189	67.0%	4	0.2%	1,776	100.0%
Transfer	2008	97	28.0%	247	71.4%	2	0.6%	346	100.0%
	2010	457	27.6%	1,194	72.0%	7	0.4%	1,658	100.0%
Menstrual Care	2008	25	24.8%	75	74.3%	1	1.0%	101	100.0%
	2010	121	21.9%	429	77.6%	3	0.5%	553	100.0%
Care & Assistance with Prosthetics	2008	44	24.9%	132	74.6%	1	0.6%	177	100.0%
	2010	359	27.2%	954	72.3%	6	0.5%	1,319	100.0%

Note: Percentages may not sum to 100 percent due to rounding.

Given the marked increase from the 2008 administration in the number of Consumers reporting reductions in their hours, it is interesting that the proportions of Consumers reporting that their hours are about right—on a task-wise basis—does not show similar large changes in 2010. A solid majority of Consumers continued to report that their hours were about right on all 12 tasks. While it is true that slightly more Consumers reported that their hours were not enough on 10 of the 12 tasks (as compared to 2008), the changes are modest.

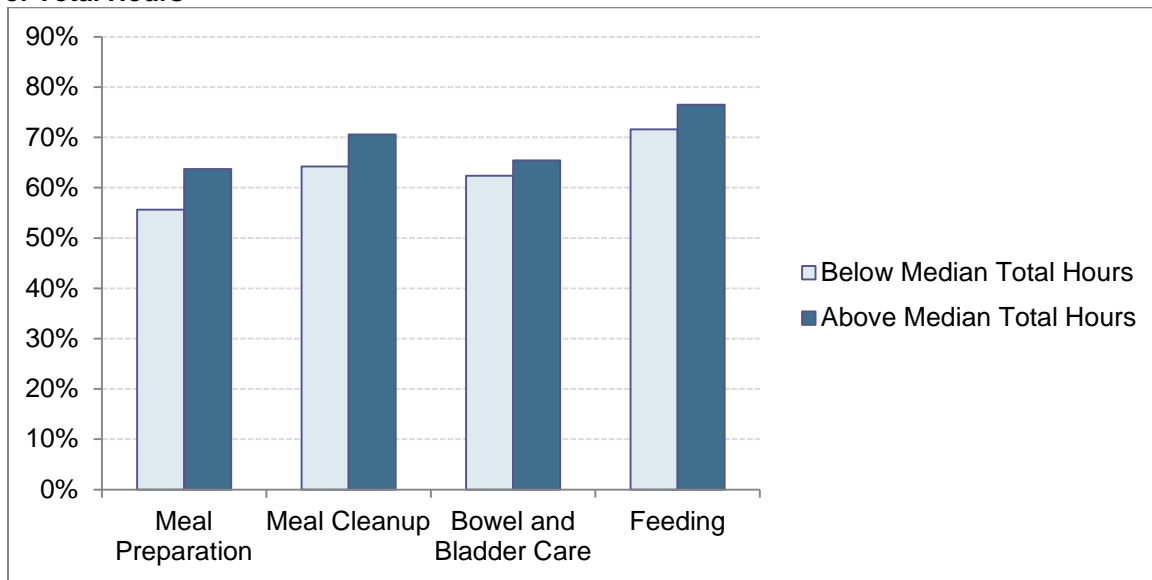
The consistency in Consumer responses between the 2008 survey and the current 2010 survey are illustrated in Figure 1.3.

Figure 1.3. Question 3: Percentage of Consumers Reporting that Hours Are “Not Enough,” “About Right,” or “Too Many” by Task (2008 vs. 2010)



To examine whether Consumer satisfaction with hours allotted for each task might depend on an individual’s level of need, respondents were assigned to high-hours and low-hours groups. This assignment was based on whether a respondent’s total hours fell above or below the median number of total hours for an individual in the statewide caseload.

Figure 1.4. Question 3: Percentage of Consumers Reporting that Hours are “About Right” by Level of Total Hours



As was observed in the 2008 survey, Consumers with **higher** levels of total hours tended to evaluate the hours they receive **more positively** than those with **lower** levels of total hours. This pattern was observed in all 12 task areas. This pattern is illustrated in Figure 1.4 for Meal Preparation, Meal Cleanup, Bowel and Bladder Care, and Feeding. Data for all 12 tasks is presented in Table 1.6.

Table 1.6. Question 3: Percent of Consumers Reporting that Hours Are “Not Enough,” “About Right,” or “Too Many” by Task and Level of Total Hours

	Below Median Total Hours			Above Median Total Hours		
	Not enough hours	About right	Too many hours	Not enough hours	About right	Too many hours
Meal Preparation	44.2%	55.6%	.2%	36.1%	63.7%	.3%
Meal Cleanup	35.4%	64.2%	.4%	29.2%	70.6%	.2%
Bowel and Bladder Care	36.8%	62.4%	.8%	34.1%	65.4%	.5%
Feeding	28.3%	71.6%	.1%	23.2%	76.5%	.3%
Routine Bed Baths	40.8%	58.4%	.8%	32.4%	67.2%	.4%
Dressing	29.8%	69.9%	.4%	24.5%	75.4%	.1%
Ambulation	31.4%	68.4%	.3%	30.0%	69.7%	.3%
Bathing, Oral Hygiene, and Grooming	38.9%	60.5%	.6%	35.0%	64.8%	.2%
Rubbing Skin & Repositioning	35.4%	64.3%	.3%	29.7%	70.2%	.1%
Transfer	30.3%	69.2%	.6%	24.2%	75.6%	.3%
Menstrual Care	26.6%	72.8%	.7%	16.1%	83.5%	.4%
Care & Assistance with Prosthetics	30.0%	69.4%	.5%	23.6%	76.1%	.4%

Note: Percentages may not sum to 100 percent due to rounding.

Question 4A: If you need more hours, did you ask the county to reconsider?

The percentage of Consumers who asked their county to reconsider their authorized hours decreased slightly from 2008 to 2010. Given the emphasis Consumers have placed on the impact of across-the-board hours reductions elsewhere on the survey, it is likely that Consumers understand that such decisions are made at the state level and are not within the power of the counties to change.

- 25.1% of Consumers reported they requested more hours from the county
- 74.9% reported they did not request more hours

Table 1.7. Question 4A: If you need more hours, did you ask the county to reconsider?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
If you need more hours, did you ask the county to reconsider?	Yes	186	28.6%	774	25.1%	-3.5%
	No	464	71.4%	2,310	74.9%	3.5%
Total		650	100.0%	3,084	100.0%	

Question 4B: When you asked the county to reconsider, what happened?

Among the 25.1 percent of Consumers who requested additional hours from the county, less than one-half (40.2%) reported receiving more hours, while a majority (59.8%) reported not receiving more hours (see Table 1.8). The percentage of Consumers who were successful in their request to the county for more hours declined 5.3 percent, as compared with the 2008 survey. Taken together with the slightly lower percentage of Consumers requesting additional hours, this is suggestive of a somewhat less flexible assessment environment.

Table 1.8. Question 4B: When you asked the county to reconsider, what happened?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
When you asked the county to reconsider, what happened?	I received more hours	86	45.5%	328	40.2%	-5.3%
	I did not receive more hours	103	54.5%	488	59.8%	5.3%
Total		189	100.0%	816	100.0%	

Question 4C: What reason did the county give for its decision?

Write-in responses were provided by 568 Consumers, detailing the reasons given by the county for its decision to grant or deny the Consumer's request for additional hours:

Reasons for Denial—191 comments

Many Consumers commented on why their request for additional hours had been denied. The most common reason given for the decision was due to the California budget crisis; answers included reference to the 3.6 percent cut back, and comments such as, "*budget restraints.*" Several Consumers also mentioned that the request for more hours was denied because their provider is their spouse or close family member and the guidelines differ for these types of providers. Some Consumers were denied because, according to the guidelines, they had already reached the limits for hours in the tasks in which they requested assistance, as demonstrated by the comment, "*My worker said that's all they would allow for hours of care.*" A few Consumers reported that their social workers did not agree that more hours were needed. A small number of respondents simply stated they were "*denied,*" and one mentioned that their request was denied due to "*provider problems.*"

No Response from County—164 comments

Many respondents said they did not know the rationale behind the decision the county gave for rejecting their appeal, as exemplified by the comment, "*No reason was given.*" Several Consumers expressed frustration with a lack of communication during their attempts to follow up on submitted requests, as demonstrated by the comment, "*I called and they did not return my calls and that was it.*" There were a good deal of respondents

who were still waiting for the outcome and subsequent rationale for why the decision had been made. A typical comment depicting this theme was, “*Waiting for what they decide.*” Some had been told to wait until their next regularly scheduled assessment, and one respondent reported being told there was no time to do a reassessment.

Increased Hours–142 comments

The most common explanation given to Consumers who were granted additional hours can be typified by this comment: “*In-home care needs increased.*” The counties recognized the additional needs of these Consumers and granted an increase in hours. Some Consumers had received additional hours, but were not satisfied with the increase. A few had increased hours due to surgery, and other short-term reasons. Instead of discussing the rationale behind the increase in hours, some Consumers simply listed the areas in which they received the increase in hours such as, cooking, shopping, cleaning, and attending doctor’s appointments. A few mentioned the increase but gave no specific reason why the increase was granted, and only a small few were granted additional hours after a fair hearing was held.

Did Not Request–54 comments

Some participants noted that they have never thought to ask the county to reconsider the decision to reduce their IHSS hours. A few discussed not having been aware that Consumers could appeal for more hours outside of their scheduled annual reassessment, as highlighted in the comment, “*Last month was the first month that they reduced the hours. Moreover I did not know I can ask for more hours.*”

Requests–17 comments

Some Consumers used this opportunity to request more hours, and a few requested a reassessment. One comment that characterizes requests for more hours, states, “*I have only 2 hours a day. It is not enough hours for me. I need 2 hours more.*”

Question 5A: Did you request a fair hearing to appeal the amount of hours approved by your social worker?

As in the 2008 survey, it was rare for Consumers to report having filed an appeal for a fair hearing.

- Only 82 Consumers who responded to the survey (2.8%) reported filing an appeal for a fair hearing. When compared with the number of Consumers (774) who asked their county for more hours, it is clear that filing a judicial appeal is a step that Consumers were less likely to take.
- It is also interesting to note that 488 Consumers requested additional hours from their county and were denied, while only 82 Consumers filed a request for a fair hearing. Thus, it would seem even when denied additional hours, few Consumers pursue the matter further with an appeal.

Table 1.9. Question 5A: Did you request a fair hearing to appeal the amount of hours approved by your social worker?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
Did you request a fair hearing to appeal the amount of hours approved by your social worker?	Yes	23	3.7%	82	2.8%	-0.9%
	No	592	96.3%	2,810	97.2%	0.9%
Total		615	100.0%	2,892	100.0%	

Question 5B: When you requested a fair hearing, what happened?

Due to the small number of Consumers responding to this question in the 2008 survey, caution is warranted in drawing conclusions from changes observed between the 2008 administration and the current 2010 survey.

Table 1.10. Question 5B: When you requested a fair hearing, what happened?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
When you requested a fair hearing, what happened?	The hearing has not taken place yet	8	38.1%	37	42.0%	3.9%
	The county and I agreed, and I withdrew my hearing request	0	0%	11	12.5%	12.5%
	The judge gave me the hours I need	4	19.0%	19	21.6%	2.6%
	The judge gave me more hours, but not as many as I need	2	9.5%	6	6.8%	-2.7%
	The judge agreed with the county	1	4.8%	6	6.8%	2.0%
	I had a hearing and I am waiting for a decision	2	9.5%	3	3.4%	-6.1%
	Some other outcome	4	19.0%	6	6.8%	-12.2%
Total		21	100.0%	88	100.0%	

Note: Percentages may not sum to 100 percent due to rounding.

A write-in space was provided so that Consumers could provide explanations of alternative outcomes to their request for a fair hearing. There were 59 responses to this question.

Several Consumers simply stated that they had never asked for a fair hearing to appeal their allocated hours. Reasons behind the choice not to request a fair hearing included: problems with transportation, health complications, frustration with language barriers, and the worry that their plea would not be considered. Some mentioned that they had tried to resolve their request for additional IHSS hours through their social worker instead of going through a fair hearing. A few reported not being aware the process existed and was available, and commonly took the opportunity of the survey to request more hours and/or a fair hearing. Some Consumers said they were told not to request a

fair hearing due to the current budget problems, as typified by the comment, “We are told to wait for a period to apply because the government has no money now.”

A few Consumers discussed being dissatisfied with the outcome of their appeal, even when granted additional hours. One respondent had this to share, “The judge agreed, after coming out of the hospital and my fragile condition, I needed to be reassessed, and hours were raised but not enough.” One Consumer mentioned not having had any communication back from the county since requesting a fair hearing.

Question 6: Do you know who to contact if your provider does not show up as scheduled?

The large majority (83.2%) of Consumers reported that they know who to contact if their provider fails to show up for work when scheduled and there is an immediate need for services. These results are very similar to what was reported in the 2008 survey.

Table 1.11. Question 6: Do you know who to contact if your provider does not show up as scheduled?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
Do you know who to contact if your provider does not show up as scheduled?	Yes	549	81.0%	2,653	83.2%	2.2%
	No	129	19.0%	537	16.8%	-2.2%
Total		678	100.0%	3,190	100.0%	

Question 7: How well did your social worker explain the IHSS program to you and answer any questions that you had about the program?

Nearly three-fourths (73.7%) of Consumers reported that their social worker fully explained the program to them and answered all their questions. These results are very similar to what was reported in the 2008 survey.

- An additional 19.2% reported that their social worker explained most of the program and answered most of their questions
- 4.4% reported that their social worker only explained part of the program and didn't answer many questions
- 2.7% reported that their social worker did not adequately explain the program or adequately answer their questions

Table 1.12. Question 7: How well did your social worker explain the IHSS program to you and answer any questions that you had about the program?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
How well did your social worker explain the IHSS program to you and answer any questions that you had about the program?	The social worker fully explained the program and answered all my questions	455	72.2%	2,228	73.7%	1.5%
	The social worker explained most of the program and answered most of my questions	115	18.3%	581	19.2%	0.9%
	The social worker explained only parts of the program and didn't answer many of my questions	35	5.6%	132	4.4%	-1.2%
	The social worker did not explain the program and didn't answer most of my questions	25	4.0%	81	2.7%	-1.3%
Total		630	100.0%	3,022	100.0%	

Note: Percentages may not sum to 100 percent due to rounding.

Question 8: How long have you received IHSS?

With respect to tenure in the program, the median (midpoint) number of years Consumers reported receiving IHSS services was 3.4.

- The upper 25% reported more than 5.8 years in the program
- The middle 50% reported between 2.2 years and 5.8 years in the program
- The lower 25% reported less than 2.2 years in the program

It should be noted that these data on tenure in the program are from the self-report of Consumers and are subject to errors of memory; in fact, some Consumers wrote comments in this area of the survey form indicating that they couldn't remember how long they'd been receiving IHSS, or that they weren't certain but would provide their best estimate.

Question 9: How many hours per month of IHSS are you authorized to receive?

The median reported number of authorized hours per month was 60.0.

- The upper 25% of Consumers reported more than 90 authorized hours per month
- The middle 50% of Consumers reported between 41 and 90 authorized hours per month
- The lower 25% reported less than 41 authorized hours per month

Question 10: Is your IHSS program important for maintaining your health and well being?

Consumers were nearly unanimous in their response. This question was not included in the 2008 survey, so no comparison data point is available.

Table 1.13. Question 10: Is your IHSS program important for maintaining your health and well being?

		2008		2010	
		Count	Percent	Count	Percent
Is your IHSS program important for maintaining your health and well being?	Very important	--	--	3,206	97.4%
	Somewhat important	--	--	77	2.3%
	Not important	--	--	7	.2%
Total		--	--	3,290	100.0%

Note: Percentages may not sum to 100 percent due to rounding. This question was not asked in the 2008 survey.

Question 11: Does the IHSS program meet your needs?

More than nine out of ten (91.0%) Consumers reported that the IHSS program currently meets their needs, a substantial increase over the 2008 survey. This was true for Consumers in both high-hours and low-hours groups equally. It is interesting to note that despite the emphasis given elsewhere on the survey to the 3.6 percent across-the-board hours reduction, the proportion of Consumers reporting that their needs are being met *has actually increased* by nearly 10 percent.

Table 1.14. Question 11: Does the IHSS program meet your needs?

		2008		2010		Change 2008-2010
		Count	Percent	Count	Percent	
Does the IHSS program meet your needs?	Yes	547	81.4%	2,932	91.0%	9.6%
	No	125	18.6%	289	9.0%	-9.6%
Total		672	100.0%	3,221	100.0%	

Question 12: What would help the IHSS program better meet your needs?

The final open-ended question of the survey was included as an opportunity for the Consumer to explain his or her opinion of the program and what can be done to better meet Consumers' needs. The following 12 discussion themes are presented in order from most to least frequently mentioned. There were 1,721 comments offered in response to this question.

Overall Satisfaction with IHSS Program—708 comments

Overwhelmingly, respondents expressed an overall level of satisfaction with the IHSS program, typified by the comment, *“At this time the program is meeting my needs, thank*

you.” Similarly, the majority of Consumers who commented expressed their gratitude towards the IHSS program, many of whom did so by writing a simple “thank you.” While most respondents kept their expressions of gratitude and overall satisfaction short, others were more expansive, providing comments such as, “I think the IHSS program is sufficient to meet our needs. Thanks,” and “Thank you very much for this program; it’s been very helpful to me.”

Some Consumers used the open-ended forum to explain the important role IHSS plays in their lives, as described in comments like, “I do not drive because I am disabled. My provider takes me to doctors appointments shopping medication cooks meals cleans apartment, does my paperwork, etcetera and much more” and “I think the IHSS program is excellent in helping older and sick people I believe this is the best program in the world for no other nations have this program.”

A few participants even credited IHSS with having saved their lives, and expressed anxiety at the thought of living without IHSS services, as portrayed in this comment, “I am grateful for the program and don’t know how I would survive without it.” The desire to remain independent was yet another theme that was associated with gratitude, as depicted by the comment, “I believe without the help of my provider I could not continue to live and function independently.”

Requests for Additional Hours–683 comments

Overwhelmingly, respondents reported that the best way for IHSS to better meet Consumer needs would be to increase the amount of authorized hours. While the majority of responses provide simple requests such as, “Please give us more hours of IHSS service,” many Consumers requested increased hours in the following specific areas:

Personal Care

- Bathing and Grooming
- Meal Preparation
- Ambulation
- Exercise
- Bowel and Bladder Care
- Rubbing Skin and Repositioning
- Feeding
- Transfer
- Assistance with Administering Medication or Medical Devices

Personal Affairs

- Attending Doctors’ Appointments
- Shopping, Errands, Picking Up Medication and Medical Supplies
- Companionship
- Paying bills and Assistance Filling Out Forms

Household Chores

- House Work and Laundry
- Yard Work

With respect to Consumer requests for increased hours for meal preparation and exercise, some Consumers pointed out that their doctors ordered them to follow special diets and increase their exercise. Without additional help and hours from IHSS they are not able to follow the treatment plan prescribed to them by their physician. Declining

health situations, memory loss, and recent surgeries were also mentioned as reasons why additional hours of care were needed. In addition, several respondents explained that their providers' assistance is required during their doctor's appointments, and feel this time is not sufficiently compensated.

Less frequently mentioned, but still important, were Consumer requests that providers be allowed to offer more types of services than are currently offered. Increased flexibility of when hours may be used was mentioned twice, and one request was made for a special program or consideration of more hours for Consumers with autism.

California State Budget Concerns–216 Comments

Several budget-related comments expressed concern over the current and future cuts to the IHSS program. Some comments simply stated the facts of the cuts such as, *"Hours will be reduced by 3.6% in February."* Others pleaded their case with comments such as, *"Give me the hours that I need and don't take any away because I need the help very badly. If they cut the hours, that cuts my provider from doing all she needs to do to help me and I need her assistance very much."* Consumers often made a case for the overall continuation of the IHSS program with comments such as, *"This program should continue because it is very beneficial for me and for those in need."* Faced with current reductions and anticipating further budget cuts, respondents expressed the importance of the role IHSS will play in their futures. As one comment illustrates, *"As I get older I will need more help."* Although concerned about budget-related issues, respondents also expressed understanding and flexibility, as highlighted in this comment, *"I am willing to wait for a period until California recovers from the financial crisis. I think the best way for us is to join our hands to tide over the current difficulties."*

Consumers felt that more consistent and stable funding streams would enable IHSS to better meet the needs of Consumers: *"If government would provide a permanent budget and larger funding for the IHSS program that will last for an indefinite period of time."* Other Consumers believed that funding the IHSS program may be cheaper than the alternative of convalescent care. Arguments such as, *"If the TD (totally disabled) patients are not given the proper amount of hours they will end in a convalescent facility, which will cost the state triple the amount of money they could have given to an in home provider— \$70,000 in a convalescent versus \$25,000 on IHSS."*

A small number of respondents associated a lack of IHSS funding with government corruption and greed which, they felt, permeated the healthcare system at the state level. A small number of respondents argued that the IHSS program was not the cause of the budget deficit, and therefore should not suffer from budget cuts.

Providers–180 comments

Consumers stressed the important role their providers play in meeting their health needs. Many pointed out that better compensation and working conditions for providers ultimately means better care for Consumers. Several Consumers took this open-ended forum as an opportunity to recognize the good work their providers are doing, as typified

by the comment, *“My care provider takes care of my needs, and she's doing an excellent job taking care of me and my household chores.”*

Provider Compensation

The most frequent request Consumers made on behalf of providers was to request a pay increase. These requests were not only made in the interest of the provider, but also as a way to better meet the needs of the Consumer, as illustrated by the comment, *“Several, even good caretakers, are often tempted to ‘steal’ or forge in order to get by. A safe worker is a well paid worker. Many great workers can't afford to live on this wage and the good ones go on to other employment.”* Several Consumers asked that their provider be paid in a more timely manner: *“I have one thing that needs your help-- I want you to mail the check to my social service provider in time. Sometimes she gets this a month late or a half month late. For a poor person who has difficulty in life, she needs it in time.”* Respondents pointed out that timely payment of provider wages is also a benefit to the Consumers; if providers are not paid on time, they may lack the funds required for transportation to work. Some Consumers suggested that instituting a payroll tracking system or direct deposit option may also help prevent some of these issues. A few Consumers requested, on behalf of providers, that IHSS provide health insurance and vacation days for long-term providers. A few respondents commented that provider union fees are too high and offer little service to the provider in return.

Provider Training

Many respondents expressed that increasing provider training would help better meet Consumer needs. Respondents shared that more training would improve the level of care they receive, raise the standard for provider work habits, and build stronger relationships between Consumers and their providers. The comment, *“I hope the government could enhance training on the caregivers, not only technically, but also improving their quality and qualifications,”* exemplifies the type of comments Consumers made when making such requests. Connected to the notion of additional training, some Consumers requested that providers have the appropriate non-English language skills to more effectively communicate with non-English speaking Consumers, in addition to being able to act as interpreters at times when needed.

Consumer Access to Providers

Also mentioned was the idea that independent agencies that pair up Consumers with providers are not beneficial to Consumers, due to the small number of allocated hours usually assigned for care. Less frequently mentioned, but still important, was the complaint that Consumers are not able to find a reliable provider to meet their needs. In fact, a few requested help in securing a back-up provider in case their usual provider is unable to care for them for the day.

Social Workers–140 comments

The need for improved communication with their social worker was a common theme discussed by respondents, as highlighted by the suggestion, *“Better communication*

with social workers, it is hard to talk to them.” The overwhelming majority of these comments simply asked for increased access to telephone communication and prompt return of messages. A few Consumers acknowledged that a lightened caseload would enable social workers to improve in this area. Some Consumers felt improved rapport with social workers would aid in meeting their IHSS needs. For instance, when describing what would be helpful, one respondent said, *“A good social worker, who actually cares about my health and wants to help me.”*

IHSS Assessment Practices–82 comments

Several Consumers felt that the assessment process did not adequately consider their individual needs: *“It could help more if the social worker had reviewed the condition of the patient better and had accordingly added the hours for care when necessary.”* Others requested that assessments should be more frequent, as articulated with comments such as, *“I think that they should make appointments more often than they do - and I think that they should get more involved in the personal lives of the clients.”* A few respondents took this opportunity to request a reassessment: *“I cannot agree that the evaluation was correctly done. I require a re-evaluation.”* A couple of Consumers also requested that their doctor’s input be considered in the assessment process. *“Yearly evaluation and doctors input will be good enough. Thank you.”* A couple of Consumers wanted to request an appeal by way of the fair hearing process, and one respondent asked for additional information to be sent regarding the assessment prior to the assessment date.

Spouse or Family Provider–78 comments

Many Consumers felt it was unfair to treat family providers differently under the regulations than non-family providers. *“I feel that a spouse should be paid the same way other people in the program are. They do more for us, and some spouses can’t work outside of the home because of the health problems we have.”* Some Consumers explicitly asked for more authorized hours for their family providers, with requests such as, *“I need more hours for my wife to take care of me.”* One Consumer requested a pay increase for their spouse provider, and another explained that their family member provider had to quit working for them due to low compensation.

Communication–65 comments

Translation services, whether in person, on telephone calls, or in written materials were requested by some Consumers as a way to facilitate communication. As one respondent mentioned, *“Difficult with social worker who doesn’t speak Farsi, there are many unanswered questions.”*

A few Consumers seemed uncertain about why a change in, or discontinuation of, their services had occurred, perhaps due to a lack of communication with IHSS, as demonstrated by this comment, *“They keep taking me off my in home service saying I’m disqualified?”*

Share of cost was also a source of confusion to Consumers. Frustration and uncertainty over how the costs are figured stand out in comments such as, *“Why do I have to pay so much (my share of cost) for my provider. I almost have to pay my whole month’s pension.”*

Lastly, a desire for more information about the IHSS program was requested by a few Consumers, some of whom specifically requested that IHSS provide information in a monthly or quarterly newsletter.

Material Needs—50 comments

Many Consumers requested that IHSS provide and/or facilitate transportation with comments such as, *“Provide some form of transportation to appointments”* and *“Provide gas allowance—my needs for doctors visits have increased and worker spends more time taking me to all my doctor’s appointments.”* Some respondents explained they did not have enough income to supply basic needs for themselves, and a few said they could use assistance to find affordable housing. A small handful of Consumers requested that IHSS help provide additional money or services to acquire healthier food, and cover the cost of other necessary goods such as adult diapers.

Procedures—36 comments

Consumers expressed frustration over losing trusted caregivers who cannot comply with the newly required background checks and other requirements needed to continue as a caregiver. *“My husband was recently terminated due to his not being able to complete the background check. I want my daughter to take over, but she is helping with my care and doesn’t have time to leave to do the requirements. Is there a way around this?”* Consumers reported that the cost of background checks was an obstacle when both Consumer and provider are on limited incomes. This issue arises with family and non-family providers alike.

The topics of fraud and surprise visits were rarely mentioned, but a few Consumers did recognize that surprise visits may limit the amount of fraud, thereby benefiting Consumers overall, as expressed by this respondent: *“Maybe surprise visits to be sure nobody is cheating which takes away from those of us who really need it.”* In contrast, however, one Consumer expressed concern that surprise visits are a *“violation of search and seizure.”*

Hospitalization procedures were mentioned by only a few respondents. Some argued that it is inconvenient to have to reapply for services after a lengthy hospital stay, as demonstrated by the comment, *“Extend the time that I can be in the hospital, without being cancelled. If I’m there more than a month my caregiver has to re-file to get back on the program.”* Others explained that a caregiver’s assistance is still needed if and when they are admitted into the hospital. *“I am alone and still need help if put in the hospital.”*

A few Consumers requested additional services, as indicated by the comment, *“I would like more programs for physical therapy and physical exercise.”*

In addition, respondents discussed wanting to fill out less paperwork and closer office locations.

Equipment Needs–19 comments

Some Consumers requested IHSS help with obtaining handicapped accessibility equipment in their homes, such as, “*More assistance with finding home devices such as ramps for electric wheel chairs installation of shower handles, and easier higher toilets.*” A few requests were also made for hospital beds and power wheelchairs.

Health Insurance–15 comments

A little over a dozen respondents mentioned needing better health care coverage with comments such as, “*Better health coverage. I have Medi-Cal it doesn't cover enough, doesn't cover some doctor medications.*”