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# IHSS: Repackaging Consumer Information

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**IHSS: Repackaging Consumer Information** 

BH 645: Masters of Science in Behavioral Health Capstone

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## **Executive Summary:**

In-Home Supportive Services (IHSS) is a Medicaid funded program in California which provides personal care assistance to low-income elderly and young disabled adults (Benjamin & Matthias, 2002). The program enables Medicaid qualified individuals, also known as consumers, to hire home care providers at low-to-no personal cost (Hanchett, 2001). IHSS deviates from the traditional care deliveries such as provider agencies (typically an out-of-pocket cost), assisted living, or skilled nursing facilities (Benjamin & Matthias, 2000). The program is based on a consumer-directed care (CDC) model (Benjamin & Matthias, 2002) which places the control of care plan directly into the consumer's hands.

Despite the good consumer satisfaction rating throughout the state, IHSS consumer satisfaction surveys have indicated that many consumers are not satisfied with low the level of navigational support they have received from IHSS (Benjamin & Matthias, 2002). In response, SFIHSSPA is designing consumer navigation information to help consumers better navigate the IHSS program. The materials will be provided to new consumers after they have enrolled in the program. The communication channels will be multi-media based and shown during consumer orientations.

Original method included four focus group sessions preceded by a pilot group, with each sessions hosting consumers from the dominant race/ethnicity groups based on language.

Participants who were current consumers for up to one year, were San Francisco residents, and were willing to speak with the principle investigator and the bilingual interviewers without their provider present. However, the method proved to be unfit for the non-English speaking

participants. Additionally, some consumers had family providers navigating the IHSS as proxy. Because of these complexities, specific methods had to be created for the non-English speaking consumers which were a better fit for the different subgroups for these groups. Consequently, qualitative methods included focus group discussion and semi-structured in-depth interviews. Inhome supportive services (IHSS) social workers and counselors were shadowed and interviewed for primary research. Additional interviews were also conducted with consumer mentors from the Public Authority.

Results indicated that consumer interest in resource varied among different language groups. English speaking and Spanish speaking consumers, regardless of age distribution, were more likely to request information on hiring and supervising providers. Consumers also had differing behavioral responses to the qualitative survey process which also differed by race. Bivariate analysis also revealed that older consumer tended to hire family members as providers than younger disabled adults. However, all consumers did not understand the IHSS structure, including the agencies under the Medical program. Interviews with IHSS counselors, social workers, and mentors gave further information on consumers' journey through the IHSS program.

Based on the qualitative survey consumer information handouts were created to be delivered by IHSS staff to new consumers. Information handouts will be printed in English and other dominant non-English languages.

#### **Literature Review:**

**Consumer-Directed Program:** Consumer Directed home care (CDC) was created as a result of the efforts of persons with disabilities during the 1970s. These individuals demanded

the right to live independently and to have more integration into the mainstream society. Activists recognized that one large barrier to achieving this vision was the lack of long-term care services such as personal assistance support (Batavia, DeJong, & McKnew, 1991; Doty, Mahoney, & Simon-Rusinowitz, 2007). Historically, the group focused on pushing for broad changes within their community to achieve their vision. However, the work done to provide consumer directed personal care assistance came largely from health care professionals (Batavia, DeJong, & McKnew, 1991; Doty, Mahoney, & Simon-Rusinowitz, 2007). One of the largest efforts by the contemporary health care professionals were to push the federal government to adopt and fund consumer directed care CDC model programs nationwide (Batavia et al, 1991; Mahoney, et al, 2007).

The Consumer directed home care (CDC) model is designed to support consumers with personal care support in their homes under consumer supervision (Hanchett, 2015). Some personal support includes assisting in their activities of daily living (ADL) such as bathing, dressing, and transferring; and instrumental activities of daily living (iADL), including shopping, driving, and cooking. The model deviates from the traditional method of care delivery where consumers used agencies to deliver and manage their care plan.

Since its inception, the model's appeal has been high among consumers. Frail elderly and younger adults with disabilities are increasingly looking for ways to stay in their home rather than be placed in an institutionalized care (Benjamin, Matthias, & Franke, 2000; Batavia, DeJong, & McKnew, 1999). However, the program did not increase in size until 1992 under the Clinton Administration Task Force on Health Care Reform proposal. As a result, federal funding was largely redirected to increase more consumer directed programs in the country. One of the largest support from the federal government occurred when they established the Medicaid

Personal Care Servcies Benefit Option. This funding gave large funding into the CDC program through their community-based service waiver programs (LeBlanc, Tonner, & Harrington, 2001) funds. Since its adoption, 103 consumer-directed programs have been established in the United States (Low, Chilko, Gresham, Barter, & Brodaty, 2012). Medicaid programs in several states include coverage for the CDC models (Hanchett, 2001), thus the cost of the program is significantly reduced for consumers and their family members. Funding for these Medicaid programs have also increased (Applebaum, 1993). For example, Medicaid's Home and Community-Based Waiver program funds more home-based long term support services (LTSS) using the CDC model than institutionalized long term support services (Applebaum, 2002). With consumers having increased control over their personal care, the CDC program demands higher consumer responsibility for managing the outcomes from these services. Consumers are responsible to hire providers (in-home care assistants) who are paid through the program rather than out of pocket.

Depending on state requirements, consumers may have several CDC program options under the Medicaid program (Ottoman, Allen, & Feldman, 2013). However, all Medicaid covered CDC program is follow the same protocol for consumer enrollment. Eligible individuals are assessed by a registered nurse (RN) or a social worker, who are also called eligibility workers (Batavia et al., 1991). The assessment screens out individuals with acute health needs and individuals who cannot or will not be able to fulfill their role as the consumer. Although not typically denied, experts have also recommended that individuals who do not have a social network or are isolated are not suited for the model (Batavia et al., 1991).

California's CDC model approach - the In-Home Supportive Services Program: In-Home Supportive Services (IHSS) is a Medicaid funded program which provides personal assistance care services to qualified consumers. Qualified individuals include the frail elderly and disabled (including blind) California residents who have low income and receive Supplemental Security Income (SSI). Similar to other CDC models, IHSS includes personal care to assist with ADLs and iADLs, paramedical services, protection and supervision.

Consumer characteristics: IHSS consumers are a mixed population of older adults and younger adults with disabilities or mental health issues. Most have severe mobility impairment, multiple chronic illnesses, chronic incontinence and severe cognitive challenges (Borrayo, 2004). They predominantly reside in geographically isolated neighborhoods which are riddled with high crime and poor transportation (Mathias & Benjamin, 2003; Ottoman, Allen, & Feldman, 2009). Because of these limitations, family members who become care providers for their loved ones usually see becoming a care provider for their family member as an opportunity to acquire stable employment and health benefits (Matthias & Benjamin, 2003; Ottoman et al., 2009). However, this pattern is not replicated in UK-based CDC programs, suggesting that socioeconomic factors greatly influence how consumers utilize the CDC programs (Benjamin & Matthias, 2001).

Although the program is designed to promote independent living, one study found that consumers using the CDC model programs prioritized service provision rather than independent living (Newbronner, Chamberlain, Bosanquet, Bartlett, Sass, & Glendinning, 2011). This result supports the data showing that majority of consumers typically hire family members or friends as their care provider (Hanchett, 2015). The older consumers' capacities and skills vary widely and are shaped by their work history, medical status, and cognitive status (Benjamin & Matthias, 2001; Glendinning, Challis, & Fernandez, 2008). Long term care utilization differs by race and ethnicity. For example, African Americans and Hispanic older adults tend to utilize more community based long term care (LTC) than non-Hispanic Whites (Barroyo, 2004; Green &

Ondrich, 1990; McBride & Coughlin, 1994; Anderson & Kington, 1997). Sciegaj and his team (2004) performed a large qualitative study to determine whether race or ethnicity affected how consumers utilized CDC programs. According to their study, Chinese elders had the highest sense of autonomy and thus were more likely to enroll in a CDC model program. In contrast, Latino elders reported having the least sense of autonomy and had the most request for information about the program offerings and providers. African Americans also had a preference for CDC models and were more interested in exercising their supervisory roles over providers than the other groups (Sciegaj, et al, 2004). However, Sciegaj and his team (2004) did not observe any difference in program satisfaction among the groups. Instead, the study determined that consumers with the least control over their care plan had the strongest desire for a traditional case-management model. However, the study did not show how many of the program's consumers qualified versus how many had the option of choosing a case-management model.

Consumer satisfaction with the consumer-directed programs: Although CDC models provide consumers with more control over their personal care, the satisfaction level for these approaches have been mixed. This may be due to the different CDC model programs available in different states. There has been a generally positive correlation between consumer choice and consumer satisfaction. For example, several studies (Doty, Kasper, & Litvak, 1996; Benjamin & Matthias, 2001; Heuman, 2003; Hagglund et al, 2004; Simon-Rusinowitz et al, 2005; Brown, Carlson, Dale, Foster, Phillips, & Schore, 2007; & Wiener, Anderson, & Khatusky, 2007) found that majority of the older U.S. consumers were satisfied with their CDC model programs. However, other studies who have reviewed evaluations from CDC programs have found older consumers stated they were less likely to stay in consumer-directed programs than younger consumers (Brown et al, 2007; Davey, Fernandez, Knapp, Vick, Swift, Tobin, Kendall, et al,

2007; Glendinning et al, 2008, Newbronner et al, 2011). In California (Benjamin & Matthias, 2001), the majority of the older participants had lower favorability for CDC models, particularly for self-direction, and reported having fewer service options than younger participants. It wasn't clear whether the dissatisfied older consumers had existing family or social support or if they hired family as their care providers. However, the same studies found that both older and younger adults enrolled in the CDC programs had high program satisfaction.

In contrast, two other studies (Hagglund et al, 2004; Grossman, Kitchener, Mullan, & Harrington, 2007), found no variance between CDC directed care and agency-directed care for older participants. However, older adults tend to have multiple changes in their health conditions (Benjamin & Matthias, 2001) which may influence their level of satisfaction with CDC model programs.

Consumer's Ability to Navigate the CDC programs: Although several studies have examined consumers' satisfaction level have with the CDC model programs, there is sparse studies that have measured consumer feedback for program quality improvement. However, one study (Applebaum & Woodruff, 1993) determined that consumers were less likely to be forthcoming about their complaints regarding the CDC program even if they found their situation unsafe or unhealthy (Applebaum & Woodruff, 1993). However, this study is reflective of CDC programs in Ohio and may not be generalizable to California, much less IHSS. The study did highlight the importance of including consumer participation in quality improvement, and showed that consumers were capable of evaluating their care plan and were willing to share their concerns if asked (Applebaum & Woodruff, 1993). In another report (Carson, Foster, Dale, & Brown, 2007) older Floridian adult consumers reported experiencing delays in receiving care

through the CDC program due to administrative tasks such as completing enrollment forms for both themselves and their provider, hiring providers and accurately filling timesheets.

Gaps in delivering resources and support to new IHSS consumers have existed since the late nineties (Benjamin & Matthias, 2000). In one of the initial studies regarding IHSS consumers' navigational support (Benjamin & Matthias, 2000), new IHSS consumers compensated for the inadequate informational support by relying on informal support from family and friends in hiring, training, and supervising care providers (Benjamin & Matthias, 2000). In 2000, one in four IHSS consumers did not hire family or friends as their care providers and depend heavily on community support, resources and informal help to hire providers.

Although the study more than a decade old, the consumer make-up has remained stable (Torres, Ketzman, & Wallace, 2015). Apart from Consortium (now called Homebridge) and the Registry, the study did not identify other resources which IHSS provides to their new consumers. Despite these gaps, the study recommended the IHSS program due to the generally positive reviews by the consumers.

Previous recommendations for filling the service gap: Older consumers' fluctuating health can impact how prepared they will be to deal with emergencies, such as when their care provider doesn't show up or if they want more authorized home care hours. Such changes can seem catastrophic to consumers. To address these concerns, Benjamin and Matthias (2000) recommend that 'contingency plans' are created by IHSS and other CDC programs. Another study (Desmond, Mahoney, Simon-Rusinowitz, Shoop, Squillace, & Fay, 2000) recommended that CDC programs assist their clients in executive tasks such as finding, interviewing, hiring and supervising care providers. The authors further recommended that consumer advocacy and sympathetic services should be provided via case managers or peer led support (Desmond et al,

2002). Other studies (Sciegaj et al, 2004; Foster, Brown, & Shapiro, 2005; Simon-Rusinowitz et al, 2005, Brown et al, 2007) also recommended to provide administrative support which will help new consumers, particularly older adults, better navigate through CDC programs and have a higher satisfaction with the services.

One study (Phillips, Mahoney, Simon-Rusinowitz, Schore, Barrett, Ditto, Reimers, & Doty, 2003) which evaluated the CDC programs in Arkansas, Florida and New Jersey recommend consumers are provided with information materials that use plain language with easy terms to describe the program. In addition, the study also found that information delivery to consumers were more effective when it was customized to each user. When comparing delivery between in person and over the phone, the study determined that home visits were a more effective and efficient method of explaining the program and assisting the consumers with their concerns (Phillips et al, 2003)

Several assessments of written health information materials show that consumers do not have access to plain-language materials. In fact, most of the health information materials are unsuitable for consumers with low literacy (National Institute of Health [NIH], 2012). By ensuring the document follows the plain language format, it will be able to target a wider audience (DeWalt, & Hink, 2009). The design components include the layout, text, color, and also images. Layouts can also be customized to be relevant with different culture (National Institute of Health [NIH], 2012). In fact, individuals with low literacy or who do not have English as their first language prefer to use pictures and simple presentation (National Institute of Health [NIH], 2012). Designing information materials for consumers, it is important to consider the diffusion of such materials, its usability and also the level of access consumers have to such information.

Since majority of the consumers experience cognitive issues or are from low socioeconomic status (SES) homes, it is important that materials designed for these individuals address the difficulties they may experience understanding the information. Some studies (Cutilli & Schaefer, 2011; Hart, Blacker, Panjwani, Torbit, & Evans, 2015; Sobel, Paache-Orlow, Waite, Rittner, Wilson, & Wolf, 2009) have recommended using multimedia components for delivering health and administrative information. However, further evaluation of multimedia interventions showed an increase in knowledge only among individuals with higher literacy than with individuals with lower literacy. In fact, a 2005 national survey (Kaiser Family Foundation) shows only fifteen percent of older adults with income less than \$20,000 used the internet while nearly sixty percent of older adults with income higher than \$50,000 used the internet. Although multimedia platforms are a low fit for current low literacy aging consumers, it may still be an important platform for younger adult consumers with disabilities who have high technological skills or use technology to perform their daily tasks. For example, younger adults with low vision have shown to greatly benefit from computer based materials because they are able to manipulate documents to make them larger. And with the advent of funded programs offering people with disabilities assistive devices and software, consumers are able to access information that used to be only available on traditional platforms.

## **Agency Profile:**

**Background:** In Home Supportive Services Public Authority (IHSSPA) is a Medicaid funded program which assists low-income elderly and disabled adults who need assistance to continue living at their residence after change in their physical/health status. The program ensures its target population (consumers) as much autonomy and independence in order to remain in their residence. This option is much more desirable than the alternative of out-of-home

care in institutionalized settings (ex: skilled nursing facilities, boarding care). IHSSPA is a consumer directed personal assistance program (CDPAP), meaning that the consumers have majority control in the program through membership, voting, decision-making in meetings, and board member representation. San Francisco In Home Supportive Services Public Authority [IHSSPA] assist consumers match to independent providers (IPs) who deliver assistance such as grocery shopping, housekeeping, transportation to doctor's appointment, personal care and protective supervision (for individuals with a cognitive impairment).

**Programs and Services:** San Francisco In Home Supportive Services Public Authority (IHSSPA) will assist consumers to be matched to IPs but will expect the consumer to interview, hire, train, supervise and terminate the IPs. Public Authority provides crucial support to IHSS consumers. First, the PA houses the Central Registry, which is an online database of IPs who have been screened and available to consumers upon request. Second, the PA has an on-call program which offers last minute care provider services to consumers who may require urgent or last minute independent provider support. Examples of urgent provider support include when a provider does not show up to their consumer's house, or if the consumer requests an urgent request for an IP. The latter situation is typically for new and existing consumer who are being discharged from the hospital and need immediate in-home support. Due to the urgent need, consumers are not involved in the interviewing/hiring process. Instead, SFIHSSPA will quickly match IPs to consumers based on their needs. Third, the SFIHSSPA provides the Registry services; a program similar to Central Registry, the Registry services is a list of IPs are given to individuals who do not qualify for IHSS-PA for a small fee. Fourth, the IHSSPA is also the IPs' Employer of record. Essentially a union service, the IHSS-PA negotiates pay rates with

consumers on behalf of the IPs, ensures independent provider rights, and offers health and dental insurances (after consecutively working for a minimum of three months).

The Public Authority also provides provider and consumer support throughout the city. For example, SFIHSSPA holds consumer and provider workshops in the city's senior centers. Additionally, SFIHSSPA conducts free training classes through their partnership with the Homebridge. Along with provider training, Homebridge is a San Francisco based non-profit agency contracted with the city and Medicaid to provide personal and non-personal care to elderly and disabled adults who are unable to hire and manage IPs by themselves. San Francisco's In-Home Supportive Services, Public Authority (IHSS-PA) also has a mentorship program which offers consumers workshops and trainings about their roles as a consumer, including training in basic computer skills, employer information, and health and well-being classes. However, the Mentorship program is reorganizing and will eventually include workshops that will teach consumers how to find, enroll and supervise independent providers. Lastly, SFIHSSPA perform several outreach programs, including meeting with policymakers, state legislators, senators and assemblymen regarding agency's work, funding, and reform proposals. The primary outreach is conducted via media, including Facebook, twitter, Instagram, and their agency website.

History, Vision and Mission statement: IHSS-PA was created by the push of former IHSS Executive Donna Calame in the 1990s to provide consumer-majority services for low income seniors and disabled adults looking for personal care and other non-medical supportive services (San Francisco In-Home Supportive Services Public Authority [SFIHSSPA], 2016b). By 1995, IHSS created the first Public Authority (PA) program where consumers had more power in defining care and the delivery of care services to them ([SFIHSSPA], 2016b). This format, called

the consumer-directed program, also encouraged better work and pay for IPs, resulting in union contract, comparable IP wages and health and dental coverage for IPs. By 1996, Public Authority established the Central Registry for its consumers ([SFIHSSPA], 2016b). Following its success, the agency developed their on-call system a year later.

Public Authority envisions "people [who] live independently at home, in homes of their choosing, and participate in their communities with the hands-on assistance of others" (California In-Home Supportive Services Consumer Alliance [CICA], 2016). Its mission is to "provide and promote a service delivery model of consumer directed, in-home support that maximizes the potential of older adults and people with disabilities to live independently and participate in their communities" (San Francisco In-Home Supportive Services Public Authority [SFIHSSPA, 2016a). The program's objectives are as follows (Dearman, 2015): Internal members:

Staff make-up: The organization is made up of 16 paid employers consisting of full-time and on-call mental health counselors, fiscal & operations manager, program manager, human resource manager, executive director, and administrative coordinator (Dearman, 2015). Their responsibilities include Central Registry maintenance, fiscal business management, tracking state and/or local policy affecting IHSS, partnering with other local organizations to update consumer/IP resources (Dearman, 2015). Additionally, the agency has a paid 10-member governing board which is a mix of consumers, public agency representatives, worker and union representatives (Dearman, 2015). The primary goal of the governing body is to represent and make legal decisions on behalf of the SFIHSSPA.

Consumers and Independent Providers. Majority of the consumers are Chinese, Caucasian (including Russian), Latino and Filipino who predominantly speak Cantonese,

English, Russian and Spanish, and Tagalog, respectively (Dearman, 2015). Nearly three quarter of the consumers are over the age of sixty-five, and a third over eighty years old (Dearman, 2015). Almost two-thirds are females and nearly two-fifths have disabilities and require personal assistance and housekeeping support (Dearman, 2015). The predominant racial make-up of IPs includes African-Americans, Latinos and Asian/Pacific Islanders. Nearly nine out of ten IP is female, with the average age of 51 (Dearman, 2015).

Changes occurring at the agency level: Public Authority has gone through a few staff restructuring. First, Executive director Kelly Dearman has hired two employees as the mentor liaison and mentorship/Onestop supervisor. The latter position was created by Kelly Dearman who wanted to have someone oversee the new Onestop project. At present, the mentorship is a semi-active program which periodically holds consumer training information at local senior centers. However, the current consumer trainings have been put on hold as the Mentorship program undergoes administrative changes. Both the Executive Director and Onestop program supervisor envision a Onestop program which will provide informational support to consumer via in-person, phone, or home visits. Consumer trainings will still be a component of the program. However, the format may shift to include on-site classes at the PA site rather than the senior centers. No assessments have been conducted to see how the consumers may utilize/want/navigate the proposed program. For example, the mentorship supervisor wants to have majority classes and support on site but don't know if this would be feasible for the consumers.

**Funding and Expenses Overview:** Over half of the subsidy comes from federal funding (56%), while the rest are pooled from state (4%) and city/county funds. According to the last fiscal year (Dearman, 2015), majority of the capital was allocated towards worker health and

dental benefits for the IPs (95.77%), while the remainder was spent on service program maintenance, staff payroll/benefits, and other administrative costs.

## **SWOT Analysis:**

San Francisco In Home Supportive Services Public Authority is an established branch of IHSS that has a strong reputation of supporting its consumers to ensure they have a positive experience navigating the IHSS program. As part of that mission, Executive Director Kelly Dearman is focused on making sure that this study is well-supported. The Public Authority staff has a very collaborative culture where individuals are encouraged to share information across departments. Interns are encouraged to join the sharing system and are also encouraged to seek out staff to collaborate with on various studies. Due to these factors, the study had open access to multiple staff members with various skills and knowledge who assisted in the development and completion of the study.

Because of the nature of the project, the Mentorship and Onestop program department were keen on learning what results this needs analysis would garner. As a result, the program evaluator collaborated with staff from that department to recruit and conduct the focus group pilot test. Funding for participation compensation and focus group materials was not an issue either. Budget for mentor's hours was part of the general fund. However, the agency approved mentors paid time to assist with the needs analysis for the 2015 fiscal year.

One major factor which proved difficult was the number of consumers that had difficulty in attending the focus group due to health issues, appointments, or both. This was particularly high among non-English speaking group, where older and typically appointed their family members as proxy to navigate the program. Due to these limitations, the needs analysis method had to change from focus group method to in-depth interviews where consumers were given the

option of conducting the interview either on the phone or in-person. The methods also had to adjusted to include family consumers during the in-depth interview since some of the consumers had their family members navigate the program by proxy.

There were some factors which impeded the project's goals. First, the project required commitment from Public Authority mentors to complete the data collection. However, the mentors had limited hours due to their prior commitment to other Public Authority projects. As a result, their hours of availability were short and spread out. The needs analysis required three non-English translators. However, another fiscal year started in August which created budgetary constraints and limited availability. As a result, only two mentors were secured for the non-English portion of the needs analysis for Spanish and Cantonese participants.

See Appendix D for SWOT Analysis

#### **Problem Statement:**

Newly enrolled consumers are unprepared to navigate the IHSS program. As a result, these consumers struggle to retain independent providers and are likely to have higher provider turnovers. In turn high provider turnovers can result in either consumers losing their program eligibility. Consumers who are unable to retain IHSS providers are more likely to experience health emergencies and are also more likely to lose their home. This problem is compounded by the limited information materials currently accessible to consumers. Although the information is available, it is not accessible by majority of the consumers. In fact, majority of the resources and its delivery platform are more accessible for individuals with high literacy and high socioeconomic status. This is not reflective of the IHSS consumers.

San Francisco In Home Supportive Services Public Authority participates in a statewide biennial quality assurance program. The data is used by the California Department of Social Services (CDSS) to see how cases are efficiently managed with minimal gaps in services (California Department of Social Services [CDSS], 2016). In 2015, IHSSPA conducted a consumer satisfaction survey to determine what consumers would like more information on regarding the IHSS program. The results showed consumers had interest in receiving IHSS information materials (California Department of Social Services [CDSS], 2016). However, the survey did not explore the navigation gap within IHSS. Thus, no data exists on what are the concerns for new IHSS consumers and how they would prefer to access this information. In order to answer these questions, needs analysis must be conducted with new IHSS consumers regarding their experiences with navigating the program, and their platform preferences for consumer information materials.

See Appendices A & B for Gap Analysis

### **Goals and Objectives:**

The project was originally divided into two goals. The first goal focused on collecting qualitative data via various methods to understand what information new IHSS consumers need after enrolling in the program. However, initial data collection proved to be an insufficient method for assessing the target population. To close the gap, other data collection methods were designed and used. Interviews with IHSS staff were also conducted to ensure that the data collected accurately identified the information gap among the targeted population. The second goal focused on designing deliverables that will be a good fit for new IHSS consumers. By the end of the project, 25 consumer information handouts were created for use by new IHSS

consumers. In addition, two storyboards were created for videos that would complement the consumer information handouts.

Goal #1: Conduct Formative evaluation to design orientation materials for new IHSS consumers.

- By March 15<sup>th</sup> 2016, complete a 1 1.5 hour long pilot focus group with English
   Speaking consumers regarding their experience with navigating the IHSS program.
- By March 19<sup>th</sup>, 2016, identify at least three existing online and hardcopy education materials or resources for newly enrolled IHSS consumers.
- By May 10<sup>th</sup>, 2016, conduct one 3-hour long focus group with English speaking consumers regarding their experience with navigating the IHSS program.
- By June 3<sup>rd</sup>, 2016, complete two interviews with IHSS social workers at the IHSS department.
- By June 6<sup>th</sup>, 2016, shadow one IHSS social worker during an in-home intake and assessment appointment.
- By June 28<sup>th</sup>, 2016, complete 4-6 one-on-one interviews with Spanish speaking consumers by phone or in-person regarding their experience with navigating the IHSS program.
- By July 1<sup>st</sup>, 2016, complete 4-6 one-on-one interviews with Cantonese speaking consumers by phone or in-person regarding their experience with navigating the IHSS program.
- By July 8<sup>th</sup>, interview all three translators (Spanish-, Cantonese-, and Russian- speaking PA mentors) about the Spanish, Cantonese, and Russian speaking consumers, respectively.

• By July 12<sup>th</sup>, 2016, complete 4-6 one-on-one interviews with Russian speaking consumers by phone or in-person.

## Goal #2: Create education materials for newly enrolled IHSS consumers

- By April 8<sup>th</sup>, 2016, identify at least two multimedia formats which will be used for the consumer education materials.
- By April 18<sup>th</sup>, 2016, create a concept design for at least three consumer information handouts.
- By April 22<sup>nd</sup>, 2016, design 30% of consumer training materials.
- By May 18<sup>th</sup>, 2016, complete 60% of consumer training materials.
- By June 12<sup>th</sup>, 2016, complete 100% of consumer training materials.
- By June 8<sup>th</sup>, 2016, complete draft for consumer and staff checklist.
- By June 24<sup>th</sup>, 2016, propose concept design for two consumer informational videos.
- By July 12<sup>th</sup>, 2016, present deliverables at the governing board meeting.

# Goal #3: Create information checklist for newly enrolled IHSS consumers and staff

- By June 10<sup>th</sup>, 2016, propose concept design for consumer and staff checklist.
- By July 6<sup>th</sup>, 2016, submit checklist drafts for feedback to preceptor and key PA staff.
- By July 12<sup>th</sup>, 2016, present checklists at the governing board meeting.

# See Appendix C for Goals and SMART Objectives

#### **Methods:**

The purpose of the study was to identify what information new IHSS consumers needed and how they wanted the information delivered to them. The study used multiple qualitative methods to collect data which helped create deliverables for the consumers.

The qualitative methods used in the study were one focus group and multiple in-person and over the phone in-depth interviews. The focus group and pilot focus group study focused on identifying information most needed by new consumers and the best delivery platform among English speaking consumers. The study had also planned to conduct focus groups with other non-English speaking consumers, particularly the Spanish-, Cantonese-, and Russian-speaking consumers. However, the focus group design deemed an unfit method for non-English speaking consumers. In order to gather similar data from the remainder of participants, the study opted to conduct in-depth interviews either in-person or over the phone. The in-depth interviews also focused on identifying information most needed by new consumers including the best delivery platform among non-English speaking consumers.

Materials for methodology: Topic areas for discussion were extracted from the California Department of Social Services (CDSS, 2011). Informed consent was adapted from the focus group, research, and evaluation guide by First Work (First Work, 2011). Focus group guide was created using the guide sample from University of Pennsylvania (University of Pennsylvania, 2016). Audio recording was recorded using an iPhone and a PC laptop.

**Materials for deliverables:** Handout layout was designed using the guidelines for senior friendly written materials set by the National Institute on Aging [NIH] (NIH, 2008)

Senior friendly materials: National Institute on Aging (2008). Handouts were created using the Microsoft word software. Handouts were created in both word documents and pdfs for online publication and easy printing. Usability testing was conducted with five IHSS consumers to test the material's population and content fit.

Two storyboards and scripts were created based on selected topics complementary to the handouts. The storyboard was created using the Storyboard That program. Script was drafted using a Microsoft Word program then incorporated into the storyboard. The video uses roleplaying to teach consumers tips and information on the IHSS program. The role modeling employs Albert Bandura's Social Cognitive Theory, which postulates that an individual is able to modify his or her behavior by observing another complete the modified behavior successfully (Bandura, 1988). The storyboard design is crafted around the modeling concept that will increase an individual's self-efficacy to complete a behavior (Bandura, 1988).

See Appendix S for Consumer Information Handout Sample

See Appendix T for Storyboard

Sample: All participants were current IHSS consumers who had enrolled between March 2015-March 2016. Consumer contact information (name and number only) were provided by the SFIHSSPA Human Resource manager. However, the generated list had many outdated contact information which prompted the study to include screening questions as part of their study invite. The study recruited consumers from four language groups: English, Spanish, Cantonese, and Russian. The language groups were chosen because majority of IHSS consumers speak these languages. The qualitative research methods included one pilot study, one focus group and multiple in-depth interviews. One of the requirements for the focus group was that consumers

must have navigated the IHSS program by themselves. This requirement was not observed for the in-depth interviews as many non-English speaking consumers relied on family members as their proxy program navigators. However, no paid providers were invited to participate in the data collection methods as it may have generated conflicts of interest with other consumers. Consumers were not excluded based on their disabilities unless they were observed to have difficulty with comprehension and memory during the focus group and in-depth interview invites.

**Recruitment:** Invitations for pilot study, focus group and semi-structured in-depth interviews were conducted over the phone. The recruiter would introduce himself or herself as a member of the IHSSPA. After the introduction, the recruiter stated his or her reasons for calling, and offered an invitation to participate in either a discussion. Pilot study and focus group invites were only provided to the English speaking consumers while the semi-structured in-depth interviews were offered to the non-English speaking consumers. Reasons for decline were logged. If participants were interested, consumers were then screened to see if they could complete the participation through a self-report questionnaire. During the screening phase, consumers were asked if they would be able to sit long periods of time, if they were current consumers, and if they would feel comfortable participating without their care provider present. Individuals were also informed about focus group or interview process and asked if the consumers would feel comfortable participating. If answered no, the invite would be terminated, the consumers thanked and the phone call would be ended. If answered yes, consumers would then be provided with pilot study and focus group times. For the in-depth interviews, participants were given the option to choose a day and time for an in-depth interview. Consumers were also given the option to complete the in-person interview at the Public Authority headquarters or at a

location of their own choosing. Lastly, consumers were notified of the \$15 gift card and refreshments (pilot test and focus group only) to the consumers.

Pilot study: The method was used to determine which information new English speaking consumers needed and how they wanted the information delivered to them. The pilot study was conducted at the Public Authority Headquarters. The test study was designed to be 2 hours in length. All materials, including the focus group guide, focus group questions, and informed consents were drafted with the co-facilitators Renesha Westerfield and David Arajuo and Program Director Kathleen Raffel. A laptop was placed in the room with a recording feature active. Refreshments were specifically chosen to be suitable for individuals with diabetic health conditions.

Participants and co-facilitators sat around a large table facing each other, arranged in a circle format to encourage group atmosphere among participants a copy of informed consent, a ball point pen, and a name tag were placed at every sitting. A group of eight topic areas written per paper were placed in front of all seating. Participants were encouraged to read the informed consent by themselves. After everyone were sitting, the co-facilitator began with an introduction to the focus group design. The principle facilitator read aloud an introduction and focus group overview. After reading the introduction, the co-facilitator read the informed consent out loud. Participants read the informed consent along with the principle facilitator. After the facilitator read the informed consent, she paused for questions or concerns. After answering the participant's questions, the principle facilitator asked all participants to sign the sheeting. After all the participants signed the informed consent, the principle and co-facilitator collected the signed sheets from the participants. Once she received all signed consent forms, the co-facilitator turned on her video recording. Next, she described the layout of the pilot study and then asked

each individuals to take the list of topics written on the sheets in front of them and prioritize the topics based on personal interest. Participants were instructed to look at all eight topic areas and arrange them on their desk from left to right, with the least interesting topic on the left and increasing interesting topic on the right. Participants were given three minutes to complete this activity. After the three minutes, the results were tallied and the order of topic areas for questioning was established. Participants were asked three specific questions for each topic areas: what information they received on the topic, how did they receive this information, and what information were they looking for. The pilot study concluded almost two hours later, whereby each participant was given a \$15 value gift card.

Modifications after pilot study: Based on the pilot study, a few adjustments were made for the focus group method. First, the time length was increased from two hours to three hours to accommodate late comers. During the pilot study, all participants used public transportation to reach the site and were unable to reach on time. Also, the co-facilitators were unable to ask all of the questions. Second, a larger pool of consumers was invited to participate in the focus group. Of the eleven participants invited, only four showed up to the study. Instead, the number of confirmed participants was increased to nineteen to ensure a minimum of six participants arrived for the focus group. Participants also suggested that some of the topics were similar and could be combined instead. Many felt they were repeating themselves and noticed a lot of their answers had overlap for certain topics. Additionally, the participants felt that there were too many topics to cover in one setting. Thus, the topics with similar were combined themes in order to not confuse the participants during discussion.

**Focus group design:** The principle facilitator introduced herself and the two co facilitators to the participants. After introduction, the facilitator read the introduction and

described the focus group layout. The principle facilitator then paused for questions. Next, the facilitator read the informed consent out loud while the participants read from their forms. After reading the consent form, the principle facilitator paused for questions. Next, the principle facilitator asked participants to sign the consent form. Following the autographs, all consent forms were collected by the principle facilitator. The video recording was then activated and the co-facilitator was asked by the principle facilitator to record observation notes. The principle facilitator completed an ice-break activity followed by a brief outline of the focus group. Next, the principle facilitator asked participants to provide feedback on selected topic areas in an interactive session. The session lasted 2.5 hours in length with a ten-minute bathroom break. Following the interactive feedback session, the principle facilitator requested participants write down what information they would have liked as a new IHSS consumer and how would they want to receive this information. The principle facilitator gave the participants a few minutes to complete this activity.

The principle facilitator assisted one participant who was unable to write during this activity. After all participants had stopped writing, the principle facilitator asked the participants to read their list to her. All feedback was recorded on the whiteboard. After all feedback was recorded, the principle investigator notified the end of the session and thanked the participants for their feedback and time. The recording was terminated at this point. However, participants were asked to not leave until they had received a \$15 gift card.

Interviewer training: Two SFIHSSPA mentors were trained to conduct semi-structured in-depth interviews to the participants. Trainings were conducted in two sessions. The first session was designed as a question and answer portion with the mentors and a introduction to the study's purpose, objectives; and the interview implementation process including recruitment,

screening, and interview procedures. During the second session, mentors observed the principle investigator while she conducted phone interviews with the English-speaking participants, performed a role-play with the participants regarding the interview process, and asked any questions to the principle investigator regarding any of the interview implementation phases.

Semi structured in-depth interviews: All semi structured in-depth interviews were conducted with the principle investigator and a translator who spoke the participant's language. The translator introduced himself or herself and the principle facilitator to the participant and spent a few minutes having an informal conversation to increase the participants comfort level and willingness to share their experiences. Next, the translator informed the participants the reason for the interview. The translator then asked the participants if they had any questions. After answering the interviewees' questions, the principle investigator read the After answering their queries, the translator asked the prepared questions to the interviewee. The translator would then inform the principle investigator of their response in English. The principle investigator would then ask a follow-up question which the interpreter would ask the interviewee in their native language. The translator would pause to after each question for the interviewee to respond. Responses were then translated into English. The process repeated until the principle investigator was satisfied with the responses. After the questions were answered, the principle investigator asked the translator to notify the interview of the completion of the interview. The interviewee was provided with a \$15 gift card.

Analysis: Audio recordings from the focus group and semi structured in-depth interviews were transcribed by the principle investigator using Microsoft word and iPhone. Texts were fist analyzed for initial coding based on participant's activities. The categories were then focused to activity coding. Coding was conducted using OneNote for note taking, transcription, Microsoft

Word for data input in a table format. Analysis were presented at the Public Authority governing body meeting.

See Appendix I for GANTT Chart

See Appendices E, P, Q, R for Focus Group and Interview Invite (Russian, Spanish, Cantonese).

See Appendices M, N, O for Focus Group/Interview Questionnaire (English, Spanish,

Cantonese, Russian)

See Appendices G, J, K, & L for Informed Consent (English, Spanish, Cantonese, Russian)

See Appendix F for Focus Group guide

## **Findings:**

The study aimed to determine what information new IHSS consumers need after enrollment. Specifically, the study identified topic areas consumers needed to have knowledge about in order to improve their experience navigating the program. The study also aimed to understand what platforms new IHSS consumers would use to access this information.

**Demographic Breakdown:** Nearly forty-three percent (129 out of 297) Consumers responded to the invite. Of the 129 responses, 99 declined to participate due to poor health (38), schedule conflict (17), lack of interest (19), transportation issues (5), change in enrollment status (6), and death (3), and other (11). Data was collected from the remainder thirty participants. From the data collected sample, four were excluded due to insufficient responses. Analysis and coding was completed on the remaining twenty-six participants' recorded feedback.

Age distribution was much narrower among non-English speaking consumers (71+ years) than English speaking consumers (30-75 years). All but one Non-English speaking participants were between seventy-five and ninety-eight years old. In contrast, the youngest English speaking participant was thirty years old and the oldest was seventy-four years old. Sixty-five percent of all participants were female. Female participants were recorded higher among all language groups except for Cantonese, where the distribution was equal. Most of the participants identified as either being widowed, divorced, or separated. However, a breakdown by language showed that the trend only remained among the Russian speaking participant population. In contrast, other language groups showed a higher prevalence of participants who identified as either divorce/widowed/separated or never married. Eighty-five percent of all participants had hired a family member as their paid care provider. However, a breakdown by language sowed that the trend remained among all non-English speaking groups only. In contrast, all English-speaking participants had hired their providers through the IHSS (see Table 1).

Table 1. Demographic Breakdown of Consumer Participants by Age, Gender, Marital Status, and Provider

	English	Spanish	Cantonese	Russian	Total			
	0 -	-1						
	6(23%)	6(23%)	6(23%)	8(30%)	26(100%)			
Age								
>55	5 2(33%)	0(0%)	0(0%)	1(12%)	3(12%)			
55-60	0(0%)	1(17%)	0(0%)	0(0%)	1(4%)			
61-65	5 0(%)	0(0%)	0(0%)	0(0%)	0(0%)			
66-70	0(%)	0(0%)	0(0%)	0(0%)	0(0%)			
71-	4(66%)	5(83%)	6(100%)	7(88%)	22(84%)			
Gender								
Male	e 2(33%)	1(17%)	3(50%)	3(38%)	9(35%)			
Female	e 4(67%)	5(83%)	3(50%)	5(62%)	17(65%)			
Marital Status								
Single	e 3(50%)	1(17%)	1(17%)	1(13%)	6(23%)			

Divorced/Widowed/ Separated	2(33%)	3(50%)	3(50%)	5(62%)	13(50%)
Never Married	0(0%)	2(33%)	2(33%)	0(0%)	4(15%)
Married/in	1(17%)	0(0%)	0(0%)	2(25%)	3(12%)
relationship					
Living Status					
Alone	5(83%)	3(50%)	2(33%)	2(25%)	12(45%)
Family/Friends	1(33%)	3(50%)	<i>2</i> (33%)	3(37%)	9(35%)
Not Sure	0(0%)	0(0%)	<i>2</i> (33%)	<i>3</i> (37%)	5(20%)
Provider					
None	<i>0</i> (0%)	<i>0</i> (0%)	<i>0</i> (0%)	0(0%)	0(0%)
Paid Family Worker	<i>6</i> (100%)	4(66%)	<i>6</i> (100%)	<i>6</i> (75%)	22(85%)
Non-Family Paid Worker	0(0%)	2(33%)	0(%)	<i>2</i> (26%)	4(15%)
Other	0(%)	<i>O</i> (0%)	<i>O</i> (0%)	0(0%)	0(0%)

Consumer role and responsibilities: Consumers felt that there was no official briefing on the roles and responsibilities of a consumer and thus did not understand the scope of their new role. They also stated that they assumed being a consumer meant that they were responsible for figuring out how to navigate the IHSS system on their own. One participant had recently transferred to the Homebridge program, an agency which recruits, hires, trains and monitors Independent Providers for Consumers who are unable to do so. She lamented on the loss of freedom to hire her own Provider, but is very happy to have a point of contact at the Homebridge office whom she can call and ask for advice on any consumer related concerns. "If, you know, I had been told [how to hire and train providers] earlier, then I may not have to be [in Homebridge]. I miss not having to be my own care boss."

The result was found not to be the same among non-English speaking consumers. Half of the Cantonese-speaking consumers stated receiving information regarding consumer roles and

responsibilities. All who reported receiving the information stated that their social workers had provided them with the information. The information was in a literature format but was explained by their social workers in-person. However, Hispanic groups had a dissimilar experience. All except one user reported having received information regarding consumer roles and responsibilities. Russian speaking consumers reported a similar experience as the Cantonese speaking consumer group. They reported receiving information from their social workers through the mail. All groups stated that information regarding consumer roles and responsibilities would be important for new IHSS consumers to receive after enrollment.

- Provider role and responsibilities: Majority of the consumers reported having insufficient information regarding provider roles and responsibilities. Consumers typically reported having high dissatisfaction with what providers would and would not do for them.

  Consumers perceived caregivers who refused to complete certain tasks as lazy, unreliable, or money-hungry. "They just want to sit nice. They don't wanna do nothin'. But that's okay cuz we don't want [the care provider] to do nothing if she don't wanna do anything." Results were consistent for each individual language groups as well. Consumers reported having confusion about what roles their providers can complete. For example, consumers are not aware that a provider will only complete tasks which are specifically authorized by the Consumers, even if the tasks they wish the provider to complete are typically covered under the IHSS program. "She can cook, she can clean, she can help my mama. But she say no, she won't do that cuz she wasn't supposed to do that."
- Meeting and interviewing providers: Most consumers stated they had not received any information on how to meet and interview providers. Many did not know how to have negotiate tasks or interview caregivers. "[Providers] just start asking me about my hours.

How much hours do you have? How much work will it be?" In particular, English speaking consumers felt the most overwhelmed with meeting and interviewing providers. Many did not know whether it would be appropriate to invite providers to their home or meet outside for the initial interview. "Can I tell you [about my interviewing experience]? I don't, like I don't feel safe having them in my house the first time. Who knows who they are. Maybe I can meet them somewhere else? I don't know." English speaking consumer reported feeling pressure to appear compromise with their desired care plan out of fear of not securing a provider. One participant mentioned that he did not receive any information or tips on how to undertake these steps in the five years he has been an IHSS consumer: "It's sort of....you're on your own." This sentiment was held by majority of the English-speaking consumers. Spanish-speaking consumers also had similar experience with their care providers. However, both Cantonese and Russian speaking consumers had higher satisfaction with meeting and hiring providers.

Consumers acknowledge that although they are given a comprehensive list of providers (A.K.A Registry) they find themselves spending an inordinate time going through the list to get viable providers. Consumers also noticed that there was a high turnover in provider with low retentions: "When I was looking [for a provider] ....I've go through fifteen in one year." It was common among these participants to have surplus hours left unassigned. Consumers also shared their dissatisfaction in receiving a list of providers to hire without any additional supportive information.

Supervising providers: All English speaking consumers reported never receiving information on how to supervise the care providers. Many stated that the information might have helped them feel a little less uncomfortable about discussing the tasks and schedule. Spanish speaking consumers reported not receiving the information either. In contrast, both Cantonese and Russian speaking consumers also reported receiving this information through their social workers or family members who navigated the IHSS program by proxy. Both groups further admitted that they did not seek information on how to supervise consumers as they typically have family members or friends who manage the caregivers on their behalf.

- Communicating with providers. Participating consumers stated that they did not receive any materials regarding ways to effectively communicate with providers. This was similar across all language groups that were interviewed. However, preference for this information varied across the language groups. English speaking consumers stated they would have preferred to receive information on how to effectively communicate with their provider. Spanish speaking consumers expressed the similar interest in receiving this information. In contrast, both Russian and Cantonese speaking consumers did not express a desire to receive information on communicating with the providers. However, all consumers recommended that the information should be provided to the new IHSS consumers.
- Building healthy relationships with providers: "[Building healthy relationships with providers] is the only way I have them with me." English speaking consumers reported that they did not receive information on how to create and maintain healthy relationships with their providers. They acknowledged this information would be important for new IHSS consumers to have. However, no English speaking consumers had no knowledge that IHSS provided information on this topic. All Spanish speaking consumers also had no knowledge that the information was available through the IHSS. However, the Spanish speaking consumers did not consider looking for information regarding this topic and thus did not try to ask for this information material. Both Russian speaking consumers and Cantonese

speaking consumers did not seek this information. They too did not know that IHSS provided information on this area. However, consumers from both language groups did not think the topic area to be an important for them. Despite their disinterest, they did recommend that new IHSS consumers receive information on how to create and maintain healthy relationships with their providers.

- relationship with providers, but felt that achieving this required better screening during the hiring process. Consumer participants expressed feeling unsure as to the best way to communicate their needs and requirements with their providers and most often felt they unconsciously let the providers lead the communication. Consumer participants also expressed concerns about how to comfortably relay any concerns they may have to the providers, especially if they were unsatisfied with the provider's work or communication style.
- Consumer safety. No consumer received any information on consumer safety. In fact, consumers did not understand what consumer safety meant and what it entailed. Consumers also had not sought this information soon after enrolling in the program. However, all consumers felt that consumer safety information must be provided to all IHSS consumers. "I don't want anything happening to me. I don't want to go [to an assisted living facility]. I want to stay safe in my home as long as I can."

**Delivery platform for the informational material:** Consumer recommendation for delivery platform varied by age group. Individuals who were under fifty-five years of age recommended that the information be available online and be compatible with mobile devices. Consumers over fifty-five years of age recommended that the information be delivered through written hardcopy

materials. Since consumers were already comfortable with receiving IHSS information through the mail they felt that receiving information through such communication channel will be sufficient. "When we have [the information material] we can look at it whenever we like. Much better than someone telling us or the computer. I don't [understand] computer."

#### **Discussion:**

All consumers reported never having received navigational materials on the topics discussed from IHSS. Consumers also did not spend an extensive amount in searching for information through the IHSS program. Some of the participating consumers did call for further information, but only one received consistent support from an IHSS staff member for their consumer needs. This particular consumer also emphasized that their provider hiring problems could be resolved through 'common sense' approaches. However, further discussion also revealed that this consumer had a high access to supportive staff who were available to resolve any consumer related questions or concerns. Another participant also mentioned receiving navigational information from an IHSS staff (Homebridge), but admitted it was not consistent and minimal.

Consumers did not have an expectation regarding the kinds of information they needed once they after enrolling in IHSS. This may be due to the fact that none of the participating consumers were ever in an employer role and thus did not know what kinds of information should they expect on it. Additionally, participating consumers also assumed that IHSS does not provide standard information or support to consumers, and did not expect IHSS to have sufficient supportive information to give to consumers. This may be due to the cessation of consumer education classes by Public Authority, as they try to revamp their consumer education program and launch it within the next eight months. Consumer classes were typically held at

local community centers where consumers were invited to participate and learn skills which would help them become effective consumers and employers. Classes included cooking, computer, and recently, the time sheet adjustments (however, majority of the timesheet courses are tailored to the providers as they are the individuals who complete the paper). Participating consumers had the least expectations and knowledge on consumer safety, the kinds of information they would need to ensure themselves, and how to look for this information within IHSS, even after they had felt unsafe as consumers.

**Limitations:** The study had several limitations. Because the study used focus group for the English speaking consumers only, the discussion is not ad in depth as an interview. However, analysis of the feedback from the focus group and the in-depth interview show similarity in responses. Because the study only conducted one focus group it is unable to determine the validity of the feedback. However, analysis of the feedback from the pilot discussion and the focus group show that the data appeared to have reliability and addressed the study's objectives. Another concern may be that individuals in the group were hesitant to express their thoughts, particularly if their ideas opposed the views of another consumer. However, individuals were vocal about their disagreements in the discussion group and expressed any concerns openly. In contrast to focus group discussions, in-depth interviews provided richer data from the consumers. However, data collected at an individual level cannot be generalizable. Because the participants the multi-lingual participants were semi randomly sampled, the likelihood of the data being non-generalizable may be mitigated. Lastly, because the trained bilingual interviewers who conducted the in-depth interviews were from the Public Authority, there is a possibility that some bias may have been introduced into the study based on their perception of the IHSS program.

**Implications:** Governor Jerry Brown had cut funding for IHSS program in 2013-2014 (). However, the governor reversed the cut by seven percent to all IHSS programs. This would ensure that more consumers are able to get adequate hours of care. In February 2016, new overtime rules went into effect under the California's Fair Labor Standards Act (FSLA). Under the new overtime rules, providers will be paid overtime for hours which exceed eight hours a day or forty hours a week (County Welfare Directors Association of California [CWDA], 2016). Although a boon for the low-wage providers, the new rules limit how much overtime a provider can acquire per pay cycle. If the number of overtime hours exceed the allowed limit, providers can be penalized and may even lose their jobs. This rule applies to both hired and family caregivers. The current FSLA modifications are projected to put more financial stress on consumers, particularly consumers with high needs. Many consumers who use single providers for their hours may be forced to find other caregivers to avoid paying overtime. The County Welfare Directors Association of California project that the demand for providers will require IHSS to higher at least 10,000 more providers to fill the gap (CWDA, 2016). As a result, consumers who are unable to find providers are at a high risk of injuries or health crisis which may go unnoticed (CWDA, 2016) Many family caregivers may also be forced to make the tough choice of placing their loved ones into nursing homes. However, the exodus of consumers moving into nursing homes results in loss of the consumers' rights and health and an increase of cost to the taxpayers (CWDA, 2016).

Because of the high demand for providers, consumers will be in direct competition with each other to secure long term care. Consumers must learn to be better prepared in finding providers after enrollment. Currently, IHSS terminates approved consumers who do not enroll caregivers within sixty days after enrollment. In addition, the smaller pool may cause consumers

will mean consumers will take a longer time to complete the hiring process and may lose their ability to receive care. This can potentially create a vicious circle, whereby consumers may be placed into the states care and thus lose its independence. Consumers will have to be ready to ride the ripple effect caused by the new FLSA change by becoming smart consumers. However, without accessible information, consumers will soon experience a bottleneck effect, where qualified individuals lose too much time securing care services and ends up losing their independence.

The deliverables do not substitute for a comprehensive list of what new IHSS consumers should know after enrollment. However, the deliverables are designed to provide important takeaway information which consumers can quickly synthesize when navigating through the IHSS program. Furthermore, the information can be delivered in tandem with other supportive resources, such as phone check-ins by the mentors or Registry counselors. The deliverables can also be disseminated with other consumer related information such as when consumers request for a list of available providers from the Public Authority's registry.

**Future research:** Data collected from this study showed that Cantonese speaking and Russian speaking consumers had low need of consumer related material. It is possible that the scope of the stud was too narrow to capture what needs might exist among these groups.

Additionally, both Spanish and Cantonese speaking consumers had been consistently cautious with their interaction with the principle investigator and the bilingual interviewer.

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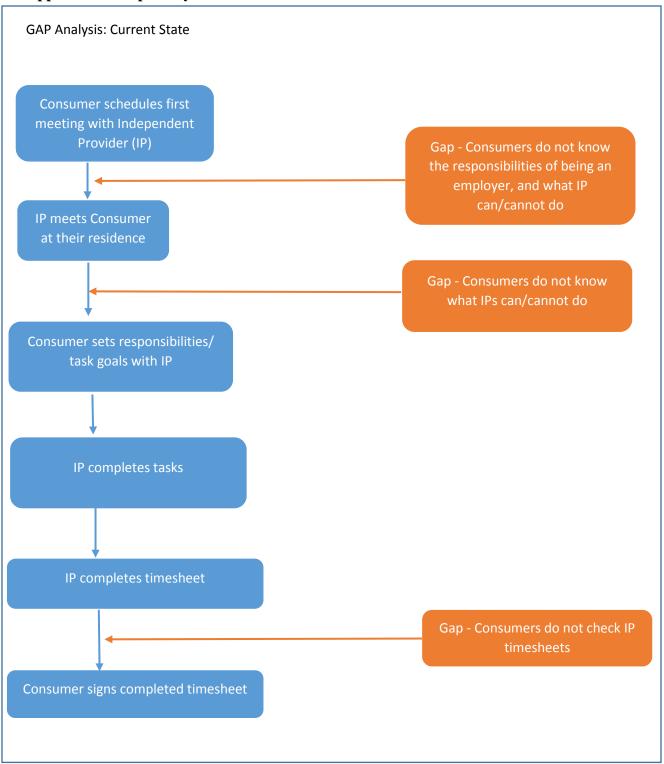
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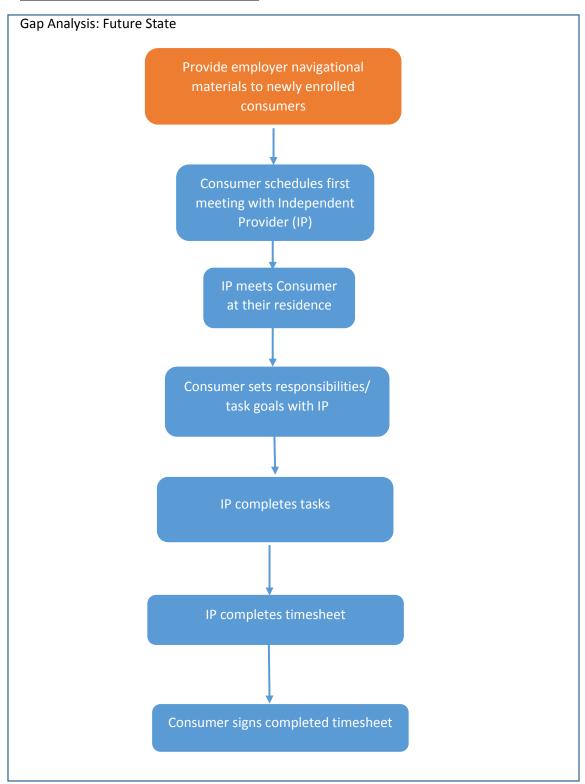
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# **Appendices**

**Appendix A: Gap Analysis – Current State** 



**Appendix B: GAP Analysis: Future State** 



# Appendix C: Goals and SMART Objectives

# **Appendix C: Goals and SMART Objectives**

Goal 1: Conduct Formative evaluation to design orientation materials for	Parameter
new Ihss consumers	
1.a Conduct a focus group with IHSS Intake staff	Specific
Collect feedback from IHSS intake staff using audio recording on new consumer	Measurable
Yes; focus group will be 1-1.5hours long and will be scheduled at staff worksite	Achievable
Yes; staff will have time to prepare for focus group (reserve time; prep notes)	Realistic
Completed by Marth 30, 2016	Time-
	framed
Objective 1.a: By March 30 <sup>th</sup> 2016, a 1 hr-1.5 hr long focus group will be conducted	with the IHSS
intake staff at their worksite to collect data on all troubleshoot issues they assist the	new
consumers with.	
1.b Conduct a focus group with IHSS consumers	Specific
Feedback using audio recording will be collected on what issues they struggled with during the first 6months-year after enrolling in IHSS.	Measurable
	Achievable
Yes; focus group will be 1-1.5 hrs long and will be scheduled at PA headquarters Yes; consumers will have time to prepare for focus group	
Completed by March 25, 2016	Realistic Time-
Completed by March 23, 2010	framed
Ol' 4' 11 D M 1 25th 2014 11 151 1 1 6 141 11 1116	
Objective 1.b: By March 25 <sup>th</sup> 2016, a 1hr-1.5hr long focus group with the IHS consumers will be conducted at the PA headquarters to collect data on issues	
faced during the first 6months-1 year after enrolling in IHSS	consumers
· · ·	a
1.c Identify at least three existing online and hardcopy education materials and its	Chaptin
C 1 11 1 TITOO	Specific
sources for newly enrolled IHSS consumers	
Copies of online materials will be printed out and marshalled; link to online videos will be	
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected	
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.	Measurable
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.  Yes; will require using online search engine and phone calls to organization offering	
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.  Yes; will require using online search engine and phone calls to organization offering information materials for copy and referrals	Measurable  Achievable
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.  Yes; will require using online search engine and phone calls to organization offering information materials for copy and referrals  Yes; information would be freely available to consumers and are the same statewide	Measurable  Achievable  Realistic
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.  Yes; will require using online search engine and phone calls to organization offering information materials for copy and referrals	Measurable  Achievable  Realistic  Time-
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.  Yes; will require using online search engine and phone calls to organization offering information materials for copy and referrals  Yes; information would be freely available to consumers and are the same statewide Completed by March 19, 2016	Measurable  Achievable  Realistic
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.  Yes; will require using online search engine and phone calls to organization offering information materials for copy and referrals  Yes; information would be freely available to consumers and are the same statewide Completed by March 19, 2016  Objective 1.c: By March 19 <sup>th</sup> , 2016, at least three existing online and hardcopy	Measurable  Achievable  Realistic  Time-
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.  Yes; will require using online search engine and phone calls to organization offering information materials for copy and referrals  Yes; information would be freely available to consumers and are the same statewide Completed by March 19, 2016	Measurable  Achievable  Realistic  Time-
Copies of online materials will be printed out and marshalled; link to online videos will be cashed with source information; samples of existing hardcopy materials will be collected and cataloged.  Yes; will require using online search engine and phone calls to organization offering information materials for copy and referrals  Yes; information would be freely available to consumers and are the same statewide Completed by March 19, 2016  Objective 1.c: By March 19 <sup>th</sup> , 2016, at least three existing online and hardcopy education materials and its sources for newly enrolled IHSS consumers will be	Measurable  Achievable  Realistic  Time-

Copies of online materials will be distributed to staff who will make notes on the documents; audio recording will collect feedback on all material analysis, including videos, hardcopy materials, and other handouts	Measurable
Yes; expert panel will be held at the local PA headquarters and requires no preparation Yes; only requires consumers to allocate time for the expert panel meeting Completed by April 11, 2016	Achievable Realistic Time- framed
Objective 1.d: By April 11 <sup>th</sup> , 2016, determine the pros and cons of at least three existi	
hardcopy consumer education materials.	
Goal 2: Create orientation/education materials for newly enrolled IHSS consumers	Parameter
2.a Identify at least two deliverables that will be used to provide consumer orientation/education materials to new IHSS consumers	Specific
Create a pros/cons list of each deliverable	Measurable
Yes, as long as deliverables are within agency's budget	Achievable
Yes, since project deliverables used will be similar to existing deliverables	Realistic
Completed by April 8, 2016	Time-
	framed
Objective 2.a: By April 8th, 2016, identify at least two deliverables that will be used to orientation/education materials to new IHSS consumers	o provide
2.b Design new consumer orientation materials, including web-based, hard-copy, and in-person deliverables	Specific
Create outlines of web-based, hard-copy and in-person deliverables, including content and delivery format	Measurable
Yes; all content will overlap between deliverables and interconnected to existing IHSS programs	Achievable
Yes; will be designed for SF headquarters, but may be feasible for other headquarters state-wide	Realistic
Completed by April 18, 2016	Time- framed
Objective 2.b: By April 18 <sup>th</sup> , 2016, create a concept design for at least three or materials.	rientation
2.c Conduct a 1hr-1.5hr long concept study with IHSS consumers on proposed orientation/education materials	Specific
Audio feedback will be recorded during the 1-1.5hr long study. Participants will be given samples of hardcopy deliverables on which they can make comments. All hardcopy samples will be collected at the end of the study.	Measurable
Yes; if conducted after completing the first objective	Achievable
Yes; but will only include participants at local level and not county-wide	Realistic
Completed by April 22, 2016	Time- framed
Objective 2.c: By April 22 <sup>nd</sup> , 2016, conduct a 1hr-1.5hr long concept study with IHSS consumers on proposed orientation/education materials.	

2.d Present orientation/education material proposals to hey IHSS stakeholders	Specific
Collect feedback from each stakeholder regarding the recommendation	Measurable
Yes, provided objective 3 is completed first	Achievable
Yes; stakeholder will include staff from both PA and IHSS SF headquarters	Realistic
Completed by May 6, 2016	Time-
	framed

Objective 2.d: By May 6<sup>th</sup>, 2016, present orientation/education material proposal to key IHSS stakeholders.

#### **Appendix D: SWOT Analysis**

#### Helpful

to achieving the objective

#### to acmeving

# **Harmful** to achieving the objective

#### Strengths

- Positive inter-relationship between staff
- Collaborative style within agency
- Open to new ideas
- Diverse skills, backgrounds within staff
- Consumer feedback encouraged by preceptor/director
- Emphasis on meeting consumers where they're at
- Established and well-funded agency
- New position added to oversee creation/addition of consumer education as well as intern support
- Use of technological skills high among staff
- Hire mentors who are either consumers themselves or are from similar backgrounds as consumers
- Director a champion of the project

#### Weaknesses

- Staff limited in level of interaction with consumers
- Mentors are usually unavailable
- High internship turnover rate may limit who I can collaborate with
- Availability hours of interns may not match with my project schedule
- New membership coordinator is still learning about the program and is not ready to provide insight/support at the moment

## **Opportunities**

- Project approval from PA director and IHSS Director
- DAAS support in implementing changes to help better support consumers
- Consumers interested in receiving more support/training
- Recent Consumer satisfactions survey data collected from 2015
- Multi-media available for deliverables (website, Youtube, Facebook, twitter, handouts, powerpoint)
- Sufficient budget for the project
- Sufficient access to materials/stationary
- Remote access to work feasible

#### Threats

- Consumers are hard to reach population due to age/disability
- Limited survey data, feedback collected on what consumers want from the program
- Physically challenging for consumers to visit agency

Internal origin (attributes of the system)

**External origin** (attributes of the environment)

### **Appendix E: Activity and Open-ended Questions**

I'd like everyone to do a quick introduction. Just say your first name and what would you do if you won a million-dollar lottery. I will go first.

# Activity #1:

Place seven cards with topic names on each for all participants: In front of you are 7 cards with phrases written. Each phrase is a topic which IHSS covers in their consumer training handbook. I want you to:

Spread the cards on the table so you can read what is written on each. Then pick up your pen/marker. Write any number between 1 and 7 on the card, with 1 being the least important topic card and 7 being the most important topic card.

After participants complete this task: Next, I'll ask everyone to give me the list of the topic cards from their pile, with the most important first to the least important.

Write everyone's responses; tally then announce the top four topics that will be discussed first. The remainder can be grouped together.

# **Open-Ended Questions:**

**Introductory Questions** (participants are introduced to the topic of discussion):

1) How do you use the IHSS program? SEE note below.

**Participatory Questions** (participants explore and are lead up to the topic):

Think back to when you signed up for IHSS.

- 1. What information have you gotten about consumer roles and responsibilities?
- a. How did you get this information?
- b. Was there any other information that you would have wanted to know (about your role and responsibilities an IHSS consumer)?
- 2. What kinds of information have you gotten about Provider roles and responsibilities?
  - a. How did you get this information?
  - b. Was there any other information that you would have liked to know (about the role of a Provider)?
- 3. What kinds information or tips have you gotten on meeting and interviewing provider(s)?
- a. How did you get this information?
- b. Was there any other information you would have wanted *before* meeting or interviewing provider(s)?
- 4. What tips or information have you gotten on how to supervise provider(s)?
- a. How did you get this information?
- b. Was there any other information that you would have liked to get on how to supervise provider(s)?
- 5. What tips or information have you gotten on communicating with provider(s)?
- a. How did you get this information?

- b. Was there any other information that would have helped you to better communicate with provider(s)?
- 6. What information have you gotten on building healthy relationships consumer-provider(s)?
  - a. How were you able to find this information?
  - b. Was there any information that you were not able to find?
- 7. What information have you gotten on enrolling and paying your provider?
- a. How did you get this information?
- b. Was there any information that you would have concerning enrolling and paying provider(s)?
- 8. What kinds of consumer safety information did you get from IHSS?
  - a. How did you get this information?
  - b. Was there any other information that you would have liked on consumer safety?

# **Key Questions** (participants get to the meat of the issue):

- 1) Of all the things we've discussed, what were the MOST important to you?
- 2) Of all the topics we've discuss, which were the LEAST important to you?
- 3) Overall, how helpful did you find the information?

**Ending Questions** (these questions ask participants to check if anything was missed in the discussion):

If you could give a piece of advice to a new IHSS consumer, what would it be?

### **Appendix F: Focus Group Guide**

#### **Introduction: 2 minutes**

 Hello, everyone! Thank you for joining our group discussion today! My name is Deloras and this is David Araujo. We will be your facilitators during this discussion. David and I are part of the team IHSS PA. We are helping to improve the information and education we provide to people who use our IHSS –PA services.

#### Ice-breaker: 10 minutes

o I'd like everyone to do a quick introduction. Just say your first name and what would you do if you won a million-dollar lottery. I will go first.

#### **Program Overview: 20-25 minutes**

 Before we get started, we will go over the informed consent form. This document will explain the reason for the study and what will happen during our discussion. After we have read the document together, and you feel confident that you understand what has been discussed, please sign the form. A copy of the form will be provided for your records:

```
**Read the informed consent form aloud**
```

Lastly, you may have noticed the refreshments in this room. Feel free to get some snacks and drinks (we can also bring them to you) anytime during our discussion. We thank you for your valuable time and feedback. There will be a short break after the first hour of the discussion, so you can get more refreshments or use the restrooms. Please ask any of us to direct you to the restrooms and we will be happy to assist you. Lastly, as a small token of our gratitude, we will give everyone a Target gift card.

Any Questions?

Let's get started!

#### Semi-structured questions:

#### **Bathroom Break:**

#### **Activity:**

 Next, I would like you to pick up the sheet of paper and in front of you. Draw a line down the middle of the page. On the left, write down all of the things you wish you knew when you were a new consumer. On the right, jot down how you wanted the information delivered to you. You have 10 minutes to complete your list.

#### End of focus group

<sup>\*\*</sup>Have the participants sign the informed consent form\*\*

## **Appendix G: Informed Consent**

#### **IHSS Consumer Feedback**

The purpose of the focus group is to understand your experiences as an IHSS Consumer. We want to know if the information IHSS provides is useful, complete, or relevant to you. In other words, are we able to give you information, resources, or materials to help you be an effective Consumer? Can we do a better job of supporting you?

## What will the group discussion look like?

The group discussion will take about two hours. During this time, we will ask you a few questions on IHSS topics. We will use a digital voice recorder to record the discussion.

## How will the discussion help IHSS?

We are thinking about making information handouts and videos for IHSS clients, so your answers and feedbacks will help us develop our materials.

#### Is this confidential?

Yes. Anything you say today will be recorded anonymously. Instead of your real names, we will be using code names to record your feedback, so no personal identifying information will be used. This information will NOT be a part of your IHSS file, and will not affect your program eligibility. We will be using an iPhone voice recorder to make sure we don't miss out on anyone's responses. All of the recorded information will be used for this study only, and the information will then be destroyed. None of this information will be given to other IHSS staff members.

## To Stay or Not to Stay

Your participation is absolutely voluntary. You may choose to pull out from this discussion at any time. If you choose to leave before the end of the session, you will still receive you thank you gift.

#### **Ground rules**

- Two hours can go by fast, so we might move you along in our conversation.

  If you'd like, we'd be more than happy to talk to you after the group discussion on any topic in further detail.
- We want to hear from everyone so we might ask people who have not spoken up to comment sometimes.
- There's no right or wrong answer to the questions we will ask. We want to hear what each of you think and it's okay to have different opinions. Things you have experienced may be similar or different from what others have gone through.
- We want to make sure that anything shared today is kept confidential so we ask that you not use your full names or share anything directly identifying yourself when you talk about your personal experiences. We also ask that you not discuss what other participants share outside of the group discussion today. However, because this is a group setting, the other participants will know your answers to the questions, so we cannot guarantee that they will not discuss your responses outside of the focus group.

REPACKAGING CONSUMER INFORMATION

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Well, what about....?

If you have more questions about today's discussion, please ask us. If you think of any questions in the future, you can contact me (Deloras Puran) using this

contact information:

**Deloras Puran** 

**IHSS-PA Intern** 

Tel: (510) 427-8139

Email: dnpuran@dons.usfca.edu

Agreement to Participate

I, \_(first, last name)\_\_\_\_\_, have read the

information on the IHSS-PA Consumer Feedback study, as well as an overview

of today's group discussion.

My role in the group discussion is as a participant to help IHSS-PA collect information about their Consumer program. If I had any questions, I am satisfied that they have been answered. By signing this consent form, I agree to attend the session, and to have it recorded. I understand that my name will not appear in any report, that my comments will remain anonymous, and that

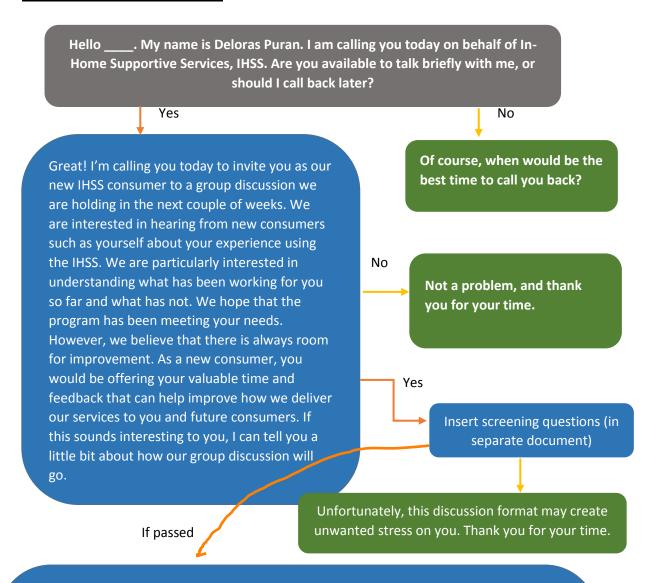
all information will be kept confidential.

I know that I can contact Deloras Puran for further information.

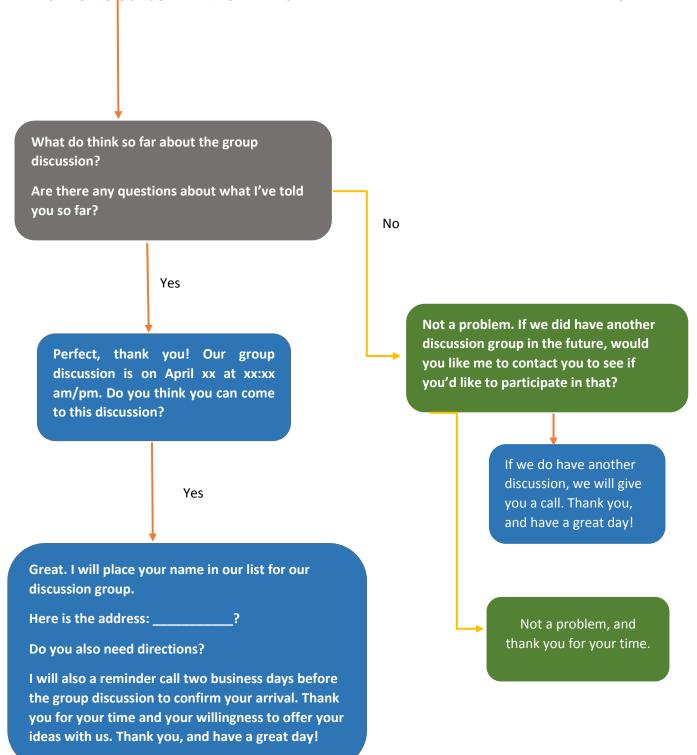
I have read this consent form and I understand its contents. A copy of this form is also provided for my records. I agree to participate.

Signature:	X	
Date:X_	<del></del>	
<b>Person Obtaini</b> Signature:	ng Consent	
Name:		
Date:		

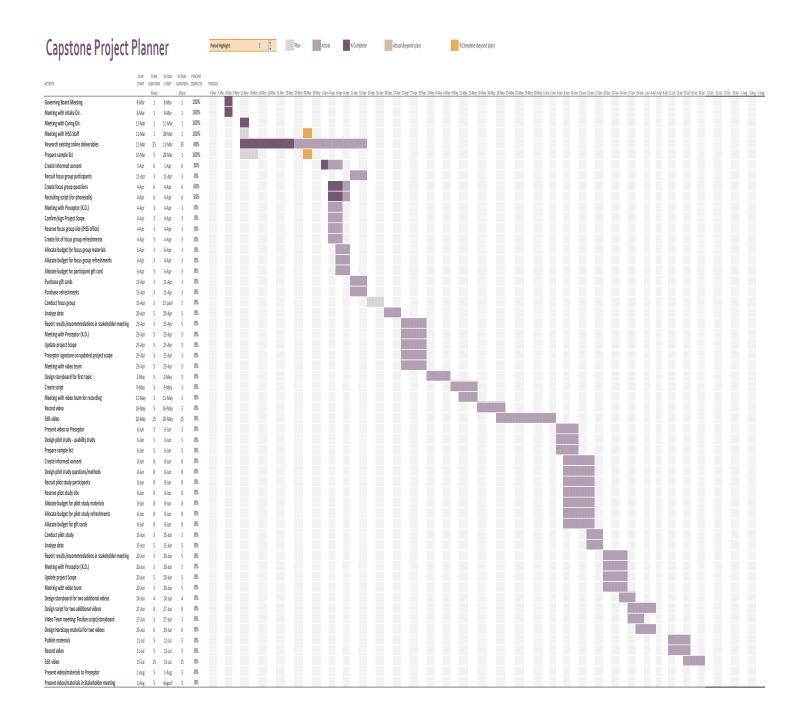
### **Appendix H: Recruiting Tool**



Ok! First, I'd like to let you know that there is a gift card offered to every consumer who joins the group discussion. There is no personal identifying information collected before, during, or after the discussion. You are also free to leave anytime during discussion if you decide you no longer wish to participate. Your participation does not affect your enrollment in the IHSS program. The group discussion will have 5-8 IHSS consumers (including you) who will meet at the IHSS headquarters. The discussion will be between 1.5-2 hours. There will be refreshments offered during this meeting. The group discussion will be led by a quality improvement staff who will engage the group in a few activities. All of the activities are designed to be done while sitting down. It will include having a question and answer portion about what you have experienced as an IHSS consumer and what you have liked/disliked so far about the services. There will be a short activity about what you would like to see improved in the services. Lastly, we may ask you to look at a video and some and documents that have consumer education information and ask you your opinion on these materials.



## Appendix I: GANTT Chart



## Appendix J: Informed Consent – Cantonese

感謝您參加今天的小組討論。本同意書說明了這次討論的內容和目的。我, Deloras Puran,將會主持本次討論。在我們閱讀了同意書之後,請在最後一 頁簽名和註明日期,然後交回給會場的主持人。

## 家居護理服務雇主的意見反饋

小組討論的目的是為了了解您作為家居護理服務雇主的經歷。我們想知道家居護理服務所提供的資訊是否有用、完整或與您有關聯。換句話說,我們是否能夠給您信息、資源或材料,以幫助您成為一個有效的雇主?我們怎樣才能更好地支持您?

# 小組討論會是什麼樣子的?

小組討論大約需要兩個小時。在這段時間裡,我們會問您幾個有關家居護理 服務的問題。我們會用錄音機錄下討論的內容。

# 這個討論將會如何幫助家居護理服務?

我們正在計劃為家居護理服務的客戶製作資訊手冊和視頻,因此,您的回答 和意見反饋將有助於我們開發製作這些材料。

# 這是保密的嗎?

是的。今天您說的任何事情都將匿名記錄。我們將會用名字代碼來記錄您的意見反饋,而不是用您的真名,所以不會使用個人識別信息。您的反饋信息不會歸入到您的家居護理服務檔案裡,也不會影響您在計劃裡的資格條件。我們將會使用一台iPhone的語音錄音器來錄音,確保不會漏掉任何一個人的回答。所有記錄下來的信息將僅用於這項研究,然後這些信息會被銷毀。任何的這些信息都不會提供給其他家居護理服務的職員。

## 留下或提前離開

您的參與是絕對自願的,您可以隨時選擇退出本次討論。如果您選擇在討論會結束前離開,您仍然會收到感謝禮品。

## 基本規則

- 兩個小時的時間會過得很快,所以我們可能會有意地推進交談的進度,以涵蓋所有的話題。如果您願意,在小組討論結束後,我們會很樂意與您討論關於任何話題的進一步細節。
- 我們想聽取每個人的意見,所以我們會不時地要那些沒有發言的人發表意見。

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• 對於我們所提的問題,您的回答沒有所謂的對或錯。我們想聽聽您們

每個人的看法,你們可以有不同的意見。您所經歷的事情可能與其他

人的經歷有相似或不同的地方。

因為我們要確保所有今天分享的信息都是保密的,所以當您談論您的

個人經歷時,我們要求您不要使用您的全名或分享任何能夠直接識別

您真實身份的信息。我們還要求您不要在今天的小組討論以外談論其

他參與者所分享的信息。然而,因為這是一個小組討論,其他參與者

將會知道您的回答,所以我們不能保證他們不會在小組討論以外談論

您的回答。

好吧,那麼...?

如果您對今天的討論有更多的疑問,請向我們諮詢。如果在將來您想到任何

問題,您可以通過以下的聯繫方式與我,Deloras Puran,聯繫:

Deloras Puran

家居護理服務公共服務機構 實習生

電話: (510) 427-8139

電子郵箱:dnpuran@dons.usfca.edu

同意參加

我在小組討論中擔當參與者的角色,幫助家居護理服務公共服務機構收集有關其雇主計劃的信息。如果有任何問題,我很滿意這些問題已經得以回答。通過簽署這份同意書,我同意參加這次小組討論,並允許錄音。我明白,我的名字將不會出現在任何報告中,我的意見將保持匿名,所有的信息將被保密。

如果需要進一步的信息,我知道可以聯繫Deloras Puran。

我已經閱讀了這份同意書,並理解了其中的內容。我也得到了此同意書的副本作為留底。我同意參加。

參加者	
姓名:	X
簽名:	X
日期:	X
小組主持人:	
簽名:	

姓名:	
日期:	

Appendix K: Informed Consent – Spanish

Gracias por participar en la conversación grupal de hoy. Este formulario de consentimiento le informa sobre la conversación y su propósito. Yo (Deloras P.) seré el moderador durante esta conversación. Cuando hayamos leído el formulario de consentimiento, por favor firme y feche la última página y entréguela a cualquier facilitador presente en la sala.

## Opiniones del Consumidor de los servicios de IHSS

La finalidad de este *focus group* (grupo de investigación) es comprender sus experiencias como un Consumidor de los servicios del IHSS. Queremos saber si la información que IHSS le proporciona es útil, completa o relevante para usted. En otras palabras, ¿somos capaces de darle la información, recursos o materiales que le ayudarán a ser un Consumidor efectivo? ¿Podemos hacer un mejor trabajo para ayudarle?

# ¿Cómo será la conversación en grupo?

La conversación grupal durará alrededor de dos horas. Durante este tiempo, haremos algunas preguntas relacionadas a temas del IHSS. Usaremos un grabador de voz digital para grabar la conversación.

# ¿Cómo ayudará esta conversación al IHSS?

Estamos planeando hacer folletos informativos y videos para los clientes del IHSS, así que sus respuestas y comentarios nos ayudarán a desarrollar nuestros materiales.

# ¿Es confidencial?

Sí. Cualquier cosa que diga hoy será grabada anónimamente. En lugar de usar su nombre real, utilizaremos un alias para registrar sus comentarios, así que no se utilizara información personal que permita identificarle. Esto NO será parte de su archivo en IHSS y no afectará su elegibilidad para el programa. Utilizaremos el grabador de voz de un iPhone para asegurarnos de no perder las respuestas de ningún asistente. Toda la información grabada será usada solamente para este estudio, y luego la información será borrada. Nada de esta información será entregada a otros miembros del personal del IHSS.

## Participar o no participar

Su participación es totalmente voluntaria. Usted puede elegir retirarse de esta conversación en cualquier momento. Si opta por salir antes del final de la sesión, de todos modos recibirá su regalo de agradecimiento.

# Reglas de procedimiento

- Dos horas pueden pasar rápido, así que puede que le pidamos apurarse un poco durante la conversación. Si desea, estaremos dispuestos a hablar con usted sobre cualquier tema con mayor detalle después de la conversación grupal.
- Queremos escuchar a todos así que a veces podríamos pedir a personas que no han hablado, que hagan sus comentarios.
- No hay respuestas correctas o incorrectas a las preguntas que haremos.
   Queremos escuchar qué es lo que cada uno piensa y está bien tener opiniones distintas. Las cosas que usted ha experimentado pueden ser similares o diferentes a las que otras personas han pasado.
- Queremos asegurarnos que cualquier cosa que se comparta hoy se mantendrá confidencial así que le pediremos no usar su nombre completo ni compartir

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nada que pudiera identificarle directamente cuando comente sus experiencias personales. También pedimos no comentar lo que otros participantes compartieron fuera de la conversación grupal de hoy. Sin embargo, ya que esta es una conversación grupal, los otros participantes sabrán sus respuestas a las preguntas, así que no podemos garantizar que no comentarán sus respuestas fuera del *focus group*.

## Bueno, ¿y qué me dicen de...?

Si tuviera más preguntas acerca de la conversación de hoy, por favor pregúntenos. Si tuviera cualquier pregunta en el futuro, puede contactarme (Deloras Puran) utilizando esta información de contacto:

Deloras Puran

**IHSS-PA Intern** 

Tel: (510) 427-8139

Email: dnpuran@dons.usfca.edu

# Acuerdo para participar

Mi rol en la conversación grupal es como participante para ayudar al IHSS-PA a obtener información acerca de su programa para Consumidores. Si tuve cualquier pregunta, quedo satisfecho con que han sido contestadas. Al firmar este formulario de consentimiento, acuerdo asistir a la sesión y que sea grabada. Entiendo que mi nombre completo no aparecerá en ningún reporte, que mis comentarios permanecerán anónimos y que toda la información se mantendrá confidencial.

Sé que puedo contactar a Deloras Puran para cualquier información adicional.

He leído este formulario de consentimiento y comprendo su contenido. Se me entrega una copia de este formulario para mis registros. Estoy de acuerdo con participar.

Participante
Nombre: X
Firma: X
Fecha:X
Facilitador del <i>Focus Group</i> :
Firma:
Nombre:
Fecha:

### <u>Appendix L: Informed Consent – Russian</u>

Благодарим Вас за участие в сегодняшней групповой дискуссии. Данная форма информированного согласия поясняет порядок проведения дискуссии и объясняет, с какой целью она проводится. Я, Долорес П. (Deloras P.), являюсь координатором. После прочтения формы информированного согласия поставьте свою подпись на последней странице, укажите соответствующую дату и передайте форму координатору.

### Комментарии и замечания клиентов IHSS

Данная фокус-группа создана для получения информации о пользовательском опыте клиентов IHSS. Мы хотим выяснить, является ли информация, предоставляемая клиентам IHSS, полезной, полной и актуальной. Другими словами, узнать, как предлагаемые материалы и информация помогают нашим клиентам стать эффективными пользователями программы. Мы также хотим понять, что необходимо сделать для улучшения нашей работы.

### Что представляет собой групповая дискуссия?

Групповая дискуссия занимает около двух часов. Во время дискуссии Вас попросят ответить на несколько вопросов, связанных с деятельностью IHSS. Дискуссия будет записана при помощи цифрового устройства для ведения аудиозаписи.

#### Как это может помочь IHSS?

Мы планируем подготовить информационные раздаточные материалы и видео для клиентов IHSS. Ваши ответы и комментарии будут использованы при разработке этих материалов.

## Мои ответы не подлежат разглашению?

Да. При записи ответов на вопросы сохраняется анонимность отвечающего. Вместо настоящего имени участника используется кодовое имя, таким образом личная идентификационная информация не разглашается. Данная информация НЕ БУДЕТ ОТОБРАЖЕНА в Вашем персональном файле и никаким образом не сможет повлиять на Ваше участие в программе IHSS.

Дискуссия будет записана при помощи устройства iPhone, что позволит сохранить ответы всех участников. Все полученные данные предназначены для использования исключительно в исследовательских целях. Сотрудники IHSS не будут иметь доступа к этим данным.

### Добровольное участие

Участие в дискуссии является добровольным. Вы можете прекратить участие в дискуссии в любое время. Даже отказавшись от участия в уже идущей дискуссии, Вы получите подарок в качестве благодарности за участие.

### Общие правила

- На дискуссию отводится всего два часа, поэтому при необходимости мы будем рады обсудить возникшие у Вас вопросы по окончании обсуждения.
- Нам важно мнение всех участников. Мы можем попросить высказаться тех участников, которые не сделали это ранее.
- Задаваемые вопросы не имеют однозначных ответов. Мы хотим знать точку зрения каждого участника, и разнообразие мнений является нормальным явлением. Ваш личный опыт может отличаться от опыта других участников дискуссии.
- Мы заботимся O сохранении Ваших конфиденциальных Пожалуйста, не используйте свое полное имя и не сообщайте другую конфиденциальную информацию, принимая участие в дискуссии. Не информацию, полученную передавайте других участников ОТ сегодняшнего обсуждения, посторонним лицам. Помните, что другим участникам будут известны Ваши ответы на вопросы. Принимая во внимание групповой характер дискуссии, мы не можем гарантировать неразглашение информации другими участниками фокус-группы.

## Получение дополнительной информации

Вы можете связаться с нами в случае возникновения вопросов о сегодняшней дискуссии. Для получения дополнительной информации обращайтесь к Долорес Перан (Deloras Puran):

Долорес Перан (Deloras Puran)

Стажер IHSS-PA

Тел.: (510) 427-8139

E-mail: dnpuran@dons.usfca.edu

### Согласие на участие

Данная групповая дискуссия призвана помочь собрать информацию о программе для клиентов IHSS-PA. На все имевшиеся у меня вопросы были получены ответы. Подписывая данную форму, я соглашаюсь на

участие дискуссии и не возражаю против ведения аудиозаписи. Я понимаю, что мое имя не будет указано в отчетах, а анонимность моих комментариев и конфиденциальность информации будет сохранена.

Мне известно, что для получения дополнительной информации я могу обратиться к Долорес Перан (Deloras Puran).

Форма согласия мною прочитана, и мне понятно ее содержание. Копия этой формы предоставлена для моего личного использования. Я выражаю свое согласие на участие в дискуссии.

#### Участник

Полное имя (печатными буквами): Х					
Подпись:	X				
Дата:X_					

## Координатор фокус-группы:

Подпись:	 	 	
Полное имя:	 	 	 
Дата:			

### Appendix M: Interview Questions - Spanish

	Los papeles y las responsabilidades del consumidor
1.	CONSUMER ROLE AND RESPONSIBILITIES

2. PROVIDER ROLE AND RESPONSIBILITIES

Los papeles y las responsabilidades del proveedor

3. MEETING, INTERVIEWING, AND SUPERVISING PROVIDERS

Los encuentros, las entrevistas, y supervisando los proveedores

- 4. COMMUNICATING AND BUILDING HEALTHY RELATIONSHIPS WITH PROVIDERS Communicando y construyendo relaciones sanas con sus proveedores
- 5. ENROLLING AND PAYING PROVIDERS

Inscribi \( \bar{n} \) ndo y pagando los proveedores

6. CONSUMER SAFETY

La seguridad para los consumidores

$\frown$	nnn	000	$\sim$	l augetiones
U	ben	-enu	ıeu	l auestions:

- a. What information have you gotten about \_\_\_\_\_?
  Que informaci\(\hat{n}\) recibi\(\hat{u}\) usted de \_\_\_\_\_?
- b. How did you get this information?

  Como adquiri usted esta informaci n?
- C. What information were you looking for on \_\_\_\_\_?

Que informaci\(\begin{aligned} n \) estaba buscando usted?

### <u>Appendix N: Interview Questions – Cantonese</u>

- 1.雇主的角色和责任
   2.护理员的角色与职责
   3.会议,面试和监督护理员
   4.与护理员沟通和建立良好的雇佣关系
   5.招收和支付护理员
   6.雇主的安全
- 开放式问题:
  a: 你学会了什么信息\_\_\_\_\_?
  b: 你是如何得到这些信息的?
  c: 你正在寻找什么信息\_\_\_\_\_?

### Appendix O: Interview Questions - Russian

- 1. IHSS может предоставить информацию о роли потребителя и ответственности за потребителя. Получали ли Вы какую-либо информацию о роли потребителя и ответственности?
- 2. IHSS так же имеет информацию о том что предоставитель услуг может и чего не может делать для Вас. Какую информацию получили Вы о роли провайдера и его ответственных обязанностях?
- 3. Некоторое потребители находят для себя простым поиск и наем помощника, в то время как другие не знают как это сделать. IHSS может предоставить информацию о том как найти помощника по дому. Какую информацию Вы получили о том как встретиться, провести собеседование и нанять помощника?
- 4. Некоторые потребители знают как общаться с помощниками, в то время как другие могут испытывать трудности в построении здоровых отношений с помощником. Какую информацию получили Вы о взаимодействии и построении здоровых отношений с помощником?
- 5. После наема IHSS должны зачислить в штат и оплачивать услуги предоставителям услуг (помощникам)ю Какую информацию получили Вы о зачислении и оплате услуг помощника?
- 6. IHSS так же предоставляет информацию о безопасности клиента. Какую информацию Вы получили о безопасности клиента?
- 7. Каую бы информацию Вы бф порекомендовали предоставлять новым клиентам IHSS
- 8. Какой с Вашей точки зрения самый лучший способ для IHSS предоставлять информацию своим клиентам?

#### Appendix P: Interview invite – Russian

## Вопросы фокус группы:

- 1. IHSS может предоставить информацию о роли потребителя и ответственности за потребителя. Получали ли Вы какую-либо информацию о роли потребителя и ответственности?
- 2. IHSS так же имеет информацию о том что предоставитель услуг может и чего не может делать для Вас. Какую информацию получили Вы о роли провайдера и его ответственных обязанностях?
- 3. Некоторое потребители находят для себя простым поиск и наем помощника, в то время как другие не знают как это сделать. IHSS может предоставить информацию о том как найти помощника по дому. Какую информацию Вы получили о том как встретиться, провести собеседование и нанять помощника?
- 4. Некоторые потребители знают как общаться с помощниками, в то время как другие могут испытывать трудности в построении здоровых отношений с помощником. Какую информацию получили Вы о взаимодействии и построении здоровых отношений с помощником?
- 5. После наема IHSS должны зачислить в штат и оплачивать услуги предоставителям услуг (помощникам)ю Какую информацию получили Вы о зачислении и оплате услуг помощника?
- 6. IHSS так же предоставляет информацию о безопасности клиента. Какую информацию Вы получили о безопасности клиента?
- 7. Каую бы информацию Вы бф порекомендовали предоставлять новым клиентам IHSS
- 8. Какой с Вашей точки зрения самый лучший способ для IHSS предоставлять информацию своим клиентам?

Appendix Q: Interview Invite – Spanish

La pr\(\time\) xima semana tendremos una discusi\(\time\) n de grupo. Estamos invitando a los consumidores de IHSS para compartir con nosotros sus experiencias con el programa IHSS.

Queremos saber si fueron capaces de nevegar f il cilmente el programa y si ten il an alguna dificultad para encontrar informacion. Tambi in queremos saber cimo se reolvieron sus preocupaciones.

Nuestro objetivo es hacer que sea mas f i cil para usted para navegar el programa IHSS. Su reac i muy apreciada.

## <u>Appendix R : Interview Invite – Cantonese</u>

你好\_\_\_\_\_。我的名字是\_\_\_\_。我是三藩市家居 护理的辅导员。

下星期我们会有一个小组讨论。

我们将邀请IHSS 的雇主参加下星期的讨论会。

IHSS的雇主们会与我们分享关于IHSS这个项目的经验。

我们想知道你是否很容易明白我们的项目,和在查找信息时是否遇到困难。

我们也想知道你是怎么解决您遇到的问题。

我们希望帮助你更容易明白HISS这个项目。

我们想知道,你是否有兴趣参加我们在\_\_\_\_\_的讨论小组。

我们将非常感激你的意见。

### Appendix S: Sample of Consumer Information Material

# Questions for the telephone interview

Here are some questions you might consider asking during the telephone interview:

- Can you tell me something about yourself?
- I need help on (DAYS) at these times (times you want

Adapted from the IHSS Consumer Training Handbook, 2011 http://www.cdss.ca.gov/agedblinddisabled/res/2011\_IHSS\_Consumer\_Training\_HB\_v2.pdf

#### Appendix T: Storyboard

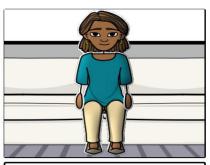


Consumer Information:
Authorized and Unauthorized Tasks

Image will appear on screen for 3-5 seconds. Then image fades.



Woman appears sitting, facing the camera.



"Hello! My name is \_\_\_\_\_\_, and I am an independent provider with IHSS. "



"You might be getting ready to hire a provider, or have already hired a provider. In order to make sure that you are able to make a practical to-do list for your provider, I will go over tasks which are authorized and tasks which are not authorized by HISS."



"As a provider, I am authorized to do all light housekeeping in your home. I can make your meals, do your laundry, ironing, mopping, dusting, and other general housecleaning. However, I am not authorized to do any heavy cleaning. Some unauthorized cleaning includes washing windows, cupboards, or walls; cleaning carpets or rugs; and gardening."



"I will be happy do your shopping! However, I am unauthorized to deliver your bill payments. The only time I can deliver your bill payments are when they are overdue.



"Family members are the number one support systems for many of our consumers. As a provider, I will work with your loved ones to assist you the best way possible. However, I cannot provide services directly for your family members unless they are enrolled as IHSS consumers."



"Your pets are your family, and I will treat them as such. However, I am not authorized to provide pet care, such as taking them for a walk, grooming, cleaning their litter box or picking up their droppings."



Just let me know if you need any personal care services! Some of these tasks can include bathing or bed bath, bowel and bladder care, grooming, oral hygiene, help with walking, getting in and out of bed, medication reminders, and assistance with your prosthesis. I can even provide paramedical services, such as blood sugar checks and injections. However, I will need to be trained by your health care provider before I do any of the paramedical care.



"There was a lot that I covered' So, feel free to replay this video, IHSS also provides handouts on authorized and unauthorized tasks. You can request these forms from IHSS Public Authority at xxx-xxxx-xxxx, or download it from the IHSS Public Authority website at:

www-dot-s-f-i-h-s-s-p-a-dot-org."



"Thank you for watching! And best of luck with your new provider!"

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Screen showing SF IHSS PA Logo and contact info. Scene fades after 5-7 seconds.

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