

ANALYSIS OF STATEWIDE CDSS IN-HOME SUPPORTIVE SERVICES (IHSS) 2008 CONSUMER SURVEY



Prepared for the California Department of Social Services
Adult Programs Division

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ANALYSIS OF STATEWIDE CDSS IN-HOME SUPPORTIVE SERVICES (IHSS) 2008 CONSUMER SURVEY

KEY FINDINGS

- Slightly more than 80% of Consumers* reported that the IHSS program meets their needs, and slightly less than 20% reported that the program does not meet their needs.
- The majority (67.3%) of Consumers who experienced a change in hours at their last assessment report that the change was due to a change in their health situation.
- The majority of Consumers (about 60% to 75% depending on task) feel that their hours are about right, while a minority (about 25% to 40%) feels that their hours are not enough.
- Among the 28.6% of Consumers who requested additional hours from their county, slightly less than half (45.5%) received additional hours, while the remainder did not.
- Few Consumers (3.7%) requested a fair hearing to appeal the number of approved hours.
- The overwhelming majority (90.5%) 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
 - Improved accessibility of social workers
 - Better pay and benefits for providers

*Note: In this report we refer to findings related to "Consumers". The reader should bear in mind that the results we report are based on a random sample of Consumers and not the entire Consumers population.

The CDSS Adult Programs Branch mailed out 6,500 surveys to a random sample of IHSS Consumers on March 14, 2008 and the surveys were mailed back to the California State University/Institute for Social Research (CSUS/ISR). As of May 6, 2008, ISR received 1,018 completed and/or partially completed surveys, of which, 707 are included in the analysis that follows. The 707 responses constitute a statistically valid sample of the IHSS population (please see Appendix A for details on the survey methodology). The ISR analyzed the data and the following are their findings:

FINDINGS

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

Most Consumers¹ (80.3%) found the written materials provided by the IHSS program to be helpful (see Table 1.1).

- 53.5% of Consumers reported that the written materials were very helpful
- 26.8% reported that the materials were somewhat helpful
- 2.2% reported that the materials were not helpful
- 14.7% did not receive written materials
- 2.8% reported receiving written materials in a language that they do not read

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

| | | Count | Percent |
|--|---------------------------------------|-------|---------|
| How helpful are the pamphlets, booklets, and forms that you received about the IHSS program? | Very Helpful | 363 | 53.5% |
| | Somewhat Helpful | 182 | 26.8% |
| | Not Helpful | 15 | 2.2% |
| | I did not receive any | 100 | 14.7% |
| | They were in a language I do not read | 19 | 2.8% |
| Total | | 679 | 100.0% |

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

- 71.1% of Consumers indicated that they had received a reassessment
- 28.9% reported that they had not been reassessed

¹ Note: In this report we refer to findings related to "Consumers". The reader should bear in mind that the results we report are based on a random sample of Consumers and not the entire Consumers population.

Table 1.2: Have you had a reassessment?

| | | Count | Percent |
|------------------------------|-----|-------|---------|
| Have you had a reassessment? | Yes | 466 | 71.1% |
| | No | 189 | 28.9% |
| Total | | 655 | 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 an increase in hours outnumbered those reporting a decrease in hours by about three to one. Slightly more than one-third reported no change in their hours (see Table 1.3).

- 45% reported hours went up (8 hours being the median increase)
- 34.2% reported no change in hours
- 15.3% reported hours went down (12 hours being the median decrease)
- 5.5% did not know if hours were changed

Among Consumers who reported an increase in hours at their last assessment, 8 hours was the median reported increase. Among Consumers who reported a decrease in hours at their last assessment, 12 hours was the median reported decrease.

It should be noted that a great deal of variability was observed in these reported changes, and some of the values reported were very large. This suggests the possibility that the question was not interpreted the same way by all Consumers. Specifically, it is possible that certain Consumers interpreted the question to mean weekly hours, while others interpreted it to mean monthly hours. Thus, while the general finding regarding increases or decreases is likely reliable, caution is urged in interpreting the magnitude of reported changes in hours (both up and down) as a result of the most recent reassessment.

Table 1.3: Did your hours change based on your last reassessment?

| | | Count | Percent |
|--|--|-------|---------|
| Did your hours change based on your last reassessment? | My hours went up by (blank) hours | 214 | 45.0% |
| | My hours went down by (blank) hours | 73 | 15.3% |
| | My hours did not change | 163 | 34.2% |
| | I do not know whether my hours changed | 26 | 5.5% |
| Total | | 476 | 100.0% |

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

By far, the most commonly reported reason given for a change in hours was a change in the Consumers' health situation (see Table 1.4).

- 67.3% reported a change in their health situation
- 5.4% reported a change in their home situation
- 4.2% reported a change in the program rules
- 11.8% reported a change in hours without a reason being given
- 11.3% reported some other reason

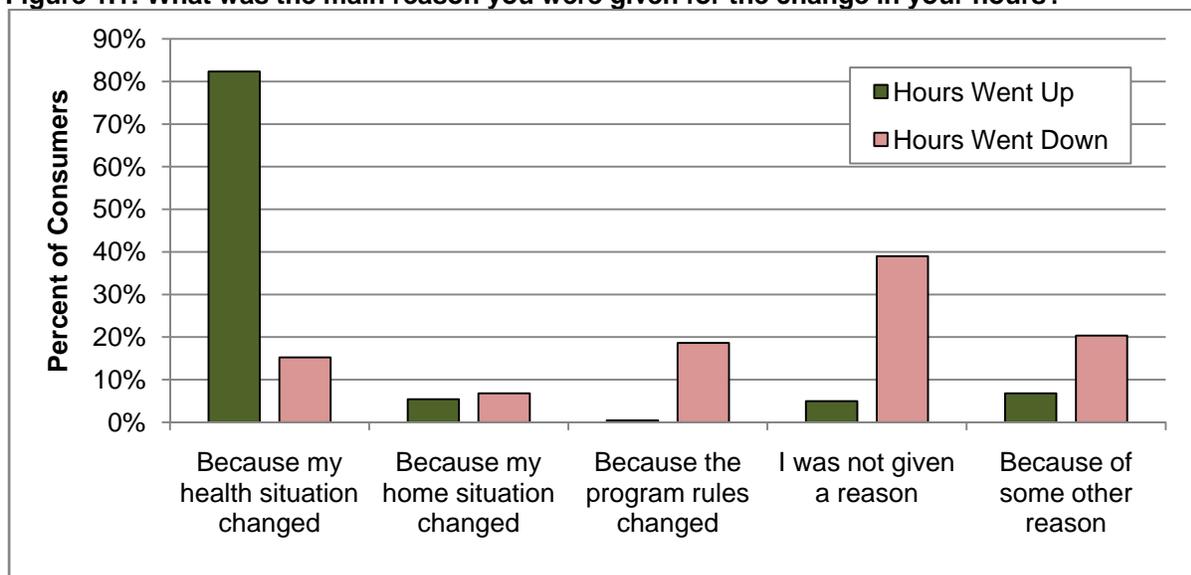
Table 1.4: What was the main reason you were given for the change in your hours?

| | | Count | Percent |
|---|-------------------------------------|-------|---------|
| What was the main reason you were given for the change in your hours? | Because my health situation changed | 239 | 67.3% |
| | Because my home situation changed | 19 | 5.4% |
| | Because the program rules changed | 15 | 4.2% |
| | I was not given a reason | 42 | 11.8% |
| | Because of some other reason | 40 | 11.3% |
| Total | | 355 | 100.0% |

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 1.1.

- Consumers who had an **increase** in hours tended more often to report a change in health situation as the primary reason for the change (82.4% of those experiencing an increase vs. 15.3% of those experiencing a decrease).
- Consumers who had a **decrease** in hours tended to report more often that they were not given a reason for the change (39.0% of those experiencing a decrease vs. 5.0% of those experiencing an increase).
- 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 (18.6% of those experiencing a decrease vs. less than 1% of those experiencing an increase).

Figure 1.1: What was the main reason you were given for the change in your hours?



The survey form provided a write-in space for Consumers who reported that the change in their hours was due to “some other reason.” The large majority of responses described specific physical and health challenges that they are currently facing, often to point out that their overall health is deteriorating and that their need for IHSS services is on the rise. A small number of Consumers reported that changes in their hours were due to administrative issues such as state and program budget cuts or changes in policy.

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:

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).

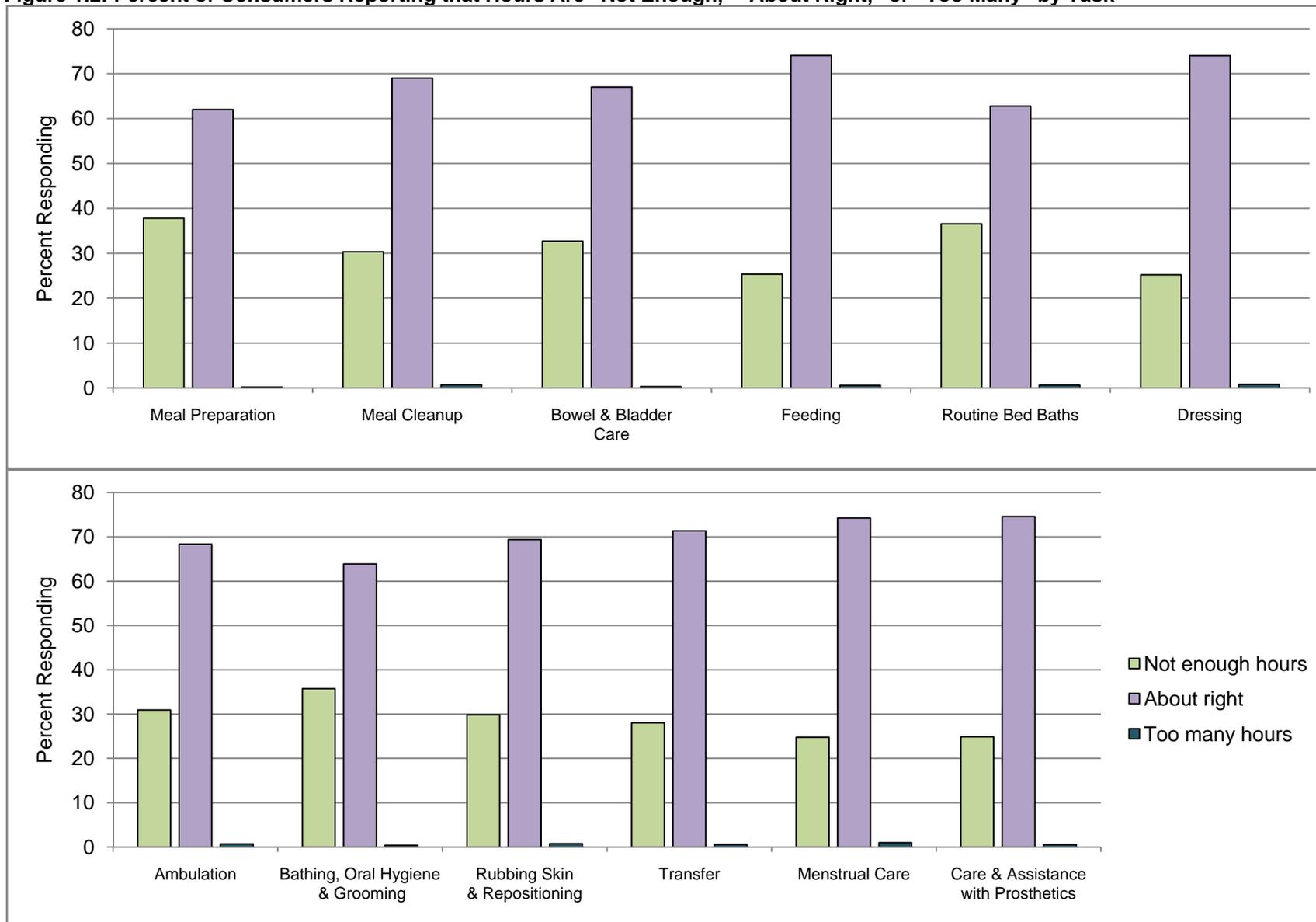
- A majority of Consumers reported that their hours are about right on all twelve tasks, with percentages ranging from a low of 62.0 percent (Meal Preparation) to a high of 74.6 percent (Prosthetics).
- By contrast, 25 to 40 percent of Consumers reported that the hours they receive are not enough across the twelve tasks.
- Less than 1% reported receiving too many hours. (Figure 1.2 illustrates these findings graphically.)

Table 1.5: 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 | % Within Task | Count | % Within Task | Count | % Within Task | Count | % Within Task |
| Meal Preparation | 223 | 37.8% | 366 | 62.0% | 1 | .2% | 590 | 100.0% |
| Meal Cleanup | 178 | 30.3% | 405 | 69.0% | 4 | .7% | 587 | 100.0% |
| Bowel and Bladder Care | 120 | 32.7% | 246 | 67.0% | 1 | .3% | 367 | 100.0% |
| Feeding | 89 | 25.4% | 260 | 74.1% | 2 | .6% | 351 | 100.0% |
| Routine Bed Baths | 113 | 36.6% | 194 | 62.8% | 2 | .6% | 309 | 100.0% |
| Dressing | 129 | 25.2% | 379 | 74.0% | 4 | .8% | 512 | 100.0% |
| Ambulation | 133 | 30.9% | 294 | 68.4% | 3 | .7% | 430 | 100.0% |
| Bathing, Oral Hygiene, and Grooming | 189 | 35.7% | 338 | 63.9% | 2 | .4% | 529 | 100.0% |
| Rubbing Skin & Repositioning | 120 | 29.9% | 279 | 69.4% | 3 | .7% | 402 | 100.0% |
| Transfer | 97 | 28.0% | 247 | 71.4% | 2 | .6% | 346 | 100.0% |
| Menstrual Care | 25 | 24.8% | 75 | 74.3% | 1 | 1.0% | 101 | 100.0% |
| Care & Assistance with Prosthetics | 44 | 24.9% | 132 | 74.6% | 1 | .6% | 177 | 100.0% |

Interestingly, a significant number of Consumers marked either “Not enough hours” or “About right” for all of their tasks, suggesting that some Consumers may evaluate the adequacy of their hours globally rather than making distinctions between tasks.

Figure 1.2: Percent of Consumers Reporting that Hours Are “Not Enough,” “About Right,” or “Too Many” by Task



It should be noted that Consumers with higher levels of total assessed need tended to evaluate the number of hours they receive on certain tasks differently than Consumers with lower levels of total assessed need.

- Specifically, Consumers with **higher** levels of total assessed need tended to evaluate the hours they receive **more positively** than those with **lower** levels of total assessed need in the following task areas:
 - Meal Preparation;
 - Routine Bed Baths;
 - Bathing, Oral Hygiene, and Grooming; and
 - Care and Assistance with Prosthetics (see Table 1.6).

These results were statistically significant, meaning that it's unlikely that the differences observed are due to chance.

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

| | Below Median Total Need | | | Above Median Total Need | | |
|-------------------------------------|-------------------------|-------------|----------------|-------------------------|-------------|----------------|
| | Not enough hours | About right | Too many hours | Not enough hours | About right | Too many hours |
| Meal Preparation | 44.9% | 54.7% | .4% | 31.1% | 68.9% | .0% |
| Meal Cleanup | 34.9% | 64.4% | .7% | 26.1% | 73.3% | .7% |
| Bowel and Bladder Care | 30.9% | 68.3% | .7% | 33.8% | 66.2% | .0% |
| Feeding | 30.8% | 68.5% | .7% | 21.6% | 77.9% | .5% |
| Routine Bed Baths | 45.1% | 54.9% | .0% | 31.6% | 67.3% | 1.0% |
| Dressing | 29.1% | 70.0% | .9% | 22.3% | 77.1% | .7% |
| Ambulation | 34.7% | 64.7% | .6% | 28.5% | 70.7% | .8% |
| Bathing, Oral Hygiene, and Grooming | 41.4% | 57.8% | .9% | 31.3% | 68.7% | .0% |
| Rubbing Skin & Repositioning | 34.8% | 64.6% | .6% | 26.5% | 72.7% | .8% |
| Transfer | 33.6% | 65.8% | .7% | 24.0% | 75.5% | .5% |
| Menstrual Care | 27.5% | 72.5% | .0% | 23.0% | 75.4% | 1.6% |
| Care & Assistance with Prosthetics | 34.8% | 65.2% | .0% | 18.5% | 80.6% | .9% |

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

- 28.6% of Consumers reported they requested more hours from the county; and
- 71.4% reported they did not request more hours.

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

| | | Count | Percent |
|---|-----|-------|---------|
| If you need more hours, did you ask the county to reconsider? | Yes | 186 | 28.6% |
| | No | 464 | 71.4% |
| Total | | 650 | 100.0% |

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

Among the 28.6 percent of Consumers who requested additional hours from the county, slightly less than half (45.5%) reported receiving more hours, while slightly more than half (54.5%) reported not receiving more hours (see Table 1.8).

Table 1.8: When you asked the county to reconsider, what happened?

| | | Count | Percent |
|---|------------------------------|-------|---------|
| When you asked the county to reconsider, what happened? | I received more hours | 86 | 45.5% |
| | I did not receive more hours | 103 | 54.5% |
| Total | | 189 | 100.0% |

Question 4C: Describe the reason you were given by the county for its decision to grant or deny your request for additional hours:

A write-in space was provided. The most frequent use of this space on the survey was to indicate that no reason was given or that the Consumers had not been able to contact their social worker to request more hours.

Consumers reported difficulty reaching their social workers by telephone, and often noted that their phone messages were not returned. Many Consumers who contacted the ISR research team through the toll-free telephone line also reported frustration and difficulty trying to reach their social workers by telephone, again reporting that telephone messages often go unreturned.

Among those who were granted additional hours, it was common for the Consumers to provide detail about the specific physical and health challenges that made the additional hours necessary.

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

The first detail to notice with respect to Consumers' reports of their participation in the fair hearing process is that it was relatively uncommon for Consumers to file a judicial appeal (see Table 1.9).

- Only 23 Consumers (3.7%) reported filing an appeal for judicial review. When compared with the number of Consumers (186) who asked their county for more hours, it is clear that to file a judicial appeal is a step that Consumers were less likely to take.

- It is also interesting to note that 103 Consumers requested additional hours from their county and were denied, while only 23 Consumers filed a request for a fair hearing.
 - It appears that only a minority—in this sample, about 20%—of Consumers who unsuccessfully petitioned for additional hours from the county took the additional step of filing for a fair hearing.

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

| | | Count | Percent |
|--|-----|-------|---------|
| Did you request a fair hearing to appeal the amount of hours approved by your social worker? | Yes | 23 | 3.7% |
| | No | 592 | 96.3% |
| Total | | 615 | 100.0% |

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

Due to the relatively small number of Consumers who filed an appeal, caution is urged in generalizing the pattern of outcomes observed here to the overall IHSS population (see Table 1.10).

- 38.1% of Consumers who filed a request for a fair hearing, reported that the hearing had not yet taken place
- 19% reported that they were awarded the hours they need;
- 9.5% reported that they were awarded some additional hours, but not as many as they need
- 4.8% (one Consumers) reported that the judge upheld the county’s decision
- 9.5 % reported that they had a hearing and are awaiting the decision
- 19.0 reported some other reason

A write-in space was provided on the survey for Consumers to further describe the outcome of their request for judicial review. Several Consumers indicated that they did not know what a fair hearing was, or that they didn’t know that they were entitled to request a fair hearing. Several Consumers mentioned that they cannot get away from their homes to attend a hearing. One Consumer described the hearing she’d been granted with a judge whom she described as very empathetic and concerned for her well-being.

Table 1.10: When you requested a fair hearing, what happened?

| | | Count | Percent |
|---|--|-------|---------|
| When you requested a fair hearing, what happened? | The hearing has not taken place yet | 8 | 38.1% |
| | The judge gave me the hours I need | 4 | 19.0% |
| | The judge gave me more hours, but not as many as I need | 2 | 9.5% |
| | The judge agreed with the county I had a hearing and I am waiting for a decision | 2 | 9.5% |
| | Some other reason | 4 | 19.0% |
| Total | | 21 | 100.0% |

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

The large majority (81%) 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 (see Table 1.11).

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

| | | Count | Percent |
|--|-----|-------|---------|
| Do you know who to contact if your provider does not show up as scheduled? | Yes | 549 | 81.0% |
| | No | 129 | 19.0% |
| Total | | 678 | 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 (72.2%) of Consumers reported that their social worker fully explained the program to them and answered all their questions (see Table 1.12).

- An additional 18.3% reported that their social worker explained most of the program and answered most of their questions
- 5.6% reported that their social worker only explained part of the program and didn't answer many questions
- 4.0% reported that their social worker did not adequately explain the program or adequately answer their questions

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

| | | 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% |
| | The social worker explained most of the program and answered most of my questions | 115 | 18.3% |
| | The social worker explained only parts of the program and didn't answer many of my questions | 35 | 5.6% |
| | The social worker did not explain the program and didn't answer most of my questions | 25 | 4.0% |
| Total | | 630 | 100.0% |

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 3.0 years.

- The upper 25% reported more than 6.0 years in the program
- The middle 50% reported between 1.3 years and 6.0 years of tenure
- The lower 25% reported less than 1.3 years of tenure

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 68.3.

- The upper 25% of Consumers reported more than 98.0 authorized hours per month
- The middle 50% of Consumers reported between 45.2 and 98.0 authorized hours per month
- The lower 25% reported less than 45.2 authorized hours per month

Question 10: Does the IHSS program meet your needs?

The large majority (81.4%) of Consumers report overall that the IHSS program currently meets their needs and this was true for Consumers at both higher levels and lower levels of need (see Table 1.13).

Table 1.13: Does the IHSS program meet your needs?

| | | Count | Percent |
|--|-----|-------|---------|
| Does the IHSS program meet your needs? | Yes | 547 | 81.4% |
| | No | 125 | 18.6% |
| Total | | 672 | 100.0% |

Question 11: What would help the IHSS program better meet your needs?

The final question on the survey was open-ended. Open-ended questions are often useful for uncovering information and opinions that might not otherwise be shared. This question was included immediately following the global question about whether or not the IHSS program meets the Consumers’ needs, and was intended to provide a forum for each Consumers respondent to expand on his or her overall impression of the program. In the discussion that follows common themes are discussed, in order of their frequency of mention, beginning with those themes that came up most often.

Praise and Gratitude for the Program

Praise and gratitude for the program, social workers, and providers were the most common themes in the responses. Many of these responses were brief, simple comments such as, *“At this time I get all the help I need. Thank you!”* Other Consumers expressed themselves more strongly, *“I am extremely happy with my IHSS worker. This program makes my life safer, easier, and happier. Without it I would be in a nursing home. Thank you!”* Many Consumers reported that the IHSS program has been a great help to them in dealing with their challenging health situations, and that they are grateful for the help it provides. Some of these Consumers also asked that services be continued as they are and not changed or taken away.

Additional Hours and Services

A need for additional hours and services was the second most commonly expressed theme. A large proportion of Consumers requested additional hours so that their providers could spend more compensated time assisting them. A typical response: *“I need more service. The IHSS hours I receive are not enough to cover my everyday needs. I need more service hours. I can’t do a lot of household chores, like buying groceries, cooking, cleaning, and visiting the doctor.”* The majority of Consumers who reported needing more hours mentioned specific medical or physical conditions that were driving the need for more help.

Among Consumers who reported the need for additional help with specific tasks, some of the most commonly mentioned tasks were transportation to and from doctors’ appointments, food shopping and other errands outside the home. One typical Consumer wrote: *“I need someone who can drive. I need this person once in the morning and once in the afternoon. I need someone...to take me to the hospital when I’m sick, and check me out of the hospital. When both I and my spouse are sick, I need the provider to take us to the hospital.”*

Mention was frequently made of the high cost of gas, and that providers are not compensated adequately or at all for transporting the Consumers by car. Meal Preparation, Meal Cleanup, assistance with bathing and showers, and help with the laundry were also mentioned.

Accessibility of Social Workers

The third most commonly expressed theme was the difficulty Consumers have experienced trying to contact their social workers. Many Consumers reported that they were unable to reach their social workers by telephone and that their telephone messages were often unreturned or were not returned promptly. Several Consumers reported that they were also unable to reach their social worker's supervisor. Consumers reported a great deal of frustration arising from the difficulty getting in touch with their social workers and frequently requested that their social workers be more responsive to their telephone calls.

Better Pay and Benefits for Providers

Among Consumers who reported the need for additional hours was a subgroup who mentioned that their provider is currently working additional unpaid hours to help meet the Consumers' needs that are not being met within the authorized hours. Visits to medical appointments, trips to the grocery store, and other transportation-related tasks were often associated with uncompensated services being rendered by providers. A number of Consumers advocated for higher wages and benefits (sick leave in particular) for their providers. Several Consumers pointed out that their providers' paychecks are routinely delivered late and requested that the paychecks be made available on time each month.

Family Members as Providers

A number of Consumers felt that the way IHSS deal with spouses as care providers is unfair. One Consumer wrote: *"[IHSS] should pay the spouse for the same services as for those who are single. The spouse still cannot work outside [the home] because of all the help needed. She's penalized if she gets a part-time job by Share of Cost deductions from IHSS pay. The system is unfair..."* This response captures the sentiment of many Consumers who responded this way, namely that they felt it was unfair for married Consumers to be granted fewer authorized hours due to the presence of an able and available spouse in the home.