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# Leveraging In-Home Supportive Services Programs to Engage People in Advance Care Planning: Input from Staff, Providers, and Client Stakeholders

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### Abstract

*Background:* In-Home Supportive Services (IHSS) cares for millions of Medicaid-eligible older adults who are often homebound and socially isolated. Advance care planning (ACP) can be challenging for this population, and IHSS programs may play an important role.

**Objective:** To explore the feasibility of an IHSS ACP program for frail older adults.

Design: Semistructured focus groups.

*Setting/Subjects:* Fifty IHSS stakeholders (20 administrators, 9 case managers, 13 in-home caregivers, and 8 clients) participated in 10 focus groups in San Francisco.

*Measurements:* Qualitative thematic content analysis by two independent coders.

**Results:** Four main themes emerged: (1) Unmet needs: patients' wishes unknown during a medical crisis, lack of education/training for clients and staff; (2) Barriers: conflict of interest and potential medical overreach of IHSS caregivers, lack of billing avenues, time limitations, and cultural, literacy, and language barriers; (3) Facilitators: leveraging established workflows, available technology, and training programs; and (4) Implementation: use a tailored, optional approach based on clients' readiness, focus on case managers not caregivers to prevent conflict of interest; use established intake, follow-up, and training procedures; consider cultural and literacy-appropriate messaging; and standardize easy-to-use procedures, simple scripts, and educational guides, within established workflow to support case managers.

*Conclusions:* An IHSS ACP program is important and feasible for Medicaid-eligible, frail older adults. Implementation suggestions for success by IHSS stakeholders include focusing on case managers rather than inhome caregivers to prevent conflict of interest; tailoring programs to clients' readiness, literacy, and language; creating educational programs for IHSS staff, clients, and community; and standardizing easy-to-use guides and procedures into IHSS workflows.

Keywords: advance care planning; case managers; In-Home Supportive Services; patient education

### Introduction

A DVANCE CARE PLANNING (ACP) is considered the standard of care, especially for frail older adults facing complex medical decisions about their ongoing care needs and end-of-life care.<sup>1–4</sup> However, barriers to ACP in this population include social isolation and competing priorities during medical office visits.<sup>5,6</sup>

The In-Home Supportive Services (IHSS) Program for Medicaid participants<sup>7,8</sup> may hold promise for ACP education,

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LEVERAGING IN-HOME PROGRAMS TO ENGAGE PEOPLE IN ACP

thereby improving activation and engagement in ACP.<sup>9</sup> Over two million IHSS caregivers deliver paid, personal, in-home assistance for 2.7 million U.S. older adults.<sup>10–13</sup> IHSS is a social model providing personal care services. IHSS case managers do not provide medical care, work for organizations that provide medical care, nor become involved in medical billing. The Department of Aging and Adult Services, which coordinates San Francisco's IHSS program,<sup>14</sup> evaluates the need of each IHSS client. IHHS clients then hire and supervise IHSS caregivers. IHSS caregiver wages are paid through a county-funded program.<sup>15</sup> For IHSS clients unable to manage an IHSS caregiver, an independent nonprofit organization performs these responsibilities. An IHSS case manager provides ongoing evaluation of needed services for every IHSS client.

Little is known about whether or how an IHSS program can help older frail adults engage in ACP. The goal of this study was to explore with IHSS stakeholders the feasibility of introducing ACP within the IHSS program infrastructure.

#### Methods

#### Setting and participants

A six-member IHSS advisory board suggested potential IHSS stakeholders, including IHSS administrators, case managers, in-home caregivers (family, friends, or caregivers from a registry),<sup>16</sup> and older adult clients.

We recruited a convenience sample through snowball sampling of English-speaking stakeholders with  $\geq 1$  years' experience with the IHSS program. Administrators, case managers, and caregivers were included if  $\geq 18$  years of age and clients  $\geq 55$  years. We excluded individuals who reported blindness, dementia, psychosis, or cognitive impairment.<sup>17–19</sup> Participants provided informed consent and were reimbursed \$50. This study was approved by the Institutional Review Board of the University of California, San Francisco.

#### Procedures

We developed semistructured focus group discussion guides (Table 1) based on IHSS advisory board input and our prior work.<sup>6,9,20,21</sup> Topics explored included barriers and facilitators of an IHSS ACP program and stakeholders' opinions about the use of an evidenced-based easy-to-read advance directive (AD) and interactive ACP program called PREPARE (www.prepareforyourcare.org). These tools have demonstrated improved engagement in the ACP process and documentation of medical wishes.<sup>9,22–24</sup> Recruitment continued until thematic content saturation was achieved.

#### Data analysis

We audiorecorded and transcribed all discussions. Qualitative thematic content analysis was conducted by two independent coders who synthesized codes into themes using ATLAS.ti 7.<sup>25,26</sup> We ensured trustworthiness by utilizing deductive and inductive coding, multiple coders, and maintaining records of changes.<sup>25,27</sup> All transcripts were double coded, and disagreements were adjudicated by consensus. Inter-rater agreement was 84%, considered good to excellent.<sup>28–32</sup>

TABLE 1. FOCUS GROUP OUTLINE GUIDE
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AUD	 1.51.1	rators

Introduction Discussion of ACP in the context of the IHSS Program Current role of IHSS personnel in ACP Willingness of staff and clients to participate
Facilitators
Agency and workforce strengths
Existing mechanisms/infrastructure that could facilitate a program
Potential benefits of a program
Barriers
Potential challenges to a program
Possible solutions
Implementation logistics
Brainstorm about a program in the context of current
IHSS infrastructure
How to maximize IHSS staffs' ability and willingness to assist with ACP
Workflow, work rules, existing priorities
Training and other agency's needs
Feasibility of using PREPARE videos and easy-to-read ADs
-

Case management staff

#### Introduction

Current knowledge around ACP in staff and clients Current case management procedures/workflow Consumer and other attitudes toward ACP Facilitators Need for IHSS ACP Program Potential benefit to IHSS clients/case management/ agencies Possibility of leveraging existing training/procedures Barriers Potential challenges to a program

Potential challenges to a program Possible solutions

Implementation logistics

Brainstorm about an ideal IHSS ACP Program in the context of current IHSS infrastructure

Training needs for case management staff

- Resources and procedures
- Time and workflow management
- Feasibility of using PREPARE videos and easy-to-read ADs

### IHSS caregivers

Introduction

- Description of current and past clients (IHSS consumers): age, disability, etc.
- Time spent with consumers, tasks performed, interaction with case management personnel
- Older adults' attitudes toward ACP with IHSS case management staff

#### Facilitators

- What IHSS programs are already in place to facilitate an IHSS ACP program?
- What suggestions do you have for a successful ACP program?
- What are your thoughts about whether or how caregivers can follow-up on ACP provided by IHSS case management?

(continued)

All participants (n=	
Age Mean years±SD	
Gender Male	
Female Other/unknown	
Race/ethnicity White, non-Hispa African American	
Asian or Pacific	
Latino or Hispan Other/unknown Education Postgraduate <sup>a</sup> College HS and associate < High school or <sup>a</sup> Masters or doctora GED, general educ standard deviation.	
for the direct care. "There is also the p abuse" by IHSS car that ACP may be an providing personal c personally employ. Furthermore, IHSS	

ACP, advance care planning; ADs, advance directives; IHSS, In-Home Supportive Services.

#### Results

Fifty IHSS stakeholders participated in 10 focus groups: four administrator groups (n=20); and two groups each with IHSS case managers (n=9); IHSS caregivers (n=13); and IHSS clients (n = 8). Demographics are listed in Table 2. Four overarching themes emerged: unmet ACP need, barriers, facilitators, and implementation logistics (Table 3).

#### Unmet need for ACP

Participants described poor outcomes of several clients who had not expressed ACP wishes: "A client who was dying of cancer...I don't think he had a planner and he didn't want to go to the hospital," and "She lives alone... we feel really sad that we don't have a chance to know...what was she wishing." Participants also discussed that IHSS case managers, IHSS caregivers, and IHSS clients are not knowledgeable about ACP; as per a case manager, "90% said they never heard what an advance healthcare directive was." Administrators also reported that the frail older adult population on Medicaid "...is not an empowered consumer group," and discussed how "[ACP] gives them power that they've done this, that they have a plan."

#### Barriers

Participants cautioned about potential conflicts of interest, "especially if it is a family member and they are getting paid

TABLE 2. PARTICIPANT CHARACTERISTICS

All participants (n=50)	n (%)
Age	
Mean years $\pm$ SD (range)	55±16.2 (24–92)
Gender	
Male	16 (32)
Female	32 (64)
Other/unknown	2 (4)
Race/ethnicity	
White, non-Hispanic	27 (54)
African American	10 (20)
Asian or Pacific Islander	7 (14)
Latino or Hispanic	6 (12)
Other/unknown	0
Education	
Postgraduate <sup>a</sup>	23 (46)
College	12 (24)
HS and associates	14 (28)
< High school or GED	1 (2)

ate.

cation development; HS, high school; SD,

e." For example, an administrator said, potential for a lot of misuse and a lot of regivers to clients. Many clients reported in overreach of IHSS caregivers' roles in care, "IHSS [caregivers] are people that I They are not about my medical needs." S administrators reported that ACP is beyond IHSS caregivers' scope of work. IHSS case managers also discussed time constraints, "We are more or less overwhelmed," and participants discussed cultural barriers and stigma, "In a lot of cultures bringing up death is sort of taboo," as well as limited health and computer literacy and language barriers.

#### Facilitators

An IHSS ACP program was received positively by all IHSS stakeholders and thought to be able to leverage existing roles and procedures. Case managers establish ongoing relationships with clients and are "in [clients'] homes three times a year...They do care planning and they could probably do it [ACP] in that context." Case managers also reported access to technology as an informational platform as they have "portable laptop(s) that folds into a tablet. So, we do have the potential to show that [PREPARE website]." IHSS's existing training infrastructure for case managers and caregivers could also be leveraged for ACP: "We do everything from two-hour classes to three-week classes."

#### Implementation

Suggestions for implementing an IHSS ACP program include: clarifying that it is "an opt-in, voluntary" program, tailored to clients' choice and readiness, "not a one-size-fitsall"; focusing on case managers instead of IHSS caregivers, "This is very much in the wheelhouse of what case managers do"; leveraging established intake and follow-up procedures for "longitudinal tracking where we initiate the conversation"; providing training for IHSS case managers and IHSS

Theme	Role	Quotes
Unmet need for ACP Unknown wishes	Case manager	"I would have a client who was dying of cancer and I'm like 'Oh my God; I'm calling paramedics.' I don't think he had a planner and he didn't want to go to the hospital."
	Administrator	"We have a clientand she lives alone and she does not have any relatives around her. Her family is back in [X country], and her only son abandoned her and moved. So, at the very, very last days of her life, she was in a coma. And we feel really sad that we don't have a chance to know what she had planned for herself, or what was she wishing."
	Client	"The more people who know what you need and what's wrong with you, the better off you are. If you're just sitting in some place and nobody knows anything about you, then anything can happen and you're gone."
Lack of knowledge	Administrator	"I don't think either group of people, the worker or the consumer, is very knowledgeable about advance care planning. Because I just think as a general population we're probably notso you get a two- for-one thing here."
	Case manager	"The clients would always trip up on a notice saying "What is this?" Like, 90% said they have never heard what an advance health care directive was. And they didn't really tell us what to tell [clients] when we were going to train."
Need to empower	Administrator	"This is a population that is all on MediCal [Medicaid], so their relationship to the healthcare system is a complicated one This is not an empowered consumer group. It's the opposite It [ACP] gives them power that they've done this, that they have a plan, they've thought about it, and they don't feel just sort of out there as an isolated individual."
Barriers		
In-home caregiver conflict of interest	Administrator	"For some folks, a personal attendant is a professional relationship and in some cases, it might be a family member whether or not it is a trusted relationship is the question there is also the potential for a lot of misuse and a lot of abuse in that category as well."
	Administrator	"What is the relationship between the consumer and the worker especially if it is a family member and they are getting paid for the direct care. So, if we are talking about maybe doing an advance healthcare directive and long-term planning it could also be a component of financial concern"
Over medicalization	Client	"The idea just as a worker as part of a care team just makes me cringe. IHSS workers are people that I personally employ. They are not about my medical needs; they are about my activities of daily living and getting to work If I want them to, that's fine, but for me and the many people I know that's not the level of care that they need or want."
	Administrator	"The issue I think is from some aspects of the disability community is to what extent that continues to perpetuate consumer control and directionsomehow the personal assistance services aspect is somehow becomes re-medicalized. On the other hand, there are potential extraordinary benefits if handled correctly."
IHSS caregivers unable to bill	Administrator	"So, there are very specific IHSS tasks that we assess for [ACP is] not one of the ongoing tasks. It is not an activity of daily living The IHSS service menu will not pay for that."
	Administrator	"So, there is no part of IHSS that pays for advance care planning; there
Time limitations	Case manager	just isn't." "It is definitely not something that is expected of usThere is definitely quite a bit of opportunity but to be straightforward, we are more or less overwhelmed in the capacity that we are serving at this time."
	Administrator	"Often times our clients are presenting with these urgent situations like "We are getting evicted" or they have an open leg wound that's not getting treated or they have an infestation. Those are the things that we are following up on first."

TABLE 3. STAKEHOLDER INPUT FOR AN IN-HOME SUPPORTIVE SERVICES ADVANCE CARE PLANNING PROGRAM

(continued)

Theme	Role	Quotes
Cultural barriers	Administrator	"In a lot of cultures, I see just bringing up death as sort of taboo. And people don't want to discuss it, because to discuss it is to invite it."
	Administrator	"Well, what do I do now, because I went to the doctor with my client and the son. And the doctor told the client that she didn't have much longer to live, and the son refused to translate thatThat was something for the family to know, but not for the mother to know."
	Case manager	"I think [there are] cultural and emotional barriers to having that discussion I think that is really extraordinarily difficult for people that are intimate in our clients' lives to have that conversation."
Technical, literacy, and language barriers	Case manager	"We're dealing with real low health literacy; not everyone but I would say most. They are just unfamiliar with this."
	Client	"There also is an issue too that she's from [X country], so I'd say especially in the medical side of it, you know. She speaks English but there's a lot of things she doesn't understand."
	Case manager	"I think even with a tablet they wouldn't know how to work it. Unless they for sure had a close family member seniors are very illiterate in computers."
Facilitators	Client	"I have problems with typing certain things. I have two landline telephones and that's it. No cell phone."
Facilitators Leverage established case manager roles	Administrator	"We really train our case managers in talking with clients. I mean, it's a very good fit for that particular serviceas well [as] for our social workers when they do their assessments and reassessmentsSo, I could see [ACP] being part of the kind of longer assessment and conversation that our workers might have with the client."
	Administrator	"We have case managers, service coordinators who are out in consumers' homes three times a year or so, and they are doing involved assessments and care coordination, making sure that the workers' schedules and the workers are fitting what the consumer needs are. They do care planning and they could probably do it [ACP] in that context."
Leverage established technology	Case manager	"Every case manager and service coordinator is provided a brand new portable laptop that folds into a tablet. So we do have the potential to show willing and able clients that information [PREPARE website]. We do have opportunities to at least broach the subject."
	Client	"I got three new workers with me that are with their phones I bet [they] know how to use a computer so if they [the consumer] don't know how to use the computer, I bet someone else does."
Leverage established training programs	Administrator	"We do everything from two-hour classes to three-week classes, and we do nighttime and we are building sort of an online capacity so we have a lot of training capacity and we are centrally located."
	Administrator	"The training program has about a 70-hour basic training. It has a lot of specialized training also."
Implementation Tailored to client choice and readiness	Administrator	"Just make sure that it is an opt-in, voluntary thing and that is not something that the consumer has no control over; so I think to me that is one of the most paramount things to a project like this."
	Client	"I think it's a good thing to a point but it depends on how independent a person wants to be, how engaged they want to be with social workers. A lot of people don't want to be involved with social workers or case managers because you feel like I can do it myself, I'm in my own life and I'm doing it."
	Administrator	"Consumers in IHSS are very diversethere are consumers who are fully capable of doing advanced care planning on their own. And then there are the folks that have dementia or other situations So it is not a one-size-fits-all with IHSS consumers. So whatever we come up
	Case manager	with should be flexible enough to fit different types of consumers." "So we do have the potential to show willing and able clients [the PREPARE website]; but then the question would be whether or not that would be mandated or whether it is the determination of the coordinator if that person has the capacity to do that at that time or if it is even appropriate."

TABLE 3. (CONTINUED)

TABLE 3. (CONTINUED)		
heme	Role	Quotes
Focus on case managers not caregivers	Client	"I don't want to have my employee tell me that I should be working of my managed care or directives. I just don't think that is their role. think that should come from you [case managers]."
	Administrator	"We have case managers. And this is very much in the wheelhouse what case managers do as part of an overall plan is to assess and he structure a plan."
	Case manager	"I do understand the importance though of a service coordinator or case manager being involved in that conversationSo I think a thi party initiating and educating is definitely a great area of opportunity that family members don't have to just lay it out like where are yo going to live? What am I going to do with you? It's less of that and le personal and more just this is a part of planning in the same way th you would plan your doctors' visits or plan your financial stability.
	Client	"My case manager can get as much information to the doctor that c help me Whoever my case manager is, as much as they know abc me, tell the doctor, and then the doctor will try their best to help me
Use established intake and follow-up procedures	Case manager	"Like part of an intake actually is not a bad idea at all because we caleave them with some information in whatever form it needs to take not electronically, a piece of paper or whatever You would be planting the seed and maybe they will sign the form later or think about it in five years, or a year."
	Case manager	"We create a care plan for them; it's like their treatment plan, servi plan. And long-term planning often comes up in that initial assessment we bring it up in our program, at least initially. An
	Case manager	<ul><li>then we might revisit it at one of our quarterly visits."</li><li>"I feel like it almost has to be something that's kind of part of the we culture to make it like, okay, this is a regular thing that you are expected to do on intake."</li></ul>
Training for IHSS staff and clients	Case manager	"I do think the first step would be education for our staff, for us [ca managers], too, about like I said ways to put a positive spin on it, he to talk about it with your client, the importance of it, ways that w can just start putting the plug in, because we are building relationships with these people over time."
	Caregivers	"The classes helped me a lot. And it made the biggest difference They have all those classes, which I took them all when I learned [about] it. Every time they have a new one I take them."
	Client	"It would be helpful to have a case manager to go through it with n Or one of my family members but they're so far away A group Yeah, that would help me."
	Client	"Yeah, I can go to a class [about ACP] I think the consumer shou take it."
Provide simple guides and scripts	Administrator	"And so, I think training even culturally competent caregivers to sort bring up that conversation. Because that's really the hardest part about this is how do you start that conversation."
	Caregivers	"So I think it should be implemented, a checklist they don't know what kinds of questions to ask."
Messaging	Administrator	"So, really what we bring I guess to the discussion is this concept of what is healthy aging all aboutand what are the things that you want to [be] thinking about at this time in your life. And it's not ju- end-of-life decisions, it's what's the legacy you want to leave, an what's on your bucket list, and who's the support team that's going help you."
	Administrator	"One of the most successful models I've seen is nested in the conversation about what are your social networks, who is there to help you in an emergency, who would take care of your dog if you were in the hospitalI mean that is kind of one step but also thinki about end of life issues, but they do it in a way that is very non- medical model-ish, very much of a social model, very much of an approach that really tries to help people feel empowered."
	Client	"Normalize it you never see anything about this. Do you have you plan in place in case something happens? Just a simple conversation realistic—I really think—education, educate the public."

TABLE 3. (CONTINUED)

(continued)

Theme	Role	Quotes
	Case manager	"Education for our team would be super helpful and ways that we can approach it with clients to talk about it in a more positive light, as a positive planning process not associated only with death and sickness."
Cultural considerations	Administrator	"When they get into the conversation with their clientyou might need to say it at the right time, right place, the right language. And before you discuss that with your client, maybe you need time to observe what your client's belief, and culture. Because we don't want to offend the client at all."
	Administrator	"I would also be sensitive also to language, because I mean, it's so well-known that different cultures respond differently to different wordsAnd so, you want to be sure that not only is it culturally, but also linguistically appropriate."
	Case manager	"Even individual ethnicities and cultures might have—they have their own thoughts and feelings about it So bringing that piece into it would be really good and could be for anybody, any age, any disability and not just like an older person."
Addressing literacy, language, and technical barriers	Case manager	"We have a lot of—seniors are very illiterate in computers and anything. It's more likely you are going to sit down and one-to-one talk is much better-this [is] how we communicate."
	Client	"The best way the most effective way would be read aloud to peopleOnly face-to-face."
	Administrator	"I think it's really important if the IHSS worker, they speak the same language. Like the case I mentioned before, they sent the IHSS worker, she speaks the languageso while she was working in her home, they talked [about] everything."
	Administrator	"But that's another way we can sort of support, is that we have some technology that we can bring out to clients that we can actually do this with them in the home."
	Client	"I would probably come to that group [to watch the PREPARE movie]."
	Client	"I'm all for it [PREPARE group viewing]. A symposium, or something like that."

TABLE 3. (CONTINUED)

caregivers to educate clients as, "you get a two-for-one" increase in ACP knowledge; providing simple, standardized guides and scripts to case managers as "the hardest part about this is how do you start that conversation"; addressing messaging "to normalize it," "nested in a conversation about social networks" and "healthy aging"; and addressing health literacy and cultural differences by using easy-to-read, culturally appropriate educational materials, providing "one-toone" conversations, and leveraging existing technology so case managers "can actually do [PREPARE] with them in the home, or show PREPARE movies in a 'symposium' or group setting."

#### Discussion

This study provides a multistakeholder perspective about leveraging IHSS infrastructure to develop and implement an ACP program. We found that such a program is greatly needed, and given existing relationships, training infrastructure, and available technology, IHSS case managers are well positioned to introduce ACP education to clients. A prior study of care coordinators within an academic health system showed benefit using a home health care model, as have studies of lay health navigators in other populations.<sup>33,34</sup>

In this study, all groups discussed the need and feasibility of an IHSS ACP program. They stressed that case managers, not in-home caregivers, should initiate the ACP process to prevent potential conflict of interest. Participants also reported difficulty in discussing sensitive topics. However, facilitators included case managers' ongoing relationships and frequent contact with clients in the home, the ability to provide ACP written information, access to technology to use the PREPARE program, and existing client symposium and staff training programs.

Stakeholders provided practical suggestions for implementation: tailoring to clients' readiness and health literacy to accommodate the diversity of IHSS clients; leveraging established intake and follow-up procedures to more easily integrate into case managers' workflow; conducting educational groups for clients and their family; providing case managers with easy-to-use, literacy-appropriate scripts and ACP tools; and normalizing ACP as part of the IHSS program. Stakeholders felt the easy-to-read AD and PREPARE website could feasibly be shown in home or group settings. PREPARE has been shown to increase ACP engagement in older adults in various settings.<sup>35,36</sup>

Several subthemes were brought up by all groups, including unknown wishes necessitating a need for ACP and several implementation suggestions: tailored content; a focus on IHSS case managers; messaging; and addressing literacy, language, and technical barriers. Given the acceptability and feasibility within the IHSS program, future considerations of extending reimbursement to ancillary staff, including IHSS case managers, would allow for greater dissemination of ACP information. Furthermore, providing IHSS case manager and IHSS caregiver ACP education is important because many caregivers and case managers have witnessed the untoward outcomes of unrepresented clients and those without the opportunity to express their medical care wishes. It is imperative to empower the homecare workforce as there is high turnover in this important field, which helps keep older adults in their homes. Providing training has been shown to increase retention and job satisfaction and increase empowerment.<sup>37,38</sup>

Strengths of this study include the racial/ethnic diversity of participants and the novelty of exploring the feasibility of an IHSS ACP program. Limitations of this study include recruitment in one geographic location in the San Francisco area and the exclusion of clients with cognitive impairment, limiting generalizability. Participants felt IHSS case managers would not have a conflict of interest because they are not involved in direct medical care, or medical care decisions for clients. In other IHSS contexts, involvement of case managers may be considered a potential conflict of interest. Participation was voluntary, and recruitment occurred through snowball sampling potentially resulting in selection bias. More research is needed to assess the needs of other cultural backgrounds, other in-home programs, and clients with cognitive impairment.

#### Conclusion

An IHSS ACP program using case managers is needed and feasible by leveraging existing relationships, procedures, and educational infrastructure. Key points are tailoring the program to clients according to their readiness, culture, and language, and create training and education opportunities at all levels (case managers, caregivers, clients, and family). Further research is needed to test the implementation of an IHSS ACP program.

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No authors report any competing financial interests.

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