

December 2012

### “Carmen”-A Case Study

- 65:** Age
- 44:** Number of IHSS hours currently received each month.
- 8+:** Number of IHSS hours potentially lost if budget cuts are triggered.

**Other formal supports received:** IHSS, Meals on Wheels, rent-controlled apartment

**Informal supports:** home repairs by building manager

**Reductions of supports in recent years:** IHSS hours reduced by 3.6%, extended periods of time without an IHSS provider, SSI reduced

#### Introduction

Carmen is in her mid-60’s and suffers from several conditions, including a congenital spine problem, arthritis, hepatitis C, and several mental health conditions including depression and anxiety. She has lived with chronic pain for decades. Currently, she receives just over 40 IHSS hours a month and needs help with housework, laundry, and shopping. While she receives relatively few hours each week, these hours are critical to her daily living. Without the assistance provided through IHSS, she would be unable to maintain her home and meet her domestic and personal needs.

#### Background

Carmen struggles with several health conditions, including chronic back pain. She lives alone in a rent-controlled apartment where she has been living for more than thirty years. Because of her disability, lifting, carrying, and moving items are difficult and make housework a strenuous and painful process. To respond to these challenges, Carmen’s IHSS provider plays a major role by assisting with the housework, laundry and shopping.

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### The HOME Project (Helping Older- adults Maintain independence)

...is an ongoing qualitative study that is documenting the experiences of older Californians with disabilities, who depend on fragile arrangements of paid public programs and unpaid help to live safely and independently at home.

In-depth interviews are being conducted with older adult consumers of In-Home Supportive Services (IHSS) and their caregivers; most receive other public supports and/or informal help as well. The following case study illustrates how changes in need and supports impact older adults in the state.

#### See the related policy brief:

*“Independence At Risk: Older Californians with Disabilities Struggle to Remain at Home as Public Supports Shrink”*

<http://www.healthpolicy.ucla.edu/pubs/files/homepolicybrief2011.pdf>



Carmen lives on the third floor of a “walk up” only apartment building and this exacerbates her mobility challenges. Carrying groceries and laundry up and down the stairs is nearly impossible for her, but with the help of the IHSS provider, she is able to take care of her day-to-day needs.

Having someone available to assist with physical needs and tasks helps address Carmen’s mobility limitations, and also helps to minimize her anxiety and stress. Ironically, however, Carmen experiences stress when trying to plan her time with the IHSS provider, to ensure that she can accomplish the most important tasks during the few hours a week the provider comes into her home.

### Health Changes Over the Course of the Year

Many of the symptoms related to Carmen’s health conditions are imperceptible. She explains that much of her disability is invisible because others cannot see her chronic pain. Her pain is further compounded by the fatigue she feels as a result of the hepatitis C. She describes always feeling tired and wanting to sleep for great lengths of time. She also experiences bouts of seasonal affective disorder that come and go through the year.

Well I’ve been increasingly tired and with the incredible amount of rain we had last year, I got to be a little depressed. But like, you know, that’s seasonal disorder.

Carmen’s physical health did not fluctuate much during the study period as her chronic back pain remained constant. Her mental health status, however, was less predictable, as her mood disorders flared up at different times throughout the year and some months were more challenging than others. She hinted that at times her fluctuating moods affected her relationships with others and, in particular, her relationships with her IHSS caregivers.

For consumers with mood disorders, effectively communicating with IHSS providers and others can be especially difficult. In Carmen’s case, anticipating her caregiver’s arrival and trying to optimize the few hours that the provider was “on duty” caused stress and anxiety for both Carmen and her caregiver.

### Changes in Public Supports

Carmen has experienced a number of changes in the mix of public supports she receives. She switched IHSS caregivers during the study year and went for some extended periods without a caregiver. During these times she struggled to do any housework and left many necessary tasks undone.

Carmen also sought additional assistance during the past year and now receives Meals on Wheels. This service provided her with a microwave oven and delivers meals to her home twice a week. This was especially helpful to Carmen during the periods when she did not have a caregiver to help with grocery shopping and meal preparation. For a time, it helped to make up for some of the IHSS provider support she was missing. This was especially helpful when she was also fighting an acute illness exacerbated by the hepatitis C.

It’s big help, I had a cold, there was a virus going around, and with my liver problem, it made it worse, so I was in bed sick and they started delivering these things and it was marvelous...

Carmen has received several cuts to her SSI income in recent years. Since she already lives on a very low and fixed income, any reduction is quite noticeable. Receiving Meals on Wheels helps somewhat because now she can budget slightly less for food. However, the continued reduction of income is a source of anxiety for Carmen, and affects her sense of security and well-being.

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Reductions in income also threaten Carmen’s ability to remain in her own home. She has been able to maintain her living situation with a very limited income largely because of local rent control laws that keep her monthly payment well below market rates. Otherwise, she would not be able to continue living in her building. She worries that if her income is reduced and she can no longer make the rent, she could end up on the street. At the same time, she makes a tremendous compromise by staying in a building that is not ideal for one who struggles with mobility limitations. The stairs are a huge challenge for Carmen, especially now that her health has worsened. The alternatives, however, are more bleak and so Carmen is determined to hold on to her rent-controlled apartment for as long as possible.

### Changes in Availability and Scope of Informal Supports

Carmen has few informal supports. She discussed feeling frustrated when social workers encourage her to seek additional help from family and friends. For Carmen, those options are simply not available. Her only child lives out of state and, as the years have passed, she has lost touch with the few acquaintances she once had.

Carmen has tried to seek social support through support groups and community-sponsored events, but has never found a place where she feels like she fits in. Apart from sporadic interactions with her IHSS caregiver, she has not found other suitable programs or outlets for social engagement. When she has the energy to get out of the house, Carmen likes to visit the library where she picks up books and audio tapes. Reading — and now listening — to books has always been a comfort to her, so she makes a special effort to continue this activity, especially as other, more physical activities have become more difficult.

### Reliance on Services and Supports Over the Course of a Year

As Carmen’s physical and mental health conditions worsen, her dependence on public services increases. Although the IHSS caregiver provides only about 10 hours of assistance per week, Carmen relies quite heavily on this support to manage the domestic and personal tasks in her home. She depends on her provider to shop for groceries and bring them up the three flights of stairs to her apartment. She cannot do her laundry or maintain the apartment without her provider’s help.

The centrality of the provider’s role in Carmen’s life became even more apparent when she went through periods of time without receiving any help. It was then that she began receiving Meals on Wheels. Now, this program has become an important addition to her support system and provides her with another source for groceries and meal preparation.

For consumers like Carmen, who have limited assistance, each support is critical because *Continued...*

#### How “Carmen’s” Situation Has Changed Over Time

Carmen’s mental health conditions changed over the course of the study, as she experienced increasing symptoms of depression, stress, and anxiety. Her mental health status was exacerbated by physical health conditions which often limited her ability to engage in activities and get out of the house. Carmen struggles with managing the few hours of IHSS help she has to complete essential tasks and, as a consequence, her stress and anxiety are heightened. Carmen also feels that the invisibility of her disability, especially the chronic pain and stress, pose a challenge to her ability to receive services or assistance from programs that might be helpful to her. She has recently started to identify and access other resources, such as Meals on Wheels, to build her network of support.

there are few, if any, options. Carmen does her best to make the most of her IHSS time because she has limited hours. She cannot turn to family or friends for assistance, so when supports are reduced, she struggles to find alternatives and sometimes has to go without.

## The Challenge and Potential of Consumer-Direction

IHSS allows consumers the flexibility to choose their caregivers, recognizing that many benefit from being able to manage their own care. However, this poses a challenge for some, who may lack the skills or experience to effectively manage this role. Carmen discussed the challenges of consumer-direction and the stress associated with finding, training, and retaining a good caregiver. She describes the difficulties she has experienced finding an IHSS provider:

Also, um, see, my interviewing skills are not that good because although I have had a long and checkered career in the work force, uh, I never had a job where I had to interview or hire and fire people. And so, I don't know what questions to ask.

Carmen felt that she could not optimize the interview process since she did not know what to look for in a provider. Although she has had several types of jobs and has acquired many skills, the process of hiring and firing was new to her. Carmen's experience suggests that she may have benefitted from an orientation to the new role she was assuming.

Most consumers appreciate being able to choose their providers; however, not all have the experience to make the most informed decisions. Knowing what questions to ask during an interview, and learning how to communicate expectations may relieve stress and empower some consumers to make better choices.

## Conclusion

Carmen experienced several changes to her supports during the last one year. The caregiver she had at the beginning of the study did not work out and Carmen had to go through the process of hiring and training a suitable new caregiver. While she is pleased with her current provider, she went for an extended period without any assistance. This was a very difficult time for Carmen, especially because she had no other options; she has no family or friends to call on, even for short-term assistance.

Carmen did begin receiving Meals on Wheels, which is a new source of support. The delivery of meals provides a significant benefit for Carmen, as she now saves money on groceries and the service reduces the IHSS time and effort previously dedicated to shopping.

Carmen's physical health conditions continue to cause chronic pain and fatigue, and this limits her ability to maintain her home without assistance. Her mental health symptoms are heightened by her physical conditions, and have resulted in her increased isolation and anxiety. Carmen relies on few public services, but each is critical to her independence and ability to live in her own home. The hours she receives from IHSS, in combination with Meals on Wheels and her rent-controlled apartment, form a small but critical network that provides Carmen with choices about where she lives and the care she receives.



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