

STATEWIDE CDSS IN-HOME SUPPORTIVE SERVICES (IHSS) 2012 CONSUMER SURVEY



Prepared for the California Department of Social Services
Adult Programs Division

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IHSS 2012 CONSUMER SURVEY

KEY FINDINGS

- Consumer response to the survey was 39%, which was consistent with the 40% response rate in the 2010 survey administration.
- The majority of consumers remain very positive about the benefits they receive from the program and indicate that it meets their needs.
 - About nine out of ten (89.1%) consumers reported that the IHSS program meets their needs--on par with the results of the last Consumer Survey in 2010 and up from 81.4% in 2008.
- The proportion of consumers reporting a decrease in their hours at reassessment declined slightly from 33.6% in 2010 to 30.9% in 2012.
- Among consumers reporting a recent reassessment, roughly equal numbers reported increases (31.4%), decreases (30.9%), or no change (30.9%). The median reported increase was 10 hours, while the median reported decrease was five hours.
- Among consumers reporting a decrease in hours, 51.4% attributed the decrease to a change in program rules.
- The majority of consumers (about 60% to 70%, depending on the task) feel that their hours are about right, while a minority of the respondents (about 30% to 40%) believes that their hours are not enough. This is consistent with the 2010 survey.
- 29.4% of consumers reported that they had requested additional hours from their county, a slight increase from the 2010 survey.
- Among consumers who requested additional hours from their county, 33.9% received additional hours. The proportion of consumers successful in their requests for additional hours declined in 2010 and again in 2012.
- Consistent with both earlier surveys, few consumers (4.1%) requested a fair hearing to appeal the number of approved hours they received.
- The overwhelming majority (91.7%) of consumers reported that their social worker either fully or mostly explained the IHSS program to them, and answered their questions. This remains consistent with the 2010 survey.
- Common themes in consumers' responses to the open-ended question "How could the IHSS program better meet your needs?" included:
 - Requests for additional hours and services
 - Praise and gratitude for the program
 - Concerns regarding cuts to IHSS, the California state budget, and difficult overall economic conditions
 - Provider issues, including assistance locating and retaining suitable providers, better pay and benefits for providers, and timely processing of provider timesheets
 - Difficulty communicating with IHSS social workers and administrative staff by phone, including unanswered calls and unreturned messages.

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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.

The enactment of Senate Bill 1104 (Chapter 229, Statutes of 2004) directed CDSS to implement a variety of oversight and program integrity measures within the IHSS program. These program integrity measures are referred to as the Quality Assurance Initiative. This consumer survey was initially developed to evaluate the impact of the Hourly Task Guidelines (HTGs) implementation on individual consumers, and to more broadly assess Consumer perceptions of the IHSS program.

CDSS has undertaken three 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 process. The survey was initially sent out in spring of 2008, again in 2010, and this report presents results from its third administration in the spring of 2012.

METHODOLOGY

The 2012 Consumer Survey was mailed to 5,878 randomly-selected consumers across California in March of 2012. Two additional follow-up mailings were made to consumers. 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 speak languages for which written translations were not provided.

Data collection began in mid-March 2012 and concluded mid-June 2012. A total of 2,269 completed surveys were returned, resulting in a 39% overall response rate.

Most of the survey questions provided close-ended categorical (check-the-box type) response options. Results from the responses to categorical questions for the 2012 survey are provided below along with comparisons to the two previous surveys.

The survey also contained four open-ended, write-in response 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. These 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 also 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?

Four out of five (82.6%) consumers found the written materials provided by the IHSS program to be helpful (see Table 1.1). The observed pattern of responses to this question has remained fairly stable across the three administrations of the Consumer Survey. In the current survey:

- 56.6% of consumers reported that the written materials were very helpful
- 26.0% reported that the materials were somewhat helpful
- 2.5% reported that the materials were not helpful
- 11.5% indicated they did not receive written materials
- 3.3% 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		2012	
		Count	Percent	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%	1,217	56.6%
	Somewhat helpful	182	26.8%	892	27.8%	559	26.0%
	Not Helpful	15	2.2%	73	2.3%	54	2.5%
	I did not receive any	100	14.7%	326	10.1%	248	11.5%
	They were in a language I do not read	19	2.8%	114	3.5%	71	3.3%
Total		679	100.0%	3,214	100.0%	2,149	100.0%

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

Question 2A: Have you had a reassessment?

About two-thirds of those surveyed had received at least one reassessment, while about one-third had never received a reassessment. In the current survey, the percentage of consumers indicating they had received a reassessment dropped by about four percent.

- 67.5% of consumers indicated that they had received a reassessment
- 32.5% reported that they had not been reassessed

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

		2008		2010		2012	
		Count	Percent	Count	Percent	Count	Percent
Have you had a reassessment?	Yes	466	71.1%	2,182	71.8%	1,367	67.5%
	No	189	28.9%	857	28.2%	657	32.5%
Total		655	100.0%	3,039	100.0%	2,024	100.0%

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

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

In the 2008 administration of the survey, consumers reporting an increase in hours following their last reassessment outnumbered consumers reporting a decrease in hours by about three to one (see Table 1.3). The mandatory reduction in hours implemented across the board in 2010 shifted that ratio to the point that roughly equal number of consumers reported decreases in hours as increases in hours, though the median reported increase was twice the median reported decrease.

In the 2012 administration:

- 31.4% reported increased hours
- 30.9% reported decreased hours
- 30.9% reported no change in hours
- 6.9% did not know if their hours had changed

Among consumers who reported an increase in hours at their last assessment, they reported a median of 10 hours more per month. Among consumers who reported a decrease in hours at their last assessment, they reported a median of five hours less per month.¹

¹ Changes to consumer hours are self-reported and were not cross-checked against other data sources, such as the Case Management, Information, and Payrolling System (CMIPS) database.

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

		2008		2010		2012	
		Count	Percent	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%	485	31.4%
	My hours went down by (blank) hours per month.	73	15.3%	804	33.6%	478	30.9%
	My hours did not change.	163	34.2%	703	29.4%	478	30.9%
	I don't know whether my hours changed.	26	5.5%	123	5.1%	106	6.9%
Total		476	100.0%	2,390	100.0%	1,547	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?

In the 2012 survey, the proportion of consumers reporting program rules changes as the reason for their change in hours increased slightly, from 25.5 percent to 27.2 percent. As in previous administrations of the survey, the most common reason that consumers reported being given for a change in hours remained a change in the consumer's health situation. As in the 2010 administration of the survey, the second most common reason given for a change in hours was "Because the program rules changed."

In the 2012 administration:

- 43.9% reported a change in hours due to a change in their health situation
- 4.4% reported a change in hours due to a change in their home situation
- 27.2% reported a change in hours due to a change in the program rules
- 15.1% reported a change in hours with no reason given
- 9.4% reported a change in hours due to some other reason

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

		2008		2010		2012	
		Count	Percent	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%	459	43.9%
	Because my home situation changed	19	5.4%	76	4.4%	46	4.4%
	Because the program rules changed	15	4.2%	443	25.5%	284	27.2%
	I was not given a reason	42	11.8%	272	15.7%	158	15.1%
	Because of some other reason	40	11.3%	144	8.3%	98	9.4%
Total		355	100.0%	1,737	100.0%	1,045	100.0%

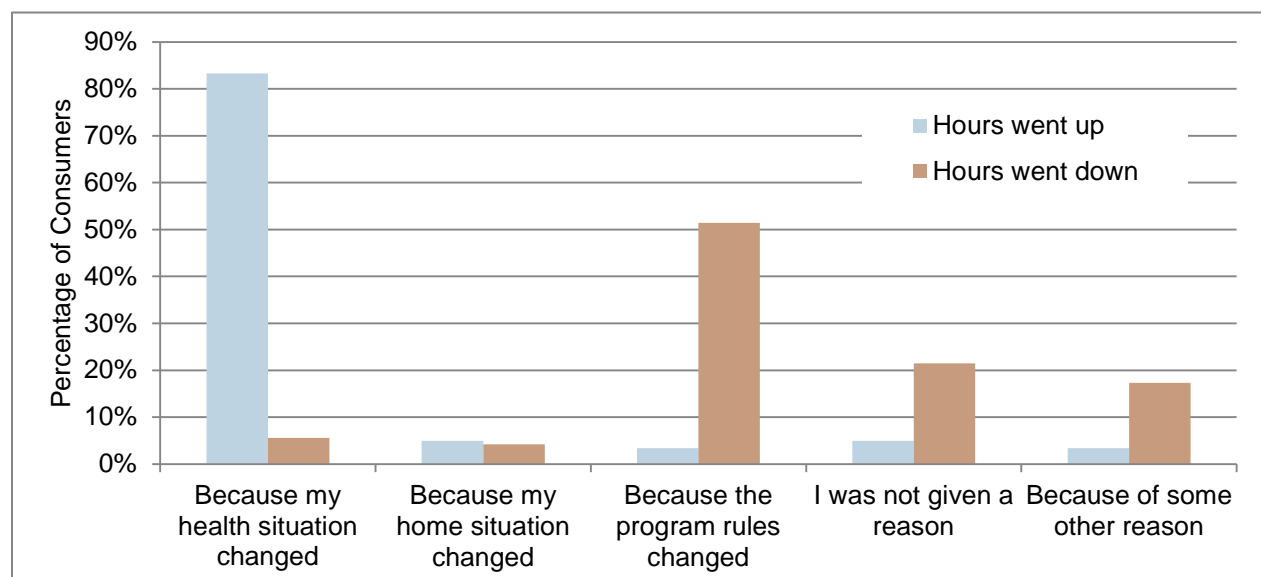
Note: Percentages may not sum to 100 percent due to rounding.

There was a large increase from 2008 to 2010 in consumers who reported program rule changes as the reason for their change in hours. There was also a commensurate decrease in the proportion of consumers who reported a change in health situation as the reason for their change in hours. This shift was less significant in the 2012 survey.

A different response pattern was observed for those consumers whose hours increased as a result of their most recent assessment, compared with those whose hours went down. Consumers whose hours went up tended to report a change in their health as the reason they were authorized for more hours, while those whose hours went down tended to cite a change in the program rules. This effect was first observed in the 2010 survey and was noted again in the 2012 survey. (The pattern is illustrated in Figure 1.1 below.)

- Consumers whose hours went up tended more often to report a change in health situation as the primary reason for the change (83.3% of those experiencing an increase versus 5.6% of those experiencing a decrease).
- Consumers whose hours went down were more likely to report a change in the program's rules as the reason for the change (51.4% of those experiencing a decrease versus 3.4% of those experiencing an increase).
- Consumers whose hours went down tended more often to report that they were not given a reason for the change (21.5% of those experiencing a decrease vs. 5.0% of those experiencing an increase).

Figure 1.1. Question 2C: What was the main reason you were given for the change in your hours? (consumers whose hours went up vs. consumers whose hours went down)



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 290 write-in

responses²; the two most common answers written in were some variation of “program rules changed” or “health situation changed.”

The most common theme cited by consumers to explain the changes to their hours continues to relate to mandated across-the-board cuts, State budget limitations, and the poor economy. One consumer wrote, *“New state law. California Department of Social Services said they must reduce all IHSS recipients total authorized monthly hours by 3.6 percent. A new state law (section 12301.06 of the Welfare and Institutions Code) is supposed to remain in effect until June 30, 2012. July 1, 2012 total hours will go back to full authorized services level.”* Another consumer was more succinct: *“Because of state budget cuts.”*

The next most common theme in Consumer responses was discussion of specific changes in their health condition or level of ability that gave rise to a change in hours. A typical response from this category was given by this Consumer, *“The principal motive was that I was in the hospital for several weeks, I was operated for a hernia. They took out part of my colon and now I have to check my blood weekly. Thank you to those who help us with this program, may god bless you.”* Another Consumer explained, *“Because my health is delicate I cannot do anything anymore, I need help for everything.”*

Some Consumers were unsure why their hours had changed, or could not remember the reason they were given. One Consumer wrote, *“I don't know why they took hours away. I just started receiving less hours since about a month ago and I would like them to return the hours they took because I really need them. Thank you.”*

A small number of Consumers reported that their hours had changed due to program regulations regarding spouses as providers. The following response was typical, *“Because my wife is my provider. They took away 20 hrs, Before I had 43.9 hrs, because somebody else was my provider before. Because she is my wife they didn't want to give me more hours.”*

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 sizeable majority of Consumers indicated their hours are about right. Further, the responses show this view is consistently held 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% of Consumers reported receiving too many hours.

² It was common for Consumers who did not mark “some other reason” to offer write-in comments.

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

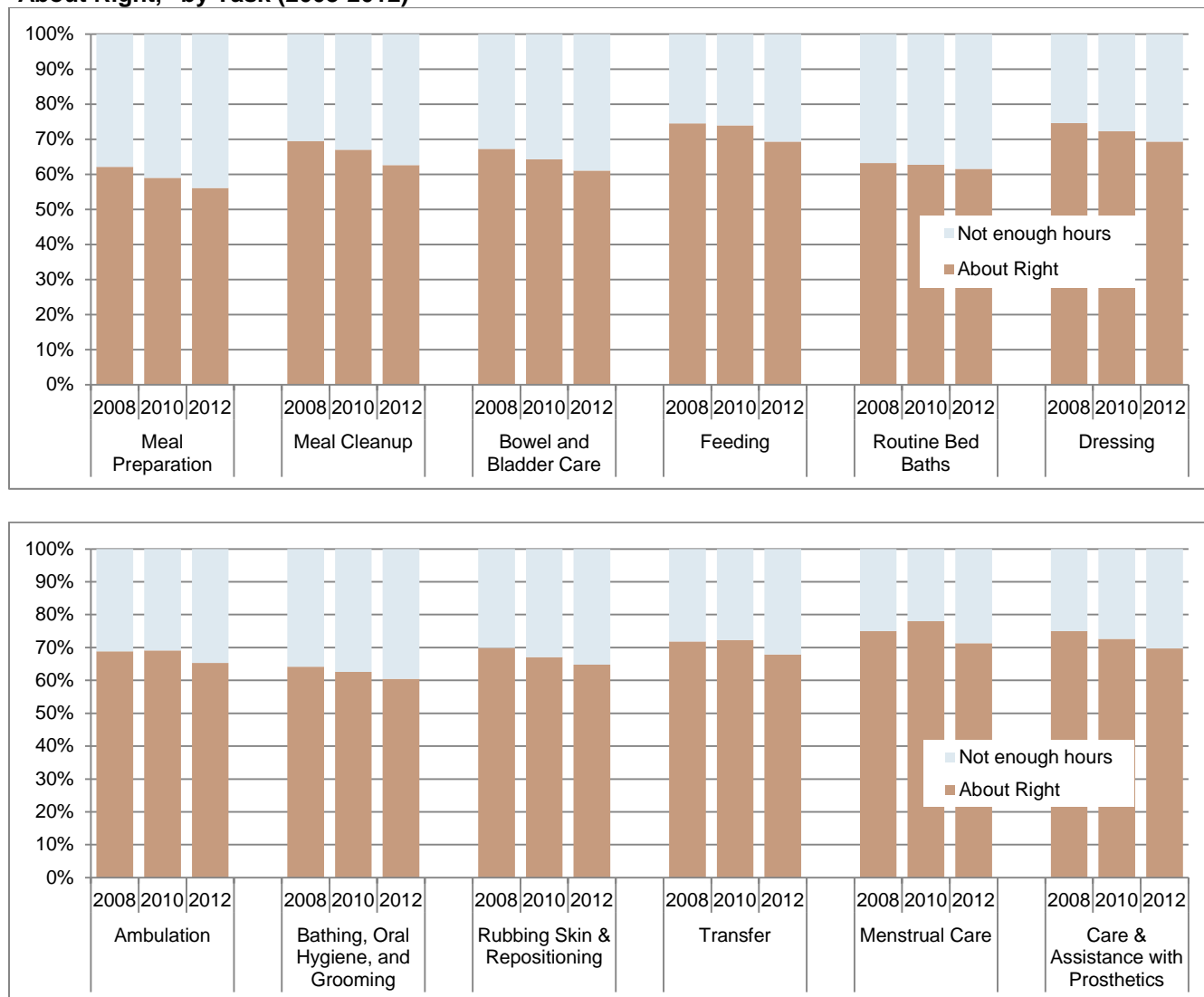
		Not enough hours		Hours are about right		Too many hours		Total	
		Count	Percent	Count	Percent	Count	Percent	Count	Percent
Meal Preparation	2008	223	37.8%	366	62.0%	1	0.2%	590	100.0%
	2010	1,187	40.9%	1,709	58.9%	6	0.2%	2,902	100.0%
	2012	839	43.6%	1,073	55.8%	11	0.6%	1,923	100.0%
Meal Cleanup	2008	178	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%
	2012	709	37.2%	1,187	62.3%	10	0.5%	1,906	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%
	2012	482	38.7%	755	60.6%	9	0.7%	1,246	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%
	2012	366	30.6%	825	68.9%	6	0.5%	1,197	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%
	2012	462	38.3%	738	61.1%	7	0.6%	1,207	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%
	2012	547	30.6%	1,236	69.1%	7	0.4%	1,790	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%
	2012	529	34.5%	998	65.1%	5	0.3%	1,532	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%
	2012	733	39.3%	1,120	60.1%	12	0.6%	1,865	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%
	2012	458	35.1%	843	64.6%	4	0.3%	1,305	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%
	2012	393	31.9%	831	67.5%	7	0.6%	1,231	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%
	2012	119	28.4%	296	70.6%	4	1.0%	419	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%
	2012	307	29.9%	708	69.0%	11	1.1%	1,026	100.0%

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

Looking across results from the current 2012 Consumer Survey and its two past administrations, it is apparent that the proportion of Consumers who report that their hours are “about right”—on a task-wise basis—has declined slightly. This decline is visible below in Figure 1.2.

It is important to note that this measure represents perceptions only, but this trend is consistent with an overall climate of budget shortfalls and service reductions.

Figure 1.2. Question 3: Percentage of Consumers Reporting that Hours Are “Not Enough,” or “About Right,” by Task (2008-2012)

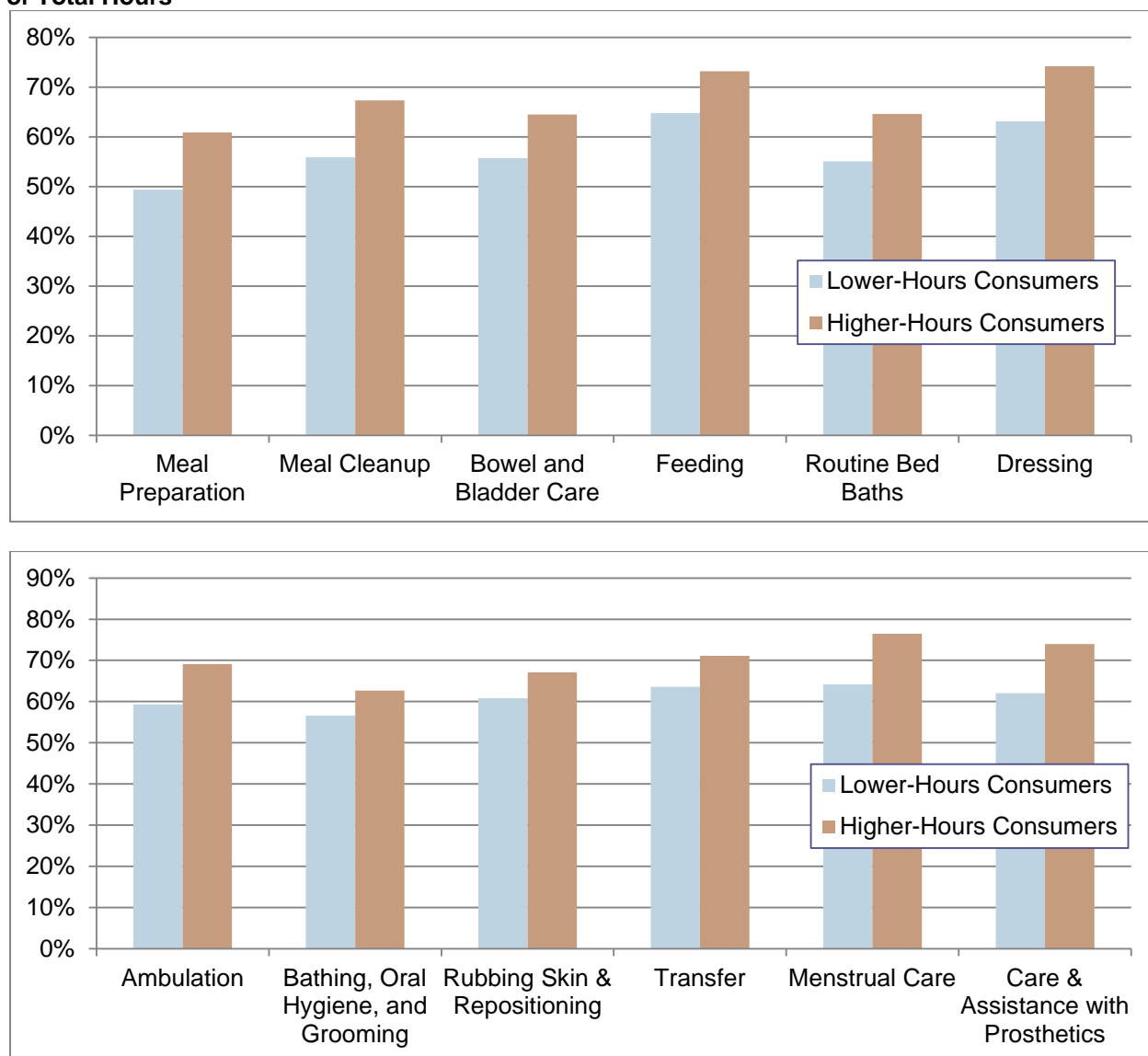


Note: Less than 1% of Consumers believed their hours were “too many.” Consumers reporting “too many” hours are not shown in Figure 1.3.

Consumers vary widely in their authorized level of IHSS service, from those who receive minimal assistance with a few tasks to those who require extensive care and receive a greater number of hours across many tasks.

To determine whether Consumer satisfaction with hours varied with level of service, respondents were divided into lower-hours and higher-hours groups. This division was based on whether a respondent's total authorized hours fell above or below the median number of total authorized hours for all respondents. Figure 1.3 below shows the proportion of Consumers who reported that their hours were "about right," with lower-hours and higher-hours Consumers shown separately.

Figure 1.3. Question 3: Percentage of Consumers Reporting that Hours are "About Right" by Level of Total Hours



Consistent with both earlier surveys, in the 2012 survey Consumers in the higher-hours group tended to evaluate the hours they receive *more positively* than Consumers in the lower-hours group. This pattern was observed in all 12 task areas. More higher-hours Consumers than lower-hours Consumers reported that their hours are "about right." Data for all 12 tasks is presented below 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

	Lower-Hours Consumers			Higher-Hours Consumers		
	Not enough hours	About right	Too many hours	Not enough hours	About right	Too many hours
Meal Preparation	50.0%	49.4%	.6%	38.6%	60.9%	0.6%
Meal Cleanup	43.4%	55.9%	.7%	32.3%	67.3%	0.3%
Bowel and Bladder Care	43.7%	55.7%	.7%	34.9%	64.5%	0.6%
Feeding	35.0%	64.8%	.2%	26.1%	73.2%	0.6%
Routine Bed Baths	44.5%	55.1%	.4%	34.7%	64.6%	0.6%
Dressing	36.5%	63.1%	.4%	25.3%	74.2%	0.4%
Ambulation	40.5%	59.3%	.2%	30.4%	69.1%	0.5%
Bathing, Oral Hygiene, and Grooming	42.6%	56.6%	.8%	36.6%	62.7%	0.7%
Rubbing Skin & Repositioning	39.2%	60.8%	.0%	32.3%	67.1%	0.6%
Transfer	36.4%	63.6%	.0%	28.2%	71.1%	0.7%
Menstrual Care	35.8%	64.2%	.0%	22.1%	76.5%	1.3%
Care & Assistance with Prosthetics	37.7%	62.0%	.2%	24.5%	74.0%	1.5%

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 all Consumer respondents who reported having asked their county to reconsider their authorized hours increased slightly from 2010 to 2012. Consumer responses to this question, while showing some variability over time, do not show a clear directional trend.

- 29.4% of Consumers reported they requested more hours from the county
- 70.6% 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		2012	
		Count	Percent	Count	Percent	Count	Percent
If you need more hours, did you ask the county to reconsider?	Yes	186	28.6%	774	25.1%	609	29.4%
	No	464	71.4%	2,310	74.9%	1,459	70.6%
Total		650	100.0%	3,084	100.0%	2,068	100.0%

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

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

Among the 29.4 percent of Consumers who requested additional hours from the county, about one-third (33.9%) reported receiving more hours, while about two-thirds (66.1%) reported not receiving more hours (see Table 1.8). Across the three survey administrations, consumers are reporting proportionally fewer requests for additional time being granted.

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

		2008		2010		2012	
		Count	Percent	Count	Percent	Count	Percent
When you asked the county to reconsider, what happened?	I received more hours	86	45.5%	328	40.2%	208	33.9%
	I did not receive more hours	103	54.5%	488	59.8%	406	66.1%
Total		189	100.0%	816	100.0%	614	100.0%

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

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

Write-in responses were provided by 489 Consumers, detailing the reasons given by the county for its decision to grant or deny the Consumer's request for additional hours.

The most commonly reported theme again related to State budget cuts, changes in law (such as the enactment of 3.6% across-the-board reductions), and the poor economy. One Consumer put it this way, *"They said that the economy was bad and the county did not have funds to give more hours and they decreased my hours."* Some Consumers expressed frustration that their hours were being reduced despite their considerable need, *"The laws had changed and instead of increasing hours, they reduced them without taking into consideration the necessities I have."*

The next most common theme mentioned by Consumers was that they had received no answer from the county, or that they were still waiting for a response. A typical Consumer wrote, *"Last year we asked for more hours, stopped by the county office, same answer—wait. We are still waiting for an answer from the county. I need more help and more hours. I am in a wheelchair now, I can't help myself now."* Also included in this group were Consumers who reported that they were not given a reason for the county's decision. One such Consumer commented, *"They gave me hours for some of the things but not for all. I did not receive a reason for why!"*

As in both past survey administrations, a number of Consumers reported difficulty getting in touch with their social workers in the 2012 survey. Some were dismayed because their phone calls to the county workers went unreturned. One Consumer noted, *"Social worker never responded to my call neither did his supervisor."* Another frustrated Consumer reported, *"She [social worker] has yet to return my reassessment forms or a phone call. Every time I call she never returns calls."* Difficulty reaching social

workers by phone and lapses in follow-up on Consumer phone messages is a considerable source of frustration for many Consumers. Similar frustrations were reported by Consumers at both earlier administration of this survey.

The next most common theme reported involved changes to the Consumer's health situation. A typical response read, *"The decision to change my hours was made by the social worker, because she saw that it was much needed, with this new disease in my body."* Many Consumers went into detail about their specific physical limitations and ailments that necessitated a change in their authorized hours.

Finally, a smaller but not insignificant number of Consumers touched again on the theme of regulations governing spouses as providers. Typically, this was to note that their request for additional hours was denied because their spouse provider was not eligible for compensation for certain services. One Consumer wrote, *"Since my caregiver is my spouse a lot of things are expected for her to do and are not covered with hours."*

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

As in past survey administrations, it was rare for Consumers to report having filed a request for a fair hearing. Only 4.1 percent of all Consumer respondents reported filing a request for a fair hearing. It is worth noting that although roughly 30 to 40 percent of Consumers reported that their hours were "not enough" (depending on the task), and more than one-quarter (29.4%) reported asking their county for more hours, only a much smaller share of respondents (4.1%) reported filing an appeal request with the State Hearings Division.

It is not clear why the proportion of Consumers who chose to pursue a fair hearing was small compared to those who reported inadequate hours and those who sought additional hours from the counties. Several possible explanations are suggested in the write-in responses to Question 5B below.

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

		2008		2010		2012	
		Count	Percent	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%	82	4.1%
	No	592	96.3%	2,810	97.2%	1,896	95.9%
Total		615	100.0%	2,892	100.0%	1,978	100.0%

Note: Due to the small number of Consumers who reported having filed a request for a fair hearing, caution is warranted in drawing conclusions from any apparent changes or trends in these data. Percentages may not sum to 100 percent due to rounding.

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

Consistent with both earlier administrations of the survey, the most commonly-reported outcome of a fair hearing request was that the hearing had not yet taken place. Because so few Consumers reported filing a request for a hearing, and because many of those who did file were still awaiting their hearing date, there is not a great deal of data from which to draw conclusions concerning Consumer experiences with the fair hearing process.

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

		2008		2010		2012	
		Count	Percent	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%	28	36.4%
	The county and I agreed, and I withdrew my hearing request	0	0%	11	12.5%	10	13.0%
	The judge gave me the hours I need	4	19.0%	19	21.6%	6	7.8%
	The judge gave me more hours, but not as many as I need	2	9.5%	6	6.8%	9	11.7%
	The judge agreed with the county	1	4.8%	6	6.8%	7	9.1%
	I had a hearing and I am waiting for a decision	2	9.5%	3	3.4%	2	2.6%
	Some other outcome	4	19.0%	6	6.8%	15	19.5%
Total		21	100.0%	88	100.0%	77	100.0%

Note: Due to the small number of Consumers who reported having filed a request for a fair hearing, caution is warranted in drawing conclusions from any apparent changes or trends in these data. 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 70 responses to this question.

The most common response theme was for Consumers to report that they had not actually requested a fair hearing, or had not requested one yet. A number of Consumers also reported that they were unaware that the fair hearing process was available to them or that they did not know what steps to take in order to file a request.

A number of Consumers indicated that they would like to file an appeal, but that their situation makes it a challenge for them to do so. One Consumer explained, *"I would like to file an appeal, but because I must tend to my wife 24 hours a day and I cannot appear in court."* Another Consumer wrote, *"I don't like being involved in things that require me to travel, wait, speak too much for my health. I'm satisfied like this even if they take my hours."*

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

In the 2012 survey, four out of five (81.3%) 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. There has been little change in Consumer responses to this question across the three survey administrations.

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

		2008		2010		2012	
		Count	Percent	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%	1,743	81.3%
	No	129	19.0%	537	16.8%	400	18.7%
Total		678	100.0%	3,190	100.0%	2,143	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 (72.3%) of Consumers reported in the 2012 survey that their social worker fully explained the program to them and answered all their questions. Consumer responses to this question have remained stable across all three administrations of the survey.

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		2012	
		Count	Percent	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%	1,499	72.3%
	The social worker explained most of the program and answered most of my questions	115	18.3%	581	19.2%	403	19.4%
	The social worker explained only parts of the program and didn't answer many of my questions	35	5.6%	132	4.4%	111	5.4%
	The social worker did not explain the program and didn't answer most of my questions	25	4.0%	81	2.7%	59	2.8%
Total		630	100.0%	3,022	100.0%	2,072	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 number of years Consumers reported receiving IHSS services was 4.2 years.³ This number increased from 3.4 years in the 2010 survey and 3.0 years in the 2008 survey.

In the 2012 survey:

- The upper 25% reported more than 8.0 years in the program
- The middle 50% reported between 2.0 years and 8.0 years in the program
- The lower 25% reported less than 2.0 years in the program

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

The median reported number of authorized hours was 66.0 hours per month.⁴ This represents an increase from 60.0 in the 2010 survey, but a slight decrease from 68.3 in the 2008 administration.

³ Consumer hours are self-reported and were not cross-checked against other data sources, such as the Case Management, Information, and Payrolling System (CMIPS) database.

⁴ Ibid.

In the 2012 survey:

- The upper 25% of Consumers reported more than 93.0 authorized hours per month
- The middle 50% of Consumers reported between 43.0 and 93.0 authorized hours per month
- The lower 25% reported less than 43.0 authorized hours per month

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

As in 2010, Consumers were nearly unanimous in their belief that the IHSS program plays a very important role in maintaining their health and well-being.

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

		2008		2010		2012	
		Count	Percent	Count	Percent	Count	Percent
Is your IHSS program important for maintaining your health and well being?	Very important	--	--	3,206	97.4%	2,152	97.6%
	Somewhat important	--	--	77	2.3%	47	2.1%
	Not important	--	--	7	0.2%	6	0.3%
Total		--	--	3,290	100.0%	2,205	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?

Despite concerns with reduced hours noted elsewhere in the survey responses, nearly nine out of 10 (89.1%) Consumers reported that the IHSS program currently meets their needs. This measure of Consumer satisfaction with their IHSS services has been consistently high across all three survey administrations. Again in 2012 as in past administrations, satisfaction was equally high among both higher-hours and lower-hours Consumers.

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

		2008		2010		2012	
		Count	Percent	Count	Percent	Count	Percent
Does the IHSS program meet your needs?	Yes	547	81.4%	2,932	91.0%	1,924	89.1%
	No	125	18.6%	289	9.0%	236	10.9%
Total		672	100.0%	3,221	100.0%	2,160	100.0%

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

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 could be done to better meet Consumers' needs. There were 1,252 comments offered in response to this question. The following discussion themes are presented in order from most to least frequently mentioned.⁵

Requests for Additional Hours and Services—485 Comments

Consumer comments varied from brief statements such as, *"I need more hours,"* to lengthy and detailed descriptions of specific medical conditions that required additional care. Often, requests for additional hours and services were paired with expressions of gratitude for the program. One Consumer wrote, *"I am very grateful for the IHSS program because it allows me to receive medical/personal assistance, without having to be confined to a 'rest home', which would cost the state a lot more money. While the program does meet my needs, I believe I should be eligible for more than just 5 hours daily. I am totally dependent on my workers, who put in a lot more hours than they are paid for. My doctor has confirmed that I need care 24 hours a day. I do not feel that I am a burden to the state, or taxpayers, because I had worked all my life, paying taxes and contributing to society. More hours of assistance would be greatly appreciated."*

Additional time allowances for transportation to medical appointments and assistance during medical appointments was a common request. Some Consumers noted that their providers play an important role in their visits to the doctor. One respondent noted, *"I think IHSS would help me more if they understood that certain operations/procedures require you to have someone with you for 4-6 hours after and that those hours are not being calculated. Also, I wish my caregiver could get paid for me to have hours for being in the doctor's office. I need someone to be there to advocate for me. Someone to write down what is needed from me from the doctor and what has been said. Also, as a live in caregiver my caregiver knows me best and helps me get across things I've forgotten or am too medicated to repeat to the doctor. I think all recipients would benefit from this. Thank you for your time and for this survey. I'm very grateful to have IHSS, without it I would be in a home or suffering from more than pain."*

Some Consumers who requested more hours stressed the importance of their providers' presence as a source of companionship. One respondent noted, *"If it was possible, I would like more hours because every day I feel worse, more alone, and more useless. There are just too many hours that I have to be alone. Thank you for your attention. May God bless you."*

⁵ Total number of Consumer comments may not balance with sum total of comments under the thematic subheadings. This is because some Consumer comments may reflect more than one content theme.

Satisfaction, Gratitude, and Praise—456 Comments

Overall, Consumers reported a high level of satisfaction with IHSS services statewide. In addition to numerous brief comments such as, *“Thank you, everything is great!”* many Consumers went into detail about the many ways that their IHSS services improve their health, safety, happiness, and independence. The following Consumer comments are illustrative of this theme:

“Your program allows me to stay in my in my own home! I don’t how you could do more than that!”

“I believe the IHSS is a great help to individuals like me and I want to thank the state of CA for having such a program. Thank you.”

“I’d like to say thank you very much because it has helped my severely disabled husband to live with me and he doesn’t need to live in nursing home.”

“I feel safer at home because of the IHSS program.”

“This program helps me because I have several illnesses that keep me from doing my things. I cannot maintain health. I need help dressing, making something to eat, washing my clothes, and other things. Because of my illnesses I cannot do anything. I am happy with this program so I can have a healthier life.”

Many Consumers stressed that their IHSS services are directly responsible for enabling them to remain at home, and avoiding an institutional placement. Consider the following Consumer’s remarks:

“I am so grateful for the IHSS program, I could not live independently without it. I spent mid 2001 - mid 2007 in assisted living - in my attempt to find a situation where I could live independently. I contacted IHSS and a rep. came and explained the program and that I would be eligible but must first move out. The person who helped me became my IHSS aid and with IHSS aid I have been able to live in my own home. I so appreciate the opportunity to live free of assisted living. To have my own mobile home and independence is possible only with this help.”

It was also common for Consumers to specifically praise their providers and social workers for the quality of their services. This comment was typical, *“Having this program is a blessing from god. When one gets to be this old age it is very difficult and very confusing having to understand the necessities of life. The people that help us are very efficient. I am very happy with them. Thank you IHSS for all of your services.”*

IHSS Program Cuts, California State Budget, and Economy—120 Comments

Consumers often made reference to recent mandated reductions in hours in the IHSS Program, to the tenuous condition of California’s finances, and to statewide economic conditions that they perceived to be generally poor. A number of respondents indicated that the threat of future reductions in authorized hours was a source of anxiety. One

Consumer wrote, *"To know that we didn't live under the "sword of Damocles" of budget cuts. IHSS does an excellent job, in my opinion."*

Other Consumers were concerned that the entire program might be discontinued. One such respondent commented, *"To keep the program. Because it's a lot of help for us, as this program helps people of old age like me. I am 83 years old and if it wasn't for this program, we seniors wouldn't know what to do. I am very grateful; I thank the state for helping us to live a better life."*

Providers—101 Comments

As in past administrations of the Consumer Survey, respondents emphasized the important role that their providers play in their lives. In the current survey, two themes emerged as particularly important: access to providers, and timeliness of provider timesheet processing / paycheck issuance. One Consumer described the difficulty of locating a provider, *"Better system to find care providers. This system takes a long time, often weeks to find help. I've had better luck with Craig's list. One of my providers works for [care coordinating agency]. [Agency's] Consumers won't go 24 hours without help. With IHSS I've gone quite a few days without help."*

Another Consumer remarked that the process of recruiting a suitable provider has become more difficult than in the past: *"It has always been hard and time consuming to recruit but I have been lucky to find the right people in the past. However, it has gotten harder lately, especially with the Justice Department background check and the approximately six weeks time for it to go through. Currently I work with two aides, I did have three, but my third aide passed away suddenly last October and I have not been able to find a suitable replacement. The last time I recruited was eight years ago, and since then it seems to have gotten harder."*

Alongside provider recruitment issues, Consumers also advocated for higher provider wages, health benefits for providers, and provider training. The following Consumer comment brings together several of these themes:

"Better and thorough screening of care providers. Increase minimum wage. Create a software program to be able to have time sheets submitted online through internet. Have a software program created so that once you submit your timesheet online on the 1st and 16th payment goes directly to checking or savings account. More info provided for resources; support groups for both recipient and provider, provider training, updated provider lists if need new or additional providers."

Communication and Language—99 Comments

As in 2008 and again in 2010, Consumers continue to report major frustration and difficulty reaching social workers and IHSS administrative staff by phone. Busy phone lines and delays or failures to return messages were frequently reported. A frustrated Consumer wrote, *"Social workers and provider clerks should attend their phones and get back to us in a timely manner."*

A number of Consumers requested that services be made available more readily in their preferred languages. Specific languages mentioned included Spanish, Japanese, Korean, and Cantonese.

Assessment—56 Comments

A number of Consumers commented that the current assessment process isn't sufficiently flexible to take into account the unique needs of individuals. One such Consumer wrote:

"A better understanding that no two people are alike and it takes longer for some people. Special circumstances. We are not all "cookie cutter" cases. There are special needs not addressed for bariatric clients. They don't take into consideration people with mental issues can cause workers to need more time. Ex: Someone with panic attacks could take a lot longer because they have to stop and calm down before they can finish dressing and taking a shower. Also people with breathing issues or in severe pain—it takes longer to move around. They have to take their time. Also afraid of falling."

Some Consumers whose primary language is not English wrote in to request services in their preferred language. A typical comment read, *"Social worker who speaks Cantonese to help me understand. I don't really know how many hours are given for each activity. We don't think of it that way. We just do what is needed to take care of my mother."*

Spouse Provider—43 Comments

Although in the final tally of Consumer comments the theme of spouses as providers was not mentioned as frequently as a number of other themes, it was without doubt an area that Consumers expressed strong opinions. A typical comment read, *"I feel that it's unfair to a caregiver to get allowed WAY less hours than others due to the fact that they are a spouse... I've been told by many disabled people whose caregivers aren't related and get A LOT more hours... I once was told by a social worker when I expressed this issue it was due to the fact that the spouse is considered to be his/their responsibility, I felt that was absurd and ridiculous."*

Consumers pointed out that many spouse providers were unable to seek outside employment—indeed many had given up their careers—due to their caregiving responsibilities. Other Consumers noted that their spouse was their preferred choice as caregiver, but that the regulations surrounding spouse providers made this choice a difficult one:

“The reason why I am not able to use basic services such as meal preparation, meal cleanup, or dressing is because my provider is my wife. If caregiver is one's spouse those services are not considered as "care". I was recommended by social worker to let my wife work outside and hire provider from third party; however, I prefer to receive care from my wife, my wife is willing to take care of me. My wife is taking care of me 24 hours a day seven days a week, so, even 160 hours per month, if my wife could receive salary, it would be very helpful for our life.”

Social Workers—35 Comments

Consumers often mentioned that they would appreciate more frequent contact with their social worker. Respondents emphasized the importance of being able to reach their social worker by phone when necessary, as well as the need for timely return phone calls.

Other Consumers reported satisfaction with the service they had received from their social workers. One Consumer wrote, *“They're helping me very nicely and my social worker is very helpful. He calls me back right away. He's really friendly.”*

Outreach and Referral—23 Comments

Some Consumers provided constructive suggestions for improving program knowledge, connecting individuals to needed services, and building a more positive relationship between IHSS administration and the Consumer community. The following Consumer comments contain such suggestions:

“Possibly have discussions or meetings with representatives or central office when there are new changes, and services available to the Consumer. Expose more information and familiarity of the program for the Consumer. More information, better program and use of the services that the central regional office provides.”

“Know my limitations and goals. Have a user friendly website for recipients. Have a resource fair once a year network with other agencies like Independent Center. Give recipients how-to DVDs/books/ CDs.”

“Should have programs for those who live alone and have no family - like a buddy companion program. To alleviate loneliness. Resource information fair once in awhile. Political types, non-profit, business/commerce, education, and social services. Open house/ mixer to learn what's going on in the IHSS world. Disabled community would like to visit administrative offices--establish a personal, tighter bond. Disability sensitivity training for IHSS staff--teach folks what it's like to live in the lifestyle of a disabled person. Such training could also increase workers' sensitivity for the chronically and terminally ill or those under hospice care. Resources for disabled persons to defend against hate crimes--disabled persons are seen as weak and are often targeted and taken advantage of. We need to know what tools are available to us in order to defend ourselves.”