

December 2011

## “Jill” - A Case Study

- 72:** Age
- 104:** Number of IHSS hours currently received each month.
- 20+:** Number of IHSS hours potentially lost if budget cuts are triggered.

**Other formal supports received:** MSSP social worker, HUD subsidized housing, SSI

**Informal supports:** Phone calls from family, weekly visit from friend, pet cat

**Reduction of supports in recent years:** IHSS cut 40 hours per month, SSI reduced

### Introduction

Jill is in her early 70's and suffers from several conditions, including a neurological disorder that causes fatigue, pain, and repeated falls. She also has a heart condition, sleep apnea, and has been diagnosed with depression. Her main source of support comes from her IHSS caregiver, Sue, who provides 104 hours of care each month. Jill has trouble with mobility, and much of it is due to her neurological problems. She needs help with bathing, dressing, respiration, and preparing meals, in addition to assistance with housework, laundry, and shopping. She has been getting help from IHSS for about three years, and Sue has been her caregiver for most of that time.

### Background

It was a struggle for Jill to first admit that she needed help. When she became ill and was diagnosed with a neurological illness, she was initially able to continue with her life, working and maintaining a house. However her health continued to deteriorate, and she landed in the

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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>



hospital in 2003. At that point, Jill realized that if she were to remain living independently, she would need some help. She describes what finally led her to seek assistance:

Well that was my daughter getting upset with me, it was about eight years ago and she insisted that I find somebody, but I had always been so independent and private, I couldn't stand the thought.

Now, with the combination of several supports, Jill is able to live at home with some independence. Living in a HUD senior complex provides her with an affordable living arrangement. Through IHSS, she is able to choose a caregiver she trusts. In the absence of these supports, Jill would not be able to go to the grocery store on her own, clean her apartment, or even make a meal for herself. A social worker through the MSSP program visits her every month, and has helped Jill get some of these supports in place, including some assistive equipment she needs.

## Health Changes Over the Course of the Year

Jill's health changes often, sometimes from day to day. Her energy level and mobility vary the most, and this fluctuation affects how much assistance she needs at any point in time. Her caregiver notes that there are days when Jill feels extreme fatigue and cannot do much at all. Jill describes these challenges:

I have ups and downs and we've tried to figure out what causes it. It doesn't seem to be caused by overdoing myself or not doing anything. It just seems to come as a wave over me and I just have to respect it so to speak. And I'm a person by nature who's always very driven and have energy to burn. I've been going through this for close to 15 years, when I first started falling. It's something I've learned to accommodate.

While Jill did not have any major health events during

the course of the study year, Jill describes a continuous decline and worsening symptoms.

My brain has gotten worse and my body's gotten worse and more than anything, I'm totally unpredictable. And, uh, in June I fell three times in a week. Once was on the way to the hospital, I fell, and so I walk like a snail now.

## Changes in Public Supports

When we first met Jill, her IHSS hours had recently been cut from 140 to 104 hours per month. She was first assessed for IHSS following a hospitalization for hip surgery and pneumonia and at the time needed intensive assistance. The following year her IHSS hours were reduced because she no longer had the same acute care needs. The cut in hours has resulted in significant changes to her care arrangement. Her IHSS caregiver, Sue, now helps Jill 5 days, instead of 6 days each week.

I was getting about 5 ½ hours a day, which was perfect, you know. And it was dropped from 140 hours a month to 104...And, it's difficult for me, to be honest with you, to tell you what Sue does because she's just like part of me. She just like comes in and takes over and does the things that I can't, which is almost everything now. Very little that I do, you know? I used to be very much into needlework, which I still have it here but I haven't been able to get myself motivated and I just can't right now, I don't seem to do anything.

Changes in supports, even when small, can make quite an impact on the daily life of older adults with disabilities. Jill has a limited income, which includes SSI and Social Security, and during the study period experienced cuts to her SSI check. As a result, Jill has begun to make changes to her food purchases, since that is the only place where she can afford to spend less.

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I just have to watch, I go over the ads when they come, and you can get along pretty well to cut back...And I know a lot about nutrition and I can stretch certain foods...the things that I'm paying out right now, you know, I don't really have any luxuries...it doesn't go very far.....I have zero left over at the end of the month.

For Jill, and for many older adults in similar circumstances, food is often the first cut made.

## Changes in Availability and Scope of Informal Supports

Jill does not have any family nearby, but they do stay in contact by phone and through occasional in-person visits. She also has a close friend who visits weekly. Although she does not have a large social network, she remains focused on what she does have.

I've had to accommodate so much, you know. I went from a large home to a small apartment. I went from being financially very comfortable to having nothing, anything that anybody goes through unless they have a kind of savings, goes through when they've been sick for years. So, I'm not unique this way. But I've tried pretty hard not to let it get me feeling sorry for myself, let's put it that way...I've tried very, very hard to work on my plants; so when I don't feel like doing anything, I can go out and water them, so there's some life going on. And I have a cat.

In addition to the social support from family and friends, having plants and a pet in her home provide Jill companionship and enjoyment in her daily life.

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

Jill describes the crucial role that her IHSS caregiver plays in helping her manage with fewer hours and time alone, even though she acknowledges that more hours would be ideal.

Well, what I basically do is on the week-ends, well, I prepare for it food-wise and because she basically does all of my shopping for me and she does a lot of cooking for me as well. And I just kind of, for lack of a better word, I hang out. There's nothing I can do. I'm very apprehensive about losing more hours...I count on her a lot. If it was up to my doctor she'd have somebody here all of the time because of my falling...

And although she does not get out of her apartment very often, she does rely on her caregiver for her transportation needs, especially to get to doctor appointments.

Despite the supports she has in place for her day to day needs, in the event of an emergency, Jill has few options. Because Jill has a close relationship with Sue, her IHSS caregiver, she feels comfortable calling on her for extra help. On one occasion, Sue spent the night at Jill's apartment when she had just been released from the hospital. Sue was concerned for Jill's health, and decided it would be best if she stayed just in case anything happened.

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### How "Jill's" Situation Has Changed Over Time

While her health has worsened, Jill's greatest comfort is the knowledge that she can stay in her own home.

Jill went from living in a private home to living in a small one-bedroom apartment in a public housing complex -- a big change. But she has adapted to the smaller space and is completely comfortable surrounded by her books, pictures, and memories.

While Jill's health and mobility limitations make it difficult to care for herself, with the help of her IHSS caregiver, she is able to maintain her home and attend to her daily needs. For Jill, considering any other option, and especially a nursing home, provokes a great deal of anxiety.

During times when more intensive care is needed, Sue is willing to put in the extra time. However, this is often the time of greatest challenge for consumers without family or other sources of assistance nearby. Not everyone can count on the kindness of strangers. In the event of an emergency, even someone like Jill, who has a caregiver and friends nearby, may struggle to get the help she needs.

## The Challenge and Potential of Consumer-Direction

IHSS is a consumer-directed personal assistance program that allows consumers to hire, train, supervise, and if necessary, fire a caregiver of their choosing. For Jill, the ability to manage her own care comes from personal experience. As she describes:

Well, I'm fortunate and was blessed in the fact that, when I was doing volunteer work, I did a lot of reaching out for other people. And so I knew how to work the system so to speak. I knew how to find services for other people. That's a lot of what I did with my volunteer work. So, it's helped me to know how to reach out for myself. Not everybody knows how to do that, though.

Through years of engagement in volunteer work, Jill was able to help others find the help they needed. So when it came time to find care and services to meet her own needs, she felt capable. She understands that not everyone knows how to advocate for themselves, and feels fortunate that she has been able to manage.

For Jill, however, the challenge has often been recognizing when she needs the help. Her family has been instrumental in encouraging her to seek help when she needs it. It was Jill's daughter who initially encouraged her to apply for IHSS. For Jill, it sometimes takes an outsider, like her daughter or a social worker, to step in and provide advice. In the absence of the support

provided by her family, IHSS caregiver, or social worker, Jill might face additional challenges in getting her health needs met. This is a common problem for older adults. Identifying and acknowledging one's own needs, and knowing when and where to ask for help, often requires a combination of informal and formal supports.

## Conclusion

Jill faces many health challenges, which change on a daily basis. Her caregiver has become a close friend who understands the nuances of her disabilities and is sensitive to what Jill may need most on any given day.

As her health has changed, Jill has experienced additional challenges including reductions to her IHSS hours and to her income. She makes adjustments as best she can, but there are often times that she must make difficult choices, such as cutting back on food or minimizing her activities when she is alone. Jill relies on the supports she has to manage her changing needs and live independently. Each support plays a critical part in meeting her needs. When there are changes to these supports, it takes time to adjust and find alternatives, and unfortunately, at times that means going without.

Living in her own space and having independence is important to Jill. She appreciates being able to make choices about her health and personal care. With the support of public programs and family and friends, she is grateful for her ability to continue to live independently, despite her health challenges.



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