

January 2012

“Roy”-A Case Study

- 67:** Age
158: Number of IHSS hours currently received each month.
32: Number of IHSS hours potentially lost if budget cuts are triggered.

Other formal supports received: Meals on Wheels, local transportation, care management through MSSP and a local aging services provider, subsidized housing

Informal supports: Service animal

Reductions of supports in recent years: IHSS reduced by 3.6%, SSI eliminated

Introduction

Roy has lived in California since 1968, when he finished college and started working a number of odd jobs. For many years, Roy led an active life but things changed after he was diagnosed with diabetes incipidus and muscular atrophy, conditions that limit his ability to take care of his home and continue to live without assistance. In 2002, Roy stopped working and applied for California’s In-Home Supportive Services (IHSS) program. He currently receives 158 hours of assistance per month from an IHSS provider who helps him manage his complex care needs at home.

Background

Roy first received elder care services through Linkages, a public program administered through California’s Department on Aging that provides older adults with comprehensive care management to fill the gaps when not eligible for other supportive services. Through Linkages, Roy learned about IHSS and hired a caregiver who currently provides assistance with

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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>

bathing, housework, preparing meals, getting around outside of the house, shopping, and managing medication six days a week.

Roy also utilizes other public services, including Meals on Wheels for home-delivered food, a local transportation service that gets him to medical appointments, and psychological counseling services offered by a nearby hospital which help him manage his anxiety and other psychiatric concerns. Additionally, Roy receives assistance from a non-profit community based organization that has been instrumental in connecting him to a number of needed services.

Roy's service animal provides him an important source of companionship and PAWS, an organization that helps older adults and the disabled maintain their pets, helps Roy care for his dog when needed. Despite his health conditions and physical limitations, Roy maintains control of his care; for example, he keeps track of his IHSS worker's hours, and regularly communicates with his social workers to maintain a viable network of interconnected services.

Health Changes Over the Course of the Year

Although Roy did not have any major health events over the course of the study year, his health and energy does fluctuate from day to day. His caregiver notes that on days when Roy feels under the weather, his care needs go up and he requires more assistance with getting out of bed and walking around. On these days, more IHSS hours are devoted to personal care rather than housework.

As Roy's mobility has deteriorated over the years, he has begun to use walking aids, such as a cane, a walker, and numerous support bars throughout his house. These physical supports, combined with the personal care provided by his IHSS caregiver, allow Roy to function on days when his muscular atrophy is most acute.

Because of a tendency to lose his balance, Roy receives hours from IHSS for help with personal care such as bathing and dressing. These hours are especially important on the days that Roy is unsteady on his feet. The regular presence of the IHSS caregiver is tremendously reassuring to Roy and is especially helpful when his health conditions flare up. Furthermore, Roy has been going to the same hospital for all of his medical appointments and surgeries since 1985; there he has developed close relationships with a network of health care professionals who work with each other to provide Roy with comprehensive care.

Changes in Public Supports

Roy describes his recent experience with IHSS as quite positive due to the flexibility and availability of his current caregiver. However, his earlier years navigating the web of senior services in California were not nearly as smooth. Roy remembers having a hard time finding an adequate IHSS worker during his first few years with the program.

Um, I had a great deal of trouble really finding a worker with IHSS that was satisfactory, that I would really want in my home...I was not very comfortable.

Roy also experienced some difficulty transitioning from the Linkages program to the Multipurpose Senior Services Program (MSSP) when he turned 65. He felt that his new MSSP social worker was not very effective. To remedy this, Roy turned to another social worker, located at a non-profit community-based organization, who proved to be a tremendous advocate and helped to connect him to the services he needed.

Roy's IHSS hours were decreased over the course of the year, from 158 to 152. While this did not strongly affect Roy and his care needs, he expressed uneasiness with the prospect of more cuts.

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Well every time hours are taken away I notice that, you know, fewer things get done.

It is important to Roy to be able to keep his house clean and orderly, and with this recent reduction in hours, less time is now dedicated to housework.

Roy also experienced a reduction in income this past year that limits his ability to purchase all the things that he requires. There was no cost-of-living increase to his Social Security income, he lost his SSI completely, and started to receive food stamps. He is grateful to have the food support but reports that he has cut back on other supplies and services, such as non-prescription drugs, personal care items, and repairs around the house. While Roy states that he could use more help, he understands the direness of the current budget situation and manages to get by with what he has.

Over the course of the past year, Roy began to receive additional psychological counseling services. Previously, he visited a counselor every three months at a local hospital close to his home. Now, the social worker at the non-profit community-based organization has connected him with an psychological intern who provides counseling in Roy's home once a week. The in-home provision of psychological services has helped Roy get more frequent care without the stress of having to leave his home.

Changes in Availability and Scope of Informal Supports

All of Roy's immediate family is deceased, so he relies entirely on public supports for his care. However, he does have a network of friends who, although they do not provide care, visit and provide valuable companionship. This steady network of personal friends helps Roy maintain some stability in his life. In addition, the constant companionship provided by his service dog is critically important to Roy's well-being.

Reliance on Services and Supports Over the Course of a Year

Without the help of the IHSS program and the dense network of services and supports he has constructed over the years, it is unlikely that Roy would be able to maintain his independence. Centrally important to his daily life is the assistance provided by his IHSS caregiver.

It makes me more secure, knowing that things will get done, um because if they don't then I just become too uh it creates a hazard for me.

His caregiver is available to assist on the days Roy is unable to get out of bed or is in jeopardy of falling while trying to get into the bathtub. In these instances, his IHSS worker acts as a safety net that Roy can rely on when he most needs help.

Oh, I couldn't maintain living at home if I didn't have In-Home Support Services. Um, I just can't, I just can't do everything that needs to be done in a day's time. I just —my mobility is very, very slow. Um, my cognitive abilities would be interfered with, um, being able to function.

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How "Roy's" Situation Has Changed Over Time

Roy's health has been relatively stable over the past year, although each day is different. Some days he has less physical mobility and has difficulty moving freely around the house to get basic tasks done; other days he is immobilized psychologically by acute anxiety and stress. The daily support provided by his IHSS caregiver and his service dog helps him to adjust and manage his ever-changing physical and psychological needs.

Roy's greatest joy is found in his ability to retain his independence and a strong sense of autonomy. With regular assistance, he is able to respond to the daily changes in his care needs. Being able to manage his own care, in his own home, brings Roy a sense of security that is central to his health and well-being.

Having assistance from an IHSS caregiver six days a week has allowed Roy to establish a regular routine that enables him to effectively manage his health conditions. In addition, Roy's IHSS worker fills an important companion role which helps to ease Roy's depression and anxiety. Many IHSS consumers who do not have a family support system develop strong, personal relationships with their paid IHSS workers.

The Challenge and Potential of Consumer-Direction

Roy has demonstrated that he is capable of navigating the complex network of public services available to him. His success in managing his own care is evidenced by his ability to: identify appropriate programs and services; enlist the assistance of the individuals most likely to help; screen, interview, hire and train potential caregivers; establish a routine and plan for care; and, effectively communicate his needs.

Roy's case exemplifies the potential of consumer-directed care. His direct involvement in the screening, hiring and training of his caregivers increases the likelihood of cooperation and fosters a positive care relationship. Furthermore, through an IHSS option called Advanced Pay, Roy is responsible for overseeing his IHSS worker's hours and paying him directly. This empowers Roy by making him accountable and giving him a very tangible sense of control over the direction of his care.

While Roy offers a successful example of the potential for consumer-directed care, some consumers are not as adept at assuming the bulk of the responsibility for directing their own care. Many older adults are unfamiliar with the programs and services available to them and may have trouble identifying the supports from which they could most benefit. In these cases, the care management services offered by social workers through MSSP or other aging services programs

may be instrumental in helping consumers navigate and access needed supports while also encouraging the development of self-advocacy skills.

Roy is a good advocate for himself and has been successful in directing his own care through IHSS and other programs as necessary. In the absence of family or friends advocating on his behalf, Roy's self-advocacy has been essential to maintaining independence and ensuring that his care needs continue to be met.

Conclusion

Roy takes great satisfaction and comfort in the knowledge that he can remain in his own home. Despite health and mobility limitations, he continues to live independently where he is well supported by a number of public programs including IHSS, Meals on Wheels and MSSP. These services, combined with regular medical care and the companionship provided by a service animal, provide Roy with the care that he needs on a daily basis, as well as connections to additional information and support should his needs change. Roy has made the most of the consumer-directed model of in-home care offered by IHSS; he carefully oversees his own health and social care needs and, in so doing, continues to live where he prefers to live — in his own home.



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