

January 2012

“Vickie”-A Case Study

- 89:** Age
- 112** Number of IHSS hours currently received each month.
- 22+** Number of IHSS hours potentially lost if budget cuts are triggered.

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

Informal supports: Phone calls from family, pet dog

Reduction of supports in recent years: 3.6% cut in IHSS hours

Introduction

Despite the disability and health conditions that have kept her homebound for the past nine years, Vickie remains grateful and optimistic about living in her own home. She is almost 90 years old, has suffered for several years from chronic back pain and has trouble swallowing due to problems with her throat and gastro-intestinal tract. Sitting up for long periods of time is a challenge and walking more than a few steps is nearly impossible. However, with the correct assistive equipment, including a hospital bed and wheelchair, and the help of her two caregivers, Vickie is as comfortable as possible in her own space, where she prefers to live.

Background

Vickie lives in a small one bedroom apartment and has two caregivers hired through In-Home Supportive Services (IHSS). She spends much of her time reading, watching television, and chatting with her caregivers. She has two children who live out of state and are not involved in her day-to-day care, but are reassured to know that their mother is able to live

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>

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independently in her own home with the assistance of various services and supports.

Vickie relies on a number of programs and services to live independently. Each plays a specific role in the network of care that she needs to remain at home. Two IHSS caregivers provide assistance for Vickie seven days of the week. Their duties include helping with personal needs such as bathing, dressing, and toileting, as well as the housework, laundry, meal preparation, shopping, and running errands. The caregivers are her links to the outside world and provide transportation to all medical appointments.

A home nurse also visits Vickie twice a month to check her vitals and hemoglobin levels. Medicare delivers nutrition shakes each month, and also provides and maintains an oxygen tank for Vickie's respiratory troubles. A social worker from the local aging services agency pays quarterly visits to her home and Vickie knows that another social worker from her doctor's office is also available if she needs extra assistance. In an emergency, Vickie can use her lifeline alert necklace, or contact her home nurse or the building manager's wife.

Health Changes Over the Course of the Year

In the past year Vickie has experienced several changes to her health and care. Her immediate health concern is her throat and inability to swallow. After several months of pain and stress, she and her doctors decided to take the next step in her medical care by inserting a stomach feeding tube. Because of the severity of her struggles with swallowing and the daily fear of choking, Vickie says that the feeding tube has improved her quality of life. During this time her IHSS caregivers have been there to keep a watchful eye, and to help her prepare the food and medications that she now administers through the feeding tube.

While Vickie's care needs have intensified, her caregivers have been happy to accommodate these changes in exchange for her enhanced quality of life and well-being.

Like many consumers of long-term care services and supports, Vickie cherishes the ability to remain independent in her own home. Despite her health needs and the assistance she receives from a variety of sources, her ability to be in her own home bolsters a great sense of independence. For Vickie, being in her own space also translates to good health. She is healthy enough to manage her needs when she is alone, averting the need for 24-hour care.

For Vickie, maintaining independence and remaining in her own home is of key importance. She goes to great lengths to stay healthy, both physically and mentally, and describes this effort as something that she consciously and constantly strives for.

Well the worst thing that would happen would be to go to a nursing home, that's why I fight that, I keep my mind agile and ready to go, it's something you have to work with all the time.

Changes in Public Supports

While managing her most recent health troubles, Vickie experienced additional stressors concerning her living situation. She lives in a subsidized complex for older adults and four times a year the management inspects each unit. Following a recent inspection, the management asked her to make some repairs inside the apartment. Vickie felt that the request was unwarranted and delivered with a thinly-veiled threat that suggested she might lose her unit if she did not comply. Her son stepped in and addressed the problem, but it was a stressful situation for Vickie to deal with at the same time that she was adapting to changing health care needs.

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Although Vickie has received assistance through IHSS for about seven years, asking for help was not an easy process. Her illness began to limit her mobility and for several months she lived with the pain, staying mostly in her bedroom. A visit from her son, who lives out of state, prompted Vickie to get the help that she desperately needed. She contacted her local Area Agency on Aging and they began the process of setting up IHSS and outfitting her home with a hospital bed and other equipment that would make daily living easier.

And I...stayed in my bedroom for a year by myself when I first became ill. I didn't tell my children or anybody, I stayed in there every day. I did have a TV and I read and kept myself busy but I wasn't able to be up or around at all. And when my son came out to visit, he got with the [area agency on aging] right away and they stepped right in and said that she needs an electric bed, this and that. And so they went to work and helped my son [with] where to go to order these things and get them.

In spite of the health challenges Vickie has been confronted with, she remains optimistic. She is thankful for the ability to continue living in her own home, on her own terms—an accomplishment that would not be possible without the network of supports and services she has managed to cobble together.

Reliance on Services and Supports Over the Course of a Year

Vickie remains in daily telephone contact with her two children and they assist with larger decisions about her health care and well-being. Another important member of Vickie's informal network includes her pet dog. He is a source of companionship and pleasure and keeps Vickie entertained on a daily basis.

It does, I get restless, and uhh, again, I avoid that by keeping my mind busy. And I have my little poodle, who I talk to like a child, and it's company, you know. And he comes over to play with me when he needs

it. I have to accept the best of my situation, but it comes from you. If you are in a constant state of depression, you can't motivate yourself to get up and do things, I think your mind is lazy. You have to make it yourself, do it yourself.

Vickie requires assistance from several different sources but with each piece of the network in place, she is able to remain at home despite her intensive needs. She has two caregivers that provide assistance every day of the week. Vickie knows that without her caregivers, she would not be able to remain at home. For Vickie, not having her caregivers (whom she refers to with affectionate as "my girls") would dramatically curtail her ability to take care of herself.

Not to have my girls. If I didn't have my girls, I couldn't shower. I could not get in the shower. I'd just have to wash my face in the sink because I couldn't get in there. To do my shopping. I can't do that. To do all the things they do, I can't do. So, the service that you have here with In-Home Support is just magnanimous in my life.

Without daily personal assistance services, someone

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How "Vickie's" Situation Has Changed Over Time

Vickie has experienced some difficult health challenges over the years, and yet maintains a positive outlook. In the course of the past year alone, she has undergone several health procedures. And all along the way, her IHSS caregivers have been by her side, adapting their caregiving tasks to continue to meet her ever-changing care needs.

Although Vickie's care needs are intensive, she has managed to piece together programs such as IHSS, MSSP, and home health nursing, which together provide adequate support to keep her living at home. However, even a seemingly dense network can be disrupted by unanticipated problems with housing or finances. Vickie relies on her network of care to carry her through many of these unpredictable changes.

with Vickie's level of need and disability would be unlikely to be able to remain safely at home. Vickie is able to remain on her own in the late afternoons and evenings largely because of the actions and considerations of her caregivers. They prepare Vickie for the time she will be alone, making sure that everything she needs is within reach. Anne, one of her caregivers, describes the little things she does to ensure that Vickie is able to take care of her needs when left alone.

Yeah, she can go to the refrigerator with the scooter and open. So, we place everything in the fridge so it's easy for her to take it out of the fridge. Yeah, everything-even the ice cubes, we put in the cup for her so if she needs to take it out... yeah, everything's prepared so there's an easy way for her to get it.

Additional personalized care is often a part of the support provided by the IHSS caregivers. Anne tries to ensure that Vickie maintains a good quality of life by meeting her health care needs and providing companionship. She ensures that the flowers and plants on the balcony are well taken care of since that is Vickie's main view directly outside of her small apartment.

She has the balcony, you know, the flowers make her feel fresh, you know, happy, so that's why I help her water plants.

Vickie also likes to look her best whenever possible, and her caregiver assists by doing her hair and painting her nails. All of these small things help Vickie enjoy her life, even in the face of disability and health limitations.

The Challenge and Potential of Consumer-Direction

In our last interview, Vickie told us that because she felt that one of her caregivers was not as attentive to her needs as she once had been, she decided to let her go. She was able to transition quickly to another caregiver, and felt empowered by her ability to decide who would provide the help.

Vickie describes her past business experience as an asset when managing her own care. Those skills gave Vickie the confidence she needed to fire and hire caregivers as she saw fit. She describes the recent process of letting her caregiver go as part of a business arrangement, while also acknowledging that it was not an easy decision or process.

Despite the challenges that come with directing her own care, Vickie feels that handling her own care arrangements bolsters her goal of maintaining her independence, even when physically she cannot do many things on her own. She describes why she likes directing her own care:

Yes, I like doing it. I like doing my own. I wouldn't like it if somebody had to do it for me. If somebody had to, of course I would allow that. But, I don't want that to happen. I want to stay mentally alert enough that I can always take care of my own self.

Conclusion

Vickie has close relationships with her IHSS caregivers who, in addition to providing assistance with personal and domestic tasks, offer her companionship and personalized care. Vickie receives assistance from several programs and supports, all of which play a critical role in helping her remain at home. Without all of those care components in place, Vickie would have great difficulty living independently. Given the intensity of her health care challenges, Vickie remains ever optimistic and grateful for the ability to continue living in her own space and on her own terms.

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