Original Investigation

Walking the Line: Navigating Market
and Gift Economies of Care
in a Consumer-Directed Home-Based Care
Program for Older Adults

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Policy Points:

- Policies that cut or restrict formal long-term services and supports for older adults can either push caregivers to provide uncompensated care or leave older adults with unmet needs for care.
- Increased pressure to provide uncompensated care to older adults in the aftermath of cuts in formal services can have negative economic and health consequences for both related and nonrelated caregivers.
- Policies that assume (implicitly or explicitly) that related caregivers can readily fill gaps in care (and that unrelated caregivers will not) should be reassessed. Both related and unrelated caregivers face financial and health-related barriers to filling gaps in formal services for older adults.

Context: Paid caregivers of low-income older adults navigate their role at what Hochschild calls the “market frontier”: the fuzzy line between the “world of the market,” in which services are exchanged for monetary compensation, and the “world of the gift,” in which caregiving is uncompensated and motivated by emotional attachment. We examine how political and economic forces, including the reduction of long-term services and supports, shape the practice of “walking the line” among caregivers of older adults.

Methods: We used data from a longitudinal qualitative study with related and nonrelated caregivers ($n = 33$) paid through California’s In-Home Supportive

Services (IHSS) program and consumers of IHSS care ($n = 49$). We analyzed the semistructured interviews ($n = 330$), completed between 2010 and 2014, using a constructivist grounded theory approach.

Findings: Related and nonrelated caregivers are often expected to “gift” hours of care above and beyond what is compensated by formal services. Cuts in formal services and lapses in pay push caregivers to further “walk the line” between market and gift economies of care. Both related and nonrelated caregivers who choose to stay on and provide more care without pay often face adverse economic and health consequences. Some, including related caregivers, opt out of caregiving altogether. While some consumers expect that caregivers would be willing to “walk the line” in order to meet their needs, most expressed sympathy for them and tried to alter their schedules or go without care in order to limit the caregivers’ burden.

Conclusions: Given economic and health constraints, caregivers cannot always compensate for cuts in formal supports by providing uncompensated time and resources. Similarly, low-income older adults are not competitive in the caregiving marketplace and, given the inadequacy of compensated hours, often depend on unpaid care. Policies that restrict formal long-term services and supports thus leave the needs of both caregivers and consumers unmet.

Keywords: caregivers, long-term care, policy, older adults.

AS THE DEMAND FOR LONG-TERM CARE IN THE UNITED STATES grows alongside a rapidly aging population, there is increased interest in the experiences of those who provide this care. Caregiving has traditionally been viewed as a component of family life, as a personal obligation rather than a legitimate form of paid work.^{1,2} The expectation is that elder care will be provided, at least in part, as a “gift,” an uncompensated act born out of emotional bonds, trust, and reciprocity.³ This belief often underlies decisions to limit public benefits that support paid caregiving for older adults.^{1,4,5}

Despite hesitation in the public policy arena to pay for care historically provided at the expense of family members, there has been a shift toward greater support for home-based caregiving for older adults and the disabled as a way to reduce institutional care, including programs that allow family members to be paid. Starting in 2004, the Centers for Medicare and Medicaid Services (CMS) expanded the definition of who can be compensated for providing home-based care, thereby allowing states to pay relatives.⁶ In some states, Medicaid’s Cash and Counseling

demonstration program has expanded the scope of consumer direction by offering consumers a monthly cash allowance for goods and services related to their daily care needs, including an option to hire, train, and determine their caregivers' wages and activities.⁷

The ability to pay nonrelated caregivers is also essential to older adults who may not have family members available to provide care or who prefer nonrelated caregivers. Paid nonfamily caregivers will become increasingly important as the availability of family caregivers declines for the baby boom generation and beyond.⁸ Nevertheless, there are significant challenges to growing this segment of the health care workforce due to low wages, limited or no benefits, and few options for career mobility.^{5,9,10}

In California, the In-Home Supportive Services (IHSS) program is a key long-term services and supports (LTSS) program that assists low-income persons with disabilities by providing personal and household care. California's IHSS program is the largest consumer-directed care program in the United States,¹¹ with around 402,000 caregivers providing home-based care for more than 490,000 low-income disabled individuals,¹² about two-thirds of whom are age 65 and over.¹² Unlike Cash and Counseling, IHSS is a defined benefit for home care only, and consumers are not free to set caregivers' wages. Nevertheless, IHSS is considered a consumer-directed program, as recipients are able to select, hire, supervise, and fire paid caregivers of their choosing, including family members and friends as well as nonrelated and previously unknown individuals. The benefits and wages provided by these programs are an important driver of the recruitment and retention of related caregivers,⁹ given that uncompensated elder caregiving can lead to reduced work hours and lower earnings.¹³

Paid IHSS caregivers are the focus of our analysis. Using data from a longitudinal qualitative study, we explored the experiences of both these caregivers and the older adults whom they care for. We wanted to understand how caregivers navigate their role as paid employees, often in the context of familial, pseudofamilial, or other emotional ties that motivate them to provide care that may be uncompensated and may extend beyond activities approved by IHSS. Providing unpaid care is particularly common among caregivers working under a consumer-directed model like IHSS, in which family members are more likely to provide care or family- or friend-like relationships are likely to develop between nonrelated caregivers and the people they care for.¹⁴ We

expected that caregivers might be constantly renegotiating their ability to go above and beyond their compensated care, given the reductions in public benefits following California's budget crisis. These cuts have resulted in fewer paid work hours for caregivers and have left low-income older adults with unmet needs for care.

Paid Caregivers "Walking the Line"

We view the experiences of both consumers and providers of care using Hochschild's concept of "walking the line,"³ or working at the "frontier" of the world of the market in which services are exchanged for pay, and the world of the gift, in which services are provided based on emotional ties and feelings of moral or personal responsibility and reciprocity. Paid caregivers often operate at this intersection: in a gift economy, relatives and nonrelatives provide care under the auspices of familial, pseudofamilial, or societal responsibility, which is based on emotional ties to the person receiving care. In a market economy, compensation is expected for each hour of care or service provided. Paid caregivers, including non-related caregivers, often describe their motivations and care activities as rooted in a context of close emotional ties to the consumer of care and as a sense of moral obligation to the individual or the population of older adults with disabilities more generally.^{9,15-17} But they do so in a context of financial strain, particularly given the low wages for caregivers' work. Furthermore, the line between a market and a gift economy is not clearly marked for any single caregiver or consumer of care. On the one hand, caregivers are real people for whom the distinctions between self-interested market exchanges and gift giving—motivated by altruism, relationship building, and reciprocity—are often not clear.² On the other hand, real people must also grapple with decisions made by institutions and policies, in this case through IHSS, about what "counts" as caregiving that should be paid or unpaid.

We also expect caregivers' decisions related to the care they provide to change and respond to policy changes over time, a point that has not yet emerged from cross-sectional studies of paid home-based caregivers.^{16,17} For example, nonrelated paid caregivers who assume a caregiving role with the intention of defining it as a market transaction may nonetheless form emotional bonds over time with consumers that draw them into the world of the gift, in which they go beyond a market exchange to

provide extra, unpaid care, or care that is not deemed reimbursable by the IHSS.¹⁶ Paid family caregivers or pseudofamily caregivers may lose hours of work that can then also cause them to lose health care benefits as the result of program cuts, forcing them either to continue to provide care with less compensation or to set firmer boundaries, limiting their hours and care activities to those compensated. In some cases, caregivers may go from “walking the line” to walking away, at least from individual consumers of care, when they are no longer able to fill in the gaps left by porous state supports for low-income older adults. Changes in caregiving arrangements may also result from consumers’ own changing health conditions and care preferences. For example, consumers’ health may gradually decline, or they may develop acute health conditions, leading to a greater need for care hours that formal LTSS are slow to accommodate, thereby placing pressure on caregivers to provide unpaid care or unapproved services.

We also consider caregivers’ ability to provide uncompensated care in the broader context of their own lives that can involve physical and mental health challenges, financial burdens, and pressures to care for other family members. Caregivers, including paid caregivers, report financial strain due to low wages and financial barriers to health care.^{5,10,13} Family caregiving has been linked to declines in physical and mental health status,^{18,19} and nonrelated home-based caregivers also experience emotional and physical strain, including workplace injuries.^{10,20}

Finally, because the consumers’ perspective is often missing from studies of home-based caregivers’ experiences and burdens, we consider their perspective of care as they describe their own role in shaping caregivers’ experience of “walking the line.”^{15,17} Consumer-directed care assumes that consumers of care have the ability to decide who will provide their care. In some cases, consumers prefer caregivers that remain at a distance, offering less intimate care, and care that follows the rules of what is acceptable for compensation. In other cases, consumers prefer care that is flexible and responsive to their needs, regardless of institutional rules governing what kinds of care activities are reimbursable in the caregiving marketplace. We consider consumers’ preferences for caregivers who go above and beyond to meet their needs, and how consumers help create emotional bonds with caregivers who operate partially within the gift economy of care.

Design and Methods of Our Study

The data we used in this study came from the Helping Older-adults Maintain independence (HOME) Project. The HOME Project is a longitudinal, qualitative study of low-income older adults and their caregivers in California.²¹ All respondents were dual eligible for Medi-Cal (California's Medicaid program) and Medicare and were also receiving IHSS. Respondents were recruited through IHSS programs in 5 California counties in partnership with county public authorities and program administrators. IHSS caregiver wages in these counties ranged from \$9.30 to \$11.75 per hour. Even though all counties offer health insurance, eligibility for coverage varied. For example, 2 of the 5 counties required 3 consecutive months of employment and a minimum of 80 hours of work per month to be eligible, and another county required 2 consecutive months of employment with a minimum of 25 hours in one of those months. In 2 of the included counties, IHSS caregivers faced waiting lists of 1.5 to 2 years to receive their health insurance benefits, even after working the required hours for eligibility, because of caps on the number of providers the county will cover with those benefits.

To be eligible for the study, consumer participants had to receive IHSS, be 65 or older, and be able to communicate in English or Spanish. Our sampling strategy was to find a range of consumers based on assessed need (ie, number of care hours allotted by IHSS), participating California county, age, and race/ethnicity. Recruitment was through county social services departments and public authorities who mailed or hand delivered invitation letters in English and Spanish to IHSS recipients who met our inclusion criteria. Interested respondents were given a toll-free number to call, were provided with more information about the study, and were screened for eligibility and enrollment. Those respondents with caregivers were asked to pass along the study information and the toll-free number so that their caregivers could call and enroll. All the respondents were given a \$20 gift card after completing the baseline interviews.

Our study yielded 2 "waves," one between December 2010 and September 2011 and the second between December 2012 and March 2014, with a total of 54 cases (33 caregivers and 49 consumers). By "cases," we mean one or more respondents representing a single IHSS consumer. This could be the IHSS consumer alone but most often was

a consumer-caregiver dyad. In 4 cases, only the caregivers were able to complete the interviews and to represent the “case.” Each study “wave” consisted of 4 interviews for each respondent carried out over the course of about one year. The respondents completed between 1 and 8 interviews over the 2 study waves, for a total of 330 interviews. We conducted the baseline interviews, which were designed to last for one hour, in the respondents’ homes. We then carried out the follow-up interviews, which were designed to last for 30 minutes, over the phone.

The first wave of the study focused on how consumers managed a formal and informal network of long-term services and supports in order to remain independent and how they responded to changing policies affecting the availability of these services. The second wave of the study turned to how consumers managed and coordinated their medical care and long-term services and supports. The interviews were based on semistructured guides that included domains related to care needs, networks of supports and services, and health and health care–related goals and preferences. Table 1 gives more details on the domains included in the interview guides from waves 1 and 2. The interviews were tape-recorded and transcribed. All names have been changed, and the participants’ ages were altered by 1 or 2 years for confidentiality. The Institutional Review Board at the University of California, Los Angeles, approved both waves of the study.

We coded the transcripts using constructivist grounded theory, which employs a mix of deductive and inductive procedures to assign “codes” to each line of the transcript.²² For example, our explicit objective was to document all paid and unpaid sources of care, and even though the caregivers’ negotiations between paid and unpaid care were not an explicit focus of the study, this theme nonetheless emerged from the interviews. Two researchers coded each transcript using ATLAS.ti 5.0 software, and the entire study team met regularly to discuss emerging codes and to carry out line-by-line coding as a group. Once the transcripts were coded, those data from codes relevant to the topic of caregivers and consumers negotiating care and experiencing unmet needs were extracted. We reviewed all these data to identify patterns and contrasting experiences (across-subject variability), as well as exemplary quotations and cases. Given the challenge of analyzing longitudinal data with the existing qualitative software,²³ we documented changes over time for individual cases (within-subject variability) through the reconstruction

Table 1. The HOME Project (2010-2014): Interview Guide Domains and Select Subdomains

Caregiver Interview Guide

Current needs of care recipient (CR) (eg, activities of daily living, assistive equipment)

CR's current services and supports (including formal and informal services/supports)

Caregiver's experience

How caregiver came to care for CR

Description of a typical day of care for CR

Rewarding and challenging aspects of caregiving

Caregiver role in coordinating health care

CR's health care needs and experiences

Unmet needs

Challenges of locating/receiving services

Transportation to medical appointments

Health services utilization and follow-up (eg, hospitalizations since previous interview)

Service changes and information needs (eg, how CR learns about changes to services or care)

Caregiver's demographics

Care Recipient Interview Guide

Current needs for care (eg, activities of daily living, assistive equipment)

CR's current services and supports (including formal and informal services/supports)

Unmet needs for care

Availability of family and friends

Involvement of caregivers and family with medical care (eg, communicating with providers)

Health care needs and experiences

Experiences of delays in care

Experience coordinating care (eg, making appointments, providing transportation)

Communication and coordination with health care providers

Health services utilization and follow-up (eg, hospitalizations since previous interview)

Health care access and health insurance coverage

Quality of life

Service changes and information needs (eg, how CR learns about changes to services or care)

CR's demographics

Domains reflect interview guides from waves 1 and 2 of the study.

Table 2. Characteristics of Caregiver Participants in the HOME Project, Paid Through California's In-Home Supportive Services ($n = 33$)

	Mean	(Range)
Age	49.3	(23-74)
Education, years	12.7	(4-18)
	N	(%)
Gender		
Female	28	(84.8)
Male	5	(15.2)
Nativity		
US born	20	(60.6)
Foreign born	13	(39.3)
Race/ethnicity		
Latino/a	14	(42.4)
Non-Latino white	10	(30.3)
African American	4	(12.1)
Vietnamese	3	(9.1)
Unknown	2	(6.0)
IHSS only job	21	(63.6)
IHSS not only job	12	(36.3)
Related	15	(45.4)
Nonrelated	18	(54.5)

of case studies to include the details of the respondents' needs and available supports and services over the entire study period. The caregivers' and consumers' characteristics are summarized in Tables 2 and 3, respectively.

Results

"On Your Own Time": Caregivers Are Expected to "Gift" Care

Family caregivers in the HOME Project expressed that they were often expected to provide care aside from what they were paid for. These expectations reflected socialized norms in families or communities as well as personal beliefs about giving back to family members. But they

Table 3. Characteristics of Older Adult Consumer Participants in the HOME Project Receiving Hours of Care Through California's In-Home Supportive Services (<i>n</i> = 49)		
	Mean	(Range)
Age	74.4	(65-94)
Education	13	(0-20)
	N	(%)
Gender		
Female	39	(80.0)
Male	10	(20.0)
Race/ethnicity		
Latino/a	8	(16.0)
Non-Latino white	30	(60.0)
African American	6	(12.0)
Asian	3	(8.0)
Other	2	(4.0)

were often reinforced by the institutional rules and policies governing the number of paid hours that each consumer of IHSS received, which set the boundaries for what caregiving counts as reimbursable; what is left over is assumed to be provided without pay. These expectations hold even when family members are unable to fill in the gaps between consumers' need for care and the services and supports that they receive.

The institutional expectation for unpaid family care was exemplified in the case of Ella, a 79-year-old woman with diabetes and depression whose hours of paid care through IHSS had been drastically cut about 5 months before the study period, from about 120 to 70 hours per month. Ella lived with her daughter, son-in-law, and young adult grandchildren, but they could provide only limited care and struggled to remind Ella about and help her with her diabetes medication. Ella's live-in daughter, Sofia, was severely disabled by rheumatoid arthritis, and the other members of the household worked full time and also helped care for Sofia. A second daughter, Isabel, was Ella's paid IHSS caregiver, and she had to drive across town to provide Ella's care hours. Isabel herself faced severe financial challenges and had trouble paying for gas to get to Ella's house, in addition to dealing with her own diabetes and depression.

Ella's daughters explained that the IHSS social worker who reduced the number of her hours following her annual needs assessment based these cuts on the assumption that Ella's live-in family should be helping with her care needs without pay, even though her live-in family members had reiterated their inability to provide much care in the home. Ella's live-in daughter explained:

They did tell her . . . if she was living by herself, she would get all the help she needs . . . she would be able to have the Meals on Wheels and the LifeAlert, but because she lives with family, they are assuming the family is supposed to be there for her. So it's kind of hard when my children go to work; I'm the only one here and I'm limited on what I can do for her, so no, she does need help . . . her health has worsened . . . she needs more assistance.

For Ella's daughters, the expectation that "the family is supposed to be there" underlies the decision to cut the number of paid hours, even though Ella's family members are severely limited because of their own chronic and disabling health conditions as well as work commitments.

Nonrelated caregivers also came up against the institutional expectation of simply filling in the gaps between paid hours and respondents' needs. One common complaint was that the state did not fully compensate caregivers for taking consumers to needed medical care appointments. This situation is exemplified by Diane, a nonrelated caregiver for Michael, a 74-year-old military veteran with severe diabetes. Diane believed that IHSS was "ineffective" about addressing the gap between consumers' needs and the number of their caregivers' paid hours. As an example, she recalled that during her orientation as an IHSS caregiver, another new caregiver in the audience asked about how time spent at consumers' medical appointments was compensated. The caregiver in the audience was allotted 1.7 hours per month for transportation to medical appointments, and she asked what would happen if an appointment took more time because of traffic and long waits. The IHSS staff member reportedly replied, "Well, then the rest of it is your own, your own. You're on your own time." For Diane, this represented an expectation at the level of IHSS, a government institution, that caregivers either "gift" care "on their own time" or choose not to meet their consumers' needs. The expectation of providing uncompensated care was reinforced by the caregiver's concern for the person she was caring for, since she understood that if she did not provide the assistance for free, no one else would. Diane herself tried to meet Michael's needs with extra hours of

work until he moved into a skilled nursing facility—after his needs for assistance managing his diabetes exceeded the hours and type of care he received through IHSS.

Jess, a caregiver for her grandmother, Margaret, described how IHSS regulated caregiving on the market frontier by enacting policies regarding what was acceptable, or at least was reimbursable, for paid caregivers. She suggested that even though her grandmother was blind and had special needs for her care, IHSS would not reimburse some of these caregiving activities:

Unfortunately, though, IHSS doesn't consider a person being blind [as having] an illness. They require what an IHSS person could do: they don't want you working in the garden, they don't want you to take care of pets . . . or cleaning windows. . . . She needs to get her gardening done; she needs to take care of her pets at times. I think she needs help doing her shopping. All the things she can't do for herself, I do it for her, and IHSS doesn't recognize that.

Blindness is one of IHSS's eligibility categories, but Jess indicated that her grandmother's needs related to her blindness extended beyond the list of tasks approved and compensated by IHSS. She suggested that if she wanted to meet her grandmother's needs, she would have to do so outside the market economy of caregiving, beyond what she was paid for. She told us, "If she needs it and asks for it, I would do it for free anyways," but added that this extra care was given as a granddaughter rather than as a paid provider.

Within this framework, paid caregivers must choose whether to leave their clients with unmet needs or to begin providing care "on their own time." In the absence of sufficient paid hours, or in the aftermath of cuts in the number of care hours, caregivers are often pushed further into providing uncompensated care, often in the context of their own financial struggles, as with Isabel, Ella's daughter and paid IHSS caregiver. Many caregivers, both related and nonrelated, decided to provide additional hours without pay, citing as their motivation their personal relationships or obligations to consumers and consumers' very limited networks of formal and informal support. Many also, however, faced significant challenges in offering uncompensated care hours, as we explain later, and some chose to opt out of caregiving that was not strictly limited to the world of the market (ie, paid for in full).

*Caregivers Struggle to Gift Care Hours Critical
to Meeting Consumers' Needs*

Ella's daughter described the difficulty for her and her other family members to "gift" any needed care beyond that reimbursed by IHSS. Although cuts in IHSS hours sent the message that Ella's family should be providing more uncompensated care, they faced considerable barriers to making this shift. Here Isabel, Ella's caregiver and daughter, reflected on the impact of the cuts and her ability to compensate for them with unpaid care:

Sometimes [my mom] has 2 appointments in the same day. I can't put more hours so I just put the hours I'm supposed to put, no matter if I go over. . . . But if she would have her hours, I would get my hours paid and I wouldn't be so tight on my bills too. . . . I'm in a Section 8 program myself. . . . Thank god they reduce my rent, because I'm not making enough money. But still it's not enough. It's not enough, and at the end of the year, I go, like, renewals on my [registration], renewals on my insurance, and I go "Oh my god, no."

Here Isabel was explaining that in order to meet her mother's needs, she continued to work more hours than her mom received from IHSS, even though the state reduced the number of her paid hours. She described the financial consequences she faced as the result of losing hours and being pushed to provide gifted care, but felt fortunate that she could count on public services to help her in the aftermath of a large reduction in pay. Isabel also has an adult son with disabilities whom she provides some care for, a responsibility that also limited her ability to simply compensate for the loss of paid care hours by taking on an additional client through IHSS.

Isabel tried to offset the negative consequences of the reduced hours for Ella by preparing meals that Ella could reheat in the evenings and on weekends. But both of Ella's daughters worried about her safety when she was alone, noting that she had bruises on her legs from trying to get into the shower on her own and had experienced severe hypoglycemic episodes while doing her own grocery shopping.

Many other caregivers did continue to meet consumers' needs despite the cuts in the number of IHSS hours and despite the other difficulties they had in receiving payment. We heard from both caregivers and consumers about the long delays in the caregivers' receiving initial paychecks, temporary lapses in payment, and sudden reductions in the

amount of pay due to fluctuating IHSS hours. For example, Sue reported that she was always on call for her nonrelated long-term client, Jill, a 72-year-old woman with Parkinson's and depression, and someone Sue considered to be like a sister to her. She told us, "She calls me anytime, she calls me and hollers a little bit and I am there already. If she calls and says she's going to the emergency, then I will come running behind." Seeing that Jill's needs were met was Sue's highest priority, motivated by her affinity for Jill as well as her faith-based principles that valued serving others.

Although Sue expressed that she had chosen to provide extra, uncompensated care for Jill, she struggled financially in the face of cuts in her paid hours and a month-long lapse in her paycheck due to an administrative mistake at the IHSS agency. Over time, she provided more hours of uncompensated care, given that she felt Jill's needs remained steady despite the official IHSS assessment that her needs for care had diminished. Sue felt that the cut in Jill's hours had presented a dilemma, given that she feared for Jill's safety, worrying that she might fall when at home alone during the weekend days that Sue was not with her. However, the combination of lower monthly income and the temporary cessation of pay led Sue to financial distress: "Right now, it's been more than a month and I haven't been paid a cent. Right now, I ask how am I supposed to survive? I can't have enough water to drink, and I am eating rice with fish sauce and that is still not enough." Although Sue was normally willing to negotiate between the market and gift economies of caregiving, the cut in the number of her paid hours had pushed her further into poverty, and experiences of stress and poor nutrition.

Whereas caregivers like Isabel and Sue were further pushed into "walking the line" between compensated and uncompensated care, some caregivers opted out of caregiving completely. This was particularly true for nonrelated caregivers who were starting out with a new consumer. For example, Bertha's new caregiver, Sasha, stated that although she was going above and beyond the requirements of IHSS to provide for Bertha's needs "out of the kindness of my heart," she felt that Bertha was expecting her to gift additional hours or services, including transportation, whose costs Sasha would have to cover herself. She told us that she was put in the position of having to decide whether or not to provide care for Bertha that was neither compensated nor approved. Nevertheless, Bertha had legitimate needs for transportation: Sasha told us that she did not feel

Bertha was a safe driver and also that she had difficulty walking to the nearest city bus stop.

Although several HOME Project participants lived in metropolitan areas with public transportation, struggles with physical mobility or painful health conditions made even short walks to city bus stops impossible, and even a routine doctor's appointment might involve multiple bus transfers and long waits. Paratransit services or shuttles were available to most participants, but nearly all who had used these services described long waits for drivers to arrive before or after an appointment and complicated procedures for making shuttle reservations, which, in some cases, resulted in missed appointments.

Despite being well aware of these challenges, Sasha did not feel comfortable offering personal transportation to Bertha:

She keeps pushing it. I told her we're not supposed to take my car. . . . I don't get reimbursed for gas. . . . She was asking me to use my car, and I'm, like, "You know, gas isn't cheap" and she's, like, "Oh, you're one of those." And you know, I bit my tongue. . . . And I told her straight up, though, this job does not pay enough for me to be driving people around in my car.

Here Sasha was explaining that her own financial needs had not been met, that she did not want to gift uncompensated resources in order to fulfill Bertha's needs that were left unmet owing to IHSS's restrictions on reimbursement for transportation costs. During Sasha's baseline interview, she said that she had given her notice to end her position as Bertha's caregiver after working for less than 2 weeks. She had opted out of what she called an "awkward situation" in which she was pressured to provide uncompensated care.

In some cases, those caregivers who had not yet opted out of providing care to consumers nonetheless indicated that there was a threshold at which they would do so. Jennifer, the full-time caregiver for Pearl, a 69-year-old woman who was on a ventilator and needed 24-hour assistance, responded when we posed the possibility of cuts in the number of IHSS hours: "As much as I love Pearl and everything, I have 2 children . . . if [a cut] were to happen, I would need to look for another form of income." Jennifer indicated that while she did provide care beyond what she was paid for, citing her close emotional bond with Pearl, there was a point at which she would no longer be able to provide more care than what was

paid for by IHSS, that is, the point at which her own basic needs would no longer be met.

Anne, the caregiver for Vickie, 89, also expressed the possibility of opting out in the event of cuts in her hours. Anne herself lives in poverty and has breast cancer, so the health insurance she receives as an IHSS caregiver is critical to her. When asked about the possibility of cuts in her hours, she told us:

Oh my god . . . right now I think 35 [hours] is still qualified to have the benefits. . . . I have 38 hours, only \$450 a month, OK? So that money that I put into gas from home to come here [to the consumer's home], you know how much it costs? And also to take her to the doctor, you know? . . . But if they cut the budget so I don't have enough money for insurance, I'm not going to do it. I enjoy helping her, but I have to have insurance to take care of myself.

In this passage, Anne is suggesting that she enjoys caring for Vickie and is willing to do what it takes to meet Vickie's needs, including paying significant transportation costs to commute to work and to take Vickie to her medical appointments. But she indicates that there is a point at which she would no longer be able to fill in the gaps. Any drastic cuts in her paid hours as Vickie's caregiver could mean falling below the minimum number required for health insurance coverage in her county. Losing insurance coverage would interfere with Anne's ability to take care of her own chronic health condition, and then she would no longer be able to provide care beyond what she was paid for.

Consumers' Perspectives on "Walking the Line"

The consumers we interviewed presented a wide range of responses to the experience of their caregivers negotiating between compensated and uncompensated care. Most were highly sensitive to the fact that their caregivers struggled to walk the line between providing care that was compensated and providing much needed care that was not compensated through formal services like IHSS. Many of these consumers described actively trying to limit their requests for any uncompensated care, expressed wishes for better wages and benefits for their caregivers, and worked within their capacity to give emotional or logistic support to their caregivers and to modify their schedules in accordance with their caregivers' needs.

Wilma is an example of a consumer who was sensitive to the challenges that caregivers faced in providing uncompensated care when first starting out as an IHSS employee. She referred to an issue that was frequently mentioned, that owing to administrative delays, new IHSS employees often had to wait several weeks to months after starting employment to receive their first paycheck: "I had one lady . . . and she signed up to In Home Care [IHSS], and it had been 2 months before they sent her a time card. How can you keep people when you do things like that? So, I understand why she doesn't come over anymore." Wilma clearly understood the conflict that potential caregivers face when choosing employment that may involve unpaid care or, in this case, delays in pay for 2 months. Partly because of the difficulty of securing a new caregiver and ensuring that the new caregiver would be properly compensated, Wilma decided that she would move to an assisted living facility. Her needs for care increased dramatically over the course of our study, following multiple hospitalizations and rehabilitation stays after bad falls and the onset of diabetes and depression. Despite the dramatic decline in her health status, Wilma's appreciation of the dilemmas faced by nonrelated caregivers did not change. She fully understood that new caregivers would not be willing to provide temporarily uncompensated care, even though this also meant that she was no longer able to remain safely and independently in her home.

Besides Wilma's sympathy for the challenges faced by nonrelated caregivers, other consumers were also sensitive to the ways in which their family caregivers employed by IHSS struggled to go above and beyond to meet their needs. For example, Lucy received care from her grandniece, who was employed as her caregiver, and described how she structured her own needs in a way that limited the amount of money her grandniece had to spend driving back and forth to her house:

Yes, I try to relieve her a little bit . . . although she has her own car, I tell her that gas is expensive now and for her to be coming and going. That's why I ask her to leave my dinner . . . so that she isn't driving around. But she's always on the phone, "Auntie, how are you? Do you need anything?" "No, my child, I'm fine," I tell her. . . . She doesn't live very far, but in any case she has to come in the car, and gas is going to cost her a lot.

Other sympathetic consumers continue to rely on their caregivers but try to reciprocate by accommodating their caregiver's schedule or offering instrumental assistance or emotional support. The question is

whether these acts of reciprocity move caregiver-consumer relationships toward a market relationship (in a barter way) or whether they reinforce the gift relationship (ie, you gift me and I am in your debt; then I gift you, completing the bond and facilitating future gifting).

For example, although Lucy's family caregiver is willing to come and go throughout the day, spending her earnings on transportation costs in order to meet her great-aunt's needs, Lucy is sensitive to the costs that her grandniece would incur on top of her already low wages. In this case, the caregiver attempts to provide more care than is compensated, motivated by her emotional and familial bond with the consumer. But these attempts are partly blocked by Lucy, the consumer, whose own emotional ties make her sensitive to the economic constraints of her grandniece and willing to accommodate her needs. Many other consumers described accommodating the caregiver's needs for time off for doctor's appointments or family emergencies, given that caregivers do not receive compensation for sick days or vacation.

Consumers also provided emotional and instrumental support to caregivers, often indicating relationships of mutual exchange and closeness. For instance, many expressed a policy of treating their caregivers with "decency and respect," as Bea, an 85-year-old consumer described it, "humanely, like I would want to be treated." Some older adults also helped caregivers in more instrumental ways. For example, Edna, a consumer with a long-standing relationship with her caregiver, Tricia, advocated for Tricia when she had trouble activating her health insurance benefits. Although Tricia became eligible after meeting the minimum work hours required for health insurance benefits in her county, she was told that the wait for health insurance benefits could be up to 2 years. Edna supported Tricia—who had limited English proficiency and challenges communicating with union representatives—by meeting with the representatives and serving as her advocate. Edna's actions helped sustain the emotional and supportive bonds that motivated Tricia to go above and beyond in her care, creating a sense of reciprocity. Other forms of consumer compensation included providing room and board and small amounts of cash to caregivers to cover gas or extra hours worked.

While many consumers were generally sympathetic to the extra demands placed on their caregivers, others were frustrated by the restrictions that IHSS placed on compensated activities. That is, activities related to comfort, transportation, and other forms of support were not covered. Instead, these consumers were focused on finding a caregiver to

meet their needs, which is aligned with the idea of consumer-directed care, and were less concerned with how their care was compensated.

This was the case for Bertha, the 77-year-old woman we described earlier who was frequently hospitalized for upper respiratory infections over the course of the HOME Project. Bertha complained about her former caregiver Sasha's unwillingness to provide transportation at her own expense. She herself did not make a sharp distinction between what was compensated and not compensated but instead focused on whether her needs were met. For example, she wished that her caregivers would help her put lotion on her legs, which she could not do by herself. Although some caregivers were happy to do so, others resisted providing this kind of personal care. As Bertha told us, "If I need someone to do that, they're supposed to do it. That's their job, to take care of my needs." Again, while Bertha clearly prioritized her needs for care, some caregivers felt that certain personal tasks went beyond what they were compensated for, and they set boundaries that limited their activities to only those authorized by IHSS.

Eventually, Bertha found a caregiver who met her needs by doing what she asked rather than strictly following the rules of compensated care defined by IHSS. This new caregiver often completed extra tasks and used her own time to visit during Bertha's stints in the hospital. When asked if these visits in the hospital were part of her caregiver's compensated hours, Bertha told us, "No, no, that was as a friend." By the end of the study years, their caregiver-consumer relationship had become quasifamilial, according to Bertha, who stated that in contrast to other workers, the new caregiver "seems to have my interests at heart" and is willing to "help me with what I need help with." Unlike the kind of conflict described by her previous caregiver, Sasha, Bertha expressed contentment with a caregiver who was willing to "walk the line"—who was paid but also motivated by emotional bonds and her best interests, rather than a strict exchange of only authorized services for pay.

Agnes, a 74-year-old woman with diabetes, arthritis, and chronic gastrointestinal disorders, expressed frustration with finding a caregiver who could meet her care needs and also with the IHSS regulations that prevented her from doing so. Again, the rules applying to compensation are often at odds with IHSS consumers' actual needs for care, which presents them with a dilemma: either go with unmet needs or ask for uncompensated care, pushing caregivers to provide time and resources

at their own expense, potentially compromising their caregiver's own needs. Agnes explained:

The Public Authority [which oversees IHSS], who is not the boss who determines how I am going to get the hours that are going to pay for the caretaker, and what duties can be done for those hours, will not allow the caretaker to be paid while they take you to the doctor. Only going to the doctor and coming from the doctor, but not while at the doctor, you are not supposed to pay them. . . . I need my caretaker in there listening to what my doctor says because my head isn't always together every day, and she's going to remember maybe [what] the doctor said.

Here Agnes was explaining that when IHSS prohibited compensation for her caretaker to go with her to her doctor's appointments, either she had to go without a companion for the duration of her medical appointment or her caregiver would have to provide care "on her own time" (as Diane learned in her IHSS orientation, described earlier). Agnes argued that IHSS should not be in charge of determining how hours are compensated under the principle of consumer-directed care. Many other respondents echoed Agnes's insistence that her caregiver's accompanying her to the doctor's office was critical to her ability to coordinate her medical care and to remember her doctor's information. Agnes had no available family members or friends who were able to fill in the gaps between her needs and the services provided by formal supports like IHSS.

Discussion

In many of the cases described here, IHSS, a consumer-driven program to provide home-based care for low-income older adults in California, does not fully meet the needs of either consumers or caregivers. For low-income older adults, the compensated care often is not sufficient to meet their needs, either because of an inadequate number of care hours or limitations on the specific kinds of services that are compensated. In the case of both related and nonrelated caregivers, the world of the market often does not provide sufficient pay and benefits for their labor, particularly when they are committed to meeting consumers' needs.

For the consumers' needs to be met, caregivers often must go above and beyond, providing care hours and activities "on their own time," walking

an ever-shifting line between market and gift exchanges. In ideal cases, gifting of care takes place in consumer-caregiver relationships that are characterized by mutual respect, emotional bonds, and reciprocity. But these qualities, necessary characteristics of a gift-giving relationship, are often not enough, as with Tricia, who has a close, quasifamilial bond with her client Edna, formed over a long-time friendship with mutual benefits. Still, Tricia is struggling with untreated hypertension and diabetes as she waits to receive the health insurance benefits for which she has been qualified for nearly 2 years. Given her small income, Edna is in no position to compensate her privately for her care and depends on IHSS to at least meet the agreements set forth within the market-based contract of pay and benefits for care that Tricia provides.

In the face of consumers' unmet needs, state IHSS regulations depend implicitly on the assumption that unmet needs for care will be met outside the caregiving marketplace, that family and nonfamily caregivers will go beyond their compensated hours and activities to provide for low-income older adults. This assumption is made at the microlevel when hours are cut for older adults who live with their family members, regardless of their ability to provide care. The assumption is also implied when IHSS regulations do not reimburse time spent at medical appointments, as with the caregiver who was told at her orientation to "take a break" without compensation while waiting for consumers to complete a doctor's appointment. This sentiment echoes what Boris and Klein described as the persistent invisibility of caregivers' important health and health-care related activities.⁵ Caregivers who were part of the HOME Project often carried the burden of transportation costs to and from doctor's appointments, and many caregivers were also critical members of the consumer's health care team (eg, actively communicating with medical providers, providing medication reminders), even when consumers' needs for skilled medical assistance often exceeded allowable activities under IHSS. Federal regulations for overtime pay led California to pass legislation in 2014 that now compensates IHSS workers for waiting time when they take a consumer to a doctor's appointment, as well as pays overtime for working more than 40 hours a week. But the implementation of this regulation has been delayed, and even when implemented, caps on allowable hours may continue to push caregivers into providing uncompensated care for some of these tasks.²⁴ Paradoxically, even the new provisions for overtime pay may, in practice, have the unintended consequence of further limiting the allocation of

service hours if the state tries to save money by reducing the number of overtime hours that are currently allowed.

At a macrolevel, policies that cut services and supports for low-income older adults put pressure on care that was formerly compensated to now be provided within the gift economy, often by relatives as well as nonrelatives who are struggling to make ends meet, address their own health concerns, or attend to other family and work obligations. In some cases, caregivers do meet these needs, providing more care within the world of the gift, motivated by their emotional bonds with consumers, a sense of mutual benefit and respect, and also by internal beliefs and motivations, including religious principles or a sense of themselves as people that help out. In other cases, being pushed to go above and beyond—by providing more hours, being on call, completing tasks that are not compensated (eg, transportation, personal care in some cases), or managing clients with mental health concerns—leads some to limit their role as a caregiver or to opt out entirely.

Many consumers are sympathetic to the struggles that their caregivers face at the frontier of the caregiving market, with constant pressure to operate outside this marketplace, providing extra, unpaid care. In some cases, sympathetic consumers try to compensate for the gaps in pay and benefits through a number of strategies: being flexible in their schedules, paying out of pocket for gas and additional hours of care, providing free room and board, and serving as advocates for their caregivers in other realms. In these cases, they are acknowledging that IHSS does not adequately compensate caregivers, and they do what they can to address this limitation, even if all they can do is lend an ear and provide emotional support and understanding. Part of this motivation emerges from consumers' own emotional bonds with caregivers, either related or not related, and their sense of respect and reciprocity. It also stems from the fact that consumers, particularly those with high levels of need, depend on caregivers who will go beyond the hours and activities approved and paid by IHSS. In several cases, consumers would not survive or live safely in their homes with only the levels of care allowed and paid for by IHSS.

Our findings of caregivers' experiences navigating the worlds of the market and the gift are reflected to some degree in other studies. For example, a study of IHSS and agency-based home care workers in a California city describes the way in which nonrelated caregivers find themselves "being asked to stay a little longer, lend a little money, or

take on a little more cooking and cleaning” after they begin to develop a sense of loyalty or affinity for their clients.¹⁵ In her study of nonrelated caregivers and their older adult clients in the Midwest, Piercy¹⁶ also found that caregivers with friend- or family-like relationships with their clients found themselves doing “extras” like stopping to pick up a meal for their client on the way to work. In contrast, caregivers who were simply friendly with their clients set boundaries around such “extras” at the outset of their relationship, limiting the degree to which they would go beyond their compensated hours and tasks.

Nevertheless, our study adds to this previous research by examining how these negotiations take place over time, which allowed us, in several cases, to follow consumer-caregiver relationships to their end. In contrast to previous studies, we found that negotiations over going above and beyond were often prompted by cuts in formal services rather than by consumers’ explicit requests for additional, unpaid care. In the face of these cuts, many consumers also tried to make do with less in order to accommodate the service cuts. In addition, while other studies typically make sharp distinctions between related and nonrelated caregivers’ negotiations over compensated and uncompensated care,¹⁷ we found the choices and challenges faced as the result of policy cuts often were similar for both groups. Furthermore, we discovered that the outcomes of consumer-caregiver relationships after service cuts do not always align with traditional caregiver role expectations: our respondents included family members who no longer provided care once the uncompensated demand became too high after cuts in IHSS service hours and/or if their pay was deemed to be insufficient to meet their daily needs, as well as nonrelated caregivers who continued to provide additional care without compensation.

Our most important finding is that the needs of neither caregivers nor consumers are typically fully met in the current system. The numerous gaps in formal LTSS mean that older adults must make arrangements for related and nonrelated caregivers to fill them. However, low-income older adults do not have the resources to be competitive within the market economy of caregiving and instead must rely on caregivers who are willing to straddle the line between market and gift exchange, with gifts of uncompensated care based on a history of emotional connection, ongoing acts of gratitude, or other kinds of nonmonetary compensation by the consumer. Similarly, low-wage home-based caregivers, whether related or not, struggle to meet their own financial and health-related

needs when providing uncompensated time and resources to meet the needs of older adult consumers.

Even consumers and caregivers who lived together reported unmet needs in the face of cuts in the number of formal service hours of pay. Consumers who live with their caregivers are targeted for IHSS service cuts because it is assumed that live-in caregivers will provide uncompensated care and that other living expenses are shared.²⁵ This was not the case for our sample of respondents. Given their low incomes, consumers had few financial resources to contribute to the household. Furthermore, their live-in family caregivers reported using nearly all their IHSS earnings to cover the costs of consumers' food and housing, and a few held other jobs in order to make ends meet. As with the case of Ella, her live-in family members were absent for much of the day working at other jobs; the combination of limited live-in family member availability and dramatic cuts in service hours meant that both her care needs and the financial needs of her daughter/IHSS caregiver were left unmet.

Since the push into the gift economy is conditioned by IHSS policies, recent policy changes represent potentially promising directions as well as continued challenges. California is currently implementing a pilot program funded by CMS, called Cal MediConnect. The purpose of Cal MediConnect is to improve care coordination for dual-eligible consumers, including LTSS and medical care, by providing these services through a managed care delivery system. If successful, this might mean fewer gaps in formal services such as transportation to medical appointments that related and nonrelated caregivers are left to manage.

California is also planning to adopt a universal assessment tool (UAT) that unifies needs assessments for consumers of multiple LTSS, including IHSS.²⁶ Streamlined assessment tools have already been implemented in some other states²⁷ and are intended to move LTSS in California toward better coordination. Furthermore, given that other LTSS social workers may have more frequent contact with consumers (ie, more often than the once-per-year IHSS assessments), the adoption of uniform assessments across LTSS, including IHSS, may lead to a more rapid identification of and response to consumers' changing care needs.

Elsewhere in the United States, Medicaid has implemented a demonstration Cash and Counseling program that, in contrast to IHSS,

provides a cash benefit that can be spent on home care and other goods and services, and allows for greater flexibility for consumers to define care activities for home-based caregivers. The Cash and Counseling program has been linked to improved care for consumers as well as less financial and physical strain for caregivers in some cases, as compared with agency-based home care.⁷ Adoption of the flexibility allowed under the Cash and Counseling model may mean fewer unmet needs for California's low-income consumers and caregivers, although it does appear that directly hired caregivers under Cash and Counseling continue to provide unpaid care hours.⁷ The benefits of this model should be carefully considered in conjunction with demonstrated improvements in worker experience achieved through collective bargaining. In California, IHSS worker unions have secured higher wages and health insurance coverage for caregivers; there has been a documented association between union participation and greater worker satisfaction.²⁸ Fair labor practices should be considered for all home care workers, family and nonfamily alike.

Limitations and Strengths

The sample for the HOME Project was limited to 5 California counties with primarily suburban- and urban-dwelling respondents. The challenges and resources of caregivers in sparsely populated rural areas are likely to be different, although they will face the same IHSS program and policy limitations as their urban counterparts do. Because ours was a qualitative study, we were able to document the caregivers' experiences in negotiating the line between market and gift relationships, but we could not accurately estimate their frequency among the more than 400,000 IHSS caregivers. An additional limitation is that the caregivers we interviewed did not necessarily represent the entire paid caregiver team, since we interviewed only one paid caregiver per case. While many of our older adult respondents struggled to maintain even one caregiver, some consumers had a team of caregivers, including related and unrelated, paid and unpaid, whose experiences were not fully captured in our study.

Despite the limitations, our study makes a significant contribution to our understanding of the fuzzy empirical line between paid and

unpaid caregivers, despite the stark boundaries placed around formal and informal, or paid and unpaid, care in the research literature. We shed light on the political and economic circumstances that push some care out of the market economy and into the gift economy and offer a more nuanced understanding of how related and nonrelated caregivers respond to changes in compensation, by either assuming or rejecting additional uncompensated work. Because we followed 16 “cases” of consumers and caregivers over 4 years and nearly all the remaining 38 cases over at least 1 year, we were able to capture within-case variability in how caregivers navigate the market frontier in caregiving for older adults. Longitudinal methods like those used in the HOME Project are critical to understanding the interaction between individual and structural changes over time.²³ We could not have captured the dynamic nature of both individual needs for health and personal care and shifts in the availability of formal and informal supports by interviewing respondents at only one point in time. We also were able to understand the impact of changes in policy and cuts in the number of formal (IHSS) hours on how caregivers “walk the line” between the gift and market economies.

Conclusion

Without the paid care provided by related and nonrelated caregivers, our older adult consumer respondents would not be able to live safely and independently in their own homes. Cuts to this care appear to be made on the assumption that family members and others will simply fill in the gaps. While many do fill in these gaps to the best of their ability, they are compelled to negotiate between a market economy of care, in which they are compensated for their hours of work, and a gift economy, in which they provide care out of a sense of emotional attachment, often without compensation. While the gifting of care may have mutual benefits for caregivers and consumers, it can also place undue financial and emotional burdens on both related and nonrelated caregivers. Public policies related to the long-term care of older adults should therefore rethink the expectation that caregivers can fill in the gaps in formal services and see that the needs of both consumer and caregiver are met at the same time.

References

1. Levine C, Halper D, Peist A, Gould DA. Bridging troubled waters: family caregivers, transitions, and long-term care. *Health Aff.* 2010;29(1):116-124.
2. Folbre N, Nelson JA. For love or money—or both? *J Econ Perspect.* 2000;14(4):123-140.
3. Hochschild A. Emotional life on the market frontier. *Annu Rev Sociol.* 2011;37:21-33.
4. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Aff.* 1999;18(2):182-188.
5. Boris E, Klein J. Organizing home care: low-waged workers in the welfare state. *Politics & Society.* 2006;34(1):81-108.
6. Newcomer RJ, Kang T, Doty P. Allowing spouses to be paid personal care providers: spouse availability and effects on Medicaid-funded service use and expenditures. *The Gerontologist.* 2012;52(4):517-530.
7. Foster L, Dale SB, Brown R. How caregivers and workers fared in Cash and Counseling. *Health Serv Res.* 2007;42(1):510-532.
8. Redfoot D, Feinberg L, Houser A. *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers.* Washington, DC: AARP Public Policy Institute; 2013.
9. Howes C. Love, money, or flexibility: what motivates people to work in consumer-directed home care? *The Gerontologist.* 2008;48(S1):46-59.
10. Delp L, Wallace SP, Geiger-Brown J, Muntaner C. Job stress and job satisfaction: home care workers in a consumer-directed model of care. *Health Serv Res.* 2010;45(4):922-940.
11. Reinhard SC, Kassner E, Houser A, Ujvari K, Mollica R, Hendrickson L. *Raising Expectations, 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers.* AARP, Commonwealth Fund, and SCAN Foundation; 2014.
12. Gorman A. As caregiving shifts to the home, scrutiny is lacking. *Kaiser Health News.* 2015.
13. Wakabayashi C, Donato KM. Does caregiving increase poverty among women in later life? Evidence from the Health and Retirement Survey. *J Health Soc Behav.* 2006;47(3):258-274.
14. Benjamin AE, Matthias RE. Work-life differences and outcomes for agency and consumer-directed home-care workers. *The Gerontologist.* 2004;44(4):479-488.

15. Stacey CL. Finding dignity in dirty work: the constraints and rewards of low-wage home care labour. *Sociol Health Illness*. 2005;27(6):831-854.
16. Piercy KW. When it is more than a job: close relationships between home health aides and older clients. *J Aging Health*. 2000;12(3):362-387.
17. Stacey CL, Ayers LL. Caught between love and money: the experiences of paid family caregivers. *Qualitative Sociology*. 2012;35(1):47-64.
18. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA*. 1999;282(23):2215-2219.
19. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA*. 2014;311(10):1052-1060.
20. Stone RI, Weiner JM. *Who Will Care for Us? Addressing the Long-Term Care Workforce Crisis*. Washington, DC: Urban Institute and American Association of Homes and Services for the Aging; 2001.
21. Kietzman KG, Wallace SP, Durazo EM, et al. A portrait of older Californians with disabilities who rely on public services to remain independent. *Home Health Care Serv Q*. 2012;31(4):317-336.
22. Charmaz K. *Constructing Grounded Theory*. 2nd ed. Thousand Oaks, CA: Sage; 2014.
23. McLeod J, Thompson R. *Researching Social Change*. Thousand Oaks, CA: Sage; 2009.
24. Megerian C. Union drive for home care aides' overtime pay could backfire in California. *Los Angeles Times*. January 20, 2014.
25. Legislative Analyst's Office. *The 2012-13 Budget: In-Home Supportive Services Budget Update*. Sacramento, CA: Legislative Analyst's Office; 2012.
26. Legislative Analyst's Office. *The Universal Assessment Tool: Improving Care for Recipients of Home and Community-Based Services*. Sacramento, CA: Legislative Analyst's Office; 2015.
27. Ingram C, Lind A, Ensslin B. *Uniform Assessment Practices in Medicaid Managed Long-Term Services and Supports*. Hamilton, NJ: Center for Health Care Strategies; 2013.
28. Delp L, Muntaner C. The political and economic context of home care work in California. *New Solutions*. 2010;20(4):441-464.

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