

December 2011

### “Yvette”-A Case Study

- 78:** 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:** Adult Day Health Care

**Informal supports:** Daughter and son-in-law provide 24-hour care in their home. Another daughter provides limited care on weekends as respite.

**Reduction of supports in recent years:** : IHSS care hours reduced 4 hours in Jan 2011 & unspecified additional cut to hours as of Oct 2011. Adult Day Health Care center closed, closure of the one she moved to was pending.

#### Introduction

Yvette is 78 years old and lives with her daughter Monique and son-in-law George, who are her In-Home Supportive Services (IHSS) care providers. Yvette’s primary health condition is schizophrenia, which she developed in her mid-30s. She has additional comorbid conditions, including dementia and hypertension. Due to her health conditions, Yvette needs support with most activities of daily living, including bathing, toileting, dressing, taking medications and getting in and out of bed. In addition, Yvette requires constant companionship given concerns that she may wander away from home or otherwise be unsafe. Yvette is assessed at the highest level of need under IHSS.

#### Health Changes Over the Course of the Year

Over the course of the year, Monique observed that her mother was increasingly agitated, with more frequent night waking. Monique was eventually able to communicate with Yvette’s psychiatrist about her worsening anxiety, who consequently adjusted her medication. Monique explained

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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>



that although her mother's health was declining significantly, changes to her medication were nothing new. The constant shift in Yvette's medication requires Monique to closely monitor her dosages as well as manage any side effects. In addition, Monique continually reassesses her mother's care needs as evidenced by her shifts in mood and behavior. Here she describes efforts to change adult day service providers as a result of Yvette's need for specialized care:

Just maybe a couple of weeks ago we noticed that she is using more medication, because regarding the two medications that she takes, you know, different doses all the time... I contacted one of those regional health centers and... we got a reply from an adult day health center, which is specialized in mental disabilities. So I'm trying to see if... we can do it. Hopefully there will be a specialist and she can see exactly what she needs, what kind of program or medication she needs to be put on.

In addition to these overarching changes in Yvette's health, Monique stated that her mother's needs often change from day to day. Monique described that the intensity of her care depends on a number of factors, including unpredictable changes in Yvette's psychological well-being and her ability to get adequate rest. When asked about a "typical" day caring for her mother, Monique describes:

I think sometimes there's days, very critical days than others. It depends when she doesn't have a good sleep during the night, I wake up three or four times a night, you know, to make sure what's wrong with her or what she needs.

## Changes in Public Supports

Yvette has attended an adult day health care (ADHC) center for three hours a day, five days a week throughout the study period. The time that she spends at the ADHC program affords her son-in-law George some respite during the day; he works the night shift and is

able to take a nap before resuming caregiving responsibilities in the afternoon until Monique arrives home from work. Yvette also benefits from her time at the ADHC center as Monique notes here:

Oh yeah, she enjoys [the ADHC program]. Some nurses tell me that when she's there she feels more motivated and happy because she's surrounded by different people, which is good for her social skills.

However, the first ADHC program that Yvette attended was slated to close due to budget cuts by August 2011. Although Monique enrolled Yvette in another ADHC program — one that was better tailored to her mental health needs — the future of that program was also in jeopardy. Because she needs to continue to work full time, Monique was unsure of what she would do if her mother was no longer able to attend an ADHC program.

Monique reported that two cuts have been made to Yvette's IHSS hours over the course of the study period. At the beginning of 2011, Yvette's hours were cut from 116 to 112 hours per month due to a 3.6% across the board cut made to all IHSS consumer hours. After the last interview Monique reported that Yvette's IHSS hours had been cut yet further, due to the results of an annual reassessment of need. These cuts to IHSS hours have increased the financial stress experienced by Monique and her husband. Because Yvette has no income, she is completely dependent on her daughter and son-in-law, who use most of their IHSS earnings to cover the cost of her food, clothing, and medication.

## Reliance on Services and Supports Over the Course of a Year

Family is essential to Yvette's ability to remain living safely at home. Monique and George not only provide personal care, financial support and shelter to Yvette, they also arrange for her medical care and other support services. In fulfilling these needs,

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they also provide her with an intangible sense of comfort. Here Monique describes the sense of security that her mother expresses:

She feels very secure, she feels very secure. In the mornings when I'm gone she's here eating breakfast and my daughter says that sometimes she'll go and look for me in the bedroom and she's asking for me: where did I go, where I was... and I think that she relies so much on me... I'm her right hand.

The importance of family extends well beyond ensuring Yvette's feelings of security. By being attuned to Yvette's non-verbal cues and moods, Monique is able to help her fulfill her basic needs. Here Monique describes her way of making sure that her mother's nutritional and medication needs are met:

She can be starving but she's never going to tell you 'I'm hungry'. I notice when she's very hyper or shaking, either she needs the other dose of medication or she hasn't been fed enough. And when she goes in the daycare they give her, kind of to do with her blood pressure, they give her something with low sodium.... When she comes in she's hungry... so I have to give her like a little pasta that I make for her, like a pasta soup, minestrone soup and she loves that.

Monique's attention to her mother's changes in moods, such as increased agitation or acting "hyper", and to physiological signs like shaking, allows her to respond quickly to her mother's needs. Often she responds to her mother's increased anxiety by comforting her, including during the two or three times per night that Yvette typically wakes up. The comforting, familiar touch that Monique provides for her mother is not easily substituted. Her care, and the care provided by her husband, is essential to ensuring that Yvette is safe and that her health care needs are sufficiently met. Given Yvette's limited verbal communication, her family caregiver's familiarity with her non-verbal cues and changes in mood is essential to her remaining independent and safe at home.

## The Challenge and Potential of Consumer-Direction

Although Yvette is challenged to direct her own care by significant mental health needs and limited verbal communication, the model of consumer-directed care provided by IHSS affords the flexibility that allows Yvette's family to participate in directing her care and advocating for her needs and preferences. Monique has spent a great deal of time locating supports and services that are best suited to Yvette's needs. She pays careful attention to her mother's moods and behaviors to assess whether Yvette feels comfortable in different care settings. For example, when Monique first connected Yvette to an adult day health care (ADHC) program, she noted that her mother was becoming increasingly aggressive with staff. So she quickly transitioned Yvette to a more appropriate setting:

I found one [day care]... but then she got really aggressive and she hit some of the nurses. So, the people, they probably didn't have patience, you know, they don't focus with dealing with these kinds of people. So, they told me that she was not welcome to be there anymore... So, *Continued...*

### How "Yvette's" Situation Has Changed Over Time

Over the year, Yvette's health needs increased, primarily in relation to her schizophrenia and cognitive health conditions. These changes included being increasingly anxious and wakeful at night, and led to further medication needs.

These changes were managed by Yvette's daughter, Monique, her primary caregiver. Monique was sensitive to Yvette's increased need for services and medication adjustments based on her declining health. Indeed, understanding Yvette's changing needs required Monique's very careful attention to her mother's moods and behaviors, often at all hours of the night.

then I was searching for more and then finally I found one and they told me ‘oh, no, no, your mother... she’s going to interact with everybody. We treat everybody equal. So, she’s going to be sitting, not being separated from everybody.’ So, I really liked that one and she’s been there since, for over like, yeah, two years I believe.

Here Monique describes recognizing that the first ADHC program she tried was not appropriate for her mother, given Yvette’s erratic behavioral changes. She responds by searching for a center that was better equipped to support her mother:

I have been in there and they do a lot of activities for them. And one of the things I notice is she enjoys playing Bingo. And she interacts with other people there, which is good for her. And you know, they do like dancing or singing and a little bit of moving, make her walk. You know, they check the blood pressure and everything, they have nurses. So, it’s very, very helpful. She really enjoys that.

Over the course of the study period, Monique demonstrated profound familiarity and concern with her mother’s needs and preferences. By making continual adaptations based on Yvette’s comfort-level, health status, and the appropriate match of her needs with available services, Yvette’s program of care remained consumer-directed, albeit by proxy. Despite the significant communication challenges evidenced in this case, the flexibility of the consumer-directed model allows family caregivers like Monique, who have intimate knowledge of the consumer, to effectively assist with directing their care.

## Conclusion

Because of the personalized, around-the-clock care that Yvette receives from her daughter Monique and son-in-law George, she is able to remain living safely and comfortably at home despite complex mental and physical health conditions. However, the double burden of full-time work and caregiving that Monique and George have assumed has been exacerbated by recent cuts to the public supports and services that Yvette also relies on. Most drastically, the adult day health care program that benefited Yvette and her family closed and the future of the entire program was unclear.<sup>1</sup> In addition, Yvette’s IHSS hours have been reduced twice in 2011 despite her intensive care needs. It is clear that the careful attention that Monique pays to her mother’s needs and preferences is unmatched by other providers. Until these most recent cuts, the consumer-directed model provided by IHSS has enabled Monique to arrange and adapt the supports and services her mother needs in an appropriate manner. It remains to be seen how they will continue to provide 24-hour care as supplemental supports continue to dwindle.



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