



Impact of Budget Cuts on the Lives of In-Home Support Services Consumers in San Francisco

Prepared for the
San Francisco In-Home Supportive Services Public Authority

by the Institute for Civic and Community Engagement at
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Executive Summary

In April 2008 when California Governor Arnold Schwarzenegger proposed drastic budget cuts for IHSS services, San Francisco In-Home Supportive Services (IHSS) Public Authority sent a letter in four different languages to all its consumers asking them to describe how these proposed cuts would impact them. By June 2008, more than 4500 consumers responded expressing their trepidation with detailed accounts of the devastating effects that any reduction in services or SSI/SSP monthly income would have on their own lives as well as their providers' lives.

These responses were translated and tabulated by student volunteers at San Francisco State University and analyzed both qualitatively and quantitatively by a multi-disciplinary team of faculty researchers working with the Institute for Civic and Community Engagement. This report presents a summary of these responses and the true picture of how important supportive services are in the lives of low-income disabled and elderly IHSS consumers in San Francisco.

Research Objectives

The analysis was conducted to address the following five questions:

- What IHSS means to consumers and what loss of hours would mean to their lives
- If a family member could no longer be an IHSS provider, how would that affect the consumer's family and their ability to stay in their own home?
- If the consumer is an SSI/SSP recipient, how would any reduction in the monthly cash assistance affect the consumer?
- What services beside IHSS helps consumers to stay in their own homes.
- What does the demographic analysis of the respondents tell us about who perceives themselves to be most impacted by the budget cuts.

Key Findings

- 67.3 percent responded to say that the loss of hours will severely impact them. The main themes that emerged were that consumers relied on IHSS to provide the capacity to live independently, and in their own homes, with family members.
- 30 percent of the respondents wrote back with potential impacts on their lives if family members could no longer be their IHSS provider. Increased isolation and depression as well as loss of assistance and general well-being were the two most discussed categories.
- 50 percent of respondents wrote that a reduction in SSI/SSP grants will severely impact their lives. One quarter of the respondents said that it would be difficult to pay for basic living costs such as rent, utilities, transportation, hygiene and cleaning supplies and fresh food.
- Single and female consumers appear to be the most vulnerable in the face of these budget cuts.

Conclusions

Any reductions to In-Home Support Services and SSI/SSP grants will have a devastating effect on low-income vulnerable elderly and disabled adults in San Francisco County. The main findings are that:

- **Reduction in IHSS would mean a loss of independence**
- **Reduction of IHSS would mean the loss to assistance in managing debilitating health conditions at home**
- **Reduction in paid family caregiver hours would mean the following for vulnerable elderly and disabled adults:**
 - Loss of needed assistance would impact overall general well-being
 - Increased burden on families
 - Increased isolation and depression
 - Forced institutionalization and homelessness
 - Early deterioration of health
- **Reduction to SSI/SSP will affect basic survival in the city and county of San Francisco**

In addition, there would be indirect implications of reducing IHSS services on other State services that support low-income disabled and elderly populations. There would be significant cost-shifting onto long term care facilities, health care system, and loss of productive, experienced and contributing members of society. The IHSS program is a cost-effective part of California's long-term care system, enabling thousands of Californians, including seniors and persons with disabilities, to stay out of nursing homes and other institutions and remain active and involved in their communities.

Introduction

In-Home Supportive Services is a publicly funded program in California that provides domestic and personal assistance services to low-income individuals who are disabled and who need such assistance to remain safely in their homes and stay connected to their community. In April 2008 when California Governor Arnold Schwarzenegger proposed drastic budget cuts for IHSS services, San Francisco In-Home Supportive Services (IHSS) Public Authority sent a letter in four different languages to all its consumers asking them to describe how these proposed cuts would impact them. By June 2008, more than 4500 consumers responded expressing their trepidation with detailed accounts of the devastating effects that any reduction in services or SSI/SSP monthly income would have on their own lives as well as their providers' lives. This report presents a summary of these and the true picture of how important supportive services are in the lives of low-income disabled and elderly IHSS consumers in San Francisco.

The following sections contain a discussion of the proposed budget cuts and how the consumers perceive that these budget cuts will affect them. A description of the IHSS consumers, their needs and aspirations has been analyzed using qualitative and quantitative methods.

Background: Budget Proposal and Modifications for IHSS

The California Governor's Fiscal Year 08-09 Budget proposal included two significant cuts to IHSS that would have reduced program funding by a total of \$361 million¹. The cuts proposed would have resulted in:

- a) 18% reduction in IHSS hours for domestic and related services
- b) Loss of a state cost-of-living adjustment for Supplemental Security Income/State Supplementary Payment (SSI/SSP) cash assistance grants.

What would each of these mean?

a) 18 percent reduction in IHSS hours for domestic and related services

The Governor proposed to reduce funding by \$336.6 million by reducing domestic and related services by 18 percent. Domestic and related services include meal preparation and clean-up, laundry, food shopping, and shopping errands. The proposed cut would be made automatically by the Case Management Information & Payrolling System (CMIPS).

According to the State Department of Social Services, approximately 96% of all IHSS consumers receive domestic and related services. The average consumer receives 37 hours per month for these services. The budget proposal would have resulted in those consumers losing an average of 6.6 hours of help per month.

The Administration proposed this cut with the impression that this reduction would have minimal impact since approximately 60% of IHSS consumers are provided services from a relative caregiver. The budget proposal also clarified that since more individualized and intimate personal care was not being impacted by these cuts, the IHSS recipients' safety would be ensured along with their ability to remain safely in their own homes and institutionalization would be avoided.

The response from the consumers presented in this report will elucidate the true impact such cuts would have on their lives.

b) SSI/SSP Cost of Living Adjustment (COLA)

About 80% of IHSS consumers receive a minimal SSI/SSP monthly income that faces a reduction from \$907 to \$830. The proposed SSI/SSP program reductions in the State budget included \$23.3 million in FY 07-08 and \$300.3 million in FY 08-09 which would be achieved by suspending the June 2008 and June 2009 state COLAs. Under this proposal, SSI/SSP recipients would see increased payments in total benefits in both years due to the provision of the federal COLAs – but because of the suspension of State's contribution to cost of living adjustment, an individual will receive 4.9 percent less and a couple will receive 5.2 percent less than they would otherwise.

The net effect would be a very small increase in SSI/SSP payments to the eligible population that would not help defray rising cost of living.

¹ IHSS Coalition, accessed May 12, 2009 at <http://www.ihsscalifornia.org/budgetproposal/2008/summary.html>

In the **July 2009 Budget Agreement** signed by the Governor that included his line-item vetoes, the approved changes affecting IHSS consumers and providers were:

- Supplemental Security Income/State Supplementary Payment (SSI/SSP) Program. Adopted a \$5-per-month reduction for individual recipients but reduced grants for couples to the federal minimum. The maximum grant for individuals will drop from \$850 to \$845, and the maximum grant for couples will drop from \$1,489 to \$1,407, effective October 1, 2009. Estimated savings in 2009-10: \$115.9 million.
- Cost-of-living adjustments (COLAs) for SSI/SSP. Permanently eliminated the statutory COLAs, effective in 2010-2011.
- IHSS eligibility. Eliminated, with some exceptions, IHSS domestic and related services for recipients with “functional index” (FI) rankings—measured by the need for each individual service—below 4. Also eliminated, with some exceptions, all IHSS services for recipients with FI scores below 2. Estimated savings in 2009-10: \$53.2 million. Using his line-item veto, the Governor cut an additional \$29.8 million from IHSS, reflecting, according to the Administration, its contention that certain IHSS recipients should not be exempted from the more restrictive eligibility requirements for domestic and related services.
- IHSS: State subsidy for recipients who are required to pay a “share of cost” for services from their own income. Eliminated this state subsidy, effective October 1, 2009. Estimated savings in 2009-10: \$41 million.
- IHSS: Provider wages. Rejected the Governor’s proposal to cap the amount at which the state will share in the cost for wages for IHSS providers at \$8.00 per hour plus \$0.60 for health benefits. (A federal lawsuit is also under way, which requires the state to maintain its contribution to the wage at this time. The state has appealed this injunction.)
- IHSS: Policy changes asserted to improve program integrity. Estimated \$130 million in state savings in 2009-10 from a number of policy changes and efforts that the Governor asserts will prevent fraud, including requiring both consumers and providers to be fingerprinted. The costs of criminal background checks must be borne by the home care worker applicant.
- IHSS: Public Authorities (PAs). Cut state funding for PA administration by \$13.3 million in 2009-10. This cut included a unilateral gubernatorial veto of \$8.7 million.

Thus, it is evident that by October 2009, significant cuts to the IHSS program and other social and entitlement programs will negatively affect IHSS consumers and their providers. Neutral legal advice to the legislature is of the opinion that the Governor overstepped his Constitutional authority to line item veto as he did. Senator Darrell Steinberg has filed suit to challenge these cuts by the Governor.

Impact of cuts in services on IHSS consumers

a) Research Methodology

In April 2008, in response to the proposed drastic cuts to IHSS, Medi-Cal and other services outlined by Governor Schwarzenegger in his proposed state budget, the San Francisco Public Authority sent out a letter and questionnaire (see Appendix B) in English, Cantonese, Russian and Spanish to its 20,000+ San Francisco IHSS consumers. Executive Director Donna Calame asked consumers to let them know how these cuts, if approved, would affect them, their lives and loved ones. By the end of June 2008, over 4,500 (24 percent response rate) consumers had written back with their own personal accounts about the catastrophic impact these cuts would have on them.

These responses were translated and tabulated by student volunteers of San Francisco State University. A total of 4554 consumers responded. Of the total respondents, about 48% wrote back in Chinese, 26.5% were Russian speakers, 5.4% Spanish, 18.2% English and about 2.4% responded in English but identified themselves as native speakers of other languages such as Vietnamese, Tagalog, etc. Even though the sample was self-selected, it represents all the major language groups spoken by the San Francisco IHSS population (see Table 1 below).

Table 1: Distribution of Respondents by Language

Language	Number of Respondents	Percentage
English	828	18.2%
Chinese	2,165	47.5%
Spanish	247	5.4%
Russian	1,205	26.5%
Other	109	2.4%
TOTAL	4,554	100.0%

Note: A breakdown of the Others category is provided in Table A.1 in Appendix A.

Qualitative responses written in English were copied into spreadsheets with the corresponding data for the respondent. Qualitative responses hand-written in Chinese, Spanish and Russian were translated and entered in English as well. Bilingual San Francisco State University students were enlisted to assist with this translation.

The qualitative responses were scanned carefully for themes utilizing qualitative research methodology. Following the procedures for grounded theory analysis², the investigators developed and used codes to give structure and organization to the hand-written responses. The responses for each question were independently reviewed for commonalities and differences. Next, the text for each question was independently coded for themes that appeared repeatedly in the text. Coding was iterative and refinements were made based on internal discussions until a consensus was reached on the final definition of each code. Finally, text within a coding category was evaluated to determine whether it accurately fit the definition of the code. Thus, verification of the accuracy of the coding scheme (conceptual categories, their definitions, and

² Strauss, A. L., & Corbin, J. M. *Basics of qualitative research: grounded theory procedures and techniques*. Newbury Park, Calif.: Sage Publications; 1990

the observations coded within each category) occurred using both inductive and deductive methods³. These codes were also entered and used to quantitatively analyze the reporting frequencies of each of these themes. Furthermore, representative quotes were chosen to illustrate each of these themes.

These coded responses were then matched with the Case Management Information and Payrolling System (CMIPS) database to find demographic information on the respondents. Since some of the respondents were family members of the IHSS consumers and some respondents wrote back anonymously, matches were possible with 82% of the respondents to the CMIPS database. This prepared database was then used to carry out quantitative analysis of the nature of responses of the consumers.

The qualitative and quantitative analyses were conducted by a multi-disciplinary team of SFSU faculty to understand the following:

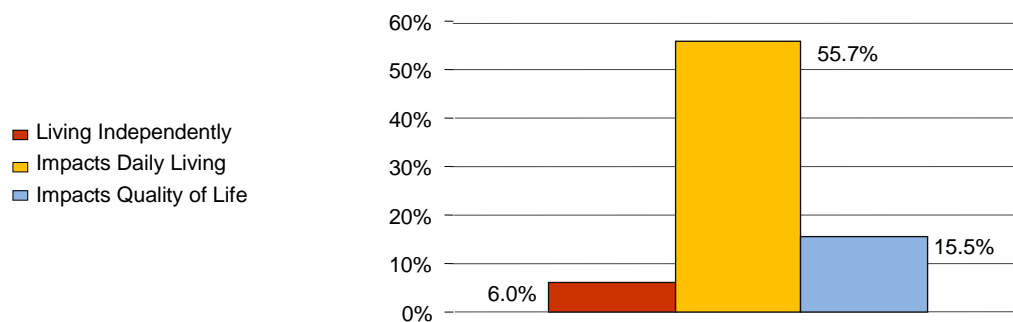
- What IHSS means to consumers and what loss of hours would mean to their lives
- If a family member could no longer be an IHSS provider, how would that affect the consumer's family and their ability to stay in their own home?
- If the consumer is an SSI/SSP recipient, how would any reduction in the monthly cash assistance affect the consumer?
- What services beside IHSS helps consumers to stay in their own homes.
- What does demographic analysis of the respondents tell us about who perceives themselves to be most impacted by the cuts.

b) Research Findings

1. What IHSS means to consumers and what loss of hours would mean to their lives

67.3 percent responded to this question and wrote back saying loss of hours will severely impact them. The main themes that emerged were that consumers relied on IHSS to provide the capacity to live independently, and in their own homes, with family members. Further, by providing assistance in daily living (both in terms of ADL and IADL⁴ assistance as well as financial assistance), consumers are able to stay safely in their homes and in their community. Many consumers also mentioned that IHSS helps them maintain a basic quality of life by helping with cleanliness and hygiene, and by allowing consumers to get help from family members instead of strangers. IHSS thus significantly helps consumers maintain their physical and mental health conditions and allow them to remain an active member of the community.

Figure 1: What IHSS Means to Consumers



Note: Respondents could indicate more than one category of difficulty.

³ Strauss, A. L., & Corbin, J. M. *Basics of qualitative research: grounded theory procedures and techniques*. Newbury Park, Calif.: Sage Publications; 1990

⁴ Activities of daily living (ADL) include eating, dressing, taking a bath or shower, using the toilet and getting out of bed. Instrumental activities of daily living (IADL) are activities related to independent living and include preparing meals, managing money, shopping, doing housework, and using a telephone.

IHSS means independence

As evidenced by thousands of written comments, IHSS means many things to its consumers. IHSS is important to individuals in San Francisco because it provides the opportunity to live independently, manage daily needs and ultimately maintain a minimal quality of life. Without the services of IHSS, many frail, disabled individuals in San Francisco would find themselves homeless or living in long term care facilities.

Living independently means the ability to live at home without being a burden on family members. Thousands of IHSS consumers have written stating how important this is to them:

IHSS means my independence and dignity to stay in my apartment in my final days, with my family and friends near by. This means the world to me.

- 84 year old female, Spanish

Thousands of IHSS consumers mention that without the services of IHSS that they would be forced to living in a skilled nursing facility. Many wrote that the assistance provided enabled them to live and manage their health conditions at home:

IHSS services allows me to live independently. Loss of help would require me to have to move to Laguna Honda or "worse".

- 64 year old male, English

IHSS means I can live independently in my home, otherwise without IHSS, I would go to a nursing home. IHSS workers helped me with my daily activities such as bathing, preparing meals, do my shopping, going to the pharmacy for my medication, take me to the doctor appointment and they helped me with my house chores and personal hygiene.

- 102 year old female, Spanish

For many vulnerable elderly and disabled adults, in-home support services meant that they could remain in their homes, and many felt if this service were not able, they would be sent to a skilled nursing facility.

As a sickly senior citizen, IHSS helps me to live a normal life as much as possible. The loss of hours will mean hardship to me without anybody assisting with my daily personal and household chores, doctor's appointments and whatever service I need.

-76 year old female, English

IHSS manages daily living for vulnerable elderly and disabled adults

The thousands of vulnerable elderly and disabled adults who responded to this survey were living through debilitating health conditions that were often complicated and difficult to manage. Respondents often mentioned at least three health conditions including diabetes, kidney failure, high blood pressure, stroke, cancer and others that required everyday assistance. At a most basic level, these conditions are debilitating, often accompanied by impaired walking ability or other kinds of limited mobility. Some need direct hands on assistance for basic movements like getting in and out of bed, dressing and grooming, using the toilet, washing, cooking meals, and meeting fundamental daily needs that require moving about. In addition, these health conditions often require following a complex schedule of multiple daily medications, along with frequent medical appointments with physicians. Help to manage all this is also necessary. Finally, for those who live alone, IHSS may be the only way they can live without institutionalization.

Thus using IHSS is a simple way of maintaining independence for vulnerable elderly and disabled adults through the assistance of managing daily life through the assistance with activities of daily living (ADL) include bathing, dressing, eating, using the toilet, getting in and out of bed. This independence is also facilitated with the support for instrumental activities of daily living (IADL) which includes housework, meal preparation, taking medications, shopping for groceries, and managing money. Thousands of IHSS consumers wrote that assistance with these aspects of daily living is essential to their health and quality of life.

Those who responded to the survey mentioned that assistance using the toilet, bathing, meal preparation, shopping and doctor's appointment were essential to their survival:

Without IHSS will be difficult to live independently at my house. Translation help me communication with my doctor and a lot of services. It will be hard for me to pay my provider. I will not be able to stay in my own home/shopping/cook/doctor appointment/socialize.

-84 year old male, Cambodian

Without IHSS, I cannot eat, poop, bath, etc. and I will forget to take the medicines. Without caregiver, I'm unable to walk/move, because I could fall on the ground at any time. I might poop or pee on the bed and leave there without cleaning. My children will not concentrate on their jobs without the IHSS taking care for me.

-88 year old female, Chinese

It really helps reduce the cost of living. It literally puts food into my mouth. With the cost of food, transportation, clothes, medicine... well, you can get the picture. Without the help of IHSS I would literally be malnourished and unable to get out of the house. You see, I am in an electric wheelchair. I have to depend on taxi cabs with wheelchair ramps to get around. I thank you for your help it helps me a great deal.

-64 year old male, English

I am 80 years old with many diseases. I have glaucoma, hearing problems, high blood pressure, heart problems and joints and vertebra problems. And I had kidney operation and lost one of them. I need IHSS to help me and my life. The reduction will affect me a lot. To see a doctor, it's very difficult to me by myself, I need help to take care of. please do not reduce the hours.

-81 year old female, Chinese

I am 86 years old, I went to hospital and had cardiac surgery twice. I have poor hearing and rely on hearing-aid for 12 years. I was blind since 2006, and went to the pacific hospital for treatment, and the vision has recovered a little. I used to be a paralytic, thanks for the doctors, I can move a little bit, but I'm almost unable to walk. I have to rely on wheelchair, crutch, and someone's help. Because I'm old, I have many diseases, so I need IHSS desperately. I can not imagine how could I survive with the reduction. I want to add more hours NOT reduce the hours!

-86 year old female, Spanish

IHSS impacts the quality of life for vulnerable elderly and disabled adults

When IHSS provides assistance for a variety of tasks -- cooking, transportation, cleaning, and grooming -- this care has a vital and indispensable impact on the care receivers' daily life. The impact extends to benefitting their physical and emotional health, and quality of life.

My IHSS worker helps me in nearly every aspect of my daily life. She cooks, shops, picks up my prescriptions, cleans the whole apartment, helps me bathe, does my laundry and picks up my mail-all in FOUR hours a day! She accompanies me to doctors appointments, to the Senior Center and on any type of emergency situation

-76 year old male, Spanish

My provider gives me support, cooks my meals, takes me to and from doctors appointment, cleans my house, washes my clothes, cuts and grooms my hair/facial hair, helps with baths, picks up all my medications. I am disables, use a walker to get around, and need desperately my IHSS provider in my daily life. He also is a very good mental support to help with my stress and painful days.

- elderly male, age unidentified, Laos

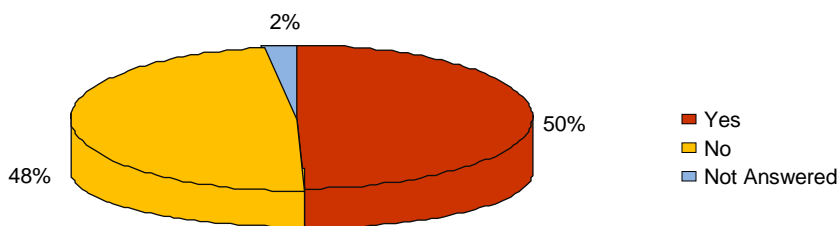
IHSS services help keep me independent. If services are reduced/taken away, I will not be able to function in my household, i.e., clean house, clean self, grocery shopping, medical appointments, etc

-92 year old female, Spanish

2. If a family member could no longer be an IHSS provider, how would that affect the consumer's family and their ability to stay in their own home?

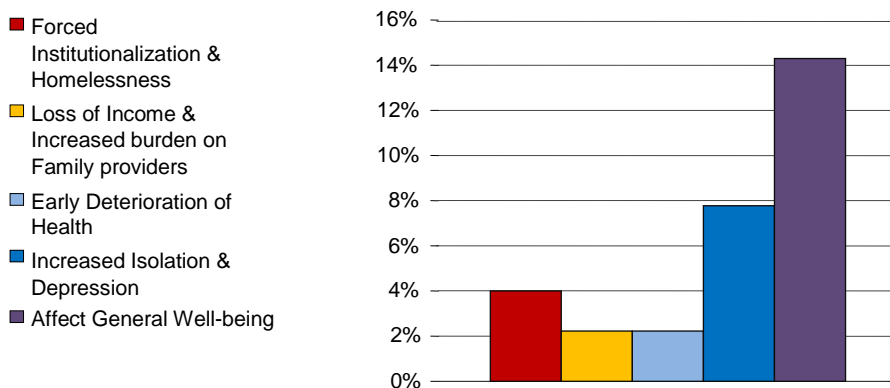
A total of 4554 responses were received from SFIHSSPA's consumers. Of the 4554 respondents, 50% had family members including parents, spouses and children as their care providers.

Figure 2: Proportion of Respondents Who Use Family Care Providers



About 30% of the respondents wrote back with potential impacts on their lives if family members could no longer be their IHSS provider. Increased isolation and depression as well as loss of assistance and general well-being were the two most discussed categories. Early deterioration of health and early entry into long term care facilities were also mentioned extensively (see Figure 3).

Figure 3: What Would Happen if Family members Could No Longer be a Provider



Rather than live in an institution, the disabled person who lives at home can retain the psychological trust, social warmth and personal dignity of living with family members and receiving support from those people who are most likely to know them and love them. Even though the paid hours to IHSS workers are extremely limited, the payment provided for care-giving by IHSS has lightened some of the family's burden, either by freeing their attention or, in many cases, by paying them for the services. Many of those surveyed mentioned that IHSS has made it possible to hire family members to care for them.

50% of IHSS consumers utilize family members as care providers. Although limited in the number of hours that they are paid for their care-giving, family members are often essential in providing daily care to their

disabled or elderly loved one. A loss of the use of a family member as a paid caregiver would mean a loss of fundamental comfort and trust that is badly needed by ailing and vulnerable IHSS consumers. For many, family members are the only people they can depend on to know them well, treat them with love and respect, and truly protect their best interests. Getting help from an outsider means dealing with an unknown entity. A stranger might have difficulty understanding the care receiver's needs, or worse, when entering the personal and private space of the care receiver's home, might take advantage of their vulnerability, treat them disrespectfully, or otherwise abuse the power they wield as caregiver. Receiving care from non-family would require finding someone who is a really good match and trustworthy.

Loss of Needed Assistance would impact General Well-Being

Families choose available family care provider to provide assistance because there is a built-in trust and respect. Moreover, the care of vulnerable elderly or disabled adults for bathing and toiletry requires that IHSS consumers feel comfortable with their care provider. As a result, for many families, cutbacks for family care provider hours would mean less care for themselves and ultimately would impact their well-being. Many stated needs similar to the following:

My one and only child passed away about 7 yrs ago and my granddaughter is all I have left. If she couldn't be my provider it would be devastating because there aren't enough trust worthy people in this world. But w/out IHSS she would have to work a second job that wouldn't let her come help me like she does. I'm grateful for IHSS. It helps her, help me! Arnold Schwarzenegger should be ashamed of himself! But I guess not because he can go to sleep at night without a care in the world.
- 83 year old female, English

If family member no longer a provider, it will affect me who leave alone at home and my family very badly. Hiring a good provider is quite difficult, mismatched temper, poor skill, less patience. I would like to have family member as provider to take care for me. Because he/she knows my needs as well as my temper, living habit. she can provide more thoughtful and considerate services. I am comfortable with it. Thank you!

-79 year old female, Chinese

Increased hardship for family caregiver and increased burden on families

The hours paid by IHSS to a family caregiver may have enabled them to stay home and care for ailing or vulnerable family members. Thus, IHSS allows families to stay together. The loss of IHSS would mean loss of needed income to the family, which would most likely force the care provider to take another job to make ends meet, thus reducing the amount of care they can provide to the disabled person.

By a family member no longer being my IHSS provider causes a hardship on me and provider. She would loose income and I would loose some one I could trust to make sure all my needs are taken care of. For I live with her and our finances would no longer meet our living expenses (such as rent utilities, food, etc) She would have to look for another job. I need some one to take care of me. In July 24, 2008 I will be 90 yrs. old.

-89 year old female, English

My daughter is my provider, and this is her only job. She knows me, my health condition and needs and always does not care working overtime to take care of me. If she is no longer as my provider, it will affect her too. Because the job she has right now is to be my provider and this is her whole income resource. She is thoughtful and considerate to take care of me, what she does is way better than the IHSS worker. Without her, my life will be horrible and full of inconveniences. I beg you to maintain the current situation what I have, do not change it, please let my daughter as my provider as usual.

-80 year old female, Chinese

In addition, the family care provider often addresses a range of needs that are uncompensated by IHSS. Living in the same residence as the disabled or elderly person means the family member can assist them as needed around the clock with tasks like waking up at night to use the bathroom, going to the bathroom when the need arises, taking showers, and so forth. Some need assistance simply with getting out of bed or standing up, movement which might produce dizziness. Health problems might crop up at any time in the 24 hour cycle, so that a family caregiver living on site can be there in ways that hired outside caregivers cannot. Many have stated the benefits of family caregivers similar to the following:

Right now my daughter is my provider. She is staying with me 24 hrs/ 7 days a week. She quit her job and live with me as my provider with the doctor's advice. Because I need somebody not only during the day but also during the night. I have a heart bypass, diabetes, nerve damage, I can't walk without my walker. I have to urinate every 30 minutes especially during the night. I'm always dizzy. Its only my daughter who can stay with me for that kind of situation. Please try to understand, thank you.

-83 year old female, English

It will bring a big issue. Nobody will help me take a shower. I have constipation, it will be inconvenient. Because I have to take half an hour every time, when I feel dizzy when I stand up. There is one time I almost fell down, it is very dangerous to me. I feel better if my son is around me. hiring a stranger, do you think I can wait for him and then go to the bathroom? pooping cannot be self-controlled. everybody knows it. At this point, I'm worried about asking a stranger to be a provider. If you enforce it, I have to use the diaper for a longer time. It is very inconvenient.

-78 year old male, Chinese

If family member no longer provider, I have to negotiate with the provider about the schedule, because I only have a few hours. I have heart problem, health condition is not really good. It is better to have someone during the night. I had Gastric bleeding and heart beat is 150, which happened at 3am. Fortunately my family were with me and called an ambulance and sent me to the ER. I stayed at hospital for 3 days and now I still suffered heart problems. I an unable to walk a lot, otherwise my heart beat I will go up.

-88 year old female, Chinese

Unavailable family care provider: Forced Institutionalization or Homelessness

The most dreaded outcomes that might result from losing a paid family care provider are institutionalization and homelessness. In the case of institutionalization, not only would the warmth, security and safety of having family nearby be lost, but the cost of long term care facilities might be prohibitively high. Listed are some of the comments from respondents:

If my daughter could no longer be my IHSS provider we would not be able to stay in this house where I sublet the in-law apartment. She, her 22 month old daughter, and I would become homeless, as the total rent for the upstairs we she and her daughter live and the apartment downstairs would become unaffordable, and I cannot rent anything in San Francisco for what I pay to sublet the apartment.

-51 year old female, English

I may "rot" in my apartment or my health will deteriorate. I don't have any direct family member (spouse or children) here, so more likely it will be almost impossible for me to survive or live a healthy life and stay in the senior apartment if the government will reduce the IHSS hours and the SSI monthly cash assistance. I will end up homeless and very sick.

-76 year old female, English

My daughter is my main source of help in my life. If my daughter could not help me I would be institutionalized because other family members could not assist me and it would cause a economic emotional crisis.

-65 year old female, English

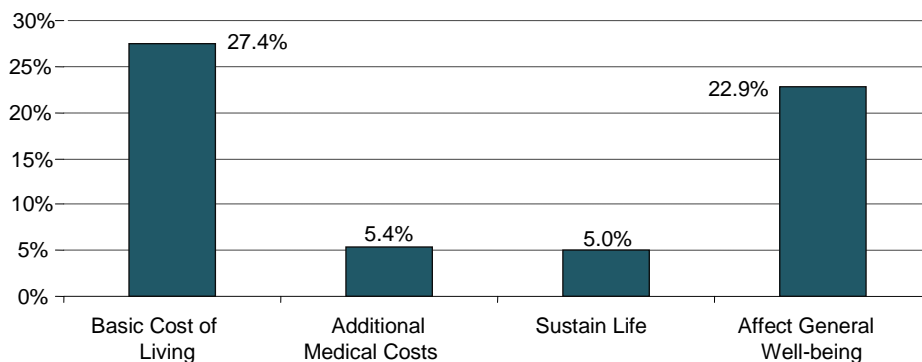
Right now, my family members are the only one I can contact with, to see a doctor, buy foods and medicines, I rely on them. My family members quit their jobs to take care of me. If family member no longer provider, they have to find a job and I will live without care. I can not take care of myself at all. Stay at a government senior nursing home seems the only solution, which can worsen the government economic burden.

-91 year old female, Chinese

3. If the consumer is an SSI/SSP recipient, how would any reduction in that monthly cash assistance affect them?

50% of the respondents wrote that a reduction in SSI/SSP grants will severely impact their lives. One quarter of the respondents said that it would be difficult to pay for basic living costs such as rent, utilities, transportation, hygiene and cleaning supplies and fresh food. A reduction in SSI/SSP would also negatively impact purchase of vitamins and alternative medical therapies that are not covered under Medi-Cal or Medicare.

Figure 4: Main Areas in Which a Cut in SSI/SSP Will Affect the Consumer



Recipients of SSI depend on SSI income to cover basic survival expenses of food, shelter, utilities, unreimbursed health expenses, and prescription medications. Even with the help of SSI and IHSS, some survey respondents describe a life of frugal poverty, barely making ends meet. Elderly people on SSI experience increased vulnerability with aging; to lose the crucial support of SSI and IHSS would jeopardize their lives. The support they receive now is indispensable to their survival. Considering the grave prospect of reductions, they can't imagine how they will get by.

Being in San Francisco, the high cost of living impacts those on SSI, and any further reductions could be catastrophic. SSI recipients are already living on the margins in San Francisco. Their limited benefits cover the basic necessities of living. Any further reduction would mean the potential for malnutrition and homelessness. Included are statements from individuals who fear this loss:

The amount SSI provides causes me to live under the poverty level although I am grateful for the help, but it allows me at this rate to cover my housing and overhead (i.e. PG&E, ATT, Comcast basic TV), transportation (Bus pass) monthly, laundry, and very little food. There is rarely a time when I have any extra to go to coffee with a friend. I have no (zero) social life. If it was to be cut I would not be able to buy food and my out of pocket medications that are necessary for my illness. I will do anything in my power to vote accordingly or anything else that will prevent Gov. Schwarzenegger to apply cuts to this area. We are the poorest of the poor and illness combines with poverty is almost an overwhelming combination. If we had programs to overcome our condition, such as rehabilitation and job training courses that were paid for by the government, then it would be cost-effective and in the long run could help alleviate the burden on those who were on assistance.

-Anonymous, English

It is the only service I need at present to maintain my life style. I barely have enough as it is now, any reduction in cash would restrict the types of food I could afford, like vegetables and fruits. I now must buy any type of clothing through Goodwill. With the price increase of basic like milk and cheese and bread, even a sandwich and a glass of milk is almost a luxury and/or treat. With IHSS support and the few dollars I get from SSI I might as well not have a life.

- 58 year old male, English

Any reduction in my monthly chk would be a disaster for me as I'm barely making it now! I don't know how but for the grace of god! Also any reduction in medi-cal services would be almost unbearable for me! As far as my meds go, as well as the services that are already hard to get. I'm having a hard time already, just getting an electric wheel chair because of budget concerns! As it is now I'm almost confined to my room! I don't know what I would do with-out IHSS. I take money out of my food money now just to give people around the apt \$500 and \$500 there, just to help me do things I need help in doing etc, etc... Thank you.

-57 year old male, English

4. What services beside IHSS helps consumers to stay in their own homes.

Other than IHSS, consumers use other services including help with shopping and groceries, cleaning service, home oxygen Service, delivery of medication and delivered meals. Some of the services mentioned were provided by the Open Hand Project, Westside Services, Meals that Heal, Meals on Wheels, Swords to Plowshares and the SF Food Bank.

5. Demographic analysis of the self-selected respondents to identify who perceives themselves to be most impacted by the cuts

To understand who were moved to respond with their personal stories, the names and addresses of respondents were matched with the Case Management Information and Payrolling System (CMIPS) database to find demographic information on the respondents.

Since some of the respondents were friends or family members of the IHSS consumers, and several respondents wrote back anonymously, only 82% of the respondents were found identifiable in the CMIPS database. This sub-sample was then used to carry out a demographic analysis of the identified respondents. The total number of observations in this analysis is 3704 (82% of 4554).

Of the sub-sample of 3704, 85 percent of respondents are aged 65 years or older. About 37 percent are male and 58 percent are single. 45 percent of the respondents are Chinese and 35 percent are whites (see table 2).

Table 2: Ethnic Distribution of Identified Sub-Sample of Respondents

Ethnicity	Frequency	Percent
Alaskan Native or American India	1	0.03
Asian Indian	11	0.30
Black	259	6.99
Cambodian	3	0.08
Chinese	1,682	45.41
Filipino	137	3.70
Hawaiian	1	0.03
Hispanic	240	6.48
Japanese	2	0.05
Korean	7	0.19
Laotian	2	0.05
Other Asian or Pacific Islander	15	0.40
Samoan	1	0.03
Vietnamese	31	0.84
White	1,312	35.42
Total	3,704	100

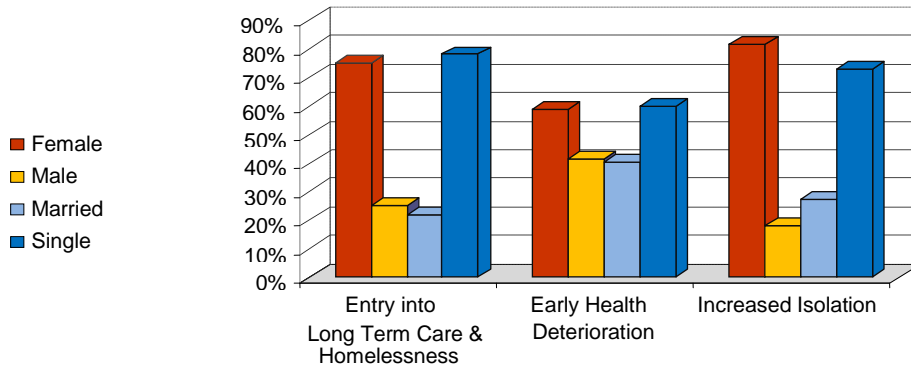
Table 3 presents the distribution of this sub-sample by gender and marital status. Of the identified sub-sample of respondents who wrote back, majority are female (63.12 percent) and are single (58.34 percent).

Table 3: Distribution of Identified Sub-Sample of Respondents, by Gender and Marital Status

	Married	Single	% of Total
Female	31.8	68.2	63.1
Male	58.5	41.5	36.9
% of Total	41.7	58.3	100

If a family member could no longer be an IHSS provider, there would be multiple impacts on IHSS consumers as discussed in previous sections. Single and female consumers appear to be the most vulnerable in the face of these cuts. To illustrate this point, Figure 5 presents three potential results of a loss of supportive services for consumers and depicts that single and female consumers would be impacted the most.

Figure 5: Demographic Distribution of Impact of Loss of IHSS on Consumers



Conclusion

Any reductions to In-Home Support Services and SSI/SSP grants will have a devastating effect on low-income vulnerable elderly and disabled adults in San Francisco County. The main findings are that:

- **Reduction in IHSS would mean a loss of independence**
- **Reduction of IHSS would mean the loss to assistance in managing debilitating health conditions at home**
- **Reduction in paid family caregiver hours would mean the following for vulnerable elderly and disabled adults:**
 - Loss of needed assistance would impact overall general well-being
 - Increased burden on families
 - Increased isolation and depression
 - Forced institutionalization and homelessness
 - Early deterioration of health
- **Single and female IHSS consumers appear to be the most vulnerable in the face of these budget cuts**
- **Reduction to SSI/SSP will affect basic survival in the City and County of San Francisco**

In addition, there would be indirect implications of reducing IHSS services on other State services that support low-income disabled and elderly populations. There would be significant cost-shifting onto long term care facilities, health care system, and loss of productive, experienced and contributing members of society.

- The IHSS program is a cost-effective part of California's long-term care system, enabling thousands of Californians, including seniors and persons with disabilities, to stay out of nursing homes and other institutions and remain active and involved in their communities. The Legislative Analyst's Office⁵ estimated that annual cost for each IHSS recipient is around \$10,000. In contrast, nursing home costs approximately \$60,000 a year per person.
- The cut in IHSS hours would mean less income for home care providers which will discourage workers from entering this field of work. This would result in a limited supply of home care providers that will ultimately make it difficult for seniors and disabled people to remain safely in their homes and possibly force them into formal long-term care institutions such as nursing homes. A 2005 article⁶ by Economist Candace Howes showed that wages and especially benefits have a significant impact on the retention of providers; in San Francisco when the wages increased from \$5 per hour to \$10 per hour and health insurance was added between 1997 and 2002, the one year retention rate for new providers increased from 33 percent to 61 percent. With the proposed cut in IHSS hours and wages for care providers, there will be a potential shortage of home care providers in the near future.
- Moreover, many IHSS providers will potentially lose their health benefits because the cut in hours could put the workers below the eligibility limits set by the Public Authorities (San Francisco requires 25 hours of service per month) to qualify for health benefits.

⁵ Legislative Analyst's Office, In-Home Supportive Services: Background on Budget, Providers, and Registries, October 16, 2007.

⁶ Howes, Candace, Living Wages and Retention of Homecare Workers in San Francisco, *Industrial Relations*, Vol. 44, No. 1, pp. 139-163, January 2005.

Finally, more than one quarter of the respondents (26.7 percent) wanted to attend a consumer forum or a training where they and other IHSS recipients could discuss problems and brainstorm solutions. About 30 percent of those who wrote in wanted to convey their personal stories to government officials and policymakers. As with any sound policy-making, IHSS consumers and providers may be the key informants in devising more cost-effective policies in their best interest in this difficult economic environment.

Appendix A: Additional Table

Table A.1: Distribution of Respondents by Language - Others

Language	Number of Respondents
Albania	1
American Sign Language	1
Bosnian	2
Cambodian	6
Cantonese/English/Japanese	1
Did Not State	2
Ethiopian	1
Filipino	12
Greek	1
Hindi	2
Hungarian	1
Italian	2
Korean	4
Laos	3
Samoan	1
Tagalog	37
Tagolu	1
Tibetan	1
Tigrigna	1
Vietnamese	28
Visayan-Cebuano	1
Total	109

Appendix B: Survey Letter and Questionnaire

B.1: Survey Letter



I H S S
In-Home Supportive Services
Public Authority

April 2008

Dear San Francisco IHSS Consumer:

If you do not follow the dynamics around development of the state budget, please do – both this year and into the future. The amount and quality of IHSS assistance are greatly affected by California's budget.

In his proposed state budget for 2008-09, **Governor Arnold Schwarzenegger has SUGGESTED drastic cuts to services on which you probably depend. But these cuts do NOT have to happen.** Legislators must approve his suggestions for them to take effect. Many Senators and Assemblymembers are seeking other solutions to the state budget crisis. Everyone in Sacramento needs to hear why these services are crucial to you. Let them know how the Governor's proposals would affect your life if the cuts start July 1, 2008:

- An 18% cut in "domestic and related services" hours for everyone on IHSS.
- A 10% cut in state payment to doctors who treat Medi-Cal patients and cuts to many important Optional Medi-Cal Benefits.
- Loss of a state cost-of-living adjustment for Supplemental Security Income/State Supplementary Payment (SSI/SSP) cash assistance grants.

Want to learn more about the budget process and how to communicate to people in government or the community about IHSS? The San Francisco IHSS Public Authority would like to help you and 19,000 other people who use IHSS in the City who will be affected by all these cuts. **But we need to hear from you first.** Please fill out the questionnaire we've enclosed **now** and return it in the envelope provided.

We look forward to hearing from you soon,

Donna Calame
Executive Director

832 Folsom Street, 9th Floor, San Francisco, CA 94107
Ph: 415-243-4477 Fax: 415-243-4407 TTY: 415-243-4430 e-mail: info@sfihsppa.org www.sfihsppa.org

B.2: Survey Questionnaire in English

First Name: _____

Last Name: _____

Address: _____

City: _____

Zip Code: _____

Telephone Number: _____

Email Address: _____

Language (circle one): Cantonese English Russian Spanish

Other: _____

Is your home care provider a family member? ____ Yes ____ No
____ Spouse ____ Parent ____ Other

May we contact you for additional information: ____ Yes ____ No

Can we use your story in the media (newspapers, TV, radio): ____ Yes ____ No

Is it OK for the media to contact you? ____ Yes ____ No

Best times to contact you: _____

Are you interested in...

- Meeting with other IHSS consumers? ____ Yes ____ No
- Attending a consumer forum or a training, where you and other IHSS recipients would discuss problems and brainstorm solutions? ____ Yes ____ No
- Telling your story before a legislative body, such as the Board of Supervisors or a state committee? ____ Yes ____ No
- Having a friend or family member tell your story for you? ____ Yes ____ No
- Learning more about IHSS and how it works and working to improve it? ____ Yes ____ No

In the space below and on the back of this page, please tell us:

- What IHSS means to you and what a loss of hours would mean in your life.
- What services beside IHSS help you stay in your own home.
- If you're an SSI/SSP recipient, how would any reduction in that monthly cash assistance affect you?
- If a family member could no longer be your IHSS provider, how would that affect your family and your ability to stay in your own home?

B.3: Survey Questionnaire in Chinese

姓_____，名_____

地址:_____

城市:_____

郵區:_____

電話:_____

電郵地址:_____

語言(請圈): 中文 英文 俄文 西班牙文

其它: _____

您的員工是您的家庭人員嗎? _____是 _____否

_____配偶 _____父母 _____或其它

可否與您聯絡了解詳情 _____是 _____否

是否可將您的故事放在傳媒上(報章,電視,電台): _____是 _____否

可否讓傳媒聯絡您? _____是 _____否

最適當時間:_____

您有興趣.....

會見其他顧主 _____是 _____否

參與聚會商討及解決問題 _____是 _____否

告訴立法會政要人仕有關你的故事 _____是 _____否

由朋友或家人傳述你的故事 _____是 _____否

更了解家居護理, 其運作, 及如何改進該計劃 _____是 _____否

請告訴我們:

家居護理對您的重要性, 減鐘點對您生活的影響.

除了家居護理, 有否用其它家居服務?

福利金(SSI/SSP)領取者, 減少福利金對您有什麼樣的影響?

如果您的家人不能成為您的護理人, 會對您的家人及您留在家中構成什麼樣的影響?

請寄回以下地址:

SF IHSS Public Authority, 832 Folsom St., 9th Floor, San Francisco, CA94107

B.4: Survey Questionnaire in Russian

Имя: _____ Фамилия: _____

Адрес: _____ Город: _____

Почтовый Индекс: _____

НомерТелефона: _____ ИнтернетАдрес: _____

Язык (Обведите нужное): Русский Английский Другой: _____

Является ли Ваш работник по уходу членом Вашей семьи? ____Да ____Нет

_____ Супруг(а) _____ Родитель(ница) _____ Другое

Можно ли связаться с Вами для получения дополнительной информации?: ____Да ____Нет

Можно ли нам рассказать о Вашем случае Средствам Массовой Информации? (Печать,

Телевидение, Радио) ____Да ____Нет

Можно ли представителям Средств Массовой Информации установить с Вами контакт?:

____Да ____Нет

Когда лучшее время для контакта с Вами?: _____

Интересуетесь ли Вы...

- Встречей с другими получателями услуг (IHSS) ____Да ____Нет
- Посещением форумов или учебных программ, где Вы могли бы дискуссировать о своих проблемах с другими получателями услуг (IHSS) для принятия решений? ____Да ____Нет
- Рассказать о своей истории законодателям, таким как Совет Супервайзеров или законодатель ным Комитетом штата? ____Да ____Нет
- Чтобы Вашу историю за Вас описал Ваш друг или член Вашей семьи? ____Да ____Нет
- Узнать больше о IHSS, как это функционирует и что сделать для улучшения её работы? ____Да ____Нет

В пространстве на обратной стороне страницы этого текста, пожалуйста сообщите нам:

- Что IHSS значит для Вас и как на Вашей жизни отразится потеря часов по уходу за Вами.
- Какие услуги помимо IHSS помогают Вам проживать в Вашем доме.
- Если Вы получатель SSI/SSP, как на Вашей жизни отразится снижение ежемесячной финансовой помощи.
- Если член Вашей семьи не может больше быть Вашим IHSS работником по уходу, как это отразится на жизни Вашей семьи и возможности Вашего проживания в своём доме.

Пожалуйста верните по адресу:

IHSS Public Authority, 832 Folsom St., 9th Floor San Francisco, CA 94107

B.5: Survey Questionnaire in Spanish

Primer Nombre: _____

Apellido: _____

Dirección: _____

Ciudad: _____

Código Postal: _____ Número de Teléfono: _____

Dirección de Correo Electrónico: (Email) _____

Idioma (identifica uno): Cantones Inglés Ruso Español Otro Idioma: _____

¿Es su proveedor/a un miembro de su familia? ___Si ___No

___Esposo/a ___ Padre/Madre ___ Otro

Podemos contactarle por información adicional: ___Si ___ No

Podemos utilizar su historia por los medios de comunicación (periódico, televisión, radio): ___Si ___No

¿Aprueba que estos medios de comunicación se pongan en contacto con usted? ___Si ___No

Las horas más apropiadas para contactarle: _____

Esta interesado/a en.....

- ¿Juntarse con otros consumidores? ___Si ___No
- ¿Participar en un foro o entrenamiento para consumidores donde usted y otros beneficiarios de IHSS puedan analizar problemas y aportar ideas como solucionar problemas? ___Si ___No
- ¿Contar su historia frente a un comité legislativo, como Comité de Supervisores o un comité estatal? ___Si ___ No
- ¿Que un/una amigo/a o miembro de su familia pueda contar su historia por usted? ___Si ___ No
- ¿Obtener mejor conocimiento sobre IHSS y cómo funciona más como participar en su mejoramiento? ___Si ___No

En el espacio proveído en la parte trasera de esta página, por favor infórmenos:

- Lo que IHSS significa para usted y como el recorte de horas impactaría su vida.
- Cuales servicios en adición de IHSS le ayudan a permanecer en su hogar.
- ¿Si usted recibe SSI/SSP, como le impactaría una reducción en la asistencia económica?
- ¿Si no fuera posible que un miembro de su familia fuera su proveedor/a, que impacto tendría esto sobre su familia y su habilidad de permanecer en su hogar?

Por favor devuelva esta encuesta a SFIHSSPA, 832 Folsom St., 9th Floor, San Francisco, CA 94107

Appendix C: Research Brief

Research Brief¹

Impact of Budget Cuts on the Lives of IHSS Consumers in San Francisco

In April 2008 when California Governor Arnold Schwarzenegger proposed drastic budget cuts for In-Home Supportive Services (IHSS), San Francisco's IHSS Public Authority (a publicly funded agency created to improve the provision of domestic and personal assistance services to very low-income individuals with disabilities who need such assistance to remain safely in their homes or with family) sent out a letter in four different languages to all its consumers asking them to describe how these proposed cuts would impact them. By June 2008, more than 4500 consumers wrote back. This research brief provides a snapshot of consumer responses and the potential impact that budget cuts could have on the lives low-income disabled and elderly IHSS consumers in the City and County of San Francisco.

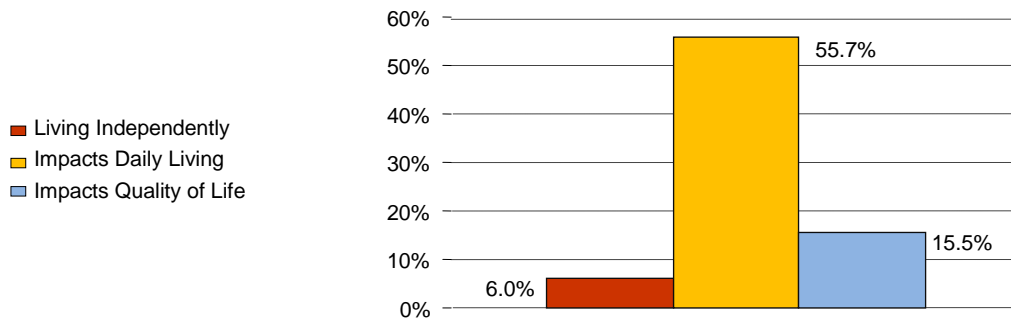
Key Concerns Voiced by IHSS Consumers

Over four thousand IHSS consumers in San Francisco have written by hand the difficulties they would face if IHSS services were cut. With the impending cuts, IHSS consumers are in fear of not being able to continue to live in their homes and face incredible angst that without the needed support to manage their disabling conditions, they may be forcibly institutionalized or, worse yet, face homelessness or private struggles to survive without support. Moreover, the cuts to SSI/SSP grants for individuals from \$907 to \$830 per month (income support upon which most IHSS consumers rely) generate considerable fear about not meeting expenses for not only health but also basic necessities such as housing, utilities, and food.

For many respondents, IHSS has meant the ability to live independently with debilitating conditions due to the daily assistance of their providers. Figure 1 illustrates that majority of consumers rely on IHSS to provide the capacity to live independently, and in their own homes.

Further, by getting assistance in daily living, consumers are able to stay safely in their homes and stay connected to their community. IHSS also helps them maintain a basic quality of life by helping with cleanliness and hygiene, and by allowing consumers to get help from family members instead of strangers. IHSS thus significantly helps consumers maintain their physical and mental health and allows them to remain an active member in their community.

Figure 1: What IHSS Means to Consumers



¹ This research brief is a summary of a report by Gerald Eisman, Anoshua Chaudhuri, and Grace Yoo entitled *Impact of Budget Cuts on the Lives of IHSS Consumers in San Francisco*. The full report will be available after June 15, 2009 on request from Institute of Civic and Community Engagement at San Francisco State University. This study was supported with funding from San Francisco IHSS Public Authority.

- **Reduction in IHSS means a loss of independence**

IHSS means I can live independently in my home, otherwise without IHSS, I would go to a nursing home. IHSS workers helped me with my daily activities such as bathing, preparing meals, do my shopping, going to the pharmacy for my medication, take me to the doctor appointment and they helped me with my house chores and personal hygiene.

- 102 year old female, Spanish

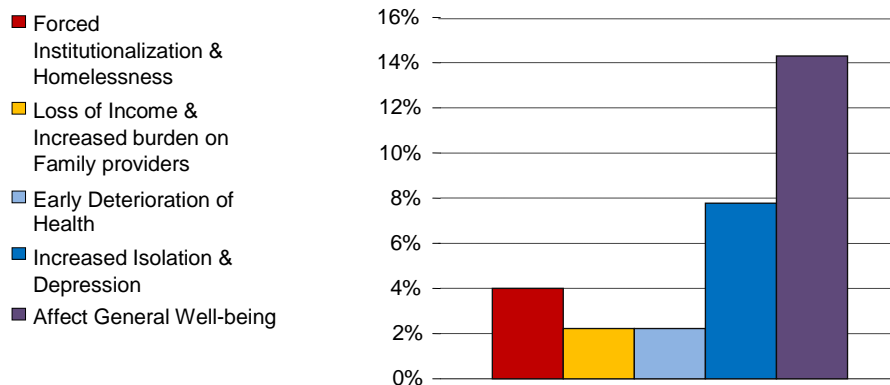
- **Reduction of IHSS means the loss of assistance in managing debilitating health conditions at home**

I am 80 years old with many diseases. I have glaucoma, hearing problems, high blood pressure, heart problems and joints and vertebra problems. And I had kidney operation and lost one of them. I need IHSS to help me and my life. The reduction will affect me a lot. To see a doctor, it's very difficult to me by myself, I need help to take care of. please do not reduce the hours.

- 81 year old female

Over 50% of IHSS consumers utilize family members as care providers. Although by law they are not paid for providing certain tasks otherwise covered by IHSS, family members are often essential in providing daily care to their disabled or elderly loved one. A loss of the use of a family member as a paid caregiver would mean a loss of fundamental comfort and trust that is badly needed by ailing and frail IHSS consumers. For many, family members are the only people they can depend on to know them well, treat them with love and respect, and truly protect their best interests.

Figure 2: What Would Happen if Family Members Could No Longer be a Provider



Reduction in paid family caregiver hours would mean the following for frail elderly and disabled adults:

- Loss of needed assistance would impact overall general well-being
- Increased burden on families
- Increased isolation and depression
- Forced institutionalization and homelessness
- Early deterioration of health

Respondents wrote lengthy responses of the difficulties that this would impose on them and their families.

My one and only child passed away about 7 yrs ago and my granddaughter is all I have left. If she couldn't be my provider it would be devastating because there are not enough trust worthy people in this world. But without IHSS she would have to work a second job that wouldn't let her come help me like she does. I'm grateful for IHSS. It helps her, help me! Arnold Schwarzenegger should be ashamed of himself! But I guess not because he can go to sleep at night without a care in the world.

-83 year old female, English

Right now my daughter is my provider. She is staying with me 24 hrs/ 7 days a week. She quit her job and lives with me as my provider with the doctor's advice that I need somebody not only to care for me during the day but also during the night. I have had a heart bypass, diabetes, nerve damage, and I can't walk without my walker. I have to urinate every 30 minutes especially during the night. I'm always dizzy. It's only my daughter who can stay with me for that kind of situation. Please try to understand, thank you.

-83 year old male, English

This survey also asked respondents how they felt about possible reduction to their SSI/SSP grants. More than half of the respondents wrote that a reduction in SSI/SSP grants would severely impact their lives. One quarter of the respondents said that it would be difficult to pay for basic living costs such as rent, utilities, transportation, hygiene and cleaning supplies and fresh food. A reduction in SSI/SSP would also negatively impact purchase of vitamins and alternative medical therapies that are not covered under Medi-Cal or Medicare.

- **Reduction to SSI/SSP will affect basic survival in the City and County of San Francisco**

The amount SSI provides causes me to live under the poverty level although I am grateful for the help, but it allows me at this rate to cover my housing and overhead (i.e. PG&E, ATT, Comcast basic TV), transportation (Bus pass) monthly, laundry, and very little food. There is rarely a time when I have any extra to go to coffee with a friend. I have no (zero) social life. If it was to be cut I would not be able to buy food and my out of pocket medications that are necessary for my illness. I will do anything in my power to vote accordingly or anything else that will prevent Gov. Schwarzenegger to apply cuts to this area. We are the poorest of the poor and illness combines with poverty is almost an overwhelming combination.

-Anonymous, English

Any reductions to In-Home Support Services and SSI/SSP grants will have a catastrophic effect on very low-income aging and other persons with disabilities in San Francisco City and County.