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Katherine_Miller Jul 2024

Family caregivers have traditionally been defined as individuals who provide help to family members or friends with activities including, but not limited to, activities of daily living (e.g., eating, bathing, etc.) and instrumental activities of daily living (e.g., errands).

A growing number of states have implemented programs called "self-direction" which allow for the care-recipients to hire individuals to help with some activities of daily living and instrumental activities of daily living. Individuals can hire a member of the direct care workforce (e.g., personal care aide) or a family caregivers (who will then be paid to provide care).

Are family caregivers who are paid to provide care through self-directed programs classified as home health care aides/personal care aides in the dataset? Would the industry they work in be classified as a private household (if hired directly by the care-recipient) or home health care (if hired through a home health care agency, which is the model some states use)?

Ivan_Strahof ♥ IPUMS Staff

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Personal care aids, identified with OCC = 3602 (2018-onwards) and OCC = 4610 (2000-2017), provide personalized assistance to individuals with disabilities or illness who require help with personal care and activities of daily living support. Home health care aides, identified with OCC = 3601 (2018-onwards) and OCC = 3600 (2000-2017), provide routine medical care under the direction of offsite or intermittent onsite licensed nursing staff; they may additionally provide assistance for activities of daily living. ACS OCC codes correspond to codes in the Standard Occupational Classification (SOC) System, which you can refer to for a detailed description and illustrative examples for each occupation code. Personal care aids are identified with SOC code 31-1122 and home health care aides with code 31-1121 in the 2018 SOC system (used in the 2018-onwards ACS samples). Occupation codes in the 2010-2017 ACS samples meanwhile are based on the 2010 SOC system where personal care aides are identified with code 39-9021 and home health aides with code 31-1011. Note that while home health aides have their own SOC code, they are not identified with their own

code in the ACS data from 2000-2017, but are grouped together with psychiatric aides, nursing assistants, and orderlies into a single OCC code (3600).

Please be aware that OCC reports the person's primary occupation. Generally, the primary occupation is the one from which the person earns the most money; if respondents were not sure about this, they were to report the one at which they spent the most time. This means that respondents who worked as family caregivers as a secondary job will not be identified in OCC. There is also no variable that reports the relationship of the respondent to the care recipient that would allow family caregivers to be separately identified.

Regarding industry, your understanding is mostly correct. If hired directly by the care recipient, they would be classified into the *private household* industry (IND = 9290). Otherwise, they would be classified as working in *individual and family services* (IND = 8370) if providing non-medical home care through an establishment or *home health care services* (IND = 8170) if providing medical home care. This refers to industry codes from 2018-onwards that are based on the 2017 North American Industry Classification System (NAICS). For information about industry codes from prior years, please refer to the *codes* tab for IND.

You might also want to take a look at the American Time Use Survey (**IPUMS ATUS**), which includes information from respondents on their occupation, who they spent time with on activities throughout the day, as well as separate variables about time spent on care work for household and non-household members.

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Thank you - this is helpful. I'm primarily worried that when trying to identify personal care aides/home health care aides I'm potentially also identifying family caregivers whose primary job/source of income is being paid to be a family caregiver. I think your response confirms that my worry could happen, but there is not a way to tease how many people may be impacted.

Ivan_Strahof ♥ IPUMS Staff

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You may be able to tease out some family caregivers from unrelated people employed as personal care aides or home health care aides with the variables CLASSWKR (class of worker) and TRANWORK (means of transportation to work). CLASSWKR may be useful for this as it allows you to identify persons who work at a company separately from those who are self-employed or those who work without pay for family. The questionnaire text tab for CLASSWKR shows how these different options were presented to respondents. Viewing the layout of the respondent questionnaire might also be helpful in contextualizing this self-reported occupation data and determining in which cases family caregivers are most and least likely to be included in these occupations. In addition, TRANWORK can help isolate family caregivers when they live together with the family member that they take care of (i.e., those who report TRANWORK = 80, "worked at home") . You can use RELATE (relationship to household head) with TRANWORK to further separate relatives from unrelated live-in caregivers.

The American Time Use Survey may also help you find additional details about time spent on care for household and non-household members, since the data includes the relationship of the respondent to anyone who was present during an activity (see RELATEW). You might use this data to determine the frequency of paid family care as a primary occupation among all personal care aids and home health care aids (see OCC).

Katherine_Miller

That is brilliant- thank you!!

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