

December 2011

“Bertha”-A Case Study

- 78:** Age
123: Number of IHSS hours currently received each month.
24+: Number of IHSS hours potentially lost if budget cuts are triggered.

Other formal supports received: HUD subsidized housing, home health nurse, social worker

Informal supports: Senior Center

Reduction of supports in recent years: IHSS hours reduced by 3.6%, time without an IHSS provider

Introduction

Bertha is a woman in her late 70’s who struggles with diabetes and mobility problems from chronic knee pain. She needs help with housework, preparing meals, shopping, and laundry. More recently she has begun to need assistance with bathing and personal grooming. Her main source of support comes from her IHSS caregiver, although that assistance has been tenuous. At the beginning of the year-long study Bertha spoke about having trouble finding a stable caregiver, however midway through the study she had found a provider she trusted and enjoyed.

Health Changes Over the Course of the Year

Bertha has had great challenges with her health through the course of the study. Bertha has problems with her knees, experiencing several falls and chronic pain. She describes a time when she fell out of bed and struggled on her own for several hours to get up:

I just do the best that I can. You know, it’s hard for me ‘cause I can’t get around very well. But, you do what you gotta do. It’s hard. Like, not too long ago I, even though there was nobody here but me ‘cause the provider was gone, wasn’t here at that particular time in

Continued...

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>



the evening, I fell out of the bed. And then I couldn't get up and it was hard. And I finally figured a way to get up. I finally did get up on my bed and that's the way I made it up but... see I don't have anyone in the afternoon. I just have someone mornings.

Bertha's needs vary throughout the day but she is alone in the afternoons. She tries her best to adjust and does very little once her provider has left for the day. Most afternoons she remains in her room watching television or napping, keeping her movements to a minimum when the provider is gone.

Midway through the study, Bertha was hospitalized for several weeks with pneumonia and congestive heart failure. The hospitalization marked a significant deterioration in her health, one that she struggles to recover from. She came home still weak and several weeks later still had some good days and some bad days as she attempts to recuperate.

Well, it's up and down, you know. They want me to, they want me to get up and do quite a few things to get my strength back but I've tried that and it, I found that I have to take it easy 'cause I was very weak. And I'm still weak and I've tried to do a few things and it didn't work out, it shouldn't have been so soon. So, I'm trying to take it easy now and go at my own pace...they let you come home, to get well, so I'm trying to get my stuff back and get back to it. Oh it takes time when you are as sick as I was.

Not only was she coping with the physical recovery process, but she also faced emotional challenges. Her chronic depression appeared to flare up once she got home from the hospital, a situation we also observed with other older adults who had experienced recent hospitalizations.

Umm, this is hard to explain, but the illness and going to the hospital, it did something to my depression, I am very depressed after that, it

did something to me, and I get very sad and very lonely and I can't tell you why, but I just get those feelings.....I didn't recognize being here, I didn't have the comfortable feeling of being home, I don't much understand myself, but I've been feeling that way since I've been home and I'm trying to get back to feeling normally, like I had.

A hospitalization can cause significant disruptions to the physical and emotional well-being of older adults. Recovery can be difficult, even when in their own home, making the supports in place even more valuable and necessary. Fortunately, Bertha had an IHSS caregiver in place before she became ill, making the transition home from the hospital somewhat easier. However, additional needs can arise after a hospitalization or with declining health and the older adults must make changes, when possible, to their public and informal supports.

Changes in Public Supports

Bertha's main source of support is her IHSS caregiver. However, she has had trouble finding a caregiver who is reliable and able to stay with her long-term through her emotional ups and downs. She did find such a caregiver a few months into the study, which was a relief to Bertha. She depends on the IHSS provider for all of her personal care needs and assistance with housework, shopping, laundry, and doctor appointments. Bertha described the new caregiver she trusts and feels comfortable with.

Well like I said, I like her well enough and none of the other people were like her, she's almost like family to me, you know. She's very good, she seems to have my interests at heart, she helps me with everything and she's there to give it to me.

The caregiver came to visit Bertha in the hospital, even though IHSS does not cover home care

Continued...

during the time of hospitalizations. For someone who is isolated and has no other assistance, the caregiver can become a friend and an important piece in the older adult's network of care.

Bertha's hospitalization and health deterioration resulted in some temporary and long-term changes to the types of supports she now requires. After her hospitalization, a nurse visited three times a week to check on Bertha's progress. The last time we spoke to Bertha, the nurse was visiting twice a week and would eventually end the visits. Bertha now also needs more personal help with bathing and grooming, which her IHSS caregiver has begun to provide.

When we first met Bertha she was able to drive herself to doctor appointments and for small errands, but by the end of the study she had stopped driving as a result of her declining health. Now her caregiver takes her to all doctor appointments. Adding to her health restrictions, financial limitations may also prevent Bertha from keeping her car.

Yeah, it's not going to last too much longer though, I don't think, and I'm not going to be able to get out because I can't afford, one of the social workers that comes in, has said that he had put in application for me at the paratransit place, where they come and give transportation, but uh, that takes a little time.

Bertha's health changes have resulted in changes in her needs. Her social worker attempts to connect Bertha with additional services and it can be difficult to match up the supports with the new needs. Help may need to come from new or different sources, and this can take time to implement.

Changes in Availability and Scope of Informal Supports

Informal supports are limited for Bertha. She has limited assistance from family so most of her supports

consist of public programs.

Initially Bertha frequently visited a senior center near her home. She attended weekly bingo games and talked about trips that she had taken through the senior center. However after her illness and hospitalization, Bertha no longer visits the senior center, mainly because she does not feel well enough to leave her home. For Bertha, her health has created many limitations and changing needs. However she has not always been able to find replacements for her previous support systems.

With her declining health, Bertha has become increasingly isolated. Despite the limited social supports and challenges that she experiences living at home with a disability, there is no other place Bertha would choose to live. When asked if she has considered other options such as a nursing home, she responds:

I wouldn't want that. But if I have to, that would be better than being homeless, you know. But I would rather be in my own home, even if I have to be in pain to do it,

Continued...

How "Bertha's" Situation Has Changed Over Time

Bertha's health worsened through the course of the year. At the beginning she was able to drive herself and visit the senior center across the street. A several week-long hospitalization led to a steep decline. Coming home she only had the assistance of her IHSS caregiver and a nurse that visited twice a week. During her recovery at home, Bertha became increasingly isolated and depressed. Her health limited her activities and may have triggered increasing symptoms of depression. She no longer drives and it is now too difficult for her to get to the senior center.

Bertha is managing at home and is attempting to piece together other sources of support to better match her new care needs. This has been a difficult process. However, Bertha treasures the ability to live in her own home, even in the face of physical or emotional challenges.

I'll manage, you know. There's nothing like being in your own home. Nothing.

Reliance on Services and Supports Over the Course of a Year

Bertha's reliance on public services and supports has increased as her health has declined. As her mobility becomes more limited, leaving her apartment becomes difficult. Even inside her own home Bertha struggles to remain motivated. She increasingly relies on her caregiver for personal needs and taking care of her home. Bertha describes the importance of her caregiver getting her "set-up" in the morning:

Oh, if I didn't have help. If I didn't have someone helping me in the morning, I couldn't continue to do that, all day, you know. They come in and they give me a jump start on my day in the morning and by the noon, afternoon when they get ready to leave, I'm set and, uh, maybe I'll have to have something to eat a couple of times after they're gone, but a lot of times I will get them to help set me up for that... They will have washed dishes and cleaned everything so that I don't have to do it, you know. And it's a big help, it's a help, yeah.

Bertha's caregiver provides much more than just doing chores and running errands. The caregiver provides motivation and companionship to help Bertha start her day and get through the afternoons when she is alone. Caregivers and other social supports can be critical to older adults that have little or no family nearby.

The Challenge and Potential of Consumer-Direction

Bertha relies on the IHSS caregiver as her main source of support. But she also relies on the flexibility of the IHSS program to allow for changes in her needs that can occur from one day to the next. For Bertha, having

someone there and being able to ask her caregiver for help is important:

And then there's sometimes when, and I explain to the provider, there's sometimes when I don't want anyone here to be *doing* something, it's just that I want someone here so in case I want something done, someone will be here to do it for me 'cause I spend most of my time back in the bedroom.

Bertha appreciates the ability to ask the provider for assistance depending on what she most needs that day. However, asking for help and knowing what you need is not always easy. Some consumers struggle to understand and communicate their needs, resulting in unstable relationships with their providers. Others go through several providers before finding a good match.

Conclusion

During the year-long study, Bertha faced many changes to her health and needs. She has been able to get by with the few supports she has in place. She was able to make some changes in her supports to address her new needs, such as the nurse that visited after her hospitalization. However she also became more isolated and experienced increasing mental health challenges. Bertha's declining health has resulted in new and different needs, some of which can be handled by the IHSS caregiver, but others that require different programs and services. Bertha is attempting to piece together new resources to address her changing needs. This is a difficult process, especially for the ill and disabled.



This study was supported by a grant from
[The SCAN Foundation](https://www.scanfoundation.org/)