

September 2012

“Ana” -A Case Study

- 53:** Age
- 235:** Number of IHSS hours Ana’s mother, Maria, currently receives each month
- 47+:** Number of Maria’s IHSS hours potentially lost if budget cuts are triggered.
- 90:** Number of IHSS hours Ana’s father, Jose, currently receives each month
- 18+:** Number of Jose’s IHSS hours potentially lost if budget cuts are triggered.

Other formal supports received: IHSS, local rehabilitation center care

Informal supports: Ana and her family provide unpaid care around-the-clock — above and beyond paid IHSS hours; Ana visits her father, Jose, in the rehabilitation center 2x per day.

Reduction of supports in recent years: Loss of adult day health care services for Jose; cuts of 3.6% to IHSS hours for both Maria and Jose

Introduction

Ana is a 53-year-old IHSS caregiver to her mother, Maria, and father, Jose, both of whom live in Ana’s home. Both Maria and Jose have advanced dementia and experienced significant declines in their health status over the course of the year. Ana is responsible for every aspect of caring for her parents, including meal preparation and feeding, personal care and hygiene, administering medication, and coordinating their health care and finances. As a consequence of providing around-the-clock care to her parents, Ana describes feeling isolated and depressed, and her stress is compounded by the diminishing formal supports available to her parents. For instance, her father was recently dismissed from participating in an adult day health care center, and this eliminat-

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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>



ed an important source of respite for Ana. Her daughter also worked as an IHSS caregiver for two hours each day, providing Ana time to exercise or attend church services. But the ability of her daughter to continue providing respite will be threatened by any further cuts to her parents' IHSS hours. While she provides highly personalized care to her parents, the increasing lack of formal supports weighs heavily on Ana and has begun to negatively affect her health.

Health Changes Over the Course of the Year

Ana's parents, Maria and Jose, experienced significant changes in health status over the course of the year. Both have advanced dementia and Maria also has hypertension and osteoporosis. In January 2011, Maria had a bad fall that precipitated a drastic decline in her cognitive and physical health. By the second interview she was no longer able to talk or feed herself. She was also temporarily unable to walk, but resumed with the help of physical therapy sessions. Here, Ana describes the impact of these changes:

She can no longer eat on her own... So, I sit with her and I feed her one spoonful at a time, making sure she eats well... It's been a huge change. Now I can't stop watching her for even one second. Now that she doesn't talk, I have to guess, 'do you want to go to the bathroom?' And she claps two times and I take her to the bathroom.... I have to be even more careful, making sure that my dad is in a safe place so that he doesn't get too close to her. She doesn't know and all of a sudden she'll come and slap him, like this, as if to speak to him, although she no longer speaks.

As her mother's health declined, Ana needed to be increasingly vigilant to ensure her parents' health and safety. She also made a great effort to learn new ways to care for her parents – for example, by developing methods of non-verbal communication with her mother and learning techniques to keep her parents separate as her mother became increasingly aggressive, presenting a safety concern for her father.

Soon after adjusting to her mother's changing health needs, Ana's father also had a bad fall, which left him hospitalized and later in a rehabilitation center for about two months. While her father was there, Ana continued to provide highly personalized care by visiting him two to three times daily, bringing him food and ensuring that he was making progress towards recovery. She describes her daily routine caring for both her parents while her father was recovering from his fall:

For me, more than anything, its impacted me, its been a big change because I've had to be running around... since I don't trust that they are going to feed him, or that they're going to have patience. I go at noon to feed him. At five I go to give him dinner. Every day its the same, it's come and go, come and go. And, well, my mother comes too—sometimes I take her and sometimes my daughter stays and watches her... That's how its been. Its been tough.

Once back at home, her father Jose was no longer able to do his own toileting and relied on Ana for increased support with personal care. In addition, he used a wheelchair more often for mobility, given that the impact of the fall reduced his ability to walk. The decline in health status for both of Ana's parents, including serious falls, led to significant increases in their care needs.

Changes in Public Supports

Just before our first interview, Ana's father was dismissed from an adult day health care center, because he was not able to remain awake and participate in center activities. Ana went from caring for her mom during the weekdays to caring for both her parents around-the-clock. This presented Ana with a number of challenges. For one, because her mother is often aggressive with others, this poses a safety risk for Jose if she is not watched vigilantly. Secondly, Ana was now much less able to get out during the day;

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while she used to take her more mobile mother, Maria, to the store or to visit family, this was no longer feasible. Here, Ana describes what it was like when she first came to care for both her parents all day, every-day:

Its been a month since they told me he couldn't go to the [adult day health care center] because he was sleeping during his time there. They told me to talk to the social worker about paying more for him, and I'm not sure what else. I started crying because what was I going to do with the two of them? I started to feel depressed, thinking about what I was going to do. With my mom I could take her with me. Now with my dad, what am I going to do? It's hard. But, I started and things are okay. Everything happens for a reason.

Ana's parents rely very little on other public supports and services outside of IHSS and health care services. Both Maria and Jose experienced cuts of 3.6% to their IHSS hours at the beginning of 2011. In addition, Jose's IHSS hours were suspended during his time in a rehabilitation center. While the stop in coverage was expected, Ana was unclear how to reactivate his hours once he returned home, and did not know how long this process would take. While Ana stated that she would continue to provide care regardless of reductions in IHSS hours, such cuts would likely result in a significant financial burden given that Ana ultimately left her job to take care of her parents. Furthermore, cuts to IHSS hours might limit Ana's ability to hire her daughter or another family member to provide two hours of daily respite.

Additional public supports for Ana's parents have come in the form of assistive equipment and incontinence supplies that Ana believes are supplied by Medicare, although she is not certain. These resources have remained consistent over the course of the year. Finally, Maria and Jose continue to receive psychiatric and other health services from a local rehabilitation center.

Changes in Availability and Scope of Informal Supports

In addition to the hours Ana works as an IHSS caregiver, she has continued to regularly provide numerous unpaid hours of care to both parents over the course of the year. In fact, despite reductions in IHSS hours, the scope of support Ana provides has expanded as her parents' health has diminished.

However, the increased amount of informal support that Ana provides, with limited public support, has taken its toll on her health and well-being. By the second interview, Ana had made arrangements to receive therapy, given the strong feelings of isolation and depression she was experiencing. Here she describes her need for additional support given that she is on-call, even when she attempts to leave for an evening engagement:

Well, that's why I need a psychiatrist – I work 26 hours a day. I don't get a break and I don't rest. I'm here all day with my mom and dad —all day. So, at night, if something happens in the middle of the night I have my cell phone and my daughter has her cell phone and she'll call to say 'Mom, hurry, Grandma

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How "Ana's" Situation Has Changed Over Time

As the primary caregiver for her parents, both of whom are in the advanced stages of dementia, Ana's situation changed significantly when her father's participation at an adult day health care center was terminated towards the end of 2010. Ana adjusted by juggling both of her parents' needs on a daily basis; she monitored her mother's aggressive behavior to ensure her father's safety and was no longer able to leave the house during the day given the difficulty of taking both her parents along.

The increased burden of caregiving and isolation led Ana to have symptoms of depression. Over the course of the year, she struggled to find affordable, culturally competent mental health services for herself .

fell' or she's hurting my dad, or she's pacing. I have to come because no one else can communicate with her.

Ana stated that her own husband and children, all of whom live in the same house with Maria and Jose, were a good 'team' that helped support Ana, even if they could not replicate the kind of around-the-clock care that Ana provided.

What was less certain throughout the year was the availability of Ana's extended family, including her siblings, to support her with caring for her parents. At the beginning of the year she expressed frustration that, while her siblings were critical of the care she was providing, they were not doing very much to help. For example, her sister had promised to provide care for some of her father Jose's allotted IHSS hours but rarely fulfilled this obligation. After her father's fall, however, Ana expressed more optimism that her siblings were going to make more of an effort to contribute to their parents' care.

Reliance on Services and Supports Over the Course of a Year

Given that they are in the advanced stages of dementia, both Maria and Jose are highly dependent on the informal support provided by their daughter Ana, and the network of formal and informal supports that she coordinates. Over the course of the year, they have relied on Ana to adapt to and manage their changing health needs.

The care that Ana provides, both as an IHSS caregiver and family member, is highly personalized, with special attention to her parents' preferences and comfort.

This is exemplified by visits to bring her father home-made food while he was in a rehabilitation center after a bad fall. She also describes the careful attention she pays to her parents' diet to ensure they receive balanced meals and variety. She details the measures she takes to keep them healthy, particularly during the flu

season, and clearly takes great pride in the care she provides:

They never get sick and, well, I take good care of them. When it's cold outside, I don't take them out... I give them hot beverages and I change them, but keep them in nice warm pajamas so that they stay comfortable.

Conclusion

Over the course of the year, Ana's parents each suffered serious falls, which precipitated an increase in the intensity of their care needs. Ana's mother, Maria, lost the ability to speak and feed herself; her father, Jose, was no longer able to walk and needed more personal care. Their intensified needs occurred at the same time that they experienced reductions in IHSS hours and adult day center services were terminated for Jose.

Ana's parents are not well connected to public services outside of their primary health care provider and IHSS. This may be partially because of a lack of information but also because of a cultural expectation that care for aging parents be provided within the family. Even while her father was being cared for in a rehabilitation center, Ana visited and provided him with meals twice a day.

With a limited amount of public support, the intensive care that Ana provides through IHSS and beyond has taken a toll on her health and well-being. By the end of the year, Ana was fortunate to locate culturally competent mental health services for herself, but she continues to struggle with the intensive demands of providing care to both of her parents.



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