

December 2012

“Ella”-A Case Study

- 79:** Age
- 72:** Number of IHSS hours currently received each month.
- 14+:** Number of IHSS hours potentially lost if budget cuts are triggered.

Other formal supports received: Reduced-price food box

Informal supports: Lives with family members, family helps with insulin injections

Reduction of supports in recent years: IHSS hours reduced by 40% in August 2010 and 3.6% in January 2011

Introduction

Ella is a 78 year old woman living with her daughter, son-in-law and grandchildren. Ella’s primary health condition is diabetes, which is controlled by insulin that her family members help inject four times a day. She also suffers from episodes of depression. Another daughter who does not live in the same household is Ella’s IHSS caregiver. She comes three days a week to support Ella with food preparation, housework, and transportation to medical appointments. Just prior to the study period, Ella experienced a drastic cut in IHSS hours and her family members struggled to address her needs while also grappling with their own health and financial constraints.

Background

Ella purchased her own home in 1970; she raised her children and cared for her ailing father there. In the 1990s, her daughter Sofia’s family moved in to support Ella as she struggled to pay the mortgage on her own. However, over the course of the study year, the entire family faced losing the home due to persistent financial challenges.

Ella has experienced some stress as a consequence of living

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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>



with her daughter and extended family in a more crowded and constrained living space. Nevertheless, Ella says that staying in her own home is extremely important to her:

Well, yes it's important. Since I bought this house in '70, I believe, I've been here. So, I've become rooted in this place and, well, here I know where my doctors are, how I get there and how I get back.

Ella's daughter Sofia suffers from rheumatoid arthritis and fibromyalgia, which severely limits her mobility and ability to provide hands-on care for her mother. Ella's other daughter Isabel is currently her IHSS worker, but it is difficult for her to provide additional unpaid care to make up for the lost IHSS hours. Isabel has chronic care conditions of her own and also cares for a son with severe disabilities. Ongoing financial challenges further limit her ability to cover the costs of gas and car use for the long commute to Ella's house.

Health Changes Over the Course of the Year

Ella has numerous co-morbid conditions, including diabetes, depression and a recent stroke which has affected her eyesight. Her family members help as much as they can with administering her insulin but Ella still has difficulty with some aspects of diabetes management, including food preparation and knowledge about insulin measurement. These challenges have contributed to several hypoglycemic episodes that required emergency care and hospitalization. Here, Ella describes one of these incidents, as well as frustration with her doctor, whom she felt did not adequately support her efforts to take better care of herself and avoid such adverse health events:

I asked the doctor to send me someone to help with my injections and arrange my medications because I can't see well. I had an accident because I can't see. I'm not sure, but I think I tested at 225 and for me that sugar level was high. I don't remember how much insulin I gave myself. I think that I might have given my-

self 10 units, even though the doctor said five units, 'no matter what'. I must have put more than five and my sugar dropped to 18 (from 225). I went into a coma and the paramedics came to revive me.

Ella and her family described at least five similar episodes occurring within the past two years. These experiences empowered Ella to change her health care provider. However, at the end of the study year, Ella was still seeking additional diabetes management support and remained at risk for medication errors.

While trying to better manage her diabetes, Ella also struggled with feelings of depression. Her daughters expressed concerns about her mental health, and observed that her depressive symptoms had contributed to her becoming increasingly isolated within her own home. They further noted that these episodes of depression had an adverse impact on her other health conditions:

The time that she went to the hospital for over a month, the doctor noticed that she was very depressed. They found out that she was anemic, her kidneys were shutting down, she was not taking care of herself.

Changes in Public Supports

Shortly before our first interview with Ella in late 2010, her IHSS hours were cut by forty percent — from 122 to 72 hours. Because Ella was living with family members, it was expected that they would cover all unmet support needs. In reality, her family struggled to meet all of her care needs, given their own health and mobility challenges and financial constraints. Then, in 2011, Ella's hours were again reduced, by 3.6% as part of an across-the-board cut for all IHSS consumers.

Isabel — Ella's daughter and IHSS caregiver — was also affected by these cuts. Primarily, she helps Ella with housework and sometimes provides *Continued...*

transportation to medical appointments. She has done her best to compensate for the reduced IHSS hours by preparing large portions of food that Ella can microwave throughout the week, and by prioritizing tasks like helping Ella bathe. However, Isabel lives across the county and has financial and health concerns that limit the amount of support she can provide. For example, she is no longer able to assist with meal preparation over the weekend or with preparing her insulin on a daily basis.

Other sources of public support were unpredictable over the course of the year. Ella's family arranged for her to receive a low-cost box of food from a local service provider, but at least twice during the study year period she did not get this service. Ella also started getting Meals on Wheels, a service she had received following past hospitalizations. She was not always sure, however, why or when the services she received started or stopped over the year.

Changes in Availability and Scope of Informal Supports

Ella lives with several family members who might be perceived as readily available to provide informal support. However, Ella's daughter Sofia has rheumatoid arthritis and fibromyalgia and is not able to provide care due to her own struggles with pain and mobility. Sofia's husband and children work. With the exception of a grandson who helps Ella with her insulin injections, Ella's family members face many barriers to providing additional support. Sofia describes their health and work-related constraints:

My daughter works, my son works, the only one that's here is Miguel, the one that gives her the injections... Me, specifically, I have a hard time taking care of myself so it makes it more difficult for me, taking care of my mother.

The combination of limited informal support and diminishing formal support sometimes led to unsafe conditions in the home, particularly as Ella attempted to manage her own care needs. Her daughter Sofia observes:

A couple of times she was peeling an apple for me, she cut herself... Sometimes she'll have bruises on her body... she doesn't remember how she got them. A couple of times I feel that she hurt herself in the shower...I think that she tipped and hurt herself.

Although Ella's family expressed much concern about her physical and mental health — particularly given the reduction in formal support through IHSS — they were largely unable to increase the amount of informal support they provided to adequately meet her needs.

Reliance on Services and Supports Over the Course of a Year

Ella continued to manage an extremely fragmented network consisting of diminished IHSS hours, limited and intermittent food assistance, and tenuous informal support from family members. She did not partici-

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How "Ella's" Situation Has Changed Over Time

Ella experienced a significant cut to her IHSS hours – from 122 to 72— in the summer of 2010. As a consequence, Ella had to manage much more of her personal care on her own. Her daughters reported she often had cuts or burns on her hands from attempting to prepare her own meals, and bruises on her legs from attempting to bathe herself.

Ella also struggled with effectively addressing her health needs over the course of the year. She experienced hypoglycemic episodes resulting from insulin dosage errors and increased pain in her legs as a complication of diabetes. In addition, Ella suffered several depressive episodes and feelings of increased anxiety and isolation.

pate in senior centers or receive care-related services from other community service agencies. As such, she often remained isolated in her own home. This weakening social support network took a toll on Ella's already fragile physical and mental health status, especially since she received little support related to managing her diabetes and depression.

While the level of care Ella receives is not ideal, her IHSS hours remain an essential support that enables her to continue living safely in her own home. Any additional cuts to IHSS hours would raise concerns about the potential for increased safety risks related to bathing and preparing meals on her own, as well as preparing her insulin.

The Challenge and Potential of Consumer Direction

Overall, Ella is confident in her ability to manage her IHSS caregiver hours. Although she described some negative experiences with previous IHSS caregivers, she felt confident enough to make changes when she felt that they were not successfully meeting her needs.

Ella was able to take charge of her medical care by letting go of a doctor whom she felt was not communicating effectively with her; she expressed disappointment over his lack of concern for her health during a recent hospitalization and located a new doctor whom she believes better meets her needs. Ella also worked with her family members to ensure that her insulin injections were completed properly.

Ella did express some difficulty directing certain aspects of her care. For instance, Ella would likely benefit from additional support with managing her medical bills and other financial paperwork. However, when tasked with managing her IHSS caregivers and healthcare providers, Ella was able to clearly express her needs and preferences.

Conclusion

Over the course of the year, Ella encountered several challenges to maintaining the goal of remaining safely in her own home. Most notably, she experienced difficulty managing her diabetes, which led to frequent hypoglycemic episodes. In addition, she struggled throughout the year with episodes of depression and the fear of losing her ability to continue to live independently at home.

Ella's increasing health concerns coincided with a significant reduction in her IHSS hours. The decision to cut her hours was based on the faulty assumption that her live-in family members would be able to "pick up the slack" and provide additional care at no cost. However, due to a combination of health, mobility and financial challenges, Ella's family members are not able to make up for the cuts in IHSS hours. As a result, Ella largely manages on her own, and her safety is often compromised, as she increasingly has to prepare her own meals and bathe herself. Even surrounded by what might appear to be an available family support network, Ella struggles to remain living safely at home in the absence of adequate formal supports.



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