Medicaid plays critical role in supplementing informal care for older disabled workers

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RESEARCH OBJECTIVE

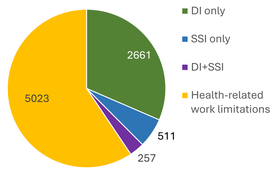
- People who experience a work-limiting disability may need temporary or permanent assistance with personal and instrumental activities of daily living (ADLs/IADLs) such as bathing, dressing, cooking, and cleaning.
- Not everyone has family members able to provide all the needed assistance. Medicare does not cover most home care. Medicaid coverage of home care is a preferred and less costly alternative to nursing homes.
- **This study examines how paid and unpaid care use differs between beneficiaries of Supplementary Security Income (SSI), which qualifies recipients for Medicaid, and beneficiaries of Social Security Disability Insurance (DI), which does not.**

STUDY DESIGN

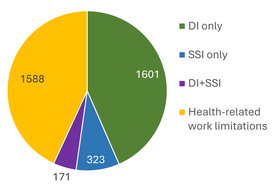
- We used publicly available data from the 2000 to 2020 waves of the Health and Retirement Study, a nationally representative longitudinal survey of Americans over age 50 with oversampling of Black and Hispanic individuals.
- This cross-sectional analysis describes the ADL and IADL needs and amount of paid and unpaid care received by respondents in four groups: those receiving DI only, SSI only, or DI+SSI, and nonbeneficiaries with work limitations
- We used linear regression to analyze how hours of paid and unpaid care and number of unmet needs differed by beneficiary status and type of insurance.

POPULATION STUDIED

- **Recipients of DI, SSI, DI+SSI, and nonbeneficiaries with work limitations**
- **Age 50–64** (*N*=8,452) at the first interview wave when they were disability beneficiaries or reported health limiting their work
- Unweighted sample: 59% female; 63% White, 25% Black, and 12% another race
- About one-third (35%) reported at least one ADL difficulty, and 28% reported at least one IADL difficulty.



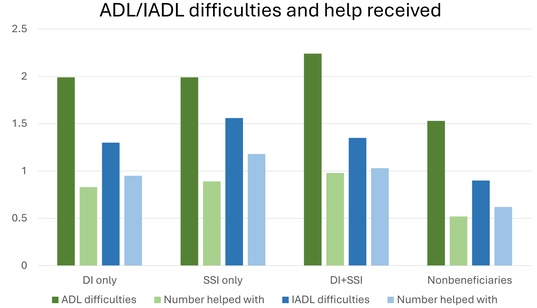
- Among those reporting **any ADL/IADL difficulties** at baseline (*N*=3,683): 60% female; 56% White, 30% Black, and 15% another race



PRINCIPAL FINDINGS

Unmet needs exist

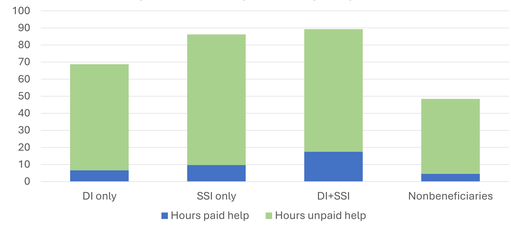
ADL/IADL difficulties and help received



Among those with any ADL or IADL difficulties at baseline (61% of beneficiaries and 31% of nonbeneficiaries), beneficiaries reported an average of 2 kinds of ADL difficulties and nonbeneficiaries 1.5. All groups reported getting help with fewer than half of reported ADL needs and about three-quarters of IADL needs.

Use of paid/unpaid care differs by program

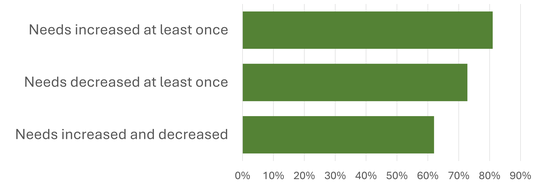
Hours of paid and unpaid help in past month



Most home care was unpaid, but the proportions differed by beneficiary group. Asked about person-hours of care in the past month, DI-only beneficiaries and nonbeneficiaries reported receiving more than 9 hours of unpaid care for 1 hour of paid care; for SSI-only beneficiaries, the ratio was about 8 to 1; and for DI+SSI beneficiaries, the ratio was about 4 to 1.

Needs fluctuate

ADL limitations changed from wave to wave



Among those who ever reported ADL needs (*N*=5,007), 61.5% reported both increases and decreases in ADL limitations over the reporting period. Respondents also reported fluctuations in help received and beneficiary category (DI only, SSI only, DI+SSI, or none).

Medicaid is associated with more paid care, fewer unmet needs

We conducted regression analyses adjusting for the number of ADL and IADL needs as well as race, gender, urbanicity, and type of insurance.

- DI status was associated with fewer hours of paid care ($B = -5.495$, $p = .015$) compared with nonbeneficiaries.
- Medicare, Medicaid, and private insurance were significantly associated with more hours of paid care (respectively, $B = 7.609$, $p < .001$; $B = 6.703$, $p = .003$; $B = 4.321$, $p = .045$) than no insurance.
- Beneficiary status and type of insurance were not associated with hours of unpaid care.
- Medicaid was associated with fewer unmet needs ($B = -0.119$, $p = .002$) than no insurance.

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CONCLUSIONS

- Many workers disabled before retirement age have significant home care needs.
- Informal care predominates, but Medicaid is critical in providing access to paid care.

POLICY IMPLICATIONS

- Upcoming budget cuts are expected to end Medicaid home- and community-based services (HCBS) in many states. Strategies are needed to ensure people with disabilities can remain in the community.
- The proposed HCBS Access Act would require that states cover HCBS and would provide 100% federal funding for these services for 10 years.
- Given the high rate of fluctuations in need, states and organizations could structure shorter-term programs to provide fill-in care with flexibility.

ACKNOWLEDGMENTS

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Kaufman, J., & Yin, N., "Contending with Home Care Needs After a Work Disability" (2025), *Generations Journal 49*(3). https://generations.asaging.org/contending-with-home-care-needs-after-a-work-disability/

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