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Personal Care Aides: Assessing Self-Care Needs And Worker Shortages In Rural Areas

ABSTRACT Previous research has documented shortages of personal care aides who provide Medicaid home and community-based services, but there are few detailed geographic data to determine the areas of greatest need and assess the availability of personal care aides nationwide. Using 2013–17 data from the American Community Survey and the Office of Management and Budget, we analyzed potential need for personal care aide services among adults and the supply of aides across the US. Areas with the highest percentages of adults with self-care disability were mainly in the South, and the gap between the potential need for personal care aide services and the aide supply was greatest in southern states. Within states, there were fewer personal care aides per 1,000 adults with self-care disability in the more rural and most rural areas than in the least rural areas. Wage and benefit increases, improved training and career opportunities, increased flexibility in state Medicaid policies on paid family caregiving, incentives and compensation for travel, and increased data collection and government tracking of workforce data could help boost the supply of personal care aides in rural America.

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According to data from the Census Bureau's American Community Survey (ACS), approximately 7.5 million adults ages eighteen and older in the US identified a self-care disability.[1] The prevalence of having any type of disability is higher in rural counties compared with urban counties.[2] Rural residents also have been found to have higher levels of poverty and mortality compared with those living in urban areas,[3] and racial and ethnic minority populations in rural areas have been found to have worse health status and higher rates of disability than White rural residents.[2,4–6] Disability rates among rural adults ages sixty-five and older are also higher than in their counterparts in urban areas.[6]

Given the greater prevalence of disability and poverty in rural areas, Medicaid is an important source of health insurance coverage for rural populations. Nearly 25 percent of adults younger than age sixty-five in rural areas are covered by Medicaid, and about 22 percent are dually enrolled in Medicare and Medicaid.[7]

As the primary funder of long-term services and supports (LTSS), Medicaid plays an important role in addressing the unique needs of rural populations.[8] Within the Medicaid LTSS program, states are required to cover benefits for nursing facilities, but coverage of home and community-based services is optional, and spending varies by state.[9]

Long-term services and supports include assistance with activities of daily living (ADLs), such as eating, bathing, and dressing, and with instrumental activities of daily living (IADLs), such as preparing meals, managing medication, and housekeeping.[9,10] For more than three decades, national LTSS policy and state laws have gradually evolved to support the rebalancing of LTSS

toward home and community-based services through Centers for Medicare and Medicaid Services (CMS) incentives and waiver programs intended to reflect consumers' preferences for those services over institutional care.[10–12]

There are challenges in reaching this policy goal, especially in rural areas.[13] Despite the incentives for states to shift Medicaid LTSS dollars away from institutional services and toward home and community-based services, the availability and use of these services remain lower in rural compared with urban areas, and institutional services have made up a larger portion of expenditures for rural adults than for urban adults.[13] There are currently no federal standards to assess the adequacy of personal care aides based on the demand for home and community-based services in the US, but several studies have documented chronic shortages in the personal care aide workforce.[14,15] Little is known about how these shortages vary across geographic areas. This study addresses gaps in research on the potential need for and supply of workers to provide personal care services across the US.

Background And Context

Personal care aides are vital to ensuring that people with disability can remain in their homes and communities. These are paid professionals whose work focuses on assisting people with self-care, which includes help with ADLs and IADLs.[10] They are found and hired either through agencies, through home care aide registries, or independently, and they are paid by Medicaid, public social service programs, or directly by consumers.[16] Personal care aides' work differs from that of home health aides in that the scope of personal care aide work is limited to assisting with self-care needs; they do not address clinical issues and are not subject to the federal requirement for seventy-five hours of training that applies to home health aides.[17] State and local agencies' training requirements vary widely. For example, some require no training at all, whereas others require personal care aides to complete several hours of online or in-person training.[18]

In this study we compared the characteristics of the personal care aide workforce in US nonmetropolitan and metropolitan areas and assessed the potential need for and supply of these aides throughout the country. We measured potential need based on the number of adults with self-care disability, as the needs associated with such disability are aligned with the range of services that personal care aides provide. We discuss policy implications and recommend solutions to address the gap between the availability of these aides and the potential need.

Study Data And Methods

The principal source of data used in our analysis of the personal care aide workforce and the population of adults with a self-care disability was the 2013–17 American Community Survey ACS) five-year Public Use Microdata Sample (PUMS). We used the this data file to describe characteristics of the personal care aide workforce in rural areas. The ACS collects survey data continuously, and this information is aggregated into one-year and five-year files. The five-year files are used for rural analyses because they contain a large enough sample for a rural analysis. The estimates produced from the ACS five-year file should be interpreted as a period estimate specific to the data collected during the period 2013–17.

All of the estimates describing the personal care aide workforce and the population of adults with a self-care disability that were derived from the 2013–17 ACS five-year PUMS file were weighted according to ACS methodology and were produced using the person-level sample weights included with the data file.[19]

IDENTIFICATION OF PERSONAL CARE AIDES In the ACS data, occupation is identified using the Census Occupation Code List, which is analogous to the Standard Occupation Classification system. In the 2013–17 ACS five-year PUMS file, the Census Occupation Code for personal care aides was 4610 (analogous to Standard Occupation Classification 39-9021), and it was grouped with other "personal care and service occupations." Our analysis of the supply of personal care aides was based on their place of work. For this reason, we had to limit the sample to cases in which employment status was reported as "civilian employed, at work" because information on place of work is available only for people with this status. In addition, we excluded sample cases in which a person's class-of-worker status (for example, private company, government, or self-employed) was reported as "working without pay in family business or farm" so as not to include unpaid family caregivers in the analysis.

IDENTIFICATION OF POTENTIAL NEED FOR SERVICES There are no national-level data identifying people who live in rural areas and need personal care aides. Therefore, we approximated this population by identifying people ages eighteen and older in the 2013–17 ACS five-year PUMS sample with a potential need for personal care aide services. The ACS includes questions about six disability types, defined as having difficulty with the following functional areas: hearing (deaf or serious difficulty hearing), vision (blind or serious difficulty seeing), cognitive (difficulty remembering, concentrating, or making decisions), ambulatory activities (serious

All personal care aides had a significantly higher poverty rate than the general US civilian workforce.

difficulty walking or climbing stairs), self-care (difficulty bathing or dressing), and independent living (difficulty doing errands alone, such as visiting a doctor's office or shopping).[20]

We identified respondents who answered "yes" to the question, "Do you have difficulty dressing or bathing?," as having self-care disability that indicates a potential need for personal care aide services, because we believe that this question is the survey item most closely related to the services provided by personal care aides. Rates of self-care disability were calculated for each place-of-work Public Use Microdata Area (PUMA) by dividing the population ages eighteen and older reporting self-care disability by the total population ages eighteen and older and multiplying the result by 100. The ratio of personal care aides for every 1,000 people with self-care disability was calculated by dividing the number of personal care aide workers by the number of people with self-care disability in each place-of-work PUMA and multiplying the result by 1,000.

CLASSIFICATION OF RURALITY The Office of Management and Budget routinely publishes county-level classifications, based on residential and commuting patterns, that identify counties as either metropolitan (those with an urban core of at least 50,000 people) or nonmetropolitan.[21] Nonmetropolitan counties are further divided into micropolitan counties (an urban core with a population of 10,000–50,000) and noncore counties (counties with a population below 10,000). However, the ACS PUMS data are organized by PUMAs, which are geographic areas defined specifically for the dissemination of PUMS data, and place-of-work PUMAs, which are used in the publication of ACS PUMS files to provide data on place of work. According to Census Bureau standards, place-of-work PUMAs must contain a population of at least 100,000 people and are based on county boundaries. However, to reach this population threshold, the ACS may define them to contain more than one county.[22]

To classify place-of-work PUMAs as more or less rural, we used a crosswalk file to determine whether the majority of the population in a given PUMA (and corresponding place-of-work PUMA) lived in a metropolitan, micropolitan, or noncore county. Where a majority of the population lived in a noncore county, we designated the PUMA and corresponding place-of-work PUMA as "most rural;" where a majority of the population lived in a micropolitan county, we designated the PUMA and corresponding place-of-work PUMA as "more rural;" where a majority of the population lived in a metropolitan county, we designated the PUMA and corresponding place-of-work PUMA as "least rural." We defined rural states based on the percentage of the state's population living in metropolitan counties. We grouped states into terciles, with the lowest tercile being "most rural," the middle being "more rural," and the highest being "least rural."

ANALYSIS OF PERSONAL CARE AIDE CHARACTERISTICS Because of concerns about small sample sizes of personal care aides for noncore ("most rural") and micropolitan areas ("more rural") in the ACS five-year PUMS file, we combined these two geographies into a single category, which we defined as "nonmetropolitan" in the analysis of personal care aide characteristics. We performed bivariate analysis of selected characteristics to describe differences in the workforce based on whether the aide worked in a metropolitan or nonmetropolitan location. We conducted the statistical analysis using Pearson's chi-square to test for statistically significant differences in the characteristics of these two groups.

GEOGRAPHIC ANALYSIS To examine the geographic distribution of adults with self-care disability across the US, the self-care disability rates and personal care aide ratio data were loaded into geographic information system software, ArcMAP version 10.1. We produced estimates of the total number of personal care aides and used data on number of adults reporting a self-care disability for each place-of-work PUMA that were available in the ACS data set. The calculated ratios were mapped to show where personal care aides work relative to where adults with self-care disability live. The classifications used in the maps were devised using the "Jenks Natural Breaks" classification algorithm.[23] This method identifies natural breaks in a data set's range to ensure that the most similar values are grouped together while maximizing the difference between groupings for map presentation. Geographic areas described in the findings are based on census division regions.[24] The place-of-work PUMA–level estimates of personal care aides and the self-care disability population were used to calculate ratios of aides per 1,000 people ages

eighteen and older with self-care disability for most rural, more rural, and least rural states and most rural, more rural, and least rural areas within states.

LIMITATIONS Our study had several limitations. First, we examined potential need for personal care aide services rather than actual need. Second, the analysis did not include data or an analysis of children with self-care disability. Third, data limitations and small personal care aide sample sizes limited our analysis to PUMAs and place-of-work PUMAs. In the ACS PUMS data, each PUMA or place-of-work PUMA must contain at least 100,000 people. As a result, in rural areas with small population sizes, PUMAs and place-of-work PUMAs may contain multiple counties. This county aggregation may mask potential variation in the number of personal care aides between a rural area and an urban area within the same place-of-work PUMA designation. Fourth, our analysis examined the population of adults who had difficulty with bathing or dressing, defined as self-care disability; this disability is one of six included in the ACS data. We focused on self-care disability, as it is closely linked to the potential need for personal care services and the types of services provided by personal care aides. Because we did not include other types of disability, our results may be considered conservative estimates of the need for aide services. Fifth, we did not include home health aides in our analysis because they provide health-related services and are not necessarily focused on assistance with self-care needs. However, home health aides could be providers of personal care. There are no federal standard metrics to assess the adequacy of personal care aides for an adult population that would allow us to put our findings in context. Our study was the first of its kind to identify potential shortages by linking availability of workers to potential need for services across different geographies.

EXHIBIT 1

Characteristics of personal care aides employed in metropolitan and nonmetropolitan areas of the US, 2013–17

	Place of work	
Characteristics	**Metropolitan**	**Nonmetropolitan**
Weighted *n*	1,152,037	169,596
Unweighted *n*	49,891	10,073
Age category, years		
Younger than 35	31.5%	33.7%
35–44	17.5	15.7
45–54	21.8	20.3
55 and older	29.3	30.3
Gender		
Male	17.2	13.8
Female	82.8	86.2
Racial and ethnic group		
White	41.3	74.9
Black	24.2	11.3
American Indian/Native American	0.8	2.1
Asian	9.4	0.
2 or more races	1.9	1.4
Hispanic	21.6	9.3
Other[a]	0.8	0.2
Educational attainment		
Less than high school diploma	15.9	12.8
High school diploma or GED	33.4	40.7
Some college, no degree	29.2	29.4
Associate's degree	8.2	9.0
Bachelor's or higher degree	13.3	8.2
Nativity		
US born	71.0	95.6
Foreign born	29.0	4.4
Language other than English spoken at home		
Yes	34.8	9.5
No	65.2	90.5

SOURCE American Community Survey (ACS), 5-year Public Use Microdata Sample, 2013–17. **NOTES** Pearson's chi-square tests were used to determine the statistical significance of proportional differences comparing personal care aides by metropolitan versus nonmetropolitan place of work. All race categories shown are non-Hispanic. All percentages are based on the weighted *n*s, which were produced using the person-level sample weights included with the ACS data file (see note 19 in text). All results were significant ($p < 0.01$). [a]Includes Native Hawaiian or Pacific Islander and some other race.

Study Results

CHARACTERISTICS OF AIDES BY RURALITY The characteristics of personal care aides in nonmetropolitan and metropolitan areas in 2013–17 differed in several ways (exhibit 1). Compared with the personal care aide workforce in metropolitan areas, the nonmetropolitan workforce was more White (74.9 percent in nonmetropolitan areas compared with 41.3 percent in metropolitan areas) and included a higher proportion of females (86.2 percent nonmetropolitan, 82.8 percent metropolitan), people with a high school diploma or more (87.3 percent nonmetropolitan, 84.1 percent metropolitan), people born in the US (95.6 percent nonmetropolitan, 71.0 metropolitan areas), and people who spoke only English at home (90.5 percent nonmetropolitan, 65.2 percent metropolitan). Results of all comparisons were statistically significant ($p < 0.01$).

Our additional analysis comparing the entire personal care aide workforce (metropolitan and nonmetropolitan combined) with the overall US civilian workforce found that the aide workforce significantly differed from those of other civilian occupations with regard to two other important characteristics (online appendix exhibit 1).[25] Nearly 19 percent of personal care aides lived below the poverty threshold, whereas the average across all other occupations was 6.8 percent. The percentage of personal care aides with

health insurance coverage was lower (80.2 percent) than the average across all other occupations (87.8 percent). Both of these differences were statistically significant ($p < 0.01$).

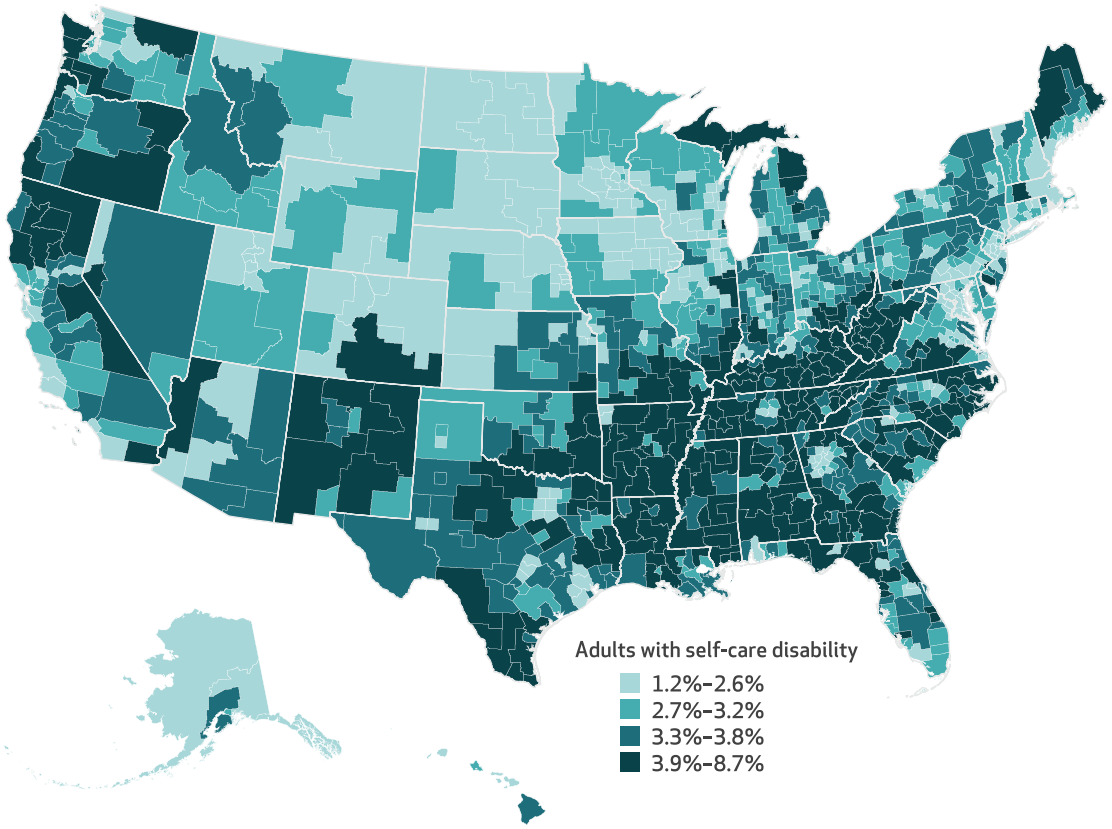
PERCENT OF ADULTS WITH SELF-CARE DISABILITY BY GEOGRAPHY The geographic distribution of rates of self-care disability is shown in exhibit 2. Many areas in the southern and south-central US, as well as parts of Maine, the Pacific Northwest, and New Mexico, had the highest percentages of adults with self-care disability in 2013–17, ranging from 3.9 percent to 8.7 percent. Areas in the northern mountain areas of the country had the lowest rates of adults with self-care disability, ranging from 1.2 percent to 2.6 percent.

Exhibit 3 shows the geographic variation in the supply of personal care aides per 1,000 adults with self-care disability. The areas that have the nation's lowest number of personal care aides per 1,000 people with self-care disability (0–95 aides per 1,000 people with self-care disability, shown in warmer colors) represent areas where the gap between potential need for personal care aide services and the supply of personal care aides is greatest. These areas are mostly in southern states such as Mississippi, Alabama, Georgia, Florida, and North and South Carolina, as well as in Arkansas, Oklahoma, Tennessee, Kentucky, Indiana, and Ohio. In areas with higher numbers of personal care aides per 1,000 people with self-care disability, such as parts of California, Washington, Oregon, Minnesota, and Montana, there is a larger supply of personal care aides relative to potential need.

Exhibit 4 shows the average number of personal care aides per 1,000 adults with self-care disability in the most, more, and least rural areas and states. The most rural areas of the most rural states had a ratio of 142 personal care aides to

EXHIBIT 2

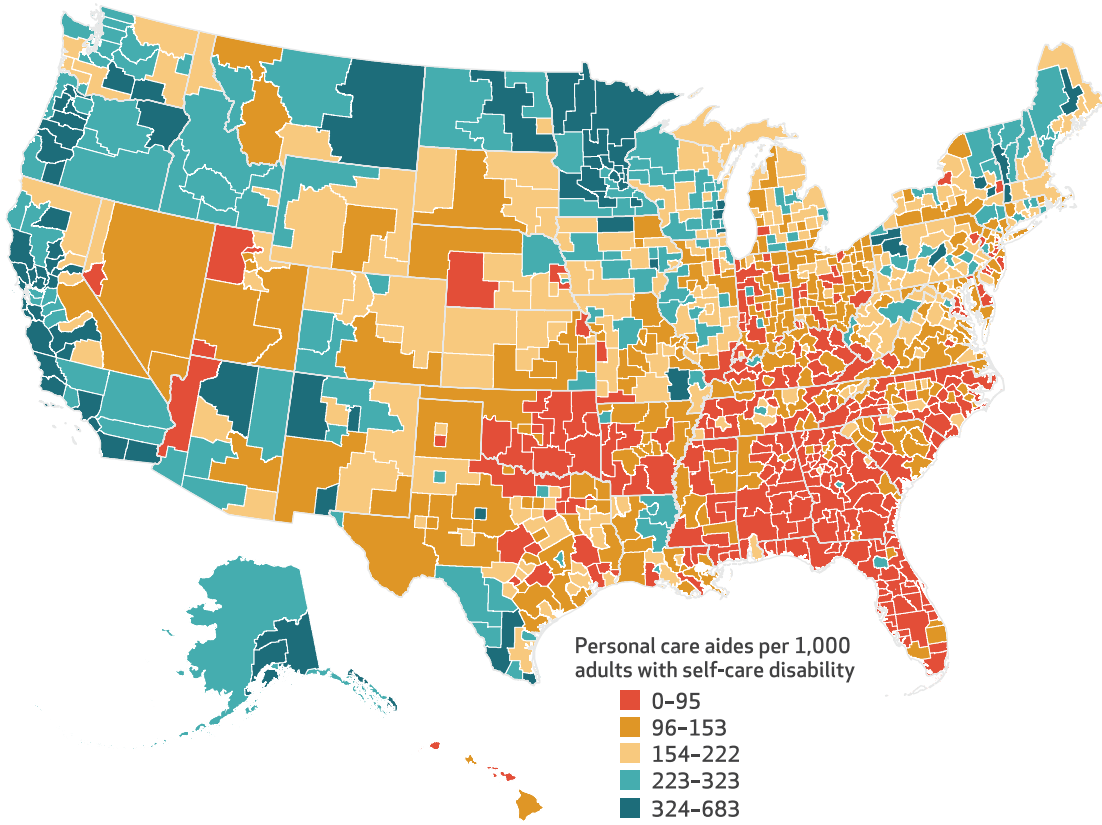
Adults with self-care disability, by US geographic subdivision, 2013–17



SOURCE American Community Survey (ACS) 5-year Public Use Microdata Sample (PUMS), 2013–17. **NOTES** We defined self-care disability based on survey respondents' responding "yes" to the question, "Do you have difficulty dressing or bathing?" The geographic subdivisions shown within states are used in the publication of ACS PUMS files to provide data on place of work. Place-of-work Public Use Microdata Areas (PUMAs) must contain a population of at least 100,000 people and are based on county boundaries. However, to reach the population threshold, the ACS may define them to contain more than one county. A total of 278 place-of-work PUMAs had 1.2–2.6 percent adults with self-care disability, 277 had 2.7–3.2 percent, 192 had 3.3–3.8 percent, and 235 had 3.9–8.7 percent.

EXHIBIT 3

Supply of personal care aides per 1,000 adults with self-care disability, by US geographic subdivision, 2013–17



SOURCE American Community Survey (ACS), 5-Year Public Use Microdata Sample (PUMS), 2013–17. **NOTES** Alaska and Hawaii are not to scale. We defined self-care disability as described in the exhibit 2 notes. The geographic subdivisions shown within states reflect place-of-work Public Use Microdata Areas (PUMAs), also as described in the exhibit 2 notes. A total of 250 place-of-work PUMAs had 0–95 personal care aides per 1,000 adults with self-care disability, 271 had 96–153, 236 had 154–222, 149 had 223–323, and 76 had 324–683.

potential need per 1,000 adults with self-care disability. In contrast, in the least rural areas of the least rural states, the ratio of aides to adults with self-care disability was the highest, at 206 per 1,000 adults with self-care disability. Across most and more rural states, the number of aides per 1,000 adults with self-care disability was lowest (129 per 1,000) in the more rural areas, whereas in the least rural states, ratios were lowest (129 per 1,000) in the most rural areas.

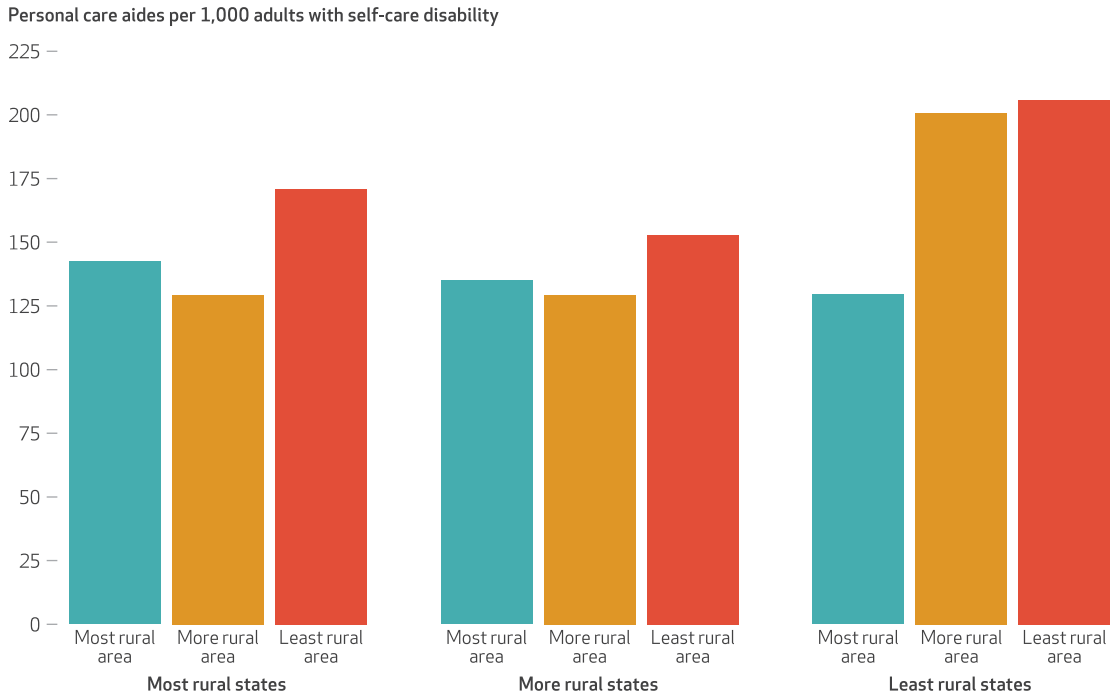
Discussion

There is little published research on personal care aide supply and demand in the US. Our study found that many areas in southern and south central states had the highest percentages of adults with self-care disability, and the gap between availability of personal care aides and potential need for aide services is particularly large in southern states, where, notably, nearly half of people ages sixty-five and older lived as of 2012–16.[26] Seven of the twelve states that have not expanded Medicaid are clustered in the southern US, where there are large rural populations who can potentially benefit from expanded Medicaid coverage, especially if it includes expansion of long-term services and supports that included home and community-based services.

Personal care aides are critical to the health, safety, and community living of rural adults with self-care disability.[10,27] When people have to go without vital personal care services, their dignity and stability are compromised.[28] Having unmet needs for personal care negatively affects health and social outcomes and is associated with increased use of medical exams, as well as emergency department, hospital, and rehabilitation services, in addition to reduced capacity for active participation in the community and interaction with family and friends.[27] Ultimately, unmet needs for personal care lead to excess morbidity and mortality.[29]

EXHIBIT 4

Average number of personal care aides per 1,000 adults with self-care disability in US geographic regions, by rurality, 2013–17



SOURCE American Community Survey (ACS), 5-Year Public Use Microdata Sample (PUMS); Office of Management and Budget (OMB) Metropolitan Area Delineation File, 2010. **NOTES** We defined self-care disability based on survey respondents' answer of "yes" to the ACS question, "Do you have difficulty dressing or bathing?" We defined "least rural areas" as place-of-work Public Use Microdata Areas (PUMAs) in which a majority of the population lived in a metropolitan county (defined by the OMB as having an urban core of at least 50,000 people). We defined "more rural areas" as place-of-work PUMAs in which a majority of the population lived in a micropolitan county (defined by the OMB as having an urban core with a population of 10,000–50,000). We defined "most rural" areas as place-of-work PUMAs in which a majority of the population lived in a noncore county (defined by the OMB as having a population below 10,000). We defined rural states based on the percent of the state's population living in metropolitan counties. We grouped states in terciles, with the lowest tercile being "most rural," the middle tercile being "more rural," and the highest tercile being" least rural."

There are many long-standing challenges to the recruitment and retention of personal care aides, including low wages ($10–$12 per hour), limited or complete lack of employment benefits, unpredictable schedules, and an isolating work environment.[14,15,29–31] Delivering personal care services in rural areas is more difficult than in other regions because of limited public transportation services to bring clients to and from medical appointments, poor internet connectivity for personal care aide follow-up or "checking in" via telehealth, and a limited number of home care agencies that employ these aides.[29] Personal care workers testifying before the New York Senate noted difficulties with long and costly long drive times between clients, which limits the size of caseloads that they can serve.[32]

The COVID-19 pandemic created additional challenges in recruiting and retaining workers to provide home and community-based services, including personal care aides, in all areas of the country because of difficulty in gaining access to personal protective equipment, fear of exposure to the virus, stress associated with personal care aide work, and COVID-19 infection within the aide workforce.[33–35]

Low wages, which affect the ability to recruit and retain personal care aides, are found across the personal care aide workforce.[15] Our analysis revealed that all personal care aides, including those working in metropolitan and nonmetropolitan areas, had a significantly higher poverty rate than the general US civilian workforce as of 2013–17.

Given the current state of the personal care aide workforce, exacerbated by the COVID-19 pandemic, and the decreasing population of working-age people in rural areas,[36] policy makers and home care service providers need creative solutions to address the need for services among rural adults with self-care disability. Possible solutions include increasing personal care aide wage levels, adding requirements in Medicaid home care provider contracts stating that

rate increases must be accompanied by increases in aides' wages, providing retention bonuses, and compensating workers for travel expenses and travel time.[14,15,31] Raising wages makes economic sense in that it helps lift workers out of poverty and makes them potentially less reliant on public programs for assistance for health insurance, food, and other subsidies. Wage increases also have the potential to increase retention and thus reduce high personal care aide turnover and its associated costs.[15]

Another option to increase the supply of personal care aide workers in rural areas is for state home and community-based services programs to increase flexibility in state Medicaid waiver programs that allow family members to be paid for providing personal care services for adults with self-care disability.[37] State policies on payment for family caregiving vary on dimensions such as who can be considered a family caregiver and what kind of training is required.[37]

Rural-focused approaches to improving training and career development could help expand the availability of personal care aides in rural areas. Training should be designed to address the unique transportation and time limitations facing potential trainees in rural areas. Such trainees should have options for online and asynchronous learning if internet access is available, as well as evening or weekend classes. They should be able to take classes in convenient, nearby locations, instead of having to travel to urban settings.[32] Many proposed solutions to address workforce shortages are still in the conceptual phase, in pilot programs, or limited to a few states. More rigorous testing and evaluation are needed so that evidence-based approaches can be scaled up and supported across rural areas of the US.

Recruitment of older residents could help increase the supply of personal care aides in rural areas, as rural counties have a higher proportion of adults older than age sixty-five than urban and suburban counties.[36] Offering part-time and flexible work options (for example, split shifts to accommodate child care needs) has been suggested to make personal care aide work more attractive to the limited supply of young workers with children in rural areas.[14] Payment for travel expenses and travel time is especially important for rural personal care aides, given the long distances they need to travel to clients' homes. Relocation incentives for workers to move to the areas of highest need could help address aide worker shortages.

Policy makers and home care service providers need creative solutions to address the need for services among rural adults with self-care disability.

There are few detailed geographic data on the availability of the personal care aide workforce that could be used to assess the adequacy of the available workforce compared with the need for services. Increased data collection and government tracking of data at the state and national levels on the number of personal care aides, their places of residence, and resources to connect them to available local jobs could help increase recruitment and retention in the most underserved areas.[31]

Conclusion

Increasing wages and benefits, improving training and career development options, adding flexibility to state Medicaid waiver programs to pay family caregivers for providing personal care services, providing incentives and compensation for travel, and new data collection and tracking efforts would go a long way toward improving the personal care aide workforce in rural America. To develop effective solutions to the rural shortage of aide workers, policy makers need to bring rural personal care aides and adults with self-care disability into the conversation. ■

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25 To access the appendix, click on the Details tab of the article online.

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