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## Barriers to Workers' Compensation and Medical Care for Injured Personal Assistance Services Workers

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# Barriers to Workers' Compensation and Medical Care for Injured Personal Assistance Services Workers

Teresa Scherzer, PhD, MSW  
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**ABSTRACT.** *Objectives.* We documented barriers to workers' compensation and injury-related medical care faced by homecare or Personal Assistance Services (PAS) workers. We explored differences between independent providers and agency-employed workers.

*Methods.* We conducted in-depth, semi-structured interviews with a diverse sample of 38 injured workers. Participants were primarily female and racial-ethnic minorities.

*Results.* Most participants (82%) were independent providers. Common barriers to reporting injury included commitments to clients and financial pressure. Unlike agency employees, many independent providers knew little about workers' compensation eligibility and injury reporting procedures, and frequently were given "the runaround" by the social service bureaucracy when they attempted to report injury and access injury-related medical care. Among independent providers, delays in filing a claim and receiving timely medical attention were common.

*Conclusions.* The lack of a traditional employment infrastructure has important implications for vulnerable workers' health and the sustainability of consumer-directed PAS programs. We provide recommendations for

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**KEYWORDS.** Occupational injury, disability, homecare, personal care, independent provider, injured worker experience, injury reporting, qualitative methods

## INTRODUCTION

Personal Assistance Services (also known as “home care” or “personal care”) is a primary mode of long-term care, employing nearly 900,000 workers who provide essential support such as bathing, dressing, and grocery shopping for elders and persons with disabilities who live at home. The workforce is composed predominantly of mid-life women of low socioeconomic status, many of whom are racial/ethnic minorities and immigrants (Kaye, 2006; Montgomery, Holley, Deichert, & Kosloski, 2005; Yamada, 2002). Working conditions are often poor, characterized by low wages, few if any benefits, unstable hours, and physically and emotionally strenuous work (Arteaga et al., 2003; Hayashi, Gibson, & Weatherley, 1994; Kaye, 2006; Montgomery et al., 2005; Yamada, 2002). Occupational injury and work-related disability are widespread (see Scherzer, Chapman, & Newcomer, 2006 for a review). However, little is known about PAS workers' access to workers' compensation and injury-related medical care.

The occupational injury literature documents numerous barriers to reporting injury and accessing workers' compensation, especially among low-wage and vulnerable workers. Barriers include not knowing about reporting procedures, fear of jeopardizing one's job, reluctance to deal with the workers' compensation bureaucracy, and difficult interactions with workers' compensation agency personnel (Azaroff, Levenstein, & Wegman, 2002; Boden, Biddle, & Spieler, 2001; Evanoff et al., 2002; Pransky, Snyder, Dembe, & Himmelstein, 1999; Rosenman et al., 2000; Scherzer, Rugulies, & Krause, 2005; Strunin & Boden, 2004b). PAS workers may also face job-specific barriers, such as personal commitments to family members or vulnerable clients. In addition, PAS workers may face structural barriers to reporting injury and accessing workers'

compensation due to fundamental changes in their employment arrangements, which we describe in the following sections.

Historically, PAS workers have been employed by agencies, but publicly funded PAS programs are increasingly adopting a “consumer-directed” approach in which PAS recipients (“consumers”) hire, schedule, supervise, and can fire their attendants; and many consumers hire relatives (Benjamin, 2001). Of several major consumer-directed approaches (Scherzer, Wong, & Newcomer, 2007), one is the “independent provider model,” in which PAS consumers directly employ workers, who are known as “independent providers” because they do not work for an agency. In this model, traditional employment arrangements (i.e., an identifiable “management” responsible for all employer-related tasks) are replaced by a more complex infrastructure. The consumer hires, schedules, and directs the worker, and various state agencies or other organizations assume the fiscal or administrative tasks (e.g., processing worker timesheets and payroll) (Scherzer et al., 2007).

Recent research suggests that the independent provider model may exacerbate existing barriers to workers’ compensation or create new ones. A recent study found that workers’ compensation agency personnel frequently deemed independent providers ineligible for coverage—despite state law mandating coverage—and reported that hearings were necessary to determine their eligibility (Scherzer & Newcomer, 2007). There also may be ambiguities about responsibilities for providing information about workers’ compensation, and assisting injured workers. In 2004, a Health Hazard Evaluation report stated that many independent providers had little or no knowledge about how to address occupational injury (National Institute for Occupational Safety and Health, 2004). In addition, consumer-directed programs may not have systems for backup coverage to replace an injured or ill worker. These potential factors may lead workers to work while injured or delay seeking medical attention (Scherzer et al., 2006).

To understand the linkages between the employment arrangements and injured workers’ lived experience, we conducted an exploratory, qualitative study of California PAS workers who sustained an occupational injury. In-depth interviews were conducted with 38 independent providers and PAS agency employees. The study’s purpose was to learn how PAS workers’ employment arrangements shaped their experiences of and responses to their injuries, especially reporting or filing a workers’ compensation claim, and accessing injury-related medical care. In this article, we examine PAS workers’ experiences of access to workers’ compensation and injury-related medical care, focusing on California’s

major PAS program, the personal care option under Medicaid, "In-Home Supportive Services."

## METHODS

### *Study Background and Setting*

In-Home Supportive Services (IHSS) is the nation's largest consumer-directed PAS program, serving approximately 400,000 consumers annually (Kang, 2006). Most PAS workers in the IHSS program are independent providers, paid by the state. Family members, including spouses and parents of minor children, may be paid providers, unlike other publicly funded programs. Consumers are the official employers of workers, with authority to hire and fire, schedule and supervise, and approve and sign timesheets. Consumers set their PAS workers' schedules and assign them tasks, but the number of hours and specific duties are those previously authorized by the consumers' IHSS social workers.

IHSS differs from other publicly funded independent provider programs due to its size and the permission for spouses and parents to be paid providers. However, it also stands apart because of the sustained coalition of consumers, labor, social services, and government, which produced the state-wide system of county "IHSS Public Authorities," established by the 1992 legislation. This provides a structure through which consumers and workers have a collective voice regarding services and wages and benefits (Boris & Klein, 2006; Delp & Quan, 2002; Heinritz-Canterbury, 2002). The Public Authorities' mandates are to maintain a consumer-majority advisory board, provide training opportunities for consumers and workers, maintain worker registries (pre-screened lists of potential workers for IHSS consumers seeking attendants), and serve as the employer of record for purposes of collective bargaining. IHSS also stands apart because all workers are unionized.

The study setting was two urban counties in northern California.<sup>1</sup> These counties were selected because they established their Public Authorities in the mid-1990s, have stable IHSS infrastructures and collective bargaining agreements, and have a large and ethnically diverse IHSS workforce. There are over 10,000 IHSS workers in each county, and substantial African American, Chinese, Russian, and Latino populations (Howes, 2002; Howes, Greenwich, Reif, & Grundy, 2002). While both counties use the independent provider model, one county also uses an agency that has contracted with IHSS since 1994. This agency employs

approximately 475 PAS workers, who are supervised by agency staff. However, the tasks and hours are IHSS-authorized, as in the independent provider model. The agency employees are represented by the same union local as the county's independent providers (Personal communication [e-mail], Margaret Baran, Director, March 16, 2007; In-Home Supportive Services Consortium, n.d.).

### ***Sample***

Data were drawn from a qualitative study of PAS workers in northern California who sustained an occupational injury in the last two years. For this study, occupational injury was self-reported and described by potential interviewees, and then evaluated by the first author as to its work-relatedness and its severity, using guidelines from another study about occupational injury and low-wage workers (Scherzer, Rugulies, & Krause, 2005). Injuries could be either acute (e.g., fracture) or chronic (e.g., musculoskeletal disorder). We constructed a purposive sample that included related and non-related caregivers, and had gender, racial/ethnic, and language diversity. Outreach materials were available and interviews were conducted in English, Spanish, Cantonese and Mandarin. We recruited independent providers as well as employees of one PAS agency. At the time of their injury, workers had to be working in either of two selected counties, and affiliated with In-Home Supportive Services (IHSS).

### ***Participant Recruitment and Data Collection***

The study was conducted in close collaboration with two locals of Service Employees International Union (SEIU) and the PAS agency. An invitation letter, study description, and outreach flyer (in English, Chinese, or Spanish) were sent to workers whom our community partners identified as having sustained occupational injuries. Multilingual announcements were made and flyers distributed at union membership and agency meetings and events, community-based clinics, and IHSS county offices during "timesheet drop-off" days.

In-depth, semi-structured interviews were conducted with 38 injured PAS workers. Interviews usually took place at workers' homes and averaged 45 minutes. Interviews were tape-recorded and transcribed, except in two cases, when detailed fieldnotes were taken. A \$20 supermarket giftcard was given to participants after the interview. All study procedures were approved by the UCSF Institutional Review Board.

Following established methods for in-depth interviewing (Strauss & Corbin, 1990), we asked open-ended questions that permitted workers to describe their experiences in their own words. Interviews began with the question, "Can you tell me the story of how you got hurt?" When necessary, we used follow-up probes about workers' responses to injury, interactions with the consumer, the IHSS office or PAS agency, and experiences with filing a workers' compensation claim and accessing injury-related medical care. We also asked workers to describe the impact of the injury on their health and ability to work.

### *Data Analysis*

The initial interviews and detailed fieldnotes were independently coded by each author, using a preliminary thematic coding schema based on the research questions. We then met to discuss the coding decisions, resolve differences, and discuss new themes we identified in the data. We constantly compared data between interviews to assess the variation and identify areas to be explored in subsequent interviews (Strauss & Corbin, 1990). The thematic coding schema was modified as needed. All coded documents were entered into the qualitative data analysis application ATLAS-TI for further analysis of the text. This analysis was conducted to identify the different dimensions of and variations within each thematic domain, and the relationships between them.

## **RESULTS**

### *Participant Characteristics*

Table 1 presents the characteristics and injuries of the 38 study participants. Thirty-one were independent providers and seven were agency employees. Participants were mostly women between the ages of 30 and 60 (they preferred to tell us their approximate age) and were of diverse ethnic backgrounds. Among the Latino/a and Chinese participants, the vast majority were immigrants, including three of the seven agency employees (data not shown). Eight interviews were conducted in Mandarin or Cantonese, and six in Spanish. Eleven independent providers were relatives or friends of their consumers. The most frequently cited injuries were those to the lower back. Approximately one-third of the independent providers filed a workers' compensation claim, compared to 71% of the agency employees.

TABLE 1. Characteristics and Injuries of Study Participants, Occupational Injuries Among PAS Workers, N = 38

	n (%)
Employment arrangement	
Independent provider	31 (82)
Agency employee	7 (18)
Age group	
20-29	2 (5)
30-39	10 (26)
40-49	10 (26)
50-59	10 (26)
60+	6 (16)
Sex	
Female	33 (87)
Male	5 (13)
Ethnicity	
African American	17 (45)
Chinese/Chinese American	10 (26)
Latino/a	8 (21)
White	3 (8)
Language of interview	
English	24 (63)
Chinese	8 (21)
Spanish	6 (16)
Relationship to consumer	
Parent	3 (8)
Spouse	1 (3)
Other relative	6 (16)
Friend	1 (3)
No relation	27 (71)
Injured body part	
Upper back or neck	2 (5)
Shoulder, arm, elbow, wrist, or hand	9 (24)
Lower back	12 (32)
Knee	4 (11)
Foot	5 (13)
Multiple	6 (16)

TABLE 1 (continued)

	n (%)
Type of injury	
Acute (Examples: fell trying to break a client's fall, car accident while driving client, wheelchair ran over foot)	22 (58)
Chronic (Examples: cumulative strain from lifting or transferring consumers, pushing or carrying wheelchairs)	16 (42)
Filed workers' compensation claim	
Independent provider	10 (32*)
Agency employee	5 (71†)

\*Percentage of the 31 independent providers, † percentage of the 7 agency employees.

### ***Barriers to Reporting Occupational Injury or Filing a Workers' Compensation Claim***

Workers faced both personal and structural barriers to reporting injury and filing a workers' compensation claim, and accessing injury-related medical care. These barriers frequently overlap and inter-connect, but for clarity we present the results thematically. We provide brief summaries of barriers that are shared between independent providers and agency employees, and focus on the structural barriers stemming from the employment arrangements.

#### *Personal Barriers*

*Commitment to the consumer.* A prominent barrier among both independent providers and agency employees was the personal bond with—and sense of responsibility toward—the persons for whom they worked. While eleven independent providers were friends or relatives of their consumers, the majority of workers were not. Both independent providers and agency employees with caring relationships with consumers frequently expressed a need to keep working for the consumers' well-being, especially if consumers had no family, or had families the workers felt were neglectful. These workers frequently voiced that they had “really no choice” in terms of stopping their caregiving work. There did not appear to be much difference between unrelated and related providers in their consideration of stopping their work or receiving

workers' compensation. As we describe below, other factors appeared more prominent in the interview data.

*Financial concerns and "manageable" versus "un-manageable" injuries.* Another prominent barrier was financial concerns, as many interviewees expressed reluctance to jeopardize their job. We describe these findings in detail elsewhere (Scherzer & Wolfe, 2007b), and present a summary here. Financial concerns were shared by all workers, but they were especially prominent among workers who described limited employment options, including workers with limited English proficiency. Among independent providers who described finding PAS jobs through referrals by individuals in their communities, there was a pressing concern that if they filed a claim, they would not only lose their income from their current job, but also damage their reputation for securing future work.

Workers tried to manage chronic injuries through various means, including: pain medication, acupuncture, herbal remedies, and attempting to do their PAS work differently and resting to provide relief to the affected body part. Only when the pain from the injuries became unmanageable and disabling did workers seek medical attention and report it to a doctor. For acute injuries, participants—all the agency workers and some independent providers—generally responded quickly and attempted to file a workers' compensation claim.

### *Structural Barriers: The Role of Employment Arrangements*

Overall, agency employees and independent providers differed markedly on their knowledge of workers' compensation and injury reporting procedures, and their ability to file a workers' compensation claim and receive timely medical attention.

*Knowledge about workers' compensation.* In agency employees' narratives, it was clear they knew to report occupational injuries to agency staff and that they were covered by workers' compensation. In contrast, many independent providers we interviewed knew little about workers' compensation and believed they were not covered. Several independent providers told us that when a doctor informed them they should file a workers' compensation claim, they told the doctor "homecare workers don't have workers' comp." One injured worker was told this by her clients' daughters and accepted it as fact.

Independent providers who already knew about workers' compensation gained this knowledge primarily from previous employment (as a matter of routine knowledge about workers' rights on the job), or from

friends or family. Although each county has an official procedure for independent providers to report an occupational injury (e.g., workers should report the injury to the consumer's social worker) (Scherzer, 2006), few interviewees recalled seeing information provided by IHSS or the union.

*Attempting to file: Getting "the runaround."* Agency employees experienced few or no problems filing a workers' compensation claim. Their narratives described the routine nature of how agency workers processed the injury report, offered assistance with the claims form, and referred the workers to authorized workers' compensation physicians. Independent providers' experiences of reporting their injury and/or filing a claim with IHSS varied widely in both study counties. Some participants described a relatively smooth process similar to the agency workers; this was consistently due to talking to someone at IHSS—with little or no delay—who was both responsive and knowledgeable about the injury reporting procedure. More frequently, however, independent providers told us of leaving numerous (and unreturned) messages, getting "the runaround," and fighting their way through a bureaucratic maze.

In the following example, TD attempted to report her back injury (sustained when transferring the consumer from commode to wheelchair) to the appropriate office at IHSS, but IHSS incorrectly directed her to contact the registry (the organization maintaining the list of potential IHSS workers). After three months of "the runaround," she asked her union for help, on advice from a registry worker. The union staff also encountered "the runaround" from IHSS, but successfully helped TD file the workers' compensation claim.

*TD:* I called IHSS to tell them [report the injury and file the workers' compensation claim], but they kept giving me a runaround and stuff, and they kept telling me that I need to call [the registry]. So it was like a lot—a lot of runaround. It was stressful, they sent me through a lot, plus I was in pain also. So when I called [the registry], L\_\_ said she sent the paperwork to IHSS. . . . I kept callin' IHSS, they kept tellin' me my name wasn't showin' up, the social security wasn't showin' up, and they kept givin' me a runaround, and dial this number, dial that number—I did all that. And I got so fed up and I called L\_\_ again and then asked her has she heard anything? She said, "no." She said, "go to the union." So that's when she gave me the union number and that's when I called the union and I talked to a lady named R\_\_ . . . So I went there and she got on the phone and she got everything started for me.

*INT:* So you started this process in January and it wasn't until April that you were kind of able to—to really have things start to come together.

*TD:* Yeah, yeah, April, that's when everything started. When I went to the union and R\_\_ got on the phone. And they gave her the run-around but she stayed on the phone and she got everything together for me. (40s, African American woman)

Several other workers also mentioned seeking assistance from the union, but, as in TD's case, only after they made repeated and unsuccessful attempts to report the injury to IHSS. Most expressed gratitude for prompt support and assistance, and described how union staff helped them by persistently calling IHSS to follow up with the claim. Some other workers, however, complained that it was as difficult to reach union staff as IHSS.

Workers' limited English proficiency compounded the personal and structural barriers described above. For example, one Latina independent provider who was injured carrying the consumer downstairs experienced "the runaround" after she completed her claim form (in Spanish) and delivered it to the IHSS office. She heard nothing for several months, during which she was unable to work and lived off her savings, supplemented by loans from friends. When she called to ask about her claim status, a bilingual IHSS staffperson informed her that her claim was not processed because it needed to be filled out in English.

*SN:* I said, "Why didn't you send it back to me?" They gave me another application and told me to fill it out in English. And I asked who could help me, and nobody could. I had to take the form home, had someone help me translate what I had said in Spanish into English. And then I took the application in person back to IHSS and the lady at the office told me to wait. I waited for a whole year! They called me in June and sent me to a doctor to evaluate me and find out what happened and say if I was injured, and determine if I would get compensation or not. (30s, Latina)

The same worker reflected that the bureaucratic problems she and others faced were largely due to (1) the lack of a specific contact person for independent providers who need assistance with occupational injury, and (2) the massive client caseloads assigned to IHSS social workers, who could not feasibly also attend to workers' concerns.

*INT:* Did you have a contact person or a supervisor there [IHSS]?

*SN:* There is no supervisor; if you do not get your check you call payroll, and whoever is there answers. There is not a designated person following a case. It is like a herd and the shepherd. But there are thousands of sheep. (30s, Latina)

### ***Barriers to Injury-Related Medical Care Through Workers' Compensation***

When workers report an occupational injury to their employers, the employer is supposed to refer the worker to an authorized physician, who treats the injury and assesses its work-relatedness. This was how agency employees in this study received treatment for their injuries. However, independent providers' access to this injury-related medical attention varied depending on their knowledge of their eligibility and procedures for reporting/filing, and whether IHSS provided timely and correct information and referrals.

We limit our findings to injury-related medical care received through workers' compensation, as elsewhere we focus on workers' other health care experiences (Scherzer & Wolfe, 2007a). Briefly here we note that independent providers were more likely to seek medical attention before (or without) reporting the injury to IHSS. Among these workers, timely access to injury-related care often depended on consumers' willingness or ability to release their workers from their usual work schedules. A few workers were told by consumers to leave work immediately or early, to seek medical attention, rest, or apply home remedies. In contrast, workers whose consumers treated them like personal servants were told they could not go to the doctor except when they finished their work, or else they would be fired. As a result, many injured workers delayed seeking medical attention—from several days to several months.

### ***The Runaround for Medical Care***

Agency employees were more likely than independent providers to have fewer barriers to workers' compensation and fewer delays in accessing timely and appropriate injury-related medical care. While several independent providers reported relatively smooth experiences similar to the agency employees, most had frustrating—and painful—delays before receiving treatment for their injuries. An illustrative example of how “the runaround” delayed medical care involves one worker who—despite

her knowledge of workers' compensation and ability to persevere through a difficult bureaucracy—did not receive injury-related care until over a week after her injury occurred (she fell off a ladder). She sought immediate medical attention at the emergency room but was told she could be treated only by an authorized workers' compensation physician. Even after the claim was filed, medical attention was delayed due to bureaucratic delays.

*NG:* I was hurt on Oct. 25th. I didn't see an actual Workers Comp doctor I think 'til Nov. 7th. . . . I had finally gotten the name of the doctor that I could see [from IHSS]. . . . I had an appointment Nov. 3rd but I was not able to go because IHSS would not confirm I was an employee. I went on the 7th, finally, to the doctor. They had finally confirmed it. . . . I had been calling IHSS all morning—"You guys have not called. I'm going to miss my second doctor's appointment." And I had to three-way—the doctor's office, myself, and IHSS—to confirm that I was an employee.

*INT:* So were it not for your perseverance . . .

*NG:* Yeah, I wouldn't have gotten anywhere. I would have been stuck with my regular doctor and just paid up. And I thought, "How many people in IHSS, that don't speak very good English, what would they have done?" Because I could speak English perfectly well and I was getting nowhere with IHSS. (40s, Latina)

### ***Impact on Workers' Health and Well-Being***

Once the claim was processed and workers received injury-related medical attention, their experiences were generally positive. Most workers told us that through workers' compensation-authorized medical benefits, they were referred to specialists, chiropractors, or physical therapists, and were receiving regular treatments for their injuries; several workers mentioned upcoming back, knee, or wrist surgeries.

In this study, independent providers' narratives described personal and structural barriers that often appeared to result in poor health outcomes, especially among workers with chronic injuries due to cumulative strain. These workers described pain so severe it woke them at night, and prevented them from everyday tasks such as grasping a coffee cup or washing their hair, carrying out household activities or interacting as usual with family members. One worker specifically attributed her chronic pain to the delays she faced when filing a workers' compensation claim.

*SL:* So it's just like nothing's stopping it [the pain]. And then it's really frustrating 'cause now they've waited so long for me to even be able to go see somebody, now they can't figure out what the problem is. They know that I'm in pain but they can't put their fingers on exactly what's wrong. Like I said, it's been a year-and-a-half now. (30s, African American woman)

## DISCUSSION

This study documents the numerous personal and structural barriers to workers' compensation and injury-related medical care faced by a large, growing, and vulnerable workforce, and is the first effort to explore the impact of the independent provider model of consumer direction on PAS workers' experiences of occupational injury. Provided with the opportunity to "tell the story" of their injury, PAS workers described a wide range of experiences in responding to or seeking help for their injuries, and the barriers they encountered. Despite the considerable diversity of study participants, the qualitative data suggest that while certain barriers to reporting injury (e.g., commitment to consumers, financial concerns) were shared between agency employees and independent providers, access to workers' compensation was strongly influenced by the presence or absence of a traditional employment infrastructure, or identifiable management that can support injured workers.

This study serves as a bridge between two rarely integrated areas: long-term care for elderly and disabled individuals and occupational health of vulnerable workers. In each area, some of our findings echo those of other studies. For example, we found that injured PAS workers' reluctance to report injury often stemmed from a strong commitment to continue caring for vulnerable individuals, despite the increasing toll this took on workers' bodies. In our study, this self-sacrifice occurred among workers both related and unrelated to the consumers. Other studies of PAS workers also found similar self-sacrifice, as workers often provided unpaid labor or emotional or material support to their clients, despite the disadvantages to the workers (Aronson & Neysmith, 1996; Stacey, 2005). Our data also show that PAS workers' reluctance to report injury also stem from financial concerns, which contributed to a tendency to tolerate and manage chronic injury. These findings are comparable to those of other studies of vulnerable workers and occupational injury, including those in other industries and in traditional employment arrangements (Scherzer et al., 2005). However, our study adds to the literature

by showing how employment arrangements matter in shaping workers' experiences of and responses to injury.

### ***The Fundamental Importance of an "Identifiable Management" to Support Injured Workers***

As consistently described in their narratives, agency employees knew they were eligible for workers' compensation, knew the reporting procedure, and received timely assistance from agency staff (filing a claim and receiving a referral to authorized workers' compensation physicians). In contrast, independent providers' experiences varied widely in both study counties, as access to workers' compensation was primarily mediated by two factors: (1) knowledge about the correct reporting procedures (among both independent providers and IHSS personnel), and (2) an individual who provided timely assistance to the injured worker. Specifically, access to workers' compensation often depended on a combination of knowledge about independent providers' eligibility, skill or persistence in dealing with bureaucracies, assistance from the union, English-language proficiency, and the sheer luck of connecting with a responsive individual at IHSS. Absent this responsive individual at IHSS, delays were common, even among independent providers who were knowledgeable and persistent, or who were assisted by their union. Those independent providers who encountered the fewest problems were those who reached an IHSS staffperson quickly, and who received prompt and accurate assistance from that individual.

The interview data suggest that the problems experienced by independent providers stem from gaps in the decentralized arrangements of IHSS. The current IHSS infrastructure—and the infrastructure of other independent provider programs—is set up to address client/consumer concerns (Scherzer et al., 2007). This includes processing worker payroll and other fiscal matters on behalf of consumers. In California, each county has an official procedure for independent providers to report injury, but there is no designated contact person or office for workers who may need assistance. This "employer function" is placed on IHSS personnel or units that have primary responsibilities other than injury reporting and workers' compensation (Scherzer, 2006). As noted by SN, there is only one "shepherd" for "thousands of sheep."

Our data suggest that not only were many independent providers unfamiliar with the injury reporting procedure, but consumers and some IHSS staff were unfamiliar with this as well. Several independent providers described their attempts to call specific offices or contacts at IHSS

that reflected the county's official injury reporting procedure. The "run-around," then, appeared to occur when (1) the independent provider did not know who to call at IHSS, and/or (2) IHSS personnel did not follow the county's official procedures.

### ***Recommendations: A Designated "Worker Support" Office or Staff***

The problems identified in this study may likely occur in other independent provider programs, and indicate the need for a designated office or staff to which independent providers can report occupational injury or inquire about other work-related issues. A designated office or staff for independent providers could address several issues and benefit multiple parties, and would maintain consumers' authority to self-direct their supportive services. First, a designated office or staff would serve as the "identifiable management" to which workers would turn for assistance for occupational injury or other work-related concerns. Despite the complex employment infrastructure that characterize independent provider programs, workers would have a visible and dedicated source for information and assistance, and thus avoid "the runaround." Timely assistance, especially for occupational injuries, would also benefit consumers by linking them to resources (such as the Public Authority, in California) to assist them in hiring backup or replacement workers.

In addition, a designated "worker support" office or staff would also relieve IHSS personnel of the "employer functions" (e.g., providing assistance with workers' compensation claims) assigned to them in addition to their primary work responsibilities. Dedicating resources specifically to assist independent providers could avoid inconsistencies of knowledge and responsiveness documented in this study. While individual training for IHSS staff on injury reporting procedures may appear as a quick fix to the problems we document, it is not a solution. Without creating a designated office or staff for independent providers, "employer functions" would remain assigned to offices or individual staff that already have a substantial workload of high-priority tasks. Independent providers who need prompt assistance may continue to risk "the run-around" by depending on individual staff's knowledge and responsiveness.

To make this office or staff "visible," and to explicitly describe certain important rules and procedures (including occupational injury reporting), one possibility would entail requiring independent providers to

come to this office as a potential or new hire. As we describe elsewhere (Scherzer & Wolfe, 2007b) many of the independent providers we interviewed were hired simply by completing and mailing the necessary paperwork to IHSS. Few recalled seeing written information about workers' compensation and injury reporting. This suggests that independent provider programs need alternative means to communicate important procedures to a diverse and vulnerable workforce. A face-to-face interaction with the "worker support" staff could help educate workers about their responsibilities and rights, procedures for reporting occupational injury, and introduce this office as a potential resource for assistance should problems arise. This information provided in person may likely be absorbed more readily than written material, although this should still be provided.

In California, the location and other details of this proposed designated office or staff would have to be decided by the multi-stakeholder coalition that guides IHSS. This study documents that in both study counties, injured independent providers sought help first from IHSS. The two Public Authorities were mentioned by interviewees only with regard to trainings and the registry. While IHSS may be the logical site for a dedicated "worker support" office or staff, there would need to be a sustained dialogue among the various stakeholders about how—or whether—to make this a reality.

### *Study Limitations*

Several limitations of this study should be noted. First, this is a qualitative study that does not aim to generalize to the larger population of PAS workers, or IHSS workers in California. Our sample comprised more independent providers than agency workers, and the one agency from which we recruited agency workers may be atypical in its efficient response to workers' injuries. Rather the purpose is to examine the variation of experience among a diverse group of vulnerable workers. The sample was purposively constructed to reflect the diversity of the PAS workforce in the study counties, including immigrant and monolingual Latino and Chinese workers, and included PAS workers with both chronic and acute injuries, and workers who were both related and unrelated to consumers. Workers' experiences may be very different in California counties that are smaller, rural, or with a less established Public Authority or union presence, a higher percentage of workers related to consumers, other IHSS contractor agencies, or a more supportive county infra-

structure. Further studies would benefit by exploring more in depth how differences between workers (e.g., related vs. unrelated, immigrant vs. USA-born) may shape their experiences of injury, and exploring the variation of workers' experiences across a wider geographic area.

It would be useful for future research to include more agencies and consumer-directed programs outside of California. This is especially important because IHSS, unlike many publicly funded independent provider programs (e.g., Cash and Counseling), is guided by a coalition between consumers and their advocates, workers and labor unions, social service providers, and government officials. There is a collective voice for both consumers and workers, through consumer-majority advisory boards, and unionization and collective bargaining for IHSS independent providers. In other regions, this coalition and potential for worker support may not yet exist, or exist in a less-developed model.

In addition, California is one of only 15 states in which workers' compensation coverage is in place for independent providers. Across different states, there is substantial variability of this coverage for independent providers; this is detailed elsewhere (Scherzer & Newcomer, 2007). Moreover, future research outside California would be particularly useful to explore how access to workers' compensation and medical care is addressed within both independent provider and other consumer-directed models (Scherzer et al., 2007).

Another limitation concerns the retrospective nature of the study and its reliance on self-reported data. Recall might be influenced by negative affectivity or workers' continued pain (Viikari-Juntura et al., 1996; Watson & Clark, 1984). Since we interviewed workers whose injuries occurred within the past two years, it is possible that participants' narratives of their experiences may reflect partial recall or an incomplete or biased accounting. In addition, we did not have access to medical records, IHSS or workers' compensation data to triangulate workers' accounts or their reported health status. However, self-reports about work-related pain may be more reliable than administrative, medical, and workers' compensation claims data. Our study contributes to research that demonstrates that occupational injury and work-related disability may be more prevalent than assessed by workers' compensation claims data, especially among vulnerable populations (Azaroff et al., 2002; Boden et al., 2001; Evanoff et al., 2002; Krause et al., 2001; Pransky et al., 1999; Rosenman et al., 2000; Scherzer et al., 2005).

Our data about worker health and well-being are based solely on workers' descriptions of their post-injury work and personal lives, and we cannot conclude that independent providers who had delayed injury-

related care had poorer health outcomes compared to workers who received timely care. Nonetheless, our data suggest this possibility, which warrants further investigation in subsequent studies. Workers who experienced delayed care described chronic and often disabling pain—a recurring and frequent theme—which prevented them from continuing their PAS work, working elsewhere, and participating as usual in household activities and family relationships. These consequences are also described elsewhere (Dembe, 2001; Keogh, Nuwayhid, Gordon, & Gucer, 2000; Morse, Dillon, Warren, Levenstein, & Warren, 1998; Strunin & Boden, 2004a).

## CONCLUSIONS

This study describes how the employment arrangements of PAS play a prominent role in workers' experiences of and responses to occupational injury, especially access to workers' compensation and injury-related medical care. Other factors such as English language proficiency, financial pressure, and commitment to consumers also play important roles. However, despite the considerable diversity of participants in this study, those employed as independent providers identified specific problems related to their employment arrangements and lack of an identifiable management in the decentralized landscape of IHSS. Identifying these problems is the first step in solving them, and participants' narratives of injury and help-seeking also suggest ways to address these problems by working within the available infrastructure.

In California, addressing these problems will most likely involve the multi-stakeholder coalition that guides IHSS. This coalition contributes a historical and ongoing commitment to improve working conditions for independent providers, and offers the potential to ameliorate the problems identified in this study. We have presented some preliminary recommendations for this coalition—and other coalitions and stakeholders, outside of California—to consider.

This study shows that there are important implications for workers' health and the sustainability of consumer-directed programs—within and beyond California. Since 2001, nearly every state and U.S. territory has implemented at least one consumer-directed program within their Medicaid PAS programs (Kitchener, Ng, & Harrington, 2005). This calls for increased attention to the well-being of the PAS workforce to ensure the sustainability of these programs (Dale, Brown, Phillips, & Carlson,

2005), as the problems identified by this study are likely to multiply, unless steps are taken to address these issues. Building on the recommendations we present to more effectively respond to occupational injury would be a feasible first step.

## NOTE

1. A description of each county's IHSS infrastructure and Public Authority is beyond the scope of this study, but there are generally more similarities than differences in terms of services provided (e.g., training opportunities, collective bargaining). The two counties' IHSS Public Authorities were among the first ones established in the mid-1990s; since then, each Public Authority has negotiated labor contracts with a local of Service Employees International Union. One county's Public Authority does not operate its own worker registry, due to the precedent of well-known community-based organizations (e.g., Centers for Independent Living) that have operated worker registries before the Public Authority was established. This county has multiple registries, which are not linked or centralized. In the other county, the Public Authority operates the registry (Scherzer, 2006).

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