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Are Caregivers of Older Adults Expected to "Gift" Hours of Care Above and Beyond their Compensation?

New York, New York, December 2, 2015—Caregiving has traditionally been viewed as part of family life, and as a personal obligation rather than a form of paid work. Even within programs that pay family members and non-family members to provide care to low-income older adults, caregivers have to negotiate the care they provide as paid caregivers with uncompensated "gift" assistance motivated by emotional attachment.

A new <u>study</u> in the December issue of *The Milbank Quarterly* looks at the blurred line between market and gift economies of care—and finds that policies that cut or restrict formal long-term services and supports for older adults can either push caregivers to provide more uncompensated care or leave older adults with unmet needs for care. Written by Jacqueline Torres from the University of California, San Francisco, and colleagues, the study also found that policies that assume that family caregivers can readily fill in gaps in care should be reassessed.

Background

The data used in this study came from the Helping Older adults Maintain IndependencE (HOME) Project, a longitudinal, qualitative study of low-income adults and their caregivers in California. All respondents in the study were receiving In-Home Supportive Services (IHSS), a consumer-driven program to provide home-based care for low-income older adults in California. The researchers followed 16 cases of consumers and caregivers over four years—and nearly 38 cases over at least one year.

Findings

The researchers found that the current system—IHSS—often does not fully meet the needs of either caregivers or consumers. For many consumers, compensated care is not enough to meet their needs, either because of inadequate hours or limitations in services. For caregivers, including both relatives and non-related caregivers, the market does not provide sufficient pay and benefits for their labor, especially when they are committed to fully meeting consumers' needs.

- For consumers' needs to be met, caregivers must go above and beyond in many cases, providing care hours and activities on their own time.
- Family caregivers in the HOME Project were often expected to provide care aside from what they were paid for. There was an expectation that the "family was supposed to be there," which underlay the decision to cut the number of paid caregiving hours, even if the family's ability to help was limited because of work commitments or poor health.
- IHSS regulations depend on the assumption that unmet needs for care will be met outside the market by family and nonfamily members who will work beyond their compensated hours.

This study adds to the research by examining how caregivers negotiate the balance of paid and uncompensated care over time, says Torres. This long-term view is an important contribution, given that consumers' needs for care often change substantially, and compensated care hours were often reduced or remained the same even when consumers' had increased need for care. The researchers found that consumers were often sympathetic to the challenges faced by their caregivers and sometimes went without needed care in order to limit the provision of uncompensated care. Unlike other studies that highlight differences between related and nonrelated caregivers, the researchers found that there was substantial overlap in the choices and challenges both groups experienced when faced with policy cuts.

About The Milbank Quarterly

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