Family Caregiving Counts: Adding Family Caregiver Questions to American Community Survey

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Background

The Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregiver Act, which passed Congress with strong bi-partisan support and was signed into law by President Trump on January 22, 2018, established the RAISE Family Caregiver Council.[1] This Council brought together federal agencies and non-governmental appointed members, solicited broad public input, and produced the first ever National Strategy to Support Family Caregivers, which was released in 2022.[2] The National Strategy consists of five major goals and hundreds of actions for the federal government, states, local communities and the private sector to take to support family caregivers.

Goal 5 of the National Strategy aims to expand data, research, and evidence-based practices to support family caregivers.

Specifically, the National Strategy calls for the following:

A national infrastructure will exist to support the collection of population-based data, using standardized wording of the definition of family caregiving, and standardized wording of questions that address the core characteristics of the family caregiving experience.

Few national surveys currently include questions that identify family caregivers and the characteristics of caregiving, which limits our ability to inform policy and practice to support family caregivers. Environmental scans have identified opportunities to add questions to national surveys to advance the goals of the National Strategy.[3]

This brief focuses on the addition of family caregiver questions to the American Community Survey (ACS). It highlights the value of adding family caregiver questions to this survey, identifies potential core questions for consideration, and details the process for making additions and changes to the survey.

What is the value of adding family caregiver questions to the ACS?

The American Community Survey (ACS) is a nationally representative, cross-sectional survey conducted by the U.S. Census Bureau on an annual basis. The ACS provides detailed information on social, demographic, economic, and housing characteristics of U.S. households.[4] The federal government uses data from the ACS to make data-driven decisions about how trillions of dollars of federal funds are allocated.

Inclusion of family caregiving data in the ACS would help to inform policies and funding allocation to programs that support family caregivers. Ultimately, the addition of questions about family caregiving to the ACS would help to achieve the National Strategy goal of expanding data, research, and evidence-based practices to support family caregivers, monitor progress on implementation, and inform future revisions.

Addition of caregiver questions on national collected data:

"Do you provide care for a disabled family member"

- Improved policies
- Improved funding allocation
- Expanded data for evidenced-based practices
- Monitor progress on new policies

Caregiving questions in the ACS would have the following impacts:

1. Improve national population-level estimates on the prevalence of caregiving across the lifespan to inform the National Strategy and caregiving policies
2. Improve caregiving data at the state and local levels and for subpopulations to inform policy and practices to support family caregivers
3. Improve data on health care and financial and workplace security of caregivers and ability to evaluate impacts of policies on caregivers

1

Improve national population-level estimates on the prevalence of caregiving across the lifespan to inform the National Strategy and caregiving policies

- Most national surveys which currently identify family caregivers are limited to certain populations, conditions, or age groups. For example, data from the Behavioral Risk Factors Surveillance Survey (BRFSS) is limited to respondents who are 18 years of age and older and to states that participate in the optional BRFSS Caregiving module.[5] Data from the Health and Retirement Survey (HRS) is limited to respondents 50 years of age and older and data from the National Study of Caregiving (NSOC)/National Health and Aging Trends Study (NHATS) is limited to caregivers of Medicare beneficiaries 65 years of age and older.[6–9] The ACS would provide better estimates of the prevalence of caregiving across all caregiving populations, including improved data on children who are caregivers.

- The most widely referenced national estimates on the prevalence of family caregiving are those from the Caregiving in the U.S. survey conducted by the National Alliance for Caregiving and AARP.[10,11] The RAISE Council used these estimates to inform the National Strategy. This is an online survey conducted in English and Spanish that used a probability-based panel to survey caregivers 18 and older. It is conducted approximately every 5-years. While this survey is critically important and provides depth in understanding the impacts of caregiving, the robust methods of the ACS would enhance prevalence estimates and provide data on an ongoing annual basis to help inform policy and practice.

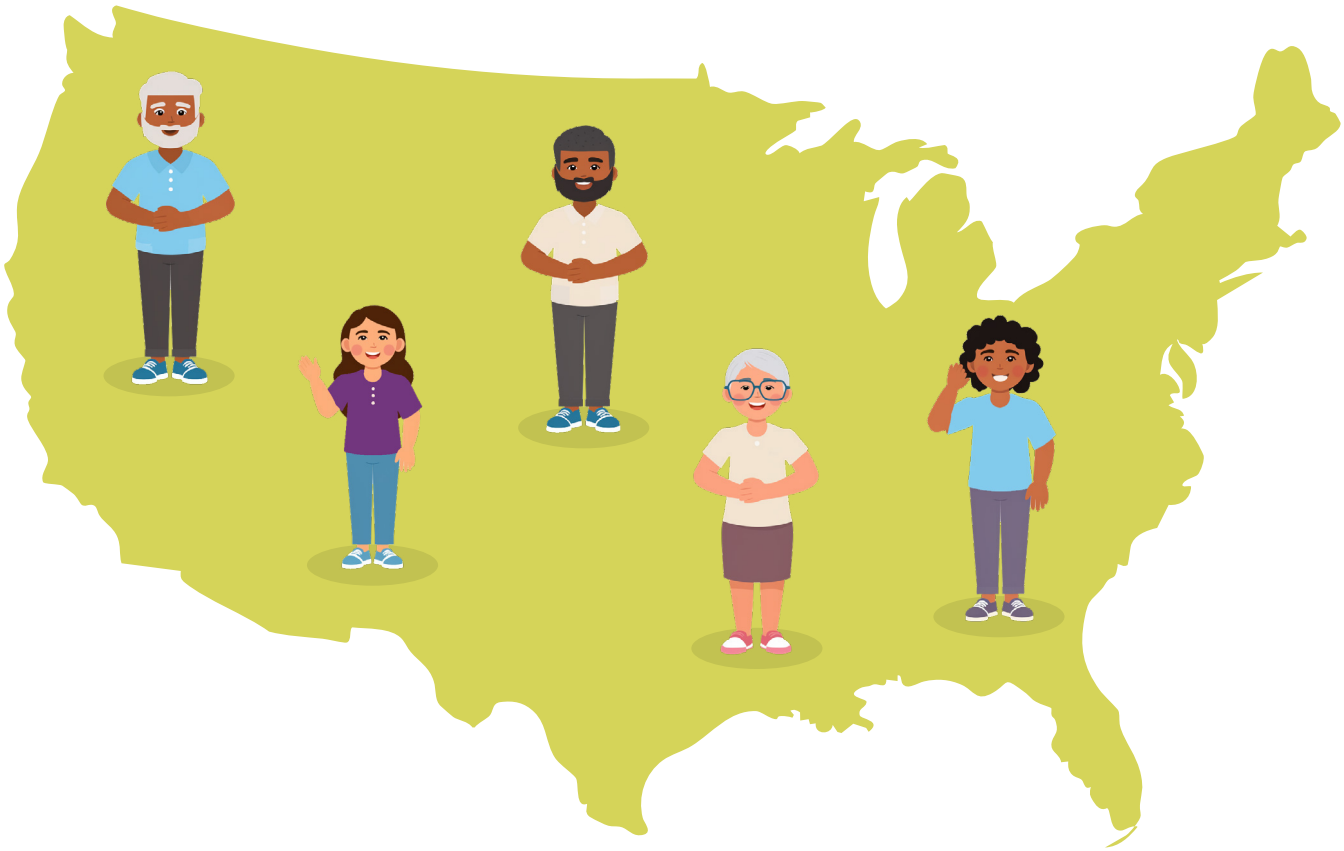
- The ACS currently is able to identify grandparents who are caring for children. This important data source helped inform the National Strategy and the Grandparents Raising Grandchildren Council, which was also established in legislation.[12] While maintaining the ability to identify this important subpopulation within the ACS, additional caregiving questions would enhance our ability to inform broader caregiving policies across populations of caregivers.

2

Improve caregiving data at the state and local levels and for subpopulations to inform policy and practices to support family caregivers

- Currently, population-level data on family caregiving at the state and local level is primarily limited to state specific surveys and states that administer the optional BFRSS Caregiving module. Most other surveys that include family caregiver questions do not allow for population-level estimates at more narrow geographic levels. The ACS sampling methods would provide reliable estimates at state and local levels. As highlighted in the National Strategy, policies and practices to support family caregivers are often driven at the state and local level. Improving data on caregiving at these levels would allow states to plan for demographic shifts in their populations and local providers such as Area Agencies on Aging (AAAs) to better understand populations they serve. For example, state and local data from the ACS could help inform implementation of the National Family Caregiver Support Program within the Older Americans Act. Data could also help inform planning and development of family support services through Medicaid, the Lifespan Respite Care Act, and state-funded services and supports.

- By identifying family caregivers in the ACS, researchers, policymakers and communities could examine demographic characteristics of family caregivers, such as their race, ethnicity, sex, age, disability, marital status, and nativity. The ACS also provides detailed information about the household composition and characteristics of the respondent's place of residence, which could identify whether caregivers are living within the same household as the care recipient.

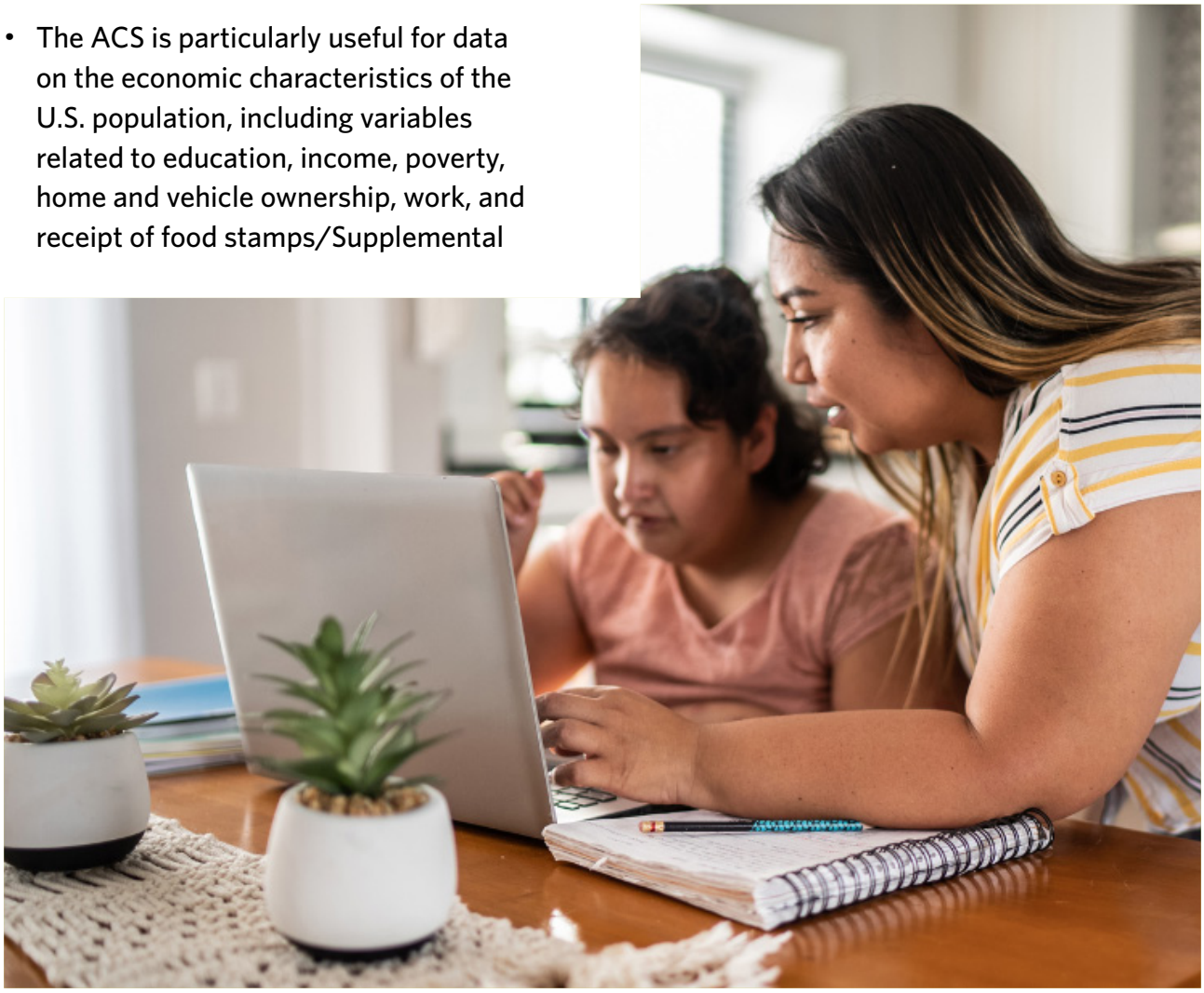


3

Improve data on health care and financial and workplace security of caregivers and ability to evaluate impacts of policies on caregivers

- The ACS would provide data on health insurance coverage, making it possible to examine the extent to which caregivers are insured and type of health insurance coverage. Given well-documented health disparities experienced by caregivers relative to non caregivers[13,14] it is important to track health insurance coverages and potential impacts of policies over time.

- The ACS is particularly useful for data on the economic characteristics of the U.S. population, including variables related to education, income, poverty, home and vehicle ownership, work, and receipt of food stamps/Supplemental Nutrition Assistance Program (SNAP). The work-related data in the ACS includes information on employment status, labor force participation, occupation, industry, usual hours worked, and absences from work. Income data not only includes total individual, family, and household-level annual income but also the source of personal income, such as from employment, government, savings, or other sources. This information could be used to inform and assess other goals of the National Strategy goal. For example, data could inform needs and actions aligned with Goal 3 (Strengthen services and supports for family caregivers). It could also help inform and assess policies and practices to support Goal 4 (Ensure financial and workplace security for family caregivers), such as state adoption of paid leave.[15]



What caregiving information and characteristics could be added?

The National Strategy called for the development and inclusion of a core set of standardized caregiver questions which could be added to other national surveys and data collection efforts to improve harmonization.[16,17] This is somewhat similar to what the Census Bureau has led in identification of individuals with disabilities using a standard set of six ACS disability questions. In addition to the ACS, these disability questions have been added to dozens of other national surveys and allow for comparisons across surveys.

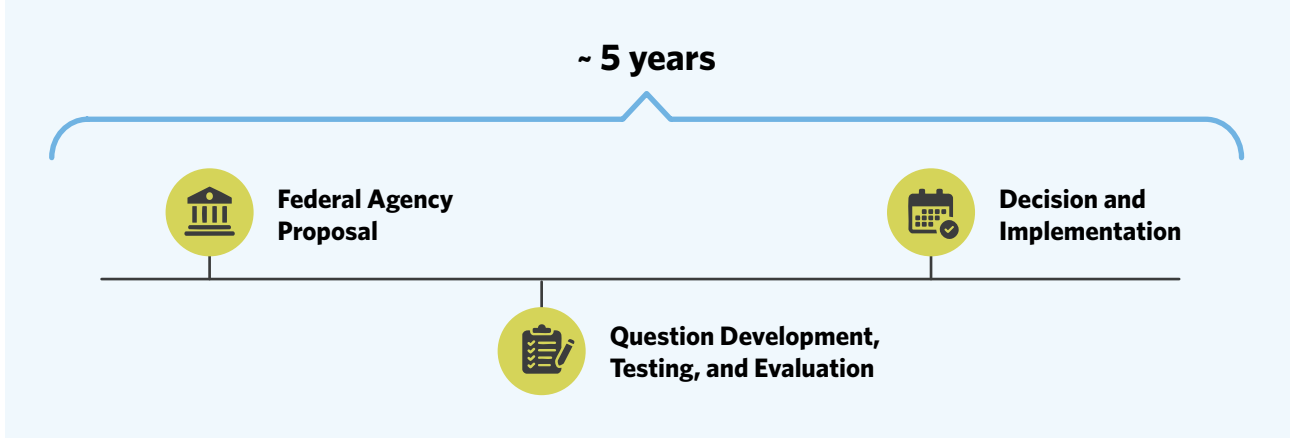
Questions from the BRFSS optional Family Caregiving module could provide a set of model questions for the Census Bureau to consider as a starting point.[20] The advantage of these questions is that they have already been cognitively tested by CDC, are widely in use, and cover many of the areas of the caregiving context described earlier.
In response to the National Strategy, CDC recently added a single question modeled on the BRFSS to identify caregiver status to the 2025 National Health Interview Survey. In addition, the Census Bureau could consider questions from other established surveys and align them within the structure of the ACS and other data already collected. ACL recently awarded a national Technical Assistance Center on implementation of Goal 5 of the RAISE National Strategy which is compiling survey questions and has formed a network of caregiving researchers who could provide assistance to the Census Bureau.

There is general consensus[18,19] that at a minimum, caregiving questions should identify family caregivers and important characteristics of the caregiving context, such as:

- ☐ Caregiver status
- ☐ Caregiver and care recipient relationship
- ☐ Intensity of caregiving (including number of hours per week and length of caregiving)
- ☐ Demographics of the caregiver
- ☐ Demographics of the care recipient (including health conditions and functional needs)

What is the process for additions to the ACS?

The process for addition or changes to the ACS is lengthy and can typically take up to five years. This process ensures that the change is necessary and will produce quality, useful information for the nation.[21,22]



An overview of the major steps in the process is outlined below:

Federal Agency Proposal

- Requests for additions or changes to the ACS must be made by a federal agency. The proposed change must also have a policy basis in statute or regulations. Along with the request, the agency provides the rationale, initial ideas for the proposed additions or changes, and impact of the change.

  Office of Management and Budget (OMB) and Census Bureau decide whether the change has merit, in consultation with the Interagency Council on Statistical Policy Subcommittee on the American Community Survey (ICSP SAC).[23] This Subcommittee includes the Chief Statistician of the U.S., the director of the Census Bureau, and 3 other statistical agency leads who serve on a rotating basis.

Question Development, Testing, and Evaluation

- If the proposal is determined to have merit it advances to question development and testing. This is the longest step in the process and can take upwards of four years.

  — *A topical subcommittee consisting of subject matter experts is formed to develop wording options.*

  — *The Census Bureau then conducts cognitive testing of questions to evaluate how well individuals understand and answer questions. Subject matter experts review the results and make recommendations for field testing.*

  — *A Federal Register Notice is published soliciting input on field test plans. Census Bureau staff finalize the wording for the test, create instruments to field the test, develop the systems to process the data, and conduct the field testing. They analyze the results and provide them to the federal agency that proposed the addition or change.*

Decision and Implementation

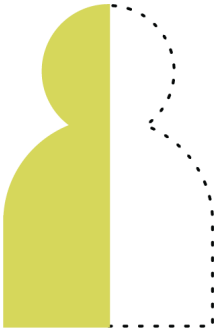
- The Census Bureau and requesting federal agency review the results of the field testing and decide whether to move forward with full implementation. A Federal Register notice is published soliciting public input in consultation with the OMB and ICSP SAC.

- If approved by OMB, the Census Bureau updates systems, questionnaires, and materials. Implementation takes effect at the start of the next calendar year.

Conclusion

There are over 63 million people within the US providing informal, usually unpaid, care and support to aging family members and people of all ages with disabilities.

The National Strategy to Support Family Caregivers is a call to action to improve supports for the more than 63 million people within the US providing informal, usually unpaid, care and support to aging family members and people of all ages with disabilities.[11]



Family caregivers are an "invisible" population, not identified within most current national surveys.

The addition of family caregiving questions to the ACS would provide critical new data, at state and local geographic levels, on an ongoing basis to help inform implementation of the National Strategy, revisions, and other caregiving policies at the federal, state, and local levels.

The RAISE Act and implementation of the National Strategy provide an overarching statutory and policy basis for the addition of caregiver questions to the ACS. The US Department of Health and Human Services (HHS) is charged with implementing the RAISE Act. The Secretary of HHS has designated implementation of the National Strategy to the Administration for Community Living.

The Secretary in coordination with the designated agency overseeing the National Strategy could take the first step in this process by making a formal request for the addition of a caregiving question. This brief helps provide the rational, initial ideas for proposed questions, and value of adding questions.

The ACS question addition process is lengthy. However, much groundwork has already been laid that could be leveraged to help facilitate this process. The infrastructure of the RAISE Council and technical assistance entities assisting with implementation could assist the Census Bureau with question development and cognitive testing across the broad range of family caregivers. Instead of reinventing the wheel, the Census Bureau could closely coordinate with other federal agencies that administer surveys with established caregiving questions, such as CDC and the National Center for Health Statistics. This would not only help expedite the process, but also promote standardization and harmonization on a core set of questions across surveys in line with recommendations in the National Strategy.

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