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### “Eileen”-A Case Study

- 76:** Age
- 80:** Number of IHSS hours currently received each month.
- 16:** Number of IHSS hours potentially lost if budget cuts are triggered.
- 3:** Number of IHSS hours cut in recent years

**Other formal supports received:** Meals on Wheels, Legal Assistance for Seniors

**Informal supports:** Phone calls from family, assistance and advice from friends and neighbors, pet cat

**Reduction of supports in recent years:** IHSS hours reduced 3.6%

#### Introduction

Eileen has lived a complete and largely independent life. She worked as a college instructor, raised two daughters, and purchased a home - all in the same community. Now she has developed several health concerns, including arthritis and a spinal condition that causes chronic back pain and forces her off her feet for extended periods a couple times a year . A botched knee surgery conducted two years ago, has made it difficult for her to walk, and climbing stairs is nearly impossible. During this time she began In-Home Supportive Services (IHSS) and Meals on Wheels.

Eileen lives alone in her own home and continues to work a few hours a week as an on-line tutor. She mainly needs assistance with housework, laundry, and shopping. Once or twice a year her back goes out without warning and her movement becomes even more limited. As a result, she needs additional assistance, especially with dressing and bathing. The twenty or so hours of help she gets from IHSS each week are especially critical during these periods.

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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>



## Background

At 76 years of age, Eileen tries to maintain an active life. She exercises three times a week, takes computer classes at a senior center and, when possible, enjoys attending community and cultural events. While she enjoys her work as an on-line tutor, employment is also a necessity for Eileen. Although she worked most of her life as a college instructor, once she left her position she no longer qualified for benefits. As part of a program for the working disabled, the few hours she works each month make her eligible to receive IHSS. This seems to be the best possible arrangement for Eileen at this time.

Most of Eileen's income is from Social Security and an IRA. She has just enough money to meet her daily needs, but as a homeowner there are additional expenses that come up and are sometimes beyond her budget. In order to remain in her home and be able to pay for the upkeep, she made a difficult decision to take a reverse mortgage which enabled her to replace the roof and electrical wiring. She explains that this is a financial and conscious commitment on her part to continue living in her home.

Eileen does not have any family nearby to help with her daily needs. She does have a small set of trusted friends who provide companionship and advice, and she also relies on neighbors for help around the house, such as lifting heavy items. Her IHSS caregiver is her main source of daily support, and provides assistance with day-to-day activities.

It has been a challenge for Eileen to find a dependable caregiver. When we first interviewed her, she had just hired a new IHSS caregiver but unfortunately, that arrangement was short-lived. This was a difficult time, as Eileen had a gap in care for a couple of months and realized just how much she depended on the caregiver for assistance.

## Health Changes Over the Course of the Year

Eileen's health improved somewhat over the year, but there were some definite ups and downs. She regained some mobility following her knee surgery but continues to have trouble navigating stairs, and this inhibits her from doing essential household chores.

With the help of a chiropractor, I've gotten my normal gait back. It took me a year to practice, with him, walking up and down a hall in front of a mirror. But I walk pretty normally on the level. I can't do stairs. I have a washer and dryer in the basement but it's seven steps down to the basement...I've not been able to figure out any way to do my own laundry, believe it or not.

Acute pain is an unwelcome and recurring theme. Because Eileen's primary care doctor cannot always address the pain, she regularly sees a chiropractor and an acupuncturist - services she typically pays for out-of-pocket. These are financial choices she makes because they provide her relief. Eileen has come to terms with her increasing physical limitations.

Well there has been pluses and minuses, I had to face the fact that there are things that I can do before that I can't do anymore and I don't like that. And I think it's a plus that I'm better, umm, so long as I got somebody here to help me. It's better that...I know it's really hard for me to do stairs, it's better that, umm, I see myself checking the impulse to go ahead and try to climb up a ladder and do whatever it is that I think needs to be done, that's recent.

Now she restricts her activities around the house and resists a tendency to take on more than she can handle. She increasingly depends on her caregiver for help with the tasks and activities that are likely to pose a hazard, such as climbing a ladder to change a light bulb. Having a caregiver that she trusts, along with other public and informal supports, has been important during this emotional and physical transition.

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## Changes in Public Supports

After much trial and error, Eileen is now pretty savvy about the services that allow her to continue living in her own home. She first began receiving IHSS and Meals on Wheels following a surgery about two years ago—services that provide the foundation that Eileen now relies upon. She also makes use of the gym at her local YMCA and a social worker from a disability rights advocacy organization. While she has sought and received immediate help through senior centers and other aging services, such as legal assistance, she has learned that certain others needs are more difficult to address, such as transportation, or times spent without a caregiver.

This past year Eileen experienced great difficulty finding a stable and consistent caregiver. The absence of support made Eileen realize how much her quality of life was affected. She describes how she felt when she had to take care of domestic tasks and shopping on her own:

The six weeks I tried to do for myself as an experiment, I was exhausted all the time. I cancelled any other activity. If I had an invitation for lunch, if I had an invitation to go hear music, I cancelled. I couldn't do any of it because I was exhausted... I'm getting back. I'm doing some of the things that I enjoy.

Eileen experienced some tough weeks when she had to take care of things on her own. Everyday activities like preparing a meal, cleaning up the kitchen, or shopping for necessities became overwhelming. She no longer had time to engage in the activities she enjoyed and she experienced increasing social isolation. Now that she has a steady caregiver, Eileen is getting back to her normal routine. With help available for housework, laundry, and shopping, Eileen is once again able to dedicate energy to her physical and social health.

## Changes in Availability and Scope of Informal Supports

Eileen has several sources of informal support, including a close circle of friends. Because Eileen's family is out of state, her friends have taken on a greater role in her life. She relies on them for emotional support and recently, they helped her make important decisions about her home and medical care. Over the years, pets have also played an important role in providing social support; currently, Eileen has a cat that she counts on for company. For day-to-day personal care needs, however, the IHSS caregiver is critical.

Transportation is an increasing concern as Eileen's appointments and social interactions all depend on her ability to get around. She continues to drive but is starting to have some difficulties.

It's hard, because once the shoulder had a serious injury, you see, it's the left leg that doesn't work, it's unstable, a combination of left leg being unstable and my right shoulder...and the other issue is that I can't do anything about my reflexes, and I'm a good driver, but my eyes don't adjust after dark, and I, you know, I wanted the eye doctor to give me a magic pill for that.

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

Despite generally stable health over the past year, Eileen's needs have changed. She now needs more assistance from her IHSS caregiver, especially with preparing food, shopping, personal care, and attending doctor appointments. Eileen also anticipates a time when she will need more help with transportation and so is beginning to evaluate her options.

For Eileen, the process of aging has been challenging. Fortunately, she is a strong advocate for herself and attempts to meet her needs by seeking out as much information as possible. Eileen has begun to recognize and acknowledge her physical limitations. While this has been a difficult transition, it has become more manageable with the help of her caregiver. Eileen truly appreciates the assistance she receives, especially because it allows her to live in her own home and remain engaged in her local community.

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

Because of Eileen’s changing health needs, her caregiver has taken on new responsibilities. The caregiver now does most of the shopping and attends many of Eileen’s doctor appointments. Now, Eileen needs more frequent help with grooming and bathing, and so her caregiver also helps out with these personal care tasks.

Yes, I see, I don’t do the shopping anymore, there was a while when I was trying to push myself into having it be something that I can do alone and the fact is that it’s too hard, and so I don’t, and I can wash my own hair, but I can’t do anything with it. And I’d like to have my hair look nice every once in a while.

Although Eileen’s health has been stable and her recovery from surgery has led to improved mobility, she now needs more assistance with personal care and everyday tasks in her home. Eileen’s caregiver has also taken a more active role in her health care and medical appointments, serving as another pair of ears to take in important medical information. Eileen, however, remains in charge of coordinating the many providers she sees.

## The Challenge and Potential of Consumer-Direction

As her health status has changed, Eileen has had to come to terms with her increasing physical limitations. This has been a challenging time for the consumer who describes herself as “the do-it-yourself” woman. Part of the process of getting appropriate help from her IHSS caregiver has been acknowledging her needs and allowing herself to receive help when necessary.

I just cannot do enough of the physical work to keep me in clean clothes and a clean environment and I am so bonded to the notion of independent living.

In order to live independently, Eileen has had to accept that she cannot always do it alone. Her health,

despite some improvements, has declined to the point where she cannot perform certain activities. With the right amount of help from IHSS and other programs, Eileen maintains her independence and continues to experience a sense of autonomy when it comes to her health and personal care needs.

## Conclusion

With the right supports in place, Eileen is managing to maintain her independence in her own home. Quality of life for Eileen may well be measured by her ability to remain in her home, manage her own care, enjoy time with friends, and continue to engage in some of her favorite social activities. However, the process of recognizing and negotiating her needs for assistance has been a bit of a struggle. As Eileen’s needs change, she is likely to have to continue to adjust the amount and type of assistance that she receives from both public and informal supports.

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