

January 2012

“Michael”-A Case Study

- 74:** Age
- 137:** Number of IHSS hours currently received each month.
- 27+:** Number of IHSS hours potentially lost if budget cuts are triggered.

Other formal supports received: Meals on Wheels, food pantry, local aging service provider, nursing home care, health services including physical therapy and a diabetes support group

Informal supports: Help from family members and a former IHSS caregiver with transition to a nursing home

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

Introduction

Michael is a 74-year old man with diabetes and a history of strokes. He currently uses a wheelchair for mobility. Michael began using IHSS services 11 years ago, when he realized that he was unable to clean and maintain his home by himself. His care needs include help with bathing and other personal care, as well as housework, shopping, meal preparation and transportation to medical appointments. Michael’s primary source of support has been his IHSS worker, who provided highly personalized care until Michael moved into a skilled nursing facility in December 2010. This move to institutional care was precipitated by repeated occasions in which Michael miscalculated his insulin dosage and ended up in the emergency room. Despite Michael’s strong desire to remain living independently in his own home, as his needs increased, he realized that he could no longer do so without additional help.

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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>



Health Changes Over the Course of the Year

Michael's primary health condition is diabetes; in addition, he is visually impaired, uses a wheelchair for mobility, and suffers from incontinence. Several years ago, he was placed in a skilled nursing facility following a stroke, but returned home after family members offered to provide care.

Michael has faced numerous health challenges in recent years which ultimately led to the need for more care than he was receiving through his formal support network. Prior to his recent move to a skilled nursing facility, Michael was active in addressing his care needs by attending diabetic and stroke support groups offered by his health provider and regularly attending physical therapy sessions with the help of his IHSS provider. Michael's IHSS worker described the motivation behind his efforts to improve his health:

You know, he wants so badly to be healthy and to get better and to work—and you've never seen anyone work so hard to stay on his own and stay independent. He's fiercely independent.

Despite his determination, on several occasions Michael administered the wrong type of insulin and ended up in the emergency room. Here his IHSS provider describes those incidents:

He was having trouble reading his syringes. He had accidentally injected himself once with fast-acting that should have been long-acting. It was just getting messy, and he had a couple incidents in the middle of the night, and he was alone...on one occasion he called me, and on one occasion he called 911.

At the skilled nursing facility, staff provide Michael with regular doses of insulin. While avoiding medication errors, Michael feels that this practice diminishes his control over his own health care. He complains that the set regimen often leaves him feeling ill because the predetermined dosage is not responsive to changes in his blood-sugar levels.

Changes in Public Supports

Over the past decade, Michael developed a network of public supports to help provide for his care needs at home. Recent changes to these supports largely reflect Michael's entry into a skilled nursing facility. Michael's IHSS caregiver was instrumental in helping Michael make the transition to institutional care, and worked numerous extra, unpaid hours in order to help him pack and make the move. Michael also called on additional public supports to help with this transition, including a legal service agency that helped him create a will.

Although Michael knew that his support network was no longer sufficient to keep him living safely in his home, he describes the significant loss of independence he experienced as a result of moving to the nursing facility:

I made a note to myself about the ten most awful things that create a lot of stress and this, it wasn't a death or a marriage or a divorce but a big move from the time I was [in my home] and I had some form of independence. I could get up or move my wheelchair and, um, make a sandwich or think about getting a bag of potato chips... Or, taking a blood sugar reading and giving myself insulin, fast-acting, and maybe 2, 3, units instead of the 6 units I have here, whether I need it or not. That's a big, big, big change in anybody's life.

Lack of Availability and Scope of Informal Supports

Michael still keeps in contact with family members through a monthly newsletter he writes. Some of his siblings came from out of town to help him transition to nursing home care but it seems unlikely that they will be involved with Michael's ongoing care. Over the past 10 years, Michael has transitioned from informal supports provided by family and friends to the formal supports offered through public programs like IHSS, and now to a skilled nursing facility.

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Michael expressed a preference to have his needs met through public services, partially because of past family conflict and partially because of his strong desire for privacy and independence. When he was living at home, he had limited interactions with neighbors or with community-based social programs like senior centers. Michael's weak informal support network and fragmented formal support network was insufficient to provide the care he needed, given his complex health conditions. His IHSS worker described:

It's really more than one person, meaning me, can do. I'm getting it done 'cause it has to be done, you know, but it's really not a one-person job...There's no family. There's no other providers. ...I don't think anybody should rely solely on one person... I think he needs to have someone there a lot more often.

Reliance on Services and Supports Over the Course of a Year

As Michael transitioned to a formal network of care over the last decade, he made use of a number of different programs and patched together a network of services that he relied on for food assistance, health care, personal care and socialization.

For food assistance, Michael received Meals on Wheels services and deliveries from a food pantry. Daily visits from the Meals on Wheels delivery-person also provided Michael with a brief but regular opportunity to socialize. In addition, his IHSS caregiver shopped for food and household items and prepared all of Michael's meals, including provisions for the weekend.

Michael depended on his healthcare provider and a local aging service provider to support his health needs. Together, these two agencies provided assistive equipment that allowed Michael to remain safely in his home, including grab-bars, a hospital bed, a wheelchair, incontinence supplies and a computerized diabetes monitoring system.

More than any other source of support, Michael depended on his IHSS caregiver, who worked with him over 40 hours per week until he moved into a skilled nursing facility. His caregiver served a range of needs, including transportation, management of health conditions and companionship. Michael's IHSS caregiver drove him to his steady stream of medical appointments, assisted him with physical therapy sessions and helped managed his dietary needs. Here Michael describes the personalized care that his caregiver provided during physical therapy sessions:

I go to [my healthcare provider] for exercise and use the gym and the kinesiotherapy. And [my IHSS caregiver] has been there. She knows the machines, she knows what I do. She holds on to the wedgie so that I won't slip while I try to walk. I walk and hold on, just moving one or two steps... So she's always around. Other people don't know how to do that.

Michael indicated that the intensity and quality of care he received from his IHSS caregiver would have been exceedingly difficult to replace. For instance, she was usually the first person he would call after incidents of medication error or if he had other imme-

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The Importance of Home

Michael described the meaning of remaining in his own home even as he made the transition to a skilled nursing facility. In his own home, Michael was able to maintain privacy and independence by directing his own care and having a say in who was part of his support network.

Despite his strong desire to maintain independence, Michael realized that, given his complex health conditions and sparse and fragmented support network, he could no longer remain at home. Still, the emotional impact of leaving home was profound. Michael describes the move as a significant life event, akin to a divorce or death of a family member. His IHSS caregiver concurs, describing how Michael continues to go through a process of grieving the loss of his home and independence.

diate needs for help. She was also instrumental in preparing Michael for the transition into nursing home care. She worked numerous unpaid hours, later partially compensated directly by Michael, to help him pack his belongings. Importantly, she also helped Michael manage the emotional upheaval that she describes here:

Intellectually I think he knew it was time. His needs were beyond...the help he was receiving, or could receive. So, on the one hand he knew that it was the best thing for him. On the other hand, he absolutely didn't want to...Giving up that independence...he went into a funk when he first got the news... kind of the process of grief, you know...I never worked so hard in my life.

The Challenge and Potential of Consumer-Direction

Michael exhibited a number of strengths when it came to directing his own care. He took initiative to attend support groups and collect information about his health conditions. He was clear about the kinds of services that would best suit his own care needs and personality. For example, he turned down offers to attend adult day health care and a local senior center because he was not sure that he would get along with the other participants and was concerned they might not understand his preferences for privacy. He stopped using a local transportation agency after he no longer felt safe, relying instead on his IHSS caregiver for transportation to medical appointments.

Michael often expresses his concerns about the care and services he receives in writing. When asked about the potential cuts in IHSS care, he said:

I think about...other elders, who have similar stuff but they don't complain because they say 'that's the way the government works'. But I figure I complain a lot and mostly in writing and I get very little done. Can you imagine what is being done to people who do not complain...?

Michael's IHSS caregiver has also supported his advocacy efforts to get his care needs met, often by communicating with others at Michael's request or organizing services for him, particularly around his medical care and transition to the nursing home. Michaels' advocacy skills continue to serve his interests in the skilled nursing facility where he now resides; there, he regularly expresses concerns to staff about his care and about the care of fellow residents.

Conclusion

After having lived independently at home with the support of an IHSS caregiver and a fragmented network of other public services, Michael has now transitioned to a skilled nursing facility. Despite the intensive and personalized care provided by his IHSS caregiver, Michael required more care than he could continue to patch together while remaining in his own home. Michael's limited network of support, and especially his IHSS caregiver, were instrumental in helping Michael make the physical and emotional transition to nursing home care. Michael continues to struggle with adjusting to his life in a skilled nursing facility and is especially challenged by the limited opportunities to direct his care according to his own needs and preferences. However, he continues to advocate for his health and other care needs at every opportunity.



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