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August 16, 2010

TO: Carol Rowan, Bureau of Labor Statistics

RE: New ATUS module on eldercare

FROM: Carol Levine, Director, Families and Health Care Project, United Hospital Fund, New York

I commend the Bureau of Labor Statistics for adding new modules to the American Time Use Survey concerning unpaid eldercare activities and workplace paid leave and flexibility. These are important issues for millions of Americans and will become even more critical in the future as the population ages and as more workers find themselves with dual responsibilities to their families and their employers. I will restrict my comments to the module on elder care activities.

The United Hospital Fund is a nonprofit, nonpartisan health services research and philanthropic organization whose mission is to shape positive change in health care for the people of New York and the nation. Since 1996 I have directed the Fund's Families and Health Care Project, which is dedicated to raising awareness about the essential role of family caregivers in the health care system and promoting partnerships with health care professionals.

Obtaining more comprehensive information about family caregivers is, in fact, the first recommendation my colleagues at the United Hospital Fund and I included in our article "Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care" (C. Levine, D. Halper, A. Peist, and D. Gould, *Health Affairs*, 29 January 2010: 116-24). The ATUS proposal is an important step in that direction. However, it could be even more useful with a few changes that I believe are feasible and entirely consistent with the existing approach.

1. **Consider adding "chronic illness" to the first sentence of the introduction.** It is not aging per se that typically creates the need for help; it is the presence of chronic conditions or disabilities that are related to aging or become exacerbated by aging. This is an important distinction. The chronic conditions may be physical (cancer, arthritis, respiratory, cardiovascular, etc.) or neurological and cognitive (Parkinson's disease, dementia). Often an older person who needs help has more than one chronic condition. Limiting the reason for needing help just to "aging" not only has the taint of ageism, but also fails to capture the very demanding tasks that many of those who provide unpaid eldercare for older adults undertake.
2. **Consider adding a "yes/no" question: Has the person you care for been hospitalized in the past year?** Hospitalization is a significant marker for the need for additional help. This has been shown in many studies. For example, people with dementia who are hospitalized for something other than dementia (pneumonia, fall, another chronic condition) tend to experience cognitive and functional decline after the hospitalization. Many patients experience several transitions in care settings after a hospitalization, each leading to physical and mental deterioration, and perhaps eventual nursing home placement. The responses to this question would provide an indicator of the difference between those who provide care

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to people who are basically able to manage at home with some help, and those whose conditions already or are going to require even more care in the future.

- 3. For the future, consider some way to describe activities over a longer period than one day.** It is important that the ATUS survey's "day" includes the night, as so many surveys do not make that distinction. The same activity (taking someone to the bathroom) produces a different level of stress when done in the middle of the night than in the morning. A person who is employed (as are half of all unpaid family caregivers) who suffers sleep deprivation is challenged at work and at home. However, looking at a single day does not convey the complexity of providing elder care over several days or a week, because the person's condition and needs may vary considerably from day to day. It might be possible to study a smaller subset of respondents in the future to obtain a rounded picture of providing eldercare.

In summary, adding a phrase to the introduction and a simple yes/no question to the module would produce a great deal of significant information and increase the value for researchers and others.

Thank you for your efforts in this area, and I look forward to the next steps in the process.



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